EPILEPSY TREATMENT GAP, ASSOCIATED RISK FACTORS AND INTERVENTION STRATEGIES IN KILIFI, KENYA

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Dedication

I dedicate this work to my grandmother, Mrs. Joyce Ciambaka Mwoga, for nurturing me from childhood and teaching me vital values in life. She beat all odds to ensure my upbringing was above board. Her love and care are beyond reproach. She laid a firm foundation for my education through her unrelenting hard work and determination. She was the first person to light the academic candle by naming me Kathomi (in my culture, it means someone who likes reading). She was and still is passionate about education. She is a pillar of strength and hope.

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Summary

Epilepsy is a common neurological disorder, characterized by recurrent unprovoked seizures. Globally it affects over 69 million people of whom 90% live in Resource Poor Countries (RPCs). The prevalence is high in RPCs due to parasitic and infectious diseases, head injury and perinatal insults. Despite the high prevalence, many People with Epilepsy (PWE) do not receive appropriate treatment for their condition leading to a high Epilepsy Treatment Gap (ETG). The ETG is defined as the difference between the number of people with active epilepsy (who may benefit from treatment) and the number whose seizures are being appropriately treated.

The attention given to epilepsy by international health agencies such as the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and World Health Organization (WHO) highlights its significance as the most common neurological disorder. In 1997, the Global Campaign Against Epilepsy, a partnership between ILAE/ IBE /WHO was launched to reduce the ETG in RPCs by providing information about the treatment and prevention of epilepsy among other measures.

Epidemiological studies conducted in the Kilifi Health Demographic Surveillance System (KHDSS) have shown that epilepsy is prevalent in the community but no studies have been conducted on health care utilization by PWE. Therefore, the overall goal of this study was to estimate the ETG and investigate the factors associated with treatment seeking and non-adherence to Antiepileptic Drugs (AEDs) in order to develop appropriate interventions to reduce the gap.

The studies in this thesis were conducted in the KHDSS, a rural area in the coast of Kenya, which is served by one district hospital and other public and private health facilities. Besides the biomedical resources, traditional medicine is well represented with different types of Traditional Healers (THs) offering their services to the community.

The various research methodologies used to achieve the study goals included: synthesis of existing literature, qualitative and quantitative techniques. The first literature synthesis involved reviewing previous studies that looked at magnitude, causes and intervention strategies for the

ETG in RPCs and the second one reviewed the evidence from RPCs on the efficacy of treatments and the delivery of interventions. In the qualitative studies, information was elicited on perceptions of epilepsy and its treatment from PWE and their caregivers, THs, community health workers, nurses and clinicians using in-depth interviews, focus group discussions, key informant interviews and observations. The literature review and qualitative study informed development of the Kilifi Stigma Scale for Epilepsy (KSSE) and the Kilifi Epilepsy Beliefs and Attitude Scale (KEBAS) that were used in the quantitative aspect of the study. The quantitative aspect involved administering a structured questionnaire to 673 PWE to investigate risk factors for treatment seeking and non-adherence to AEDs. Blood samples from PWE were also collected and assayed for AEDs to determine adherence. The studies were conducted by trained field staff following written informed consent.

Findings from the systematic review in Chapter 2 indicated a wide variability in ETG estimates with a prevalence of 46.8/100 in urban settings and 73.3/100 for rural regions. The ETG was mainly attributed to inadequate skilled manpower, cost of treatment, cultural beliefs and unavailability of AEDs. These factors were addressed using intervention strategies such as education and supply of AEDs.

The literature review in Chapter 7 highlighted some of the treatments available for epilepsy in RPCs: AEDs therapy, surgery and psychosocial therapy. Among the interventions feasible in these countries are: ensuring an adequate drug supply, educating PWE and caregivers about epilepsy, community-based interventions to improve awareness, training health care providers, involving THs and integrating epilepsy care into existing health services, particularly mental health.

Chapters 3 and 4 provide details of how to construct culturally varied tools. The KSSE was unidimensional, indicating that it measured only one construct (perceived stigma). In addition, it had high internal consistency (Cronbach‘s α=0.91) and excellent test-retest reliability (r=0.92). The KEBAS had five subscales (causes of epilepsy, biomedical treatment of epilepsy, cultural treatment of epilepsy, risk and safety concerns and negative stereotypes about epilepsy). The

subscales demonstrated adequate internal consistency ranging from α=0.56 to α=0.76 and acceptable test-retest reliability ranging from r=0.64 to r=0.81.

The quantitative part of the study (Chapters 5 and 6) identified the obstacles to treatment seeking and adherence as: duration of epilepsy; religion; distance to health facilities; paying for AEDs; injury during a seizure; beliefs about causes of epilepsy; beliefs about biomedical treatment of epilepsy; duration of medication; seizure frequency; number of AEDs prescribed and having a good relationship with the healthcare provider.

Multivariate logistic regression analysis indicated the most important factor influencing treatment seeking was long duration of epilepsy in children (Adjusted Odds Ratio (aOR)=8.01, 95% Confidence Interval (CI); 3.02–21.2) and in adults (aOR=9.00, 95% CI 2.87–18.9). The most important factor affecting adherence among children was long duration of medication (aOR=4.25, 95% CI 1.86–8.75) and in adults (aOR=6.50, 95% CI 1.58–9.63). The ETG based on detectable and optimal AEDs blood levels was 74.9% (95% CI; 71.4-78.1).

The qualitative part of the study demonstrated that PWE utilize both biomedical and traditional medicine. The study in Chapter 8 identified six key differences between biomedical and traditional treatments that made PWE prefer seeking treatment from THs: explanations of causation, communication styles, social roles, referral practices, location and systems of payment. The study in Chapter 9 established the following as factors that hindered treatment seeking from health facilities: lack of knowledge on causes, treatment and prognosis of epilepsy, financial constraints, distance to health facilities, unavailability of the AEDs, superstitions and beliefs about epilepsy and poor doctor-patient relationship. These findings indicated several possible avenues for intervention such as education of PWE and their caregivers, communication skills training for health providers, improving drug supplies in health facilities, increasing cooperation and dialogue with THs and supporting PWE and their families.

The studies in this thesis enabled us to examine the ETG using multi-disciplinary approaches. The results contribute to our understanding of the factors that guide PWE in their labyrinthic treatment seeking paths, including biomedical and traditional health services for the same condition. The qualitative part enabled us to understand cultural reasons for treatment seeking

behaviour for epilepsy while the quantitative part allowed us to estimate the ETG using a robust pharmacological measure. The findings further underscore the important roles that can be played by different stakeholders in order to reduce the ETG. At the community level efforts should be put to improve knowledge about epilepsy. Healthcare providers should continually improve their relationship and communication with patients in addition to educating and counseling them. Traditional healers need to be integrated in health workers' trainings and encouraged to offer interventions that are consistent with their ability and style of knowledge. Policy makers need to incorporate epilepsy in the National Health Agenda in addition to ensuring adequate supply of AEDs to health facilities. Researchers should strive to disseminate research findings to policy makers as well as the community. The study concludes by making suggestions for future research among them the need for prevalence studies to estimate ETG so that it can be used as an outcome measure in health care.

Zusammenfassung

Epilepsie ist eine häufige neurologische Störung, die durch unprovozierte wiederkehrende Anfälle charakterisiert ist. Weltweit sind 69 Millionen Menschen von dieser Krankheit betroffen, wobei 90% in Ländern mit extremer Mittelknappheit (RPC) wohnen. In diesen Ländern ist die Prävalenz aufgrund der parasitären und anderen Infektionskrankheiten, Kopfverletzungen und Geburtsschäden hoch. Trotz der hohen Prävalenz erhalten nicht alle Epilepsiepatienten (PWE) eine adäquate Behandlung für ihre Pathologie was zu einer grossen Diskrepanz zwischen Anzahl Fälle und Patienten mit adäquater Behandlung führt (Epilepsy Treatment Gap, ETG). Der ETG ist die Differenz zwischen der Anzahl Patienten mit einer aktiven Epilepsie (die von einer Behandlung profitieren würden) und der Anzahl solcher Patienten, deren Anfälle adäquate behandelt sind.

Die Aufmerksamkeit, die Epilepsie von internationalen Organisationen wie die International League Against Epilepsy (ILAE), dem International Bureau for Epilepsy (IBE) und der Weltgesundheitsorganisation (WHO) gegeben wird, unterstreicht die Bedeutung als häufigste neurologische Erkrankung. 1997 wurde in Partnerschaft zwischen ILAE/IBE/WHO die weltweite Kampagne gegen Epilepsie (Global Campaign Against Epilepsy) lanciert, mit dem Ziel, die ETG in RPC zu reduzieren. Informationen zur Behandlung und Prävention der Epilepsie sind die Hauptbestandteile dieses Programms.

Epidemiologische Studien die durch das Kilifi gesundheitsdemographische Überwachungssystem (KHDSS) gemacht wurden, haben gezeigt, dass Epilepsie in den Dörfern häufig auftritt. Bis heute aber wurden keine Studien zum Zugang von Epilepsie-Patienten zum lokalen Gesundheitssystem gemacht. Das Ziel dieser Doktorarbeit war den ETG zu bestimmen und die Faktoren, die mit der Behandlungsaufnahme und Behandlungseinhaltung mit anti-epileptischen Medikamenten im Zusammenhang stehen zu identifizieren um eine Gesundheitsintervention gegen den ETG zu entwickeln.

Die Studien in dieser Doktorarbeit wurden im KHDSS durchgeführt, eine ländliche Gegend an der Küste von Kenia, die durch ein Spital und anderen öffentlichen und privaten Gesundheitsdiensten versorgt wird. Die traditionelle Medizin bietet neben den biomedizinischen Behandlungen mit verschiedenen möglichen Behandlungen von traditionellen Heilern (TH) ihre Heilungsdienste an.

Um das Studienziel zu erreichen, wurden verschiedene Methodologien eingesetzt: systematische Literaturstudien, qualitative und quantitative Forschungstechniken. Die erste systematische Literaturstudie untersuchte frühere Studien, die das Ausmass und die Ursachen für den ETG und Interventionen gegen den ETG in RPC untersucht haben. In einer zweiten systematischen Literaturuntersuchung wurden die Beweise für die Effizient von Behandlung gegen Epilepsie zusammengetragen und analysiert. In den qualitativen Studien wurden Informationen zur Wahrnehmung der Epilepsie und deren Behandlung durch PWE und deren Pflegern, der traditionellen Heilern, der Gesundheitsdienste im Dorf, und Krankenpflegern und Ärzte untersucht; dafür wurden Interviews, Fokus Gruppen Diskussionen und direkte Beobachtungen angewendet. Die systematischen Literaturstudien und qualitativen Untersuchungen führten zur Kilifi Stigma Skala für Epilepsie (KSSE) und zur Kilifi Epilepsie Glaubens- und Einstellungsskala (KEBAS), die dann in den quantitativen Studien gebraucht wurden. Die quantitativen Aspekte der Studien beinhalteten die Anwendung von strukturierten Fragebogen an 673 Epilepsiepatienten um die Risikofaktoren für die Behandlungssuche und die Behandlungseinhaltung (Adhärenz) zu untersuchen. Blutproben wurden von den Epilepsiepatienten gesammelt um das Vorhandensein von anti-epileptischen Medikamenten nachzuweisen. Die Studien wurden durch ausgebildete Feldassistenten durchgeführt nach dem Erhalt von schriftlichen Zustimmungserklärungen der Patienten.

Die Resultate der systematischen Literaturstudien des Kapitels 2 brachten eine grosse Variabilität des Ausmasses des ETG zu Tage. In urbanen Zentren war die Prävalenz im Durchschnitt 46.8 nicht behandelte Patienten auf 100 PWE und in ländlichen Gebieten 73.3 nicht behandelte Patienten auf 100 PWE. Der ETG konnte hauptsächlich auf das nicht adäquat ausgebildetes Gesundheitspersonal die Kosten der Behandlung, der kulturellen Sichtweisen und der Abwesenheit der anti-epileptischen Medikamente zurückgeführt werden. Diese Faktoren wurden in Interventionen durch eine Verbesserung der Gesundheitsinformation und Medikamentenversorgung angegangen.

Die systematische Literaturstudie des Kapitels 7 brachte eine Zusammenstellung der Epilepsiebehandlungen in RPC zu Tage: die anti-epileptischen Medikamente, und die chirurgischen und psychosozialen Therapien. Zu den durchführbaren Interventionen in RPC gehören die Absicherung des Vorhandenseins der Medikamente, die Gesundheitserziehung der Epilepsiepatienten und deren Pflegern in Bezug auf die Epilepsie, die Bewusstseinsförderung der Bevölkerung, die Ausbildung der Gesundheitsdienste, die auch die traditionellen Heiler einbeziehen und die Integration der Epilepsiebehandlung in die existierenden Gesundheitsdienste.

Die Kapitel 3 und 4 dokumentieren detailliert das Entwickeln der kulturellen sensitiven Datenerhebungswerkzeuge. Die KSSE ist ein eindimensionales Werkzeug, das die empfundene Stigmatisierung misst. Es hatte eine hohe interne Konsistenz (Cronbach‘s α=0.91) und eine ausgezeichnete retest Zuverlässigkeit (r=0.92). Die KEBAS bestand aus 5 Unterskalas (Ursachen der Epilepsie, biomedizinische Behandlung, der Epilepsie, traditionelle Behandlung der Epilepsie, Risiken und Sicherheitswahrnehmungen und negative Stereotypen der Epilepsie). Die Unterskala demonstrierten adäquate interne Konsistenzen von α=0.56 bis α=0.76 und eine akzeptable retest Zuverlässigkeit zwischen r=0.64 und r=0.81.

Der quantitative Teil der Studien identifiziert die Hürden für Behandlungssuche und Behandlungseinhaltung: die Dauer der Epilepsie, die Religion des Patienten, die Distanz zu den Gesundheitsdiensten, die Bezahlung der anti-epileptischen Medikamente, eine Verletzung während eines epileptischen Anfalls, die Überzeugung zu den Ursachen der Epilepsie, die Überzeugung von biomedizinischen Behandlungen, die Dauer der Behandlung, die Anfallhäufigkeit, die Anzahl verschriebener anti-epileptischen Medikamente und das Verhältnis zwischen Patient und Gesundheitsdienst.

Multivariate logistische Regressionsanalysen identifizierten den wichtigsten Faktor für eine Behandlungsaufnahme als die lange Krankheitsdauer in Kindern (adjusted odds ratio (aOR)= 8.01, 95% Vertrauensintervall CI: 3.2-21.2) und in Erwachsenen (aOR=9.00, 95% CI 2.87–18.9). Die wichtigsten Faktoren, die mit der Behandlungseinhaltung assoziiert sind, waren die lange Dauer der Medikation in Kindern (aOR=4.25, 95% CI 1.86–8.75) und in Erwachsenen (aOR = 6.50, 95% CI 1.58–9.63). Der ETG basierend auf dem Blutnachweis von anti-epileptischen Medikamenten war 74.9% (95% CI; 71.4-78.1).

Der qualitative Teil der Studie zeigte, dass Epilepsiepatienten biomedizinische und traditionelle Medizin benützen. Die Studie in Kapitel 8 identifiziert sechs Schlüsselunterschiede zwischen der

biomedizinischer und traditioneller Behandlung, die Epilepsiepatienten die traditionellen Heiler vorziehen: Erklärungen der Bedeutung und Ursache der Erkrankung, Kommunikationsstil, soziale Rollen, Überweisungen an andere Dienste, der Ort der Behandlung und die Art und Weise der Bezahlung. In der Studie in Kapitel 9 wurden folgende Faktoren identifiziert, die Epilepsiepatienten von der Behandlungssuche abhalten: der Mangel an Wissen der Ursachen der Epilepsie, Behandlung und Prognosen der Epilepsie, die finanziellen Folgen, die Distanz zu den Gesundheitsdiensten, die Abwesenheit der anti-epileptischen Medikamente, Aberglaube und Überzeugungen über Epilepsie und ein schlechte Patienten-Ärzte Verhältnisse. Diese Resultate deuten auf mehrere mögliche Intervention hin, wie bessere Information für Epilepsiepatienten und deren Pfleger, Kommunikationsschulung von Gesundheitsdiensten, verbesserte Medikamentenversorgung in Gesundheitsdiensten, vermehrte Zusammenarbeit und Dialog mit traditionellen Heilern, Epilepsiepatienten und deren Familien.

Die Studien in dieser Doktorarbeit erlaubten uns den ETG mit einem multi-disciplinären Ansatz zu untersuchen. Die Resultate tragen dazu bei, die Logik, welche die Epilepsiepatienten im Labyrinth der Suche ihrer biomedizinischen und traditionellen Behandlungen verfolgen. Die qualitativen Studien erlaubten uns die Gründe der Behandlungssuche der Epilepsiepatienten zu verstehen während der quantitative Teil uns erlaubte den ETG mittels eines robusten pharmakologischen Masses zu messen. Die Befunde unterstreichen die wichtige Rolle, die die verschiednen Akteure bei der Verminderung des ETG spielen. In der Bevölkerung die sollte das Bewusstsein und das Wissen in Bezug auf die Epilepsie verbessert werden. Die Gesundheitsdienste sollten kontinuierlich ihr Verhältnis und die Kommunikation mit den Epilepsiepatienten verbessern ohne dabei die Gesundheitserziehung und das Beraten der Epilepsiepatienten zu unterlassen. Die traditionellen Heiler sollten in die Ausbildung des Gesundheitspersonals integriert werden. Zusätzlich sollten sie motiviert werden die Epilepsiepatienten nach ihren Möglichkeiten und Wissen zu behandeln. Politische Entscheidungsträger müssen Epilepsie in die Nationalen Gesundheitsagenda integrieren und die adäquate Versorgung mit anti-epileptischen Medikamenten garantieren. Die Forschung sollte sich vermehrt für eine Verbreitung der Resultate an die politischen Entscheidungsträger und der betroffenen Bevölkerung einsetzen. Diese Arbeit wird durch Vorschläge für zukünftige Forschungsfragen beendet, unter anderem die Entwicklung von Prävalenzstudien von ETG, die als Mass der Effizienz von Gesundheitsdiensten verwendet werden können.

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Utafiti wa kimatibabu uliofanywa wilayani Kilifi na Kundi la utafiti la Uchunguzi wa Afya ya Umma Wilayani Kilifi (KHDSS) unaonyesha kwamba ugonjwa wa Kifafa umeenea sana katika jamii zinazoishi wilayani humu lakini hakuna utafiti maalum uliofanywa kuhusu jinsi huduma za kimatibabu zinavyotumiwa na kuwanufaisha wanaougua maradhi ya kifafa (PWE). Hivyo, lengo kuu la utafiti huu ni kukadiria pengo la kimatibabu kwa wanaougua kifafa na pia kuchunguza mambo yanayohusiana na usakaji tiba pamoja na kutozingatia matumizi ya dawa za kutibu kifafa ili kuunda mikakati ifaayo ya kupunguza pengo hili.

Utafiti katika tasnifu hii ulifanyika katika eneo la Uchunguzi wa Afya ya Umma Wilayani Kilifi (KHDSS), ambayo ni sehemu ya mashambani katika Pwani ya Kenya, na ambayo huudumiwa na hospitali moja tu ya wilaya pamoja na zahanati nyingine chache za umma na za kibinafsi. Pamoja na rasilimali za tiba za kiasili, madawa ya kienyeji yamewakilishwa vyema na wauguzi wa kienyeji kwa kutoa huduma zao za kiafya kwa jamii.

Mbinu mbalimbali za kiutafiti zilizotumiwa kuafikia malengo ya utafiti huu ni pamoja na: uchanganuzi wa matini za kifasihi zilizomo; tathmini za matini maalum na tathmini za matini jumla. Uchanganuzi awali wa matini za kifasihi zilizomo, uchanganuzi wa kiuamilifu na uchanganuzi wa kijumla vilichunguza viwango, asili na mikakati ya kuingilia kati na kupunguza pengo lililopo la kupatikana kwa matibabu kwa wagonjwa wa kifafa kwa mataifa yenye rasilimali duni; pili, uchanganuzi huu ulichunguza idhibati kutoka kwa mataifa yenye rasilimali duni kwa kuzingatia kuwepo kwa tiba na kupatikana kwa njia za kuukinga ugonjwa wa kifafa. Katika utafiti wa tathmini maalum, taarifa zilitokana na mielekeo kuhusu ugonjwa wa kifafa na tiba zipatikanazo kwa wanaougua kifafa na watoa tiba, wauguzi wa kiasili, maafisa wa afya ya umma, manesi na wauguzi kwa jumla kwa kuzingatia mahojiano ya kina, mijadala ya makundi, kuwahoji watoa taarifa mahususi pamoja na uchunguzi. Uchanganuzi wa matini za kifasihi na tathmini na uchunguzi wa matini maalum vilipelekea kuundwa kwa Viwango wa Unyanyapaa kwa Wanaougua Kifafa wilayani Kilifi (KSSE) na Viwango vya Imani na Mielekeo Kuhusu Kifafa Wilayani Kilifi (KEBAS) vilitumika kukadiria tathmini ya jumla katika utafiti huu. Kitengo cha tathmini ya jumla kilihusu maswali yenye mpangilio maalum yaliyoulizwa watu 673 wanaougua ugonjwa wa kifafa ili kuchunguza uwezekano wa shida zinazoweza kutokana na matibabu ya kifafa na kutozingatia matumizi ya dawa za kutibu kifafa. Sampuli za damu za wagonjwa wa kifafa zilikusanywa na kuchunguzwa kwa nia ya kudhihirisha viwango vya kuzingatia matibabu kwa matumizi ya dawa za kutibu kifafa. Uchunguzi huu ulifanywa na wachunguzi wa nyanyani waliohitimu kupitia makubaliano yaliyotiwa sahihi.

Matokeo ya tathmini ya kiuzingativu yalidhihirisha kuwepo kwa utengano wa kimakadirio ya pengo la kimatibabu ya kifafa na kudhihirisha kuwepo kwa ugonjwa huu kwa asilimia 46.8 katika maeneo ya miji na asilimia 73.3 katika maeneo ya mashambani. Pengo la kimatibabu kwa wagonjwa wa kifafa linaweza kuelezwa kuwa linatokana na ukosefu wa matabibu waliohitimu, gharama ya matibabu, imani za kitamaduni kuhusu ugonjwa huu na ukosefu wa madawa ya kutibu kifafa (AEDs). Matatizo haya yalisuluhishwa kwa kutumia mbinu za kuelimisha wanaohusika pamoja na utoaji wa dawa za AEDs.

Tathmini ya kimatini katika sura ya 7 ilitaja yafuatayo kama baadhi ya aina za matibabu zinazopatikana katika mataifa yenye rasilimali duni; tiba kwa kutumia madawa ya kifafa, upasuaji na ushauri. Baadhi ya njia kuu za kupambana na ugonjwa wa kifafa katika mataifa haya ni pamoja na: kuhakikisha kuna dawa za kutosha, kuelimisha wanaougua kifafa pamoja na wauguzi kuhusu ugonjwa huu, kuingilia kati kwa njia mbalimbali kwa kuuhusisha umma ili kuihamasisha, kuwaelimisha maafisa wa afya, kuwahusisha matabibu wa kiasili na kuijumuisha huduma kwa wagonjwa wa kifafa katika huduma nyingine za kiafya zilizomo, hasa afya ya akili.

Sura ya tatu (3) na ya nne (4) zinatoa maelezo kuhusu jinsi ya kujenga nguzo mbalimbali za kitamaduni kuhusu tiba ya kifafa. Tathmini ya Viwango vya Unyanyapaa kwa Wagonjwa wa Kifafa Wilayani Kilifi (KSSE) iliegemea upande mmoja tu, jambo linalodhihirisha kwamba ilipima kitengo kimoja cha athari ya ugonjwa wa kifafa-yaani unyanyapaa. Zaidi ya hili, tathmini hii ilikuwa na uzingatiaji mkubwa wa vipimo vya (Cronbach‘s α=0.19) na ubora wa utegemeo wa majaribio rudufu (r =0.92). Viwango vya Imani na Mielekeo Kuhusu Kifafa Wilayani Kilifi (KEBAS) vilikuwa na vipimo vitano vidogo ambavyo ni: chanzo cha kifafa, tiba kwa matumizi ya madawa ya kisasa, tiba za kiasili, hatari, usalama na mielekeo potovu kuhusu kifafa. Vipimo hivi vilidhihirisha mfuatano thabiti wa matokeo yaliyosambaa katika viwango vya 0.56 hadi 0.76 na ubora wa utegemeo wa majaribio rudufu yenye matokeo yaliyosambaa kutoka 0.64 hadi 0.81.

Tathmini ya jumla ya utafiti (Sura ya 5 na ya 6) ilitambua vikwazo kwa wanaotafuta matibabu na uzingativu wa tiba kama vifuatavyo: muda ambao mgonjwa ameishi na ugonjwa wa kifafa, mielekeo ya kidini , umbali na iliko zahanati, gharama ya dawa za kutibu kifafa, kutokea kwa ugonjwa wenyewe, idadi na aina za dawa za kutibu kifafa zilizopendekezwa na uhusiano uliopo baina ya mgonjwa na tabibu.

Uchanganuzi anuwai wa upotevu na matukio awali kuhusu tiba ulionyesha kwamba jambo kuu linalochangia utafutaji wa tiba na wagonjwa wa kifafa ni kuishi na ugonjwa huu kwa muda

mrefu hasa miongoni mwa watoto; yaani kwa viwango amilifu vya kiulinganifu (Adjusted Odds Ratio (aOR)) ambayo ni 8.01, asilimia 95 ya kiwango cha kiuhakikifu (CI); 3.02–21.2) na watu wazima katika viwango amilifu vya (aOR)=9.00, asilimia 95 na kiwango cha kiuhakikifu (CI) 2.87–18.9). Jambo la kimsingi au muhimu linaloathiri watoto katika matumizi ya dawa za kutibu kifafa ni muda mrefu wanaotumia katika kupata matibabu (aOR=4.25, 95 asilimia CI 1.86 – 8.75) na watu wazima (aOR=6.50, 95 asilimia na CI 1.58–9.63. Pengo la kimatibabu la wagonjwa wanaougua kifafa (ETG) kwa kuegemea viwango vinavyoweza kugundulika na tiba kwa matumizi ya dawa za kutibu kifafa (AEDs) katika mishipa ya damu vilikuwa asilimia 74.9 ambayo ni asilimia (95 katika viwango vya CI; na 71.4–78.1).

Tathmini ya viwango mahususi katika utafiti huu vilidhihirisha kwamba wagonjwa wanaougua kifafa (PWE) hutumia madawa ya kisasa na tiba za kiasili. Matokeo ya utafiti katika sura ya nane (8) yalitambua tofauti sita kuu baina ya tiba kwa matumizi ya madawa ya kisasa na tiba za kiasili, tofauti zilizopelekea wagonjwa wanaougua kifafa (PWE) kupendelea kutafuta tiba kutoka kwa matabibu wa kienyeji; maelezo ya vianzo vya ugonjwa huu, mbinu za kimawasiliano, majukumu ya kijamii, mitindo ya kiuelekezi na urejeshi kwa wagonjwa kwa watoa matibu wengine, viliko vituo vya kutolea malipo na njia za kutoa malipo yenyewe. Uchunguzi katika sura ya 9 ulitambua sababu zifuatazo kama vizingiti vya usakaji huduma katika zahanati za umma: ukosefu wa maarifa kuhusu vianzo vya ugonjwa wa kifafa, tiba na utambuzi wa kuwepo kifafa, ukosefu wa pesa za kugharamia matibabu, umbali wa viliko vituo vya afya, ukosefu wa dawa za kutibu kifafa (AED‘s), itikadi na imani kuhusu kifafa na uhusiano mbaya baina ya madaktari na wagonjwa. Matokeo haya yalibainisha njia mbalimbali za kupambana na kifafa zikiwemo kuwaelimisha wagonjwa na wahudumu wao, kuwafunzia wahudumu na watunza wagonjwa mbinu mwafaka za mawasiliano, kuimarisha utoaji wa dawa katika vituo vya afya, kuimarisha utagusiano na mijadala kuhusu kifafa baina ya matabibu wa kiasili na kuwasaidia wagonjwa wa kifafa (PWE) pamoja na familia zao.

Uchunguzi katika tasnifu hii ulituwezesha kutathmini pengo lililopo katika kutibu kifafa (ETG) kwa kutumia mbinu anuwai. Matokeo yake yatachangia kuelewa maantiki inayowaongoza wanaougua kifafa (PWE) katika harakati zao ngumu za kuisaka tiba zikiwemo huduma za dawa za kisasa na zile za kiasili zinazolenga kuitatua hali hii. Tathmini maalum ilitusaidia kuzielewa

sababu za kiasili na tabia za kuyasaka matibabu ilhali tathmini ya jumla ilituwezesha kukadiria pengo lililopo katika kutibu kifafa kwa kutumia hatua chanya za kimaabara. Zaidi, matokeo haya yanadhihirisha umuhimu na majukumu yanayoweza kutekelezwa na washika dau mbalimbali katika kupunguza pengo la kimatibabu kwa wanaougua kifafa. Katika ngazi ya vijijini juhudi zinafaa kufanywa ili kuimarisha ufahamu kuhusu ugonjwa wa kifafa. Wanaotoa huduma za afya wanafaa kuendelea kuimarisha uhusiano wao na mawasiliano na wagonjwa pamoja na kuwaelimisha na kuwapa ushauri nasaha. Matabibu wa kiasili wanahitaji kuhusishwa katika kutoa mafunzo kwa wahudumu wa afya na pia wahimizwe kutoa huduma zinazoambatana na uwezo na mbinu zao za kimaarifa. Waunda sera wanafaa kuhusisha sera ya kushughulikia ugonjwa wa kifafa katika ajenda ya afya ya taifa pamoja na kuhakikisha kwamba kuna madawa ya kutosha ya kutibu kifafa katika vituo vya afya. Watafiti pia wanapaswa kutoa matokeo ya tafiti zao kwa waunda sera na kwa jamii yote kwa jumla. Utafiti huu unatamatika kwa kutoa mapendekezo kuhusu tafiti za baadaye ukiwemo uchunguzi wa kuenea kwa ugonjwa wa kifafa ili kukadiria pengo lililoko katika utoaji tiba kwa wagonjwa wa kifafa ili utumike kama kigezo cha kutathmini utoaji wa matibabu.

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List of abbreviations

ACE	Active Convulsive Epilepsy
AEDs	Anti-epileptic drugs
CHWs	Community Health Workers
CI	Confidence Interval
CWE	Children with Epilepsy
CT	Computerized Tomography
DCs	Developing Countries
DMOH	District Medical Officer of Health
EEG	Electroencephalography
ETG	Epilepsy Treatment Gap
FGDs	Focus Group Discussions
GCAE	Global Campaign Against Epilepsy
GPS	Global Positioning System
HIC	High Income Countries
IBE	International Bureau for Epilepsy
ICD	International Classification of Diseases
IEC	Information, Education and Communication
ILAE	International League Against Epilepsy
KDH	Kilifi District Hospital
KEBAS	Kilifi Epilepsy Beliefs and Attitude Scale
KEEP	Kilifi Epilepsy Education Program
KEMRI	Kenya Medical Research Institute
KHDSS	Kilifi Health Demographic Surveillance System
KSSE	Kilifi Stigma Scale for Epilepsy
LMICs	Low and Middle Income Countries
LRT	Likelihood Ratio Test
MeSH	Medical Subject Headings
MMAS	Morisky Medication Adherence Scale
MRI	Magnetic Resonance Imaging
MoH	Ministry of Health

List of abbreviations

NEF	National Epilepsy Forum
NERC	National Ethical Review Committee
NGO	Non-Governmental Organisation
NNT	Neonatal Tetanus
OR	Odds Ratio
PCA	Principal Component Analysis
PhD	Doctor of Philosophy
PWE	People with Epilepsy
RCT	Randomized Control Trial
RPCs	Resource Poor Countries
SD	Standard Deviation
SES	Social Economic Status
TB	Tuberculosis
THs	Traditional Healers
WHO	World Health Organization

Chapter 1

Introduction

EPILEPSY TREATMENT GAP, ASSOCIATED RISK FACTORS AND INTERVENTION STRATEGIES IN KILIFI, KENYA

1. 1 Epilepsy

Epilepsy is a common neurological disorder, characterized by recurrent unprovoked seizures (ILAE, 1993; Shorvon, 2009). It affects over 69 million people worldwide of whom 90% live in Resource Poor Countries (RPCs) (Ngugi *et al.*, 2010). An estimated 500 million people are also affected indirectly, as family members and friends of those who are living with epilepsy (WHO, 2006; Kale, 2002). The prevalence of epilepsy is reported to vary substantially between developed and RPCs: estimated as 4–7 per 1,000 persons in the developed countries (Sander & Sharvon, 1996), and 5–74 per 1,000 persons in RPCs (Preux & Druet-Cabanac, 2005). The result of a recent systematic review suggest that the annual incidence in developed countries is approximately 44.9 per 100 000 of the general population whereas in RPCs it is 80.3 per 100 000 (Ngugi *et al.*, In press). The high incidence rates in RPCs are attributable to parasitic and infectious diseases such as neurocysticercosis, toxocara, onchocerciasis and malaria, head injury, perinatal insults, possibly genetic causes, which may be the result of consanguinity in some areas (Placencia *et al.*, 1994; Pal *et al.*, 2000a; Asindi *et al.*, 1995; WHO, 2004; WHO, 2005).

Epileptic seizures are divided into three major categories: partial (focal), generalized and unclassified seizures (Shorvon, 2009). Partial seizures arise from one part of the brain and generalized seizures probably arise from the central parts of the brain or spread so rapidly that their origin cannot be determined by standard techniques. Partial seizures are further divided into simple partial seizures where consciousness is maintained and complex partial seizures where there is impairment of consciousness (Shorvon, 2009; Dekker, 1994). The types of generalized seizures are: absence seizures, tonic seizures, clonic seizures, myoclonic seizures, atonic seizures and tonic-clonic seizures (Shorvon, 2009; Dekker, 1994; Engel, 2006; ILAE, 2009; WHO, 2007). Unclassified epileptic seizures include all seizures which cannot be classified because of inadequate or incomplete data, or seizures that defy classification in the partial or generalized categories (Dekker, 1994). More details on classification of epileptic seizures can be found in Chapter 7 (Textbox 7.1).

Epilepsy has many possible causes because anything that injures the brain can lead to seizures. The type of injury that can lead to a seizure is age-dependent. Seizures in children may be caused by birth traumas, infections such as meningitis, congenital abnormalities or high fever (febrile seizures) (Shorvon, 2009; Carter *et al.*, 2004; Annegers *et al.*, 1988; Baulac *et al.*, 2004). Seizures in adulthood are commonly caused by head injuries, infections, alcohol withdrawal, stimulant drugs or medication side effects (Shorvon, 2009; Annegers *et al.*, 1998; Carpio *et al.*, 1998; Pal *et al.*, 2000a; Teasell *et al.*, 2007; Gordon & Devinsky, 2001; Hillbom *et al.*, 2003). In the elderly, brain tumors and strokes cause a higher proportion of seizures (Shorvon, 2009; Burn *et al.*, 1997; Camilo & Goldstein, 2004). However, not all seizures result from a structural problem in the brain. Epilepsy can also develop as a result of genetic abnormalities (Baulac *et al.*, 2004; Inoue *et al.*, 1997; Singh *et al.*, 2002) but in most epilepsies the cause is not found (Shorvon, 2009).

Epilepsy in RPCs can be prevented through various public health strategies. Prevention of trauma is the most effective way of preventing post-traumatic epilepsy, with use of head protection when riding motorcycles or bicycles (Dreifuss, 1997). Good prenatal care, including avoiding alcohol and treatment of high blood pressure and infections during pregnancy can prevent brain damage of the foetus that may lead to epilepsy (WHO, 2006; WHO, 2004). Reduction of childhood infections by improved public hygiene and immunization can lessen the risk of cerebral damage and the subsequent risk of epilepsy (Dreifuss, 1997; Sander). Elimination of parasites in the environment that cause diseases such as malaria and cysticercosis, use of bed nets to prevent mosquito bites as well as education on how to avoid infections may also be effective in reducing the burden of epilepsy (Pal *et al.*, 2000a; Carter *et al.*, 2004).

1.2 Epilepsy treatment gap

The Epilepsy Treatment Gap (ETG) has been defined by the International League Against Epilepsy (ILAE) as –the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point in time, expressed as a percentage (Meinardi *et al.*, 2001). The definition of active epilepsy is usually a seizure within the last five years, although in many RPCs, this is reduced to one year because of difficulties in recall and in supplying the Antiepileptic Drugs (AEDs).

The primary focus of care for People with Epilepsy (PWE) is the prevention of further seizures (Kwan & Brodie, 2002). Studies in both developed and RPCs have shown that up to 70% of PWE can have their seizures completely controlled with AEDs (WHO, 2006; Shorvon & Farmer, 1988; Coleman *et al.*, 2002). Despite this, an estimated 90% of PWE do not receive treatment for their condition in RPCs (Shorvon & Farmer, 1988; Scott *et al.*, 2001; Diop *et al.*, 2003; Diop *et al.*, 2005; Mbuba *et al.*, 2008). The factors contributing to the high ETG in RPCs have not been systematically studied, but include: cost of seeking care, distance to health-care facilities, inadequate planning at government level, poor infrastructure, non-availability of AEDs, scarcity of trained medical personnel, poor community knowledge and awareness, cultural beliefs and stigma (WHO, 2004; WHO, 2005; Das *et al.*, 2007; Stock, 1983; El Sharkawy *et al.*, 2006; Baskind & Birbeck, 2005b).

The Global Campaign Against Epilepsy was established by the ILAE, the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) in order to tackle some of the problems outlined above. The aim is to bridge the ETG and bring epilepsy out of the _shadows‘ so that the physical and socioeconomic burdens of epilepsy on individuals and society as a whole can be reduced (WHO, 2000; Reynolds, 2001; Reynolds, 2002a; Reynolds, 2002b). The WHO‘s report for 2004, which focuses on bridging the ETG in the Africa region, and the WHO Atlas on epilepsy care in the world also emphasize the need for integrating epilepsy related interventions in the existing primary health care system and the need for enhancing policy and programs for epilepsy (WHO, 2004; WHO, 2005).

1.3 Focus of the thesis

The common theme linking the various studies in this thesis is the estimation of the ETG with particular attention to risk factors and possible intervention strategies. The study was informed by a comprehensive systematic review on the subject and previous studies conducted in the Kilifi Health Demographic Surveillance System (KHDSS) (El Sharkawy *et al.*, 2006; Edwards *et al.*, 2008; Carter *et al.*, 2004). Designing a community-based study enabled us to interview all the people in the KHDSS who were identified to have active convulsive epilepsy. Relevant tools to collect data were developed based on literature review and themes from a qualitative study that was conducted among PWE and their caregivers as well as health care providers in Kilifi.

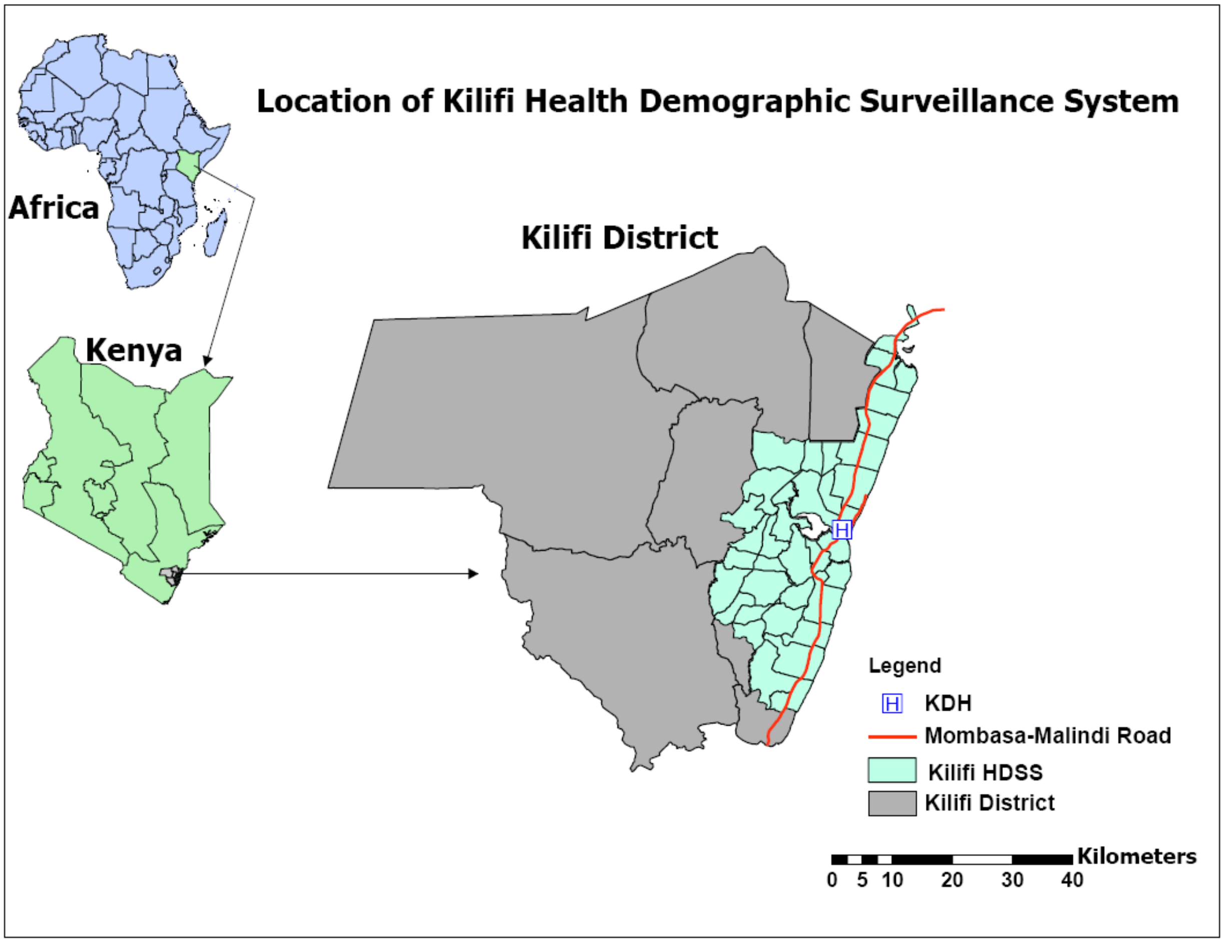
This appreciation of local cultural beliefs and terms facilitated the translation of professional concepts into terms that were locally understood and acceptable. It also provided an opportunity to develop public health interventions that are informed by the views of PWE and those working with PWE.

This research has been designed to be especially attentive to the rural context of social, economic and cultural factors in Kilifi that affect utilization of health services by PWE. These factors were classified using Andersen‘s Behavioral Model that considers health service utilization as a function of predisposing, enabling and need factors (Andersen, 1995). Predisposing characteristics are preexisting factors such as age, religion, education, occupation and beliefs that influence treatment seeking. Enabling factors describe the means individuals have available to them for the use of health services such as income, health insurance, travel and waiting time. Need refers to severity of illness and whether people judge their problem to be of sufficient magnitude to consult health services. Even when patients are predisposed to seek treatment and they have access to enabling resources, they must perceive a need to do so because need is the most immediate cause of health service use.

The studies in this thesis are presented in eight chapters, which provide the background, methods, results, and discussion of complimentary research activities. Each chapter is self-explanatory but also complementary and indicative of how different research methodologies can be applied to address a public health problem. The first of these research reports is chapter Two which provides an overview of the ETG in RPCs. The third and fourth chapters focus on the development and validation of tools that were used to collect data on perceived stigma and epilepsy beliefs and attitudes among PWE. Chapters Five and Six outline risk factors for ETG and non-adherence to AEDs in Kilifi. The seventh chapter highlights a combination of treatments and interventions aimed at improving the recognition and management of epilepsy in RPCs. It acts a precursor to the final two chapters, which look at how interventions have been developed in Kilifi to address the ETG.

1.4 Study site

Figure 1.1: Map showing the Kilifi Health Demographic Surveillance System



All the studies in this thesis were conducted in the KHDSS (Figure 1.1). The KHDSS provides population size and other demographic characteristics of the community as well as a platform upon which various studies recruit and locate the study subjects. It is located in Kilifi District of Coast Province. Most of it is the coastal plain (below 30 metres above sea level) with several creeks and swamps stretching for about 137 kilometres along the shore-line of the Indian Ocean. Soils are generally poor for agriculture and include coral limestone, marble, clay stones and limited alluvial deposits along river valleys. The only tarmac road from Mombasa to Malindi traverses the KHDSS. Farming activities include the cultivation of food crops (maize, cowpeas, green grams, bananas) tree crops (mango, citrus, cashewnuts, coconuts) and vegetables (chilli, aubergines, okra), and keeping of goats and cows.

The KHDSS comprises 15 locations with 40 sub-locations sub-divided into 187 enumeration zones which can easily be located using digital maps of homesteads. It covers an estimated area of 891 km^2 with 233,881 residents in 28,000 homesteads. This area is about 18% of the total area of Kilifi District (4779 sq. kms**)**. Re-enumeration of the population in KHDSS is carried out every 4-6 months to collect vital statistics such as births, deaths and migration. The residents are mainly Mijikenda, a Bantu grouping of nine tribes with Giriama (45%), Chonyi (33%) and Kauma (11%) dominating. The average per capita income is about Ksh.700 (10 US dollars) per month and about 55% of the population is considered poor. The majority (80%) depend on subsistence farming which is limited by the low productivity of the land, since only 19% of the land is arable. Literacy levels are low: only 45% of people can read and write (GOK, 2000).

The KHDSS is served by one District hospital, one health centre, 12 dispensaries and 23 private clinics. The staff members at these dispensaries and private clinics have little training in the diagnosis of epilepsy or its‘ management. The dispensaries stock only one AED (phenobarbital) which is often out of stock. Consequently, most PWE opt to seek treatment at Kilifi District Hospital (KDH) which serves as a primary care centre and first level referral facility for the District. Kilifi District Hospital stocks phenytoin, carbamazepine and sodium valproate in addition to phenobarbital. The Kenya Medical Research Institute (KEMRI) neuro-clinic, which offers specialized care to PWE is also located within the District hospital. It is run by a pediatric neurologist and three clinicians with experience in the management of epilepsy and provides free assessment and AEDs at subsidized prices. In addition to epilepsy patients, the neuro-clinic reviews patients from the KDH who have other neuro-cognitive disorders such as cerebral palsy.

1.5 Study goal

To estimate the ETG and investigate the factors associated with treatment seeking and non-adherence to AEDs in order to develop appropriate interventions to reduce the gap.

1.6 Study objectives

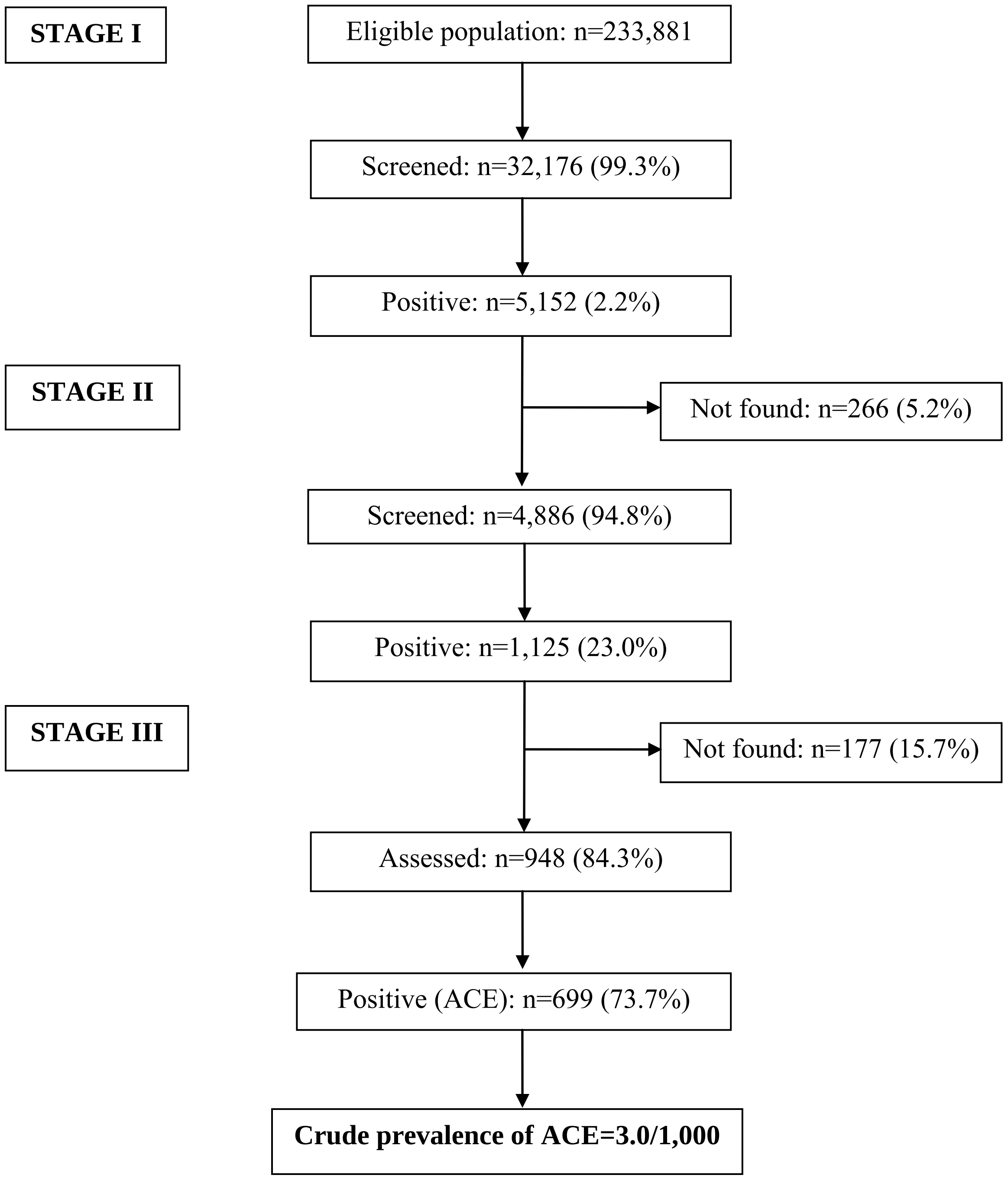
The studies in this thesis had six main objectives

1. To review existing literature on magnitude, causes and intervention strategies for the ETG in RPCs (Chapter 2)
2. To review literature on the efficacy of treatments and delivery of interventions in RPCs (Chapter 7)
3. To develop culturally appropriate tools for investigating risk factors for the ETG (Chapters 3 and 4)
4. To estimate ETG and investigate the factors associated with treatment seeking and adherence among PWE (Chapters 5 and 6)
5. To understand barriers to biomedical and traditional treatment of epilepsy (Chapter 8)
6. To explore stakeholders‘ perceptions of epilepsy and its treatment and examine possible intervention strategies to reduce the ETG (Chapter 9)

1.7 Identification of study participants

PWE were identified in a 3-stage cross-sectional survey that was conducted to determine the prevalence and incidence of epilepsy (Ngugi *et al.*, In preparation). In the first stage, all household heads were asked two questions regarding the history of convulsions for each member of their household. Those who were positive were followed- up with a more detailed questionnaire in the second stage to identify those with possible Active Convulsive Epilepsy (ACE). Active convulsive epilepsy was defined as two or more unprovoked seizures in a life-time, of which at least one was within the 12 months preceding the study. Those positive in the second stage were referred to the KEMRI neuro-clinic where clinical history and neurological examination were performed by experienced clinicians to confirm ACE. All cases of confirmed ACE were eligible for the ETG study.

Figure 1.2: Flow diagram showing how people with epilepsy were identified



1.8 Overview of methods

This thesis employed various research methodologies ranging from synthesis of existing literature to qualitative and quantitative techniques. Literature synthesis involved reviewing previous studies in the area of research interest. Qualitative and participatory methods involved in-depth interviews, key informants and Focus Group Discussions (FGD) with PWE and their caregivers, Traditional Healers (THs), Community Health Workers (CHWs), nurses and clinicians. Participatory workshops with the above stakeholders were undertaken to identify service needs and to formulate culturally appropriate interventions for PWE, with the ultimate goal of reducing the ETG in the KHDSS. Findings from the qualitative study were also incorporated into the development of stigma and epilepsy beliefs tools that were used in the quantitative aspect of the study. The quantitative aspect involved individual interviews with 673 PWE to investigate risk factors for treatment seeking and non-adherence to AEDs. It strengthened the qualitative study findings and enhanced our understanding of factors that hinder PWE from utilizing health services. The ethnographic phase of the research was undertaken to examine differences between traditional healing and biomedical care for epilepsy in Kilifi. It involved a period of participant observation and extended interactions with THs and biomedical personnel. Further details concerning research methods are presented in each chapter.

Chapter 2: Epilepsy treatment gap in developing countries: A systematic review of magnitude, causes and intervention strategies

With the aim of providing a broad understanding of the research topic, research reported in this Chapter examined previous studies concerning magnitude, causes and intervention strategies for the ETG in RPCs. A proforma was prepared that highlighted the procedures to be followed when conducting the systematic review. A literature search was carried out using three databases. Additional articles were identified by searching references cited in the key papers. Findings provided a pooled estimate of the ETG, identified its causes and examined interventions that have been instituted to address it. This provided useful background information that informed the design of the studies in Kilifi.

Chapter 3: Development and validation of the Kilifi Stigma Scale for Epilepsy

Epilepsy has long been recognized as a health-related condition that often carries with it a heavy burden of stigma (Scambler & Hopkins, 1986). This stigma has a severe impact on PWE and their families (Baker, 2002; Morrel, 2002). Cultural perceptions and values play an important role in understanding the concept and content of stigma by an individual. Therefore the purpose of this study was to develop and validate a culturally-appropriate measure of perceived stigma using findings from a qualitative study conducted among PWE and their caregivers in Kilifi. Our approach followed the set criteria for evaluating psychometric properties of the scale (Jacoby *et al.*, 1993; Cicchetti, 1994). The scale was later used to find out whether perceived stigma has any influence on treatment seeking and adherence to AEDs among PWE.

Chapter 4: Development and validation of the Kilifi Epilepsy Beliefs and Attitude Scale

Negative beliefs and attitudes towards epilepsy are still common among PWE and the general public (Rwiza *et al.*, 1993; Gambhir *et al.*, 1995; Radhakrishnan *et al.*, 2000). Traditional belief systems that attribute epilepsy to demons, possession, witchcraft and curses are still prevalent in Kilifi (El Sharkawy *et al.*, 2006). These beliefs and attitudes are important because they constitute predisposing factors that influence treatment seeking behaviour among PWE. Therefore the purpose of this study was to develop and validate a tool to measure epilepsy beliefs and attitudes among PWE in Kilifi. Literature review and formative research led to the development of a tool that had five subscales. The psychometric properties of the subscales were evaluated using criteria set out by Cicchetti (Cicchetti, 1994). We investigated whether the various subscales predicted treatment seeking and adherence to AEDs among PWE.

Chapter 5: Treatment seeking among people with epilepsy in Kilifi, Kenya

Research reported in this Chapter uses quantitative techniques to estimate the magnitude of the ETG in Kilifi. We were interested in delineating factors that influence the 673 people identified to have active convulsive epilepsy in the KHDSS to seek treatment. Some of the factors examined included: socio-demographic characteristics, socioeconomic status, distance to health facilities, cost of AEDs, seizure frequency, stigma and epilepsy beliefs and attitudes. The findings provide background data that can be used in developing culturally appropriate interventions that can reduce the ETG in Kilifi.

Chapter 6: Factors associated with adherence to antiepileptic drugs in Kilifi, Kenya

After quantifying the ETG we investigated whether the 385 PWE who reported taking AEDs were adherent to treatment. Adherence was determined using detectable and therapeutic blood levels of phenobarbital, phenytoin and carbamazepine. This was compared with self-reported adherence that was assessed concurrently using the Morisky Medication Adherence Scale. Factors influencing adherence were also explored among those who reported taking AEDs. Among the factors investigated were: socio-demographic characteristics, socio economic status, relationship with health care providers, seizure frequency, injury during a seizure, number of prescribed AEDs, AEDs side effects, stigma and epilepsy beliefs and attitudes. The findings of this study may help in developing interventions to improve patient adherence and reduce the risk of preventable seizures.

Chapter 7: Packages of care for epilepsy in low and middle-income countries

This is a review of the literature focusing on the management of epilepsy in Low- and Middle Income Countries (LMICs). Charles Newton and I reviewed the evidence from LMICs on the efficacy of treatments and the delivery of interventions. On the basis of this review, we proposed a combination of interventions aimed at improving the recognition and management of epilepsy to achieve optimal outcomes. Findings from this review provided additional information about effective interventions that can be developed in Kilifi to reduce the ETG.

Chapter 8: Comparing characteristics of epilepsy treatment providers on the Kenyan coast: implications for treatment-seeking and intervention

This study employed ethnographic techniques to examine ways in which treatment-seeking may be facilitated or deterred by the characteristics of available treatment providers. It focused explicitly on treatment providers as a source of data and the ways in which treatment-seeking may be facilitated or deterred by the availability of treatment options and the characteristics of service providers, rather than by the characteristics of the patients. The methods used included open-ended interviews using semi-structured questionnaires, FGDs, participant observations and the usually long-term participation of the researcher in the community under study.

The researcher observed a total of 52 healing sessions with eight THs in addition to taking field notes and tape recording interviews. To understand the types and delivery of treatment provided in health facilities, interviews and observation data were gathered from 12 biomedical health providers: doctors, neurological technicians, research staff, nurses and general health aids. Comparing data on treatment providers provided an account of the important role played by THs in the treatment of epilepsy in Kilifi and revealed barriers to obtaining biomedical care. Therefore there is need for biomedical providers to involve THs in designing interventions aimed at reducing the ETG in Kilifi.

Chapter 9: The reasons for the epilepsy treatment gap in Kilifi, Kenya: using formative research to develop interventions to improve adherence to antiepileptic drugs

In this Chapter I report findings from an analysis of a qualitative study that was conducted among PWE and their caregivers, THs, CHWs, nurses and clinicians. The study included a combination of strategies for data collection: individual interviews, FGDs and participatory workshops. Experiences and beliefs about epilepsy in the household and in the community were explored as well as the range of treatments available for PWE and the pros and cons of different types and sources of treatment. Drawing on the qualitative findings, a series of workshops were organized with key stakeholders to negotiate realistic and sustainable interventions to reduce the ETG in Kilifi District.

Chapter 10: Discussion and Conclusion

This Chapter gives a general overview of the study, including background about epilepsy, methodological issues, results, recommendations, implication for future research and conclusion.

Overall, the research reported in this thesis provides a comprehensive approach to investigating the ETG and designing interventions in a rural setting of a RPC. Individually and collectively, these studies address practical and relevant issues that policy makers and health providers must take into consideration, both at community and health facility level, if the ETG is to be reduced in Kilifi District. In addition to contributing to epilepsy care in Kilifi, it is hoped that these studies demonstrate an integrated approach to addressing the ETG that will be useful in other settings.

Chapter 2

The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes and intervention strategies

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Abstract

Introduction

In many Developing Countries (DCs), people with epilepsy do not receive appropriate treatment for their condition, a phenomenon called the Epilepsy Treatment Gap (ETG).

Methods

We carried out a systematic review to investigate the magnitude, causes and intervention strategies to improve outcomes in DCs. We systematically searched MEDLINE, EMBASE and PsycINFO databases, supplemented by a hand search of references in the key papers. The degree of heterogeneity and a pooled ETG estimate were determined using meta-analysis techniques. The estimates were further stratified by continent and location of study (urban and rural). Twenty-seven studies met the inclusion criteria: twelve from Africa, nine from Asia and six from Latin America.

Results

We observed a high degree of heterogeneity and inconsistency between studies. The overall estimate of the ETG was 56.0/100 (95% CI: 31.1-100.0). The variation in estimates could possibly be explained by non-uniform ETG estimation methods and the diverse study populations, among other factors. The ETG was mainly attributed to inadequate skilled manpower, cost of treatment, cultural beliefs and unavailability of Anti-epileptic Drugs (AEDs). These factors have been addressed using different intervention strategies for instance education and supply of AEDs.

Conclusion

Future research should estimate the ETG coherently and develop sustainable interventions that will address the causes.

2.1 Introduction

Epilepsy is the most common chronic neurological disorder, affecting approximately 50 million people worldwide, of whom 40 million are estimated to live in Developing Countries (DCs)[*] (WHO, 2004). Several studies have reported that over 90% of People with Epilepsy (PWE) in DCs do not receive appropriate treatment for their condition, a phenomenon known as the Epilepsy Treatment Gap (ETG) (Scott *et al.*, 2001; Diop *et al.*, 2003; Diop *et al.*, 2005; Shorvon & Farmer, 1988). However, none of the studies provide a confidence interval, suggesting that the estimate is not data driven. The ETG is defined as the number of people with active epilepsy not on treatment (diagnostic and therapeutic) or on inadequate treatment, expressed as a percentage of the total number with active epilepsy (Kale, 2002; Meinardi *et al.*, 2001). The ETG also includes the influence of epilepsy on mental and social well being (Meinardi *et al.*, 2001). For the purpose of this review, active epilepsy is defined as having at least one unprovoked seizure in the last 5 years. The ETG has been estimated by the direct method during prevalence studies, and indirectly from the amount of Anti-epileptic Drugs (AEDs) consumed in the country and the number of people with active epilepsy (Kale, 2002). The gap is reported to be influenced by various factors, including lack of access to or knowledge of AEDs, poverty, cultural beliefs, stigma, poor health delivery infrastructure and shortage of trained professionals (Scott *et al.*, 2001; Meinardi *et al.*, 2001).

The Global Campaign Against Epilepsy, a partnership between the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and World Health Organization (WHO) was launched in 1997 to bring epilepsy –out of the shadows” by addressing some of the factors outlined above (Diop *et al.*, 2003; Sander, 2002). In 2002, the Global Campaign entered its second phase and several demonstration projects were set up in various countries, to reduce the ETG and the physical, economic and social burden of epilepsy through community-level interventions (Sander, 2002; Li *et al.*, 2007).

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[*] *Developing countries were defined according to the World Bank classification for low and upper middle income as a Gross National Income per capita of less than $11, 115 (http://www.worldbank.org). Estimate of the number of PWE in the world is quoted as 50 million and not 69 million as in chapter 1 because the latter estimate was not available when this paper was published.*

Despite this concerted effort by different stakeholders, there are no systematic reviews on the magnitude, causes or intervention strategies to improve the outcomes in DCs. Therefore, we conducted a systematic review of the literature on the ETG to answer the following questions:

1. What is the magnitude of the ETG in DCs?
2. What are the factors responsible for the ETG in DCs?
3. What interventions have been implemented to address causes of the ETG?

2.2 Methods

2.2.1 Data sources and search strategy

A literature search was carried out using three databases: MEDLINE (1966 – 6/2007), EMBASE (1980 – 6/2007) and PsycINFO (1887 –6/2007) using a combined text word and Medical Subject Headings (MeSH) to identify relevant papers (Appendix 2.1). Additional articles were identified by searching references cited in the key papers. The strategy was developed by breaking the review question into its elemental facets: exposure, outcome, population, publication language and keywords according to the recommendations of the National Health Service Centre for Reviews and Dissemination (Khan *et al.*, 2001) (Appendix 2.1). Publication language was left open to ascertain how many studies were available in languages other than English.

2.2.2 Study Selection

The online abstracts of studies identified from the database search were reviewed and reprints of potential eligible studies obtained. Studies meeting one of the following criteria were chosen for more detailed review:

1. Cross-sectional studies that provide the prevalence of the ETG, or studies using the indirect method to estimate the gap;
2. Qualitative or observational studies that identify potential causes of the ETG;
3. Interventions to address some of the attributed causes of the ETG: prospective cohort or those that have used randomized control or pre-post designs and focused on either education or supply of drugs.

2.2.3 Studies excluded

1. Epilepsy prevalence studies that did not estimate the ETG;
2. Studies reported in languages other than English;
3. Reviews;
4. Editorials, letters or reports;
5. Studies conducted in developed countries;
6. Studies that reported same results in different papers.

2.2.4 Data extraction

Data were extracted using a proforma designed for the review. The first reviewer extracted all the data and the fourth reviewer re-extracted data from a sample of half of the studies. The studies were organized into three broad categories: those on magnitude, attributed causes and interventions. Information from each study was then obtained on author, year of publication, country, study design, sample size, ascertainment method, length of study, age of participants and outcome. We extracted data on magnitude of the ETG and calculated a 95% Confidence Interval (CI) around the estimates. We further stratified the ETG estimates by continent and location of study (urban and rural). All data were entered in an Excel spreadsheet and transferred to STATA version 11 (StataCorp, College Station, TX, USA) for analysis.

2.2.5 Analysis

The 95% CI for the ETG estimates were calculated and heterogeneity investigated. The ETG prevalence estimates were transformed to logits (log (p/1-p)) to improve their statistical properties and later back-transformed to prevalences and expressed as percentages. For further analysis, the data was stratified by continent and location of the study. Attributed causes of the ETG were listed and compared across continents using descriptive statistics but such comparison was not performed for the interventions because they measured different outcomes and few provided numerical estimates.

2.2.6 Description of heterogeneity and summary estimates

We used a forest plot (Lewis & Clarke, 2001) to visualize the extent of heterogeneity among the studies that investigated the magnitude of the ETG. The standard test for heterogeneity, the Cochrane χ^2 test, was used to examine the null hypothesis of homogeneity. We used a method that quantifies inconsistency across studies, thus assessing its impact on the meta-analysis. This statistic is $I^2 = ((Q - df)/Q) \times 100\%$, where Q is the chi-squared statistic and df is its degrees of freedom (Higgins & Thompson, 2002; Higgins, 2003). I^2 describes the percentage of the variability in estimates that is due to true heterogeneity (true differences in ETG prevalence) and a value greater than 50% was considered substantial heterogeneity.

The mean ETG prevalence and its confidence intervals were derived from random effects meta-analysis, an analytical approach used when heterogeneity cannot be readily explained. This assumes that the outcomes being estimated in the different studies are not identical, but follow a normal distribution, allowing for variation between studies. However, the usual CI of mean in the random effects model does not take into account the between study variance and so can be narrow where there is substantial heterogeneity. We therefore calculated the 95% CI for the true ETG prevalence as the mean of logits $\pm 1.96\ell$, where ℓ is the among study standard deviation (Goodman, 1989).

2.2.7 Assessment of methodological quality

The studies were appraised by two independent reviewers based on the criteria outlined in a critical appraisal guide (Crombie, 1996) and guidelines on how to appraise a paper (Greenhalgh, 2001). The relevant methodological aspects were identified and assessed individually for each study. The studies were then rated as good, average or poor as outlined in (Appendix 2.2). We did not use a composite numerical score to reflect overall methodological quality because there is no gold standard for the ―true” methodological quality and such scores are probably neither valid nor reliable in practice (Greenhalgh, 2001). Empirical evidence and theoretical considerations suggest that although summary quality scores may in some circumstances provide a useful overall assessment, they should not generally be used to assess the quality of studies in systematic reviews because different scales give divergent scores and rankings on one study (Juni *et al.*, 1999; Greenland, 1994).

2.3 Results

The electronic search produced 130 references. A hand search of references cited in the key papers identified fifteen additional papers (Appendix 2.3). These papers were obtained and reviewed and the majority were subsequently excluded because they did not meet the review criteria: they were review articles (n=20), editorials or letters (n=12), reports (n=20), not in English (n=2), prevalence studies that did not estimate the ETG (n=19), trials of AEDs (n=10), economic evaluation studies (n=5), studies in developed countries (n=28) or studies reporting the same results in different papers (n=2).

Twenty seven studies fulfilled the inclusion criteria. Twelve (44%) were prevalence studies that measured the ETG, eight (30%) identified attributed causes of the ETG and the remaining seven (26%) reported the effect of interventions designed to address the attributed causes of the ETG. Twelve (45%) of the studies were conducted in Africa, nine (33%) in Asia, and six (22%) in Latin America.

2.3.1 Magnitude of the epilepsy treatment gap

Out of the twelve studies identified, six (50%) were conducted in Latin America (Mendizabal & Salguero, 1996; Nicoletti *et al.*, 1999; Noronha *et al.*, 2004; Medina *et al.*, 2005; Somoza *et al.*, 2005; Noronha *et al.*, 2007), three (25%) in Africa (Coleman *et al.*, 2002; Ndoye *et al.*, 2005; Dent *et al.*, 2005) and three (25%) in Asia (Aziz *et al.*, 1997b; Radhakrishnan *et al.*, 2000; Wang *et al.*, 2003). The majority, eleven (92%) were population-based cross-sectional surveys, while one (8%) used indirect method to estimate the gap. There was wide variability in the ETG estimates among the studies that provided its magnitude (Fig 2.1). The Cochrane χ^2 statistic and measure of inconsistency were large ($Q = 1331.5$, $df = 13$, $p < 0.0001$; $I^2 = 99\%$), suggesting substantial variation among the studies that was beyond sampling variation. The random effects mean of the ETG prevalence for all of the studies was 56.0/100 (95% CI for true prevalence: 31.1- 100.0). When stratified by continent, the random effects mean of the ETG prevalence for Latin America was 55.4/100 (95% CI: 39.0 -78.6), Asia 64.0/100 (95% CI: 24.3-100.0) while that of Africa was 49.0/100 (95% CI: 14.3-100.0). The mean of the ETG prevalence for urban settings was estimated at 46.8/100 (95% CI: 34.1-64.2) and 73.3/100 (95% CI: 49.5-100.0) for rural regions (Table 2.1).

The ETG estimate from Turkey was not included in this stratification because distinct figures were not provided for rural and urban regions (Aziz *et al.*, 1997b). The ETG summary is outlined in (Table 2.1) and details of individual studies in (Appendix 2.4).

Figure 2.1: Forest plot for the epilepsy treatment gap prevalence

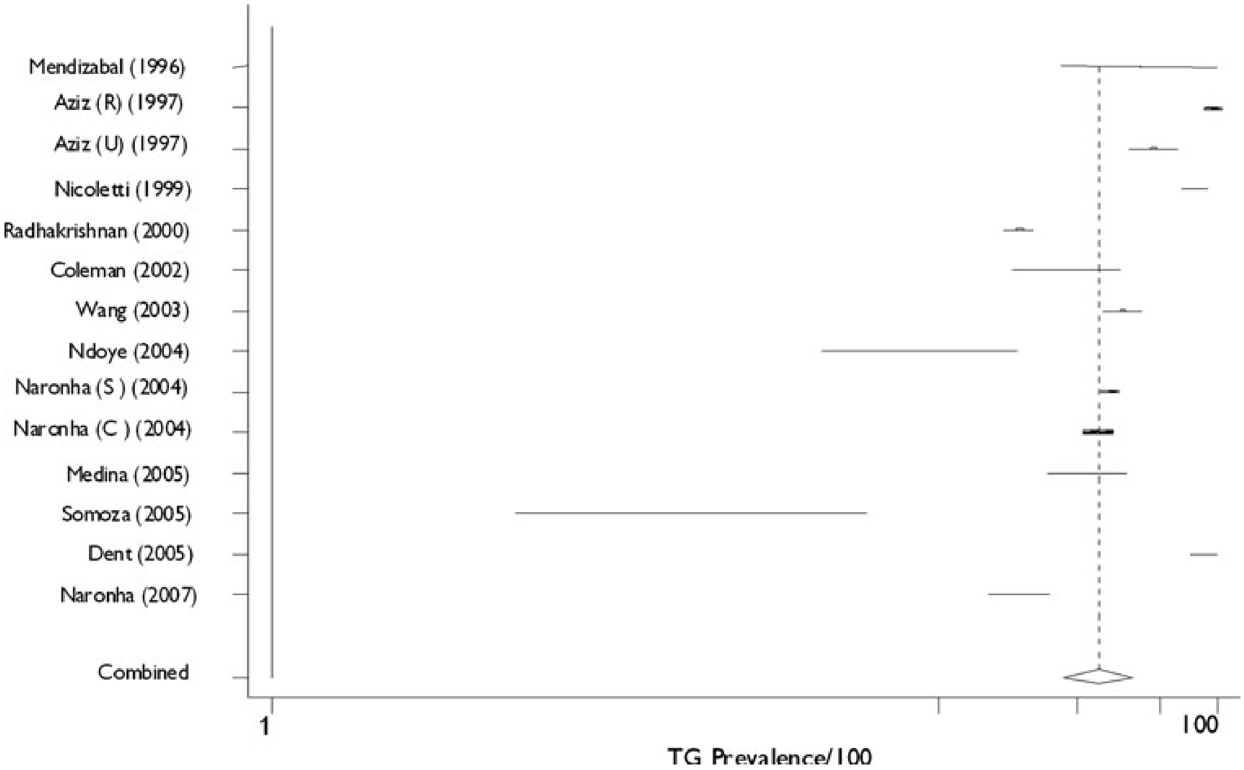

Table 2.1: Magnitude of the epilepsy treatment gap by region and location

Continent/Location	No. of studies	TG%	Lower 95% CI	Upper 95% CI
Latin America	7	55.4	39.0	78.6
Asia	4	64.0	24.3	100.0
Africa	3	49.0	14.3	100.0
Urban	7	46.8	34.1	64.2
Rural	7	73.3	49.5	100.0

2.3.2 Causes of the epilepsy treatment gap

Eight studies investigated causes of the ETG. Half were conducted in Africa (Elechi, 1991; Preux *et al.*, 2000; Bassili *et al.*, 2002; El Sharkawy *et al.*, 2006) and the other half in Asia (Pal *et al.*, 2000b; Asawavichienjinda *et al.*, 2003; Mac *et al.*, 2006; Das *et al.*, 2007). No studies were indentified from Latin America. Two were qualitative, six quantitative and one study combined both methodologies. Most of the studies were small (less than 100 participants), except two that interviewed 229 and 1450 PWE, respectively (Bassili *et al.*, 2002; Das *et al.*, 2007). All the eight studies reported that the cost associated with seeking epilepsy care contributed to the ETG (Bassili *et al.*, 2002; Das *et al.*, 2007; Pal *et al.*, 2000b; Mac *et al.*, 2006; Preux *et al.*, 2000; Elechi, 1991; Asawavichienjinda *et al.*, 2003; El Sharkawy *et al.*, 2006). Attributed causes of the ETG were multiple and overlapping in the two continents, as summarized in (Table 2.2). These causes were also similar for rural and urban regions. The highest median (70%) was associated with inadequate skilled manpower and the lowest (18.5%) with long distances to health facilities (Table 2.2). Non-adherence to AEDs, a factor that also contributes to ETG was investigated in two studies (Elechi, 1991; Asawavichienjinda *et al.*, 2003). Details of individual studies are shown in (Appendix 2.5).

Table 2.2: Cause of the epilepsy treatment gap expressed as median and range

Causes of ETG	No. of studies	Median (%)	Minimum (%)	Maximum (%)
Cost of treatment	8	62	11	90
Superstitions and cultural beliefs	5	40	7	65
Unavailability of drugs	5	53	18	44
Long distance to health facilities	3	18.5	18	19
Traditional treatment	3	44	6	82
Inadequate skilled manpower	3	70	64	76

2.3.3 Intervention strategies to address causes of the epilepsy treatment gap

Seven studies were identified that addressed attributed causes of the ETG. Five (71%) were conducted in Africa (Adamolekun *et al.*, 1999; Adamolekun *et al.*, 2000; Olley *et al.*, 2001; Berhanu *et al.*, 2002; Feksi *et al.*, 1991b) and two (29 %) in Asia (Gourie-Devi *et al.*, 2003; Liu *et al.*, 2003). No studies were indentified from Latin America. Five interventions were solely educational (Adamolekun *et al.*, 1999; Olley *et al.*, 2001; Adamolekun *et al.*, 2000; Gourie-Devi *et al.*, 2003; Liu *et al.*, 2003), one provided AEDs (Feksi *et al.*, 1991b) and one combined education with provision of AEDs (Berhanu *et al.*, 2002). The education interventions were modular in nature and were delivered verbally through workshops to PWE and health professionals. They covered different topics such as causes of epilepsy, epidemiology of epilepsy, diagnosis and management of epilepsy, psychosocial aspects and community based care. These interventions led to an increase in knowledge among PWE and health professionals, as measured by the difference between assessment before and after the intervention (Olley *et al.*, 2001; Gourie-Devi *et al.*, 2003; Adamolekun *et al.*, 1999; Liu *et al.*, 2003). In addition, education led to an increase in patient recruitment (Adamolekun *et al.*, 1999; Adamolekun *et al.*, 2000; Berhanu *et al.*, 2002). Though information pamphlets led to improvements in knowledge and a reduced default rate, they did not have any effect on adherence, as measured by self reports and serum AED levels (Adamolekun *et al.*, 1999; Liu *et al.*, 2003). However, verbal education and drug supply led to an increase in adherence (Feksi *et al.*, 1991b; Adamolekun *et al.*, 1999; Adamolekun *et al.*, 2000; Liu *et al.*, 2003). Only one study assessed psychosocial factors, which are known to affect quality of life among PWE. This study reported decreased levels of depression and neurotic disorders in the group receiving education (Olley *et al.*, 2001). Details of individual studies are summarized in (Appendix 2.6).

2.4 Discussion

2.4.1 Magnitude of the epilepsy treatment gap

A comprehensive search of the literature identified only twelve studies that estimated the magnitude of the ETG: this paucity of studies substantiates Kale's findings that the ETG as an outcome measure is not well studied in the developing world (Kale, 2002). The results of this review show that the pooled ETG estimate of 56% is lower than the 90% that is widely quoted in many studies (Scott *et al.*, 2001; Diop *et al.*, 2003; Diop *et al.*, 2005; Shorvon & Farmer, 1988; Dua *et al.*, 2006) although the CI are wide. The higher estimate is not based upon systematic review of the data and does not provide confidence intervals. To the best of our knowledge, this is the first study that comprehensively reviews the literature to assess the variability of the ETG using a robust and reproducible method. The few narrative reviews that have been conducted in DCs have addressed the epidemiology of epilepsy with a mention of the ETG (Bharucha, 2003; Mac *et al.*, 2007; Sridharan, 2002; Rajbhandari, 2004; Ray *et al.*, 2002; Shorvon & Farmer, 1988). A substantial amount of variation in the ETG among studies was demonstrated by graphical display of the estimates, a statistical test of heterogeneity and a measure of inconsistency. The pooled estimate, using a method that corrects for among study variation, provides a meaningful indication of the magnitude of the ETG. When stratified by continent, studies conducted in Africa had the highest variability whereas Latin America had the lowest. Variability was also higher in rural compared to urban areas (Table 2.1), although none of the studies in this review attempted to identify specific reasons for such rural/urban differences.

Though we did not investigate sources of heterogeneity, some variation in estimates may be explained by a failure to calculate the ETG uniformly. Seven studies calculated it using active epilepsy as the denominator (Medina *et al.*, 2005; Noronha *et al.*, 2007; Coleman *et al.*, 2002; Dent *et al.*, 2005; Aziz *et al.*, 1997b; Radhakrishnan *et al.*, 2000; Wang *et al.*, 2003) and four used both active and passive epilepsy (Mendizabal & Salguero, 1996; Nicoletti *et al.*, 1999; Ndoye *et al.*, 2005; Somoza *et al.*, 2005). In addition, studies defined active epilepsy differently: Eight confined it to five years, according to the ILAE definition (Somoza *et al.*, 2005; Coleman *et al.*, 2002; Aziz *et al.*, 1997b; Nicoletti *et al.*, 1999; Radhakrishnan *et al.*, 2000; Medina *et al.*, 2005; Dent *et al.*, 2005), two limited it to one year (Ndoye *et al.*, 2005; Wang *et al.*, 2003), whereas one study used two years (Noronha *et al.*, 2007).

Other factors that might have contributed to heterogeneity include different study populations, unskilled manpower in rural settings, variable socioeconomic conditions and diverse levels of health care development in the study regions (Nicoletti *et al.*, 1999; Jallon, 1997). The study by Somoza *et al.*, which had the widest CI (Figure 2.1) consisted of school children and only a small number failed to seek treatment. This could have been influenced by the high level of literacy and the study setting, which was described as a district where social, economic and health indicators ranked among the country‘s highest and reached levels comparable to developed countries.

2.4.2 Causes of the epilepsy treatment gap

We found that attributed causes of the large ETG in DCs were multiple and overlapped between continents (Appendix 2.5). All the eight studies included in the review reported that the cost of seeking epilepsy treatment was associated with the ETG in DCs (Bassili *et al.*, 2002; Das *et al.*, 2007; Pal *et al.*, 2000b; Mac *et al.*, 2006; Preux *et al.*, 2000; Elechi, 1991; Asawavichienjinda *et al.*, 2003; El Sharkawy *et al.*, 2006). The attributed causes with the highest medians were related to the health systems mainly: inadequate skilled manpower, cost of treatment and unavailability of drugs. This indicates that health system issues are a major obstacle for ETG. Though individual perceptions such as cultural beliefs, traditional treatment and distance to health facilities had lower medians, they greatly influence treatment seeking among PWE. The findings of this review show that superstations and cultural beliefs influence PWE to seek treatment from Traditional Healers (THs) instead of allopathic practitioners (Pal *et al.*, 2000b; Preux *et al.*, 2000; Asawavichienjinda *et al.*, 2003; El Sharkawy *et al.*, 2006; Das *et al.*, 2007). Shorvon *et al.,* also observed that many patients spent considerable amounts of money to obtain traditional cures and it was common for patients to travel hundreds of miles or donate treasured items to a healer in return for antiepileptic treatment (Shorvon & Farmer, 1988). This negates the usefulness of the advances made in the diagnosis and treatment of epilepsy (Das *et al.*, 2007; Leppik, 1988) hence the need for comprehensive programs to address these attributed causes.

2.4.3 Intervention strategies to address causes of the epilepsy treatment gap

The results of this review suggest that some attributed causes of the ETG in DCs can be addressed through educational interventions and supply of AEDs. Such interventions should target health providers (including THs), PWE and the wider community (Scott *et al.*, 2001; Berhanu *et al.*, 2002). The interventions should be tailored to the needs of each target group: those for health providers should be geared towards improving skills in diagnosis and management of epilepsy whereas for PWE emphasis should be on adherence, when and how to take AEDs as well as how to live with epilepsy. They should also include psychosocial aspects of epilepsy that may lead to the development of a positive attitude towards PWE which is essential in improving quality of life and treatment (Jallon, 1997). Educational interventions in developed and DCs have been shown to improve epilepsy knowledge, AED adherence, seizure outcome and self-esteem among PWE (Olley *et al.*, 2001; Gourie-Devi *et al.*, 2003; Adamolekun *et al.*, 1999; Liu *et al.*, 2003; Berhanu *et al.*, 2002; Snead *et al.*, 2004; Helde *et al.*, 2003; Helde *et al.*, 2005; Clark *et al.*, 2001; May & Pfafflin, 2002; Wohlrab *et al.*, 2007; Helgeson *et al.*, 1990). Other studies have suggested that adequate drug supplies have to be provided for the success of any epilepsy management program (Gourie-Devi *et al.*, 2003; Feksi *et al.*, 1991b; Mani *et al.*, 2001; Watts, 1989). However, experience in DCs with other major public health problems, particularly communicable diseases, has demonstrated that simply delivering drugs to these countries will not necessarily reduce the ETG (Reynolds, 2000). This indicates that health system interventions are not sufficient on their own. There is need to accompany such interventions with non-pharmacological, community-based interventions in order to reduce the stigma of epilepsy and reduce barriers to effective care (Krishnamoorthy *et al.*, 2003).

2.5 Limitations of the review

Studies may not have been identified at the search stage if they were not indexed in the three databases used or not published in mainstream journals. Studies on causes and interventions varied in the population studied, selection procedures, methods of ascertainment, study length and outcomes measured. Due to these variations, data from separate studies could not be statistically combined. Numeric estimates were not available for some quantitative outcomes in intervention studies hence descriptive statistics were not calculated for this section of the review.

Studies that investigated the ETG were independent of those that instituted interventions; hence it was not possible to compare differences in the ETG before and after an intervention. We did not investigate the potential sources of heterogeneity due to the small number of studies and inadequate variables in studies that estimated the ETG. Though we included all languages during the search, we were not able to translate two Chinese papers reporting magnitude of the ETG, although the abstracts indicated an estimate similar to the included studies.

2.6 Conclusion

This review provides a more accurate pooled estimate of the ETG in DCs with confidence intervals. Furthermore, it provides attributed causes of the gap and lists interventions that have been implemented to improve outcome in DCs. Given the economic, social, political and cultural context of the ETG, there is need for future research to focus on well-planned and coordinated interventions. The findings of this review suggest that such interventions should consider the medical, developmental and psychosocial needs of PWE as well as being financially, geographically and culturally accessible. These interventions should also involve health system personnel as well as other personnel such as THs who incorporate cultural beliefs and provide more comprehensive care.

Acknowledgement

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Conflict of interest

All the authors certify that they had no financial or personal interest including advisory board affiliation, in any company or organization sponsoring the research.

Appendix 2.1: Description of the search strategy

Search element	**MEDLINE**	**EMBASE**	**PSYCINFO**
Exposure	Thesaurus terms exploded AED intervention Education Intervention	Thesaurus terms exploded AED intervention Education Intervention	Thesaurus terms exploded AED intervention Education Intervention
Outcome	Thesaurus terms exploded Increased knowledge AED adherence Drug level Seizure frequency Clinic attendance	Thesaurus terms exploded Increased knowledge AED adherence Drug level Seizure frequency Clinic attendance	Thesaurus terms exploded Increased knowledge AED adherence Drug level Seizure frequency Clinic attendance
Epilepsy	Thesaurus terms exploded ***Epilepsy:*** Reflex Absence Roland Generalized Tonic-clonic Frontal Lobe Partial motor Partial sensory Post-traumatic Temporal lobe Benign neonatal Complex partial ***Epilepsies:*** Myoclonic Partial ***Myoclonic epilepsy:*** Juvenile Progressive ***Seizures:*** Alcohol withdrawal seizures Febrile seizures	Thesaurus terms exploded ***Epilepsy:*** Absence Temporal lobe Generalized Grand mal Frontal lobe Myoclonus Focal Petit mal Rolandic Reflex Startle Intractable ***Seizures:*** Atonic Audiogenic Clonic Gelastic Nocturnal	Thesaurus terms exploded ***Epilepsy:*** Absence Generalized Tonic clonic Complex partial Seizures
Developing Countries	Resource poor countries Third world countries Majority world countries South America Africa Asia	Resource poor countries Third world countries Majority world countries South America Africa Asia	Resource poor countries Third world countries Majority world countries South America Africa Asia
Treatment gap	Treatment gap Treatment status	Treatment gap Treatment status	Treatment gap Treatment status
Anti-epileptic drugs	Anticonvulsants	Anticonvulsants	Anticonvulsants
Adherence	Compliance Patient compliance Treatment refusal	Compliance Patient compliance Treatment refusal	Compliance Patient compliance Treatment refusal
Interventions	Projects Programmes	Projects Programmes	Projects Programmes
Population	Adults or Children	Adults or Children	Adults or children
Language	Any	Any	Any

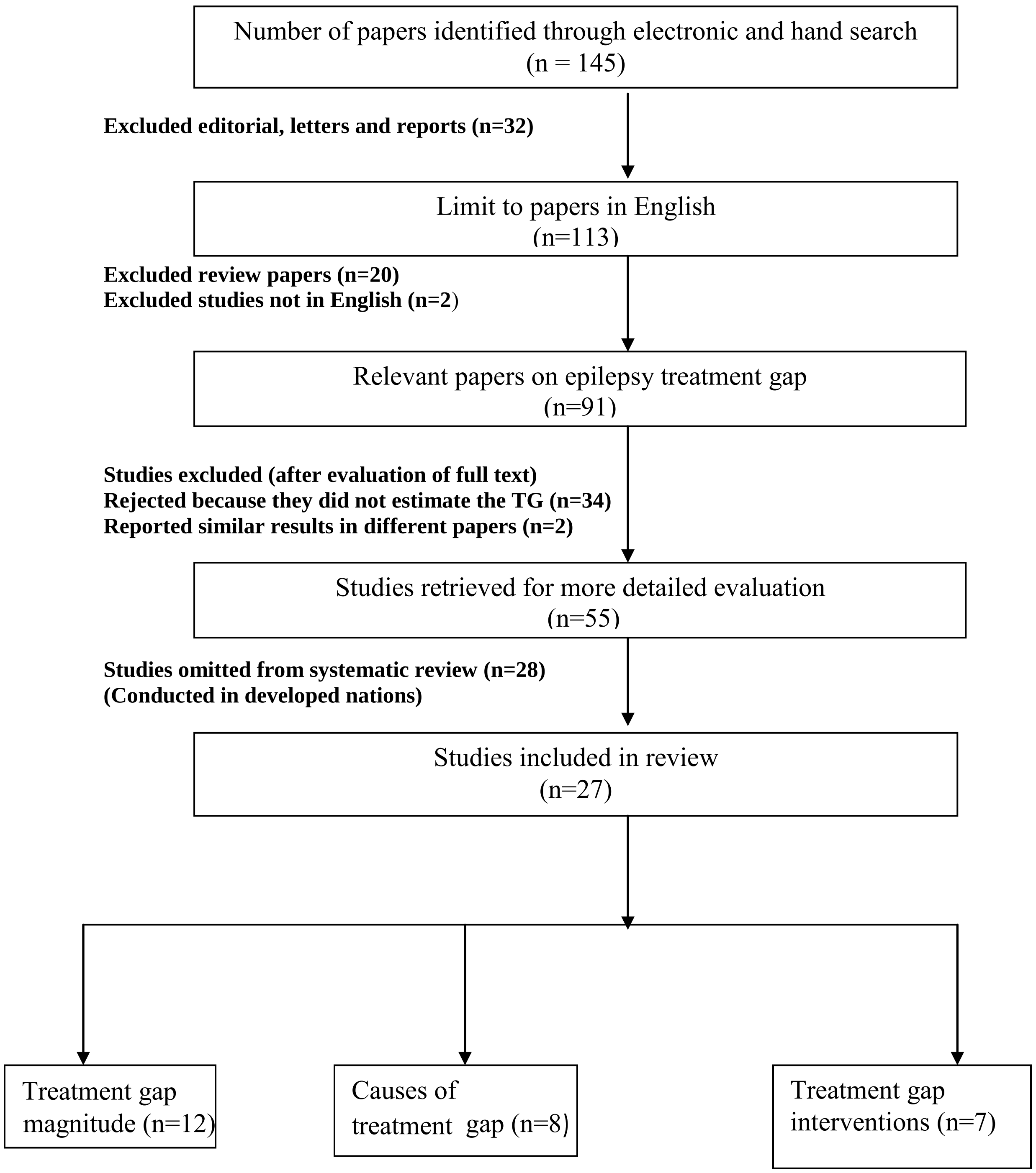
Appendix 2.2: Domain of methodological quality of studies included in the review

Cross sectional surveys				
Author	***Year***	***Description of the study population***	***Description of sampling procedure***	***Response rate***
Mendizabal	1996	Poor	Poor	Good (97.3%)
Aziz	1997	Good	Good	Good (100%)
Nicoletti	1999	Good	Good	Good (98.3%)
Radhakrishnan	2000	Good	Good	Good (98%)
Coleman	2002	Good	Good	Good (99.8%)
Wang	2003	Poor	Average	Good (94.6%)
Ndoye	2005	Good	Good	Good (100%)
Medina	2005	Good	Good 3	Good (86%)
Somoza	2005	Good	Good	Good (83.1%)
Dent	2005	Good	Good	Good (99%)
Naronha	2007	Good	Good	Good (100%)
Preux	2000	Good	Average	Average (72%)
Bassili	2002	Good	Good	Good (100%)
Thanin	2003	Good	Good	Good (89.2)
Mac	2006	Good	Good	Good (100%)
Qualitative studies				
		Description of setting and selection of subjects	***Description of data collection methods***	***Description of data analysis and quality control measures***
Gehane	2006	Good	Good	Average
Pal	2000	Average	Poor	Poor

Appendix 2.2: Continued from previous page

<table>
<tr><th colspan="5">Case control studies</th></tr>
<tr><td><i>Author</i></td><td><i>Year</i></td><td><i>Clear explanation on how cases were obtained</i></td><td><i>Selection of appropriate controls</i></td><td><i>Identical data collection for cases and controls</i></td></tr>
<tr><td>Pal</td><td>2000</td><td>Good</td><td>Good</td><td>Average</td></tr>
<tr><td colspan="5">Prospective cohort studies</td></tr>
<tr><td></td><td></td><td><i>Clear explanation of the study participants</i></td><td><i>Appropriateness of the control group if any</i></td><td><i>Adequate follow up</i></td></tr>
<tr><td>Elechi</td><td>1991</td><td>Good</td><td>N/A</td><td>Good (2.5 years)</td></tr>
<tr><td>Das</td><td>2007</td><td>Good</td><td>N/A</td><td>Good (1 year)</td></tr>
<tr><td>Adamolekun</td><td>2000</td><td>Good</td><td>N/A</td><td>Good(2 years)</td></tr>
<tr><td>Berhanu</td><td>2002</td><td>Good</td><td>N/A</td><td>Good (1.5 years)</td></tr>
<tr><td>Feksi</td><td>1991</td><td>Good</td><td>N/A</td><td>Good (1 year)</td></tr>
<tr><td colspan="5">Pre-post interventions studies</td></tr>
<tr><td></td><td></td><td><i>Description of study participants</i></td><td><i>Description of the intervention</i></td><td><i>Evaluation interval</i></td></tr>
<tr><td>Adamolekun</td><td>1999</td><td>Good</td><td>Average</td><td>Good (6 months)</td></tr>
<tr><td>Olley</td><td>2001</td><td>Good</td><td>Good</td><td>Poor (2months)</td></tr>
<tr><td>Gourie-Devi</td><td>2003</td><td>Good</td><td>Average</td><td>Average (3 months)</td></tr>
<tr><td>Liu</td><td>2003</td><td>Good</td><td>Average</td><td>Poor (1 month)</td></tr>
</table>

Appendix 2.3: Flow Diagram of Study Selection Process



Appendix 2.4: Magnitude of the epilepsy treatment gap in developing countries

Author	Year	Country	Study design	Ascertain*	Age Years	Length of study	Sample size	Active epilepsy	Prev/1000	TG %	L 95% CI	U 95% CI
Mendizabal	1996	Guatemala	CS	Q	All	N/A	1882 (R)	11	5.8	68.8	41.3	89
Aziz	1997	Pakistan Turkey	CS	Q	All	N/A	8513 (R) 15 617 (U) 6680 (R) 4817 (U)	126 (R) 115 (U) 59(R) 22 (U)	14.8 (R) 7.4 (U) 8.8 (R) 4.5(U)	98 (R) 73 (U) 70	93.2 64	99.5 80.9
Nicoletti	1999	Bolivia	CS	Q	All	2 years	9955 (R)	112	11.1	89.5	82.7	94.3
Radhakrishnan	2000	India	CS	Q	All	5 months	238 102 (SU)	1175	4.9	38	35.3	40.9
Coleman	2002	Gambia	CS	Q	All	9 months	16 200 (R)	69	4.3	48	35.6	60.2
Wang	2003	China	CS	Q	All	N/A	55 000 (R)	257	4.6	63	56.8	69.0
Ndoye	2005	Senegal	CS	Q	All	N/A	4500 (SU)	64	14.2	23.4	13.8	35.7
Noronha	2004	Brazil	Indirect method	Formula $n^1 – n^2/n^1 x100$	N/A	N/A	6324 (S) (U) 18600 (C) U)	2591 (S) 8182 (C)	18.6 (S) 18.6 (C)	59 (S) 56 (C)	57.1 55	61.0 57.1
Medina	2005	Honduras	CS	Q	All	11 days	6473 (R)	100	15.4	53.3	42.8	63.1
Somoza	2005	Argentina	CS	Q	Children	7 months	31 615 (U)	68	2.6	7.1	2.9	16.0
Dent	2005	Tanzania	CS	Q	All	5 months	4905 (R)	42	8.6	95.8	83.8	99.4
Naronha	2007	Brazil	CS	Q	All	4 months	96 300 (U)	290	5.4	38	32.3	43.8

Prev: Prevalence, TG: Treatment gap, CS: Cross sectional survey, Q: Questionnaire, R: Rural, U: Urban, SU: Semi urban, C: Campinas city, S: Sao Jose do Rio Preto city

Appendix 2.5: Causes of the epilepsy treatment gap in developing countries

Author	Year	Country	Study design	Sample size	Ascertain*	Age Years	Length of study	Causes of treatment gap
Elechi	1991	Nigeria	Prospective cohort	45 PWE (R)	Questionnaire	Adults	2 .5 yrs	Non-availability of drugs Excessive cost of drugs Continuity of seizures Side effects of drugs Long distance to health facility
Pal	2000	India	Case control Qualitative	94 children - 32 (cases) - 62 (controls) 32 parents (R)	Questionnaire Semi structured topic schedule	2-18	1 year	Seasonal income Inter-current illness in family members Domestic commitment among women Religious festivals Local cultural customs and beliefs Impassable roads during rainy season Long distance to health facilities Denial of diagnosis Drug side effects Alternative treatment Continuing seizures Lack of benefit from the treatment Symptoms resolution
Preux	2000	Cameroon	Cross sectional survey	33 PWE 26 physicians 21 pharmacists 3 distributors 8 THs (U)	Questionnaire	≥ 18	4mths	Poor health delivery infrastructure Ignorance about causes of epilepsy Uneven supply of drugs Superstitions and cultural beliefs Alternative treatment Unavailability of drugs Long term treatment Expensive to consult physician
Bassili	2002	Egypt	Cross sectional survey	229 children (U)	Questionnaire	1-15	4 mths	Lack of access to neurologists Lack of diagnostic services (EEG) Defective health education of caregivers Non-compliance to AEDs

Thanin	2003	Thailand	Cross sectional survey	72 PWE (R)	Questionnaire	≥ 15	5 mths	Misunderstanding need for long-term treatment Forgetting to take drugs Economic problems Continuity of seizures despite treatment Misbeliefs No caregiver to take PWE to hospital
Mac	2006	Vietnam	Cross sectional survey	33 pharmacies (U)	Questionnaire	Adults	2 mth	Non-availability of AEDs Cost of AEDs Lack of skilled manpower Drugs dispensed for short periods Pharmacies concentrated around hospitals and main market
Gehane	2006	Kenya	Qualitative	9 grandparents 16 parents 19 HCP 19 CWE (R)	Checklist of questions	All	N/A	Inadequate knowledge on causes epilepsy Inadequate skilled manpower Superstitions and cultural beliefs Severity of seizures Distance and time to health facilities Lack of finances Continuity of seizures despite treatment Inconsistent drug supply Alternative treatment Discrimination and stigma
Das	2007	India	Prospective cohort	1450 PWE (SU)	Questionnaire	Adults	1 year	Low annual income Unemployment Loss of jobs Marital disharmony Superstitions and beliefs and Non-availability of drugs Frustration and despair

PWE: People with Epilepsy, CWE: Children with epilepsy, THs: Traditional Healers, HCP: Health care personnel, AEDs: Antiepileptic Drugs
R: Rural, U: Urban, SU: Semi-urban

Appendix 2.6: Intervention strategies to mitigate causes of the epilepsy treatment gap

Author	Year	Country	Study Design	Sample size	Intervention/ ascertainment	Age Years	Study length	Findings
Adamolekun	1999	Zimbabwe	Pre-post	31 PHCNs 24 EHTs 296 PWE (R)	Education Questionnaire AEDs blood level	Adults	6 months	Improved knowledge in diagnosis and management of epilepsy among PHCNs by11% and EHTs by 9% as measured by pre and post test PHCNs and EHTs education led to a 35% increase in patient recruitment and drug compliance as measured by serum levels of AEDs Information pamphlets led to a reduction in patient default rate (56.3% in the control group) and 22.3% in the experimental group but did not influence drug compliance or seizure frequency
Adamolekun	2000	Zimbabwe	Prospective cohort	114 PWE (U)	Education AEDs blood level	8-56	2 years	No cases of non-compliance as defined by undetectable serum AED levels. 26% out of 38 clinically indicated cases had normal levels, 58% were below therapeutic ranges and 16 % were above the range 47% increase in PWE registered in epilepsy support group
Olley	2001	Nigeria	Pre-post	30 PWE (R)	Education Questionnaire	21-65	2 months	Significant increase in knowledge about epilepsy in the education group as measured by the knowledge about illness schedule P<0.001 Significant decrease in level of depression in education group as measured by Becks Depression Inventory (BDI) P<0.001 Significant decrease in neurotic disorders in the education group as measured by the Crown-Crisp Experiential Index (CCEI) P<0.001

Berhanu	2002	Ethiopia	Prospective cohort	813 PWE 5-10 Nurses (R)	AEDs supply Education Self reports	1-75	1.5 years	Rapid increase in number of new patients attending the clinics due to awareness created by community leaders, community health workers and the trained nurses Regular and adequate supply of phenobarbitone to each health centre
Feksi	1991	Kenya	Prospective cohort	302 PWE (R, SU)	AEDs supply AEDs blood level	6-65	1 year	76% of 249 patients had detectable serum drug concentrations and the AEDs were effective in reducing seizure frequency in 79% of the patients There was low drop-out 17%, low rate of non-compliance 6%, and good response to therapy 53%.
Gourie-Devi	2003	India	Pre-post	148 DMOs 21 SHA 28 neulog	Education Questionnaire	Adults	3 years	Increase of knowledge and skills in identification, diagnosis, investigation and management of epilepsy among DMOs as measured by pre and post test Improved understanding of issues related to compliance, medication, counselling, psychosocial and legal aspects among DMOs Endorsement of the epilepsy control program by SHAs and neurologists which lead to initiation and strengthening of epilepsy services at the periphery
Liu	2003	Taiwan	Prospective cohort Pre-post	51 PWE	Education Questionnaire AEDs blood level	18-59	7 months	Provision of drug leaflets improved medication knowledge by 30% among PWE hence an increase in Epilepsy Medication Score (EMA) $P<0.001$ Significant reduction in drug side effects after the awareness campaign $P<0.05$ Non-significant improvement in AED compliance after provision of leaflets as measured by self reports and serum AEDs levels

PHCNs: Primary Health Care Nurses, EHTs: Environmental Health Technicians, DMOs: District Medical Officers, Neulog: Neurologists, SHA: State Health Administrators, DCs: Developing Countries, R: Rural, U: Urban, SU: Semi-urban

Chapter 3

Development and validation of the Kilifi Stigma Scale for Epilepsy

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Abstract

Introduction

Stigma is considered to be one of the most important factors exerting a negative influence on the lives of People with Epilepsy (PWE) and their families. Despite its importance, there are few culturally appropriate measures to investigate it, especially in sub-Saharan Africa where the prevalence of epilepsy is high and the stigma is thought to be more severe. We developed and validated a tool to measure perceived stigma among PWE in Kilifi, Kenya.

Methods

We reviewed the existing scales that measured stigma, particularly of epilepsy. We conducted a qualitative study to determine salient concerns related to stigma in Kilifi. Themes were generated and those related to stigma were used to construct an 18-item stigma scale. A descriptive cross-sectional survey was then conducted among 673 PWE to assess the reliability and validity of the scale. Internal consistency was calculated using Cronbach‘s alpha and an interclass correlation coefficient was used to evaluate the test-retest reliability. Factor analysis was performed to examine the structure of the scale and correlation analysis was used to evaluate the relationship between the scale scores and demographic characteristics.

Results

The final scale had 15 items, which had high internal consistency (Cronbach‘s $\alpha = 0.91$) and excellent test-retest reliability ($r=0.92$). Factor analysis indicated that the scale was unidimensional with one factor solution explaining 45.8% of the variance. No association was found between perceived stigma and sex but there was an association with age, physical and sexual abuse.

Conclusion

The Kilifi Stigma Scale for Epilepsy is a culturally appropriate measure of stigma with strong psychometric properties that could be used in other resource poor settings after some adaptation and validation.

3.1 Introduction

Stigma associated with epilepsy is common in many cultures (Jacoby *et al.*, 2005) and is considered to be one of the most important factors that has a negative influence on the lives of People with Epilepsy (PWE) and their families (Baker, 2002; Morrel, 2002; Mclin & de Boer, 1995; Jacoby, 1992). It erodes individuals‘ social status, social networks and self-esteem, all which contribute to poor outcomes such as isolation, unemployment, impaired prospects for marriage and not seeking treatment (Collings, 1990; Jacoby *et al.*, 1993). PWE report that dealing with stigma and the associated prejudicial responses from others is one of their biggest challenges (Austin *et al.*, 2002). Consequently, the Global Campaign Against Epilepsy ―Out of the Shadows" project has focused attention on the problems caused by the stigma associated with epilepsy (Reynolds, 2001).

Epilepsy fits well into ‗Weiss and Ramakrishna‘ definition of stigma as ―a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem" (Weiss & Ramakrishna, 2006). Thus, epilepsy-associated stigma can best be understood by drawing a distinction between ‗enacted‘ and ‗perceived‘ stigma. Enacted stigma refers to episodes of discrimination against PWE on the grounds of their social unacceptability; whereas perceived stigma refers to the shame associated with having epilepsy and the fear of anticipated discrimination (Reis & Meinardi, 2002; Jacoby, 1994; Scambler & Hopkins, 1986). There is no distinct evidence about which type of stigma is more likely to affect treatment seeking, but we presume perceived stigma has a profound influence because it emanates from the patient.

Stigma is a complex concept to investigate in PWE because it involves personal attitudes and beliefs, elements of secrecy and disclosure management, as well as influences from the social environment (Austin *et al.*, 2004). Tools to measure perceived stigma among PWE have been developed mostly in Western countries (Jacoby *et al.*, 1993; Jacoby, 1994; Austin *et al.*, 2004; Austin & Huberty, 1993; Westbrook *et al.*, 1992; Ryan *et al.*, 1980; Austin *et al.*, 2002; Cramer *et al.*, 1999) and middle income countries (Fernandes *et al.*, 2004; Fernandes *et al.*, 2007; Fernandes *et al.*, 2008; Aziz *et al.*, 1997a). The most commonly used scale in epilepsy is a three-item scale developed by Jacoby (Jacoby, 1994), though it has been shown to produce disparate results in Western and Resource Poor Countries (RPCs) (Baker *et al.*, 1999; Baker *et al.*, 2005; Rafael *et al.*, 2010; Lee *et al.*, 2005; Birbeck *et al.*, 2007). This highlights the fact that cultural perceptions and values play an important role in understanding the concept and content of stigma by an individual. Therefore, in designing a reliable and valid tool, it is essential to accommodate the cultural beliefs and understanding of each target group. Taking this into consideration, we developed and validated a tool to measure perceived stigma among PWE in Kilifi, Kenya. Recently it was reported from Zambia that PWE experienced higher rate of physical abuse and women with epilepsy are more likely to have experienced sexual abuse (Birbeck *et al.*, 2007; Birbeck *et al.*, 2008). We hypothesized that PWE who experience abuse, whether physical or sexual, would report a much higher level of perceived stigma compared to those who had not experienced abuse.

3.2 Methods

3.2.1 Study site and previous work

The development of the scale took place in the Kilifi Health Demographic Surveillance System (KHDSS), where 86% of PWE were not receiving treatment from health facilities (Edwards *et al.*, 2008), which may be due to cultural beliefs and attitudes held by PWE (El Sharkawy *et al.*, 2006). A previous study suggested that PWE were more likely to consult Traditional Healers (THs) due to misconceptions and superstitions associated with epilepsy (Kendall-Taylor *et al.*, 2009). However, these studies did not assess the level of stigma experienced by PWE and how this might affect where and how they seek health care. Therefore, we developed the Kilifi Stigma Scale for Epilepsy (KSSE) and used it to measure perceived stigma among PWE.

3.2.2 Development of the Kilifi Stigma Scale for Epilepsy

The items for the scale were developed in three phases: (1) formative research and concept development; (2) item development and validity assessment and (3) evaluating the scale.

Phase 1: Formative research and concept development

First, we reviewed the literature to examine the existing scales that measured perceived stigma (Jacoby *et al.*, 1993; Austin *et al.*, 2002; Jacoby, 1994; Austin *et al.*, 2004; Austin & Huberty, 1993; Westbrook *et al.*, 1992; Ryan *et al.*, 1980; Cramer *et al.*, 1999; Fernandes *et al.*, 2004; Fernandes *et al.*, 2007; Fernandes *et al.*, 2008; Aziz *et al.*, 1997a). Second, we conducted a qualitative study with PWE and their caregivers to identify the issues related to stigma in Kilifi. Focus Group Discussions (FGDs) and in-depth interviews were conducted by three trained interviewers fluent in the local language. The interviews were recorded, translated and transcribed. The data were entered onto an NVivo qualitative analysis software (QSR; Melbourne, Vic, Australia; http://www.qsrinternational.com/) to enable storage, organisation and retrieval. Data were analysed using framework analysis, as described by Ritchie and Spencer (Ritchie & Spencer, 1994). Themes were independently generated from the data by two researchers (CK and JA) and once thematic consensus was reached, all the data was coded. This process served to maximise the rigour and validity of the analysis. The themes related to stigma were then used to construct the KSSE. For more information on the qualitative study refer to Chapter 9.

Phase 2: Item development and validity assessment

Item generation

The project team held discussions about the concepts to include, an appropriate response scale and the overall structure of the questionnaire. A first version was developed that contained 18-items that were considered to cover the most important aspects of perceived stigma. Eight of the 18 items in the KSSE were taken directly or revised from questions used in previous studies investigating perceived stigma in epilepsy (Jacoby *et al.*, 1993; Jacoby, 1994; Fernandes *et al.*, 2004; Fernandes *et al.*, 2007). The remaining ten items were developed from thematic analysis of FGDs and in-depth interviews. The scale was developed in English and translated into the local dialect, Kigiriama.

Scoring the scale

A simple three-point Likert scoring system was employed to make it as easy as possible to respond to the items (Atadzhanov *et al.*, 2010). PWE were asked to respond to each item by stating how much they thought a particular aspect of their life was affected by epilepsy. Responses were as follows: ―not at all‘ (score of 0), ―sometimes” (score of 1) and ―always” (score of 2). A total impact score was calculated by addition of all item scores. The higher the score, the greater the sense of perceived stigma.

Face validation of the scale

This was assessed to determine if the questionnaire contained relevant items for assessing perceived stigma in our context. Two clinicians and five research assistants with experience in epilepsy were asked to evaluate the relevance, clarity and conciseness of the items included in the questionnaire. The seven respondents were of the opinion that the questions measured stigma. Based on this initial assessment, all 18 items were retained.

The questionnaire was then pilot tested with six PWE and seven caregivers of PWE. It was administered by two interviewers fluent in the local language. The respondents were asked to: (a) comment on whether the items measured perceived stigma; (b) rate the items on a three-point rating scale (0= not at all, 1=sometimes, 2=always); (c) provide explanation supporting their decision to assign a rating to an item; and (d) comment on the clarity and flow of the questions. All 18 items were found to assess perceived stigma and were clear to all respondents.

Phase 3: Evaluating the scale

A descriptive cross-sectional survey was conducted in the KHDSS to assess the reliability and validity of the scale. Six hundred and seventy three PWE completed the scale, of whom 203 were PWE and 470 caregivers of children with epilepsy. Data on a subset of 70 PWE were then used to evaluate test-retest reliability of the scale. The interviewer administered the scale twice to the same respondents at an interval of three weeks.

3.2.3 Ethical considerations

Written informed consent was obtained from all study participants. Where PWE was a child or an adult who could not respond, a caregiver was interviewed. Approval for the study was obtained from the Kenya Medical Research Institute/ National Ethical Review Committee.

3.2.4 Data analysis

Data were double entered in MySQL and verified before being transferred to SPSS (version 15, SPSS Inc., Chicago) for analysis. Descriptive statistics were generated to evaluate the score distribution per response category. The internal consistency of the scale was calculated using Cronbach‘s alpha (α) (Cronbach, 1951). An interclass correlation coefficient was used to evaluate the test-retest reliability. Factor analysis was performed to examine the structure of the scale using varimax rotation. Items were retained if they had an item-total correlation ≥ 0.2 and a factor loading ≥ 0.40 (Dilorio *et al.*, 2004; Nunnally & Bernstein, 1994). Correlation analysis was used to evaluate the relationship between the scale scores, sex, age and history of physical and sexual abuse.

3.3 Results

3.3.1 Psychometric properties

3.3.1.1 Descriptives

The descriptive statistics show that majority of participants responded ‗not at all‘ to most of the items on the stigma scale meaning they did not feel stigmatized (Table 3.1). However, higher rate of perceived stigma was reported on three items (not relating well with family members, not being accepted by peers and not being taken seriously by other people (Table 3.1).

Table 3.1: Proportion of responses by study participants (n=673)

	Item	Not at all (%)	Sometimes (%)	Always (%)
1	Do you feel different from other people?	36.1	37.4	26.5
2	Do you feel lonely?	59.8	27.9	12.3
3	Do you feel embarrassed?	65.3	23.3	11.4
4	Do you feel disappointed in yourself?	42.0	39.7	18.3
5	Do you feel you cannot have a rewarding life?	62.0	22.7	15.3
6	Do you feel you cannot contribute anything in society?	60.9	21.6	17.5
7	Do you feel you cannot join others in public places?	56.9	19.8	23.3
8	Do you feel other people are uncomfortable with you?	59.7	29.1	11.2
9	Do you feel other people don‘t want to go to occasions with you?	57.4	27.6	15.0
10	Do you feel other people treat you like an inferior person?	54.7	26.7	18.6
11	Do you feel other people would prefer to avoid you?	62.2	25.6	12.2
12	Do you feel other people avoid exchanging greetings with you?	75.6	18.1	6.3
13	Do you feel you do not relate well with your family?	21.4	11.9	66.7
14	Do you feel you are not accepted by your peers?	6.7	18.0	75.3
15	Do you feel you are mistreated by other people?	67.8	24.8	7.4
16	Do you feel other people discriminate against you?	67.3	23.3	9.4
17	Do you feel other people do not take you seriously?	8.8	18.9	72.3
18	Do you feel other people treat you like an outcast?	69.4	19.9	10.7

3.3.1.2 Internal consistency

The alpha score for the whole scale (18 items) was 0.85. This initial analysis demonstrated that three items had a negative total correlation: not relating well with family members (-0.02), not being accepted by peers (-0.46) and not being taken seriously by other people (-0.27). After exclusion of these items, the remaining 15 items had excellent internal consistency (α =0.91). The internal consistency of the scale is outlined in (Table 3.2).

Table 3.2: Internal consistency of the Kilifi Stigma Scale for Epilepsy (n=673)

	Item	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Alpha if item deleted
1	Different	7.27	44.6	0.53	0.91
2	Lonely	7.65	44.8	0.59	0.90
3	Embarrassed	7.72	45.7	0.49	0.91
4	Disappointed	7.41	45.8	0.44	0.91
5	Rewarding life	7.64	45.9	0.42	0.91
6	Society	7.61	44.7	0.53	0.91
7	Public places	7.51	44.2	0.53	0.90
8	Uncomfortable	7.66	43.5	0.75	0.89
9	Occasions	7.60	42.9	0.74	0.89
10	Inferior	7.54	42.5	0.75	0.89
11	Avoid	7.68	43.3	0.75	0.89
12	Greetings	7.87	45.2	0.67	0.90
13	Mistreated	7.78	45.4	0.59	0.90
14	Discriminate	7.76	44.2	0.70	0.90
15	Outcast	7.76	44.5	0.64	0.90

Items were preceded with the following phrase: Do you feel…… as indicated on (Table 3.1)

3.3.1.3 Test retest reliability

Test retest reliability was estimated by computing the inter-correlation coefficient and found to be excellent (r=0.93).

3.3.1.4 Factor analysis

The dimensionality of the scale was studied using factor analysis. All the items loaded on one factor, which accounted for 45.8% of the variance (Eigenvalue=6.87). The consistently high factor loadings (0.46-0.82) strongly supported one unitary construct of the scale as depicted in (Table 3.3). These results support the use of a summated score to compute an overall index called ‗perceived stigma'.

Table 3.3: Factor loading of the fifteen items of the Kilifi Stigma Scale for Epilepsy (n=673)

	Item	Factor loading
1	Do you feel different from other people?	0.58
2	Do you feel lonely?	0.63
3	Do you feel embarrassed?	0.54
4	Do you feel disappointed in yourself?	0.48
5	Do you feel you cannot have a rewarding life?	0.46
6	Do you feel you cannot contribute anything in society?	0.57
7	Do you feel you cannot join others in public places?	0.58
8	Do you feel other people are uncomfortable with you?	0.81
9	Do you feel other people don't want to go to occasions with you?	0.81
10	Do you feel other people treat you like an inferior person?	0.82
11	Do you feel other people would prefer to avoid you?	0.82
12	Do you feel other people avoid exchanging greetings with you?	0.74
13	Do you feel you are mistreated by other people?	0.67
14	Do you feel other people discriminate against you?	0.77
15	Do you feel other people treat you like an outcast?	0.72

3.3.1.5 Construct validity

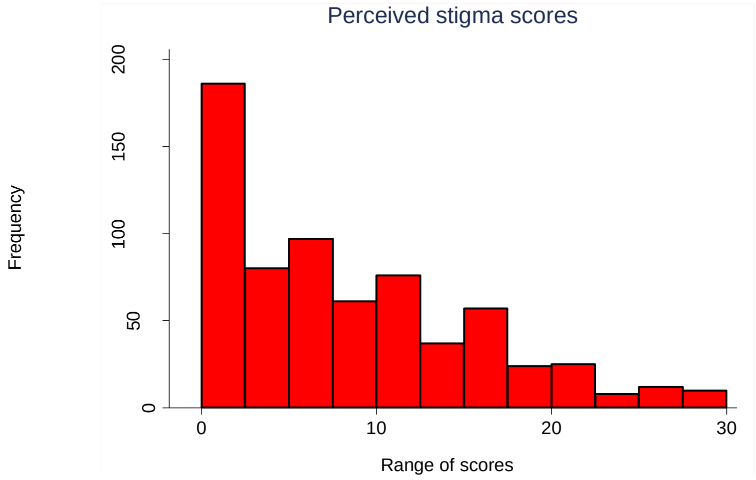
Given that we had two different samples, we split the data based on who responded to the questionnaire (203 PWE and 470 caregivers). There was no difference in internal consistency based on who responded (0.90) for PWE or (0.91) for caregivers.

Correlations were calculated to explore the relationship between socio-demographic characteristics and stigma scores. We hypothesised that there would be no differences in stigma scores by sex but we anticipated significant differences by age. Results indicated that there was no relationship between sex and perceived stigma score ($r= 0.04$, $p=0.30$). High correlations were found between age and perceived stigma score, with younger age associated with greater perception of stigma ($r=0.68$, $p<0. 03$). Our analysis confirmed there was a correlation between perceived stigma scores and physical abuse ($r=0.33$, $p<0. 001$) as well as perceived stigma score and sexual abuse ($r=0.76$, $p<0. 01$).

3.3.1.6 Perceived stigma scores

The index of stigma was calculated for each individual by adding the responses to each question. The lowest score was 0 and the highest was 30 (Figure 3.1). The lower quartile, median and upper quartile values were 2, 7, and 13 respectively. The 66th percentile was used to categorize the scores (Holding *et al.*, 2004), so that scores above 10 were considered to show the PWE who felt stigmatized. Out of the 673 respondents, 33% reported being stigmatized as measured by the KSSE.

Figure 3.1: Scores for the Kilifi Stigma Scale for Epilepsy



3.4 Discussion

The purpose of this study was to develop and evaluate a culturally-appropriate measure of perceived stigma among PWE in a rural Kenyan setting. Using a systematic approach to tool development, as previously used in Kilifi (Abubakar *et al.*, 2008; Abubakar *et al.*, 2007; Holding *et al.*, 2004), we developed a 15-item scale that provides a measure of stigma in epilepsy with proven reliability and validity.

3.4.1 Reliability

Criteria set out by Cicchetti (Cicchetti, 1994) were employed in evaluating the level of acceptability of the observed values of reliability coefficients. Correlations of 0.70 or higher are usually considered acceptable levels of internal consistency of items (Jacoby *et al.*, 1993; Cicchetti, 1994).

The excellent internal consistency and retest reliability observed in this study supported the suitability of items selected and the reliability of the tool in our setting. Furthermore the selection of culturally-appropriate items through qualitative research ensured the items were understood. The reliability of KSSE compares well to other scales developed to measure stigma in epilepsy (Jacoby *et al.*, 1993; Austin *et al.*, 2004; Fernandes *et al.*, 2007; Fernandes *et al.*, 2004).

3.4.2 Validity

Factor-analytic evidence suggests that the scale is uni-dimensional, indicating that it measured only one construct (i.e. perceived stigma). Internal consistency did not differ whether it was a PWE who responded or a caregiver. This suggests that perceived stigma of children or PWE with neuro-cognitive impairment can be assessed through a caregiver (mother, father or guardian) using the same scale.

Further analysis was conducted to examine the correlation between the demographic variables and stigma scores. Results indicated sex was not correlated with the stigma scores. However, we observed an association between perceived stigma and age, which provides support for the age-sensitivity of the scale.

Younger age was associated with greater perceptions of stigma, a finding also reported in other studies (Jacoby, 1994; Austin *et al.*, 2004; Westbrook *et al.*, 1992). Possibly, older people were less likely to report feeling stigmatized because discriminatory attitudes towards epilepsy may have less significance to them than younger people who want to fit in with peers. Given its potential negative impact there is a need to address stigma as part of a comprehensive care system especially for young PWE.

An additional approach to validation was to correlate perceived stigma and reported abuse. Consistent with our hypothesis, PWE who experience physical and sexual abuse were more likely to report more perceived stigma. This provides further evidence of the discriminant validity of the tool. Moreover, it highlights other aspects of the psychosocial needs of PWE. Future studies should examine the prevalence and impact of abuse of PWE in this context. However, such studies should also investigate physical and sexual abuse in a detailed manner in order to accurately assess the level of abuse. Our study may have underestimated the problem since we asked a single (yes/no) question regarding physical and sexual abuse.

3.4.3 Perceived stigma scores

Contrary to the observations that stigmatization and psychosocial problems for PWE are more common in RPCs (Van, 1972; Walker, 1972; Senanayake & Abeykoon, 1984), the results of our study do not indicate a high degree of perceived stigma in Kilifi. Thirty three percent of PWE felt stigmatized by their condition, which contrasts with the findings of a study in Benin that demonstrated 69% of PWE felt stigmatized (Rafael *et al.*, 2010). However, this study assessed perceived stigma using the Jacoby scale (Jacoby, 1994), that has been shown to produce disparate results in different geographical areas (Rafael *et al.*, 2010; Baker *et al.*, 1999; Baker *et al.*, 2005; Lee *et al.*, 2005; Birbeck *et al.*, 2007). The low prevalence of stigma in Kilifi could be explained by the information that PWE in the KHDSS continue to receive as a result of previous and ongoing epilepsy studies or that PWE may have deliberately unde-reported the level of stigma.

3.5 Limitations

It would have been preferable to explore concurrent validity with another stigma scale developed in an African setting but no such scale was available for this analysis.

3.6 Conclusion

Our results suggest that the KSSE is a culturally-appropriate measure with strong psychometric properties that could be adapted and validated for use in other research settings. We think that the scale allows objective quantification that can be used to assess public health interventions aimed at reducing stigma. Future work could also use the tool to understand how stigma changes over time as well as to explore reasons for the comparatively low level of stigmatization observed in this part of rural Kenya.

Acknowledgement

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Chapter 4

Development and validation of the Kilifi Epilepsy Beliefs and Attitude Scale

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Abstract

Introduction

Epilepsy remains misunderstood, particularly in Resource Poor Countries (RPCs). Studies conducted in RPCs have reported that there are considerable differences in people‘s beliefs and attitudes about epilepsy. We developed and validated a tool to assess beliefs and attitudes about epilepsy among People with Epilepsy (PWE) in Kilifi, Kenya.

Methods

A 50-item scale was developed through literature review and qualitative study findings. A descriptive cross-sectional survey was then conducted among 673 PWE to assess the reliability and validity of the scale. Internal consistency was calculated using Cronbach‘s alpha and an interclass correlation coefficient was used to evaluate the test-retest reliability. Confirmatory factor analysis was used to verify the structure of the scale and correlation analysis was used to evaluate the relationship between the scale scores and demographic characteristics.

Results

The final scale had 34 items. Alpha scores for the five subscales were as follows: causes of epilepsy: $\alpha=0.71$; biomedical treatment of epilepsy: $\alpha=0.70$; cultural treatment of epilepsy: $\alpha=0.75$; risk and safety concerns about epilepsy: $\alpha=0.56$; negative stereotype about epilepsy: $\alpha=0.76$ and entire scale $\alpha=0.70$. Test-retest reliability was acceptable for all the subscales. Participants did not differ on subscale scores by sex and age.

Conclusion

The Kilifi Epilepsy Beliefs and Attitudes Scale is a reliable and valid tool that can be used to measure beliefs and attitudes about epilepsy in RPCs. It can also be used as an evaluation tool to assess the effectiveness of interventions designed to increase knowledge, influence beliefs and improve attitudes about epilepsy.

4.1 Introduction

Epilepsy remains misunderstood, particularly in Resource Poor Countries (RPCs) (WHO, 1997; Nyamae & Biritwum, 1997). Studies indicate that negative beliefs and attitudes towards epilepsy are still prevalent among People with Epilepsy (PWE) and the general public (Rwiza *et al.*, 1993; Gambhir *et al.*, 1995; Radhakrishnan *et al.*, 2000). Beliefs are derived culturally from previous experiences, education and what people have heard and learned from families, friends and/or storytelling (Gajjar *et al.*, 2000). Attitudes are considered to develop from the evaluation of recurrent experiences within a socio-cultural context (Gajjar *et al.*, 2000; Gerow, 1993). Lack of knowledge and negative attitudes about epilepsy affects the utilization of biomedical services, particularly the use of Antiepileptic Drugs (AEDs) (El Sharkawy *et al.*, 2006; Martiniuk *et al.*, 2007). In addition, several studies have indicated that beliefs and attitudes may affect the quality of life of PWE more than seizures themselves (WHO, 1997; Gajjar *et al.*, 2000; Choi-Kwon *et al.*, 2004; Atadzhanov *et al.*, 2006).

There are a range of diverse beliefs and practices relating to the causes and treatment of epilepsy which correspond to the heterogeneity of cultures and places throughout the world (Andermann, 1995). Different models have been used to describe epilepsy in Africa, Asia, South America, North America and Middle East (Andermann, 1995; Reis, 1994; Banerjee & Banerjee, 1995; Placencia *et al.*, 1995; Khan *et al.*, 2004; Gajjar *et al.*, 2000). Despite the great differences between these cultures and settings, some generalizations can be made and traditional beliefs about epilepsy can be grouped into four main themes: epilepsy as a punishment for sin, epilepsy as bewitchment or possession, epilepsy as a contagious disease and epilepsy as a disease of the brain (Andermann, 2000). One or more of these beliefs can often be held simultaneously, for example, when people rely on both traditional and biomedical forms of healing. The problem may be complicated by different terms for epilepsy, often on perceived differences in aetiology. Thus on the coast of Kenya, El Sharkawy *et al.* found that the local community used different terms such as ‗Nyuni‘, ‗Nyago‘, ‗Nyama ya dzula‘ ‗vitsala‘ and ‗Kifafa‘ (El Sharkawy *et al.*, 2006). When medical explanations fail to help PWE to understand their condition, and the prescribed medication proves ineffective in preventing seizures, they are likely to hold onto a culture-specific meaning of the illness and beliefs about its aetiology (Gajjar *et al.*, 2000).

Understanding cultural beliefs helps to provide an insight into the way people cope with and respond to their experiences with epilepsy (Albert, 1983; Andermann, 2000; Desai *et al.*, 1998). Without knowledge of these beliefs, misunderstandings and miscommunication can occur between patients and health professionals (Albert, 1983). Treatment and other interventions may also fail. Therefore, it is important for health professionals to be familiar with patients' understanding about the causes and treatment of epilepsy so that effective communication and treatment can be maintained (Dekker, 1994; Sue, 1998; Kim *et al.*, 1996). One method to effectively assess a patient's beliefs about an illness is to administer a culturally reliable and valid tool. We developed and validated a tool to assess beliefs and attitudes about epilepsy among PWE in Kilifi, Kenya.

4.2 Methods

4.2.1 Development of the Kilifi Epilepsy Beliefs and Attitude Scale

The items for the scale were developed in four phases: (1) formative research and concept development; (2) item development and validity assessment; (3) revising the scale for the main survey and (4) evaluating the scale.

Phase 1: Formative research and concept development

This phase included literature review to locate instruments designed to measure beliefs and attitudes towards epilepsy. A number of assessments were identified and reviewed (Gajjar *et al.*, 2000; Martiniuk *et al.*, 2007; Ndoye *et al.*, 2005; George *et al.*, 2006; Dilorio *et al.*, 2004; Lowe-Pearce & Camfield, 2005; Antonak, 1990). In addition, we conducted a qualitative study to explore attitudes and beliefs relating to PWE, particularly current community perceptions and practices relating to epilepsy in Kilifi. An interview guide was developed that built on the work conducted in Kilifi by El Sharkawy and colleagues (El Sharkawy *et al.*, 2006).

Purposive sampling was used to select the participants, who included PWE and their caregivers, community health workers, traditional healers, nurses, clinicians and doctors. Efforts were made to ensure that all groups included males and females and that groups of children/parents of children with epilepsy covered the spectrum of disease severity. Focus group discussions and in-depth interviews were conducted by three trained interviewers fluent in Kigiriama, Kiswahili and English. The interviews were recorded, translated and transcribed. The data were entered onto an NVivo qualitative analysis software (QSR; Melbourne, Vic, Australia; http://www.qsrinternational.com/) to enable storage, organisation and retrieval. Data were analysed using framework analysis, as described by Ritchie and Spencer (Ritchie & Spencer, 1994). Themes were independently generated from the data by two researchers (CK and JA) and once thematic consensus was reached, all the data were coded. This process served to maximise the rigour and validity of the analysis. For further information on the qualitative study, refer to Chapter 9.

Phase 2: Item development and content validity assessment

Item generation

Based on the literature review and qualitative study findings, a pool of 56 items was generated. Twenty-eight of the 56 items in the Kilifi Epilepsy Beliefs and Attitudes Scale (KEBAS) were taken directly or adapted from questions used in previous studies investigating beliefs and attitudes towards epilepsy (Gajjar *et al.*, 2000; Martiniuk *et al.*, 2007; Ndoye *et al.*, 2005; George *et al.*, 2006; Dilorio *et al.*, 2004; Lowe-Pearce & Camfield, 2005; Antonak, 1990). The remaining items were newly-developed from qualitative study findings. The items were grouped into five subscales: causes of epilepsy (n=14); biomedical treatment of epilepsy (n=13); cultural treatment of epilepsy (n=12); risk and safety concerns about epilepsy (n=5) and negative stereotypes about epilepsy (n=12). This grouping was informed by previous studies (Gajjar *et al.*, 2000; Dilorio *et al.*, 2004; Kobau *et al.*, 2006; Martiniuk *et al.*, 2007), as well as themes from the qualitative study.

Items were worded both positively and negatively within the same subscale to avoid acquiescence, affirmation or agreement bias (DeVellis, 1991). The scale was developed in English and translated into Kigiriama, which is the local language spoken in Kilifi District, and underwent a process of back translation.

Scoring the questionnaire

The 56-item questionnaire used a 4-point Likert scale scored from 1 to 4 (Aday, 1996). The scores were assigned as follows: 0=not at all, 1=believe a little, 2= believe a lot and 3=totally believe.

Positive questions were those in which _totally believe‘ was the most positive belief or attitude with a score of _3‘ (26 items). Reverse scoring was used for negative questions where _not at all‘ was the most positive belief or attitude with a score of _3‘ (30 items). This ensured the positively and negatively worded items were scored in the same direction. The total score ranges for the five subscales were as follows: causes of epilepsy: 0-42; biomedical treatment: 0-39; cultural treatment: 0-36; risk and safety concerns: 0-15; and negative stereotypes: 0-36. Higher scores reflected positive believes and attitudes about epilepsy.

Face validation of the scale

This was assessed to determine if the scale contained items that could be used to measure beliefs and attitudes about epilepsy. Two clinicians and five research assistants with experience in epilepsy were asked to evaluate the relevance, clarity and conciseness of the items included in the questionnaire. They were asked to determine whether the set of items accurately represented the concept under study by answering the following questions.

1. Do you think the questions measure beliefs and attitudes about epilepsy found in this community?
2. Are all these questions relevant? If not, specify which ones are irrelevant?

The seven respondents were of the opinion that the questions measured beliefs and attitudes found in the community. They also agreed on the item subscales but recommended minor revisions in the wording and structuring of some items. Based on this initial assessment, all the 56 items were retained.

The questionnaire was then pilot tested with six PWE and seven caregivers of Childern with Epilepsy (CWE). It was administered by two interviewers fluent in the local language. The respondents were asked to (a) comment on whether the items measured beliefs and attitudes about epilepsy; (b) rate the items on the 4-point rating scale; (c) provide explanation supporting their decision to give a certain rating (high or low) to an item; (d) comment on the time required to complete the scale; (e) comment on the clarity and flow of the questions; and (f) comment on the cultural adaptation and sensitivity of the items. The outcome of the pilot indicated that six of the 56 items were not relevant for the purpose of the study. The six questions and reasons why they were not relevant are outlined on (Table 4.1).

Table 4.1: Items that were not considered relevant after piloting the Kilifi Epilepsy Beliefs and Attitude Scale

	Item	Reason for irrelevance
1	I believe epilepsy can be a result of having water in the brain	Respondent said they have never heard of water in the brain. It was difficult to describe hydrocephalus in local language
2	I believe that having fever can cause epilepsy	Respondents interpreted fever as malaria and there was already an item on malaria/fever
3	I believe that when a child is born and the immediate sibling enters and cries before the newborn does, then the newborn can have epilepsy	The concept was not familiar to all respondents
4	I believe prayers can treat epilepsy	Question was answered on religious grounds and was not relevant to all respondents
5	I believe that drugs can cure epilepsy completely	Not clear whether the type of drugs referred to were ―traditional or biomedical"
6	I believe there is no cure for epilepsy	The word ―cure ―was ambiguous to some respondents as it meant being seizure-free for life

The remaining 50 items were found to assess beliefs and attitudes about epilepsy and were reported to be clear to all respondents. This high level of acceptability may be explained by the use of qualitative findings to develop the scale. However, respondents said that the time required to complete the questionnaire (30-45 minutes) was too long. All of the respondents repeatedly referred to their unique epilepsy experience during the interview. They also offered divergent explanations even when they assigned the same rating to an item. This made it difficult to make generalizations about a particular group‘s ratings to the items. Maintaining focus in the interview was also a challenge: to control for this, we decided to add a vignette describing a child with epilepsy to the introduction of the scale. We adopted the vignette used in the Gajjar study (Gajjar *et al.*, 2000), but modified it to reflect secondary generalized tonic-clonic seizures which are the most common form of epilepsy in our population (Munyoki *et al.*, 2010).

Phase 3: Revising the questionnaire for the main survey

Some changes were made based on the pilot information. The revised version of the scale had 50 items and five subscales: causes of epilepsy (n=11); biomedical treatment (n=13); cultural treatment (n=9); risk and safety concerns (n=5) and negative stereotype (n=12). We maintained the 4-point Likert scale but changed the response categories as follows: the response ‗believe a lot‘ was deleted because participants did not differentiate it from the ‗totally believe‘ response. We added the response ‗don‘t know‘ because several respondents had indicated they did not know how to answer an item. This helped to minimize the perceived threat of the questions and to decrease the tendency of the respondents to guess. The new scores were assigned as follows: 0=not at all, 1=believe a little, 2=totally believe and missing (.)= don‘t know. Positive questions were those in which ‗totally believe‘ was the most positive belief or attitude with a score of ‗2‘ (23 items). Reverse scoring was used for negative questions where ‗not at all‘ was the most positive belief or attitude with a score of ‗2‘ (27 items). The total score ranges for the five subscales were as follows: causes of epilepsy: 0-22; biomedical treatment: 0-26; cultural treatment: 0-18, risk and safety concerns: 0-10 and negative stereotype: 0-24. Higher scores reflected positive beliefs and attitudes about epilepsy.

Phase 4: Evaluating the scale

A descriptive cross-sectional survey was conducted in the Kilifi Health Demographic Surveillance System (KHDSS) to assess reliability and validity of the scale. Six hundred and seventy-three PWE completed the scale, of whom 203 were PWE and 470 caregivers of CWE. Data on a subset of 65 PWE were then used to evaluate test-retest reliability of the scale. The interviewer administered the scale twice to the same respondents at an interval of three weeks.

4.2.2 Ethical considerations

Written informed consent was obtained from all study participants. Where the PWE was a child or an adult who could not respond, a caregiver was interviewed. Approval for the study was obtained from the Kenya Medical Research Institute/ National Ethical Review Committee.

4.2.3 Data analysis

Data were double entered in MySQL and verified before being transferred to SPSS (version 15, SPSS Inc., Chicago) for analysis. Descriptive statistics were generated to evaluate the score distribution per response category. The internal consistency of the entire scale and subscales was calculated using Cronbach‘s alpha (α) (Cronbach, 1951). An interclass correlation coefficient was used to evaluate the test-retest reliability. Confirmatory factor analysis was performed for each subscale using varimax rotation. Items were retained if they had an item-total correlation ≥ 0.2 and a factor loading ≥ 0.40 (Nunnally & Bernstein, 1994; Dilorio *et al.*, 2004). Correlation analysis was used to evaluate the relationship between subscale total scores, sex and age.

The ―don‘t know” responses were recorded as missing values. To ensure missing data did not have an undue effect on the scale, we excluded twelve items that had considerable missing information (more than 10% of the respondents had not answered) (Jarvie *et al.*, 1993). This reduced the number of items on the scale from 50 to 38. We estimated the probable values of the items that did not have substantial missing data using multiple imputation (Rubin, 1976; Allison, 2000).

4.3 Results

4.3.1 Psychometric properties of the final scale

4.3.1.1 Descriptives

The descriptive statistics show that majority of participants responded ‗totally believe‘ to three subscales (causes of epilepsy, biomedical treatment, risks and safety concerns) meaning they had positive beliefs about epilepsy (Table 4.2). In the other two subscales (cultural treatment and negative stereotypes) majority of participants responded ―not at all” which also showed they had positive beliefs since most items in the two scales were reverse coded (Table 4.2).

Table 4.2: Proportion of responses by study participants (n=673)

	Item	Not at all (%)	Believe a little (%)	Totally believe (%)
	Causes of epilepsy subscale			
1	…Epilepsy is inherited	22.0	11.6	66.4
2	…Head injury causes epilepsy	21.7	10.4	67.9
3	…Injury at birth causes epilepsy	42.6	5.4	50.0
4	…Malaria/fever causes epilepsy	10.2	7.0	82.8
5	…Brain damage causes epilepsy	20.0	9.6	70.4
	Biomedical treatment subscale			
6	…It is possible to treat epilepsy	9.0	8.5	82.5
7	…AEDs should be taken continuously for them to work	3.4	2.8	93.8
8	…AEDs are available in health facilities	4.9	4.9	90.2
9	…*Nyuni** is better treated by a doctor	3.9	5.5	90.6
10	…PWE should be put in a safe place during a fit	0.2	1.0	98.8
11	…AEDs control seizures	2.5	5.2	92.3
12	…Missing AEDs can make PWE fit	9.4	4.0	86.6
13	…*Vitsala** is better treated by a doctor	3.6	3.6	92.8
14	…AEDs can cause side effects	26.3	6.1	67.6
	Cultural treatment subscale			
15	…PWE who are burnt never get healed	41.6	5.2	53.2
16	…*Nyuni** is treatable but not *Vitsala**	57.9	5.8	36.3
17	…*Vitsala** is better treated by a *Mganga**	62.1	11.0	26.9
18	…Pouring water on PWE during a fit treats epilepsy	59.9	8.2	31.9
19	…Smearing paraffin on PWE during a fit treats epilepsy	61.4	5.9	32.7
20	…Fumigation treats epilepsy	64.0	7.0	29.0

Table 4.2: Continued from previous page

	Item	Not at all (%)	Believe a little (%)	Totally believe (%)
21	…It good to put a stick in the mouth of PWE during a fit	53.3	3.2	43.5
22	…Joints of PWE should be straightened during a fit	51.7	4.3	44
23	…*Nyuni** is better treated by a *Mganga**	70.1	9.4	20.5
	Risks and safety concerns subscale			
24	…PWE cannot climb trees	8.9	3.4	87.7
25	…PWE cannot drive	12.6	3.4	84.0
26	…PWE should avoid being near fires	1.2	1.9	96.9
27	…PWE should avoid being near waters	1.6	1.5	96.9
	Negative stereotypes subscale			
28	…PWE cannot marry	48.6	13.1	38.3
29	…PWE cannot go to school	58.7	7.0	34.3
30	…PWE cannot have a job	47.1	9.8	43.1
31	…PWE cannot lead a normal life	29.7	6.1	64.2
32	…PWE should be isolated	78.6	1.5	19.9
33	…PWE should be rejected	72.2	2.7	25.1
34	…PWE should be resented	89.9	1.6	8.5
35	…PWE are a burden	26.0	3.3	70.7
36	…PWE perform poorly in school	17.7	12.8	69.5
37	…PWE are dull	21.4	16.5	62.1
38	…PWE are mad	42.0	10.6	47.4

Items were preceded with the following phrase: I believe….
PWE: People with Epilepsy; AEDs: Antiepileptic Drugs; SD: Standard Deviation
**Nyuni: Fever provoked seizures or febrile convulsions*
**Vitsala: A local term for epilepsy or non-fever-provoked seizures*
**Mganga: Traditional Healer*

4.3.1.2 Internal consistency

The initial analysis demonstrated that four items had an item-total correlation < 0.2: one from the biomedical treatment subscale and three from the negative stereotype subscale: AEDs can cause side effects (-0.05); PWE cannot lead a normal life (0.13); PWE should be resented (0.10) and PWE are a burden (0.17). After exclusion of these items, the final scale had 34 items and alpha scores for the five subscales were as follows: causes of epilepsy: α=0.71; biomedical treatment: α=0.70; cultural treatment: α=0.75; risk and safety concerns: α=0.56; negative stereotype: α=0.76 and entire scale α =0.70. The internal consistency of the subscales is outlined on (Table 4.3).

Table 4.3: Internal consistency of the five subscales of the Kilifi Epilepsy Beliefs and Attitude Scale (n=673)

	Item	**Scale mean if Item deleted**	**Scale variance if Item deleted**	**Corrected item-total correlation**	**Alpha if Item deleted**
	Causes of epilepsy subscale				
1	…Epilepsy is inherited	6.50	3.85	0.34	0.68
2	…Head injury causes epilepsy	6.44	3.49	0.55	0.58
3	…Injury at birth causes epilepsy	6.66	3.22	0.47	0.63
4	…Malaria causes epilepsy	6.27	4.11	0.44	0.64
5	…Brain damage causes epilepsy	6.35	3.99	0.43	0.64
	Biomedical treatment subscale				
6	…It is possible to treat epilepsy	13.32	2.26	0.45	0.67
7	…AEDs should be taken continuously for them to work	13.17	2.83	0.36	0.68
8	…AEDs are available in health facilities	13.21	2.41	0.59	0.62
9	…*Nyuni** is better treated by a doctor	13.20	2.74	0.36	0.68
10	…PWE should be put in a safe place during a fit	13.10	3.25	0.27	0.71
11	…AEDs control seizures	13.18	2.63	0.55	0.64
12	…Missing AEDs can make PWE fit	13.27	2.67	0.24	0.72
13	…*Vitsala** is better treated by a doctor	13.17	2.68	0.52	0.65

Table 4.3: Continued from previous page

	Item	Scale mean	Scale variance	Correlation	Alpha
	Cultural treatment subscale				
14	…PWE who are burnt never get healed	9.86	19.1	0.31	0.74
15	…*Nyuni** is treatable but not *vitsala**	9.53	18.6	0.38	0.73
16	…*Vitsala** is better treated by a *mganga**	9.39	18.7	0.42	0.72
17	…Pouring water on PWE during a fit treats epilepsy	9.47	18.3	0.43	0.72
18	…Smearing paraffin on PWE during a fit treats epilepsy	9.50	18.2	0.44	0.72
19	…Fumigation treats epilepsy	9.41	17.7	0.54	0.70
20	…It is good to put a stick in the mouth of PWE during a fit	9.70	18.3	0.41	0.72
21	…Joints of PWE should be straightened during a fit	9.69	18.2	0.41	0.72
22	…*Nyuni** is better treated by a *mganga**	9.25	18.6	0.47	0.72
	Risks and safety concerns subscale				
23	…PWE cannot climb trees	5.66	0.79	0.39	0.46
24	…PWE cannot drive	5.70	0.69	0.41	0.46
25	…PWE should avoid being near fires	5.48	1.25	0.43	0.50
26	…PWE should avoid being near waters	5.49	1.25	0.36	0.52
	Negative stereotype subscale				
27	…PWE cannot marry	7.30	14.6	0.43	0.74
28	…PWE cannot go to school	7.16	13.6	0.59	0.71
29	…PWE cannot have a job	7.37	13.7	0.56	0.72
30	…PWE should be isolated	6.81	15.2	0.43	0.74
31	…PWE should be rejected	6.93	15.0	0.41	0.75
32	…PWE perform poorly in school	7.93	15.2	0.46	0.74
33	…PWE are dull	7.82	14.4	0.57	0.72
34	…PWE are mad	7.45	15.6	0.27	0.77

Items were preceded with the following phrase: I believe…..
PWE: People with Epilepsy; AEDs: Antiepileptic Drugs
**Nyuni: Fever provoked seizures or febrile convulsions*
**Vitsala: A local term for epilepsy or non-fever-provoked seizures*
**Mganga: Traditional Healer*

4.3.1.3 Test retest reliability

Test retest reliability coefficients estimated by calculating the inter correlation coefficient were as follows: causes of epilepsy: r=0.64; biomedical treatment: r= 0.70; cultural treatment: r=0.70; risk and safety concerns: r=0.80; negative stereotype: r=0.81 and entire scale r=0.70.

4.3.1.4 Factor analysis

The dimensionality of the scale was studied using factor analysis. Items in each subscale had a high factor loading (≥0.40) as outlined on (Table 4.4). The variance explained by each subscale was: causes of epilepsy: 45.3% (eigenvalue=2.27); biomedical treatment: 36.1% (eigenvalue= 2.89); cultural treatment: 33.4% (eigenvalue=3.01); risk and safety concerns: 50.2% (eigenvalue=2.01) and negative stereotypes 38.7% (eigenvalue=3.10).

Table 4.4: Confirmatory factors analysis and factor loadings of the five subscales Kilifi Epilepsy Beliefs and Attitude Scale (n=673)

	Item	Causes of epilepsy	Biomedical treatment	Cultural treatment	Risk concerns	Negative stereotypes
1	…Epilepsy is inherited	0.54				
2	…Head injury causes epilepsy	0.77				
3	…Injury at birth causes epilepsy	0.69				
4	…Malaria causes epilepsy	0.68				
5	…Brain damage causes epilepsy	0.67				
6	…It is possible to treat epilepsy		0.62			
7	…AEDs should be taken continuously for them to work		0.46			
8	…AEDs are available in health facilities		0.78			
9	…*Nyuni** is better treated by a doctor		0.57			
10	…PWE should be put in a safe place during a fit		0.40			
11	…AEDs control seizures		0.75			
12	…Missing AEDs can make PWE fit		0.34			
13	…*Vitsala** is better treated by a doctor		0.73			

Table 4.4: Continued from previous page

	Item	Causes epilepsy	Biomedical treatment	Cultural treatment	Risk concerns	Negative stereotypes
14	…PWE who are burnt never get healed			0.43		
15	…*Nyuni** is treatable but not Vitsala*			0.51		
16	…*Vitsala** is better treated by *Mganga**			0.58		
17	…Pouring water on PWE during a fit treats epilepsy			0.59		
18	…Smearing paraffin on PWE during a fit treats epilepsy			0.60		
19	…Fumigation treats epilepsy			0.70		
20	…It is good to put a stick in the mouth of PWE during a fit			0.56		
21	…Joints of PWE should be straightened during a fit			0.56		
22	…*Nyuni** is better treated by *Mganga**			0.63		
23	…PWE cannot climb trees				0.55	
24	…PWE cannot drive				0.58	
25	…PWE should avoid being near fires				0.84	
26	…PWE should avoid being near waters				0.81	
27	…PWE cannot marry					0.59
28	…PWE cannot go to school					0.74
29	…PWE cannot have a job					0.72
30	…PWE should be isolated					0.57
31	…PWE should be rejected					0.56
32	…PWE perform poorly in school					0.62
33	…PWE are dull					0.72
34	…PWE are mad					0.40

Items were preceded with the following phrase: I believe….
PWE: People with epilepsy; AEDs: Antiepileptic drugs
**Nyuni: Fever provoked seizures or febrile convulsions*
**Vitsala: A local term for epilepsy or non-fever-provoked seizures*
**Mganga: Traditional Healer*

4.3.1.5 Construct validity

Given that we had two different samples, we split the data based on who responded to the questionnaire (203 PWE and 470 caregivers). There was no difference in internal consistency based on who responded ($\alpha=0.79$) for PWE and ($\alpha=0.76$) for caregivers.

Correlations were calculated to explore the relation between sex and each subscale total score. We hypothesised that there would be no differences in subscale scores by sex but we anticipated a significant difference by age. There was no relationship between sex and any subscale scores (causes of epilepsy: $r=0.01$, $p=0.76$; biomedical treatment: $r=0.01$, $p=0.71$; cultural treatment: $r=0.02$, $p=0.97$; risk and safety concerns: $r=0.06$, $p=0.08$; negative stereotype $r=0.01$, $p=0.80$).

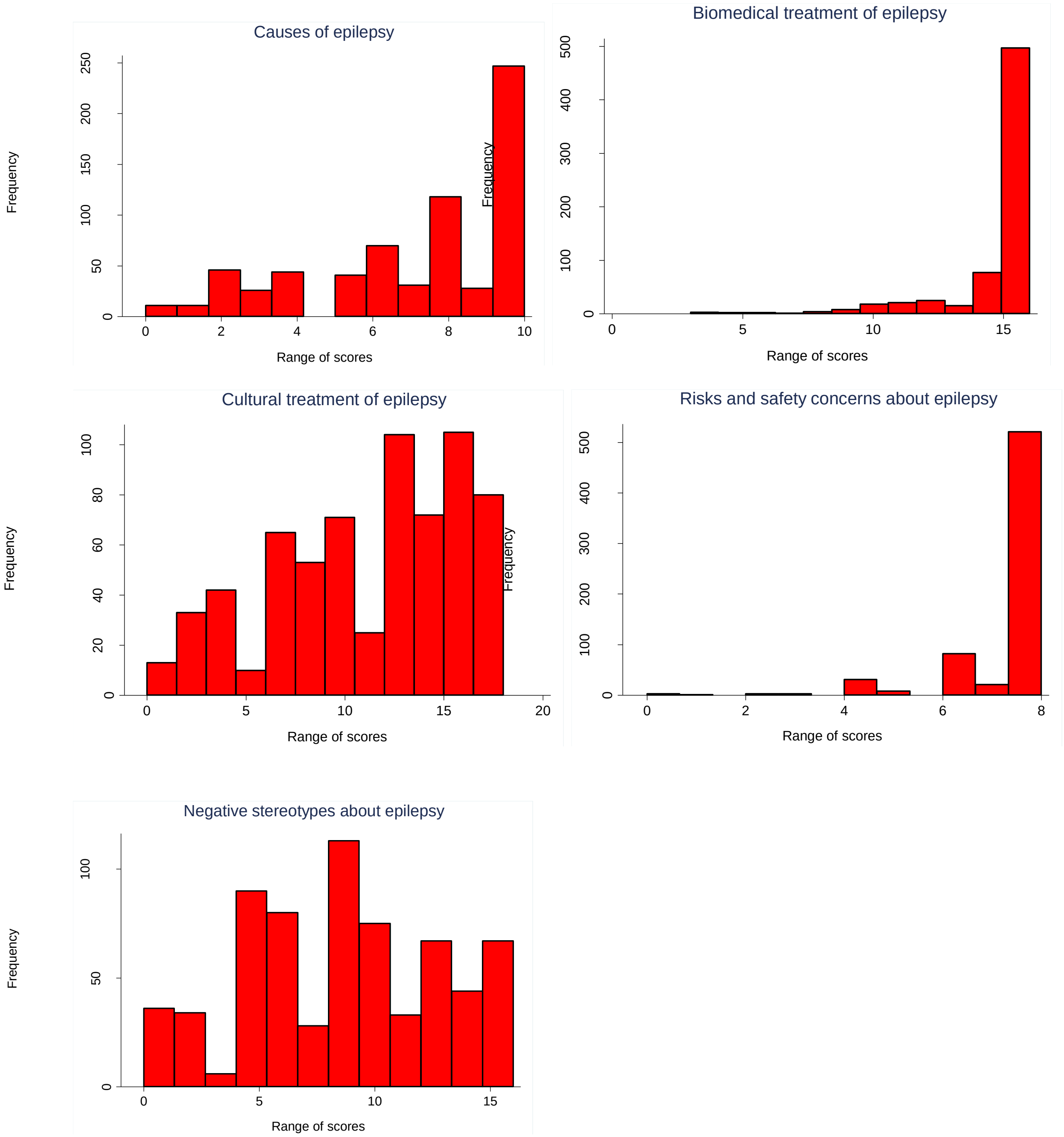
The age sensitivity of the subscales was investigated by examining their correlations with age: There was no relationship between age and any subscale scores: (causes of epilepsy: $r=0.02$, $p=0.64$; biomedical treatment: $r=0.02$, $p<0.68$; cultural treatment: $r=0.04$, $p<0.31$; risk and safety concerns: $r=0.02$, $p<0.66$; negative stereotypes: $r=0.14$, $p< 0.54$).

4.3.1.6 Beliefs and attitude scores

The final scale had 34 items and the number of items in each subscale was as follows: causes of epilepsy (n=5); biomedical treatment of epilepsy (n=8); cultural treatment of epilepsy (n=9); risks and safety concerns about epilepsy (n=4) and negative stereotypes about epilepsy (n=8). The total score ranges for the five subscales were as follows: causes of epilepsy: 0-10, biomedical treatment: 0-16, cultural treatment: 0-18; risk and safety concerns: 0-8 and negative stereotypes: 0-16 (Figure 4.1). The 66th percentile was used to categorize the scores in each subscale (Holding *et al.*, 2004). Those below the percentile were categorized as having negative beliefs and attitudes about epilepsy and those above were considered to have positive beliefs and attitudes about epilepsy. The categories for the negative beliefs were as follows: causes of epilepsy: 0-6; biomedical treatment: 0-11; cultural treatment: 0-14; risks and safety concerns: 0-5 and negative stereotypes: 0-10. The categories for the positive beliefs were as follows: causes of epilepsy: 7-10; biomedical treatment: 12-16; cultural treatment: 15-18; risks and safety concerns: 6-8 and negative stereotypes: 11-16.

Out of the 673 respondents, the majority had positives beliefs and attitudes about epilepsy as depicted in (Figure 4.1): causes of epilepsy (63%); biomedical treatment (91%); cultural treatment (73%); risks and safety concerns (93%) and negative stereotypes (69%). This may be explained by the level of exposure to health information that PWE in KHDSS have received and continue to receive.

Figure 4.1: Scores for the five subscales of the Kilifi Epilepsy Beliefs and Attitude Scale



4.4 Discussion

The purpose of this study was to develop and evaluate a tool to measure epilepsy beliefs and attitudes among PWE in Kilifi. Literature review and formative research were undertaken to identify beliefs and attitudes about epilepsy. This led to the development of a tool that had five subscales, which represented medical and nonmedical beliefs about epilepsy.

4.4.1 Reliability

Criteria set out by Cicchetti (Cicchetti, 1994) were employed in evaluating the level of acceptability of the observed values of the reliability coefficient. Correlations of $\alpha = 0.70$ or higher are considered acceptable levels of internal consistency. Reliability analysis demonstrated an acceptable alpha for the overall scale ($\alpha=0.70$). Alpha values for the four subscales were also acceptable, ranging from $\alpha=0.70$ to $\alpha=0.76$ which demonstrated adequate internal consistency meeting the standard criteria for scale development (De Vellis, 1991; Cicchetti, 1994). However, the risks and safety concerns subscale demonstrated poor internal consistency ($\alpha=0.56$) which could be attributed to the few items in this subscale.

The items in each subscale had acceptable item-to-total correlation ($r=0.24$-0.59) (Aday, 1996; Martiniuk *et al.*, 2007), suggesting that all the items correlated well with the overall subscale scores. According to the criteria set out by Cicchetti (Cicchetti, 1994), the test retest reliability for three subscales was good ($r=0.64$ to $r=0.70$) and for two subscales was excellent ($r=0.80$ to $r=0.81$). This suggests the subscales are highly repeatable and thus adequately reliable.

4.4.2 Validity

The confirmatory factor analysis suggests that the scale is not uni-dimensional, since it did not measure one construct. It had five subscales assessing different types of beliefs and attitudes among PWE. The first factor assessing causes of epilepsy captured what is perceived to cause recurrent seizures. The one on biomedical treatment looked at beliefs surrounding modern medicine, whereas the cultural treatment looked at beliefs that have a cultural orientation. The risk and safety concerns addressed activities that are perceived to be dangerous for PWE due to the unpredictability of seizures.

The final subscale assessing negative stereotypes captured beliefs that could lead to the segregation of PWE. The items in all the subscales had strong factor loading (≥0.40) (Dilorio *et al.*, 2004), similar to that reported in other studies (Dilorio *et al.*, 2004; Kobau *et al.*, 2006; Martiniuk *et al.*, 2007). Internal consistency did not differ whether it was a PWE who responded or a caregiver. This suggests that beliefs and attitudes of children or PWE with neuro-cognitive impairment can be assessed through a caregiver using the same scale.

Further analysis was conducted to examine the correlation between the demographic variables and participants' subscale scores. Results indicated that sex and age were not correlated with any of the subscale scores. The absence of sex differences supports the validity of the scale hence failure to reject our hypothesis. The correlations did not provide support for the age-sensitivity of the subscales scores hence rejection of our hypothesis. These findings lend support to the utility of the KEBAS as a tool that could capture differences in beliefs and attitudes among participants regardless of sex and age. These findings are supported by other studies that showed beliefs and attitudes did not vary by these two demographic variables (Gajjar *et al.*, 2000; Kobau *et al.*, 2006), although this is contradicted by other studies (Dilorio *et al.*, 2004; Lowe-Pearce & Camfield, 2005).

4.4.3 Strengths

The use of a Likert scale provided a systematic method of gathering information about participants' beliefs and attitudes about epilepsy. Therefore, it served as an efficient and practical way to make an evaluation within a shorter period and with less effort than would be required using interviews. Moreover, the scale provided numerical scores, which were used to compare participants with high and low scores.

The KEBAS also had two methodological strengths that are important in interpreting the findings of acceptable psychometric properties. The first is the large sample size on which the measurement was performed. Insufficient sample sizes are a common methodological flaw in principal component and factor analysis. According to a review of more than 1000 articles using principal component or factor analysis to evaluate questionnaires, about half failed to obtain appropriate sample size (Costelllo & Osborne, 2003).

Antonak and Levneh recommended that when testing the properties of a scale, the sample size should be five times the number of items on the scale (i.e. 5 x 34 = 170) (Antonak & Livneh, 1988). We had 673 respondents, lending confidence to the estimates we reported.

The second methodological strength is the excellent response rate. All the participants completed the questionnaire, which minimized the likelihood that non-responders may be systematically different than responders. This strengthens the generalizability of the findings and potentially increases the stability of the findings.

4.5 Limitations

Despite extensive efforts spent on developing and pretesting the scale, the possibility still exists that it does not represent accurately all possible beliefs and attitudes about epilepsy. Even though the test-retest reliability was conducted within an acceptable period of three weeks, responses may have been biased because the respondents were sensitized by the first testing. Lack of uni-dimensionality also suggests that the KEBAS cannot be used to measure a single construct of beliefs and attitudes.

4.6 Conclusion

The findings revealed that the 34-item KEBAS is a reliable and valid tool that captures beliefs and attitudes about epilepsy in a resource poor setting. One of its possible applications would be as an evaluation tool to assess the effectiveness of interventions designed to increase knowledge, influence beliefs and improve attitudes about epilepsy. To enhance its utility, the tool should undergo further validation in different population groups preferably in the language spoken by the participants.

Acknowledgement

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Chapter 5

Treatment seeking among people with epilepsy in Kilifi, Kenya

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Abstract

Introduction

Several studies have reported that People with Epilepsy (PWE) in resource poor countries do not receive appropriate treatment for their condition, a phenomenon known as the Epilepsy Treatment Gap (ETG). We estimated the ETG and examined the factors that were responsible for treatment-seeking behaviour among PWE in rural Kenya.

Methods

A cross-sectional survey was conducted among PWE in Kilifi District, Kenya. Three trained field staff interviewed PWE between June and December 2008. The ETG was determined by checking for detectable levels of Anti-epileptic Drugs (AEDs) in blood samples from PWE. An assets-based wealth index was developed using principal component analysis; distance to health facilities was calculated using global positioning system coordinates and stigma and health beliefs were measured using Likert scales. Factors influencing treatment seeking were explored using univariate and multivariate logistic regression models. Only variables with a p-value ≤ 0.20 in the univariate analysis were included in a multivariate logistic regression model.

Results

A total of 673 PWE were interviewed. Only 499 (74.1%) PWE reported seeking treatment from a health facility. The ETG based on blood levels of AEDs was 74.9% (95% confidence interval (CI); 71.4-78.1). Out of 673 PWE, 334 (49.6%) were aware of traditional healers (THs) who treated seizures and 277 (41.2%) reported seeking treatment from a TH.

The most important factor influencing treatment seeking was long duration of epilepsy in children (adjusted odds ratio (aOR) = 8.01, 95% CI 3.02–21.2) and adults (aOR= 9.00, 95% CI 2.87–18.9). Other significant predictors in the multivariate analysis were religion, distance to health facilities, paying for AEDs, injury during a seizure, beliefs about causes and biomedical treatment of epilepsy. Sex, education level, marital status, occupation, social economic status and perceived stigma did not influence treatment seeking.

Conclusion

The results of the study show that PWE were more likely to seek treatment when they lived close to health facilities that provided specialized epilepsy care and had epilepsy for a long time. Positive beliefs about the causes and biomedical treatment of epilepsy also influenced treatment seeking. These data can be used to inform the development of appropriate interventions in order to reduce the TG in Kilifi District.

5.1 Introduction

Over 62 million People with Epilepsy (PWE) live in Resource Poor Countries (RPCs) (Ngugi *et al.*, 2010). Several studies have reported that PWE in RPCs do not receive appropriate treatment for their condition, a phenomenon known as the Epilepsy Treatment Gap (ETG) (Scott *et al.*, 2001; Diop *et al.*, 2003; Diop *et al.*, 2005; Shorvon & Farmer, 1988). The ETG is defined as the number of people with active epilepsy not on treatment (diagnostic and therapeutic) or on inadequate treatment, expressed as a percentage of the total number with active epilepsy (Kale, 2002; Meinardi *et al.*, 2001). In a systematic review of studies conducted in RPCs, the overall estimate of the ETG was 56% (95% CI 31-100), with a higher proportion in rural areas than in urban areas (Mbuba *et al.*, 2008). In a separate review, Meyer et al. reported that the ETG was over 75% in low-income countries and over 50% in most lower middle and upper middle income countries, while many high-income countries had gaps of less than 10% (Meyer *et al.*, 2010). The ETG could be caused by lack of access to diagnosis and treatment or lack of adherence to treatment (Meinardi *et al.*, 2001; Kale, 2002).

There are few studies devoted to studying health seeking behaviour associated with epilepsy. Studies on other chronic ailments have shown healthcare seeking behaviour is influenced by household size, age, sex, education, geographic proximity of services, stigma, health beliefs, perceived need, income, cost of care, the level of service provision and the distribution of services (Sreeramareddy *et al.*, 2006; Pillai *et al.*, 2003; Habib & Vaughan, 1986; Abbas & Walker, 1986; Placencia *et al.*, 1995). Information on the health seeking behavior of PWE can help policy makers develop strategies to reduce the ETG in RPCs. We examined the effect of socio-demographic, socioeconomic, accessibility, perceived severity, stigma and health beliefs variables on treatment seeking among PWE in Kilifi.

5.1.1 Conceptual model

We used the Andersen Behavioural Model as a basis for understanding the determinants of health service utilization (Andersen, 1995). The model considers that health service utilization is a function of three categories: (a) predisposing factors such as age, sex, education status, marital status, race, religion, occupation and health beliefs; (b) enabling factors that describe the means individuals have available to them for the use of services such as income, health insurance, regular sources of care, travel and waiting time, transportation, social support and supervision and relationship with providers; and (c) need, which refers to severity of illness and whether people judge their problem to be of sufficient magnitude to consult health services (Andersen, 1995). We choose the Andersen Behavioural Model because it is one of the most frequently used frameworks for analyzing patient utilization of healthcare (Phillips *et al.*, 1998). Since its first development in 1968 (Andersen, 1968), it has been revised to integrate a range of individual, environmental, and provider-related variables associated with decisions to seek care (Andersen, 1995), unlike other models which have remained narrow in scope (Weinstein & Sandman, 2002; Bandura, 1988; Miller & Dollard, 1941; Rosenstock, 1966; Rosenstock, 1974; Young, 1981).

5.2 Methods

5.2.1 Study Area

The study was conducted in the Kilifi Health Demographic Surveillance System (KHDSS), which is described in Chapter 1.

5.2.2.1 Health Services

The KHDSS is served by one district hospital, one health centre and 12 dispensaries. Kilifi District Hospital (KDH) serves as a primary care centre and first level referral facility for the District. Kilifi District Hospital has four major drugs used to treat epilepsy – phenobarbital, phenytoin, carbamazepine and sodium valproate - although the health centres and dispensaries only stock phenobarbital.

5.2.2 Identification of study participants

People with epilepsy were identified in a 3-stage cross-sectional survey that was conducted to determine the prevalence and incidence of epilepsy in KHDSS (Ngugi *et al.*, In preparation). This methodology is described in details in chapter 1.

5.2.3 Data collection

The questionnaires for the study were developed in English and translated into the local language, Kigiriama. They were grouped into six categories: socio-demographic characteristics (age, sex, religion, education, occupation and marital status); socioeconomic aspects of the households based on asset indicators; accessibility factors (distance from home to health facility, time to health facilities and payment of AEDs); severity of epilepsy (duration of epilepsy, seizure frequency, duration of seizures, injury during a seizure); stigma and questions on epilepsy beliefs and attitudes. Three field staff were trained for four days on how the tools were developed, how to approach homesteads, how to administer the questionnaires and check data. The field staff piloted the questionnaires among 12 PWE who were outside the study area to check for clarity, flow and ease of administration of the questions. Respondents were also requested to comment on the relevance of the questions and the time required to complete the questionnaires. The questionnaires were then revised based on the comments received from the pilot study. The questionnaires were administered to all people with a confirmed diagnosis of ACE following written informed consent. Where the person with epilepsy was a child, a caregiver (mother, father or guardian) was interviewed. The participants were interviewed between June-December 2008.

Data were checked at the end of each day by the investigator for accuracy, completeness and consistency. The study was reviewed and approved by KEMRI/National Ethical Review Committee and the Swiss Tropical and Public Health Research Committee.

5.2.3.1 Measuring treatment seeking

We established treatment-seeking behaviour by asking PWE if they had ever sought treatment for epilepsy from a health facility prior to the epidemiological survey in which they were identified (yes/no). Those answering ‗yes' were asked to identify the health facility they sought treatment from. A list of health facilities in the KHDSS was provided, as well as the option to specify health facilities outside the KHDSS. Other types of care such as visiting Traditional Healers (THs) or churches and the administration of home remedies were not considered as appropriate care for the purposes of this study.

5.2.3.2 Measuring the epilepsy treatment gap

We estimated the ETG by finding out whether PWE sought and adhered to treatment. Adherence was determined by checking if PWE had AEDs in their blood. More details on how the ETG was measured are provided in Chapter 6.

5.2.3.3 Measuring socio-economic status

Data were collected from households on 15 assets including livestock (goats, cows, chickens), radio, telephone, video machine, land, television, cooking stoves (electrical/gas), refrigerators, bicycle, cars, tractors and motorbikes. Other indicators of household characteristics included roofing material, source of energy for cooking and lighting, toilet facilities, type of main wall for the dwelling and source of drinking water. Principal Component Analysis (PCA) was performed to construct a homestead wealth assets index from the range of assets and household characteristics. Households were classified into Socio Economic Status (SES) quintiles on the basis of the asset index. The assets indicator tool has been validated and used in other settings including Kilifi (Chuma & Molyneux, 2009; Seema & Lilani, 2006; Filmer & Pritchett, 2001; Montgomery *et al.*, 2000; McKenzie, 2003; Cortinovis *et al.*, 1993; Schellenberg *et al.*, 2003).

5.2.3.4 Measuring stigma, epilepsy beliefs and attitudes

Perceived stigma and epilepsy beliefs and attitudes were measured using Likert scales. The Kilifi Stigma Scale for Epilepsy had 15 questions and measured only one construct (perceived stigma). The Kilifi Epilepsy Beliefs and Attitude Scale had 34 questions, divided into five subscales (causes of epilepsy, biomedical treatment of epilepsy, cultural treatment of epilepsy, risk and safety concerns and negative stereotypes about epilepsy). The development, validation and scoring of these tools is described in Chapters 3 and 4.

5.2.3.5 Calculating distance to health facilities

Homesteads and health facilities were mapped using Global Positioning System (GPS) (Noor *et al.*, 2003; Paul *et al.*). The Euclidean (straight line) distance was calculated using GPS coordinates for the two points. The health facility used was defined as the one where PWE reported seeking treatment most frequently.

We also estimated the distance PWE would travel if they were to seek treatment from the nearest health facility and compared this with the distance to the actual health facility where they reported seeking treatment.

5.2.4 Statistical analysis

Data were double entered and verified in MySQL. Statistical analyses were undertaken using STATA version 11 (StataCorp, College Station, TX, USA). The data were screened for consistency, missing values and unexplained outliers. The distribution pattern was examined for shape and skewing before selecting the appropriate test statistic.

People with epilepsy were categorized by age into children (<18 years) and adults (≥18 years). People with epilepsy who reported seeking treatment from health facilities were compared to PWE who reported never seeking such treatment. First, a chi-square test was used to measure associations between socio-demographic characteristics and treatment seeking. Second, a univariate regression analysis was performed to identify which of the predictor variables were significant to the outcome measure, i.e. seeking treatment from health facilities. In the univariate analysis, any factor with a p-value > 0.20 was not considered an important covariate of treatment seeking.

All variables with a p-value ≤ 0.20 in the univariate analysis were included in a multivariate logistic regression model, using a forward stepwise strategy to identify their combined effect on treatment seeking among PWE. At each step, non significant explanatory variables were removed and only variables with a $p \leq 0.1$ were retained in the model. Regression models were compared with the Likelihood Ratio Test (LRT). Parameter estimates, Odds Ratio (OR), 95% Confidence Interval (CI) and p-values were recorded for each predictor.

5.3 Results

5.3.1 Study participants

The epidemiological survey identified 699 PWE, of whom 673 (96.3%) were interviewed. The remaining 26 (3.7%) were not interviewed because seven refused to participate, nine moved from the study area, two died and eight denied having epilepsy. PWE were relatively young, with 58.3% of individuals aged 18 years and below. Majority of the adults 133 (47.5%) had no formal education and only eight (2.9%) had attained tertiary level of education. The largest faith group was Christian (45.7%). The main assets owned by households were land (95.7%) and livestock (74.6%). Christians and single adults were significantly more likely to access treatment (Table 5.1).

Of the 673 PWE who were interviewed, 499 (74.1%) reported seeking treatment for epilepsy from a health facility and 174 (25.9%) reported never seeking treatment. Of the 499 who reported seeking treatment, 79.2% went to KDH, 12.9% to peripheral government health clinics and 7.9% to private clinics. Of the 673 PWE, 334 (49.6%) were aware of THs who treated epilepsy and 277 (41.0%) reported seeking treatment from a TH. Two hundred and twenty (32.7%) sought treatment from both the health facility and THs. The ETG based on AEDs blood level tests was 74.9% (95% CI; 71.4-78.1).

Table 5.1: Demographic characteristics of study participants (n=673)

Variable	Children (n=393)				Adults (n=280)			
	Sought treatment n=299	Never sought treatment n=94	X^2	P value	Sought treatment n=200	Never sought treatment n=80	X^2	P value
Age years:								
Median	11	8			29	37		
[IQR]	15-6	13-3			37-23	57- 24.5		
Sex: n (%)			1.40	0.237			0.206	0.650
Female	135 (73.4)	49 (26.6)			104 (70.3)	44 (29.7)		
Male	164 (78.5)	45 (21.5)			96 (72.7)	36 (27.3)		
Religion: n (%)			4.02	0.134			9.916	0.007
Traditional	124 (71.3)	50 (28.7)			80 (65.0)	43 (35.0)		
Christian	134 (80.2)	33 (19.8)			103 (80.5)	25 (19.5)		
Islam	41(78.8)	11(21.2)			17 (58.6)	12 (41.4)		
Educational level n: (%)			6.58	0.087			2.366	0.500
None	136 (78.6)	37 (21.4)			95 (71.4)	38 (28.6)		
Primary	139 (71.6)	55 (28.4)			88 (72.1)	34 (27.9)		
Secondary	24 (92.3)	2 (7.7)			10 (58.8)	7 (41.2)		
Tertiary	n/a	n/a			7 (87.5)	1 (12.5)		
SES: n (%)			4.08	0.396			3.499	0.478
Least poor	61 (83.6)	12 (16.4)			49 (80.3)	12 (19.7)		
Less poor	55 (73.3)	20 (26.7)			40 (67.8)	19 (32.2)		
Poor	62 (71.3)	25 (28.7)			32 (68.1)	15 (31.9)		
Very poor	55 (74.3)	19 (25.7)			42 (72.4)	16 (27.6)		
Most poor	66 (78.6)	18 (21.4)			37 (67.3)	18 (32.7)		
Occupation: n (%)	n/a..	n/a	n/a	n/a			2.401	0.493
Farmer	n/a	n/a			110 (73.3)	40 (26.7)		
Trader	n/a	n/a			30 (65.2)	16 (34.8)		
Casual	n/a	n/a			22 (64.7)	12 (35.3)		
Other	n/a	n/a			38 (76.0)	12 (24.0)		
Marital status: n (%)							9.616	0.047
Single	n/a	n/a			65 (84.4)	12 (15.6)		
Married	n/a	n/a			94 (66.2)	48 (33.8)		
Separated	n/a	n/a			5 (71.4)	2 (28.6)		
Divorced	n/a	n/a			10 (58.8)	7 (41.2)		
Widowed	n/a	n/a			26 (70.3)	11(29.7)		

** Socio Economic Status was estimated using principal component analysis*
n/a: Not applicable

5.3.2 Predictors of treatment seeking

We studied 17 variables as potential predictors of treatment seeking. Of these, seven had univariate p-values > 0.20 and were dropped from the multivariate analysis (Table 5.2). The remaining ten variables were retained in the multivariate logistic regression model building process to predict treatment seeking (Table 5.2).

There is a high density of health facilities within the KHDSS, with the majority of PWE being within 6 kilometres of the nearest health facility (Figure 5.1). However, many PWE opted to seek treatment elsewhere, especially at KDH. Consequently there was a relationship between distance and treatment seeking among PWE (Figure 5.2) because the majority live far from KDH. From the multivariate analysis, caregivers of Children with Epilepsy (CWE) and adults with epilepsy who lived more than 30 kilometres from where they sought health care were 81% and 76% respectively less likely to seek treatment compared to those who lived closer. The most important factor affecting treatment seeking among children and adults was long duration of epilepsy: Children who had epilepsy for more than ten years were eight times more likely to seek treatment than those who had epilepsy for less than one year and adults with a similar duration of epilepsy were nine times more likely to seek treatment (Table 5.3).

Adults who had biomedical beliefs about the causes and treatment of epilepsy (high scores) were more likely to seek treatment from a health facility than those with low scores. Religion influenced treatment seeking among adults with epilepsy with those belonging to Christian being more likely to seek treatment compared to those in traditional faith. Other significant predictors of treatment seeking were having to pay for AEDs and injury during a seizure (Table 5.3).

Table 5.2: Factors included in univariate analysis to predict treatment seeking among people with epilepsy (n=673)

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
Predisposing factors				
Sex				
Female	1.0		1.0	
Male	1.32 (0.83-2.10)	0.238	1.13 (0.67-1.90)	0.650
Religion				
Traditional	1.0		1.0	
Islam	1.50 (0.72-3.16)	0.282	1.76 (1.33-4.74)	0.015
Christian	1.64 (0.99-2.71)	0.055	2.21 (1.23-3.93)	0.007
Educational level				
None	1.0		1.0	
Primary	0.69 (0.43-1.1)	0.125	1.04 (0.60-1.79)	0.901
Secondary	2.86 (0.64-12.7)	0.169	0.57 (0.20-1.61)	0.180
Tertiary	n/a	n/a	2.80 (0.33-23.5)	0.343
Marital status				
Single	n/a	n/a	1.0	
Married	n/a	n/a	0.61 (0.27-1.34)	0.217
Separated	n/a	n/a	0.99 (0.14-7.12)	0.998
Divorced	n/a	n/a	0.42 (0.12-1.60)	0.208
Windowed	n/a	n/a	0.65 (0.22-1.94)	0.442
Occupation				
Farmer	n/a	n/a	1.0	
Trader	n/a	n/a	0.68 (0.34-1.38)	0.288
Casual	n/a	n/a	0.67 (0.30-1.47)	0.315
Other	n/a	n/a	1.15 (0.55-2.42)	0.710
Stigma scores				
0-10 points	1.0		1.0	
11-30 points	1.29 (0.76-2.19)	0.352	1.13 (0.67-1.93)	0.643
Beliefs about causes of epilepsy				
0-6 points	1.0		1.0	
7-10 points	3.07 (1.30-7.12)	0.010	3.61 (1.78-7.32)	0.001
Beliefs about biomedical treatment				
0-11 points	1.0		1.0	
12-16 points	2.96 (1.43-6.15)	0.003	3.97 (1.73-9.07)	0.001
Beliefs about cultural treatment				
0-14 points	1.0		1.0	
15-18 points	1.78 (0.47-1.29)	0.332	1.37 (0.75-2.52)	0.307

Table 5.2: Continued from previous page

	OR (95%CI)	**P value**	**OR (95%CI)**	**P value**
Risk and safety concerns beliefs				
0-5 points	1.0		1.0	
6-8 points	1.67 (0.78-3.58)	0.289	2.04 (0.73-5.67)	0.274
Negative stereotype beliefs				
0-10 points	1.0		1.0	
11-16 points	0.91 (0.56-1.48)	0.715	1.37 (0.75-2.52)	0.307
Enabling factors				
Distance to health facility (Kms)				
<10	1.0		1.0	
10-20	0.43 (0.22-0.84)	0.014	0.53(0.33-0.84)	0.006
20-30	0.35 (0.19-0.67)	0.001	0.51(0.31-0.82)	0.006
>30	0.19 (0.08-0.49)	0.001	0.24(0.12-0.47)	0.001
Paying for AEDs				
No	1.0		1.0	
Yes	2.57 (1.41-4.69)	0.002	3.49 (1.90-6.38)	<0.0001
SES n (%)				
Least poor	1.0		1.0	
Less poor	0.72 (0.32-1.62	0.429	0.50 (0.22-1.17)	0.112
Poor	0.57 (0.25-1.27)	0.173	0.64 (0.27-1.51)	0.311
Very poor	0.49 (0.23-1.06)	0.069	0.52 (0.22-1.26)	0.148
Most poor	0.54 (0.24-1.20)	0.134	0.52 (0.22-1.19)	0.120
Need and disease specific factors				
Duration of epilepsy (yrs)				
<1	1.0		1.0	
1-5	3.05 (1.46-6.39)	0.003	6.63 (1.25-13.1)	0.026
6-10	6.63 (2.68-9.40)	<0.0001	7.88 (1.47-14.12)	0.016
>10	8.41 (3.42-13.7)	<0.0001	9.61 (2.31-18.2)	0.003
Seizure frequency in three months				
None	1.0		1.0	
1-3	1.57 (0.87-2.82)	0.137	1.17 (0.62-2.19)	0.631
4-6	1.12 (0.54-2.30)	0.761	2.00 (0.81-4.93)	0.132
>6	1.39 (0.71-2.60)	0.305	1.47 (0.70-3.09)	0.314
Injury during seizure				
No	1.0		1.0	
Yes	2.25(1.41-3.58)	0.001	2.82(1.62-4.89)	<0.0001

Figure 5.1: People with epilepsy in relation to nearest health facility (n=673)

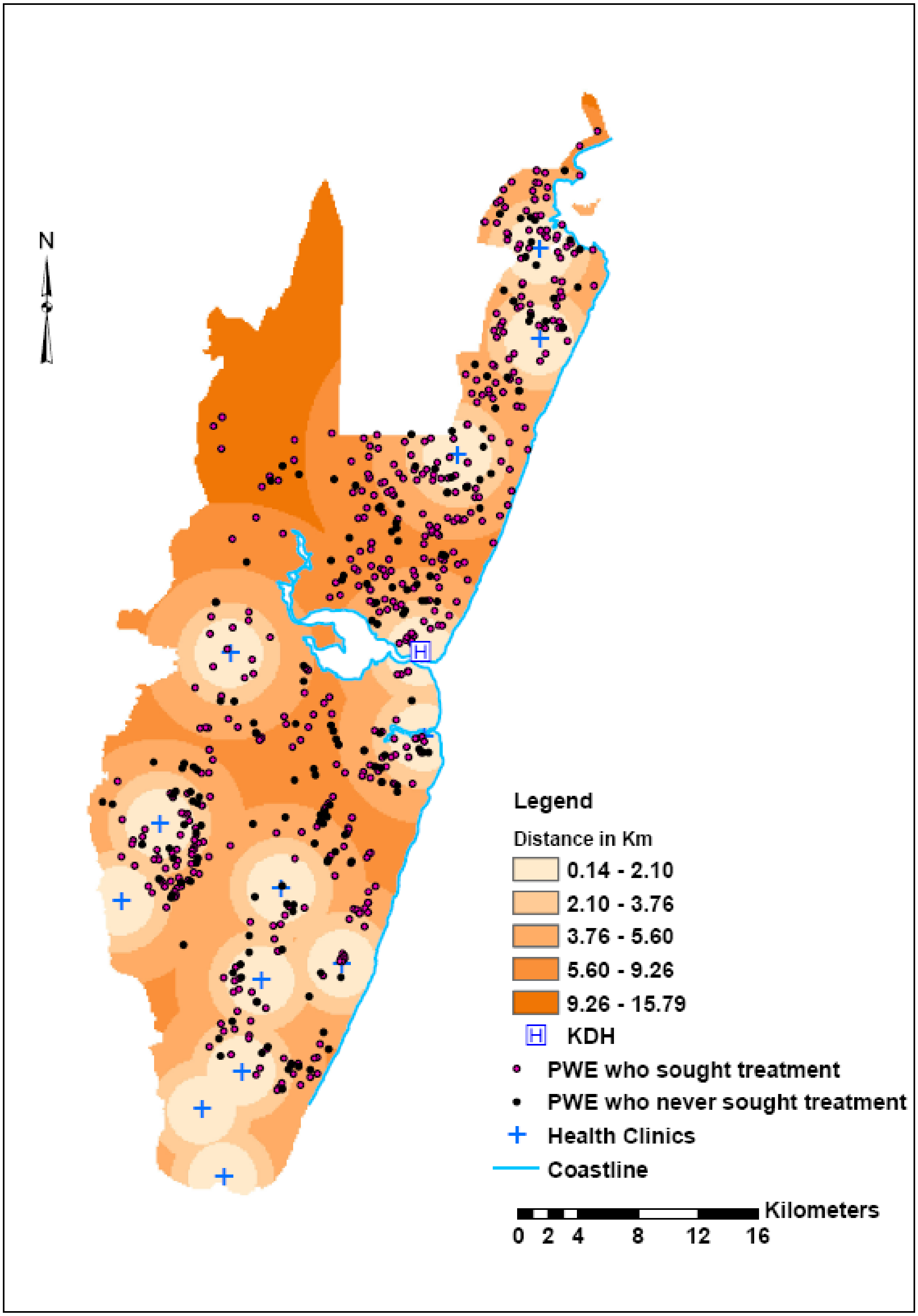

Figure 5.2: Distance to health facility where people with epilepsy sought treatment (n=499)

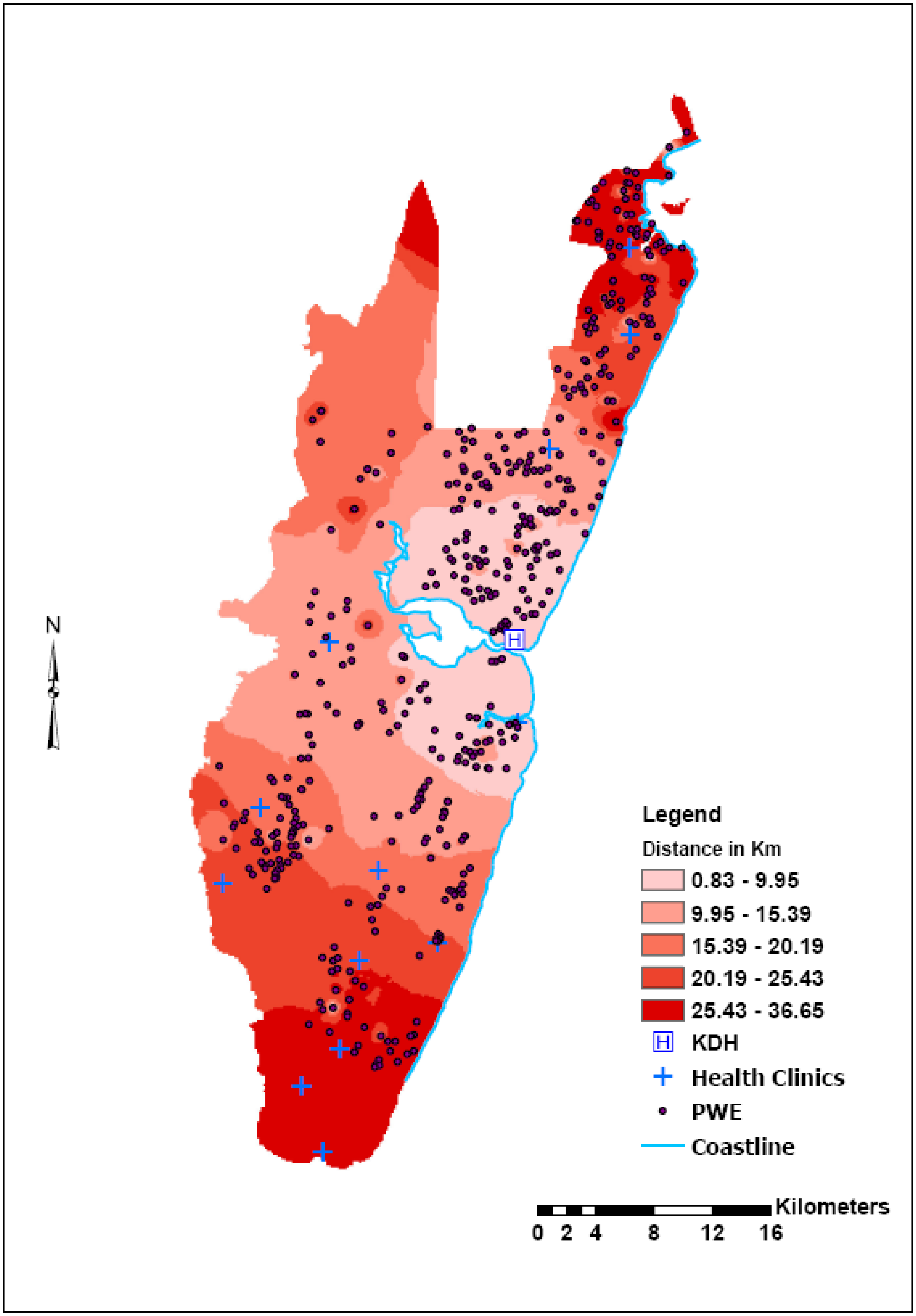

Table 5.3: Multivariate analysis of factors associated with treatment seeking (n=673)

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
Predisposing factors				
Religion: n (%)				
Traditional	n/a	n/a	1.0	
Islam	n/a	n/a	1.45 (1.15-4.81)	0.006
Christian	n/a	n/a	1.94 (1.25-5.80)	0.001
Beliefs about causes of epilepsy				
*0-6 points	1.0		1.0	
±7-10 points	3.15 (1.51-6.59)	0.002	3.36 (1.41-8.01)	0.006
Beliefs about biomedical treatment				
*0-11 points	1.0		1.0	
±12-16 points	2.81 (1.26-6.28)	0.011	4.88 (1.98-8.01)	0.001
Enabling factors				
Distance to health facility(Kms)				
<10	1.0		1.0	
10-20	0.37 (0.18-0.77)	0.007	0.45 (0.23-0.91)	0.025
20-30	0.35 (0.18-0.68)	0.002	0.42 (0.20-0.90)	0.026
>30	0.19 (0.07-0.51)	0.001	0.24 (0.09-0.68)	0.007
Paying for AEDs				
No	1.0		1.0	
Yes	2.60 (1.35-4.99)	0.004	3.56 (1.84-6.88)	<0.0001
Need and disease specific factors				
Duration of epilepsy (yrs)				
<1	1.0		1.0	
1-5	3.08 (1.39-6.83)	0.006	6.14 (2.02-13.7)	0.001
6-10	6.28 (2.36-16.8)	<0.0001	7.15 (2.22-15.0)	0.001
>10	8.01 (3.02-21.2)	<0.0001	9.00 (2.87-18.9)	<0.001
Injury during seizure				
No	1.0		1.0	
Yes	1.66 (1.17-2.35)	0.005	2.56 (1.37-4.78)	0.003

**Scores below 66th percentile that were categorized as negative beliefs*
±Scores above 66th percentile that were categorized as positive beliefs

5.4 Discussion

People with epilepsy reported seeking treatment from health facilities, particularly KDH although a minority sought treatment from both the health facility and THs.

5.4.1 Predisposing factors

Our results indicate that factors that influenced treatment seeking were religion, biomedical beliefs about causes of epilepsy and treatment of epilepsy. Adults with Christian or Islamic beliefs were more likely to seek treatment than those who held traditional religious beliefs. A study from the Philippines by Thind *et al.* reported that religion was not a significant predictor of health service utilization (Thind & Cruz, 2003), but these contrasting findings could be explained by different religious beliefs held by people in the Philippines and Kilifi. In addition, the study in Philippines only looked at two categories of religion (Catholics and Non-Catholic) and this may have failed to capture those with traditional religious beliefs (Thind & Cruz, 2003). People with epilepsy with traditional beliefs may be more likely to seek alternative medicine as opposed to going to health facilities due to misconceptions and superstitions associated with epilepsy in Kilifi (El Sharkawy *et al.*, 2006; Kendall-Taylor *et al.*, 2009).

Only two subscales of the Kilifi Epilepsy Beliefs and Attitude Scale influenced treatment seeking. PWE and their caregivers, i.e. those who had high scores on biomedical causes and treatment of epilepsy subscales were more likely to seek treatment from a health facility. A few studies have investigated PWE‘s beliefs and attitudes towards their condition, but have not linked this to utilization of health services (El Sharkawy *et al.*, 2006; Desai *et al.*, 1998). Our study correlated beliefs and attitudes held by PWE and their caregivers with their decision to seek biomedical treatment. Our findings concur with other studies, that familiarity with patients‘ beliefs and attitudes is an important step in improving patient care (Albert, 1983; Ngubane, 1981).

The following factors were not found to be significant predictors of treatment seeking: sex, education level, marital status, occupation, stigma, beliefs about how epilepsy is treated culturally, risk and safety concerns about epilepsy and negative stereotypes about epilepsy.

Our findings that sex is not associated with the decision to seek care contrasts with other studies that provide conflicting data on the influence of sex on treatment seeking (Thind & Andersen, 2003; Ganatra & Hirve, 1994; Das, 1987). A study in Dominican Republic by Thind showed that female children were more likely to use health services but the other two studies conducted in India noted a male predominance in utilization of health services by children. Some studies have documented education level as an important predictor of health care utilization in RPCs (Thind & Cruz, 2003; Sreeramareddy *et al.*, 2006; Abbas & Walker, 1986; Cleland & Van Ginneken, 1988; Streatfield *et al.*, 1990) but other studies have not found this to be an important factor (Pillai *et al.*, 2003; Thind & Cruz, 2003; Perez-Cuevas *et al.*, 1996). In Kilifi, literacy levels are low and more than half of the population cannot read or write (GOK, 2000). This is supported by our finding of low educational level among study participants (children with epilepsy and their caregivers) which may explain the insignificance of education in predicting treatment seeking.

Stigma associated with epilepsy has been shown to delay appropriate health-seeking behaviour in various studies (Rafael *et al.*, 2010; Weiss & Ramakrishna, 2006; Placencia *et al.*, 1995). However in Kilifi, the majority of PWE reported low scores on the stigma scale, suggesting they did not feel stigmatized by their condition (Chapter 3). Consequently, perceived stigma did not have an impact on treatment seeking. Our study concurs with others that failed to demonstrate high levels of perceived stigma among PWE (Ryan *et al.*, 1980; Westbrook *et al.*, 1992; Cramer *et al.*, 1999). It is possible that PWE in our setting did not experience a high level of stigma because they have been exposed to continuous information about epilepsy during census enumeration and previous epilepsy studies which started in 2003 (Edwards *et al.*, 2008; El Sharkawy *et al.*, 2006; Kendall-Taylor *et al.*, 2009).

5.4.2 Enabling factors

The enabling factors that had an effect on treatment seeking were distance to health facilities and paying for AEDs. The geographic proximity of health services to people‘s homes is an important factor that affects utilization of health services, particularly in resource poor settings where density of biomedical health facilities is often low (Habib & Vaughan, 1986; Stock, 1983). As distance increases, the level of utilization decreases and vice versa (Abbas & Walker, 1986; Stock, 1983; Muller *et al.*, 1998; Annis, 1981; Shannon *et al.*, 1969). Our study supported these findings as it demonstrated PWE who travelled the longest distance to KDH were less likely to seek treatment.

The 1997 Kenyan health policy strategic framework states that all households should have access to health services within a five kilometre range (1997), in accordance with the notion that improved physical access could lessen delays in seeking care and time travelled to obtain treatment. In KHDSS, there is a high density of biomedical health services within reach by both PWE who sought and those who never sought treatment (Figure 5.1). However, it is only KDH that offers specialized care for epilepsy, as well as AEDs other than phenobarbital. This explains why PWE opted to travel long distances to KDH as opposed to going to the nearest health facility, where the supply of AEDs was likely to be erratic. If PWE were to seek treatment from the nearest health facility the furthest one would travel is 15 kilometres.

Caregivers of CWE, as well as adults with epilepsy who reported paying for AEDs, were more likely to seek treatment than those who did not pay. The cost of AEDs in peripheral facilities was 10 Kenyan shillings (Kes) (0.13 U$), whereas at KDH it was 40 Kes (0.51 U$). This may mean the cost of AEDs per se is not a hindrance compared to the indirect costs involved in seeking care (time, days of work lost, transport costs etc). People with epilepsy travelled long distances to access specialized care and the effect of distance has been shown to be greater when it interacts with economic factors, thus combining the effects of distance with time, transport, income and cost of care (Habib & Vaughan, 1986).

Socio-economic status was not a significant predictor of health service utilization. This contrasts with findings from other studies that have shown that families with a higher SES were more likely to seek care from health facilities because they have the resources needed to do so (Thind & Andersen, 2003; Carr-Hill *et al.*, 1996; Neumark *et al.*, 1992). Multi-country studies have also shown differences in the types of care sought by wealthy people compared to poor people, with poor people more frequently opting for care outside the biomedical sector and wealthy people more frequently opting for care involving the biomedical sector (Hausmann-Muela *et al.*, 2003). In Kilifi, there was similarity in assets owned by PWE since they all come from a rural setting. This lack of variation in assets could explain why SES did not influence treatment seeking. When the same SES tool was used in rural and urban settings of Kilifi District to estimate inequalities in insecticide treated bed nets, there was a significant difference between the assets owned by rural and urban households (Chuma & Molyneux, 2009).

5.4.3 Perceived need factors

Duration of epilepsy and experiencing an injury during a seizure were the two disease-specific variables that predicted treatment seeking. PWE who had epilepsy for a long period were more likely to seek medical services, as were those who reported injuries directly associated with epilepsy such as burns, broken bones, cuts and bruises. Severity (seizure frequency) was not a significant predictor of treatment seeking despite several studies reporting that the most immediate cause of health services utilization is disease severity (perceived need) (Habib & Vaughan, 1986; Sreeramareddy *et al.*, 2006; Wolinsky, 1978; Pillai *et al.*, 2003; Kloos, 1990). This could point to inequality of access because predisposing and enabling factors were the main factors that influenced utilization of health services as opposed to perceived need (seizure frequency (Andersen *et al.*, 2001).

5.5 Limitations of the study

We relied on self-reported answers, and these may be subject to recall and reporting bias. Attempts were made to minimize this potential source of bias by piloting the questionnaires and training field staff how to administer the questionnaires. Our model does not control for quality of care, which may play a role in determining health service utilization. Unidentified predictors or confounders are still possible regarding perceptions of PWE about epilepsy and health seeking behaviour.

5.6 Conclusion

The results of the study show that PWE were more likely to seek treatment when they were close to health facilities that provided specialized epilepsy care, had epilepsy for a long time, and when they had high scores on biomedical causes and treatment of epilepsy subscales. This highlights the need for researchers to understand factors that influence treatment seeking in order to develop and implement culturally appropriate interventions that can reduce the ETG in RPCs. In our setting, we developed an educational intervention to increase awareness of epilepsy as a treatable disorder with the aim of reducing the ETG in Kilifi. Health education programs are effective in altering health beliefs and perceptions about illnesses and we are likely to increase the number of PWE who seek treatment from health facilities.

People‘s perceived need for care may also be increased through health education programs. At policy level, the government can improve the delivery of epilepsy services at the peripheral health facilities by increasing skilled manpower and supply of AEDs. This would reduce the indirect cost of seeking care especially in KHDSS where there is a high density of health facilities within reach by PWE.

Contributors

CKM and CRN conceptualized the study. CKM, PO, JAC and CRN participated in proposal development. CKM implemented and managed the study. CKM, AKN, TE, PO, JAC and CRN provided input into the analytical plan. CKM drafted the manuscript. AKN, TE, PO, JAC and CRN reviewed and edited the manuscript. All authors read and approved the final version of the manuscript.

Role of the funding source

The sponsor of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the paper. The corresponding author had full access to all the data in this study and had final responsibility for the decision to submit for publication.

Conflict of interest

We have no conflict of interest.

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Chapter 6

Factors associated with Adherence to Antiepileptic drugs in Kilifi, Kenya

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Abstract

Introduction

Patient adherence to medication regimens is important in the management of epilepsy. Research has shown that between 25% and 75% of People with Epilepsy (PWE) fail to follow prescribed drug regimes. This reduces the benefit that could be gained from the medication leading to uncontrolled epilepsy. We measured adherence to Anti-epileptic Drugs (AEDs) using blood levels of AEDs and investigated the factors associated with adherence.

Methods

A cross-sectional survey was conducted among PWE in Kilifi District, from June to December 2008. Adherence was determined using detectable and optimal blood levels of phenobarbital, phenytoin and carbamazepine. This was compared with self reported adherence, which was assessed concurrently using the Morisky Medication Adherence Scale. The sensitivity and specificity of self-reporting were determined using AED blood levels as the gold standard. Factors influencing adherence were explored using univariate and multivariate logistic regression models. Only variables with a p-value ≤ 0.20 in the univariate analysis were included in a multivariate logistic regression model.

Results

A total of 673 PWE were interviewed. Of these, 499 (74.1%) reported seeking treatment but only 385 (77.2%) were currently taking AEDs to control seizures. Of the 385, 341(88.6%) gave blood but only 169 (49.6%) were found to have AEDs in their blood. The sensitivity and specificity of self-reported adherence, compared to the assumed gold standard of blood testing was 44.4% (95% CI 36.8-52.2) and 52.9% (95% CI 45.2-60.5%), respectively. The concordance and discordance between self reporting and AEDs blood levels was 166 (48.7%) and 175 (51.3%) respectively. The epilepsy treatment gap based on detectable and optimal AEDs blood levels was 74.9% (95% confidence interval (CI); 71.4-78.1).

The most important factor affecting adherence was long duration of medication (Adjusted Odds Ratio (aOR) = 4.25, 95% CI 1.86–8.75) and (aOR = 6.50, 95% CI 1.58–9.63) in children and

adults respectively. Other significant predictors were seizure frequency, injury during a seizure, number of AEDs prescribed and having a good relationship with the healthcare provider.

Conclusion

This study identified a subset of PWE at risk of low adherence and highlighted several reasons why they fail to adhere to AEDs. This will greatly help in developing interventions to improve patient adherence and reduce preventable seizures. There is also a need for healthcare providers to continually improve their relationship and communication with patients in addition to educating and counselling them.

6.1 Introduction

Patient adherence to medication regimens is important in the management of epilepsy (Gomes Mda *et al.*, 1998; Jones *et al.*, 2006; Osterberg & Blaschke, 2005). Adherence to a medication regimen is defined as the extent to which patients take medication as prescribed by their healthcare providers (Osterberg & Blaschke, 2005). Non-adherence to medication is a major problem in the treatment of epilepsy (Kemp *et al.*, 2007). Patients may exhibit different types of non-adherent behaviour. Unintentional non-adherence may be due to forgetfulness, or inability to follow treatment instructions due to poor understanding or physical problems such as poor eyesight, whereas intentional non-adherence arises when the patient rejects either the doctor‘s diagnosis or the doctor‘s recommended treatment (Horne, 1997; Marinker *et al.*, 1997). Research has shown that between 25% and 75% of People with Epilepsy (PWE) fail to follow prescribed drug regimens (Leppik, 1990; Buck *et al.*, 1997). This reduces the benefit that could be gained from the Anti-epileptic Drugs (AEDs) leading to uncontrolled epilepsy and reduced quality of life (Dunbar-Jacob & Mortimer-Stephens, 2001; Eraker *et al.*, 1984; Leppik, 1990; Stanaway *et al.*, 1985).

Adherence to treatment regimens is a complex phenomenon, which can be best understood within the patient‘s physical, economic, psychological and social circumstances (Haynes *et al.*, 2002; DiMatteo, 2004). There are many factors that contribute to non-adherence, which can be attributed to healthcare professionals, the health care system, the community and the patients (WHO, 2003). Researchers have examined numerous factors as causes and correlates of adherence with the aim of developing effective intervention strategies to improve adherence. Factors such as age (Hassan *et al.*, 2006; Osterberg & Blaschke, 2005), sex (Bloom, 2001), low socioeconomic status (Osterberg & Blaschke, 2005), severity of disease (Osterberg & Blaschke, 2005), number of pills per day (Hassan *et al.*, 2006; Bloom, 2001), side effects of medication (Hassan *et al.*, 2006; Osterberg & Blaschke, 2005), patients‘ understanding of the disease and importance of treatment (Osterberg & Blaschke, 2005; Hassan *et al.*, 2006), co-morbid medical conditions (Osterberg & Blaschke, 2005), lack of social support, poor patient- healthcare provider relationship (Wang *et al.*, 2002), cost and forgetfulness (Almas *et al.*, 2006), have all been shown to affect adherence in various populations.

Adherence can be measured either directly or indirectly. Direct measures involve measurement of drug levels in blood, urine, saliva and hair (Paschal *et al.*, 2008). Indirect measures involve non-biological tools such as self-reported measures, pill counts, appointment attendance, medication refills or surrogate markers such as seizure frequency (Paschal *et al.*, 2008). Direct measures are more robust and allow comparative analysis since they provide quantitative data on the chemical presence of medication in a patient‘s body. An evidence base is more difficult to document for indirect measures due to variations in methodology used, although these measures also yield quantitative data about patient adherence (Paschal *et al.*, 2008). No single measurement strategy has been deemed optimal. Combining direct and indirect methods of adherence assessment may represent the most accurate way of assessing the degree to which a patient adheres to pharmacological treatment (Paschal *et al.*, 2008; WHO, 2003). We measured adherence to AEDs among PWE using blood levels and compared this to self-reported adherence. In addition, we investigated the factors associated with adherence as measured by AEDs in Kilifi, Kenya.

6.2 Methods

6.2.1 Study area

The study was conducted in the Kilifi Health Demographic Surveillance System (KHDSS). Details of the study area are described in chapter 1.

6.2.2 Identification of participants

People with Epilepsy were identified in a cross-sectional survey that was conducted to determine the prevalence and incidence of epilepsy in KHDSS (Ngugi *et al.*, In preparation). This methodology is described in details in chapter 1.

6.2.3 Data collection

The questionnaires for the study were developed in English and translated into the local language, Kigiriama. They were grouped into six categories: socio-demographic characteristics (age, sex, religion, education, occupation and marital status); accessibility (distance from home to health facilities, Socio Economic Status (SES) and relationship with healthcare providers);

severity of epilepsy (duration of epilepsy, frequency and duration of seizures, injury during a seizure); details of prescribed medication regimen (number of prescribed AEDs, frequency of taking AEDS per day, AEDs side effects and number of years they have taken AEDs); stigma and questions on epilepsy beliefs and attitudes. Three field staff were trained for four days on how the tools were developed, how to approach homesteads, how to administer the questionnaires and check data. The questionnaires were administered to participants following written informed consent. Where PWE was a child, a caregiver (mother, father or guardian) was interviewed. The participants were interviewed between June and December 2008.

Blood samples (2 mL) were collected by a clinician after obtaining informed consent from the participants. The blood samples were collected into lithium-heparinized tubes, centrifuged (3000 rpm, 10 minutes at 4^{o}C). The plasma was separated into a clean cryo-vial, labelled with the PWE‘s number, the date and time the sample was collected. The samples were stored at –80^{0} C until assayed for AEDs levels. The study was reviewed and approved by the KEMRI/National Ethical Review Committee and the Swiss Tropical and Public Health Research Committee.

6.2.3.1 Measuring self-reported adherence

Data on self reported adherence were collected using questionnaires. People with epilepsy were asked if they were currently taking any AEDs. The actual tablets were presented on the surface of a board to aid recognition of different AEDs. Those who reported taking AEDs were assessed using the Morisky Medication Adherence Scale (MMAS) (Morisky *et al.*, 1986), a four item scale with high reliability and validity (Morisky *et al.*, 1986), which was developed in America but has been adopted and used in other countries (Hashmi *et al.*, 2007; Pratt *et al.*, 2001; Krousel-Wood *et al.*, 2005; Al-Qazaz *et al.*, 2010; Stack *et al.*, 2010; Vik *et al.*, April 2005). This scale measures both intentional and unintentional adherence based on forgetfulness, carelessness, stopping medication when feeling better, and stopping medication when feeling worse. The scale is dichotomous and is scored zero points for each ―no” and one point for each ―yes”. People with epilepsy were categorized as adherent if they had a total score of 0 on all the four items and non-adherent if they had a score ranging from 1-4.

6.2.3.2 Measuring blood level adherence

Blood samples were assayed for the most commonly used AEDs in Kilifi District (phenobarbital, phenytoin and carbamazepine). Plasma drug concentrations were measured using a fluorescence polarisation immunoassay analyser (TDx FLx Abbott Laboratories, Abbott Park, IL, USA). The detectable range for the different drugs were: phenobarbital 1.1-9.9 µg/mL, phenytoin 1.0-9.9 µg/mL and carbamazepine 0.5-3.9 µg/mL (Shakya *et al.*, 2008). The optimal ranges were defined as follows: phenobarbital 10-40 µg/mL, phenytoin 10-20 µg/mL and carbamazepine 4.0-12 µg/mL (Gomes Mda *et al.*, 1998). An individual was defined as adherent if AEDs were detectable in their blood.

6.2.3.3 Measuring agreement between self-reporting and blood level adherence

We established concordance and discordance between self-reporting and AED blood levels. A Kappa statistic (k) was then used to measure the level of agreement between self-reporting and each individual AED (phenobarbital, phenytoin and carbamazepine).

6.2.3.4 Measuring the epilepsy treatment gap

We estimated the proportion of people with Active Convulsive Epilepsy (ACE) whose seizures were not appropriately treated by subtracting those who were adherent based on AED blood levels from the total number of PWE, dividing by the total number of PWE, then multiplying by 100%.

6.2.3.5 Measuring stigma, epilepsy beliefs and attitudes

Perceived stigma and epilepsy beliefs and attitudes were measured using Likert scales. The Kilifi Stigma Scale for Epilepsy had 15 questions and measured only one construct (perceived stigma). The Kilifi Epilepsy Beliefs and Attitude Scale had 34 questions which constituted five subscales (causes of epilepsy, biomedical treatment of epilepsy, cultural treatment of epilepsy, risk and safety concerns and negative stereotypes about epilepsy). The development, validation and scoring of these tools is explained in Chapters 3 and 4.

6.2.4 Statistical analysis

Data were double entered and verified in MySQL. Statistical analyses were undertaken using STATA version 11 (StataCorp, College Station, TX, USA). The data were screened for consistency, missing values and unexplained outliers. The distribution pattern was examined for shape and skewing before selecting the appropriate test statistic. The sensitivity and specificity of self-reporting was determined using AED blood levels as the gold standard.

PWE were categorized by age into children (<18 years) and adults (≥18 years) and factors influencing adherence were investigated. First, a chi-square test was used to measure associations between socio-demographic characteristics and adherence. Second, a univariate regression analysis was performed to identify which of the predictor variables were significant to the outcome measure, i.e. adherence based on AED blood levels. In the univariate analysis, any factor with a p-value > 0.20 was not considered an important covariate of adherence.

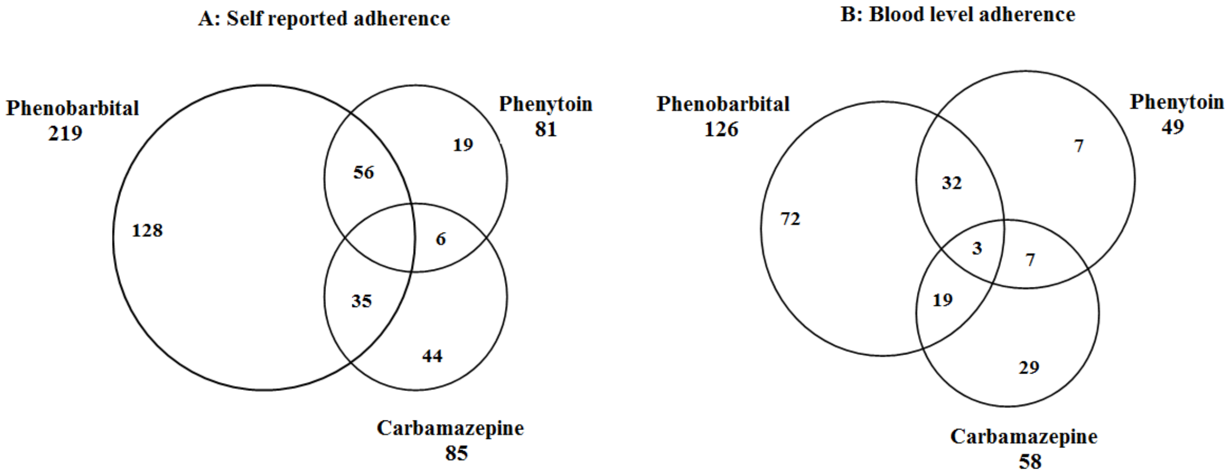
All variables with a p-value ≤ 0.20 in the univariate analysis were included in a multivariate logistic regression model, using a forward stepwise strategy to identify their combined effect on adherence. At each step, non-significant explanatory variables were removed and only variables with a p ≤ 0.1 were retained in the model. Regression models were compared with the Likelihood Ratio Test (LRT). Parameter estimates, Odds Ratio (OR), 95% Confidence Interval (CI) and p-values were recorded for each predictor.

6.3 Results

6.3.1 Study participants

A total of 673 PWE were interviewed. Of these, 499 (74.1%) reported seeking treatment but only 385 (77.2%) reported taking AEDs to control seizures (Fig 6.1, A). Of the 385 taking AEDs, 191 (49.6%) were on monotherapy and 194 (50.3%) on polytherapy (Fig 6.1, A). Of the 385 PWE who reported taking AEDs, 341 (88.6%) gave blood samples. Most PWE reported taking phenobarbital and this was evident from the large number of blood samples that had phenobarbital in the optimal range (Table 6.1). Phenobarbital also has a longer half-life which increases its ability to be detected over a long duration after ingestion. The demographic characteristics of the participants (who gave blood) are reported in (Table 6.2).

Figure 6.1: Venn diagrams of self reported and blood level adherence



***In diagram A, 385 PWE reported taking AEDs and in B only 169 had AEDs in their blood.**

Table 6.1: Self reported and blood levels of individual antiepileptic drugs

Antiepileptic drugs	Published Half life	Dose range	Number of patients reporting use	Number with detectable drug level (%)	Number with optimal drug level (%)
Phenobarbital	2-7 days	30-300 mg/day	219	30 (13.7)	96 (43.8)
Phenytoin	7-42 hours	100-600 mg/kg	81	37 (45.7)	12 (14.8)
Carbamazepine	25-65 hours	400-1200 mg/day	85	13 (15.3)	45 (52.9)

Table 6.2: Demographic characteristics of participants who gave blood samples (n=341)

	Children (n=175)				**Adults (n=166)**			
Variable	**Adherent n=78**	**Non-adherent n=97**	**X^2**	**P value**	**Adherent n=91**	**Non-adherent n=75**	**X^2**	**P value**
Age years:								
Median	13	13			26	31		
[IQR]	17-8	15-8			32-22	55- 24		
Sex: n (%)			0.55	0.457			0.904	0.342
Female	39 (54.2)	33 (45.8)			43 (51.2)	41 (48.8)		
Male	39 (37.8)	64 (62.2)			48 (58.5)	34 (41.5)		
Religion: n (%)			1.87	0.393			1.104	0.576
Traditional	29 (46.8)	33 (53.2)			31 (50.0)	31 (50.0)		
Christian	41 (46.6)	47 (53.4)			50 (56.8)	38 (43.2)		
Islam	8 (30.0)	17 (68.0)			10 (62.5)	6 (37.5)		
Educational level n: (%)			5.65	0.130			6.741	0.081
None	36 (50.7)	35 (49.3)			38 (52.0)	35 (48.0)		
Primary	32 (37.2)	54 (62.8)			44 (58.7)	31 (41.3)		
Secondary	10 (55.6)	8 (44.4)			8 (72.7)	3 (27.3)		
Tertiary	n/a	n/a			1 (14.3)	6 (85.7)		
SES: n (%)			2.45	0.653			3.499	0.478
Least poor	20 (50.0)	20 (50.0)			30 (62.5)	18 (37.5)		
Less poor	16 (41.0)	23 (59.0)			19 (59.4)	13 (40.6)		
Poor	18 (45.0)	22 (55.0)			16 (53.3)	14 (46.7)		
Very poor	10 (34.5)	19 (65.5)			12 (42.9)	16 (57.1)		
Most poor	14 (51.8)	13 (48.2)			14 (50.0)	14 (50.0)		
Occupation: n (%)			n/a	n/a			2.040	0.564
Farmer	n/a	n/a			47 (53.4)	41 (46.6)		
Trader	n/a	n/a			14 (46.7)	16 (53.3)		
Casual labourer	n/a	n/a			14 (63.6)	8 (36.4)		
Other	n/a	n/a			16 (61.5)	10 (38.5)		
Marital status: n (%)			n/a	n/a			6.801	0.147
Single	n/a	n/a			38 (64.4)	21 (35.6)		
Married	n/a	n/a			33 (44.0)	42 (56.0)		
Separated	n/a	n/a			3 (75.0)	1 (25.0)		
Divorced	n/a	n/a			5 (62.5)	3 (37.5)		
Widowed	n/a	n/a			12 (60.0)	8 (40.0)		

** Socio Economic Status was estimated using principal component analysis*
n/a: Not applicable

6.3.2 Sensitivity and specificity of self-reporting

Based on the self-reported Morisky scale, 179 (46.5%) PWE were classified as adherent and 206 (53.5%) as non-adherent (Table 6.3). Based on drug levels, 169 (49.6%) PWE had AEDs in their blood and were classified as adherent (Fig 6.1 B) whereas 172 (54.4%) were non-adherent. Of the 169, 41 (24.3% %) had drug concentrations in the detectable range and 128 (75.7 %) were in the optimal range. The sensitivity and specificity of self-reported adherence, compared to the AEDs detected in the blood was 44.4% (95% CI 36.8-52.2) and 52.9% (95% CI 45.2-60.5%), respectively. The concordance and discordance between self-reporting and blood levels for the three AEDs was 166 (48.7%) and 175 (51.3%) respectively. There was no difference between those who were concordant and discordant across socio-demographic characteristics. The agreement between self-reporting and blood levels for individual AEDs was k=0.63 for phenobarbital, k=0.59 for phenytoin and k=0.62 carbamazepine. The ETG based on AED blood levels was 74.9% (95% CI; 71.4-78.1).

Table 6.3: Self-reported Morisky Medication Adherence Scale (n=385)

Item	**No: n (%)**	**Yes: n (%)**
Do you ever forget to take your medication?	112 (29.1)	273 (70.9)
Are you careless at times about taking your medication?	114 (29.6)	271 (70.4)
When you feel better, do you sometimes stop taking your medication?	44 (11.4)	341 (88.6)
Sometimes, if you feel worse when you take your medication, do you stop taking it?	29 (7.5)	356 (92.5)
Self Reported Medication Adherence	179 (46.5)	206 (53.5)

6.3.3 Factors influencing adherence to anti-epileptic drugs

We studied 21 variables as potential predictors of adherence. Of these, 13 had univariate p-values > 0.20 and were excluded from the multivariate analysis (Table 6.4). The remaining eight variables were retained in the multivariate logistic regression model building process to predict adherence (Table 6.4).

The most important factor affecting adherence among children and adults was long duration of treatment. Children who had taken AEDs for more than five years were four times more likely to adhere to medication than those who had taken drugs for less than one year whereas adults who had taken drugs for a similar period were six times more likely to adhere to medication. Children and adults who experienced more than six seizures in three months were three times more likely to take their medication. Children and adults on polytherapy were twice as likely to take their medication than those on monotherapy. Other significant predictors were injury during a seizure and having a good relationship with the healthcare provider (Table 6.5).

Table 6.4: Factors included in univariate analysis to predict blood level adherence among people with epilepsy (n=341)

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
Sex				
Female	1.0		1.0	
Male	1.21 (0.73-2.01)	0.457	1.35 (0.73-2.49)	0.342
Religion				
Traditional	1.0			
Christian	0.99 (0.52-1.90	0.982	1.31 (0.69-2.53)	0.410
Islam	0.53 (0.20-1.42)	0.210	1.67 (0.54-5.12)	0.375
Education level				
None	1.0		1.0	
Primary	0.58 (0.30-1.09)	0.291	1.30 (0.68-2.50)	0.419
Secondary	0.97 (0.33-2.88)	0.959	2.46 (0.60-5.01)	0.210
Tertiary	n/a	n/a	0.15 (0.02-1.34)	0.090
Marital status				
Single	n/a	n/a	1.0	
Married	n/a	n/a	0.70 (0.29-1.72)	0.438
Separated	n/a	n/a	1.66 (0.16-6.95)	0.670
Divorced	n/a	n/a	0.92 (0.20-4.24)	0.916
Windowed	n/a	n/a	0.83 (0.29-2.35)	0.724
Occupation				
Farmer	n/a	n/a	1.0	
Trader	n/a	n/a	0.76 (0.33-1.75)	0.524
Casual	n/a	n/a	1.53 (0.58-4.00)	0.390
Other	n/a	n/a	1.40 (0.57-3.41)	0.465

Table 6.4: Continued from previous page

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
SES n (%)				
Least poor	1.0		1.0	
Less poor	1.08 (0.41-2.86)	0.882	0.60 (0.23-1.54)	0.289
Poor	0.53 (0.20-1.41)	0.202	0.45 (0.17-1.16)	0.299
Very poor	0.82 (0.34-1.97)	0.654	0.69 (0.27-1.73)	0.424
Most poor	0.70 (0.29-1.69)	0.424	0.88 (0.35-2.19)	0.779
Distance to health facility (Kms)				
<10	1.0		1.0	
10-20	0.58 (0.27-1.25)	0.266	0.53 (0.28-1.01)	0.361
20-30	0.62 (0.29-1.32)	0.214	0.68 (0.36-1.30)	0.244
>30	1.30 (0.37-4.60)	0.681	0.74 (0.22-2.41)	0.611
Duration of epilepsy (years)				
<1	1.0		1.0	
1-5	0.38 (0.42-1.48)	0.234	0.16 (0.06-1.44)	0.890
6-10	0.47 (0.51-2.45)	0.372	0.50 (0.91-1.71)	0.777
>10	0.51(0.64-4.54)	0.310	0.81 (0.05-3.69)	0.882
Seizure frequency in three months				
None	1.0		1.0	
1-3	2.58 (1.29-5.14)	0.007	3.06 (1.49-6.28)	0.002
4-6	1.80 (1.61-4.74)	0.023	2.45 (1.98-6.10)	0.040
>6	3.61(1.31-3.21)	0.030	1.6 (1.07-3.34)	0.065
Injury during seizure				
No	1.0		1.0	
Yes	1.21 (1.66-2.21)	0.050	1.37 (1.64-2.95)	0.041
Duration of medication (years)				
<1	1.0		1.0	
1-3	2.68 (1.09-6.56)	0.031	2.60 (1.92-4.34)	0.071
4-5	1.88 (1.65-5.44)	0.024	5.97 (1.52-3.42)	0.010
>5	4.30 (1.76-7.05)	0.001	5.02 (1.87-3.45)	0.001
No of AEDs				
Monotherapy	1.0		1.0	
Polytherapy	2.29 (1.05-4.67)	0.010	2.49 (1.15-4.47)	0.016
Stigma scores				
*0-10 points	1.0		1.0	
±11-30 points	1.00 (0.53-1.90)	0.990	1.1 4 (0.61-2.12)	0.686

***** *Those with stigma scores below 66th percentile that were categorized as not stigmatized*

± *Those with stigma scores above 66th percentile that were categorized as stigmatized*

Table 6.4: Continued from previous page

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
AEDs side effects				
No	1.0		1.0	
Yes	0.61 (0.38-0.97)	0.057	0.43 (0.20-0.89)	0.074
Good relation with provider				
No	1.0		1.0	
Yes	2.01 (1.22-3.79)	0.032	1.51 (1.18-2.57)	0.025
Availability of family support				
No	1.0		1.0	
Yes	0.59 (0.26-1.35)	0.215	0.77 (0.38-1.57)	0.479
Beliefs about causes of epilepsy				
*0-6 points	1.0		1.0	
±7-10 points	1.91 (1.03-3.56)	0.041	1.15 (1.60-2.18)	0.062
Beliefs about biomedical treatment				
*0-11 points	1.0		1.0	
±12-16 points	1.66 (0.48-5.74)	0.421	2.09 (0.48-9.07)	0.323
Beliefs about cultural treatment				
*0-14 points	1.0		1.0	
±15-18 points	1.12 (0.59-2.12)	0.711	0.67 (0.35-1.29)	0.231
Risk and safety concerns beliefs				
*0-5 points	1.0		1.0	
±6-8 points	1.87 (0.62-5.62)	0.267	1.22 (0.24-6.24)	0.809
Negative stereotype beliefs				
*0-10 points	1.0		1.0	
±11-16 points	0.34 (0.18-0.66)	0.101	0.31 (0.13-0.73)	0.126

**Scores below 66th percentile that were categorized as negative beliefs*

± Scores above 66th percentile that were categorized as positive beliefs

Table 6.5: Multivariate analysis of factors associated with blood level adherence among people with epilepsy(n=341)

	Children		Adults	
Variable	**OR (95%CI)**	**P value**	**OR (95%CI)**	**P value**
Seizure frequency in three months				
None	1.0		1.0	
1-3	1.82 (1.78-4.85)	0.008	1.55 (1.56-5.99)	0.036
4-6	2.83 (1.49-5.65)	0.006	2.66 (1.23-5.64)	0.012
>6	3.67 (1.35-7.30)	0.003	3.87 (2.79-6.42)	0.001
Injury during seizure				
No	1.0		1.0	
Yes	2.55 (1.35-5.74)	0.010	2.49 (1.37-4.56)	0.005
Duration of medication(years)				
<1	1.0		1.0	
1-3	2.89 (1.67-5.74)	0.023	2.78 (1.52-6.77)	0.031
4-5	3.60 (1.03-6.46)	0.041	5.43 (1.89-7.57)	0.020
>5	4.25 (1.86-8.75)	0.002	6.50 (1.58-9.63)	0.004
No of AEDs				
Monotherapy	1.0		1.0	
Polytherapy	2.51 (1.45-4.35)	0.001	2.28 (1.43-3.63)	0.020
Good relation with provider				
No	1.0		1.0	
Yes	2.48 (1.07-5.77)	0.042	1.91 (1.23-2.96)	0.004

6.4 Discussion

Patient adherence to treatment regimens is a complex phenomenon dependent on a number of factors. Some investigators emphasize the central role that the health care provider plays in shaping adherence, while others stress the active role of the patient. In this study we investigated factors that influence adherence among PWE in Kilifi from a patient perspective.

6.4.1 Sensitivity and specificity of self-reporting

Patient self-report using reliable and varied questionnaires is an efficient and cost-effective method for assessing adherence (Morisky *et al.*, 1986; Osterberg & Blaschke, 2005; Horne & Weinman, 1999). Self-report is also viable and useful as it can identify the reasons behind non-adherence, which could then help in addressing underlying issues (Turner & Hecht, 2001). Despite it being a good measure, some researchers have reported that patients tend to underestimate or overestimate their adherence (Stephenson *et al.*, 1993; Thorbecke, 1988). However, when self-report is combined with direct methods, it has been shown to have better sensitivity and specificity (Gomes Mda *et al.*, 1998; Ley, 1987). We evaluated the sensitivity and specificity of self reporting by using blood levels of AEDs as the gold standard. Sensitivity and specificity of self-reporting was low, indicating that self-reporting is not a reliable measure of adherence in PWE in this community. Other studies have also shown that adherence levels based on blood assays were not correlated with patient-reported adherence, indicating the relative unreliability of patient report as a measure of adherence (Hazzard *et al.*, 1990; Garber *et al.*, 2004). The discordance between self-reporting and AED blood levels observed in this study could be explained by: (a) participants giving positive responses (saying they take AEDs) because they understand expectations of the researcher or (b) participants giving negative responses (saying they don‘t take AEDs) because they expect some benefits from the researcher, such as being supplied with AEDs.

The Kappa statistic for the three AEDs ranged from 0.59-0.63. Kappa of 0.40-0.75 is considered good whereas that above 0.75 is excellent (Landis & Koch, 1977). Phenobarbital, which has a very long half life (two to seven days) had the highest level of agreement between self-reporting and blood level (Levy *et al.*, 1995; Faught, 2001). Phenytoin, which has the shortest half life (7-42 hours) had the lowest agreement (Levy *et al.*, 1995; Faught, 2001). The level of agreement for Carbamazapine was very close to phenobarbital, although it has a half life ranging from 25-65 hours (Levy *et al.*, 1995; Faught, 2001).

6.4.2 Factors associated with adherence

Most of the factors that influenced adherence were clinical (epilepsy-related) and only one factor was provider-specific.

6.4.2.1 Clinical Characteristics

We found a strong relationship between seizure frequency and adherence, which shows that PWE who perceive their epilepsy to be severe are more likely to take their medication with the hope of minimizing the seizures. In contrast, a study by Mitchell and colleagues found that seizure frequency did not affect adherence to treatment in American children (Mitchell *et al.*, 2000). Participants who reported injuries directly associated with epilepsy such as burns, broken bones, cuts and bruises were more likely to take medication because such injuries further complicate their life situation. People with Epilepsy who had taken medication for a long duration were more adherent because they had experience of the effectiveness of AEDs in controlling seizures. We found that patients on polytherapy were more likely to adhere than those on monotherapy and other studies have had similar results (Buck *et al.*, 1997; Stanaway *et al.*, 1985), although they did not mention the specific AEDs that were used. One reason for our finding could be that patients on multiple pills feel the severity of their condition and are more cautious with treatment, compared to those on monotherapy, who may take treatment less seriously. Another reason may be that when patients have to take multiple medications, they are less likely to forget to take them, compared to having to take only one pill. In Kilifi, very few PWE are on more than two AED which may also explain this finding (Figure 6.1).

6.4.2.2 Provider Characteristics

Studies suggest that patients tend to be more adherent when healthcare providers have open dialogue regarding epilepsy and its treatment and when patients are comfortable speaking with their provider (Buck *et al.*, 1997; Francis *et al.*, 1969; Feuerstein *et al.*, 1989). If the provider is viewed as concerned and prescribing medication as a reflection of that concern, then adherence may be higher than if the prescription is seen as an indication that the provider has no time for or interest in the patient. In our study, a significant relationship was found between how well patients related with the provider and adherence: those who reported a good relationship were more likely to adhere than those who felt the relationship was strained. Similar findings have been reported by other studies (Freeman *et al.*, 1971), but results from our study should be interpreted with caution because the quality of the provider-patient relation was simply measured as a (yes/no) response. Substantial research has also shown that patients base decisions about taking medication on many considerations besides their provider‘s advice (Arluke, 1980; Conrad, 1985; Trostle, 1988a; Trostle, 1988b). Scambler and Hopkins emphasize that patients are usually not passive, but play an active role in managing their own condition, and at times this will be in conflict with the advice of their provider (Scambler & Hopkins, 1988).

6.4.3 Factors not associated with adherence

None of the socio-demographic characteristics, distance from home to health facilities, SES, stigma and beliefs and attitudes predicted adherence. Two of the clinical characteristics (duration of epilepsy and AEDs side-effects) also had no association with adherence.

6.4.3.1 Socio-demographic characteristics

Our study showed that sex was not associated with adherence and other studies have reported similar findings (Buck *et al.*, 1997; Horne & Weinman, 1999; Dowse & Futter, 1991). Religion affects the self and may improve recovery by instilling hope, purpose and meaning in life in addition to affecting adherence to treatment. Although the findings from our study did not demonstrate a significant relationship between religion and adherence, a study by Borras and colleagues showed that 31% of patients with schizophrenia underlined an incompatibility or contradiction between their religion and taking medication (Borras *et al.*, 2007). Educational level showed no association with adherence probably because of the low literacy level among the study participants. Other studies have also found educational level was not correlated with adherence (Ukwe *et al.*, 2010; Dowse & Futter, 1991). Marital status did not predict adherence, which could mean PWE or their caregivers did not get the social support expected from such an institution.

6.4.3.2 Distance and social economic status

Distance did not influence adherence probably because PWE in both the adherent and non-adherent groups travelled long distances to seek specialized care for epilepsy. Both groups lived close to peripheral health facilities. This suggests that distance is likely to influence treatment-seeking as opposed to adherence because PWE had already obtained their AEDs.

Previous studies indicate that non-adherence to AED therapy is fairly evenly spread throughout social classes (Buck *et al.*, 1997; Cramer & Mattson, 1991). However, no significant differences were found between SES and adherence. Even though there was no difference in SES among the study participants, we suppose SES is likely to be a hindrance when accessing AEDs as opposed to deciding whether to take the medication or not.

6.4.3.3 Stigma and epilepsy beliefs and attitudes

Whereas some studies have reported a significant association between stigma and adherence (Buck *et al.*, 1997), we found no significant relationship between perceived stigma and adherence. This may be because over two thirds of PWE did not feel stigmatized based on their low scores on the stigma scale (Chapter 3). A study that investigated adherence to antidepressant treatment also showed that patients‘ adherence was not predicted by perceived stigma (Sher *et al.*, 2005). Horne and colleagues revealed an association between specific beliefs about medication and drug adherence (Horne & Weinman, 1999). Contrary to these findings, none of the five subscales on the Kilifi Epilepsy Beliefs and Attitudes Scale (KEBAS) were associated with adherence. If PWE had already made a decision to seek treatment from a health facility, it is likely that they had already overcome the myths and misconceptions associated with epilepsy. This is substantiated by the positive beliefs (high scores) on the KEBAS by the majority of the study participants (Chapter 4).

6.4.3.4 Clinical characteristics

The duration of epilepsy was not associated with adherence, suggesting that people with longstanding epilepsy were not more inclined to take their medication. Regarding the side effects of AEDs, Scambler and Hopkins found that some patients took it upon themselves to alter their drug taking behaviour because of adverse side-effects (Scambler & Hopkins, 1988).

A study by Buck and colleagues also demonstrated that side-effects of AEDs such as tiredness, memory problems, sleepiness, depression and headaches affected adherence (Buck *et al.*, 1997). Our findings were contrary as we did not find a significant association between AED side-effects and adherence. However, these findings need to be interpreted with caution because side effects were measured as a single (yes/no) response as opposed to recording adverse events in a detailed way like was done by Buck and colleagues (Buck *et al.*, 1997).

6.5 Limitations

The strength of this study was the use of a robust pharmacological measure of adherence but it may be influenced by factors other than adherence, including age (Yamatogi, 2004), sex (Eadie *et al.*, 1977), altered pharmacokinetics (Gidal, 2001; Faught, 2001), time since the drug was ingested and genetic differences in drug metabolism (Yamatogi, 2004). Furthermore, for patients taking more than one medication, there are drug interactions, with some drugs altering the blood level concentrations of other drugs (Gidal, 2001). Although we assessed adherence at one point in time as opposed to monitoring it over a period of time, this approach helped to estimate the ETG at a point in time, which was one of the objectives of this study.

6.6 Conclusion

This study measured adherence based on blood levels of multiple AEDs but this many not be feasible in most rural settings due to the expense. Other indirect measures such as pill counts, appointment attendance and medication refills are also not feasible in most rural settings as they are characterized by many methodological difficulties. The simplicity and feasibility of using self-reported adherence may see it continued use despite its low sensitivity and specificity.

This study has identified a subset of PWE at risk of low adherence and highlighted several reasons why they fail to adhere to AEDs, most of which are clinical in nature. Findings of this study will greatly help to develop interventions to improve patient adherence and reduce preventable seizures. In rural Africa, such interventions should focus more on clinical aspects, such as how to prevent injuries among PWE as well as how AEDs work to reduce seizure frequency. There is also a need for health providers to continually improve their relationship and communication with patients in addition to educating and counselling them.

Contributors

CKM and CRN conceptualized the study. CKM, PO, JAC and CRN participated in proposal development. CKM implemented and managed the study. CKM, AKN, TE, PO, JAC and CRN provided input into the analytical plan. SNM performed the assays. CKM drafted the manuscript. AKN, TE, SNM, PO, JAC and CRN reviewed and edited the manuscript. All authors read and approved the final version of the manuscript.

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The sponsor of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the paper. The corresponding author had full access to all the data in this study and had final responsibility for the decision to submit the manuscript for publication.

Conflict of interest

We have no conflict of interest.

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Chapter 7

Packages of Care for Epilepsy in Low- and Middle-Income Countries

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Abstract

Epilepsy is a common chronic neurological disorder, affecting over 69 million people worldwide, of whom 80% are estimated to live in Low- or Middle Income Countries (LMICs).
Anti-epileptic Drugs (AEDs) are effective in controlling seizures in over 75% of People with Epilepsy (PWE), but most PWE in LMICs do not receive appropriate treatment. This ‗Epilepsy Treatment Gap (ETG)'' is influenced by factors such as limited knowledge, poverty, cultural beliefs, stigma, poor health delivery infrastructure, and shortage of trained health care workers. Several studies implementing interventions at the community level (for example, training programs for primary health care workers) have successfully improved the identification of PWE and reduced the ETG. The sustainability of these interventions needs to be addressed, however, and efforts must be made to ensure a continuous supply of AEDs.

7.1 Introduction

Epilepsy is one of the most common and widespread neurological disorders. Recent estimates suggest that it accounts for 1% of the global burden of disease (WHO, 2005) and affects over 69 million people (Ngugi *et al.*, 2010). In addition, because the relatives and friends of People with Epilepsy (PWE) also bear the burden of this condition, more than 500 million people are indirectly affected by epilepsy (Kale, 2002). Thus, epilepsy imposes a large economic burden on global health care systems and is a major public health problem in Low and Middle-Income Countries (LMICs) (WHO, 2005).

The World Health Organization (WHO) estimates that 80% of PWE live in LMICs. The incidence and prevalence of epilepsy are thought to be higher in LMICs than in High-Income Countries (HIC)—the median prevalence in LMICs is 9.5/1,000 compared to 8/1,000 in Europe, although the prevalence varies widely among countries (WHO, 2005; Ngugi *et al.*, 2010). The incidence of epilepsy in LMICs is thought to be up to five times that in HICs, although there are fewer studies on which to base this estimate. Worldwide, mortality among PWE is two to three times higher than in the general population and it is thought to be higher in LMICs than in HICs although data are scarce (Diop *et al.*, 2005). The Epilepsy Treatment Gap (ETG), i.e., the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated, is high in many LMICs (WHO, 2005). Overall, 56% (range 7%–98%) of PWE in LMICs remain untreated, with 73% remaining untreated in rural regions compared to 46% in urban settings (Mbuba *et al.*, 2008).

The International Classification of Disease (ICD) 10 diagnostic criteria for epilepsy are given in (Textbox 7.1) (WHO, 2007). The definition of epilepsy has recently been revised by the International League Against Epilepsy (ILAE) (Fisher *et al.*, 2005), but the original classification of seizures (transient occurrences of signs and/or symptoms due to excessive or synchronous discharge of neuronal activity in the brain) as partial (focal), generalized, or unclassified remains useful (ILAE, 1981). Epilepsy has many different etiologies, with head trauma, central nervous system infections, perinatal problems, and cerebrovascular accidents most commonly identified (WHO, 2005), although in most cases a cause is not found. Focal epilepsies represent a greater proportion of epilepsies in LMICs than in HICs and risk factor analysis has identified many causes that are preventable.

Although seizures are its most overt manifestations, epilepsy is associated with significant psychological (Fisher *et al.*, 2000) and psychiatric conditions (LaFrance *et al.*, 2008), which have social consequences for everyday living (Baker, 2002). Psychiatric disorders occur in 25%–30% of PWE (LaFrance *et al.*, 2008), with depression being the most common, followed by anxiety disorders, psychoses, and personality disorders (Devinsky, 2003; Gaitatzis *et al.*, 2004). Psychiatric comorbidity appears to be particularly common in some LMICs (Nubukpo *et al.*, 2004). Stigma poses a major burden to PWE and their families, interfering with the opportunities that PWE have for employment and marriage (Baskind & Birbeck, 2005b). Finally, women with epilepsy are particularly vulnerable to sexual exploitation, physical abuse, and extreme poverty (Birbeck *et al.*, 2007).

7.2 Methods

In this article, we focus on the management of epilepsy in LMICs. We review the evidence from LMICs on the efficacy of treatments and delivery of interventions. Because this evidence is often limited, we also refer to systematic reviews, meta-analyses, and key trials from HICs where appropriate. On the basis of this review, we propose a package of care—a combination of interventions aimed at improving the recognition and management of conditions to achieve optimal outcomes—for epilepsy.

Textbox 7.1: International Classification of Diseases 10 Criteria for Epilepsy

‘‘G40.0 Localization-related (focal or partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset
Benign childhood epilepsy with centrotemporal EEG spikes
Childhood epilepsy with occipital EEG paroxysms
G40.1 Localization-related (focal or partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures
Attacks without alteration of consciousness
Simple partial seizures developing into secondarily generalized seizures
G40.2 Localization-related (focal or partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures
Attacks with alteration of consciousness, often with automatisms
Complex partial seizures developing into secondarily generalized seizures
G40.3 Generalized idiopathic epilepsy and epileptic syndromes
Benign:
  Myoclonic epilepsy in infancy
  Neonatal convulsions (familial)
Childhood absence epilepsy
Epilepsy with grand mal seizures on awakening
Juvenile:
  Absence epilepsy
  Myoclonic epilepsy [impulsive petit mal]
Nonspecific epileptic seizures:
  Atonic
  Clonic
  Myoclonic
  Tonic
  Tonic-clonic
G40.4 Other generalized epilepsy and epileptic syndromes
Epilepsy with:
  Myoclonic absences
  Myoclonic-astatic seizures
Infantile spasms
Lennox-Gastaut syndrome
Salaam attacks
Symptomatic early myoclonic encephalopathy
West‘s syndrome
G40.5 Special epileptic syndromes
Epilepsia partialis continua
Epileptic seizures related to: alcohol, drugs, hormonal changes, sleep deprivation or stress
G40.6 Grand mal seizures, unspecified (with or without petit mal)
G40.7 Petit mal, unspecified, without grand mal seizures
G40.8 Other epilepsy
Epilepsies and epileptic syndromes undetermined as to whether they are focal or generalized
G40.9 Epilepsy, unspecified’’

7.3 Results

7.3.1 The Evidence on the Treatment of Epilepsy

The evidence for most aspects of the management of epilepsy is poor in both high- and low-income settings (Table 7.1).

7.3.1.1 Detection of Epilepsy

Much epilepsy in the world is not identified, particularly in LMICs, and thus PWE may not benefit from treatment. The diagnosis of epilepsy is based on clinical history alone, but since patients may become unconsciousness during seizures, an independent observer is often necessary. In HICs misdiagnosis occurs in 5%–30% of cases (Chowdhury *et al.*, 2008), and in LMICs this is likely to be higher. In HICs, clinical examination may identify the cause of epilepsy and help with prognosis (Dooley *et al.*, 2003). For example, electroencephalography (EEG) may detect epileptic discharges, which support the diagnosis, but is not necessary for confirmation. Although this test lacks sensitivity and specificity (Chowdhury *et al.*, 2008), it is useful for classification of seizures and epilepsy syndromes. Video electroencephalography (telemetry) is particularly useful for management of intractable epilepsy. Various biochemical tests can help in differential diagnosis and can determine an underlying cause of epilepsy. Computerized Tomography (CT) scanning is useful for demonstrating gross abnormalities, haemorrhages, and calcification and for detecting parasitic diseases, e.g., neurocysticercosis (Bernal & Altman, 2003). Magnetic Resonance Imaging (MRI) is more sensitive than tomography in identifying structural abnormalities (Wieshmann, 2003). It is recommended that patients with refractory epilepsy undergo functional neuroimaging. Finally, single-photon emission computer tomography and positron emission tomography may help locate ictal foci, and are particularly useful in identifying candidates for surgery (Duncan, 2002). Unfortunately, these investigations are rarely available in LMICs.

7.3.1.2 Anti-epileptic Drug Therapy

Because the cause of epilepsy is often undetermined, and in most cases the epileptogenic focus cannot be removed, Antiepileptic Drugs (AEDs) are used to control seizures. In HICs, AEDs may be considered if the person has had seizures within the past 2–5 years (active epilepsy), but in many LMICs AEDs are only often recommended in PWE with a seizure in the past year.

AEDs are very effective in controlling seizures: 75% of those treated may become seizure free; 20%–30% of PWE have spontaneous remission of seizures without treatment (Kwan & Sander, 2004). Phenobarbital is the least expensive and most widely used AED. It controls a range of seizure types and is on the essential drug list of 95% countries surveyed by the WHO; phenytoin, carbamazepine, and valproate (also first-line AEDs) are on the essential drug list in 86%, 93%, and 87% of countries, respectively (WHO, 2005). Many other AEDs have been introduced to HICs but are not widely available in LMICs. Each of these AEDs has a profile of adverse events, which may influence their use.

Few randomized trials have compared the efficacy and effectiveness of these first-line AEDs, and most of these trials were conducted in HICs. In a recent review by the ILAE, evidence for the efficacy and effectiveness of AEDs as initial monotherapy was found only in adults with partial-onset seizures (carbamazepine, phenytoin, and valproate), children with partial-onset seizures (oxcarbazepine), and elderly adults with partial-onset seizures (gabapentin and lamotrigine) (Glauser *et al.*, 2006). In Cochrane reviews, no significant differences were documented in efficacy between phenobarbital, carbamazepine, phenytoin, or valproate in patients with generalized or partial-onset seizures (Taylor *et al.*, 2001; TudurSmith *et al.*, 2001; TudurSmith *et al.*, 2002; TudurSmith *et al.*, 2003). In LMICs, carbamazepine was not shown to be better than phenobarbital in Ecuadorian (Placencia *et al.*, 1993) or Kenyan adults (Feksi *et al.*, 1991b). In Indian children, there was no difference in efficacy between phenobarbital and phenytoin (Pal *et al.*, 1998). However, questions have been raised about the suitability of phenobarbital because of its adverse events (Scott *et al.*, 2001), and the ILAE has argued that the status of this drug is based on economic factors, rather than on efficacy and suitability (ILAE, 1985).

7.3.1.3 Surgery

Surgical removal of the epileptic focus is the only cure for epilepsy. Palliative procedures can also be performed. Surgery requires a thorough evaluation to identify the epileptic focus and the relationship of this focus to other functionally important areas of the brain (for example, the speech centre). A recent meta-analysis identified factors associated with seizure remission following surgery (Table 7.1) (Tonini *et al.*, 2004). Because surgery requires sophisticated facilities and specialized staff, it is usually only available in HICs. Nevertheless, surgery is increasingly being performed in LMICs (Asadi-Pooya & Sperling, 2008).

7.3.1.4 Vagus Nerve Stimulation

This technique is proposed for the treatment of refractory epilepsy and for the treatment of PWE who are not candidates for surgical treatment. It is effective in treatment of epilepsy patients with partial seizures (Ben-Menachem, 2002), but is not widely available in LMICs.

7.3.1.5 Lifestyle Changes

Although seizures cannot be prevented by lifestyle changes alone, PWE can nevertheless make changes that improve their lives and give them a sense of control. For example, although many PWE do not know the precipitants for their seizures, inadequate sleep, food allergies, alcohol, smoking, and flashing lights may trigger seizures in some patients and can be avoided. Similarly, exercise is important for many aspects of epilepsy (Arida *et al.*, 2008) particularly to counteract the side effects of some AEDs. However, exercise can trigger seizures in some patients. Finally, dietary changes may prevent the adverse events of some AEDs— phenytoin interferes with vitamin D metabolism, for example. The ketogenic diet (high-fat, no-sugar, low protein diet) is indicated in specific epilepsy syndromes (Kossoff, 2008) but requires specialized nutritional support that is often not available in LMICs (Seo & Kim, 2008). Other diets are unproven.

7.3.1.6 Psychosocial Therapy

Psychological interventions such as psychotherapy, individual, group, or family counseling, progressive relaxation therapy, and cognitive behaviour therapy have all been used in epilepsy (Table 7.1). However, the trials were small and were mainly conducted in HICs and a systematic review concluded that there was no reliable evidence to support the use of these treatments (Ramaratnam *et al.*, 2008).

Table 7.1: The evidence in support of epilepsy treatment

Epilepsy Management	**HICs**	**LMICs**
Detection and diagnosis	Screening questionnaires (Corey *et al.*, 2009; Reutens *et al.*, 1992); Use of medical records (Cockerell *et al.*, 1996; Hauser *et al.*, 1991); Neurological Examination (Dooley *et al.*, 2003); EEG (Chowdhury *et al.*, 2008); MRI, CT scan (Bernal & Altman, 2003; Wieshmann, 2003; Duncan, 2002).	Screening questionnaires (Feksi *et al.*, 1991b; Placencia *et al.*, 1992; Preux, 2000); EEG (Sawhney *et al.*, 1996); CT scan (Murthy *et al.*, 1998); MRI scan in those with abnormal EEG (Mohamed *et al.*, 2006).
AEDs	Systematic review of initial monotherapy in adults with partial-onset seizures (carbamazepine, phenytoin, and valproic acid), children with partial-onset seizures (oxcarbazepine), and elderly adults with partial-onset seizures (gabapentin and lamotrigine) (Glauser *et al.*, 2006). Cochrane reviews of efficacy and withdrawal rates associated with phenobarbital, carbamazepine, phenytoin, or sodium valproate use in patients with generalized or partial onset seizures (Taylor *et al.*, 2001; TudurSmith *et al.*, 2001; TudurSmith *et al.*, 2002; TudurSmith *et al.*, 2003).	RCTs of carbamazepine and phenobarbital in Ecuadorian (Placencia *et al.*, 1993) and Kenyan adults (Feksi *et al.*, 1991b) and in Indian(Pal *et al.*, 1998) and Bangladeshi children (Banu *et al.*, 2007). Observational studies of phenobarbital in China (Wang *et al.*, 2006), and phenobarbital and phenytoin in India (Pal *et al.*, 1998; Mani *et al.*, 2001).
Surgery	Meta-analysis to identify prognostic indicators of seizure remission after surgery (Tonini *et al.*, 2004).	Overview of more than 1,000 operations for epilepsy in India (Radhakrishnan, 2009).
Ketogenic diet	Systematic review of trials of the ketogenic diet (Kossoff, 2008). RCT of the ketogenic diet in children with AED-resistant epilepsy (Neal *et al.*, 2008).	Ketogenic diet (Seo & Kim, 2008).
Psychosocial and psychoeducational interventions	RCT of a 2-day psychoeducational treatment program (Helgeson *et al.*, 1990). RCT of a 6-week structured psychoeducational group intervention for adolescents with epilepsy and their parents (Snead *et al.*, 2004). RCT of a structured nurse-led intervention (Helde *et al.*, 2005).	Nonrandomized intervention study that provided leaflets about drug information to Taiwanese adults with epilepsy (Liu *et al.*, 2003).
Cognitive behaviour therapy	—	RCT of acceptance and commitment therapy in South Africa (Lundgren *et al.*, 2006).
Relaxation therapy	Two-phase experimental group investigation of a contingent relaxation treatment program (Dahl *et al.*, 1987).	—

EEG: Electroencephalography; CT: Computerized Tomography;
MRI: Magnetic Resonance Imaging; RCT: Randomized Controlled Trial.

7.3.2 Delivery of Effective Interventions

Delivery of efficacious interventions in LMICs can only be achieved if PWE are correctly identified. Unfortunately, the symptoms of some types of epilepsy (for example, hallucinations) may not be recognized as part of an illness, particularly in LMICs where epilepsy is interpreted within traditional belief systems. Furthermore, in LMICs, trained personnel for the detection and management of epilepsy and facilities for investigations of underlying causes are scarce (WHO, 2005). However, nurses, community health workers, and key informants such as teachers can improve the identification of PWE (Feksi *et al.*, 1991b; Mielke *et al.*, 1997), and these PWE can then benefit from various interventions (Table 7.2).

7.3.2.1 Interventions to Ensure an Adequate Drug Supply

One of the factors contributing to the ETG in LMICs is the lack of a continuous and affordable supply of AEDs (Scott *et al.*, 2001; ILAE, 1985). Phenobarbital is most widely used in LMICs. Other available AEDs such as phenytoin, carbamazepine, and valproate are three, 11, and 16 times more expensive, respectively, than Phenobarbital (WHO, 2005); and are often not available and/or routinely prescribed in peripheral health facilities. Because only a 1–3-month supply of AEDs is dispensed at any one time, PWE have to attend clinics frequently and the cost of these visits may interrupt adherence. Furthermore, the systems for providing a continuous supply of AEDs, particularly to rural clinics, often fail, which discourages attendance. Studies in Kenya and India have shown that programs that ensure a continuous supply of AEDs can improve adherence (Feksi *et al.*, 1991b; Mani *et al.*, 2001), thereby reducing the ETG. Drug banks set up by nongovernmental organizations (NGOs) in some LMICs to supply hospitals when there is a shortage within the government sector can help to ensure adequate drug supplies but are difficult to sustain.

7.3.2.2 Interventions to Educate PWE and Caregivers about Epilepsy

Education of PWE and caregivers about epilepsy is important for several reasons. First, PWE with limited knowledge of epilepsy are at increased risk of the complications of seizures, such as fractures, burns, and accidental death (Beghi, 2005; Josty *et al.*, 2000). Second, one of the major conflicts in LMICs is the community‘s beliefs of the cause of epilepsy, and thus its treatment.

In many societies, epilepsy is not thought to be caused by diseases of the brain, but is attributed to traditional beliefs such as spirits (Jilek-Aall, 1999). Finally, in LMICs, PWE often have cognitive impairment and psychiatric comorbidity, which impairs their understanding of epilepsy and the need to take AEDs daily. Thus, the care of PWE often falls onto family members and friends. Although psychoeducational interventions tested in randomized controlled trials in HICs significantly improved knowledge and coping with epilepsy and decreased seizure frequency in HICs (Table 1), there have been no similar trials in LMICs, and the educational interventions required are likely to be different in these settings. There have been some programs that increased the knowledge of epilepsy in LMICs as part of a package of interventions but the components of these programs with the most significant effect on AED adherence, seizure outcome, and self-esteem among PWE are difficult to identify (Adamolekun *et al.*, 1999; Gourie-Devi *et al.*, 2003; Olley, 2004).

Patient support groups are found in many countries and play an important role in educating PWE and their caregivers, as well as in advocacy (http://www.ibe-epilepsy.org/links). In addition to education, PWE and their families may also benefit from targeted psychosocial interventions. For example, a study in a London outpatient clinic provided evidence that the provision of skilled counseling to patients with epilepsy in addition to ‗routine‘‘ therapeutic intervention is useful (Usiskin, 1993). Counseling helps to deal with many of the problems associated with epilepsy that are not related to the medical or technical aspects of seizure control. Unfortunately, the resources needed for counseling PWE and their caregivers are often not available in LMICs and the provision of such services competes with other health needs.

7.3.2.3 Community-Based Interventions to Improve Awareness

Public education is generally advocated as the best method to reduce the stigma attached to conditions such as epilepsy, but interventions need to be based upon qualitative and quantitative assessments to identify the causes of stigma in each region (Baskind & Birbeck, 2005b). Information, education, communication, and social marketing are needed to enhance compassion and reduce blame (Weiss & Ramakrishna, 2006). Community programs to achieve these aims must be based on the local perceptions of epilepsy and needs and must consider social and cultural conditions in the region. To date, community programs have met with some success in

Kenya (Feksi *et al.*, 1991b), Ecuador (Placencia *et al.*, 1993), Malawi (Watts, 1989), Ethiopia (Berhanu *et al.*, 2009) and India (Mani *et al.*, 2001). Community-based studies in Kenya and India that supplied free AEDs reported low rates of withdrawal and good adherence and response to therapy (Mani *et al.*, 2001; Feksi *et al.*, 1991b). In Ethiopia, community awareness and a regular supply of phenobarbital increased the number of patients attending the clinic (Berhanu *et al.*, 2009). In Malawi, the model tested included publicity of accessible services, adequate supplies of AEDs, setting up of mobile clinics, and frequent follow up by health workers (Watts, 1989). Unfortunately, most of these programs do not appear to have been sustained since they relied on external funds. Thus, epilepsy care needs to be integrated into primary health care delivery, perhaps with patients providing some of the cost of AEDs to enhance sustainability (Adamolekun *et al.*, 1999).

The Global Campaign Against Epilepsy, a partnership between the WHO, ILAE, and the International Bureau for Epilepsy was launched in 1997 to improve the acceptability, treatment, services, and prevention of epilepsy worldwide (Reynolds, 2000). Several demonstration projects are currently underway under the auspices of this Campaign that aim to reduce the ETG and the physical and social burden of epilepsy through community-level interventions. The most successful is the Chinese project, which started with a media-based education program to create awareness about epilepsy and to convey the message that epilepsy is treatable. The program provided free phenobarbital at local health centres and patients were followed up by primary health care physicians who had received basic training in the diagnosis and management of epilepsy (Wang, 2008). Lectures and group discussions for PWE and their families were arranged and community leaders and teachers were given information about epilepsy. This project improved adherence to AEDs and significantly decreased the ETG from 63% to 50% (Wang, 2008).

7.3.2.4 Interventions to Train Health Care Providers

There are few specialists, particularly neurologists, in LMICs (WHO, 2005) and health care providers are often ignorant about epilepsies, particularly about their causes, diagnosis, treatment, and psychosocial aspects. Interventions to train health care workers should, therefore, equip them with the knowledge and skills needed to diagnose and manage epilepsy, to counsel PWE, and to make appropriate referrals. The training should promote strategies to ensure adherence and follow-up care (Gourie-Devi *et al.*, 2003). Training facilities often cannot be established in LMICs because of the expense (WHO, 2005). Thus, the training of health care providers in such countries requires the production and distribution of educational materials, including standard guidelines for diagnosis and care of PWE. Our review indicates that educational interventions that targeted health care providers in Zimbabwe and Ethiopia greatly improved the diagnosis and management of epilepsy (Adamolekun *et al.*, 1999; Berhanu *et al.*, 2009).

7.3.2.5 Interventions to Involve Traditional Healers

Despite important advances in the understanding and treatment of epilepsy, many communities in LMICs still believe that epilepsy is supernatural or sacred and is associated with possession, impurity, contagion, heredity, and madness. In many parts of Africa and Asia, notions about epilepsy are rooted not in a medical model but in a spiritual model (Whyte, 1995). Often these beliefs involve external factors and so PWE seek a contextually relevant cure from a traditional healer (TH) that removes the alien factor from the body rather than seeking preventative or biomedical treatment. Traditional healers live within the community and know the communities‘ perceptions of ill health. Their concentration is much higher in many populations than medical staff (Baskind & Birbeck, 2005a), and they provide explanations that members of the community believe. They can also provide psychosomatic support, spend longer with their clients than medical staff, and will accept flexible payment systems (Kendall-Taylor *et al.*, 2008). But as a group of health care providers, their training, expertise, and beliefs are very variable, and their activities rarely regulated. Nevertheless, because they are frequently consulted in many LMICs, involving THs in the management of epilepsy might be a useful intervention.

7.3.2.6 Interventions to Integrate Epilepsy Care into Existing Health Services

Acceptance of epilepsy treatment may be markedly improved by integrating it into existing health care services. Mental health services are particularly important in LMICs since there are more psychiatrists than neurologists and PWE often have considerable psychiatric comorbidity. Experience in both Kenya and Malawi has shown that although epilepsy care can be successfully provided in LMICs, it is much harder to sustain it when it is not integrated into such services (Feksi *et al.*, 1991b; Watts, 1989). Programs that address epilepsy alone are unlikely to be sustained, and there is a compelling argument that such programs should be incorporated into mental illness or chronic disease services. The sustainability of these programs depends on community participation in planning, implementation, and evaluation as well as integration into primary health care (Scott *et al.*, 2001). A study conducted in Ethiopia illustrated how an existing health care infrastructure developed for treatment of infectious diseases could be adapted to deal with epilepsy (Berhanu *et al.*, 2009). An Indian study showed that management of epilepsy should be set within the context of rehabilitation and incorporated into wider programs aimed at the alleviation of poverty (Pal *et al.*, 2000b). In addition, a commitment needs to be made to deal with the many preventable causes of epilepsy in LMICs such as poor perinatal care, head trauma, and parasitic infections, by integrating epilepsy into wider public health programs (Scott *et al.*, 2001).

Epilepsy services could also be improved in the community through approaches such as ‗extension services‘‘ (satellite clinic model) of apex institutions and collaboration with other organizations (Table 7.2). Satellite clinics facilitate the provision of services to the neglected populations of rural areas by reducing the distances travelled by PWE to attend health facilities. Similarly, the creation of partnerships between governmental, private, and voluntary agencies has proved a useful, cost-effective, and sustainable way to improve the identification and management of PWE (Mani *et al.*, 2001; Gourie-Devi *et al.*, 2003). More specifically, in two studies in India where workers in NGOs that were already involved in community-based health care received training in case ascertainment and in informing communities about epilepsy, the epilepsy service continued after the studies ended because it was integrated into existing health care provision (Mani *et al.*, 2001; Pal *et al.*, 2000b).

Table 7.2: Delivering epilepsy treatments

Step	How	By Whom	In What Settings
Increasing demand for the package	Advocacy campaign with the message: ‗Epilepsy can be controlled‘‘(WHO, 2005; Reynolds, 2000).	Patients and support groups; Community health workers; Nurses and physicians; Traditional healers; Public health personnel (Feksi *et al.*, 1991b; Mani *et al.*, 2001; Adamolekun *et al.*, 1999; Gourie-Devi *et al.*, 2003; Adamolekun *et al.*, 2000; Mani *et al.*, 1994)	Community meetings; Schools; Media, e.g., radio, newspapers; General practice; Homesteads
Increasing access to the package	Making AEDs available in health facilities(Feksi *et al.*, 1991b; Mani *et al.*, 2001; Berhanu *et al.*, 2009); Improving awareness about the access to AEDs in health facilities (Feksi *et al.*, 1991b; Gourie-Devi *et al.*, 2003; Berhanu *et al.*, 2009); Organizing satellite clinics (Gourie-Devi *et al.*, 2003; Watts, 1989); Collaborating with other stakeholders in the health sector (Mani & Subbakrishna, 2003; Pal *et al.*, 2002).	Ministries of Health (WHO, 2005; Scott *et al.*, 2001); NGOs (Mani & Subbakrishna, 2003; Pal *et al.*, 2002); Private and voluntary agencies	Primary health centres; Private clinics; Hospitals
Improving recognition of the disorder	Community-based and practice-based screening to identify the patients and causes; Clinical history; Neurological examination; Examination of blood AED levels and parasitic infections (WHO, 2005).	Health care workers (Feksi *et al.*, 1991b; Mani *et al.*, 2001; Gourie-Devi *et al.*, 2003; Berhanu *et al.*, 2009); Research assistants; Technicians (Adamolekun *et al.*, 1999).	Community; Primary health centres; Maternal and child health clinics; District General Hospitals; Referral hospitals
Initiation of evidence-based treatments	Supply of first-line AEDs(Feksi *et al.*, 1991b; Pal *et al.*, 1998; Mani *et al.*, 2001; Wang *et al.*, 2006); Training on principles of AED use	Health care workers with license to prescribe AEDs	Primary health centres; Private clinics; Hospitals

Managing serious or complex cases	Referral to other centres with specialist resources (Gourie-Devi *et al.*, 2003).	Specialist health care workers	Centres with medical staff with expertise in epilepsy
Achieving optimal outcomes	Increasing AED adherence to reduce seizures, e.g., adherence management until full control achieved for at least 2 years (Feksi *et al.*, 1991b; Adamolekun *et al.*, 1999).	Health care workers (Adamolekun *et al.*, 1999).	Primary health centres; Private clinics; Hospitals; Homesteads
Addressing impacts on other health/social outcomes	Improving quality of life by, for example, psychosocial counseling of the family and PWE (Usiskin, 1993; Olley *et al.*, 2001); Reducing stigma (Baskind & Birbeck, 2005b; Watts, 1989).	Health care workers (Adamolekun *et al.*, 1999; Adamolekun *et al.*, 2000); Traditional Healers (Baskind & Birbeck, 2005a; Kendall-Taylor *et al.*, 2008); Psychiatrists (Gourie-Devi *et al.*, 2003);Psychologists (Olley, 2004).	Primary health centres; Private clinics; Hospitals; Homesteads; Counseling centres

7.4 Discussion and Conclusion

7.4.1 Packages of Care for Epilepsy in LMICs

Epilepsy, one of the most common neurological conditions, is under-resourced and undertreated in LMICs. A large number of people have significant morbidity and mortality because of the failure to identify cases, difficulties with infrastructure, and the unavailability of suitable AEDs. Education of the community and of health care workers will improve the identification of PWE and thus reduce the ETG, provided inexpensive and reliable supplies of AEDs are available. Governments in LMICs need to recognize the burden of epilepsy and need to develop packages of care to reduce the disability associated with this condition in an efficient, sustainable, and equitable manner. We propose two packages of care based on the availability of resources (Table 7.3). Ideally, the delivery of these packages should be integrated into existing primary health care with the help of NGOs and other nonmedical staff involved in community-based and mental health care.

Table 7.3: Packages of care for epilepsy

Low Resourced Settings	**High Resourced Settings**
Epidemiological surveys; Key informants such as community health workers and teachers trained in identification	Primary health care workers, doctors, and neurologists trained in identification and diagnosis
Nurses and clinical officers trained in diagnosis	Specialists in epilepsy
Educational and psychoeducational interventions	Educational and psychoeducational interventions
Limited choice of inexpensive AEDs; Continuous supply of AEDs; Generic formulations	Wide choice of AEDs
Limited services for epilepsy surgery	Services for epilepsy surgery; Ketogenic diet
Health care workers trained in psychological support and counseling	Health care workers trained in psychological support and counseling
Advocacy by NGOs	Advocacy by NGOs

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Chapter 8

Comparing characteristics of epilepsy treatment providers on the Kenyan coast: implications for treatment-seeking and intervention

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Abstract

Introduction

Existing studies have identified demographic and resource-related barriers to treatment-seeking and have focused on treatment seekers in exploring and modeling decision-making. While the treatment-seeking literature acknowledges the role of the characteristics of treatment providers, few studies have adopted an explicit focus on these determinants, nor have they approached the study of treatment-seeking with an in-depth ethnographic focus on the providers themselves. The following article analyzes the structural aspects of treatment provision as one influence on how families in Kilifi, Kenya seek care for children with epilepsy. While not a comprehensive decision model, the study examines the ways in which treatment-seeking may be facilitated or deterred by the characteristics of available treatment options.

Methods

Ethnographic methods were applied, including interviews, participant observations and surveys, to examine factors that may affect the choice of families on the coast of Kenya between traditional healing and biomedical care for epilepsy.

Results

Traditional healers were found to have a profound influence in the treatment of epilepsy in Kilifi. Their treatments differ from those available at health facilities in the following key dimensions: explanations of causation, communication styles, social roles, referral practices, location and systems of payment.

Conclusion

The article identified key differences between biomedical and traditional treatments that may help to explain the existence of the biomedical treatment gap in Kilifi. This study suggests that comparing data on treatment providers reveals barriers to obtaining biomedical care, thereby offering an important tool in intervention design research.

8.1 Introduction

The prevalence of epilepsy in Kilifi, Kenya, where the present study was conducted, is estimated to be 4.5% (Edwards *et al.*, 2008) . The high prevalence of epilepsy in RPCs may be related to more prevalent alcoholism and childhood trauma (Shorvon, 1990), as well as poor sanitation that includes parasitic contamination (Diop *et al.*, 2003). Other research suggests that the high prevalence of epilepsy in RPCs may reflect marriage practices in which individuals with epilepsy are the only suitable partners for others with the disorder, or may result from perinatal head trauma associated with the birthing practices of some cultures (Jilek-Aall & Jilek, 1993). Striking gaps in Kilifi between the prevalence of epilepsy and the number of individuals receiving effective biomedical treatment make these statistics even more dramatic (Carter, 2002).

In this article, the public health issues of access to care are addressed with an intervention design from an anthropological perspective that focuses on treatment providers. Previous studies have documented the Epilepsy Treatment Gap (ETG) and identified demographic and resource-related barriers to treatment-seeking (Mansour *et al.*, 2000; Coleman *et al.*, 2002; Weisner & Matzger, 2002; Reilley *et al.*, 2002). Ethnographic studies have concentrated on the treatment decision-makers, examining motives beyond material resource factors including cultural models, past experiences and assessment of results (Beckerleg, 1994; Sussman, 1981; Young & Garro, 1994; Fabrega, 1974; Finkler, 1994; Good & Delvecchio, 1981; Kleinman, 1980; Mathews & Hill, 1990; Quinn, 1978; McGrath, 1999). However, few studies have examined the social and procedural factors that shape and constrain choices, such as the roles of providers in the community, and structural differences between biomedical and alternative treatments (Good, 1986). Furthermore, explanations by decision-makers given for past treatment-seeking events may be attempts to establish meaning and continuity for choices already made and may not capture the actual decision making process (Boster, 1984; Bibeau, 1997)

To address these shortcomings, this study focused explicitly on treatment providers as a source of data and the ways in which treatment-seeking may be facilitated or deterred by the availability of treatment options and characteristics of service providers, rather than by characteristics of the persons in need of treatment (a study by Finkler (Finkler, 1994) is a notable example of this approach).

Therefore the following analysis does not represent a comprehensive decision model about how families seek care for Children with Epilepsy (CWE). Instead it documents factors related to treatment providers in these decision-making processes. Furthermore, the comparison between provider characteristics represents an important tool in intervention research and serves as a means of identifying and assessing structural barriers to treatment-seeking and adherence.

A comparative ethnographic approach was employed to explore the distinguishing characteristics of services for childhood epilepsy in Kilifi. To our knowledge, this is the first study to contrast the characteristics of service providers as potential determinants of treatment choice for CWE. A review of data from our sample of providers revealed important differences between the two options that inform future efforts to develop a more effective healthcare delivery system.

8.2 Study area and religious beliefs

Kilifi town, the administrative center of the Kilifi District, is approximately 64 km north of Mombasa, Kenya‘s second largest city, and 64 km south of the city of Malindi. The majority of people who live in this coastal district reside in rural areas. Traditionally, Arab traders and the Islamic religion have had a strong presence on the coast. However since the time of British colonization, Christianity has become more prominent. The majority of the traditionally up-country tribes and some members of the coastal tribes practice various forms of Christianity (Parkin, 1991). Forty-seven per cent of individuals in the study area identify as Christian, 13% Muslim, 24% Traditionalists, 12% ‗other‘ and 4% unknown (KEMRI, 2005). Some tribes, such as the Giriama, have managed to retain elements of their unique religious beliefs and practices that form the basis of traditional healing and local epilepsy beliefs (Parkin, 1991).

8.3 Treatment in Kilifi

8.3.1 Traditional

While Parkin has provided invaluable background on the *Mijikenda* culture (Parkin, 1991; Parkin, 1968; Parkin, 1970; Parkin, 1972; Parkin, 1989), treatment seeking in this area remains largely unstudied from an anthropological perspective. The most notable exception is the work of Susan Beckerleg in a Swahili settlement in Watamu located in Malindi District, to the north of Kilifi District (Beckerleg, 1994). While her findings are illuminative of health beliefs and healing related to fever, or *homa*, in this Swahili cultural pocket, treatment and treatment-seeking in Kilifi District vary dramatically from what is described in her study. Differences include the underlying model used to explain illness and treatment, and the actual treatment techniques employed (Kendall-Taylor, 2009). For example, individuals in the Beckerleg study attributed illness to imbalances in hot and cold states, while for the Mijikenda, ill health is less frequently about these humoral balances and more often perceived as the physical manifestation of events occurring in the spiritual realm. Thus, while many of the treatments Beckerleg describes are designed to improve balance, Mijikenda treatments focus on communicating with spirits and addressing the needs and desires of these spirits. These differences are likely due to the fact that Beckerleg studied a Swahili population, while the present study focused on traditional Mijikenda beliefs and practices.

In the system of Mijikenda traditional healing, illnesses, as well as social problems more generally, are caused by a system of spirits. This system can be divided into four general categories. Healers deal with each of these categories by employing a different general treatment ideology.

In cases where traditional treatment is sought, the healer must divine which type of spirit is causing a particular problem, determine the best way to deal with the spirit responsible, administer the treatment, and finally follow up to assess the necessity of on-going intervention. The perception of which spirit is causing a problem is key to determining which specific treatment will be used and, because certain healers are specialists in dealing with specific spirits, who the most qualified healer is to administer such treatment.

8.3.2 Biomedical

Biomedical treatment in Kilifi is provided by a government hospital, government health centers, and private clinics. Kilifi District Hospital (KDH), the only hospital in Kilifi District, is located in Kilifi town. Thirty-four government health centers and dispensaries are dispersed throughout the district, staffed by doctors, nurses, and health workers with various degrees of training in biomedicine, ranging from limited course work and experience, to medical degrees and extensive experience in practice. In addition, approximately 25 private clinics operate in the district, which vary widely in staff training and medical supplies.

The KDH, in conjunction with Kenya Medical Research Institute (KEMRI), operates a special clinical program for CWE. It provides free assessment and clinical services and Anti-epileptic Drugs (AEDs) at subsidized prices and is staffed by three clinicians with experience in the management of epilepsy. Government health centers do not offer this level of service. The latter facilities are only permitted to prescribe the AED phenobarbital, and consistently lack supplies of this medication. The staff members at these health facilities and at private clinics frequently have little training in epilepsy diagnosis and management. Research with families of CWE in Kilifi (Kendall-Taylor, 2009) revealed that neither government nor private clinics are seen as viable options for epilepsy treatment, and that KDH is perceived as the only option for biomedical treatment of the disorder.

8.4 Methods

8.4.1 Sample and procedures

Treatment provider data was collected from approximately 200 hours of person-centered interviews (Levy & Hollan, 1998) and observations over 9 months with a group of Traditional Healers (THs). Data consisted of both audio-taped interviews and field notes from informal participant observation sessions. Researchers observed a total of 52 healing sessions with these healers. The TH sample was selected using a combination of convenience and snowball sampling. Researchers located the families of CWE in four different sub-locations of Kilifi District. Families were asked to identify THs who were known to provide treatment for epilepsy.

Healers identified by members of multiple families were located and asked if they would be willing to participate in the study. One healer was selected from each sub-location. Each of these healers was then asked to identify a colleague who also treated epilepsy. This procedure resulted in a final sample of eight THs from approximately 35 to 60 years of age. The sample of THs also represented a range of treatment specializations or specific ‗types of spirits' that the individual was known to be proficient in treating.

To understand the types and delivery of treatment provided in KDH, area clinics, and drug dispensaries, interview and observation data was gathered between the years 2006 and 2008 from 12 biomedical health workers, including doctors, neurological technicians, research staff, nurses and general health aids. This sample was also assembled using convenience and snowball sampling. Several medical professionals working in the epilepsy clinic at the District hospital were approached. These individuals referred the researcher to other health workers involved in epilepsy treatment. Efforts were made to select a sample that represented the range of biomedical services and professional specialization and training in Kilifi. However, the sample was purposefully selected to over-represent health workers at the District hospital. This choice was made after preliminary research revealed problems relating to the supply of drugs and training of staff at local clinics and dispensaries. The research suggested that the District hospital was the primary, if not the only, practical place for families to seek biomedical care for their children.

Following transcription and translation, NVivo qualitative analysis software (QSR; Melbourne, Vic, Australia; http://www.qsrinternational.com) was used to analyze both transcripts and field notes to generate themes and code materials. To assure informant anonymity, each participant was given a pseudonym that was used in all research and publication materials; only two researchers had access to data during the project.

8.4.2 Ethics

All participants in the study were given an oral description of the study design, purpose, and consent procedures. Participants were also given a page of written description of these procedures and the local contact information of the lead researcher. Each participant signed written consent to participate in the research. Human subjects approval was obtained from the KEMRI/National Ethical Review Committee and the University of California, Los Angeles.

8.5 Results

8.5.1 Epilepsy in the spirit system of traditional healing

Within the four-category framework of the Mijikenda system of traditional healing, there are three causes of epilepsy, or *Kifafa* as it is traditionally called.

8.5.1.1 Natural spirits (mapepo ya pori)

Natural spirits are believed to cause a variety of diseases and conditions, including dizziness, and loss of appetite. Individuals may be infected by one of these spirits if they have passed the residence of a natural spirit, or if the spirit is attracted to the _sweetness' of the person's blood. Mzee Haro, one of the healers in the sample, explained:

> *This woman here* [healer points to the patient] *she is having stomach problems because she now has Mapepo ya Bahari* [spirit of the beach]. *She said that she passed by a large cave at the beach the other day in the evening. This is when the spirit came to her. Now it will not leave.*

Nyagu is the natural spirit most commonly considered to cause seizures in the traditional system. Mzee Makanju, another healer, explained, *'These are spirits that live in the environment, they come as signs of animals. When a child sees the vision of a hawk in his mind Nyagu has come to him'.* Seizures occur when the spirit comes to a child and subside when the spirit leaves. Tremors and convulsions experienced during seizures are perceived as attempts to break free of the Nyagu. Nyagu is attracted by the smell or taste of certain children's blood. The spirit's preference for specific types of blood is used to explain why the spirit comes to some children and not others, as well as variation in the persistence of childhood seizures. If the Nyagu continues to visit the child, the spirit matures and reaches full maturity when the child is between the ages of five and ten, at which point the condition transforms from Nyagu to Kifafa.

Kifafa caused by Nyagu is thought to be heritable to some degree. Once a member of a family has a Nyagu spirit, it may develop a proclivity to the person's blood and be drawn to other members due to familial similarities in blood.

Mama Mzingo, a healer, explained, *'Nyagu can come from the mother to the child but then if it is not treated by a healer it can move to another child in the family'.* There is also the belief that Nyagu may be transmitted from mother to child while breast-feeding. For this reason a mother with epilepsy is not to breast feed her children.

There are two essential components of treating a natural spirit: *removal* and *deflection*. A healer must remove the spirit and assure that it does not return. As natural spirits inhabit an individual they develop an affinity for the person's blood. Treatment becomes more difficult and the prognosis less promising if the person has been living with the spirit for an extended period. An immature Nyagu is weak, can be easily pulled from the child, and prevented from re-entering. As the spirit matures, treatment becomes more difficult. For this reason, in the traditional system, early treatment of this condition is paramount.

The methods healers use to *remove* natural spirits fall into two general groups. First, a healer can drive the spirit out using herbal baths, root concoctions, or dung that the spirit is known to islike. Mzee Makanju explained, *'It [a specific herbal mixture] drives the Nyagu out. It does not like the smell of my medicines'.* Another healer explained his treatment for immature Nyagu:

> *You must look for the Mtasalafu, Mrori, and Mrashapungu. You must bring these leaves and tear them up and mix them in a container* [bucket] *of water. You may have to go far to find these, but for me they are not far. The child must come and be washed in the water* [with the leaves]. *It is very important to wash the head of that child. If you are able it is good to get elephant dung and burn this near the child to smoke him* [the child]. *The spirit does not like these two things and will go from the child…Also, if you are a Muslim and know how to read from the Koran you can read 'The Resurrection' verse. The Nyagu does not like the verse and it is very powerful for treating Nyagu. Doing these two things will make the child unattractive to the Nyagu.*

Healers also explained a process of waving a cloth or basket in front of the patient to _blow out‘ the spirit. Mzee Haro explained:

> *First I go to select those herbs. I put them in a container and fill it with water. When it has been mixed very well, I grab the child and dip his head into the water. Then I put the child on the ground and wave a basket over him 7 times. I do this thing in three different places where I know the Nyagu likes to stay* [the doorway, the rubbish area, and under a tree]. *This is an easy treatment and is not long.*

The second method of healing a natural spirit is to entice it out of the person through offerings. Objects offered included incense, herbs, rose water, honey, and animal blood. Once drawn out, the healer calls on his own spirits to battle the natural spirit. Involving other spirits in the cure is thought to be a stronger but more difficult procedure and is used to treat the more mature Nyagu. Mzee Kahindi described this procedure:

> *You must get a red chicken and a black* chicken [the healer later explained that red chickens are for attracting/appeasing spirits from the land and white chickens are for attracting/appeasing spirits that come from the beach/coast]. *First I say the part of the Koran that makes the spirit weak because it is now strong…I kill the black chicken and put its blood on the ground. This attracts the Nyagu, which leaves the person to drink the blood. Then I kill the red chicken and put its blood on the ground also. This pulls the Marahani spirit* [a very powerful Muslim spirit that Hassan uses in his healing practice]… *I then tell the Marahani to kill the Nyagu who is weak from the words of the Koran. If the Marahani is able to defeat the Nyagu, the epilepsy will be cured. It is difficult if the Nyagu is very strong… I must work hard to make the Marahani happy so that he helps me.*

Once removed, healers employed techniques to *deflect* future re-entry of the natural spirit. The two most common practices were to periodically repeat the bathing technique mentioned above and to construct an amulet. The amulet is a pouch the individual wears on a string around their neck, arm, or leg, which contains materials the spirit dislikes. These materials included herbs, roots, or parts of particular animals.

Mzee Ruwa, another healer explained:

> *I make this.* [Healer holds up a small leather pouch attached to a string]. *I give it to the child and he/she wears it around the neck…I put many things inside. Inside there is hair of the child, leaves, and the claws of a bird. The claws are to make the Nyagu know it will be defeated. It will not come to the child if they wear it.*

8.5.1.2 Majini

Majini are malevolent spirits controlled by witches and are blamed for a host of problems ranging from insomnia to social and economic troubles. Witches are contracted by jealous parties to send Majini to specific individuals or families. Majini are sent in two ways. A witch can draw a special picture in the sand. Once the targeted individual walks over the drawing, the curse is cast. A witch may also send Majini directly to a person by verbally casting a spell. Seizures caused by witchcraft are considered easier to treat than the Nyagu type because Majini are not as strong or persistent as Nyagu.

Healers employed methods of *reversal* to treat these problems. The healer typically guides the patient back across the symbol believed to have caused the illness, and in this way reverses the curse. This procedure is called *mihambo*. Mama Mzingo, a female healer explained, *'Passing over the drawing that I have said words to breaks the curse'*. Mzee Haro explained, *'This is how witchcraft comes and also the way it goes. They [the witch] did this and to heal this it is necessary that I also do this. But my medicine is much stronger'*. Majini are also thought to have a fondness for blood or certain foods including coconuts and eggs. For this reason some healers used animal blood in the drawing or placed broken coconuts or eggs beside the drawing. Mama Mzingo said, *'If it [Majini] is happy, it will leave more times than if it is mad. You can't just kick it out. You have to give it something to make it happy'*.

The following is an excerpt from an interview with Mzee Ruwa describing the treatment used for epilepsy caused by Majini.

> *Brought that boy to this sacred place here. He sat right there where you are sitting now. I made him sit there while I made the drawing in the dirt. Then I sent Katana to get me the leaves that I use for this problem. I made the boy cross the drawing seven times and each time he crossed, I threw some of the herbs on him. I was saying words to the spirits so that they would come and help me change these Majini so that this boy would not be bothered by them anymore.*

8.5.1.3 Ancestral spirits (mapepo ya kiasili)

Ancestral spirits are the descendants of original Mijikenda ancestors. The Mijikenda believe that their first TH was *Mepoho*, the mother of two sisters, *Matsezi* and *Mbodze*. These daughters were also powerful healers and had 12 children of their own who became renowned healers. The spirits of these 12 children are the primary Mijikenda ancestral spirits, and can cause various problems from bad luck in farming to headaches and infertility. Other secondary ancestral spirits may also cause these problems, and anyone who has died has the possibility of becoming a spirit of this type and affecting the world of the living.

Ancestral spirits are believed to cause problems because of unfulfilled desires. Mzee Kangwangu, another healer, said, *'Those spirits [ancestral spirits] are always wanting things. They want a chicken or goat or even a piece of cloth…They are like living people, they just want things to have them, because they are hungry'. An ancestral spirit may also demand a sacrifice due to improper behavior.*

Healers employed an *appeasement* ideology to treat illnesses caused by ancestral spirits. The healer communicates with the spirit, or through a proxy spirit, to learn what items or actions are desired. As a temporary appeasement, the healer may offer the spirit an herbal or root concoction. However, to *cure* the affliction, the desired items must be offered. Commonly desired items included goats, chickens, or swatches of colored cloth.

Epilepsy may be transferred between family members if specific rituals are not performed following the death of a member with epilepsy. When someone with *Kifafa* has died, a special set of rituals must replace normal funeral procedures. The family is not to remain in the village for the normal mourning period, and they are not to perform the normal funeral anniversary ceremony. The family is to bury the individual and must have a TH present to prepare a special herbal mixture that each family member must wash with. The concoction is believed to repel the spirit of the deceased. Several months after the burial, the family must again enlist the help of a healer to prepare a second herbal bath to ensure the spirit does not return. If these rituals are not performed, the spirit of the dead relative may return and the next child born may have the condition. As Mzee Kahindi said, *'If the funeral is handled correctly there will be no infection'*. Mzee Kahindi elaborated on the treatment used for epilepsy inherited from a relative:

> [This type of epilepsy] *can be treated. The people who have celebrated the funeral and have done all of the normal things ask for forgiveness from the spirit of the person who is causing the illness in the child. They must make offerings to this spirit. It might be a goat or even a cow if they have one. They must tell the spirit that they are sorry for having made a mistake and they should try to make the spirit happy. This is why they must make a sacrifice. If the spirit is not made happy the child will continue having seizures. This is an easy kind of epilepsy to treat because all you must do is make the spirit forgive you and then it will go.*

8.5.1.4 Islamic spirits (mapepo ya Kiislamu)

Islamic spirits are not believed to cause epilepsy. They are the spirits of important Muslim teachers and religions figures and are believed to be more powerful than their Mijikenda counterparts. This power is attributed to two factors. First, they gain strength from the spiritually powerful places they inhabit. Second, they are associated with the Koran, which is a powerful spiritual symbol in the coastal region. Because of the tremendous spiritual power required to manipulate one of these spirits, they are rarely sent. Islamic spirits, like the Mijikenda variety, come to living individuals because of specific desires.

8.6 Distinguishing features of the biomedical and traditional treatment options

Interviews with and observations of THs and biomedical personnel revealed several characteristics that distinguished these two treatment options (Table 8.1).

8.6.1 Explanations of causation

Biomedical explanations of causes, symptoms, and treatment were dramatically different from those employed in traditional healing. Traditional healers referred to spirits to explain the occurrence and intermittent presentation of seizures. The spirit comes to an individual and causes a seizure, and the individual regains consciousness with the spirit‘s departure. Symptoms are sporadic because of Nyagu‘s attraction to multiple children concurrently. Similar explanations were offered for symptoms of epilepsy caused by Majini. Healers accounted for the tremors and shaking associated with seizures as the struggle between the affected individual and the spirit grabbing them. The common looks of surprise or screams prior to seizure onset were rationalized as the individual‘s reactions to the spirit‘s sudden appearance. The traditional system offered treatments that directly addressed the assumed causes of the patient‘s symptoms. Biomedical practitioners and treatments did not address the connection between causation, treatment, and seizure symptoms.

8.6.2 Communication style

Communication during treatment also differed substantially between the two treatments. One patient summed it up:

> *When I am at this place* [the traditional healer] *I can sit and talk and explain things for many hours. Sitting here is important for healing. It is necessary to do this if you want to be cured…I walk here and then return* [over the diagram the healer has drawn]. *I turn this way and follow his instructions…when I go to Kilifi* [hospital], *the doctor does not talk to me. He just asks me some few questions and then gives me a paper* [prescription]. *That is it!*

The traditional process of diagnosis and treatment involved constant communication between healer and patient over a one- to four-hour period. To establish a diagnosis, patients were asked numerous questions and encouraged to communicate with the spirit via healer-facilitated ‗channeling‘. Conversations during treatments covered subjects directly related to the illness as well as general community topics, and the patient was a physically active participant in the healing process.

In contrast, appointments at clinics and hospitals were brief, and doctor/patient interaction limited. Patients were not acquainted with their doctors and the average length of visit was less than 20 min. Communication was frequently strained and patients were guarded in sharing personal information. Biomedical patients were also passive rather than active participants in their care. Typically, they sat in a chair in an office, answered a few questions, sometimes without having the doctor even facing them, and were handed a prescription.

Traditional healers also reported strained relationships with doctors and expressed animosity towards them. One of the healers explained, ‗*…they [biomedical doctors] do not care about us here in the community. They do not talk to healers or even know what we do, but they think we are all quacks!’* The general community perceived this dynamic, and several patients reported social pressure not to seek care from biomedical facilities.

8.6.3 Social roles of providers

Most of the biomedical practitioners interviewed were wealthy and well educated by community standards. Many of those who practiced at KDH were Kenyans from other areas of the country who trained at national universities. Some expatriate doctors working at the KEMRI also saw patients at the hospital. Doctors at KDH were generally not members of the communities they treated and were unaware of the daily activities and lives of their patients, nor did they hold much power in community social or political dynamics. Unlike THs who lived in the same communities as their patients, biomedical health workers were largely unaware of other treatments received by their patients.

However, patients and THs were often members of the same community, shared acquaintances, and were aware of important events in each others‘ lives. Such familiarity created an open dynamic in which patients freely asked questions and sought further information about the causes of illness and the specific detail of treatments. Healers were well-respected community members, and their ability to communicate with spirits contributed to their elevated status. One healer received up to 15 patients a day, and all had clear advisory roles in a wide range of social issues.

8.6.4 Referral practices

A further distinguishing feature was the manner in which THs referred patients for additional treatment. When treatments failed to reduce or eliminate symptoms, healers claimed that the offending spirit was too powerful or that they were not proficient at handling the specific spirit responsible for the child‘s disorder. A community member described this referral system:

> [Traditional healers] *say that they can treat you but when they fail they say 'this spirit was too strong' and they send you to another healer and then to another. You can go to many healers before you get cured because each healer has his own medicines.*

Seven of the eight healers in the sample described cases in which their treatments had failed to cure *Kifafa* (epilepsy). In each case the child was treated a second time. If this second attempt failed, the healer referred the patient to another healer believed to provide more powerful or specialized treatments, maintaining hope in an eventual cure within the traditional system.

In contrast, no explanation was available for the families of children treated at KDH who continued to have seizures. Although these children may have had their AED regimens modified, there were no further biomedical treatment options.

8.6.5 Location of care

The accessibility of care was another distinguishing characteristic. While THs were located within local communities, the only location for viable biomedical epilepsy treatment was in Kilifi Town. Kilifi District is large and many individuals live in rural areas a long way from Kilifi Town and KDH. Because of the lack of effective epilepsy treatment at rural health facilities, individuals had to choose between traveling long distances to KDH or walking minutes to a local TH.

8.6.6 Systems of payment

Finally, the two treatment modalities differed according to models of payment. The THs interviewed used a flexible payment system. Treatment was provided regardless of the individual‘s ability to pay and payment was not discussed until *after* treatment. If the individual was unable to pay, they were expected to return and pay at a later date. In 49 of the 52 traditional treatment interactions observed, individuals paid less than 25% of the payment asked by the healer. The balances were carried for several months, or even years, and healers and patients reported that in many cases such debts are never settled. The traditional model of payment was also flexible in terms of the type of payment accepted. Each healer in the sample accepted livestock, grain, palm wine, cloth, clothing, and labor in lieu of monetary payment.

In comparison, individuals were required to pay 40 Ksh (approximately US$0.75) to receive AEDs at KDH. While this treatment was less expensive than that provided by THs, there was no alternative form of payment, and deferrals or loans were not granted.

Table 8.1: Summary of the comparison of traditional healers' and biomedical treatments

Themes	**Provider**	
	Traditional healing	**Biomedicine**
Causation/treatment	Offered by healer Consonant with local ideas	Not explained by doctor Dissonant with local beliefs
Communication	High quality Extended and participatory interaction	Limited Strained interaction
Role in community	Centrally involved in local communities	Removed from local communities
Referrals	Rationalizes treatment failures Keeps patients within system	Infrequent and limited to KDH
Location	Within local communities	Single semi-urban location
System of payment	Flexible	Rigid

KDH, Kilifi District Hospital.

8.7 Discussion

Consistent with previous research in other areas of Africa (Birbeck, 1999; Chavunduka, 1978; Feierman, 1981; Gessler *et al.*, 1995; McMillen, 2004; Millogo *et al.*, 2004; Oppong, 1989), this study documented the importance of THs as an option for treatment of childhood epilepsy. However, investigators have rarely compared interview and observation data collected from THs with data from biomedical practitioners as a means of understanding the gap between treatment needs and healthcare utilization, and identifying potential barriers to treatment access and adherence. This research shows this comparative ethnographic method to be particularly useful in identifying targets and questions for further qualitative and quantitative research on decision-making and intervention design.

The extent to which a family‘s beliefs about epilepsy causation correspond to this traditional system of spirits is important to understanding why some families seek traditional treatments while others choose biomedicine; this is discussed in greater detail elsewhere (Kendall-Taylor, 2009). The comparative provider focus used in this study is effective due to the implicitness of cultural models and their role in decision making (Quinn & Holland, 1987) .

Individuals seeking treatment may be limited in explicitly identifying the factors that shape their treatment decisions, such as payment methods, explanations of causation, social roles of providers, and systems of referral. Service providers have a unique perspective on treatment. Their opinions and structural aspects of the services they provide are critical to understanding the determinants of health decisions.

Previous research on families of CWE has demonstrated that distance-to-facility was an important factor in treatment-seeking (Kendall-Taylor, 2009). However, cases in which families were willing to travel significant distances for either treatment option suggests that other factors, such as consonance between a family‘s beliefs of causation and that employed in treatment, appear to be important considerations in modeling treatment decisions (Kendall-Taylor, 2009). In the present study the observed ability of THs to generate convincing explanations for the mysterious, intermittent, and dramatic symptom presentation and to offer logical justifications for treatment helped explain the popularity of traditional epilepsy treatments in Kilifi. In contrast, there were no explanations for failed biomedical treatments for children treated at KDH who continued to have seizures. The traditional system‘s method of explaining treatment failures and referring patients to other healers plays a role in keeping patients in the traditional system and away from the hospital.

Biomedical practitioners would benefit from instruction in effective and appropriate communication styles. Training in culturally accessible ways of framing epilepsy, symptoms, causation, and treatment in doctor–patient interaction is vital. This component would increase patient satisfaction with biomedical services and improve treatment adherence.

Further, observations of traditional treatment encounters suggested the difference in type and flexibility of payment appears to be a significant factor in families deciding where to seek treatment for their child‘s epilepsy.

Our results suggest several promising strategies for improving access to biomedical care in Kilifi District. First, because THs are generally well accepted in local communities, and traditional treatments for epilepsy in Kilifi were found to be culturally meaningful, the expansion of biomedical care should involve the cooperation and involvement of traditional practitioners. This could be generalized to other settings where healers assume a major role in treatment.

However, before any TH inclusion program can be implemented, the quality of biomedical care must be addressed. The low quality of epilepsy treatment at health centers throughout the District and the limited accessibility of KDH to those living in remote areas suggest the need to improve services at rural health facilities. Such improvements could be accomplished through a diagnostic and treatment training program instituted and supervised by KDH. Increasing the supply of AEDs to these facilities, and implementing a more flexible payment plan should also be components of such interventions.

8.8 Limitations

The primary limitation of this study is the lack of data from individual decision-makers. To address this, research was also conducted with the families of CWE (Kendall-Taylor, 2009). This research obtained information on the perceived relevance of provider characteristics to family members‘ treatment-seeking. The results corroborate the significance to treatment decisions of factors identified in the present study, such as payment methods, systems of referral, and explanations of causation.

8.9 Implications of the study

The findings of this study have implications for future research on treatment-seeking. Comparing treatment providers is a tool for an initial step in building more comprehensive models of treatment decision-making that include factors that facilitate or deter treatment-seeking. These findings are relevant to programs aimed at improving access to health care.

The strategies discussed could be applied in intervention research designed to improve healthcare utilization for CWE. Outcomes could be assessed by evaluating program effectiveness in decreasing the epilepsy ETG and improving the quality of life of children and their families. Treatment studies could also examine the specific intervention components most responsible for improved outcomes, which could be tested in a randomized cluster trial. This would be the ultimate test of the benefits of ethnographic comparisons of service providers.

An intervention program informed by the present findings as well as additional research conducted with families of CWE is currently being designed in Kilifi. It is hoped that the effectiveness of this program will provide improved healthcare access and reduce the morbidity of childhood epilepsy in the developing world.

8.10 Conclusion

The article identified the following six key differences between biomedical and traditional treatments (explanations of causation, communication styles, social roles, referral practices, location and systems of payment) that may help to explain the existence of the biomedical ETG in Kilifi. This study suggests that comparing data on treatment providers reveals barriers to obtaining biomedical care, thereby offering an important tool in intervention design research.

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Chapter 9

The reasons for the epilepsy treatment gap in Kilifi, Kenya: using formative research to develop interventions to improve adherence to anti-epileptic drugs

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Abstract

Introduction

Approximately 75% of People with Epilepsy (PWE) in Kilifi, Kenya, do not receive appropriate treatment, a phenomenon referred to as the Epilepsy Treatment Gap (ETG). We conducted a qualitative study to investigate the reasons for this gap and identified possible interventions.

Methods

The study employed a qualitative approach using a combination of methods for data collection. Focus Group Discussions (FGDs) were carried out with PWE and their caregivers. Individual in-depth interviews were conducted with PWE, caregivers of PWE, traditional healers, community health workers, community leaders, nurses and doctors. Trained field staff fluent in the local language, conducted the interviews. The data were transcribed, translated and entered into NVivo qualitative analysis software. Two independent researchers analyzed the data thematically and validation was done through triangulation. Drawing on the information gathered above, a series of workshops were conducted to negotiate realistic and sustainable interventions with stakeholders.

Results

Nine FGDs and 17 in-depth interviews were conducted. Four factors contributing to the ETG in Kilifi, were identified: 1) Lack of knowledge about causes, treatment and prognosis of epilepsy; 2) Inaccessibility to anti-epileptic drugs associated with financial constraints, distance to health facilities and unavailability of drugs; 3) Misconceptions about epilepsy derived from superstitions about its origin; 4) Dissatisfaction with the communication skills of health providers. These data indicated several possible avenues for interventions: 1) Education and support for PWE and their caregivers; 2) Communication skills training for health providers; 3) Need for the Ministry of Health to improve drug provision.

Conclusion

The ETG was associated with a combination of factors that could be addressed through the development of appropriate interventions.

9.1 Introduction

Over 69 million people worldwide have epilepsy, of whom 62 million live in Resource Poor Countries (RPCs) (Ngugi *et al.*, 2010). More than 500 million people are indirectly affected by epilepsy as parents, relatives and friends (Kale, 2002). The World Bank has prioritised epilepsy as a highly cost-effective condition to treat (World Bank, 1993), since relatively inexpensive Antiepileptic Drugs (AEDs) are very effective in controlling seizures: 75% of those treated will become seizure free (Coleman *et al.*, 2002). Despite this, over 90% of People with Epilepsy (PWE) in RPCs do not receive appropriate treatment for their condition (Birbeck, 2000; Nicoletti *et al.*, 1999; Scott *et al.*, 2001), a phenomenon that has been called the ‗Epilepsy Treatment Gap (ETG). The International League Against Epilepsy (ILAE) has defined the ETG as the difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated (Meinardi *et al.*, 2001).

In response to the diverse factors involved in the effective treatment of PWE in RPCs, several researchers have tried to instigate affordable community-based interventions. Previous interventions at community level have met with some success in Nakuru, Kenya (Feksi *et al.*, 1991b), Ecuador (Placencia *et al.*, 1993), Malawi (Watts, 1989) and India (Mani *et al.*, 1998; Pal *et al.*, 2000b). Recent directives from the World Health Organization (WHO) state that health care delivery will increasingly have to move away from acute illness episodes and concentrate more on treatment adherence, client self-management and quality of life issues (Epping-Jordan, 2002).

The characteristic of most successful interventions is integration within community health care delivery and community involvement in the planning and implementation processes. Community-based interventions have been used with some success in several conditions. In Nigeria, community-designed and administered treatment programmes have been successful in the control of onchocerciasis (Akogun *et al.*, 2001). In Bangladesh, Community Health Workers (CHWs) have successfully identified Tuberculosis (TB) and increased adherence to treatment in their own villages (Chowdhury *et al.*, 1997) and in Malawi, a TB assistant with good standing in the local community received training and raised the cure rate from 29% to over 85%. In Kenya, an intervention to prevent Neonatal Tetanus (NNT) allowed the identification of the cultural significance of birthing rituals and negotiated culturally acceptable alternatives, involved community leaders in defining and promoting the changes in rituals and used traditional birth attendants to maintain the changed behaviour. After introduction of the intervention, death rates from NNT dropped to 0.75 per 1000 births compared to 82 per 1000 in control areas (Meegan *et al.*, 2001). However, effective behaviour change is notoriously difficult to initiate, sustain and measure. Curtis and colleagues reviewed the literature between 1987 and 2001 and found only three articles with good evidence of health interventions impacting on behaviour or health in RPCs, although they don‘t define what they mean by ‗good evidence‘ (Curtis *et al.*, 2001).

Most commentators highlight the need for good anthropological or community-based data on practices and perceptions for behavioural interventions to succeed (Green & Kreuter, 1991). In Kilifi, there is some evidence that bio-medical treatment regimens for Children with Epilepsy (CWE), are in conflict with local perceptions (El Sharkawy *et al.*, 2006). Parents may have a ‗health‘ versus ‗sickness‘ model that influences their perceptions of treatment. Occasional seizures may be placed in the ‗health‘ sphere, making the recommendation of regular and continued medication illogical for what is perceived to be a generally healthy child. If regular seizures persist beyond a certain age, the child may be placed in the ‗sickness‘ sphere, suggesting that the child is incurable and treatment attempts are futile. El Sharkawy and colleagues also found that belief in ‗external‘ causes (such as witchcraft, contact with certain animals/birds) of epilepsy was commonly held and that treatment choices favoured external treatments such as wearing charms or pouring liquid on the child‘s body (El Sharkawy *et al.*, 2006). These findings are similar to those of Hausmann-Muela and colleagues, who investigated what they termed ‗medical syncretism‘ in Tanzania (Hausmann-Muela *et al.*, 2002). They found that in the case of malaria, biomedical knowledge is blended with indigenous concepts (Hausmann-Muela *et al.*, 2002). These examples fall under Helman‘s description of ‗externalising‘ belief systems, which concentrate on aetiologies arising outside of the sick child‘s body (Helman, 1994) . If the cause of an illness is believed to be found in the natural, social or supernatural worlds, biomedicine may be sought for symptomatic relief only, but cure and explanations about causality are sought from Traditional Healers (THs) (Helman, 1994).

Identifying the cultural context, values, beliefs and community norms of target groups through qualitative research is the key to the design and implementation of successful interventions (Stephenson & Imrie, 1998). Akogun and colleagues comment that their experience of working with a Nigerian community to implement a behavioural intervention suggests that within certain parameters, the structure of interventions may be less important than the process through which they are introduced, in terms of acceptability and sustainability (Akogun *et al.*, 2001). Building upon the work of El Sharkawy and colleagues (El Sharkawy *et al.*, 2006), we aimed to carry out a qualitative investigation to develop alternative intervention strategies based on the expressed needs and perceptions of the stakeholders. While El Sharkawy and colleagues focused on the effect of attitudes and practices on service utilization for epilepsy (El Sharkawy *et al.*, 2006), we specifically conducted this descriptive research as part of preliminary work to develop an intervention to address the ETG in Kilifi. Our research questions were:

1. What are the stakeholders‘ (CWE, their families and service providers) attitudes and beliefs relating to CWE and how do they affect the utilization of the traditional and biomedical services offered to this population group?
2. What are the specific needs of PWE and their families?
3. Using techniques such as participatory workshops, can a consensus be reached with key community members on an intervention that will reduce the ETG and improve the quality of life of PWE in Kilifi?

9.2 Methods

Qualitative data gathering techniques were used because they are valuable tools for collecting meaning-centred, contextually-based data applicable to the design of culturally relevant intervention strategies.

9.2.1 Study setting

This study was undertaken in Kilifi District, on the coast of Kenya which has the highest rates of poverty, the lowest rates of literacy and the largest sex differentials in education in the country. Community-based research is focused on the Kilifi Health Demographic Surveillance System (KHDSS) which is described in Chapter 1.

9.2.2 Sample

Families from different educational backgrounds and with different experiences of AEDs treatment were purposively selected using the baseline information recorded on the KHDSS. The criteria for selection are outlined in (Table 9.1). Once appropriate participants were identified, convenience sampling was used, influenced by willingness to participate, geographical distribution and time constraints.

Table 9.1: Criteria for sample selection for focus group discussions

Key informant group	Selection factors	Method of identification
Children with epilepsy (14-18yrs)	• Have/have never received available treatment • Have received and rejected available treatment • Attending school/not attending school	• Identified from KHDSS
Adults with epilepsy	• Have/have never received available treatment • Have received and rejected available treatment • Less educated*/more educated*	• Identified from KHDSS
Parents of children with epilepsy	• Child has/has never received available treatment • Child has received and rejected available treatment • Less educated*/more educated*	• Identified via the child‘s record on the KHDSS
Other family members of children living with epilepsy	• Grandmothers of children with mild and severe epilepsy • Siblings (aged 14-18 years) of children with mild and severe epilepsy	• Identified via the child‘s record on the KHDSS

** Less educated residents indicated 8 years or less of schooling.*
** More educated residents indicated more than 8 years of schooling.*
Severe epilepsy was defined as more than one seizure per week; mild epilepsy was defined as less than one per month.

Service providers (CHWs, in the case of the FGDs) were identified from lists of active community health worker groups held by the local Ministry of Health. Initial pools of participants for individual interviews and participatory workshops were elicited from FGD participants, using a snowballing technique. Final selection and participation was again based on convenience and voluntary informed consent. The composition of key informant groups is described in (Table 9.2).

Table 9.2: Data collection methods and key informant groups

Key informant group	**Data collection method**		
	Focus group discussions (no of participants in parentheses)	**Individual interviews**	**Participatory workshops (no of participants in parentheses)**
Adults with epilepsy	1 (3)	1	1 people with epilepsy (11)
Children with epilepsy	1 (6)	1	1 people with epilepsy (1)
Family members of children with epilepsy	1 mothers (5) 1 fathers (3) 2 siblings (4, 3) 1 grandmothers (3)	2 mothers 1 father 1 grandmother	1 parents and grandparents (14) 1 people with epilepsy (2 grandparents, 2 parents, 1 sibling*)
Biomedical service providers	2 community health workers (CHWs) (8, 10)	2 dispensary nurses 2 clinical officers (private clinic) 1 psychiatrist (government hospital) 1 paediatrician (government hospital)	1 traditional healers and CHWs (7 CHWs) 1 biomedical service providers and CHWs (6 CHWs, 1 nurse**)
Traditional service providers		3 traditional healers	1 traditional healers and CHWs (3)
Community intervention organisations		1 chairlady of ‗Maendeleo ya wanawake' (women's organization) 1 member of staff at APDK (organization for the rehabilitation of people with disabilities)	
Units of analysis (number of people)***	9 (45)	17 (17)	4 (48)

** Although this participatory workshop was intended for people with epilepsy (PWE), 5 family members also accompanied some of the PWE and participated in the workshop*

** We invited other biomedical service providers to this workshop but all except one nurse said they were too busy to attend*

**** Total units of analysis = 30; total number of people involved =110*

9.2.3 Procedure

The study included a combination of strategies for data collection – FGDs, individual interviews and participatory workshops – to enhance the validity of the results and provide material for triangulation. Finally, the intervention was piloted. The progress of the study is illustrated in (Figure 9.1).

First, FGDs were held with CWE, parents of CWE, and with other family members of CWE. Efforts were made to ensure that groups of CWE and of parents covered the spectrum of severity of disease, educational levels and exposure to AED treatment. Such purposive convenience sampling is appropriate for research designs such as this, which aim to explore the range - rather than a representative cross-section - of views and perspectives. Excluded from discussions were adults or CWE who considered themselves or were considered by family members to be too ill to participate.

Focus group discussions elicited data relating to the four research questions:

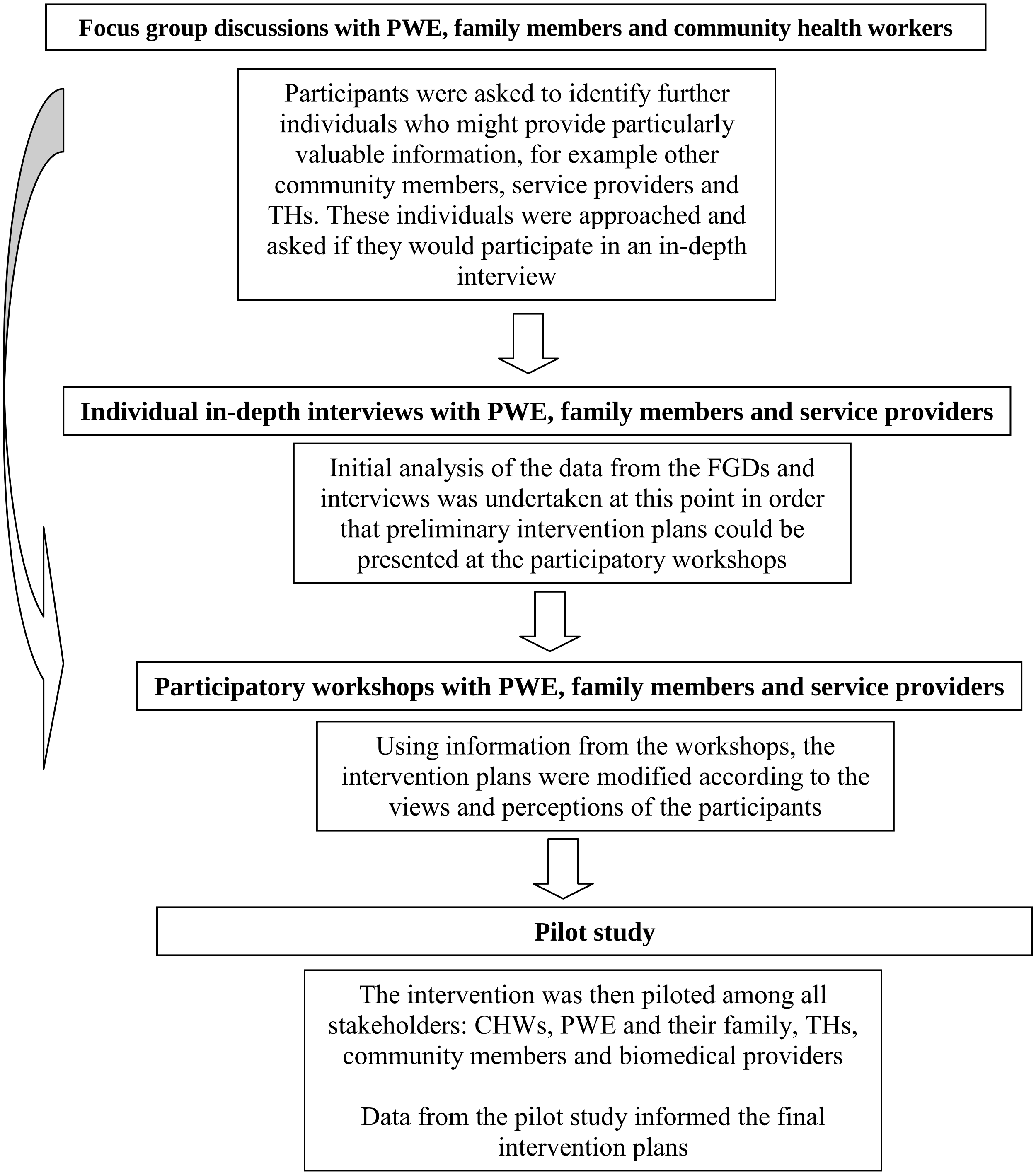
- experiences and beliefs about epilepsy in the household and in the community (particularly schools, marriage and the workplace);
- how the above relates to the quality of life, parental satisfaction and depression;
- the range of treatments available for children and the pros and cons of different types and sources of treatment, including experiences of and views about AEDs;
- perspectives of the principal needs of CWE, of the barriers to meeting these needs, and – where appropriate - of locally applicable interventions to improve access to AEDs.

Individual in-depth interviews were organised to explore issues arising in more detail, including PWE, their families and service providers. The aim was to identify providers working in a wide range of settings who have substantial experience of managing epilepsy. It was hoped that discussions with THs would bring opportunities to present locally held ideas about causation and preventive treatment (Coleman *et al.*, 2002), so particular attention was given to this group and the possible necessity for increasing the sample size to access further data. Epilepsy may offer a particularly good basis for co-operation between biomedical and traditional medicine, particularly when neither may satisfy the needs of the patients alone (Meinardi *et al.*, 2001).

Individual interviews with these participants focused on:

- experiences of and views about the range of treatments available for children;
- the extent and nature of the ETG in Kilifi, and the range of factors contributing to these gaps (including regulatory and supply factors, and information, education and communication issues at provider, patient and caretaker levels);
- relevant and sustainable interventions to reduce the ETG, and – if appropriate – the inputs that would be required to improve access to AEDs.

Figure 9.1: Progress of the study and how the findings informed intervention development



Focus group discussions with PWE, family members and community health workers

Participants were asked to identify further individuals who might provide particularly valuable information, for example other community members, service providers and THs. These individuals were approached and asked if they would participate in an in-depth interview

Individual in-depth interviews with PWE, family members and service providers

Initial analysis of the data from the FGDs and interviews was undertaken at this point in order that preliminary intervention plans could be presented at the participatory workshops

Participatory workshops with PWE, family members and service providers

Using information from the workshops, the intervention plans were modified according to the views and perceptions of the participants

Pilot study

The intervention was then piloted among all stakeholders: CHWs, PWE and their family, THs, community members and biomedical providers

Data from the pilot study informed the final intervention plans

9.2.4 Participatory workshops

Drawing on the information gathered above, a series of workshops was arranged. The workshops aimed to negotiate a realistic and sustainable intervention with key stakeholders to improve the ETG in Kilifi District. Key stakeholders included PWE, their families and service providers from the District.

We anticipated that users and providers would have differences of opinion at the outset, and that the intervention would require processes of negotiation. To ensure that all viewpoints were heard and incorporated, separate one-day workshops were held with representatives from the following groups: CWE and their siblings; parents and grandparents; and service providers (four workshops over four days). During the workshops, initial intervention plans (developed from the FGD and interview data) were presented to the participants to elicit group consensus or normative reaction. Participants were also asked to give specific input about the practicalities of the intervention: length, administered by whom, location, incentives and outcome measures.

Based on the suggestions from the workshops, an education intervention was developed for all stakeholders. It was divided into four parts: The first one for CHWs, second for THs, third for community members and fourth for biomedical providers. The intervention components for the first three groups were similar and covered the following:

- What is epilepsy?
- Types of seizures
- Causes of epilepsy
- Effects of epilepsy on child development
- Treatment of epilepsy: What drugs can and cannot do?
- Side effects of drugs
- Drug safety
- What to do and not to do during a seizure
- When to take PWE to hospital
- Prevention of epilepsy
- What PWE can and cannot do
- Advise to families on how to live with PWE

The intervention for biomedical providers had the following components:

- Epidemiology of epilepsy
- Definition of epilepsy, seizures and other terminologies
- Causes of epilepsy
- Common precipitating factors of epilepsy
- International classification of epileptic seizures
- Diagnosis of epilepsy
- Differential diagnosis of epilepsy
- Conditions co-existing with epilepsy
- Management of epilepsy

9.2.5 Pilot study

The educational element of the proposed intervention was piloted among all stakeholders: CHWs, PWE and their families, THs, community members and biomedical providers. Nineteen CHWs first attended a three-day training workshop led by three trained facilitators then initiated a visiting and educational programme for PWE and their families. Three further workshops were conducted: a four-hour workshop attended by 27 THs; second, a six-hour awareness session for community members and finally, a three-day residential programme for biomedical service providers. The sessions included lectures, group discussions, brainstorming, role plays, pictures and narratives. Evaluation was performed through informal feedback and administration of pre-post questionnaire to the biomedical providers.

9.2.6 Analysis

Focus group discussions and interviews were conducted in the languages of the participants, namely, Kigiriama, Kiswahili and English. They were recorded, translated and transcribed. The data were entered onto an NVivo qualitative analysis software (QSR; Melbourne, Vic, Australia; http://www.qsrinternational.com/) to enable easy storage, organisation and retrieval. Data were analysed using framework analysis, as described by Ritchie and Spencer (Ritchie & Spencer, 1994). Themes were independently generated from the data by two researchers and once thematic consensus was reached, all the data was coded. This process served to maximise the rigour and validity of the analysis.

Emerging patterns and relationships were used to generate an initial intervention plan that was grounded in the qualitative data. Two stages of modification then took place. The plan was presented at the participatory workshops, at which modifications were made until a consensus was reached among the participants. Second, the research team made final modifications to the educational element of the intervention following the pilot study.

9.3 Results and Discussion

9.3.1 Themes

In using these results to inform the intervention, the findings were focused on two categories: (1) reasons for the ETG and how the intervention could address these issues; (2) intervention content and format. In looking at the reasons for the ETG, five main themes emerged from the data: differing causal explanations for the causes, treatment and prognosis of epilepsy; the issue of cure; diminished access to and utilisation of biomedical health services; poor doctor-patient relationships and communication and access issues for PWE and their families.

9.3.1.1. Differing explanations for the causes, treatment and prognosis of epilepsy: Impact on treatment choice

Among PWE and their families, knowledge about the biomedical causes, treatment and prognosis of epilepsy was minimal. There were multiple causal explanations for the condition. Discussions on the root causes of symptoms suggested that they can be attributed to the natural order (brain insults following diseases such as malaria, accident, perinatal injury, inheritance, caught from contagious urine, drugs):

> *"[Epilepsy] is inherited. Some people fear even marrying from a family where people have fits…They think if you marry from such a family, it is easy to have a child who has it."* (FGD CHWs)
>
> *"[It was caused by] falling down from the back of the mother. She fell when she was still very young…the cloth loosened and she fell and the back of the head depressed. It all started from then. She fitted up to now."* (Interview grandmother)

> *“When not fitting the person is very fine and like if someone is not asthmatic and you give anti-asthma drugs, they get it so it’s the same to the epileptic person, if you give epileptic drugs he will get epilepsy.”* (Interview diviner)

Others ascribed epilepsy to interpersonal issues (bewitchment/genies due to jealousy or arguments; home/marital issues):

> *“It is said that it is witchcraft. She was bewitched, that is according to our customs. That is when you will go to a mganga [traditional healer] because you want to untrap them.”* (FGD grandmothers)
>
> *“They say it’s [caused by] jealousy from the surrounding people because you have children.”* (Interview father)

However, there were shifting causal explanations, often depending on the perceived type of epilepsy: one grandmother commented *“if it’s normal or from God, one can be healed, but if it’s due to somebody’s wish [i.e. a curse], you will treat in vain”* (FGD grandmothers).

Beliefs inevitably impacted on the type of treatment sought. One man with epilepsy commented that the cause of his condition was –*things that go wrong in the home*”. He explained: *“[A family member] can go to the extent of having sex with a cousin. When they are discovered, it’s when a sheep can be slaughtered if not, that’s what can bring illnesses”* (Interview Adult with epilepsy). El-Sharkawy and colleagues discussed the differentiation of perceived causes of epilepsy into internal and external phenomena in this community (El Sharkawy *et al.*, 2006). They found that belief in _external causes‘ (i.e. requiring an agent independent of the child, such as trauma or witchcraft) was reflected in treatment choices, usually that of traditional medicine (El Sharkawy *et al.*, 2006). Our findings were similar and reinforce the importance of THs to the treatment of epilepsy in this community, emphasizing the need to recognize this factor in the design of the intervention:

> *“With me, I think they didn’t see the illness, that’s why they discharged her. Maybe she was bewitched and the machines [at the hospital] can’t detect witchcraft.”* (FGD CHWs)
>
> *“We also tell people if they have gone to the hospital and found the condition is not the type to be treated there, they should come back to us.”* (Interview Traditional Healer)

Apart from traditional beliefs, the local churches and mosques also played a role in some people‘s treatment-seeking behaviours (usually, taking the person to be prayed for). More commonly, though, people said they had no idea what caused the condition. Several comments suggested that the transient nature of seizures and less recognizable types of epilepsy added to the confusion about causality:

> *"I don't know [what it is] because it's something that comes just for some time then it goes."* (Interview CWE)
>
> *"According to her symptoms, I have not believed it is epilepsy because there are signs that come first and then she fits…initially you will see that she has changes and becomes pale, and then she reports about leg pains; then at night she jerks and says 'my legs are pulled away'…So I think in my mind, does an epileptic person have such symptoms? No!"* (Interview mother)

9.3.1.2 The issue of cure

Adherence to drugs is known to be problematic when regimens are drawn out or where there is rapid decline of symptoms before the completion of the course of drugs (Manderson, 1998). Malaria is the most common cause of febrile illness in children living in Kilifi and thus informs much of the understanding of biomedical treatment (i.e. a biomedical condition requires drug treatment and cure will follow within days or weeks). The concept of prolonged drug regimens to control, rather than to cure, a condition is difficult to understand:

> *"If they take the drugs, they stay for a long time without fitting but they will eventually fit but what we want is that they get cured completely."* (FGD grandmothers)
>
> *"When they take drugs, instead of getting better then it comes back again, what we want is that they take the drugs – no matter for how long – but when they finish them, the illness is gone."* (Interview father)
>
> *"There should be drugs which people are sure if they take, they get cured completely."* (FGD CHWs)

Several people expressed confusion and frustration about where they should go for treatment. Many expressed comments such as —searching in vain” and –going here and there”, for example:

> *“You will find that sometimes you are moving here and there looking for the treatment which can heal your child but in vain. It is not in every place that you go that you can get healed.”* (FGD mothers)

9.3.1.3 Diminished access to and utilization of biomedical health services

Distance to health facilities as a barrier to biomedical health services was a recurrent theme from both service providers and users:

> *“I want to say that taking a child to [the hospital], it takes a long time. If you could bring the drugs here, people would save time and bus fare.”* (FGD CHWs)
>
> *“You have to make sure that you get bus fare before the drugs are finished but if you pass two weeks without drugs because you don’t have the fare, then he fits so seriously.”* (FGD grandmothers)
>
> *“The hospital is far away and we don’t have transport. We have to find a vehicle to get there.”* (Interview dispensary nurse)

Even for those who had reached the hospital, service wasn‘t always assured and participants complained that they could spend a whole day without seeing a health professional:

> *“The bad thing about the hospital service is the delay…You are sent here and there until whenever you reach where you are supposed to, you have really taken a long time and you lose hope because of the many trips you make.”* (FGD CHWs)
>
> *“Sometimes one spends the whole day [at the hospital] without being served.” (*FGD CHWs)

Focus group participants noted that the other major constraint to utilising services was financial restrictions. The recurrent cost of treatment, the effects of diverting limited financial resources from the family‘s needs to the funding of treatment and the fact that in the Kenyan medical system, an inability to pay means doing without the necessary drugs were all prominent themes, for example:

> *"The child could start fitting again or even worse until you run back to the mganga [traditional healer]. He treats him again and the money owed becomes bigger and you have to make sure you have paid fully if you want your child to get better."* (FGD mothers)
>
> *"This child is sick, so the money that I would use on another project which could support the family I use it for him. I deteriorate because of the one with epilepsy."* (FGD mothers)"
>
> *"The hospital is good but sometimes you go there, you are examined and drugs are prescribed but you need money for those drugs. So if you don't have the money, then you just remain with the illness."* (FGD CHWs)

These findings highlighted the fact that a successful intervention will have to include factors other than education and information.

9.3.1.4 Poor doctor-patient relationships and communication

With one or two exceptions, participants generally felt that the doctors they consulted showed little interest or sensitivity and lacked communication skills:

> *"Sometimes, just as you have started explaining the problem, the doctor has already finished prescribing the drugs. So you take drugs that you are not confident with at all."* (FGD CHWs)
>
> *"When the drugs had finished, I didn't understand the doctor, whether I was to go back when the drugs were over. When I went the other day, he asked me why I hadn't gone for more drugs so I told him that I didn't understand him on the first day*." (Interview mother)
>
> *"I brought my child and was taking him down from my back as the doctor was asking what was wrong. He said he didn't need to see the child and just prescribed drugs. I took the prescription and tore it in two pieces then went to see another doctor and my child was admitted to hospital."* (Participatory workshop, parents/grandparents)

Lack of understanding of what the doctor was prescribing or the course of treatment he/she was suggesting was a prominent theme. This also extended to knowledge of hospital treatment:

> *―When I go with him to the hospital, they take him inside so I don’t know what they do to him.”* (FGD mothers)

The lack of understanding was often linked to lack of time with the doctor, a feeling that consultations were rushed. A comment from a doctor during an interview suggested that they also feel these pressures: *“Usually there are so many people in the clinic, we don’t have time for them all. We are under-resourced.”* (Interview Dr L)

9.3.1.5 Access issues for PWE and their families

Many participants described the challenges in the lives of PWE and their families, emphasising the fact that epilepsy brings a range of access issues: physical, financial, social and cultural. Several families described how epilepsy had affected their children‘s development:

> *“It’s [child’s name] who is still having that problem, though it’s four years since she fitted but her brain still is not normal”* (FGD mothers*)*
>
> *“She has changed…the brain…the words show you that there is something wrong with her because you will see the words have changed.”* (Interview mother)
>
> *“With my granddaughter you have to feed her. Even toileting has to be assisted.”* (FGD grandmothers)

Perceived and actual risks also meant that some CWE missed out on schooling:

> *“My high hopes are that she gets healed so that she can go to school. For I tried taking her to school but the teachers were concerned about how it would be if she falls.”* (Interview father)
>
> *“Some children even want to go to school but they can’t because of how they are. They just stay at home.”* (FGD CHWs)
>
> *“Some parents think that because the child has epilepsy, he is not going to learn, maybe will get the seizures when at school.”* (Interview Dr I)

Physical injuries sustained during seizures were also reported:

> *"When you are cooking you may fall into the fire and lose consciousness. You may get burns."* (FGD CWE)
>
> *"My granddaughter is missing two of her teeth because she fell in a bad place*." (FGD grandmothers)

Expressions of hopelessness and despair were common and often accompanied feelings that all potential options had been exhausted or with difficulties in obtaining treatment:

> *"I am feeling so bad, I don't know how [the epilepsy] will stop."* (Interview CWE)
>
> *"I went everywhere until I had despaired. I would be given things or advised to do things but on administering, it would worsen. He could stay awake the whole night or take even a whole week fitting."* (FGD mothers)
>
> *"I try my best to take the child to the hospital for although I have a husband, he is not around, he doesn't come home. I am alone."* (FGD mothers)
>
> *"You take him to a Mganga not at will but out of desperation."* (FGD mothers)

Several family members of PWE described the desperate measures people may feel driven to:

> *"Some people are tired of taking care of that child for the illness has stayed for a long time, so they just leave the child with burns or even still on the fire*." (FGD grandmothers)
>
> *"You can be very scared, especially when you don't know anything about it. You can run away because whatever you are trying doesn't work."* (Interview father)

These findings emphasised the need for support to be part of any intervention to address the ETG and the wider issues of quality of life of PWE and their families.

9.3.2 Recommended strategies, content and format for intervention

These data indicated several possible avenues for intervention: first, a lack of understanding about epilepsy and its treatment suggested the necessity of information and education; second, dissatisfaction with the interpersonal skills of service providers suggested communication skills training for those providing epilepsy care; third, problems with accessibility of drugs suggested the need to work with the Ministry of Health to improve drug provision in the community;

fourth, the prominent role of traditional healers highlights the need to increase cooperation and dialogue with these service providers and finally, the levels of stress expressed by many participants highlighted the importance of support for PWE and their families.

9.3.2.1 Education and information

The need for information was a prominent theme during the discussions:

> *"People should be educated, especially at a time like this. In case such things happen, they shouldn't use herbal baths or urinate on the child. They should take him to the hospital."* (FGD CHWs)
>
> *"Another way I'm thinking is just advice. To know that this is caused by this or that or what their symptoms will be. Let's say it is a woman: she can avoid being near a fire or any other dangerous place. This is a good way of giving services."* (FGD Adult with epilepsy)

Service providers also expressed a desire for information:

> *"Even us, we want to know about fits. Even me, sometimes I feel there are things I have forgotten about the illness…Though we treat it, still I don't know much about it…So if they come to teach us more about the illness, we will get some experience."* (Interview dispensary nurse)
>
> *"To speak the truth, I don't know the cause of fits in children: it is caused by fever entering the head but for epilepsy, I don't know what causes it."* (FGD CHWs)

In the participatory workshops, service providers again emphasized that CHWs, doctors, nurses and public health technicians should also be included in any educational interventions, although THs and CHWs suggested that relatives of PWE should be given first priority for education.

Various suggestions for who should provide information and education were given during the participatory workshops. CHWs were keen to be involved, one commenting *"we are the ones who stay in the community so it would be better if we were involved more"* (Participatory workshop: CHWs/THs). Other participants suggested staff from KEMRI and parents and family members of PWE, supported by advisors from KEMRI, the rationale being that family members are the ones with direct experience of the issue (Participatory workshop: parents/grandparents). The participatory workshops also dealt with issues such as where an educational intervention should be held and how long it should last. On the former issue, participants in three workshops (parents/grandparents; THs/CHWs; service providers/CHWs) felt that a central place that could easily be reached, such as a church or school, would be the most appropriate location. This would reduce the cost issue (i.e. transport costs) and allow more people to attend because the disorder is everywhere. Other suggestions included a location near health facilities so that participants could make use of them at the same time (Participatory workshop, THs/CHWs) or in people‘s homes (Participatory workshop: PWE).

Regarding the time any educational intervention should take, a longer-term educational programme with regular home visits was favoured as it was felt to be new information, which needed time to be digested (Participatory workshop: PWE). In addition, participants commented that breadwinners cannot afford a chunk of time away from the household (Participatory workshop: parents/grandparents; THs/CHWs). Practicalities such as the provision of meals or compensation for time (a packet of corn flour was mentioned) were also raised (Participatory workshop: service providers/CHWs; THs/CHWs; parents/grandparents).

9.3.2.2 Communication skills training

Participants in all of the participatory workshops felt that people weren‘t given a clear explanation about AEDs and they generally didn‘t know what was happening in treatment. There was general agreement that the service provider‘s interpersonal skills made a difference to the patient‘s wellbeing and to other patients‘ use of the service, as exemplified by these comments:

> *"Sometimes it depends on the person providing the service. Some are human and treat people so well, just the reception can give you hope. But there are those who are so inhuman, they mistreat people."* (FGD CHWs)
>
> *"It's the reception that people don't know but if you treat them well, you will see other people coming. If you treat somebody well, that is a lamp already to bring more people."* (Interview APDK*)*

9.3.2.3 Increasing accessibility to AEDs

Accessibility was related to both finances and distance to the health facilities:

> *"I want to say that taking a child to Kilifi, it takes a long time. So if they could bring the drugs here, we would have saved time and fare."* (FGD CHWs)
>
> *"The hospital is far and we don't have transport. We have to board vehicles so as to reach there."* (Interview dispensary nurse)
>
> *"This hospital is good but sometimes you go there, get examined and prescribed for drugs and you need money for those drugs. So if you don't have money, then you just remain with the illness."* (FGD CHWs)

Several of the service providers stressed that any new venture should be incorporated into the existing health system to ensure sustainability:

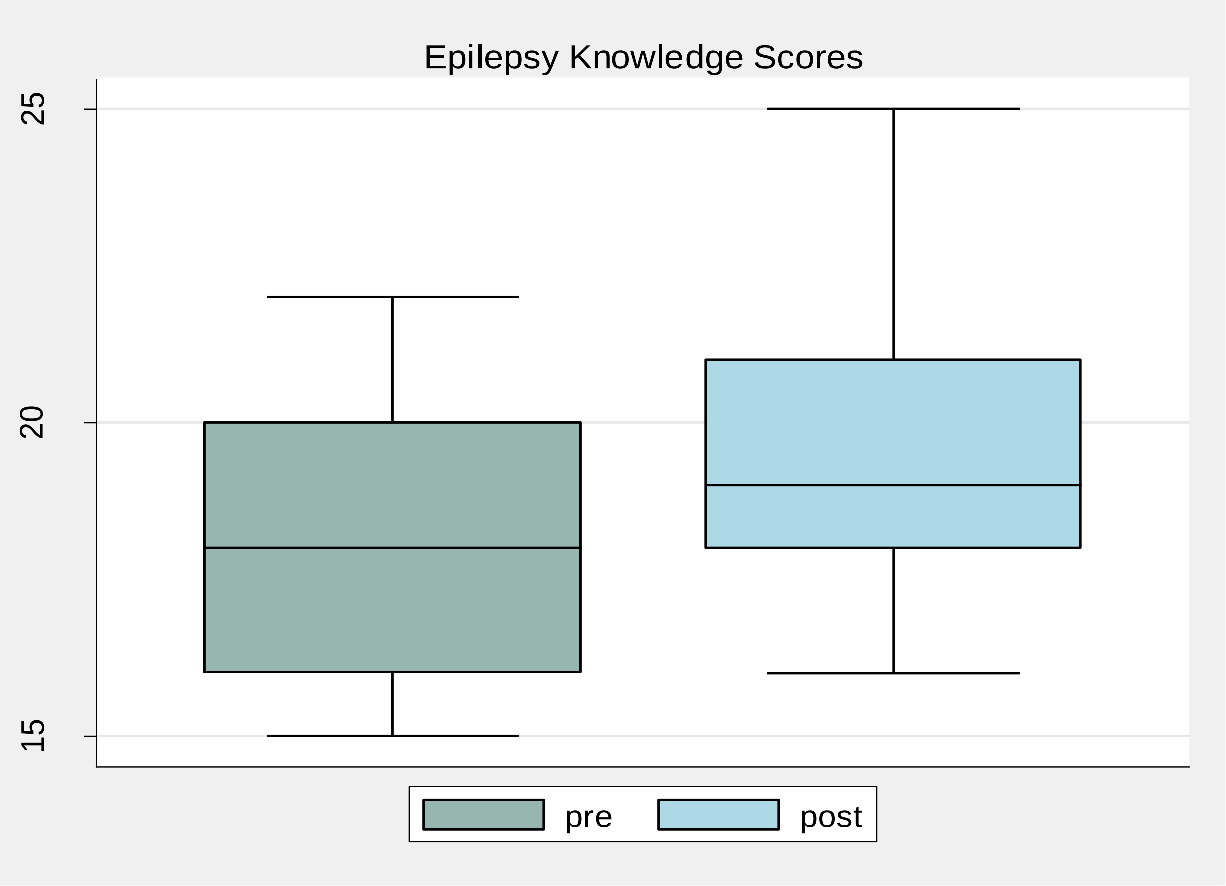
> *"If it's within the medical wards or the medical out-patients, even if the study runs out, it will have been established within an already running system so it will remain there, it will not die. But if you've got an external thing, it will stop with the study*." (Interview Dr I)

9.3.2.4 Providing support for PWE and their families

The 19 CHWs who were trained were expected to initiate a visiting and educational programme for 13 PWE and their families. Therefore an evaluation was done one month after the training to gauge the kind of information that CHWs were passing to PWE and their families. Most CHWs emphasized on the importance of taking AEDs but less information was provided on potentially harmful self-management practices such as pouring water on PWE during seizures. Overall, CHWs did a good job in reaching and supporting PWE and their families. Some made as many as four visits but the median number of visits was two. On average CHWs spent 17 minutes with PWE. They also played a role in referring PWE to the nearest health facility. Only nine CHWs were active and they provided support to only 7 PWE. The others cited long distance between CHW and PWE as a hindering factor.

The 15 biomedical providers who attended the training were drawn from the health facilities in the KHDSS. They were trained on communication skills as well as diagnosis and management of epilepsy so that they would provide efficient services to PWE. Their level of knowledge on diagnosis and management of epilepsy was evaluated using a pre-post questionnaire (Appendix IV). The training led to an in increase in epilepsy knowledge from a median of 18 to 19 as shown below (Figure 9.2).

Figure 9.2: Epilepsy knowledge scores of health providers: pre and post delivery of education intervention



It is envisaged that the awareness created among TH and community members led to better support for PWE and their families though it was difficult to evaluate this arm of the intervention.

9.4 Conclusion

Manderson emphasizes that although research into community perceptions of illness, including local taxonomies, is useful in the design of interventions, a more in-depth understanding of illness and its social and cultural dimensions is more useful in highlighting barriers to behaviour change and how interventions can be both effective and sustainable (Manderson, 1998). The process we used here was an attempt to understand these complexities. Panter-Brick and colleagues say that it is now widely accepted that to be effective, interventions should build upon local existing practices, identify and target the most receptive community members, bolster local skills and priorities, recognize constraints (time, financial, cognitive and social) on human agency and feature mobilization of the community (Panter-Brick *et al.*, 2006). We believe that the process we used to develop this intervention has resulted in a programme that is more likely to be effective and sustainable.

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Chapter 10

Discussion and conclusion

EPILEPSY TREATMENT GAP, ASSOCIATED RISK FACTORS AND INTERVENTION STRATEGIES IN KILIFI, KENYA

10.1 Introduction

This thesis investigates the factors associated with the Epilepsy Treatment Gap (ETG). It also presents an example of how results from exploratory studies can be used to inform the development of interventions aimed at reducing the ETG. This last chapter starts with a brief background about epilepsy, a review of the methodological approaches, followed by a discussion of the main research findings with reference to the original objectives described in Chapter 1. Finally this Chapter puts forward some recommendations and needs for future research.

10.2 Background

10.2.1 Epilepsy

Epilepsy is one of the most common neurological disorders, accounting for 1% of the global burden of disease, determined by the number of productive life years lost as a result of disability or premature death (WHO, 2005; Leonardi & Ustun, 2002; Murray & Lopez, 1994). The condition is associated with psychosocial problems, reduced life expectancy, social isolation and increased risk of unexpected death (Jilek-Aall & Rwiza, 1992; Jilek-Aall *et al.*, 1997; Matuja, 1990b; Nilsson *et al.*, 1999). People with Epilepsy (PWE) are vulnerable due to the unpredictable and uncontrollable nature of seizures (DiIorio *et al.*, 2003), which in many cultures are associated with witchcraft or sorcery (Baskind & Birbeck, 2005a; El Sharkawy *et al.*, 2006). Epilepsy consists of more than seizures because it imposes enormous physical, psychological, social and economic burdens on individuals, families and countries (Baker, 2002; Jilek-Aall *et al.*, 1997; Hong *et al.*, 2009; Forsgren *et al.*, 2005).

10.2.2 Epilepsy in resource poor countries

Epilepsy is more common in Resource Poor Countries (RPCs) because of poor perinatal care with greater risk of brain injury, increased traumatic head injury, endemic parasitic and infectious diseases (Shorvon, 2009; Pal *et al.*, 2000a; Carter *et al.*, 2004; Matuja, 1990a). The majority of epilepsy-related deaths and disability in childhood and adolescents also occur in RPCs (WHO, 2006), mainly because of the scarcity of resources to identify and manage epilepsy in RPCs (World Bank, 1993; Bangdiwala *et al.*). Results obtained from a survey conducted by the International League Against Epilepsy (ILAE)/International Bureau for Epilepsy (IBE)/World Health Organization (WHO) in 160 countries showed that available resources for epilepsy care in the world are insufficient when set against the large number of people needing such care (Dua *et al.*, 2006). In addition, large inequalities exist across regions and income groups of countries, with RPCs having extremely meagre resources (Dua *et al.*, 2006). Such is the case in the rural setting of Kilifi, where diagnostic services and epilepsy specialists are lacking. Poverty, unemployment and illiteracy influence the lives of PWE, by making them vulnerable to serious economic, social and emotional suffering (GOK, 2000), which affects how they seek and adhere to treatment.

The Global Campaign Against Epilepsy, a partnership between the ILAE/IBE/ WHO was launched in 1997 to improve the acceptability, treatment, services and prevention of epilepsy worldwide (Reynolds, 2000; Diop *et al.*, 2003; De Boer, 2002). In 2002, the Global Campaign entered its second phase and several demonstration projects were set up in various countries, to reduce the ETG and the physical, economic and social burden of epilepsy through community-level interventions (Sander, 2002). By 2004, activities and events in 85 countries were held and projects in China, Zimbabwe, Senegal and Brazil have been successfully completed (Wang, 2008; Ndoye *et al.*, 2005; Li *et al.*, 2007). The Global Campaign has also produced useful reports which are a good reference for countries committed to reducing the ETG (WHO, 2005; WHO, 2004; ILAE/IBE/WHO, 2003).

10.2.3 Treatment seeking for epilepsy in Kilifi

The findings of this study revealed that PWE in Kilifi utilize both biomedical and traditional medicine. Beliefs about the causes of epilepsy impacted on the type of treatment sought. Belief in ‗external causes' such as witchcraft, curses and evil spirits lead to consulting Traditional Healers (THs) whereas biomedical treatment was sought when epilepsy resulted from natural causes such as perinatal injury, accidents and malaria. In reality, PWE and their families often use both traditional medicine and biomedicine since these modalities deal with different aspects. Traditional medicine provides information about the causes of the epilepsy, offers the hope of a cure and the THs provide significant psychosocial support. In contrast, biomedicine provides AEDs to control the seizures but the explanations given by the biomedical practitioners (nurses and clinicians) are often not intelligible to the clients. These practitioners are also not able to spend much time with the clients as the THs due to clinical commitments.

10.3 Methodological issues

Research reported in this thesis demonstrates how complementary methodologies can lead to understanding of the ETG. The qualitative part enabled us to understand cultural reasons for treatment seeking behaviour for epilepsy while the quantitative part allowed us to estimate the ETG using a robust pharmacological measure. One limitation of these methods is the reliance on self-reported answers that are subject to recall and reporting bias. Attempts were made to minimize this potential source of bias by piloting the questionnaires using experienced field staff who had a good rapport with the community members. The field team was also well trained and conversant with the local language (Kigiriama). As a member of the research team, the author of this thesis participated in developing the tools, training the field team, field supervision, checking quality of data, analysis and interpretation of the results.

10.3.1 Choice of study site

The Kilifi Health Demographic Surveillance System (KHDSS) provided an excellent epidemiological framework for the studies in this thesis. The constant demographic surveillance facilitated the identification of PWE who were the main study participants (Chapters 1). However, studies conducted in the KHDSS may not be necessarily generalisable to the rest of the country. The Kilifi Health Demographic Surveillance KHDSS has been the focus of continued research since 2001 which means this population is more exposed to health information compared to the rest of the county.

10.4 Overview of findings

This research identified factors that are responsible for the ETG in Kilifi and ways that the gap can be reduced. Each of the chapters elaborated a complimentary aspect to address this issue. The systematic review in chapter 2 examined ETG in RPCs. Findings indicated a wide variability in ETG estimates with a prevalence of 46.8/100 in urban settings and 73.3/100 for rural regions. The ETG was mainly attributed to inadequate skilled manpower, cost of treatment, cultural beliefs, and unavailability of Antiepileptic Drugs (AEDs). These factors were addressed using intervention strategies such as education and supply of AEDs. These preliminary findings informed the design of the studies that were conducted in Kilifi.

Chapters 3 and 4 examined how to construct culturally varied tools that were used to collect data from study participants. The Kilifi Stigma Scale for Epilepsy (KSSE) was unidimensional, indicating that it measured only one construct (perceived stigma). In addition, it had high internal consistency (Cronbach‘s α= 0.91) and excellent test-retest reliability (r=0.92). The Kilifi Epilepsy Beliefs and Attitude Scale (KEBAS) had five subscales (causes of epilepsy, biomedical treatment of epilepsy, cultural treatment of epilepsy, risk and safety concerns and negative stereotypes about epilepsy). The subscales demonstrated adequate internal consistency ranging from α=0.56 to α=0.76 and acceptable test-retest reliability ranging from r=0.64 to r=0.81.

The studies in Chapters 5 and 6 investigated factors associated with treatment seeking and adherence. People who were identified to have active convulsive epilepsy were asked about their treatment seeking behaviour. Whereas 499 (74%) of those identified sought treatment, only 385 (77%) reported taking AEDs though there was a large discrepancy between self reporting and AEDs blood levels. The findings also showed a high ETG in Kilifi and factors that constrain PWE from seeking and adhering to treatment. Some of these factors included religion, distance from home to health facilities, paying for AEDs, injury during a seizure, beliefs about causes of epilepsy, beliefs about biomedical treatment of epilepsy, seizure frequency, duration of medication, number of AEDs prescribed and good relationship with the healthcare provider.

Chapter 7 reviewed literature that highlights the delivery of packages of care for epilepsy in low- and middle income countries (LMICs). Some of the treatments available for epilepsy in LMICs include AEDs therapy, surgery and psychosocial therapy. Among the interventions feasible in these countries are: ensuring an adequate drug supply, educating PWE and caregivers about epilepsy, community-based interventions to improve awareness, training health care providers, involving THs and integrating epilepsy care into existing health services, particularly mental health. These findings provided useful background information that informed development of suitable interventions in Kilifi.

Chapter 8 used an ethnographic approach to compare characteristics of epilepsy treatment providers in KHDSS. The study identified six key differences between biomedical and traditional treatments (explanations of causation, communication styles, social roles, referral practices, location and systems of payment). Traditional healers play a major role in the treatment of epilepsy which can be explained by the supernatural and cultural beliefs associated with epilepsy in Kilifi.

The study reported in chapter 9 outlines reasons for the ETG in Kilifi from a qualitative perspective and how the findings were used to inform development of interventions. Five main themes emerged from the data as reasons for the ETG: differing causal explanations for the causes, treatment and prognosis of epilepsy; the issue of curing epilepsy; diminished access to and utilisation of biomedical health services; poor doctor-patient relationships and communication and access issues for PWE and their families. These findings indicated several possible avenues for intervention such as education of PWE and their caregivers, communication skills training for health providers, improving drug supply in health facilities; increasing cooperation and dialogue with THs and supporting PWE and their families.

10.5 Recommendations for action

Specific recommendations which arise from the findings of this study concern the community, health care providers, policy makers and researchers.

10.5.1 Community

The community constitutes the external environment in which PWE live and the level of support derived from it can influence treatment seeking and adherence to medication. Therefore, efforts should be put to improve community knowledge about epilepsy. Some of the concepts that awareness programmes should focus on include:

1. Explaining that epilepsy is a chronic condition despite unpredictability of seizures;
2. Explaining the causes and prognosis of epilepsy;
3. How to prevent epilepsy through measures such as sleeping under bed nets and attending antenatal care for pregnant women;

4. Informing people about AEDs and importance of adherence. The most important information is to explain why seizures may persist despite taking medication and what to do if someone has a seizure;
5. Emergency treatment of seizures and how to support PWE and their families;
6. Encouraging people to be self reliant by initiating income generating activities so that they can comfortably meet their health care costs.

10.5.2 Medical providers

The use of primary health care providers to identify cases of epilepsy and initiate simple treatment protocols has been advocated as a solution to the inadequate and uneven distribution of medical manpower available for the management of epilepsy in RPCs. World Health Organization has advocated the use of primary health care personnel to identify cases of epilepsy, apply simple treatment protocols and monitor therapy within a framework of an integrated primary health care program for epilepsy (WHO, 1990; WHO, 1985). A report from Kenya confirmed the feasibility of this approach for the monitoring of drug therapy in epilepsy patients using primary care workers (Feksi *et al.*, 1991a). This emphasizes the need to give these health providers appropriate training and facilities for providing epilepsy care.

The study in Chapter 6 showed that health providers have a role to play in improving adherence hence they should explain to patients the chronic nature of their condition and the need to take AEDs over a long period of time. There is also a need for healthcare providers to continually improve their relationship and communication with patients in addition to educating and counseling them. Findings from studies in Chapters 5, 8 and 9 show that PWE consult THs hence the need for medical providers to be aware of traditional beliefs and practices that foster the use of traditional medicine among PWE. This could provide a good basis for non competitive relationship between biomedical practitioners and THs, particularly when neither may satisfactorily meet all the needs of PWE.

10.5.3 Traditional Healers

The WHO defines THs as a group of persons recognized by the community in which they live as being competent to provide health by using vegetable, animal and mineral substances. The treatment methods used by these groups of people are based on the social, cultural and religious backgrounds as well as on the knowledge, attitudes and beliefs that are prevalent in the community regarding physical, mental and social well being and the causation of disease and disability (WHO, 1976). In Africa, it is estimated that THs provide up to 80% of all health care services in poor rural families (Hoff, 1997).

In the Alma Ata Declaration of 1978, and in the context of Health for All resolution, THs started to be considered as an important potential for primary health care coverage. In 1978, WHO launched a big, cross-cultural programme of promoting the integration of THs into the formal health care sector (WHO, 1978). After a first boom of the ambitious collaboration projects, a shift towards more focused contributions of healers to specific health issues has taken place, for example in the management of AIDS and STDs (Green, 1999a; Green, 1999b).

In the case of epilepsy, THs play a major role in treatment as described in Chapter 8. This is reinforced by studies conducted in other settings which have documented the role of THs in treatment of epilepsy (Millogo *et al.*, 2004; Moshi *et al.*, 2005; Baskind & Birbeck, 2005a; Balogou *et al.*, 2000; Gessler *et al.*, 1995). This supports the potential benefits of integrating THs in health workers‘ trainings. In such trainings they can learn about first aid during seizures and the importance of referring PWE to health facilities as well as some effective interventions that are consistent with their ability and style of knowledge. However, mutual agreement between THs and biomedical providers need to be established to avoid misunderstanding especially pertaining ownership of indigenous traditional knowledge.

10.5.4 Policy makers

Findings suggest that epilepsy is an important public health problem that needs commitment of resources by governments of RPCs if ETG is to be reduced. Policy makers need to take deliberate action to address hindering factors that prevent PWE from accessing appropriate care. They also need to make commitment to deal with the many preventable causes of epilepsy in RPCs such as poor perinatal care, head trauma, parasitic infections, alcohol and drug abuse. If action is taken against these preventable causes, this will indirectly lead to reduction of the ETG. In Kenya, some of the measures that can be implemented at policy level include:

1. The division of non-communicable diseases, of the Ministry of Health (MoH) together with other stakeholders should develop an epilepsy strategic policy and come up with national guidelines for the management of epilepsy in the country. Furthermore, a National Epilepsy Forum (NEF) comprising of representatives from organisations has been constituted to bring together stakeholders involved in epilepsy work. The main objective of the forum is to improve care and access to services to PWE. Out of this forum, a eight member National Epilepsy Co-coordinating Committee was formed to coordinate epilepsy activities in the country.
2. Incorporating epilepsy in the National Health Agenda and integrating epilepsy interventions in the existing primary health care system. It would also be worth including epilepsy on the list of diseases for surveillance that are reported on a monthly basis at various health care facilities. Already a proforma has been developed by NEF to collect data from health facilities. This will provide information that is vital for planning for epilepsy services.
3. Uninterrupted supply of essential AEDs, especially in the peripheral health facilities. AEDS stock-outs are a recurrent problem in health facilities because the Kenya Medical Supplies Agency uses the _push‘ system whereby each health facility receives a pre-determined quantity of drugs. The _push‘ system does not respond to health facility needs and this leads to either stock outs or wastages. There is need for the government to adopt the _pull‘ system that allows health facilities to request for the drugs that they need which minimizes wastage.

4. Creating Information, Education and Communication (IEC) materials to raise awareness about epilepsy among the general public. There is also need to sensitize the public about the global day of epilepsy awareness (purple day) that is marked on 26th March every year.
5. The government can lobby pharmaceutical companies to reduce prices of AEDs. It should also ensure pharmaco-vigilance so that AEDs that are sold are effective and efficacious.
6. The government needs to invest in health systems strengthening so that health interventions including those related to epilepsy can be delivered effectively. Essential medical supplies and equipment such as Electroencephalography and Computerized Tomography should be availed to district level hospitals. In terms of manpower, there is need to employ enough personnel to deliver health services. This will curb staff shortages and lead to improved care for PWE.
7. The government needs to pay increased attention to the problem of economic constraints for people's health care expenditure. Implementation of universal health insurance system would be a possible way of helping PWE to cope with treatment cost. This can be achieved by ensuring both people in the formal and inform sector contribute to the National Health Insurance Scheme.

10.5.5 Researchers

One of the key roles of a researcher is to disseminate research findings. In addition to presenting the findings in international conferences and scientific journals researches should:

1. Strive to simplify the findings and present to policy makers. Follow up should also be done to be sure that action is taken on the recommendations made. The researchers in this study have began sharing findings with the department of non-communicable disease, MoH.
2. Share findings with other stakeholders involved in epilepsy work. In Kenya we have began sharing our findings with the following members of NEF: MoH, Kenya Society of Epilepsy, Kenya Association for Welfare of People with Epilepsy, Youth on the Move, Joint Epilepsy Foundation and Pharmaceuticals companies.

3. Provide feedback to the community using research summaries written in lay language. Feedback can also be given through community meetings or to individual participants. This has been done through implementation of Kilifi Epilepsy Education Program (KEEP), an intervention that was designed to create awareness about epilepsy in KHDSS.
4. The findings from studies in chapters 8 and 9 show the value of THs in providing epilepsy care and points to the need of sharing information and research findings with them. All the THs identified in KHDSS participated in the KEEP intervention that provided information about epilepsy.
5. The systematic review in Chapter 2 shows the need to improve research on the epidemiology of epilepsy in RPCs so that PWE can be correctly identified. Research tools for such studies need to be standardized and validated.

10.6 Implication for future research

The studies in this thesis have clearly looked at ETG from various perspectives. Attempts have also been made to incorporate the findings from the studies in developing tools and interventions. However, there remain a number of research issues that need to be addressed:

1. Information from study participants indicates that there is still need to increase awareness about various aspects of epilepsy. In Chapter 9 we attempted to develop an education intervention with the help of study participants. Such an intervention would call for development of IEC messages that are culturally appropriate. With our example as a background, and the fact that there are no educational materials on epilepsy that are culture specific, it would be useful to study, compare and find the best advocacy strategies for delivering epilepsy messages. Such research should also aim to evaluate if such strategies have an impact at reducing the ETG.
2. Several outcome measures are used in epilepsy care, such as seizure control, quality of life, knowledge of illness, attitudes of people, stigma and discrimination levels. There is need for prevalence studies to estimate ETG so that it can also be used as an outcome measure in health care.

3. This thesis mainly focused on personal attributes that hinder treatment seeking. Future research can look at healthcare delivery system characteristics such as policies, resources, organization and financial arrangements influencing the accessibility, availability and acceptability of epilepsy care services.
4. The cost-effectiveness of possible interventions needs to be modeled and calculated. This would allow the Public Health personnel to implement interventions that are sustainable.
5. We determined adherence by taking AEDs blood levels at one point in time. Future studies can monitor it over a duration of time to find out if there is variation in drug levels in individual patients.

10.7 Conclusion

After studying various aspects of the ETG from risk factors to intervention strategies we conclude that:

1. ETG is a public health problem that can be effectively addressed if stakeholders work together.
2. Using mixed methodologies to understand the ETG provides evidence based approaches of addressing the gap
3. There is need for advocacy strategies to increase awareness about epilepsy and to ensure sustained supply and distribution of AEDs at peripheral health facilities
4. Traditional healers may perform some useful roles in management of epilepsy such as providing psychosocial support that is deficient in the health care facilities hence a need to initiate sustainable collaboration with them
5. Measures that prevent epilepsy can indirectly lead to reduction of the ETG
6. There is need for encompassing research to inform epilepsy policy and practice

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APPENDIX I

STRUCTURED QUESTIONNAIRES

PART 1: PERSONAL DETAILS

Today's date: --------------------------------- [ ][ ]/[ ][ ]/[ ][ ][ ][ ] (TDATE)

Name: --- (NAME)

PID No: --- [ ][ ][ ][ ][ ][ ][ ](PID)

EZHHID: --- [ ][ ][ ][ ][ ][ ](RESID)

DOB: -- [ ][ ]/[ ][ ]/[ ][ ][ ][ ] (DOB)

Age: -- [ ][ ][ ] (AGE)

Sex: --- [ ] (SEX)

Respondent's name: --- (RNAME)

Relationship to index: -- [ ] (RELAT)

1. Mother
2. Father
3. Guardian
4. Self

Informed consent obtained: **Y/N [ ] (ICO)**

Questionnaires completed:

Questionnaire	**Date of interview**	**Start time**	**End time**	**Total time**	**Inter initials**
1. SOCIAL DEMO	/ /	**[ ][ ]:[ ][ ]**	**[ ][ ]:[ ][ ]**	**[ ][ ]:[ ][ ]**	
2. SES	/ /				
3. ACCESSIBILITY	/ /				
4. ADHERENCE	/ /				
5. STIGMA	/ /				
6. EBAS	/ /				

PART 2: SOCIO DEMOGRAPHIC INFORMATION

Question	**Response**	**Code**
1. Religion **(RELIG)**	1. Catholic 2. Protestant 3. Islam 4. Traditional 5. None 6. Other (specify)	[ ]
2. Education level **(EDULEV)**	1. None 2. Nursery 3. Primary finished 4. Primary Not finished 5. Secondary finished 6. Secondary Not finished 7. College 8. University 9. Other (specify)	[ ]
3. Occupation **(OCCUP)**	1. Farmer 2. Trader/Business 3. Casual labourer 4. Fisher man 5. Professional 6. Student 7. Other (specify)	[ ]
4. Marital status **(MARST)**	1. Never married 2. Married 3. Separated 4. Divorced 5. Widowed	[ ]
5. Number of siblings in the family **(SIBL)**	Number	[ ]
6. Position of sibling with epilepsy in the family **(PSIBL)**	1. First born 2. Middle 3. Last born	[ ]

PART 3: ASSETS AND OTHER INDICATORS OF SOCIAL ECONOMIC STATUS

Question (Type of asset)	**Response** 1=Yes 0=No	**How many?**
Goats	[ ]	[ ]
Cows	[ ]	[ ]
Chickens/Ducks	[ ]	[ ]
Other livestock (specify)	[ ]	[ ]
Radio	[ ]	
Television sets	[ ]	
Video machine	[ ]	
Fridges/freezers	[ ]	
Cookers (electricity/gas)	[ ]	
Telephone/mobile phones	[ ]	
Bicycle (adult)	[ ]	
Motor bike	[ ]	
Car or truck	[ ]	
Land/ Plot	[ ]	

Question	**Response**	**Code**
1. What are the *walls* of the main dwelling (house) predominantly made of? **(WALL)**	1. Stone 2. Brick/Blocks 3. Mud 4. Wood 5. Cement 6. Iron sheets 7. Tin 8. Grass/Straw 9. Other (specify)	[ ]
2. What is the *roof* of the main dwelling Predominantly made of? **(ROOF)**	1. Iron sheets 2. Tiles 3. Concrete 4. Makuti 5. Grass 6. Tin 7. Other (specify)	[ ]
3. What is the *floor* of the main dwelling predominantly made of? **(FLOOR)**	1. Cement 2. Tiles 3. Wood 4. Mud/Earth 5. Other	[ ]
4. Does your household own the land on which the structure (house) sits **(OWNLAND)**	1. Owns 2. Pays rent 3. No rent with consent from owner 4. No rent, squatting	[ ]

Question	**Response**	**Code**
5. What is the main source of water for members of your household? **(SWATER)**	1. Piped into house 2. Piped into plot/compound 3. Public tap 4. Open well in compound 5. Open public well 6. Covered well in compound 7. Covered public well 8. River/Stream 9. Lake/pond 10. Dam 11. Other (specify)	[ ]
6. How frequently is water available from this source? (**FWATER)**	**1.** Always available **2.** Several hours per day **3.** Once or twice a week **4.** Infrequently	[ ]
7. What kind of toilet facility does your household have? **(TOILET)**	1. Flush toilet 2. Traditional pit latrine 3. Ventilated Pit latrine (VIP) 4. Free range (bush) 5. Other (specify)	[ ]
8. What is the household‘s main source of cooking fuel? **(FUEL)**	1. Firewood 2. Kerosene 3. Electricity 4. Gas 5. Charcoal 6. Dung 7. Other (specify)	[ ] [ ] [ ]
9. What is the household‘s main source of lighting? **(LIGHT)**	1. Pressure lamp 2. Kerosene lamp 3. Tin lamp 4. Electricity 5. Firewood 6. Solar 7. Candles 8. Other (specify)	[ ] [ ] [ ]

PART 4: ACCESSIBILITY OF HEALTH SERVICES

Question	**Response**	**Code**
1. Have you ever sought epilepsy treatment from a health facility? **(STREAT)** ***No go to Sec 4***	1. Yes 0. No	[ ]
2. From which health facility do you seek epilepsy Treatment? **(HFACIL)**	1. Bomani dispensary 2. Chasimba dispensary 3. Junju dispensary 4. Jaribuni dispensary 5. Kilifi district hospital 6. Kizingo dispensary 7. Matsangoni dispensary 8. Mtepeni dispensary 9. Mtwapa dispensary 10. Ngerenya dispensary 11. Pingilikani dispensary 12. Takaungu dispensary 13. Vipingo health center 14. KEMRI neuro clinic 15. Other (specify)	[ ] [ ] [ ]
3. Can the health facility be reached on foot? **(FOOT)** ***No go to 5***	1. Yes 0. No	[ ]
4. How long does it take on foot? **(LFOOT)**	Minutes	[ ]
5. Do you use a vehicle to reach the health facility? **(VEH)**	1. Yes 0. No	[ ]
6. How long does it take by foot and vehicle? **(LVEH)**	Minutes	[ ]
7. Does the amount of distance you have to cover discourage you from seeking treatment? **(DISTD)**	1. Always 2. Sometimes 3. Not at all	[ ]
8. What is the total amount of fare used per person to reach the health facility? **(TFARE)**	Ksh	[ ]
9. Does use of fare discourage you from seeking treatment? **(FARED)**	1. Always 2. Sometimes 3. Not at all	[ ]
10. How long do you wait before you are attended to by a health provider? **(LWPROV)**	Minutes	[ ]
11. How long do you spend with the health provider? **(LSPROV)**	Minutes	[ ]
12. Do you feel the health provider gives you clear explanation about your medication? **(CEXPLA)**	1. Always 2. Sometimes 3. Not at all	[ ]
13. What is the total amount of time you spend seeking treatment? **(TTIME)**	Hours	[ ]

Question	**Response**	**Code**
14. Do you feel this is a long time? **(FTIMEL)**	1. Always 2. Sometimes 3. Not at all	[ ]
15. Does the total amount of time you spend discourage you from seeking treatment? **(TTIMED)**	1. Always 2. Sometimes 3. Not at all	[ ]
16. Are epilepsy drugs always available in the health facility? **(AEDS)**	1. Always 2. Sometimes 3. Not at all	[ ]
17. Does absence of epilepsy drugs discourage you from seeking treatment? **(AEDSD)**	1. Always 2. Sometimes 3. Not at all	[ ]
18. Do you pay for epilepsy drugs? **(PAY)** ***No go to 20***	1. Yes 0. No	[ ]
19. Does the cost of drugs discourage you from seeking treatment? **(COSTD)**	1. Always 2. Sometimes 3. Not at all	[ ]
20. Overall are the epilepsy services at the health facility: **(EPISER)**	1. Satisfactory 2. Indifferent 3. Unsatisfactory	[ ]

PART 5: SEIZURE FREQUENCY, SEVERITY AND ADHERENCE

Question	**Response**	**Code**
1. How many years have u had seizures **(YRSSEIZ)**	Years	[ ]
2. How often have you had seizures in the past 3 months? **(OFTSEIZ)**	1. None 2. 1-3 3. 4-6 4. >6	[ ]
3. How long do the seizures last? **(LSEIZ)**	1. Less than 5 minutes 2. 5-10 minutes 3. 11-20 minutes 4. 21-30 minutes 5. More than 30 minutes 6. Don't know	[ ]
4. Have you ever been seriously injured during a seizure? **(INJURE)** ***No go to 6***	1. Yes 0. No	[ ]
5. If yes, specify the type of injury **(TYINJURE)**	1. Burns 2. Broken bones 3. Cuts 4. Bruises 5. Other (specify)	[ ] [ ] [ ]
Thinking of the drugs used to control seizures, please answer the following questions:		
6. Have you ever taken medication to control seizures? **(MED)** ***No go to section 5***	1. Yes 0. No	[ ]
7. For how many years have you been taking medication to control seizures? **(YRSMED)**	1.<1 2. 1-3 3. 4-5 4. >5	[ ]
8. How many types of seizure medication has the doctor prescribed for you? **(TYMED)**	1. One 2. Two 3. Three 4. Four	[ ]
9. How many times per day do you take your seizure medication? **(TDAY)**	1. Once 2. Twice 3. Thrice 4. Four times	[ ]
10. How many tablets do you take each day to control seizures? **(NOTABS)**	1. 1-2 2. 3-4 3. 4-6 4. >6	[ ]
11. How often do you take your seizure medication? **(OFTMED)**	1. Regularly 2. When seizures occur	[ ]
12. Have you ever skipped taking your seizure medication? **(SKIPMED)** ***No go to 14***	1.Yes 0. No	[ ]
13. Did you have a seizure when you skipped your seizure medication? **(SKIPSEIZ)**	1.Yes 0. No	[ ]

Question	**Response**	**Code**
14. Do you think skipping medication makes a difference? **(SKIPDIFF)**	1.Yes 0. No	[ ]
15. Do you think your seizures are controlled? **(SEIZCONT)**	1. Controlled 2. Uncontrolled	[ ]
16. How long do you take to go for more seizure drugs after the previous ones are over? **(LAEDS)**	1. Before they are over 2. The day they are over 3. Up to one week after they are over 4. Up to one month after they are over	[ ]
Morisky Self Reported Medication Adherence Scale		
Question	**Response**	**Code**
17 (a). Do you ever forget to take your medications? **(FORMED)**	1.Yes 0. No	[ ]
17 (b). Are you careless at times about taking your medication? **(CARMED)**	1.Yes 0. No	[ ]
17 (c). When you feel better, do you sometimes stop taking your medication? **(SBETTMED)**	1.Yes 0. No	[ ]
17 (d). Sometimes, if you feel worse when you take your medication, do you stop taking your medication? **(SWORMED)**	1.Yes 0. No	[ ]
17 (e). Total Self Reported Medication Adherence Score (a+b+c+d) **(TSCORE)**	Total Score	[ ]
There are various factors that influence how people take medications prescribed to them by the doctor. Thinking of your seizure medication, please answer the following questions:		
Question	**Response**	**Code**
18. What encourages/reminds you to take your epilepsy medications regularly **(ENCMED)**		
(a) Understanding instructions by the doctor (**UNDINST)**	1.Yes 0. No	[ ]
(b) Understanding need for long term treatment **(UNDNLTRE)**	—	[ ]
(c) Understanding the need of medication **(UNDNMED)**	—	[ ]
(d) Understanding the effectiveness of medication **(UNDEFMED)**	—	[ ]
(e) Availability of family support system **(FAMSUPP)**	—	[ ]
(f) Making medication a habit **(MEDHAB)**	—	[ ]
(g) Accessibility /Availability of medication **(ACCMED)**	—	[ ]
(h) Good patient-doctor relationship **(GPDRELA)**	—	[ ]
(i) Keeping medication in sight **(SIGHMED)**	—	[ ]
(j) Others (specify):		

Question	**Response:**	**Code**
19. What might discourage you from taking your seizure medication regularly **(DISMED)**		
(a) Misunderstanding instructions by the doctor **(MISINST)**	1.Yes 0. No	[ ]
(b) Misunderstanding need for long-term treatment **(MISNLTRE)**	—	[ ]
(c) Lack of understanding of need of medication **(MISNMED)**	—	[ ]
(d) Lack of understanding of effectiveness of Medication **(MISEFMED)**	—	[ ]
(e) Continuity of seizures despite treatment **(CONSEIZ)**	—	[ ]
(f) Infrequent seizures **(INFRSEIZ)**	—	[ ]
(g) Drug side effects **(AEDSEFF)**	—	[ ]
(h) Lack of family support system **(LFAMSUPP)**	—	[ ]
(i) Lack of access to medication **(LACCMED)**	—	[ ]
(j) Fear of getting addicted to medication **(ADDMED)**	—	[ ]
(k) Cost of medication **(COSTMED)**	—	[ ]
(l) Forgetting **(FORGET)**	—	[ ]
(m) Dissatisfaction with treatment **(DISSTRE)**	—	[ ]
(n) Traveling **(TRAVEL)**	—	[ ]
(o) Others (specify):		

PART 6: KILIFI STIGMA SCALE FOR EPILEPSY

Question	**Response**	**Code**
Different diseases impact on people's lives in one way or another. Because of epilepsy:		
1. Do you feel different from other people? **(FDIFF)**	0. Not at all 1. Sometimes 2. Always	[ ]
2. Do you feel lonely? **(FLONE)**	0. Not at all 1. Sometimes 2. Always	[ ]
3. Do you feel embarrassed? **(FEMBAR)**	0. Not at all 1. Sometimes 2. Always	[ ]
4. Do you feel disappointed in yourself? **(FDISAPP)**	0. Not at all 1. Sometimes 2. Always	[ ]
5. Do you feel you cannot have a rewarding life? **(FRLIFE)**	0. Not at all 1. Sometimes 2. Always	[ ]
6. Do you feel you cannot contribute anything in society **(FCONSOC)**	0. Not at all 1. Sometimes 2. Always	[ ]
7. Do you feel you cannot join others in public places? **(FPUBLIC)**	0. Not at all 1. Sometimes 2. Always	[ ]
8. Do you feel other people are uncomfortable with you? **(FPUNCOMT)**	0. Not at all 1. Sometimes 2. Always	[ ]
9. Do you feel other people would not want to go to occasions with you? **(FPOCCAS)**	0. Not at all 1. Sometimes 2. Always	[ ]
10. Do you feel other people treat you like an inferior person? **(FPINFER)**	0. Not at all 1. Sometimes 2. Always	[ ]
11. Do you feel other people would prefer to avoid you? **(FPAVOID)**	0. Not at all 1. Sometimes 2. Always	[ ]
12. Do you feel other people would avoid to exchange greetings with you? **(FPGREET)**	0. Not at all 1. Sometimes 2. Always	[ ]
13. Do you feel you do not relate well with family members? **(FRELFAM)**	0. Not at all 1. Sometimes 2. Always	[ ]
14. Do you feel you are not accepted by your peers? **(FACCPEER)**	0. Not at all 1. Sometimes 2. Always	[ ]

15. Do you feel you are mistreated by other people? **(FPMIST)**	0. Not at all 1. Sometimes 2. Always	[ ]
16. Do you feel other people discriminate against you? **(FPDISCR)**	0. Not at all 1. Sometimes 2. Always	[ ]
17. Do you feel other people do not take you seriously? **(FPLSERI)**	0. Not at all 1. Sometimes 2. Always	[ ]
18. Do you feel other people treat you like an outcast? **(FPOTCAST)**	0. Not at all 1. Sometimes 2. Always	[ ]
Sometimes people fall victim of circumstances and find themselves in a helpless situation. Thinking about yourself:		
19. Have you ever been abused or beaten by anybody? **(ABUSE)**	0. Not at all 1. Sometimes 2. Always	[ ]
20. Have u ever been sexually harassed? **(SEXHR)**	0. Not at all 1. Sometimes 2. Always	[ ]

PART 7: KILIFI EPILEPSY BELIEFS AND ATTITUDES SCALE (KEBAS)

INTRODUCTION

Please listen to the following story describing a person with a particular type of epilepsy and keep it in your mind while responding to the rest of the Epilepsy Belief Scale.

This story is about Bahati. Bahati has epilepsy, and has one seizure per week. 1-2 days before the seizure, his behaviour changes. He/she may become naughty, sometimes may isolate him/herself or may look sleepy and wants to sleep. His/her eyes may become red and may also complain of headache. Just before the fit, he/she may feel her/his heart has skipped a beat and feels mixed up (a feeling you may have when you suddenly see a scaring and unexpected thing- e.g. a dead body). He/she then falls down and looses consciousness, starts jerking in all 4 limbs with eyes either rolling upwards, deviating to the sides or wide open, bites the tongue and foams for about 3 minutes then he/she urinates and the jerking movements stop. He/she remains unconscious for a couple of minutes then wakes up drowsy and goes to sleep.

This is about your belief. Only you know what you believe, so if you tell us how you feel, all your answers will be correct.

PART 7: KILIFI EPILEPSY BELIEFS AND ATTITUDE SCALE

		Totally Believe	Believe a little	Not at all	Don't know	Score
Causes						
1. I believe that epilepsy can be inherited/be caused by family ancestors **(INHERIT)**		2	1	0	.	
2. I believe that a person like Bahati can have epilepsy because he has been bewitched **(BEWITCH)**	**R**	0	1	2	.	
3. I believe that when the sun heats the brain of a person like Bahati, it may cause epilepsy **(SUN)**	**R**	0	1	2	.	
4. I believe that when a person like Bahati has a head injury/falls on the head can cause epilepsy **(HINJURY)**		2	1	0	.	
5. I believe that an injury at birth can result in a person like Bahati having epilepsy (for example prolonged labour) **(BINJURY)**		2	1	0	.	
6. I believe that when a person takes anti-convulsant medication when not epileptic can result to having the disease **(AEDS)**	**R**	0	1	2	.	
7. I believe that a serious disease (like malaria) affecting the brain of a person like Bahati can cause epilepsy **(MALARIA)**		2	1	0	.	
8. I believe that when a mother uses FPs before conception can make a child like Bahati have epilepsy when born **(FPs)**	**R**	0	1	2	.	
9. I believe that when one comes into contact with urine of a fitting person like Bahati can be infected with epilepsy **(URINE)**	**R**	0	1	2	.	
10. I believe that after a child like Bahati was born and his faeces did not clear then it may result to epilepsy **(FAECES)**	**R**	0	1	2	.	
11. I believe that a person like Bahati can have epilepsy because part of his brain is damaged **(BRAIN)**		2	1	0	.	
Treatment						
12. I believe it is possible to treat a person like Bahati **(TREAT)**		2	1	0	.	
13. I believe that if a person like Bahati is burned, he will never get healed from epilepsy **(BURN)**	**R**	0	1	2	.	
14. I believe that nyuni/nyago is treatable but vitsala isn‘t **(TNYUNI)**	**R**	0	1	2	.	
15. I believe that a person like Bahati has to take drugs continuously for them to work **(DRUGS)**		2	1	0	.	

		Totally Believe	Believe a little	Not at all	Don't know	Score
16. I believe that vitsala is better treated by a mganga than a doctor **(MVITSALA)**	**R**	0	1	2	.	
17. I believe there are drugs available that can treat epilepsy **(ADRUGS)**		2	1	0	.	
18. I believe that pouring water to a person like Bahati when fitting helps treat epilepsy **(WATER)**	**R**	0	1	2	.	
19. I believe that the best person to treat nyuni /nyago is a medical doctor **(DNYUNI)**		2	1	0	.	
20. I believe smearing rob/paraffin on the body of a person like Bahati when fitting helps treat epilepsy **(PARAFFIN)**	**R**	0	1	2	.	
21. I believe that epilepsy in a person like Bahati can be treated through fumigation **(FUMIG)**	**R**	0	1	2	.	
22. I believe that some types of fits are not suitable for hospital treatment **(HFITS)**	**R**	0	1	2		
23. I believe that during a fit, it is good to put a stick between the person's teeth to prevent biting one self **(STICK)**	**R**	0	1	2	.	
24. I believe that during a fit, it is good to straighten the joints of a person like Bahati **(JOINTS)**	**R**	0	1	2	.	
25. I believe that during a fit, it is good to put a person like Bahati in a safe place **(SAFE)**		2	1	0	.	
26. I believe that drugs (from hospital) can control seizures **(CDRUGS)**		2	1	0	.	
27. I believe that nyuni/ nyago is better treated by a mganga than a medical doctor **(MNYUNI)**	**R**	0	1	2	.	
28. I believe a person like Bahati should only take drugs when he is having a fit **(FITAEDS)**	**R**	0	1	2	.	
29. I believe that if a person like Bahati misses drugs he/she may fit again **(MISSAEDS)**		2	1	0	.	
30. I believe that the best person to treat vitsala is a medical doctor **(DVITSALA)**		2	1	0	.	
31. I believe that drugs for epilepsy can cause side effects such as drowsiness or hyperactivity to a person like Bahati **(SEFFECTS)**		2	1	0	.	

		Totally Believe	Believe a little	Not at all	Don't know	Score
Prevention						
32. I believe that preventing serious diseases like malaria will reduce the number of people with epilepsy **(PDISEASE)**		2	1	0	.	
33. I believe that proper medical care during pregnancy and delivery will reduce the number of people with epilepsy **(PREG)**		2	1	0	.	
Living with epilepsy						
34. There is a belief that people like Bahati cannot marry, what do you think? **(MARRY)**	**R**	0	1	2	.	
35. I believe that people like Bahati cannot climb trees or work high up **(TREES)**		2	1	0	.	
36. I believe that children like Bahati cannot go to school **(SCHOOL)**	**R**	0	1	2	.	
37. I believe that people like Bahati cannot have a job **(JOB)**	**R**	0	1	2	.	
38. I believe that people like Bahati cannot do risky jobs (like driving/running machinery) **(DRIVE)**		2	1	0	.	
39. I believe that people like Bahati can lead a normal life like other people **(NLIFE)**		2	1	0	.	
40. I believe that people like Bahati should avoid being near fires **(FIRE)**		2	1	0	.	
41. I believe that people like Bahati should avoid being near waters (like sea, lake or river water) **(SEA)**		2	1	0	.	
42. There is a belief that people like Bahati should be kept in isolation, what do you think? **(ISOLATE)**	**R**	2	1	0	.	
43. There is a belief that people like Bahati should be rejected, what do you think? **(REJECT)**	**R**	2	1	0	.	
44. I believe that parents feel resentful towards their children like Bahati because he/she has epilepsy **(RECENT)**		2	1	0	.	
45. There is a belief that people like Bahati are burdens to their parents, what do you think? **(BURDEN)**	**R**	0	1	2	.	
The effect of epilepsy on development						
46. I believe that continued seizures can damage the brain of a person like Bahati **(DAMAGE)**		2	1	0		

		Totally Believe	Believe a little	Not at all	Don't know	Score
47. I believe that epilepsy can affect the development and behaviour of a person like Bahati **(DEVELOP)**		2	1	0	.	
48. I believe that a child like Bahati often performs poorly in school **(PSCH)**	**R**	0	1	2	.	
49. I believe that people like Bahati are dull **(DULL)**	**R**	0	1	2	.	
50. I believe that people like Bahati are mad **(MAD)**	**R**	0	1	2	.	

R: Reverse coded

51. Are you aware of any traditional healer who treats epilepsy? **(TH) Y/N** [ ]

No go to 55

52. If yes, what is the name of the traditional healer **(NAMETH)**

53. Where does the traditional healer live? **(THLIVE)**

54. Have you ever sought treatment from this traditional healer? **(SEEKTH) Y/N** [ ]

55. Do you have any comments on these questionnaires? **(COMMENT)**

APPENDIX II

FIRST QUALITATIVE STUDY CHECKLIST

Themes and questions for initial interviews with traditional healers:

Interview 1: Initial background, general causation and treatment beliefs

Name:

1. How long you have been working at this job?
2. What types of illness/problems do you treat (list)?
3. What are the most common illnesses/problems that you treat (list):
4. How many patients do you have in a normal week?
5. You have told me that you treat ________, _________ and __________.
6. What do you think is the cause of each of these illnesses (go through these illnesses one at a time and tell me what you think causes them)?
7. Explain to me how you treat each of these illnesses (go through each of the illnesses that you have mentioned and tell me how you treat them)?
8. Why do you think that the treatments you have just discussed are good ways of treating the specific illnesses that you have mentioned?
9. We know that traditional healing is a very important part of life in the community. Why do you think that it is so important?
10. Do you like being a traditional healer? Why is this is such a good job?
11. Tell us about how you became a healer.
12. Explain to us the process of learning to be a healer.
13. If you had a teacher where did this teacher learn to be a healer and where did their powers come from?
14. Do you ever come together with other healers to share ideas/ concerns? What are these meetings like? What do you talk about and do you think these types of meetings are useful or not?

Interview 2: Tools of trade and payment

1. Tell us about the specific things/objects that you use to treat illnesses and help people with their problems.

2. Where do you get these things from and what gives them their power?

3. How do you know how much medicine to give?

Payment:

4. Tell us about what sort of payment you receive.

5. How do you decide on the payment that you ask for?

6. What happens if the person is healed? What are you given?

7. What happens if the person is not healed? What is given to the healer and what happens next?

8. Have you ever had cases where individuals were not able or willing to pay? What did you do in these cases?

9. Tell me more specifically how you know what to do when someone comes to you with an illness.

10. Tell me about the ancestral spirits. Do they have names and if so tell me a little about each one?

Interview 3: Specific spirits and views about epilepsy

1. Tell me specifically how you know what to do when someone comes to you with an illness.

2. Tell me about the ancestral spirits. Do they have names and if so tell me a little about each one?

3. You have told us some of the conditions that you treat and how you help people. We are interested specifically in the condition of epilepsy.

4. Have you had any experience treating epilepsy?

5. Tell us about some of the cases of this condition which you have treated.

6. What do you think causes this condition?

7. Describe how you treat this condition.

8. Where do you get the medicine to treat epilepsy?

9. Why do you think these types of treatments help the condition?

10. Tell us about how you know when there has been some improvement in the child after treatment or that the child has been healed. If you can think of specific cases where this has occurred these would be good examples to talk about.

11. What do you do when the child you a treating does not get better?

12. How do you know if/when you have been defeated by this particular illness (how do you know when you have failed)?

13. We know that traditional healing can be very powerful in treating this condition. Why do you think it is powerful and why is it good for people with this condition to come and seek treatment from a traditional healer such as yourself?

14. What happens when someone with epilepsy dies (are there different rituals, what happens to his spirit)?

15. Do you think epilepsy can be inherited?

Interview 4: Traditional healers

1. What makes one happy and what makes one think that they and their family are living a good life.

2. Imagine a family that you know in the community that you think is very happy with their lives. Tell me about this family.

3. Why do you think they are very happy?

4. Think about a family that you know in the community that you think is very unhappy with their lives. Tell me about this family.

5. Why do you think they are very unhappy with their lives?

6. Many people go to hospital or clinic to receive treatment for illnesses and problems. What are you opinions of hospital treatment and of the individuals who work there:

7. What conditions do you think hospitals are good at treating and why?

8. What conditions do you think hospitals are not good at treating and why?

9. Do you think that people who work at hospitals realize the power and importance of traditional healing?

10. If you could tell them some things about your job that might change what they think about traditional healing what would you tell them?

11. For people who have epilepsy, do you think it is good for them to go to hospital? Why?

12. Do you think that it is possible for traditional healers such as yourself to work with hospital doctors to improve the health of the community? How would you propose this to occur?

13. How do you think that the lives of families who have children with epilepsy are different from the lives of families who have children without this disorder?

14. Do you think that these families are as happy as other families?

15. Do you think that they are able to achieve the same goals as normal families?

Interview 5: Traditional healers (Follow up questions)

1. I have been trying to understand the system of traditional healers. I understand that there are different types of healers. Can you tell me about the different types of traditional healers that are in Kilifi?
2. I am also interested in how people make decisions on where to seek treatment. Tell me about what you think influences the decisions that people make when they choose where to seek treatment.
3. What makes one person go to a traditional healer and another to a hospital for the same disease?
4. Also what makes the same person go to a traditional healer for one illness but to hospital for another?
5. Why do you think many people come to see you for treatment?
6. If you can imagine a time back when there were no hospitals on the Coast (or very few at least), what are the differences between that time and now?
7. I would also like to know more about what you are saying when you chant during the healing.
8. You have described the treatments that you do for epilepsy. I am interested in knowing if you are aware of any other treatments that traditional healers perform to treat epilepsy?
9. Another one of the ideas that I have after talking to many healers is that individuals might be influenced in making decision based on the two different systems of payment; the one in biomedicine and the one in traditional healing. Do you think that there is a difference in the way that people pay for treatment at these two different places?
10. Would you say that you know most people that you treat (meaning, do you know their names and do you recognize them).

APPENDIX III

SECOND QUALITATIVE STUDY CHECKLIST

Appendix IIIa

Parents/Grandmothers of children from antiepileptic drug study

We would like to conduct this interview because you have been to hospital and been told that your child has epilepsy. What do you think about this?

  This condition, does it have different names?

So, you‘ve mentioned....What are the typical signs that someone has this (i.e. each one mentioned above) problem?

  What is the most important indicator of this problem (e.g. Behaviour problems, convulsions etc)?

What happens when your child has a fit?

  What does the child look like? Does he/she get hurt? Does he/she know what‘s happening?

  How do other people react? Is your child helped? By whom? How?

What do you do when this happens to your child?

  So far you have mentioned.....Anything else you would do?

  Where would you go for help?

  Who decides what to do?

So far you have mentioned.....is there anyone else who provides services for children with your child‘s condition?

Let‘s take each one (i.e. Service or action) in turn.

What‘s good about this service/action?

For everything that‘s good, there is also a bad thing. Can you tell me what are the bad things about this service/action?

What might be improved/changed?

Who uses each type of service?

  (e.g. Rich people vs. poor people? Urban vs. rural? Christians vs. non-Christians)

Going back to your child‘s condition, why do you think it happens?

What do other people think is the reason?

  What do neighbours, doctors, wagangas etc think?

What can anyone do to prevent this from happening?

  Traditional ways? Church ways? Hospital ways?

Was there a time when your child took tablets every day?

What were your experiences of doing this?

  What were the benefits?

  What were the problems? (e.g. getting tablets, getting to the clinic, finances, side effects, husband didn‘t approve, busy in shamba, child refused)

  What did you think of the idea of giving tablets every day?

  How did you or your child feel about the drugs‘ taste, size, colour, effectiveness?

  Where did you get the tablets from? What were the staff like? What were the instructions like? How did you feel about this?

Have you got any questions about what we‘ve talked about?

How do you feel your child‘s condition impacts upon your life in general?

What are your hopes for your child‘s future?

What are your hopes for your other children?

Appendix IIIb

Mothers/Grandmothers/Fathers of children with epilepsy

We would like to conduct this interview because you have been to hospital and been told that your child has epilepsy. What do you think about this?

This condition, does it have different names?

So you‘ve mentioned.....What are the typical signs that someone has this problem?

What is the most important indicator of this problem (e.g. behaviour problems, convulsions etc)?

What happens when someone has a fit?

> What does the child look like? Does he/she get hurt? Does he/she know what‘s happening?
>
> How do other people react? Are children helped? By whom? How?

What do you do when this happens to your child?

> So far you‘ve mentioned....Anything else you would do?
>
> Where would you go for help?
>
> Who decides what to do?

So you have mentioned....who else provides help/services for children with this problem?

Let‘s take each one (i.e. Service or action) in turn.

What‘s good about this service/action?

For everything that‘s good, there is also a bad thing. Can you tell me what are the bad things about this service/action?

What might be improved/changed?

Who uses each type of service?

> Rich people vs. poor people? Urban vs. rural? Christians vs. non-Christians.

Going back to your child‘s conditions, why do you think it happens?

What do other people think is the reason?

> What do neighbours, doctors, wagangas etc think?

What can anyone do to prevent this from happening?

> Traditional ways? Church ways? Hospital ways?

Was there a time when your child took tablets every day?

What were your experiences of doing this?

> What were the benefits?
>
> What were the problems? (e.g. getting tablets, getting to the clinic, finances, side effects, doesn‘t believe in it, husband didn‘t approve, busy in shamba, child refused).
>
> What did you think of the idea of giving tablets every day?

How did you or your child feel about the drugs‘ taste, size, colour, effectiveness?

Where did you get the tablets from? What were the staff like? What were the instructions like? How did you feel about this?

Have you any question about this?

How do you feel your child‘s condition impacts upon your life in general?

What are your hopes for your child‘s future?

What are your hopes for your other children?

Appendix IIIc

Children with epilepsy

Can you tell me about a typical day?

- What are the good things that happen in a typical day (or week)?
- What are the bad things that happen in a typical day (or week)?
- *Further probes if child mentions fits:*
- What do you call that?
- (*if not mentioned ask – have you ever had a fit?)*
- When this happens, what do you do?
- What if at school, church etc?
- What do you feel like afterwards?
- What do other people do when it happens?
- What do you think you can do to make it go away?

So far you have mentioned....is there anyone else who provides services for children with your condition?

Let‘s take each one (i.e. Service or action) in turn.

What‘s good about this service/action?

For everything that‘s good, there is also a bad thing. Can you tell me what are the bad things about this service/action?

What might be improved/changed?

Who uses each type of services?

(e.g. Rich people vs. poor people? Urban vs. rural? Christians vs. non-Christians)

Why do you think this happens to you?

Why do other people think this happens to you?

What can anyone do to prevent this from happening?

- Traditional ways? Church ways? Hospital ways?

Have you ever heard of drugs to prevent fits? If so, have you ever taken them?

- What were your experiences of doing this?
- What were the benefits?
- What were the problems? (e.g. getting tablets, getting to the clinic, finances, side effects, doesn‘t believe in it, busy in shamba, child refused)
- What did you think of the idea of taking tablets every day?
- How did you feel about the drugs‘ taste, size, colour, effectiveness?
- Where did you get the tablets from? What were the staff like? What were the instructions like? How did you feel about this?

What would you like to happen when you grow up?

What effect do you think your condition has on your life now/in the future?

- Does it prevent you from doing things? If so, what?

Does it affect your interaction with family/friends/other people?

Appendix IIId

Traditional healers/CHWs/dispensaries/private clinics/doctors

What illness do you treat?

Do you treat fits?

How many fits do you treat per month, for example?

Are your patients usually children or adults?

What types of fits do you treat?

In what ways do they differ (e.g. Cause, symptoms/signs, severity, age group, treatment)?

Are there some types of fits that are particularly feared/disliked in this community? For what reasons?

Are there any types of fits that you are unable to treat?

What types of fits?

What happens to people with these problems? Are they referred? To whom?

Why do you think children have this problem?

Why do other people think children have this problem?

What can anyone do to prevent this from happening?

Traditional ways? Church ways? Hospital ways?

You‘ve mentioned.........as providing services for children with fits. Are there any other places where children with fits can be assisted?

What types of fits can be treated there?

What is good about that service?

What is bad about that service?

What could be improved/changed about that service?

How do parents decide where to take their child?

How do parents know the type of fits their children are suffering from?

Is there anything else you would like to share with us relating to children with epilepsy?

Would you be interested in collaborating with our group to try to improve the care that children with epilepsy receive? If so, what form could that collaboration take?

Appendix IIIe

Adults with epilepsy

Can you tell me about a typical day/week?

    What are the good things that happen in a typical day/week?
    What are the bad things that happen in a typical day/week?
    Further probes if person mentions fits:
    What do you call that?
    (*if not mentioned, ask – have you ever had a fit?)*
    Does it have other/different names?

What happens when someone has a fit?

    When it happens to you, what do you do?
    What if at work, church, cooking, looking after children etc?
    Who decides what to do?
    How do other people react?
    What do you feel like afterwards?

So far you‘ve mentioned that you would do....when this happens to you. Is there anything else you would do?

Let‘s take each one (i.e. Service or action) in turn.

What‘s good about this service/action?

For everything that‘s good, there is also a bad thing. Can you tell me what are the bad things about this service/action?

What might be improved/changed?

Who uses each type of service?

    (e.g. Rich people vs. poor people? Urban vs. rural? Christians vs. non-Christians)

Why do you think the condition happens to you?

What do other people think is the reason?

    What do neighbours, doctors, wagangas, your spouse etc think?

What do you think you can do to make it stop?

    What do other people think they can do to make it stop?

What can anyone do to prevent this from happening?

    Traditional ways? Church ways? Hospital ways?
    Have you ever heard of drugs to prevent fits? If so, have you ever taken them?

What would you like to happen in your future?

    What effect does the condition have on your life now/in the future?
    Does it ever prevent you from doing things? If so, what?
    Does it affect your interaction with family/friends/other people?

APPENDIX IV

A pre-post questionnaire for medical providers training on diagnosis and management of epilepsy

Answer True [T] or False [F]

1. Epilepsy	**T**	**F**
A] Recurrent unprovoked seizure episodes	[ ]	[ ]
B] Can only be diagnosed in adults	[ ]	[ ]
C] Can present as partial or generalized seizures	[ ]	[ ]
D] Children less than 6yrs can‘t get epilepsy	[ ]	[ ]
E] Phenorbarbital is the drug of choice of all seizure	[ ]	[ ]
2. Classification of seizure type		
A] Does not help in management of epilepsy	[ ]	[ ]
B] Should not be taken seriously because phenorbarbital will cure the disease	[ ]	[ ]
C] Can only be done by epileptologist	[ ]	[ ]
D] Is the mainstay of making the right diagnosis of epilepsy	**[ ]**	**[ ]**
E] All above statements are true	[ ]	[ ]
3. Partial seizures		
A] Manifestation depends on the site of the lesion	[ ]	[ ]
B] Consciousness is completely lost	[ ]	[ ]
C] Consciousness may be retained or impaired	[ ]	[ ]
D] It‘s a seizure type of children	[ ]	[ ]
E] May spread to become generalized seizures	[ ]	[ ]
4. In seizures		
A] Patients can control themselves if it happens when they are conscious	[ ]	[ ]
B] Psychogenic seizures may mimic generalized tonic clonic seizures	[ ]	[ ]
C] In malingering patients are faking the symptoms	[ ]	[ ]
D] Tonic clonic seizure is the commonest presentation of all seizure types	[ ]	[ ]
E] Partial seizures can never be status	[ ]	[ ]

5. Musa is 10 years old. One Monday morning he complained of slight headache and was given panadol before he went to school. Mr. Ndegwa his class teacher noticed something unusual about Musa. His eyes were red and he looked quite dull. After lunch break, Musa suddenly fell down in class and was unconscious. He remained stiff for a few seconds then started jerking movements in all 4 limps and biting his tongue and frothing. This continued for about 3 minutes then he slept after that episode.

A] From the above history it is impossible to make a diagnosis of epilepsy [ ] [ ]
B] From the above history it is possible that Musa had an epileptic seizure [ ] [ ]
C] Musa could be having a serious medical condition [ ] [ ]
D] Musa will benefit from phenobarbital [ ] [ ]
E] The above history is enough to make a diagnosis of epilepsy [ ] [ ]

Curriculum Vitae

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2002-2004: Master of Public Health, University of Alabama at Birmingham, USA: G.P.A - 4.0
2008-2011: Doctor of Philosophy, University of Basel, Basel, Switzerland

Work experience

Jan 2001-May 2002: Nutritionist with Christian Partners Development Agency Implemented a food security project in Vihiga District, Kenya

June 2003-Nov 2003: Intern with Jefferson County Department of Health (Division of Health Promotion and Communications) U.S.A. I served as researcher, writer and editor of a monthly newsletter ―Let‘s Talk About Health".

Dec 2004-April 2005: Research assistant with Population Council on a study that addressed the Psychosocial Burden of HIV/AIDS among Teachers in Kenya

June 2005-to date: Research officer with KEMRI-Wellcome Trust. Investigating the risk factors for epilepsy treatment gap with ultimate goal of developing interventions to improve lives of people with epilepsy

Conferences

Nov 2001: The impact of food insecurity in Vihiga Distict. National Congress on Quality Improvement in Health Care, Medical Research & Traditional Medicine: Nairobi, Kenya

Dec 2006: An education intervention to improve the lives of people with epilepsy. African Health Sciences Congress: Durban, South Africa

July 2007: Barriers to utilization of anti-epileptic drugs in Kilifi District, Kenya: A qualitative study. 27th International Epilepsy Congress, Singapore

July 2009: Epilepsy treatment gap in Kilifi: using formative research to develop interventions to reduce the gap. 28th International Epilepsy Congress, Budapest, Hungary

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