Annonce du diagnostic et rupture biographique

Tinsa Francine
Département de sociologie
Faculté de Lettres et des Sciences Humaines
Universitet de Sfax, Tunisie
E-mail: tinsafrancine@yahoo.fr

Abstract

Dans ce papier, nous nous référons à la théorisation ancrée pour approfondir l'un des premiers segments de la trajectoire de la maladie cancéreuse, celui de l'annonce du diagnostic. Notre point de départ est la théorie des contextes de conscience , formulée en 1965 par Strauss et Glaser. Identifiées , durant la phase empirique, comme catégories principales ,par une analyse inductive, les différents contextes de l'annonce du diagnostic se sont construits à partir des différentes stratégies d' annonce répertoriées au moment de l' observation ,des intentions des professionnels, des attentes livrées par les patients en matière d' information souhaitée, des conditions spécifiques entourant l'action .Les informateurs principaux(n= 21) sont des patients atteints d' un cancer et hospitalisés pour une cure de chimiothérapie. D'autres informateurs contextuels (cliniciens oncologues, bénévoles, parents et proches , cadres hospitaliers…) contribuent également au recueil des données. L'objectif poursuivi est de prendre en compte les motivations des praticiens et le sens qu'ils accordent à l'étape de l'annonce et de les recontextualiser en référence à l'encadrement prévu par l'instance normative . On y discute quelques conditions spécifiques, liées au contexte organisationnel qui freinent le degré d' ouverture et on s' interroge de l' impact de ce manque d' ouverture sur l'entrée dans la maladie ainsi que sur les prochaines étapes de chaque itinéraire thérapeutique

The paper refers to the « grounded theory » (théorisation ancrée) targeting an in-depth exploration of the announcement of the diagnosis as one of the first components of the trajectory of cancer. We considered first the theory of the contexts awareness, formulated in 1965 by Strauss and Glaser. The contexts of the announcement of diagnosis have been identified as major categories through an inductive analysis within the empiric phase. They have been built based on different announcement strategies recorded during the observation of the practitioners' intentions, on expectations expressed by patients in term of information, on specific conditions around the actions. The key informants (n= 21) are patients having cancer and hospitalized for chemotherapy. Other local informants (clinical oncologists, volunteers, parents and closers, hospital cadres…)

have contribute to the data collection. The aim is to address the practitioners' motivations and the meaning they give to the step of the announcement of the diagnosis. We also aim at recontextualizing that step according to the tutoring planned by the normative instance. The paper analyses specific conditions linked to the organizational contexts that slow the scope of opening. We are wondering about the impact of such lack of opening and introduction to the disease as well as about the next steps of each therapeutic itinerary.

Introduction

Le vieillissement de la population, des changements importants au niveau du style de vie aussi bien que des modifications environnementales ou encore des progrès opérés dans le domaine du dépistage et du traitement contribuent à expliquer la progression du cancer en Tunisie , maladie chronique identifiée parmi les plus répandues et les plus mortelles , la première place des cause de décès étant les maladies cardio- vasculaires.

Le cancer reste une pathologie de la personne agée mais il touche également des hommes et des femmes de moins de 65 ans et de jeunes enfants . D'après le Registre du Cancer du Sud Tunisien , paru en l'an 2000 , concernant les années 1997-1999, l'incidence globale standardisée se situerait pour ces années , toutes localisations confondues, à 101,5 cas / 100.000 pour le sexe masculin et 66,0 / 100.000 pour le sexe féminin

Partir du cancer et des orientations stratégiques en matière de prise en charge nous place devant une diversité de choix posés et initiés . Parmi ces choix nous retrouvons la déhospitalisation des malades et par conséquent le déplacement d'une partie du traitement en ambulatoire, le projet d'élargir la surveillance et le soutien thérapeutique aux régions éloignées des centres spécialisés , une réflexion sur la mise en place d'un réseau de soutien et d'accompagnement des malades en fin de vie, dans un pays où la famille témoigne de son sens pratique et de sa volonté d' accompagner un proche devant franchir la dernière étape de sa vie et se trouve par conséquent exposée à des situations de stress , vu la lourdeur des responsabilités et la discontinuité qu' on remarque entre les structures spécialisées et les milieux familiaux .

D'autres aspects tel que la lutte incessante pour rendre la douleur plus tolérable, par l'intermédiaire de la contribution de médecins spécialistes formés à cette approche aussi bien que par l'initiation de médecins diplômés en médecine générale à travailler en relais avec les spécialistes oncologues et bien d'autres projets amorcés ou du moins planifiés se joignent à ceux énumérés précédemment. Tout ceci nous rappelle des orientations actuelles de la politique de santé en cancérologie et plus spécifiquement celles qui concernent le traitement et l'accompagnement des individus touchés par ce type de pathologie. D'abord des efforts répétitifs pour améliorer la qualité de la prise en charge tout en allégeant la structure hospitalière par la réduction des temps de séjour et quelques tentatives de redéploiement des activités des praticiens spécialisés dans le domaine de l'oncologie, partant d'un questionnement sur le type de collaboration qui pourrait s'instaurer entre différents partenaires à l' exemple des médecins généralistes.

Ces projets sont initiés à l'intérieur de la sphère médicale et se fondent autant sur des principes éthiques de la pratique que sur des valeurs d'efficience et d'efficacité.

Or on constate que de nombreux problèmes liés étroitement à l' expérience du cancer et à l'image véhiculée à propos de la pathologie continuent d' assombrir les trajectoires de la maladie et interfèrent avec l' atteinte des objectifs visés, en rapport avec le dépistage précoce et les projets d' acheminer et d'individualiser les traitements curatifs requis par l'état de santé du malade , en autant que la disponibilité des produits prescrits en laisse l'opportunité.

Parmi les problèmes identifiés, on retrouve une symbolique morbide très ancrée dans les représentations sociales de la maladie cancéreuse et des institutions spécialisées dans le domaine de l'oncologie. En raison de ces représentations, les relations du malade avec son réseau familial aussi bien qu'avec les autres mondes sociaux dans lesquels il demeure impliqué ou du moins lié, s'en trouvent affectées. Et du côté des professionnels, le non dit ou du moins la difficulté à trouver les mots que l on considèrent comme justes et non traumatisants continuent de préoccuper les spécialistes et se répercutent, selon l'opinion des malades, sur la manière de composer avec les différents événements de cette douloureuse expérience.

Cette réalité nous invite à nous interroger sur le cheminement de l' individu pour mettre en relief l' influence du contexte actuel sur la prise de décision en rapport avec toute activité qui pourrait contribuer à optimiser sa santé, lutter conte les risques de maladies ou dans le cas où la maladie se trouve déclarée, participer plus activement à la thérapeutique initiée**.**

Nous avons donc choisi, pour le présent article, de nous arrêter plus spécifiquement sur le moment de l'entrée dans la maladie au sens de Strauss le définissant comme une révélation pour le « *self* » et les autres de la transformation de l'identité sociale qui s'accomplit dans une contrainte de cheminement.

Deux enquêtes, celle de Charmaz réalisée auprès de patients touchés par la maladie chronique et celle de Bury, consacrée plus spécifiquement aux individus atteints de polyarthrite rhumatoïde illustrent cette forme de rupture marquant ,dans un premier temps, l'entrée dans la maladie. D'abord Charmaz ,1987 se situant dans la lignée de Goffman, 1975, explore les mécanismes d'imposition et de gestion du stigmate et analyse, en partant de la rencontre avec l'autre, ce qui contribue à faire vaciller les fondements du « self – care ». Quant à Bury ,1982, il approfondit le phénomène de rupture ou de bouleversement (biographical disruption) qui s'établit avec l'entrée dans la maladie qui dure , en mettant l'accent sur les structures de vie quotidienne et de formes de connaissance qui y sont associées .

Parmi les éléments explicatifs de ce bouleversement figurent le fait que le patient doit, en premier lieu, faire face à un bouleversement des conduites. Cette première remise en question provoquée chez l'acteur et enfin la réponse à ce bouleversement sont liées à la mobilisation, par l'acteur, des ressources mises à sa disposition.

Cette conceptualisation de la rupture liée à la maladie chronique sera notre point de départ pour la discussion des résultats qui vont suivre.

Il s'agit donc, en référence à une recherche réalisée en Tunisie sur la construction socio culturelle du cancer , d'approfondir l'un des premiers segments de cette trajectoire, celui de l'annonce du diagnostic , initialement présenté par l'intermédiaire de cette recherche conduite selon la méthode de la théorisation ancrée.(Tinsa, 2003) .

Ainsi au niveau du présent texte, les significations existentielles de cette étape initiatrice de l'entrée dans la maladie seront appréhendées à partir de différentes stratégies déployées par les cliniciens et reçues par les patients et le questionnement inclura l'influence de l'activité institutionnelle.

C' est donc en référence à quelques résultats en rapport avec les stratégies d'annonce ,le contexte culturel entourant l'action et les attentes spécifiques dégagées des propos qu'ont bien voulu nous livrer des malades au prise avec l'expérience de la maladie et quelques uns de leurs accompagnateurs (professionnels et familiaux) que nous reviendrons vers ces différents degrés de conscience de ces individus au prise avec l'expérience de la maladie. Notre intention sera de poursuivre ce questionnement sur leur capacité à se positionner sur ce continuum et à envisager les premiers pas à franchir dans une situation qui les renvoie obligatoirement vers l'adoption d'un nouveau rôle imposé par leur état de santé , les conduisant vers une remise en cause de leur identité et de tous les autres rôles qui les avaient , jusque là ,maintenus au contact des autres .

Notre **objectif** est donc de prendre en compte les motivations des praticiens et le sens qu'ils accordent à l'étape de l'annonce du diagnostic et de les recontextualiser en référence à l' encadrement prévu par l'instance normative pendant la période d'hospitalisation .

Par ailleurs, la présentation de conditions spécifiques au contexte organisationnel devrait contribuer à identifier d'autres freins à l'ouverture afin de saisir comment l'organisation hospitalière intervient sur le destin social des patients en interrogeant sa contribution à la transformation de son identité.

Aspects méthodologiques

Cette analyse s'appuie sur un travail de terrain de 8 mois au sein principalement d'un service de chimiothérapie d' un Établissement Public de Santé de la ville de Tunis , spécialisé en oncologie - sur la base d'observations directes et d'entretiens informels puis semi-directifs auprès de patients soumis à une cure chimiothérapique . D' autres entretiens auprès de différents membres des équipes de soins (plus précisément des oncologues, une spécialiste du traitement de la douleur, des infirmiers et des membres impliqués dans le processus de gestion à l' exemple du directeur général et de la chef de service des malades . En complément des données collectées en milieu hospitalier, d'autres matériaux ont été apportés par l' intermédiaire de contacts établis en milieux associatifs auprès de personnes ressources actives dans ce milieu et de d' autres patients, logés dans une résidence annexe à l'hôpital (mise sur pied par une structure associative , pour offrir une prise en charge gratuite à des patients issus de mieux socio économiques défavorisés et dont le domicile se trouve éloigné du centre de traitement) durant des cures programmées en ambulatoire .

L'interactionnisme symbolique est choisi comme cadre de référence pour sa capacité à souligner la nature symbolique de la vie sociale et à insister sur le fait que

> "*les significations doivent être produites par les activités inter-agissantes des acteurs*' .
> '(Blumer,1969:5).

Ce cadre théorique sert d'ancrage à l'observation minutieuse du contexte pénétrant et influençant le parcours de chaque patient, initié par la découverte ou l'annonce de la maladie cancéreuse.

Quant à l'analyse des données collectées, elle a été effectuée à partir d'une méthode de théorisation ancrée et d'induction analytique. Rappelons que la théorisation ancrée consiste à développer, à comparer et à confronter les différentes hypothèses générées par l'analyse des différentes données collectées à partir du point de vue des différents informateurs et du travail d'observation, progressivement, au fur et à mesure que le travail de terrain se déroule. Cette méthode a donc été choisie pour son apport spécifique à l'analyse des dynamiques entourant l'entrée dans la maladie cancéreuse et sa capacité à faire ressortir les conditions favorisant les différentes stratégies d' annonce et les conséquences que cette étape, abordée selon son degré d' ouverture, peut avoir sur les étapes à venir et par conséquent, sur les différents segments des principales trajectoires.

Quant à l'induction analytique, elle nous a permis de nuancer et de raffiner le travail de conceptualisation. Elle se base sur une méthode d'analyse continue et vise à faire ressortir, tour à tour , les similitudes et les différents contrastes entre les données, ceci avec l' intention de retrouver les caractéristiques ,les relations aussi bien que les déterminants des différentes variations au niveau de l'ouverture des différents contextes de conscience reconstitués à partir du procédé inductif.

Concernant les caractéristiques de l'échantillon sélectif, dernière étape de la démarche d'échantillonnage proposé en théorisation ancrée, il réunit parmi les informateurs principaux 29 patients et 4 membres de la famille. Les patients sont agés de 21 à62 ans avec un âge moyen de 42.85 ans, pour les hommes et de 48 ans pour les femmes .

Atteints de différentes formes de cancer, ils sont tous hospitalisés, au moment de l' étude, pour une cure chimiothérapique. Cette technique d' échantillonnage sélectif est elle-même précédée d' un échantillonnage ouvert, visant la découverte des catégories analytiques devant orienter vers une meilleure compréhension du phénomène étudié, l' annonce du diagnostic et d' un échantillonnage axial , d' avantage systématisé pour permettre de couvrir systématiquement l'ensemble des sous-groupes et des situations s' offrant à notre observation et fortuite, pour profiter de toute nouvelle situation pouvant émerger du travail empirique initialement entrepris au moment de la définition et de la délimitation de la population étudiée.

D'autres informateurs que l'on qualifie de contextuels réunissent différents spécialistes et plus précisément les cancérologues, impliqués dans l'annonce de la maladie, des bénévoles et quelques cadres administratifs.

Résultats

Le schéma précédent tente de représenter la variation de la démarche d'annonce du diagnostic. Il met en relief un ensemble de conditions structurelles spécifiques au contexte appréhendé par l'intermédiaire du travail empirique ainsi que celles, sous diverses formes de combinaison et selon les acteurs observés, qui entourent et par conséquent influent sur la manière de dire ou de ne pas dire.

Nous nous limiterons, dans la partie qui va suivre, à une brève description des différents contextes de conscience façonnant l'annonce du diagnostic ainsi qu'à la présentation illustrative des stratégies préférentielles des acteurs , principalement les cliniciens, puisqu' ils se chargent ,le plus souvent ,de cette annonce du diagnostic .

Le contexte ouvert et le diagnostic de la maladie

Le contexte ouvert progressivement

Ce contexte ouvert, de manière progressive, lorsqu'il s'agit du diagnostic , découle du choix préférentiel de la majorité des spécialistes rencontrés durant la phase exploratoire . Fondé sur des valeurs liées au bien-être des patients ,l'analyse de ce contexte nous conduit , bien que partiellement , au sens visé par cet acte d' annonce pour le clinicien, celui de préserver un sentiment d ' espoir, en laissant , du moins au début, le patient à l'abri d'une certaine vérité liée à l' incertitude , à la chronicité et à l' incurabilité. Il protège également le professionnel en reportant une activité qui déclenche obligatoirement un sentiment d'inconfort lorsqu' on se trouve confronté à la souffrance de l'autre , l' exercice de sa pratique médicale étant lui-même au cœur d' une vision sotériologique . En appréhendant ainsi la nature de la souffrance physique mais aussi morale, ces cliniciens rappellent que la médecine parvient à unir les domaines du matériel et celui de l'éthique , en allant bien au-delà de la matérialité et des sciences de la nature sur lesquels pourtant elle repose .(Good,1994).

La stratégie préférentielle, selon les propos collectés par l'intermédiaire des médecins en exercice ,est celle de l'ouverture progressive . S'ils rappellent qu'aucun schéma ne peut être tracé à l' avance et que chaque message s'ajuste au fil des rencontres, il est évident que l'on opte pour une ouverture progressive :

> *"il faut agir avec nos malades d' une manière très nuancée ,on prend un peu plus de temps pour annoncer le diagnostic ,c' est une révélation progressive, on parle de la maladie, de l' extension de cette maladie, des possibilités thérapeutiques , pour essayer de prononcer le mot cancer ,ce n est pas une éventualité très grande chez-nous "(médecin clinicien, spécialisé en oncologie).*

Cette ouverture progressive s'explique, selon plusieurs cliniciens, par son influence sur le maintien de l'espoir :

> "on *ne dit pas tout, on lui laisse une marge d' espoir , ce n' est pas un silence ,c' est une manière douce d' annoncer des nouvelles difficiles,…."(médecin clinicien, spécialisé en oncologie)*

Et toujours selon les spécialistes, cette stratégie convient aux besoins et difficultés des patients :

> *"au début et bien les malades ont leur propre système de défense. Bon, je ne suis pas spécialiste dans le domaine de la psychologie, mais en fait, tant qu'on est malade, on nie la maladie, on ne veut plus en parler…"*
> *"les malades ne posent pas trop de questions, le malade a envie de se protéger, déjà il a besoin de digérer ce qu'il a appris, quand cela sera fait, il se décidera à poser de nouvelles questions….. ".*

- *Le contexte ouvert d'emblée*

Il s'agit, pour ce contexte bien particulier de patients mis au courant, presque accidentellement et même plutôt maladroitement, de leur maladie. Son ouverture soudaine et sans préparation est le résultat d' un manque de coordination entre les intervenants, de l' initiative d'un soignant qui prend la décision de dire, sans prise en compte du rôle qui est d'avantage imparti au médecin traitant.

On y retrouve également des sujets instruits dont certains exercent ou ont exercé une profession orientée vers le domaine de la santé. Dans ce cas, les questions précises, directes et pertinentes laissent peu de marge pour éloigner ou retarder la vérité à propos du type de cancer , du stade de la maladie et parfois même du pronostic vital.

Le contexte fermé

Ce contexte revêt, d'après les observations, deux variations : un contexte fermé en attente d'un diagnostic (on se trouve en présence de données insuffisantes pour valider le diagnostic) et un contexte maintenu fermé après la validation du diagnostic médical, à la demande spécifique de la famille, ou selon la stratégie d'ouverture sélectionnée et entretenu par le médecin traitant.

- Le *contexte fermé ou légèrement entrouvert, en attendant la confirmation du diagnostic*

Ce contexte est celui qui accompagne le patient durant toute la période d'investigation. Si certains patients vivent cette période avec l'espoir de voir leurs doutes et leurs craintes s'estomper du fait de la confirmation d'un état de non malignité, d'autres sombrent dans un état d'abattement ou expriment des sentiments de colère à l'égard de leur entourage et plus particulièrement envers l'institution médicale.

- *Le contexte maintenu fermé à la demande de la famille*

Ce contexte maintient le patient à l'écart de son expérience de la maladie, après la confirmation du diagnostic. Il répond à la demande d'une famille ou d'un membre en particulier. On recommande à l'équipe médicale, dans ces circonstances, de ne pas révéler le diagnostic médical au patient :

Voici l'exemple d'un jeune homme de 36ans qui s'est trouvé mis à l' écart de son diagnostic, privé d'information concernant sa thérapeutique et son pronostic. Les propos qui vont suivre ont été exprimés par sa sœur qui est la première personne à avoir fait barrière à l'information :

> *"mon frère n'est pas au courant de son diagnostic, il pense qu' il s' agit d' un simple kyste qui doit réduire sous l' effet de la radiothérapie, et de la chimiothérapie, j ai menti à mon frère, je lui ai m^me dit qu' on fait de la radiothérapie pour des enfants qui ont des végétations, on doit mentir car sinon ce serait la catastrophe pour lui, il n y a que moi et mon mari qui sommes au courant……"*

Trois conditions identifiées au cours de l'étude contribuent à la compréhension de ce contexte fermé. Mises en évidence par l'intermédiaire de différents témoignages, ces conditions distinctement répertoriés éclairent sur les motifs de fermeture et sur le pourquoi de la mise à l' écart du patient. Elles correspondent à l'évaluation de ce qui ne doit pas être entendu ou porté à sa connaissance. Elles impliquent la reconnaissance d'un droit de prendre cette décision de tenir l'autre à l' écart de son vécu et enfin elles supposent l'acceptation, en tant que professionnel , d'entrer dans ce scénario dicté , imaginé et improvisé par un membre de la famille.

D'autres conditions s'opposent aux précédentes et pourraient interférer avec celles-ci et changer le cours même des interactions .Elles relèvent d'une prise de position ferme de certains spécialistes qui prend en compte leur propre pratique et leur capacité réflexive:

> *"pour moi, cela a beaucoup évolué, d'une intuition qui était fausse , oui mon intuition s' est avérée fausse, je pensais que la maladie était tellement terrifiante au début de ma pratique, oui je pensais que personne ne pouvait en parler et se parler et maintenant je souhaiterais dire la vérité sauf demande expresse du malade de ne rien lui dire… ."(*médecin clinicien spécialisé en oncologie) .

Le contexte feint

Contexte difficile à identifier, reconstruit à partir des propos des partenaires (professionnels et patients) et des données collectées au moyen de l'observation participante. Il réunit différents patients mis au courant du diagnostic médical, qui demandent expressément au médecin traitant de ne rien dire à la famille, afin de les rassurer. Dans la plupart des situations observées, on remarque que la famille, le plus souvent au courant de la vérité, feint à son tour de ne pas savoir, pour ne pas aller à l'encontre de la demande du patient. Commence alors une situation qui laisse les accompagnateurs et les proches à distance du patient, lequel ne peut verbaliser son vécu et exprimer ses souffrances et inquiétudes en présence de son entourage.

Ces quelques résultats mettent en relief différentes stratégies d'ouverture de la connaissance telle que la stratégie préférentielle qui consiste à opter pour une vérité révélée avec prudence , dans la progression , l'étalant selon les signaux et attitudes dévoilées par le patient sur différentes rencontres, l'intention première étant ,pour différents informateurs, de ne pas décourager, traumatiser en choisissant d' ajuster son discours de manière à laisser au patient , le temps d'apprivoiser une situation qui l'ouvre sur un nouveau monde.

C'est ainsi que différents axes de comparaison résultant de l'insertion d'éléments en rapport avec le vécu de la maladie, selon les contextes explicatifs, contribuent à une compréhension plus approfondie de différents phénomènes signifiant la maladie cancéreuse .

L'un des principaux axes intitulés degré d'ouverture et de fermeture du contexte de conscience, à propos du diagnostic de la maladie illustre bien les quelques trajectoires jalonnant le parcours des patients rencontrés. Il associe différents éléments contextuels (valeurs curatives et humanistes des médecins, philosophie et mission actuelle de l'Institut de Cancérologie, mentalité du clinicien, symboles –clé liés à la maladie, espoir de vivre des malades et préservation de cet espoir…..) à l'aspect dynamique de ce champ de conscience et laisse entrevoir les conséquences de l'agir sur le vécu et le niveau d'implication du patient sur sa propre expérience.

Une attention particulière portée à l'agir du sujet et aux conditions orientant ces actions guide notre démarche. Différents évènements qui indiquent une distance entretenue entre profanes et savants et une forme de silence destiné, semble t'il, à protéger celui qui ne doit pas savoir, servent de point de comparaison à d'autres situations qui mettent en évidence une recherche de la vérité, différemment exprimé d'un sujet à l'autre et d'un moment à l'autre, selon chaque parcours individuel. En effet ,s' est autour de cette confrontation du malade et des professionnels de santé à une réalité plus ou moins clarifiée ou plus ou moins prête à être envisagée et de différents modes d'interaction à partir de l'observation et des discours collectés auprès des acteurs que l'on commence à reconstruire les contextes de conscience.

Ces différents contextes de conscience se réfèrent donc, selon Glaser et Strauss, 1966, aux structures et processus impliqués dans la gestion du savoir relatif au déroulement de la maladie, tout le long de sa trajectoire, de la phase diagnostic à sa guérison ou à celle de sa fin de vie.

Ils nous aident à appréhender ou à saisir analytiquement les situations multiples repérées au cours de la phase exploratoire et à déboucher sur différentes images distinctes mais apparentées , construites à partir de ce que chaque personne interagissant avec celle vivant cette expérience de santé sait du statut défini de celle ci .À cette connaissance s' ajoute l'évaluation de l'information pouvant être dévoilée aussi bien que l'intention d'ouverture du champ de la connaissance concernant son diagnostic par différents acteurs impliqués dans ce processus de gestion de la maladie.

Discussion

La relation médecin-malade a été décrite en référence aux différentes stratégies d'annonce du diagnostic influant sur le degré d'ouverture du contexte et par conséquent sur le niveau d'information transmis au patient à propos de son état de santé et cela avant, à l'occasion ou dans d'autres cas, après cette confirmation du diagnostic médical.

Les spécialistes de la cancérologie et plus particulièrement les oncologues observés et interrogés interviennent en combinant les tactiques suivantes ou tout simplement en se centrant plus particulièrement sur l'une d'elles.

Ces tactiques peuvent se résumer ainsi :

- attendre que le patient pose lui-même les questions
- lui poser indirectement les questions, afin de savoir ce qu'il sait déjà et avec l' intention de s' ajuster au mieux à son niveau de connaissance
- mentir au malade (à la demande de la famille) en lui présentant un autre diagnostic au caractère plus bénin, tel que celui du kyste hydatique, devant masquer , aux regard du patient, le cancer du poumon
- demeurer imprécis, en survolant le problème de santé

- dire toute la vérité à ceux, qui ,selon les spécialistes, peuvent y faire face
- annoncer brusquement ou accidentellement la vérité, sans préparation ou sans progression.

Répertorier les stratégies préférentielles donne accès aux ressources de sens et à la capacité interprétative des principaux acteurs impliqués dans cette démarche d' annonce . S'intéresser à l'action et par conséquent à la manière dont les différents partenaires de la relation soignant-soigné se perçoivent mutuellement et prendre en compte les intentions qu'ils s'attribuent les uns, les autres ou s'interroger sur la rupture biographique et l'entrée du destinataire du message dans le monde de la maladie chronique n'exclut pas l'intérêt du regard posé sur l' environnement institutionnel et l' encadrement qu' il prévoit pour protéger les droits de savoir de celui qui ne sait pas encore ou du moins insuffisamment . En effet tous ces éléments interviennent, plus ou moins directement, dans le contexte de la biographie du malade, rendue discontinue par la maladie.

Stratégies d'ouverture et ressources de sens

Les stratégies préférentielles répertoriées en matière d'annonce de la maladie trouvent une diversité d'orientation qui, dans certaines situations, peut demander aux professionnels de taire la vérité à propos du diagnostic, sous évaluant de ce fait le rôle du parent et sa capacité à franchir lui-même les étapes d'une longue trajectoire qui exige sa participation éclairée. Projeté de plein pied dans ce processus de mobilisation familiale, supportée par la pensée , en tant que processus symbolique ,elle intervient pour transformer cette étape d' entrée dans la maladie en une matière première de sens et décision pesée, évaluée, réfléchie pour le bien du malade et le confort de l' accompagnateur (Thomas W,2000)

Les actions sont posées en prévision du comportement du patient. En effet , si on réduit l'information , jusqu' à dans certains cas, taire le diagnostic et contribuer à la fermeture du contexte de conscience) c' est avec l'intention de maintenir un sentiment d' espoir (Saillant, 1988,Patterson,1987,Holland,1987 et 1989,Schaffer et Lind,1990,Townsend,1978) .

La précaution de se protéger de ce climat chargé d'incertitude, dans un environnement renouvelant et valorisant des pratiques inspirées du paradigme technico-scientifique, renforce l'entité médicale. Moins affirmée, la culture soignante, malgré les nombreux besoins de soutenir et d'entretenir la vie, durant le déroulement des nombreuses trajectoires de la maladie, à l'exemple des étapes d'administration de la thérapeutique sélectionnée par les cliniciens, confirme une médecine centrée sur le curatif, l' organe, la lésion, la maladie "*disease*".

L'interaction semble bien orientée par la capacité réflexive du professionnel de la santé et sa disposition à se mettre à la place du patient pour parvenir à une meilleure compréhension.

Et ce travail interprétatif exigent de l'acteur un retour vers ses références sociales et culturelles et se sert de significations plus ou moins partagées par les membres de différents groupe . C'est ainsi que dans ce pays du Maghreb, tout comme dans différents pays méditerranées le cancer continue de véhiculer des images de mort , d'incurabilité, de souffrance et de détérioration de la personne . (Holland,1987 et 1989).

Par ailleurs ,les individus rencontrés n'appartiennent pas nécessairement aux mêmes mondes sociaux et les soignants s' appliquent à nuancer leurs approches en fonction du niveau culturel de l'individu, de la profession, de l' âge , du sexe, du type de cancer et du stade de la maladie .(Pratt L. et al. ,1957 ; Davis F. 1963 ….) ou de l' anticipation d' une réaction émotionnelle non favorable (Fitts et Ravdlin,1953 cité par J. Mc.Intosh,1974)

Toutes ces précautions ne mettent pas les protagonistes à l'abri de tensions , de malaises , qui peuvent ,dans certaines situations, lorsque le patient ne s' accorde pas le droit d'intervenir verbalement pour demander des clarifications ou pour exprimer son malaise , conduire les partenaires de la relation thérapeutique dans de réels conflits d' interprétation. C'est ainsi qu'une situation qui idéalement ne devrait cesser de se redéfinir, pour s'ajuster progressivement par l'intermédiaire de ce partage de sens , peut se trouver figer , en raison du manque ou de l'absence de rétroaction . Ce qui ne peut servir qu' à alimenter l'écart entre l'individu et cette expérience de vie et par conséquent , bien que les motivations premières puisaient dans les valeurs éthiques du praticien , interférer avec tout ce travail de gestion de la maladie (Strauss ,et Glaser,1968,Strauss ,Fagerhaugh, Suczek and Wiener,1982 Strauss et Corbin,1988,……..)

Ce modèle d'interaction, observé autour de l'annonce du diagnostic, fournit un bon point de départ pour étudier ce qui se passe quand deux personnes parlent et agissent face à face (Strauss,1992:59)

Ce temps d'arrêt fixé sur le déroulement de l'interaction à l'intérieur d'un micro contexte hospitalier, au moment de l'annonce du diagnostic, rejoint les explications fournies par Le Breton, 2004: 51 , comme quoi elles ne sont pas des processus mécaniques se greffant sur des statuts et des rôles. Ainsi bien que le cadre formel oriente le sens de l'action, les partenaires privilégient l'ajustement à partir de tout un travail interprétatif et semblent résister à toute "actualisation mécanique d' une conformité" (Le Breton D. 2004 : 51)

Cette conception interactionniste de la conscience développée par Strauss éclaire notre compréhension des logiques sociales qui orientent plus particulièrement le sens de certaines interactions. Certaines situations s'ajustent aux attentes du patient , d' autres , au contraire, auront à subir un contexte délimité avec une intention première de protéger et de nourrir un sentiment d'espoir . D' autres , moins fréquentes, se trouvent ajustées aux demandes incessantes de famille, telle que la sœur aînée, elle-même professionnelle de santé qui demanda de ne pas dire, pour le moment, sous évaluant la capacité du parent à faire face et cherchant , en tant que proche, à se protéger d' une situation difficile également pour l entourage qui n est pas nécessairement bien préparé à ce changement . Ainsi, dans cette étude ,le degré d' aliénation du patient, conséquence directe de la fermeture du certains contextes de conscience, aura une influence directe sur la perception d' un manque de pouvoir et donc sur la représentation, pour le patient, d' une incapacité à influencer, par son comportement, le résultat de différents évènements qui entravent sa vie.(Skipper J.K.,1965,Sieman et Evan, cité dans Mc.Intosh,1974) .

Annonce du diagnostic et cadre institutionnel

Les interactions nourries dans cette sphère spécifique au monde médical nécessitent différents ajustements en fonction du processus d'interprétation. Différentes conditions entourent l'action et semblent influer sur le degré d'ouverture du contexte de conscience de l'annonce du diagnostic. Parmi celles présentées précédemment, on retrouve une forte présence du stigmate de la mort qui continue de frapper l'univers de la cancérologie en Tunisie, malgré d' importants investissements au niveau de la sensibilisation et de l information du citoyen, des protocoles thérapeutiques adressés à des patients dont les trajectoires s'annoncent dominées par de nombreuses incertitudes, l'adhésion des cliniciens à la mission de la médecine curative traditionnelle qui pourrait être altérée si le patient vivait une perte d'espoir.

D' autres conditions, tel que le temps mis à la disposition des soignants pour une consultation d' annonce, les frontières qui semblent délimiter et isoler les différentes catégories professionnelles ou encore l' organisation spaciale des locaux interfèrent ,d'après les témoignages et les observations empiriques ,dans la conduite des échanges et parviennent, dans différentes circonstances, à imposer des stratégies qui correspondent peu à la conception des acteurs de leur rôle et de la manière de l' assurer .

C'est en cherchant à relier les compétences des professionnels de la santé impliqués dans l'annonce du diagnostic à différents éléments structurels que l' on peut entrevoir certaines dimensions de la dualité du structurel dans l' interaction .(Guiddens ,1987:78)

En tentant de présenter quelques facettes de l'interaction, on se retrouve donc en présence de cette interpénétration de la signification,, selon le schème d' interprétation et de la légitimation selon l'orientation des normes de pratique peu officialisées, en ce qui a trait, entre autre, au déroulement des consultations d' annonce. S'y trouve mis en évidence ces réservoirs utilisés de façon réflexive par les différents partenaires, pour produire et reproduire différentes formes d'interaction. (Guiddens,1987:. 78)

En effet, utiliser les réservoirs de connaissance de façon réflexive dans la production et la reproduction d'interactions pour décider du degré d'ouverture du contexte d' annonce ou tenter de rationaliser sa démarche d' ouverture en évaluant la compétence de l'autre à faire face à la vérité n' exclut pas d' autres éléments aussi importants de cette rationalisation de l' action .

Ce questionnement autour de cette dimension normative suggère donc un déplacement du côté de l'institué pour examiner les règles et les normes contributives à l'encadrement des professionnels en matière d'annonce du diagnostic autour de cette étape de la trajectoire. Il semble en effet difficile de parler de segments de trajectoire d' annonce dans la mesure ou les intervenants en poste ne sont pas parvenus à instituer une régulation commune .Culture organisationnelle centrée sur le non dit , stigmate de la mort, prédominances des valeurs curatives et des approches technicistes, division du travail déployée autour de l' administration des cures devraient inciter les protagonistes en interaction au moment de l'annonce à circonscrire leur champ d intervention et à officialiser les différentes contributions.

La création d'un monde social du traitement curatif du cancer (Becker et Strauss) renvoie implicitement à des réseaux de partenaires d' univers différents et de chaîne de coopérations et de complémentarité. Sa dynamique de constitution est directement liée au travail de théorisation de la discipline (Strauss,1984:176-177) et le rôle et les activités de chaque catégorie d' acteurs gagneraient à être dégagés, harmonisés et spécifiés en fonction de la philosophie d'annonce qui vise implicitement la protection de l' intégrité de la personne et un accompagnement réconfortant. Ainsi la constitution d'un monde social sert de point d'ancrage pour autonomiser et consolider une pratique orientée vers l'annonce du diagnostic et transformer une étape en un segment de trajectoire parcouru par un être réflexif capable de monitorer son expérience et de donner les raisons de ses interventions.

L'aspiration d'établir une relation de proximité avec le patient au moment de son entrée dans la maladie et l'affirmation d'une responsabilité d'accompagnement sont ainsi conçues comme d'autres compétences spécifiques à promouvoir, à entretenir et par conséquent à institutionnaliser dans ce monde de la cancérologie.

Constitution de l'identité du malade, rupture biographique et entrée dans le monde de la maladie

En s'efforçant de maîtriser le désordre provoqué par une maladie qui se caractérise par sa gravité, dépendamment, entre autre, du site de l'atteinte et de l'état d'avancement au moment de sa découverte, les professionnels de la santé prennent en compte le choc émotionnel qui sera provoqué au moment de la révélation de la maladie et tente, dans la plupart des cas, de procéder d'une manière progressive, (ouverture progressive du contexte de conscience) .

La personne cependant n'apparaît pas vraiment au centre de la démarche de travail et les valeurs curatives semblent conduire et soutenir avec force les pratiques professionnelles. Guérir, prolonger la vie, traiter la maladie deviennent la mission première de l'unité et on se centre d'avantage sur la pathologie et le corps et , malgré l' intentionnalité des praticiens de protéger et de soutenir le déroulement des tâches, la coordination de certaines informations consignées au dossier médical sont en rapport avec la thérapeutique et peu favorable à la reconnaissance de la personne comme sujet

,non réductible à une pathologie ou à un corps humain.

Ainsi cette dernière partie de la discussion , en revenant sur les modes d'interaction professionnels et patients par l' intermédiaire des différents contextes de conscience répertoriés, nous aide à saisir comment l' organisation intervient sur le destin social de l' individu en contribuant , malgré une restriction de l' information, à engager un processus de transformation de son identité sociale.

Cette phase d'admission ne peut être appréhendée comme un segment de la trajectoire d'annonce du fait de la difficulté à instituer une régulation commune. Son mode de gestion apparaît peu favorable à l'esprit de collaboration entre les différentes disciplines et, ,par conséquent, au renforcement de la complémentarité entre les différentes équipes et spécialités.

Cette étape d'annonce doit être considérée comme un moment déterminant de la carrière du malade . Elle marque le passage vers un nouveau statut, tout en tentant d' apprécier le niveau de conscience du patient à l' égard de sa maladie et en évaluant sa capacité à recevoir une information plus détaillée. Cette évaluation se base, entre autre, sur des caractéristiques socio- professionnelles (niveau d' instruction, profession, statut social, ….) et les professionnels s' efforcent de s' adapter aux contraintes de la structure actuelle (brièveté du temps accorder à chaque consultation, ouverture fréquente des portes de bureau, partage des espaces entre confrères,,,,,), comme différentes conditions largement discutées précédemment.

Si les consultations apparaissent pour chaque professionnel comme des changements de statuts organisés (Strauss 1992:.), pour lesquels il est presque nécessaire de ménager une période d' accoutumance qui suivra l' entrée officielle dans de nouveaux statuts (Strauss, 1992: 111),cette intention partagée par la plupart des cliniciens rencontrés est difficilement coordonnable entre les différents intervenants impliqués dans la consultation d' annonce (médecin, psychologue, soignant…) du fait de l'absence de règles institutionnalisés. Mais on constate que de nombreuses procédures employées dans le service d'oncologie , au jour le jour, ont une influence marquante sur les pratiques professionnelles.

Toutefois la rupture biographique ne peut être épargné quelque soit l' état d' avancement, le type de cancer et les chances de guérison. Cette rupture est d' autant plus difficile qu'elle commence par des rencontres beaucoup plus régulées dans une intention protectrice et celle de faire face aux contraintes de temps que par une organisation des pratiques qui considèrent le patient comme un partenaire du contrat. Le patient commence dans sa carrière morale de malade atteint d'un cancer (Goffman, 1994:56) marqué par de fortes périodes d'incertitude pouvant être accentuée par une limitation de l'information et par conséquent une forme de distanciation de sa propre expérience.

Certaines conséquences immédiates telle que l'anxiété, un stress émotionnel important, un état d'abattement …témoignent de cette rupture biographique qu'on souhaitait pourtant éviter ou du moins alléger (Bury ,1982:167-182)

D'autres, plus lointaines, pénétreront le déroulement du prochain segment de la trajectoire à savoir la démarche thérapeutique et mis à part tout l' inconfort sur le plan émotionnel et moral , pourront interférer avec la démarche thérapeutique et avoir , selon les témoignages, des liens directs avec des interruptions momentanées ou définitives du suivi thérapeutique.

Autre conséquence sur le déroulement des prochaines étapes ou segments de trajectoires initiés par une consultation d'annonce peu propice à une construction conjointe du sens de l'hospitalisation est la reproduction de rencontres dirigistes pour le bien du malade. En les éloignant d'un travail de contractualisation de la relation au soin et à la démarche thérapeutique, pré-requis à l'intégration d' attitudes responsables dans la gestion de sa maladie ,elle ne favorise pas la conformité ??de l'individu à son assignation statutaire à partir de laquelle il pourrait s' initier à ce long travail de gestion de la maladie portant, notamment, sur le soulagement de symptômes liés à la chimiothérapie et plus encore sur sa nouvelle expérience de vie et par conséquent sur la conception de son identité en mouvement.

Mais comment '" instituer,' assigner une essence, une compétence, imposer un droit d' être qui est un devoir être" et comment " signifier à quelqu'un ce qu' il est et lui signifier qu' il a à se conduire en conséquence " (Bourdieu,1986:126) lorsqu' on ne parvient pas circonscrire les étapes de cette consultation et à tenter un travail de collaboration entre les membres d' une équipe pluridisciplinaire?

Conclusion

Réinterroger la notion de rupture biographique en se référant à un point de bifurcation de la carrière du malade, celui de la confirmation du diagnostic ou de bouleversement du à l'émergence de la maladie (Bury:1982: 69) rappelle que l' entrée dans la maladie se déplace de la phase initiale interrogée sous l' angle de symptômes et de signes cliniques par les spécialistes de la clinique vers une succession de positions occupées par chaque acteur et distinctives entre les individus.

Faites de sorties de rôles et de création de d' autres rôles , de travail de mise en cohérence(Ricoeur,1990) dans un climat lourdement chargé d' incertitude et de symbolique morbide , cette rupture renvoie également vers l' acceptation du statut du bon malade ou le déplacement de tactiques pour parvenir à s' accorder, non sans difficultés et souffrance morale, à cette situation au niveau du soi afin de parvenir à assurer la continuité identitaire. Entendue comme point de bifurcation, de manière plus ou moins totale, plus ou moins institutionnalisée, plus ou moins conscientisée , cette rupture constitue, en effet, un moment décisif , qui se révèle par un incident dans la conception de soi.

Différentes conditions structurelles venant de la maladie chronique, de la biographie du patient et de sa vie quotidienne pèsent sur le travail de gestion de la maladie

(Strauss 1968,1978,1982,1988…) et contribuent à déterminer les points de rupture qui assombrissent les trajectoires .

D'autres éléments ,venant du contexte immédiat, entourent plus directement l' action et interviennent également de manière à influencer le cours des interactions. D' abord les *''frontières spatio-temporelles* ''Giddens, 1986) permettent de circonscrire les parcelles d'interaction, lesquelles sont imprégnées de ''*marqueurs* '' symboliques ou physiques, ensuite la co-présence des partenaires de la relation thérapeutique et enfin le degré d'implication possible pour chaque partenaire de cette relation.

Cette dimension serait apparentée selon Giddens, 1986, à une sorte de

> *''vision circulaire de la construction du monde social ou ses dimensions structurantes se situant à la fois avant l' action, comme ses conditions et après , comme des produits de celles-ci" .*

Rappelons ici que le point de départ de cet article était les différents acteurs impliqués plus ou moins directement dans les stratégies d'annonce du diagnostic. Agissant et interagissant en fonction du sens qu'ils attribuent à leur agir et à celui des autres, ils portent tous un univers symbolique de valeurs et d'idéologies qu'ils entretiennent et, selon les circonstances et les spécificités du moment, tentent de modifier et parfois de reconstruire au sein de différentes institutions qui encadrent l'expérience de la maladie.

Modernisation des structures, difficultés de régulation des activités liées à la mission de l' institution et aussi bien qu' à celle de l' unité d' oncologie observée et intention de démocratisation des droits des patients parviennent à tisser des liens inégalement resserrés entre les partenaires de la relation thérapeutique. Cependant que l' on se réfère aux propos de patients contestant la restriction de l'information en rapport avec leur état de santé et évoquant les répercussions négatives sur leur propre parcours ou que l' on s' arrête sur celui des praticiens plus directement impliqués dans le développement de la discipline et le renouvellement de pratiques institutionnelles, on s' interroge sur l' apport de la formalisation des explications concernant le dispositif d' annonce du diagnostic . Peut elle offrir des éléments de réponse aux inégalités dans la manière de vivre une situation de rencontre plus ou moins partagée, selon le parcours du patient et par conséquent lui assurer une meilleure mobilité au niveau des différents segments de la trajectoire ?

S' inscrivant au sein de structures au mode de fonctionnement peu formalisé en ce qui concerne les droits à l' information, les formalités d' accueil, le consentement éclairé, pour ne citer que ces exemples et par conséquent plus portées à nourrir des accords tacites entre les professionnels et un ajustement des" *stratégies d' annonce au cas pas cas* ''(clinicien spécialisé en oncologie) , on remarque, entre autre, que certaines conditions relatives au profil des patients peuvent influer sur les stratégies d' annonce , pensées et initiés , le plus souvent pas les cliniciens . Ce qui permet de dire que le niveau élevé d'instruction, une profession apparentée avec le domaine de la médecine, ou encore l'appartenance à une classe sociale plus favorisée, seraient des facteurs favorables à une transmission plus dense de l'information et par conséquent à un cheminement mieux éclairé.

Ces différentes stratégies d'annonce d'une maladie grave, en apparaissant "*intrinsèques à la compétence*" des patients reposent ici toute la question de la légitimité des rapports sociaux face aux contraintes de la situation, comme celle d' évaluer la capacité de savoir en partant des représentations des professionnels, des défaillances au niveau du temps de rencontre qui leur est octroyé pour dire et dire suffisamment ou encore de la disposition et de l'aménagement des espaces très souvent ouverts, achalandés , allant jusqu' à réunir différents postes de travail dans un même lieu de consultation, à l'exemple d' une consultation spécifique dans le traitement de la douleur devant partager son espace entre deux médecins spécialistes.

Ce défi de démocratisation des droits du patient , en s' appuyant sur les stratégies d' annonce du diagnostic d' une maladie qui présente une dimension sociale facilement identifiable, nous apparaît étroitement lié au contrôle réflexif des différents partenaires ,lequel ne peut cependant pas se dissocier du cadre de l' interaction.

En effets les nombreuses formes d'interaction contribuent à façonner les différents contextes de conscience qui s'initient dès que l'on soupçonne la présence de la maladie .Pouvant être regroupées selon différents degré d' ouverture-fermeture , en fonction des différentes stratégies d'annonce, pénétrées et par conséquent influencées par les différentes conditions entourant les rencontres, elles alimentent un important questionnement sur les "*conséquences non intentionnelles*" (Giddens, 1986) pouvant interférer plus ou moins directement sur la démarche thérapeutique et sur le pronostic vital de la personne (arrêt du traitement décidé par le patient , discontinuité ou interruption des consultations de contrôle , recours à un guérisseur …..) .

Toutefois si la codification d'une certaine manière de dispenser des informations recevables et discutables en rapport avec l'annonce du diagnostic et l'entrée dans la phase thérapeutique semble favorable à une plus grande ouverture du contexte de conscience, quelque soit les pré-requis du bénéficiaire et ses capacités à saisir l'information, peut-on supposer qu' elle est indispensable à l'accompagnement du patient au moment du changement initial de trajectoire ?

Selon A. Giddens, institutionnaliser ces conduites à tenir et par conséquent délimiter les orientations de l'engagement normatif n'est pas le seul élément de la rationalisation de l' action et chaque agent(Giddens,1986, 1998) ,tout en mettant en œuvre des décisions qui lui agréent, a la capacité , quoi que inégalement, de mobiliser les biais inhérents aux institutions (Bachrach et Baratz, 1962) .Il nous apparaît ainsi comme le principal moyen de préserver la liberté du patient , quelque soit le fonctionnement de la structure et son degré d' ajustement aux problématiques du moment et devient, de ce fait, la condition et le résultat d' activités entreprises par les partenaires de cette relation.

Or cet apport informatif du professionnel semble inégalement régulé d'une situation à l'autre et d'un patient à l'autre .Des critères, tel que le niveau d'instruction, la profession exercée ou encore le statut socio-économique peuvent contribuer à nuancer la densité et le type d'information à transmettre et par conséquent sous estimer la capacité de comprendre de celui qui ne dispose que d'un faible niveau d'instruction et par conséquent négliger ou dévaloriser son implication . D'autres motifs de restriction de l'information, liés à la protection de l'intégrité et à la lutte contre le stress ou contre le sentiment de perdre espoir, sont des exemples discutés et illustrés précédemment.

.Cet apport est inégalement lié à la reconnaissance du rôle actif de l' individu dans ce changement de trajectoire et par conséquent à celle de son travail de gestion qui est la condition essentielle d'un" *projet réflexif et négocié*" (Giddens,1986: 92 et 91), compris comme réel soutien à la transformation d'identité de soi, passage obligé et amorcé au moment de l' entrée d' une maladie qui dure, qui peut récidiver et dont on ignore la durée et le nombre de segments à venir et à assumer . Ce qui suppose la reconnaissance des compétences et des capacités des différents acteurs d' agir malgré les contraintes des différents systèmes, inégalement perçue , en fonction de caractéristiques individuelles, notamment.

Par ailleurs, la prise en compte des conséquences non intentionnelles sur la santé de l' individu , pouvant aller jusqu' à l' assombrissement du pronostic vital ,en raison d' un manque d' information souligne l' intérêt d' entourer les interactions de conditions favorisant leur continuité et une certaine routinisation sans perdre de vue le fait qu' elles ne peuvent ni garantir les approches systématisées ,ni une annonce de la vérité d' une même intensité , quelque soit le profil et les attentes des sujets frappés par la maladie. C'est dans ce sens que nous pensons que les plans programmant le suivi et l'accompagnement des malades chroniques pourraient devenir des artifices , si on ne prend pas en compte ce qui entoure l' action et si l' on ne s' arrête pas sur les richesses et les spécificités de nos systèmes moins formalisés mais rappelant une flexibilité à explorer et à interpréter. L" orchestration des tâches , autour et à partir de l' acteur principalement concerné par cette rupture biographique, exige des activités en amont et un nouveau regard porté sur la structure hospitalière actuelle, très peu exploré, ainsi que sur l'expérience vécue par le sujet lui-même et bien souvent, dans le cas de maladies au long cours , par les proches et les personnes les plus significatives.

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The rise to prominence of *Artemisia annua* L. – the transformation of a Chinese plant to a global pharmaceutical

Caroline Meier zu Biesen
Institute of Social and Cultural Anthropology,
Landoltweg 9-11
14195 Berlin, Germany
caromzb@gmx.de

Abstract

This paper focuses on the transformation of a recently promoted medicinal plant named Artemisia annua L. *For over 2000 years, the Chinese have used* A. annua *as a herbal tea preparation against malaria. Pharmacological studies led to the isolation of artemisinin as the principal anti-malarial compound. Since 2001, the World Health Organisation (WHO) has recommended artemisinin-based combined therapies ('ACTs') for the treatment of malaria – Novartis is the leading actor to extract the compound in tablet form. In the 1990s,* A. annua *was introduced to Tanzania. Beside the local plant-based promotion of Artemisia-tea as an efficient, inexpensive natural practice to treat malaria, Tanzania hosts influential actors who seek to commercialise the plant. By following the biography of the Chinese medicinal plant, its global transfer, production, marketing, distribution, consumption, and its transformation to a highly demanded commodity, the paper critically reveals the dialectics and reciprocities between different actors and their relation to existing powerful reference systems (such as WHO, Pharmaceutical Industry).*

Keywords: *Artemisia annua* L., artemisinin, Tanzania, ACT, effectiveness, social life of medicines

> "Artemisia (Artemisia annua) is a seemingly simple, though versatile, medicinal plant suddenly at the heart of international attention. It was long a traditional remedy for a variety of ills. But by virtue of the extraordinary qualities of a purified extract, artemisinin, it is now a key player in global efforts to help control malaria, particularly in Africa where it is a particular scourge. In doing so, it is following in the legendary footsteps of quinine, also a plant derivate (…), and has become - at least for the present - one of the most important medicinal plants in the world."
> (Dalrymple, 2008: 57)

Introduction

Malaria is the most important parasitic disease of mankind. Each year, malaria causes disease in approximately 515 million people and kills between one and three million people, the majority of whom are children in sub-Saharan Africa (Snow et al., 2005). In Tanzania, we see 14 to 18 million new malaria cases and up to 125 000 malaria-related deaths every year.[1] Researchers have pointed out that the most plausible single factor contributing to this staggering number is the resistance to widely available, low-cost antimalarials. During the past few years, traditional single drug treatments (known as monotherapies such as chloroquine) have lost appreciable effectiveness and are currently replaced by a new generation of antimalarials: artemisinin-containing combination therapies, 'ACTs' (White, 2004; Arrow et al., 2004; Namdeo et al., 2006).

ACTs derive from the Chinese medicinal plant *Artemisia annua* (its ancient Chinese name is *qinghao*, blue-green, fragrant herb), a species which is known worldwide for its antimalarial properties (Wright, 2002; Hsu, 2006a+b).[2] For over 2000 years, the Chinese have used what is commonly called *Sweet wormwood* as a herbal tea preparation for treating periodical fevers (indicative of the paroxysms of malaria) and other 'heat syndromes' (Guo Qiao et al., 1994; Valecha and Tripathi, 1997; Mueller et al., 2000).[3] The fresh juice soaked by the entire plant was found to be most effective in relieving chills and fever when used in large dosage. *Artemisia*´s historical usage to 'clear damp heat' associated with malaria has then been confirmed with modern pharmacology (Chen and Chen, 2004; Hsu, 2006a: 667). The clinical utility of a component and extract from the Chinese plant – artemisinin (*qinghaosu*) – has globally stimulated interest in traditional plants as potential sources of new antimalarial drugs. Artemisinin and its derivates have a very rapid onset of action against the most virulent form of malaria, *P. falciparum*, and have been found to be the most rapidly acting of all antimalarial drugs (Haynes, 2006).[4] As the key-ingredient in the leading treatment for malaria is an extract of an ancient medicinal plant, the (re-)discovery of *A. annua* reveals something that Dalrymple (2008:7) prospects as a "golden triangle" – an interaction between traditional medicine, modern medicine, and science. The fact, that artemisinin-based combination therapies are 'ancient' in its use and 'modern' in its formulation shows the transformation potential of the plant itself: "[...] the medical rationale for dispensing these medications has been shaped by commercial demands in ways that have worked toward transforming the formerly scholarly Chinese medical tradition […] into a consumer-near and popular ´folk medicine`" (Hsu, 2009: 111).

Pic.1 1 Artemisia annua in Tanzania (Photo by C.M.)

The Chinese plant was transferred to other socio-cultural contexts and now plays an important role in East Africa (Heemskerk et al., 2002). In the early 1990s, *Artemisia* (as an artemisinin- rich genetic variety) was introduced in Tanzania, where experts concluded that the production of the medicine locally was a viable option in combating malaria. Due to continuously developing resistance against widely used malaria drugs in the country, the Tanzanian *Ministry of Health* has been forced to call for a shift in treatments. National health authorities then considered artemisinin-based remedies as a promising approach for addressing the disease at the primary health care level (Kachur et al., 2006; MoH, 2008). The use of *Artemisia*´s semi-synthetic medicines have widened the range of treatment in Tanzania and numerous studies have demonstrated their therapeutically potential (Yeung et al., 2004; Nosten and White, 2008).

Besides this, also the *Artemisia*-leaves become increasingly used in the treatment of malaria. Tanzania hosts a wide spectrum of researchers and stakeholders who are seeking for alternative *Artemisia* - therapies, which are efficient, inexpensive, accessible, and widely available in the country, especially for the rural population. Thus, there is no single usage but a range of treatment possibilities provided by the plant-ingredients.

As has been widely reported, pharmaceutical concerns world-wide are conducting research into this medicinal plant (Bhakuni et al., 2002; Bosman and Mendis, 2007). While there has been overloading information available on *A. annua* and its chemical derivates, the antimalarial activity of artemisinin, the development of ACTs, agricultural, technical, and economical outcomes of the plant, considerably less has been written on its acceptance, adoption, and most important, cultural effectiveness – especially in regard to its global transfer.[5]

Following its trajectory, meaning and use, the *Artemisia* plant became my main object of research. I traced the plant into multiple sites in Tanzania, where it has been planted, therapeutically used, and commercially produced. My research draws on ethnographic fieldwork undertaken between 2006 and 2008.[6] During the research, special attention was given to the potential of *Artemisia* as a self-reliant treatment for malaria including local production practices followed by the possibilities for using herbal infusions from the plant leaves (Hirt 2000, 2001; Hirt et al., 2004; Hirt and Lindsey, 2006a+b; De Ridder et al., 2008: 303).[7] The feasibility of using the traditional formulation of *Artemisia* were investigated as a more affordable and accessible option for the treatment of malaria in poor and remote areas. Challenges, advantages, and renewal were documented that people face through the introduction of this new remedy; contemporary dynamics and transformations of medical knowledge gained through *Artemisia* were also explored.

Given the fact that several actors are linked with *Artemisia annua*, multiple forms of adoption, consumption and (re-) productions of the plant exist. A number of plant-based products (such as herbal tea infusions, herbal pills or artemisinin-based pharmaceuticals) are found – depending on *who* is interested in influencing the acceptance of *Artemisia*. The classification of the plant itself is subject to change. A variety of – often conflicting – attributes such as 'natural'F, 'traditional', 'modern' or 'commercial' given to the plant had a strong influence on the legitimisation of treating or healing practices with *Artemisia.* Actors such as non-governmental organisations or churches – primarily the international NGO called Action for Natural Medicine (*Anamed*) – who push the application and utilisation of *Artemisia*- tea formulation based on the Chinese pharmacopeia (Willcox et al., 2009: 104) – would classify *Artemisia* as a 'natural' plant-based medicine (in the Swahili language *dawa ya asili*), emphasising the fact that it has been extensively studied, scientifically tested, and proven. They endorse it as an alternative to pharmaceuticals and promote it in opposition to the locally available 'traditional medicine.' Traditional healers, however, would consider *Artemisia* a 'traditional' medicine (*dawa ya kienyeji*) and incorporate it into their *materia medica.* Due to significant similarities between the Chinese variety and the indigenous *Artemisia*-plant (*Artemisia afra*), the new remedy was highly accepted among healers. Likewise, malaria patients embraced the new treatment, especially in those areas where the use of indigenous plants has always played an important role in addressing malaria (Gessler et al., 1995: 131; Maregesi et al., 2007). Other actors in Tanzania who use *Artemisia* in commercial-scale cultivation would classify the plant-based products as a European (*dawa ya kizungu*) or 'modern' medicine (*dawa ya kisasa*). As a consequence of different naming and marketing strategies *Artemisia* becomes a very versatile plant and occupies different niches. Several actors are pushing the proliferation of *Artemisia* and its varying products like the *Artemesia*-tea, the efficacy of which is still controversial as Willcox et. Al. (2009) points out:

> *"[...] There has been much debate as to whether it is appropriate to recommend the use of A. annua herbal teas for the treatment of malaria. At one end of the spectrum,*

> *commercial growers of A. annua and manufactures of artemisinin have claimed that it would be `criminal´ to promote the use of A. annua teas because they contain `sub therapeutic doses´ of artemisinin, which in theory could lead to the evolution of parasites resistant to artemisinin. [...] At the other end of the spectrum, Anamed replies that it would be criminal not to provide A. annua to remote communities that do not have any other treatment of malaria. Health care infrastructure is lacking in most of the areas worst affected by malaria, making it impossible to distribute drugs to those who most need them*" (Willcox et al., 2009: 107).

The discussions on the usage of *Artemisia* in this form are as divergent as local discourses on the use of an artemisinin-based pharmaceutical in Tanzania, as demonstrated in the following part of the paper.

The drug in question is called Coartem® and was designated by the Tanzanian Ministry of Health and Social Welfare as a first-line therapy nationwide. In 2005, Tanzania began the process of initiating a second treatment policy in change, which culminated in the large scale public sector deployment of artemisinin-based drugs (NMCP, 2007). Due to long-lasting price negotiations among the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFTM) and Tanzania's Ministry of Finance, the Swiss company Novartis completed drug delivery in 2006 (Novartis, 2010). Much of the procurement was subsidised and the drug almost entirely (80%) distributed through the public sector; leading to a significant shortage of artemisinin-based combination therapies in the private sector (Wolf und Derriennic, 2005:11). There is still limited availability of the drug outside the public sector and the phase of equating of supply and demand of Coartem® remains a challenge (Dalrymple, 2008: 32, 45). In 2006, among 14-19 million malaria patients, less than six million patients had access to the new drug (Freyhold, 2008:2f). In Tanzania, 40-60% of people seek treatment for malaria from private vendors, such as pharmacies (duka la dawa baridi), drug shops and general stores (Njau et al., 2008:1). As artemisinin-combination drugs are typically sold at retail prices 20-40 times those of common alternatives (such as monotherapies), restricting their uptake by consumers, particularly in rural areas (Kachur et al., 2006). As a result, most retail sector antimalarial consumers continue to use therapies for which resistance has been proven. It is widely acknowledged that access to quality treatment is insufficient in many settings. At local community level, the affordability or availability of antimalarial drugs is only a few among a number of factors influencing effective treatment. As shown in the following case study, malaria patients also struggle with unpleasant side-effects.

Tunaogopa dawa hii – we fear this medicine!

> "All drugs are `problem´ drugs…What makes a drug a problem is not so much its inherent pharmacological risks, but the way in which it is used. It is impossible to talk about the ´safety` of medicines as if it was a laboratory problem. In the wrong hands or at the wrong time, even the most carefully quality-controlled

> medicine becomes transformed from a life-saver to a life-threatener."
> Chetley and Gilbert (1986:3)

When I visited Jonasi Daudi[8] in 2007, he held up, in one hand, a partially fractured packet of *dawa ya mseto*, which means 'mixed medicine' in the Swahili language and refers to the new antimalarial combination drug called 'ALU', also known as Coartem®. In his other hand was a set of pictures that showed remarkable skin irritations on the body of his deceased wife Bahati, a well-known woman in the outskirts of Musoma – a small town in the North-western part of Tanzania**. I got to know her as well when I stayed in the same area. I heard about Bahati´s death through the grapevine and went to find her husband to express my condolences. He shared the tragic circumstances of his wife's death with me.** According to him, after having been tested positively for malaria, Bahati got a prescription for 24 Coartem®-tablets, which she was supposed to take for three days. Shortly after having ingested the first dosage, Bahati's skin became increasingly itchy.

> "My wife started to sweat, she felt miserable and expressed doubts (*mashaka*) on this medicine", Jonasi recalled. He went on: "she thought her body would need time to get used to the new drug. But after having taken another four tablets, Bahati complained about palpitation, she had chills (*kitapo*) and her skin started to itch strongly (*ngozi yake ilianza kuwasha sana*). My wife´s started to develop blisters (*ngozi yake ilianza kutoa malenge lenge*) and it felt like burning fire (*ngozi yake ilihisi kama ime chomwa na moto*). When she started to scratch her skin, it began to peel off (*ngozi yake ilianza kubabuka*), first on the scalp (*ngozi ya kichwa*) and then on the entire body. Whenever my wife tried to move in her bed, the skin would stick to her *kanga*[9] and peel off, causing her terrible pain."

Bahati was moved to the local hospital in Musoma, but her condition got worse. Within a few days, her skin peeled off; she lost consciousness (*hakuwa amezirahi kabisa*), and collapsed. The doctors diagnosed that she developed allergic reactions caused by the tablet ingredients.[10] They tried in vain to stop the skin irritations with cortisone injections and Piriton allergy tablets, but Bahati died aged 41.

In the photographs that documented her illness episode at the hospital, Bahati looked so blemished and deformed; I could hardly recognise the strong and portly woman I used to know. The pictures gave an insight into the extent of her suffering. Her sudden death not only shocked people in her community, but provided a basis for long lasting rumours about the medicine she had been prescribed. Bahati's widower, family members, friends, and neighbours believed the side-effects (*madhara*) of the new drug to be the cause of her death. Discussions started on Bahati's usage of a 'bad medicine' (*dawa mbaya sana*) and the complications she faced. Candidly expressed statements such as: "this medicine causes allergic reactions" (*madhara ya dawa*) or: "we fear this medicine" (Sw: *tunaogopa dawa hii*) contributed to the doubts in the Musoma community about the drug.

As issue became more public and 'hot', Jonasi Daudi was impressed upon by the hospital by the hospital *not* to regard the death of his wife as a consequence of her consumption of Coartem®. When I met Jonasi a few weeks later, he would insist his wife must have been poisoned by one of her family members ("*mtu fulani alikuwa amempa sumu*") and the link to the drug was never mentioned again. Other family members of Bahati confirmed that her illness episode now was meant to be kept a secret ("*ilipangwa kutunzwa kama siri*").

I was aware that the identification and evaluation of pharmaco-therapeutic side effects is mediated through social and cultural constructs (Etkin, 1988; Kamat, 2009). Yet, I decided to direct my attention to the dynamics of drug distribution and marketing in order to find out who might benefit or lose out from a negative message being spread about the pharmaceutical product Coartem®. The incidents and reactions of people in my immediate environment gave fuel to my growing concern. An ongoing discourse emerged as numerous other patients expressed their doubts and resistance to Coartem®. Mostly common were local terminologies referring to a "loss of strength" (literary: *nguvu inashuka*), such as "Coartem® tires you" or "causes extreme exhaustion" (ALU *inachokesha sana*). Similar to Bahati's case, also other patients reported of having had strong physical reactions they believed were caused by the medicine in question. Among them were general skin irritations (*tatizo la ngozi*): "it results in mouth ulcers and rashes on the body" (*inaleta vipele mdomini mapele mwilini*) or "there is itching all over the body" (*kuwasha washa*). Those statements remained harmless in comparison to local perceptions on ALU such as "people lose their lives" (Sw: *watu wanapoteza maisha*) or "it kills" (Sw: *inaua kabisa*), that circulated only a year after the new drug was implemented in Tanzania.

My investigations into the use of Coartem® among medical authorities raised my awareness of the economic interests at play behind the scenes. It became obvious that the questioning of a highly promoted and promising medicine was almost impossible. The medical staff at the hospital in Musoma retracted their earlier statement on ALU side effects; and the Tanzanian *Ministry of Health* as well as representatives of the *National Malaria Control Programme* claimed that no serious side effects ever occurred since the introduction of the drug. A veil of ignorance and silence seemed to have descended on the case of Bahati and other patients, contributing to my understanding of how delicate research about medicines can be. The lack of transparency around the handling and control of Coartem® further supported this perspective. I merely witnessed people's reactions to taking the drug and how their voices were ignored or silensed.

As I am aware of the subjectively perceived efficacy of medicines, my paper does *not* seek to prove whether this medicine can be harmful or not. My focus is on the question of how policymakers use claims about safety in order to secure their control over the discourse on antimalarial treatment and maintain a monopoly over its production. To do so – by using its biography – I will briefly describe the processing of the *Artemisia* plant into a pharmaceutical drug in the following section. My discussion here leads to one of the key points in the paper: that medicines are powerful technical devices and cultural symbols, which can acquire 'a life of their own' in society. As vehicles of ideology and perceived sources of efficacy, they impact peoples' thoughts and actions and influence their life (Van der Geest, Whyte, and Hardon, 1996).

The social life of a medicine: the rise to prominence of *Artemisia annua* L.

Van der Geest, Whyte, and Hardon (ibid: 156ff) used a popular anthropological metaphor to capture the social and cultural dimensions of medicines: Appadurai's concept of "*Social life of Things*" (1986:57). Studies in medical anthropology illustrate pharmaceuticals as social and cultural phenomena by following their 'life cycle' from production, marketing, distribution, purchasing, consumption, and finally their efficacy. Each life stage is characterised by a specific context and particular actors; it has a "regime of values" expressed in distinctive sets of ideas about medicines. This concept also applies for the social life of the Chinese medical drug *qinghao* as particular actors are involved in every step of the drug-production chain – from seed planting to the processing of artemisinin, to manufacturing and distribution of the finished pharmaceutical:

Pic.1 2*Artemisia annua* from the Chinese *materia medica* (by Willcox et al., 2004: 103)

Within the production and marketing phase, the primary social actors were Chinese scientists, health authorities, and international pharmaceutical companies. One of the main biographical marking points of the drug was its 're-discovery' in China. The transformation of the plant to a highly demanded commodity was part of a complex historical process that began with the systematic screening of the Chinese *materia medica* to discover new drugs with antimalarial property. In 1972, the plant constituent artemisinin was isolated and subsequently identified as a sesquiterpene-lactone found to be effective against malarial parasites (Klayman, 1985; Bökemeier, 2006; Hsu, 2006a). Since then, the chemistry of the compound, the pharmacology, and the clinical applications of artemisinin and its synthetic derivates have been widely explored and analysed (Bilia et al., 2002). In fact, they became the most potent and rapidly acting anti-malarial drugs *ever* discovered (White, 2008:332; Willcox, 2009:103) – results, that marked a starting point for pharmaceutical industries to hunt, commercialise, and patent the plant-based derivates.

Pic.1 3 Commercial *Artemisia*-plantation in East Africa (Photo by C.M.)

Another prerequisite to transform the *Artemisia* plant was the development of a genetic variation as it is recognised that artemisinin content is affected by geographic and seasonal variations, growing conditions and plant breeding (Hirt, 2001; Laughin et al., 2002; Liu et al., 2006). For this reason, the science of agricultural cultivation of *Artemisia* to maximise artemisinin yields became well-developed. The company Médiplant Switzerland produced an exceptionally high yield of artemisinin, the hybrid Artemis, one of the best genetic varieties for lower latitudes to successfully achieve commercial exploitation of *Artemisia* in tropical countries such as Tanzania (De Ridder et al., 2008: 305).

Furthermore, pharmacological and clinical evidence was needed to commercialise *Artemisia*-plant based derivates. The World Health Organisation as a powerful authority provides leadership on global health matters; articulates evidence-based policy options, monitors, and assesses health trends. By 2001, WHO had officially recommended artemisinin-based combination therapies as the anti-malarial of first choice, preferably the drug Coartem® produced by the Swiss company Novartis, who holds the patent to the drug (Dalrymple, 2008:12). In a unique collaboration WHO and Novartis constructed special claims about the safety and effectiveness of this medicine which are used to justify its registration and marketing. In addition to its efficacy, safety and tolerance profile, Coartem® is expected to "increase the likelihood of patient compliance with the drug regimen" (WHO, 2001: 15, 23).

Although several other *artemisinin*-containing compounds have been registered, in Tanzania no fewer than 31, Coartem® became the leading therapy and a mainstay for malaria treatment worldwide (Kachur et al., 2006: 2; Dalrymple, 2008: 13). The number of developing countries adopting the combination-drug as the first-line treatment for *P. falciparum* has grown significantly, reaching a total of 77 by 2008 (WHO, 2008:16). While a number of firms are known to produce artemisinin-based monotherapies, the ranks of those producing ACTs have been more limited: at the international level, Novartis has been the major source (Dalrymple 2008: 17). As Novartis is the sole pharmaceutical company that manufactures *this* combination drug, and as it has been internationally criticised, it has had a long-time monopoly on its production (MSF, 2004). Through an international partnership, WHO and Novartis claim to achieve cure rates of over 96% and confirm that their products are wholesome and effective. Such established scientific claims boost the production of Coartem® in international competition.

Future demand for Coartem® is anticipated 100 million treatments per annum (Novartis, 2010).[11] In order to produce these quantities, immense volumes of raw material extracted from *Artemisia* are required. As the leading global supplier, Novartis has established an industrial partnership with the holding company Advanced Bio-Extracts Ltd (ABE), now Botanical Extracts Ltd (BEEPZ), to significantly increase agricultural cultivation of *Artemisia* and extraction of artemisinin. Together with their subsidiaries East African Botanicals (EAB) in Kenya/ Uganda and African Artemisia Ltd in Tanzania, around 1,700 ha *Artemisia*-plants have been cultivated in 2008 (Cuttler, 2008).[12] Although Novartis claims to improve local economies in East Africa by producing the raw material there, the profit for local actors in Tanzania is relatively poor. Access to technology of artemisinin-extraction methods is highly controlled. As *Artemisinin*-based monotherapies are explicitly discouraged and forbidden, local pharmaceutical companies are no longer involved in manufacturing the medicine in tablet form. Furthermore, (small-scale) farmers – who play an important role in the production chain of Coartem® – experience a strong discrepancy between production volume and their compensation for it. In Tanzania, up to 4,700 farmers are involved in the *Artemisia*-production (TechnoServe, 2005). But due to a high price fluctuation of the commodity artemisinin, the production-marketing chain got affected – sufferers being mainly farm producers of *Artemisia*, who received low prices (see also Dalrymple 2008: 46), or experienced total loss of income as it was the case in 2007.[13] Moreover, knowledge on the *Artemisia*-plant is retained, respectively wrongly handed on *Artemisia*-growers. The fact that some farmers were taught to cultivate an insecticide (*dawa ya kuua wadudu*), rather than a medicinal plant, and the fact that they are provided with protection clothes for harvesting process to avoid contamination with what they are told is poison (-*enye sumu*), indicates a powerful control and governance of knowledge on the plant. Those results are leading to a reasonable suspicion that the personal usage of the plant-leaves may be systematically suppressed.

Pic.1 4 Three month-old *Artemisia*-field, commercial cultivation (Photo by C.M.)

Pic.1 5 Small-scale farmer cultivating *A. annua* (Photo by C.M.)

Pic.1 6 *Artemisia*-raw material ready for crude extraction (Photo by C.M.)

Pic.1 7 Coartem® in a Tanzanian health facility (Photo by C.M.)

As briefly described, many steps are needed to transform *A. annua* from a medicinal herb to a registered medication. After a medicine has come into the hands of a consumer, it reaches the final stage of its life-cycle: the pharmaceutical efficacy is its ultimate and decisive life stage. It is one thing to demonstrate the clinical efficacy of antimalarials in controlled environments, and quite another thing to ensure their effectiveness when they are deployed under 'real-life conditions' (Amin et al., 2004; Yeung and White, 2005: 121). As Kamat (2009: 301) rightly states, at a time when the literature on drug resistance and the pharmacological efficacy of antimalarials is growing, the relative lack of attention to social and cultural aspects of their effectiveness is a cause for serious concern.

> *"If the full benefits of ACT [Artemisinin-Combined-Therapy] are to be realized in Africa, then international donors and African governments must continue to actively tackle the broader political, social, economic, legal, and cultural challenges to successful implementation. Rather than only focusing on efficacy, it is time to emphasize these contextual factors that affect programme effectiveness. Having a better understanding of these influences on malaria treatment policy formulation and implementation, and applying this understanding to improving health service delivery, should facilitate the provision of effective malaria therapy in Africa."* Durrheim and Williams (2005: 178)

Ethnographic studies of cultural perceptions of antimalarials provide useful perspectives not only on how people negotiate the identity of a febrile illness, but how to understand and interpret the efficacy of existing antimalarials (Kamat 2009: 293). Numerous studies in medical anthropology have argued that efficacy is embedded in culturally specific expectations of the healing process, and that is has biological *and* behavioural dimensions, both of which are equally important (Nichter 1992; Whyte et al., 2002).[14]Anthropologists look at medicines as social and cultural phenomena. They do not overlook their therapeutic function, but want to draw attention to aspects that usually *are* overlooked: their social, cultural, economic, religious and emotional effects. Medicines are a good example of valuable things that assume a wide variety of meanings, far beyond their material (chemical) properties. In the social lives of medicines, themes such as power and inequality, belief, economic rationality and globalisation merge (Van der Geest and Hardon, 2006: 1, 4).

Conclusions

> *"Given the fact, that medicines are not mere things but are socially and culturally constituted artefacts anchored in both local and global histories, medicines come to reflect, and also shape, any changes in societies and cultures in which they circulate. They tell not merely reflective stories to be interpreted but are themselves active players in a field*

> *that situates people of particular times and places within wider global trends"* (Hsu, 2009: 112).

There have been more clinical trials on artemisinin and its derivates – as monotherapies and fixed combinations – than with *any other* antimalarial drugs (Yeung and White, 2005: 121). As argued in this paper, the total drug effect of Coartem® – usually documented with observed treatment in randomised controlled trials – is not only formed by medical results, but rather based on different pillars. Discourses surrounding antimalarials remain a dominant framework for the judging and evaluation of their effectiveness on a community level. The perceived effectiveness is often dependent on several aspects, including community awareness, prescribed drug policy, shifts in national policy on (newly) recommended antimalarials, as well as the complex configuration of the local medicine market. Such factors contribute to the acceptance or rejection of medicines. Experiences and rumours about Coartem® side effects, such as the incident described earlier had a particular influence on people's acceptance of the drug. As it was the case with the first fixed combination-therapies (such as sulphadoxine-pyrimethamine), perceptions of Coartem®'s efficacy were reflected in statements about the calls made by policy makers to regularly replace antimalarials, which were negatively interpreted (see Mubyazi et al., 2005; Kamat, 2009: 294). Access and cost (Wolf and Derriennic, 2005) were additional crucial components of the drug's reception. Assumptions about Coartem®'s efficacy was closely tied to the perceived costs of the malaria episode.

In addition are considerable logistical costs (Njau et al., 2008). The high cost of Coartem® has been a fundamental obstacle to implementing changes in malaria protocols as it maintains a dependence on bilateral assistance and multilateral subsidy programs, detracting from more sustainable solutions (Dalrymple 2008: 37, 45). Another set of problems involves the fake and/or sub-standard artemisinin-drugs (Willcox et al., 2004: 3; Dalrymple, 2008: 24). As patients are supposed to ingest four Coartem® tablets twice a day for three days, adherence remains another challenge. Even if the correct regimen is received, there is concern that patients will not adhere to the recommended drug schedule, resulting in treatment failure and encouraging the development of drug resistance (Yeung and White, 2005:121ff). In summary, levels of use were generally low as widespread public-sector deployment of *artemisinin*-containing drugs has been constrained by their relatively high cost and limited global supply, access, as well as some lingering concerns about safety (Mutabingwa 2005: 307; Kachur et al., 2006: 2; Dalrymple, 2008: 7).

As Yeung and White (2005: 133) emphasise, "there has been considerable interest and concern in translating antimalarial efficacy into effectiveness, when drugs are taken unsupervised in 'real-life' settings in malaria-affected communities." The importance of understanding of how those medicines are used in the community, and how their use might be improved, have been conceived and reflected in numerous studies.

Nevertheless, malaria has a serious impact on health and economic welfare in the tropical world.

This paper lends itself to the concerns about questions of safety and efficacy from a biomedical view, and their limitations from an anthropological view. It argues that there is no singular, universal perception of (curative) effectiveness, as efficacy must be viewed as something that is essentially negotiated (Waldram, 2000:603). A lot more is at stake in malaria control than the rolling out of highly subsidised ACTs. Integrating knowledge of practices surrounding consumption of preferred antimalarial treatment possibilities can be immensely valuable in improving the effectiveness of malaria control interventions (see also Kamat and Nyato, 2010:8). By taking a closer look at the production and supply-chain of Coartem®, and by exploring alternative ways for patients to become independent in malaria treatment (through the whole plant leaves as a first-line home treatment), I have come to deeply question the overall effectiveness of its use and critically reveal the production of evidence as shaped by influential actors. No policymaker can afford to overlook the complexity of medicines or the way in which they impinge on the quality of provision and use. As I tried to show, power is exerted for financial *and* social benefit, as influential actors claim to be philanthropists. Coartem® is claimed as the hard core of good health care but in its singular manifestation it has blocked progress for other possibilities of how to consume this helpful remedy.

The aim of any effective malaria management strategy is supposed to provide a simple and inexpensive treatment that can be applied effectively in most settings (De Ridder et al., 2008: 303). A significant proportion of Tanzanians cannot easily access basic health facilities because of geographical or economic barriers, even though they recognise their illness as malaria. The inadequacies of health services – inequitable distribution, high costs, or inaccessibility – and the high burden of malaria in rural communities are among the major reasons for patients' interest in self-treatment. The simple herbal infusion of *A. annua is* an inexpensive, first-line home-treatment in areas with limited medical facilities. It rapidly reduces malarial parasites and symptomatic signs of malaria in areas with multi-drug resistance to orthodox malarial treatments and can therewith reduce the morbidity and mortality associated with severe malaria occurring through delayed treatment. Furthermore, through the suffering of fewer bouts of malaria it will allow communities to be more economically productive as the impact of the *Artemisia* introduction goes beyond medical improvements. As Elisabeth Hsu (2006: 669) argues, *Artemisia´*s importance for the future of medicine may not lie so much in its effectiveness as a modern pharmaceutical but in its potential to revolutionise the organisation of antimalarial healthcare in those areas where malaria is endemic and the *Artemisia* plant could be widely accessible.

Notes

Endnotes

1 Malaria accounts for 30% of the national disease burden, 43% of under-five outpatient attendance, 35% of under-five hospital admissions and 37% of under-five hospital deaths (NACP 2008).

2 The genus *Artemisia* comprises more than 400 species, most of them having an aromatic and bitter taste. Botanically, *Artemisia* is a vigorous weedy annual which is single-stemmed and ranges in height from one to three metres. As a member of the Asteraceae family, the genus is native to China. Now widespread, being found in Vietnam, Russia, Japan, North and South America, and South Africa and cultivated in East Africa for the pharmaceutical industry (Willcox et al., 2004: 43; Dalrymple, 2008:14).

3 First documented in "*Prescriptions for Fifty-two ailments*" existing from the Han Dynasty of 168 BC; *A. annua* was described as a treatment of hemorrhoids. Later in 340 AD, Ge Hong, author of the "*Handbook of Prescriptions for Emergency Treatment*" described the herbal infusion as an effective treatment of intermittent fevers. In the 16th century, Li Shizhen, writer of the "*Classified Materia Medica*", stated that *A. annua* was a remedy for malaria associated with fevers and chills. The Traditional Chinese Medicine recognised *Artemisia* as having cold and cooling properties useful in relieving heat syndromes (fevers) with a detoxicant effect (Yu and Zhong, 2002; Hsu, 2006: 667ff).

4 Because artemisinin itself has physical properties such as poor bioavailability that limit its effectiveness, semi-synthetic derivates of artemisinin have been developed. The primary derivate is dihydroartemisinin. Three others are drawn from it: artesunate, artemether, and arteether (Hien and White, 1993). The new derivate named artemisone was recently developed (Haynes et al., 2006). Due to the very short half-life of artemisinin derivatives, their use as monotherapy requires a multiple dose regimen of seven days duration. It is assumed that the combination with a longer half-life 'partner' antimalarial drug allows a reduction in the duration of artemisinin treatment, while at the same time reducing the likelihood of resistance development to the partner drug.

The most common ACT-treatment is Coartem® (arthemeter-lumefantrine, AL); other combinations are artesunate-mefloquine (AS+MQ), artesunate-amodiaquine (AS+AQ), and artesunate-sulphadoxine-pyrimethamine (AL+SP) (WHO, 2001b; Bekanis, 2004). For a comprehensive review of ACT formulations see Nosten and White, 2007 and Dalrymple, 2008: 19).

[5] Exceptions are the anthropological studies provided by Elisabeth Hsu (1999; 2001; 2002; 2006a+b; 2009).

[6] Results are based on 14 months of fieldwork. Research methods included participant observation, semi-structured, open-ended interviews, expert interviews, group discussions, as well as my involvement in various community projects that promote the use of *Artemisia* at household-level. I conducted qualitative interviews with *Artemisia*-consumers (41 patients, Malaria and HIV/Aids), staff members of Action for Natural Medicine (*Anamed*) (14), medical (including Chinese) practitioners using *Artemisia*-products (10), traditional healers (9), church leaders (8), local NGOs promoting *Artemisia* (6), national representatives such as WHO, NIMR, COSTECH, ITM, MoH, TFDA,TPI, UDSM (15), artemisinin producers such as BEEPZ, AA Ltd, TechnoServe (4), small-scale and commercial *Artemisia*-farmer (8). Regions involved: Mara, Mwanza, Tanga, Arusha, Iringa, Dar es Salaam, Kenya (Athi River).

[7] Supporter of the *Artemisia*-tea believe in its synergistic activity as found in the whole plant extracts. *Artemisia* contains different classes of compounds. At least 28 monoterpenes, 30 sesquiterpenes, 12 triterpenoids and steroids, 36 flavonoids, 7 coumarins, 4 aromatic, and 9 alipathic compounds. Several of these have antimalarial activity; the most active being the sesquiterpene lactone artemisinin. As *Artemisia*´s antimalarial activity is attributable to a complex mixture of constituents, it is believed that the application of the whole-leaf *Artemisia* tea makes the development of the resistance less probable compared to a single agent as found in its chemical derivates (see Willcox et al., 2004:51; Willcox et al., 2009: 103f).

[8] All names used in this paper are synonyms.

[9] Piece of printed cotton fabric.

[10] Possible side-effects that are listed for Coartem® are signs of an allergic reaction such as: exanthema, hives, difficulty breathing, and swelling of the face, lips, tongue, or throat. Other side-effects are: worsening malaria symptoms, dizziness, fainting, fast or pounding heartbeat, severe or uncontrolled vomiting or diarrhea, stomach pain, dark urine, clay-colored stools, jaundice (yellowing of the skin or eyes), weakness, mild headache, joint or muscle pain, and insomnia. See: [*http://www.zct-berlin.de/neueinfuehrungen/arthemeter.html*]; [*http://www.rxlist.com/coartem-drug-patient.htmsideeffects*]. Accessed: 15.2.2009.

[11] Details for demand and supply of ACTs are given by Dalrymple, 2008: 13ff.

[12] An extraction facility in Kenya (Athi River) carries out both crude extraction and purification of artemisinin. It is designed to process up to 4 000 tons of *Artemisia*-leaves, to purify up to 60 tons of crude artemisinin, and to produce

20 tons of pure artemisinin per year (Haynes et al., 2006; Dalrymple, 2008: 18).

[13] Results are based on personal communication with small-scale and commercial *Artemisia*-farmer in Tanzania´s northern plantations.

[14] For a more comprehensive (and critical) examination of how 'efficacy' has been conceived in medical anthropology, see for example (Etkin, 1988:300f), (Nichter, 1992:226), and (Waldram, 2000:603ff).

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Negotiating the search for diagnosis and healing tuberculosis in Namibia. A case study of a Ju/'hoansi speaking man.

Diana Gibson
Research in Anthropology and Sociology of Health (RASH)
Department of Anthropology and Sociology
University of the Western Cape
South Africa
E-mail:gibson.diana@gmail.com

Abstract
This case study of tuberculosis among Ju/'hoansi speakers in a small village in Otjodzondjupa district, Namibia, shows how different notions concerning tuberculosis and TB-like complaints become a area of uncertainty and even contention in a situation where tuberculosis education is good but diagnostics, and by extension treatment, are not always easily accessible. The paper argues that culturalism in the health services turns attention away from the socio-economic and political aspects of tuberculosis. It furthermore shows that Ju/'hoansi speakers have to turn to plant medicines to deal with their ill health when the interface with the health care services become problematic. Plants are understood as standing in a particular relationship with humans and with nature as well. Yet the use of plant medicines is also a terrain of medicinal knowledge and practice contested by the health care services as potentially unsafe and counter-productive to TB treatment.

Keywords: *Namibia, Ju'/hoansi, tuberculosis, diagnostics, medicines, plants, poverty*

Introduction

Medicines, which include pharmaceuticals, plant medicines and *materia medica*, have social and cultural meaning (Reynolds Whyte et al, 2002) and are also linked to the ways in which people make sense of, and respond to, a sickness like tuberculosis; its symptoms, diagnosis and diagnostic technology and treatment (Bennstam, 2004; Greene, 2004; Harper, 2006; Ho, 2004; Jackson, 1996; Nichter, 1994; Rodriguez-Reimann et al, 2004). This paper falls within the ambit of medical anthropology and interrogates tuberculosis and medicines use – both pharmaceuticals and plant medicines – among Ju/'hoansi, or San as they are often referred to, in a remote part of Namibia. The paper shows that, because of poor access to, and/or inadequate diagnostic technology, Ju/'hoansi - who suspect that they have tuberculosis, but are not diagnosed – have to treat themselves with local medicinal plants. We do *not* argue that localised ideas or 'models' of tuberculosis are in opposition to that of biomedicine, but show that biomedical diagnostics and technology are often absent or unreliable.

In Namibia tuberculosis affects a disproportionate number of Ju/'hoansi speakers who suffer and die from it each year. It is a disease that marks social inequality, lack of power and poor or insufficient nutrition. Tuberculosis is also a terrain of confusion and even of contestation, and this paper tries to unravel some of the intricacies of TB at local level. This involves the multi-faceted ways in which the diagnostics and treatment of tuberculosis is experienced, as well as the manner in which people, who suspect that they may be suffering from *tibi*[1], as it is locally called, try to deal with their ill health in the absence of pharmaceutical treatment. They do so by utilising plant medicines, a practice which is frowned on by health care providers and deemed as potentially unsafe and as interfering with medicines (Chinsembu, 2009). The paper explores a number of interrelated issues:

1. The way in which datasets can 'hide' the high prevalence of tuberculosis amongst a marginalized ethnically defined group.
2. Tuberculosis as a disease of structural inadequacy. As well as the inherent 'culturalism' (Lock and Nguyen, 2010:8) of the Namibian State which stereotypes San sufferers as resistant or non-adherent because of their 'culture'.
3. The problems and misunderstandings surrounding diagnostic technology.
4. The ways in which sufferers understand and use TB medicines.
5. The use of medicinal plants in the absence of positive diagnosis.

The paper uses a case study of one man, named Dam, to illustrate the complexity of understandings and practices surrounding this disease.

Methodology

The San in Namibia and Botswana have been extensively studied by anthropologists (Biesele, 1993, 2004; Gordon, 1992; Lee ,1979; Marshall, 1976, 2000; Shostak, 1981; Suzman, 1999; Widlok, 1999; Wiesner, 2005) and films, photographs, media and other representations of them have equally been widely circulated throughout the world[2] (Tomaselli, 2006; Wiesner, 2003). Yet very little anthropological research has been done in relation to tuberculosis among the San.

This study, which has been going on for three years, focused on villages of Ju/'hoansi speakers in the Tsumkwe area of Otjodzondjupa district, in north-eastern Namibia. The Tsumkwe area encompasses about 20 000 km^2, with a population of about 11000 San

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[1] *Our earlier research indicated that local people have a variety of 'categories' of tuberculosis.*

[2] *The John Marshall Ju/'hoan Bushman Film and Video Collection is held at the Smithsonian Institution's Human Studies Film Archives and includes hundreds of hours of ethnographic film of the Ju/'hoansi (earlier called !Kung) recorded in the Kalahari between 1950 and 2000.*

people. Two villages, N//hoq'ma and N≠a-Jaqna were selected for the study. The villages are small and fairly remote, with adult populations ranging from 50 to about 120 people. There are two health facilities in the area, in the larger settlements of Tsumkwe and Mangetti Duin.

Policy documents, extant literature, as well as archival records have been scrutinised. This was triangulated with life histories, observation of, interviews and group discussions with health care providers, Directly Observed Treatment (DOTs) workers, traditional healers, and people who had tuberculosis in the past or present. All of the aforementioned, as well as the vast majority of people who had been diagnosed with TB were interviewed and observed. The research is qualitative and used observation, formal and informal interviews, individual and group discussions, case studies and photographs as focus for discussions. By compiling genealogies and by comparing these to peoples' clinic cards, we were able to trace personal histories of tuberculosis over the lifetimes of individuals in a village.

Interviews and discussions with villagers were done with the assistance of Ju/'hoansi interpreters who have some high school education and who can speak both Afrikaans and English. Some of the villagers were able to speak Afrikaans and could follow the process of translation quite closely. Questions, responses, remarks and discussions were translated. Interviews and discussions were tape recorded and transcribed. Some of the activities were filmed and photographed. Informed verbal consent was obtained.

Dam: a case study

As indicated above, this paper mainly uses a case study to untangle the complexity of TB among a disadvantaged group of people in a distant village. In 2009, during research in N//hoq'ma, I took a photograph of a Ju/'hoansi man, Dam. He was sitting next to the fire, drinking a decoction of infused medicinal plant roots and telling me about his past and his experiences with TB. Dam was born in Kaudom, which is now a nature conservation area. When he was a child, his family was still able to move around the countryside to forage and hunt.

As a boy, Dam contracted tuberculosis. He was sent to the distant hospital in Rundu (in Kavango region), about 200 kilometers away, where he was treated for six months. Archival records show that, at the time, hospitalisation was viewed as the best method to ensure patient adherence to treatment. It was a frightening, lonely and confusing time for the boy, Dam. A couple of years later the South African Army removed the Ju/'hoansi from the Kaudom area to another village, where they were supposed to settle more permanently. Here, Dam contracted TB again, but this time around, in line with the directly observed treatment (DOTs) regimen, he was given a month's worth of medicine at a time to take with him and to drink under observation of a family member.

The treatment continued for six months.

When we met Dam in 2008 he, as well as the majority of the adults living in the village, suspected that he had contracted tuberculosis again. He coughed, was losing weight, felt exhausted and weak at times, became feverish and his phlegm was sometimes bloody. At the time the photograph of him was taken he was drinking a decoction of sourplum (*Ximenia caffra* or *g//oeh*), which the Ju'/hoansi often utilise to treat people who cough blood (Leffers, 2003; Gibson & Oosthuysen, 2009). In 2008 Dam was one of the villagers whose sputum samples had been taken about three months earlier by the TB education team when they visited the area. He never found what the outcome of the tests had been. Dam's health record showed that he had been tested, but did not document the results. A couple of months later another sputum sample was taken. When the health promotion staff visited the village again, Dam enquired after his own results, and was informed that he did not have tuberculosis (TB). Early in 2009, another man from the village, Xamace, was suddenly hospitalised and died from TB. Then Dam's own boy was hospitalised and passed away as a result of TB. A family member from another village had died from Multi Drug Resistant (MDR) tuberculosis about 18 months before.

In the meantime Dam remained unwell and he was tested again in 2010. This time the results were positive and a vehicle from the closest hospital, about 80 kilometers away, was sent to fetch him to the hospital. Dam baulked. He refused to get into the vehicle, claiming that he will assuredly die in the hospital. He wanted the health care staff to give him his TB pills and to allow him to take it at home. The frustrated health care staff left and a couple of days later a hospital vehicle was once again sent to pick up Dam. He was not in the village, but had gone out to search for mangetti nuts and, if lucky enough, to hunt. The vehicle arrived again a week later. This time Dam was in the village, but still adamantly refused to go to the hospital – he was convinced that he would die there. He almost came to blows with the male nurse who insisted that Dam should be hospitalised. Dam refused to go. He wanted to take his medicines at home.

Like many villagers he had learned over time that Ju/'hoansi speakers usually suffer from tuberculosis without HIV infection. He felt negated through the long and inconclusive process of diagnostics – he had after all been saying all the time that he had TB. Dam was angry and bitter that, while he had long insisted that he was sick, the health care system maintained that he was not. He felt that staff had treated him like an ignorant and fractious child and talked down to him. Dam, like most of the villagers, was also certain that the government was mostly concerned with services to and treatment of 'blacks' (people from the adjacent Kavango and Hereroland areas) who had TB in combination with HIV. Dam died five weeks later.

Databases and biopolitics

To critically bring into focus TB among the San, it is necessary to first analyse the biopolitics of this disease in Namibia by focusing on health statistics and the national epidemiology. This requires an investigation of government policies and its collection of data sets – to calculate mortality, morbidity, infection and cure ratios and indicators. These statistics are utilised for surveillance, interventions, the implementation of prevention strategies and to curtail the spread of this infectious disease (Youde, 2008). Data sets are disaggregated along certain selected dimensions, which in turn affects which groups are targeted, what kind of interventions are done, and which issues receive most urgent attention.

At international level, statistics (concerning TB in Namibia) appear in a worldwide data-base which compares infection and rates of Directly Observed Treatment (DOTs) from individual countries in relation to the 85% treatment target rate as set out by the World Health Organization (WHO) as its international surveillance, prevention and control strategy. At face value this may seem like an example of Foucault's (1998) notion of a style of government that regulates populations through biopower. Yet, dominant State discourses and policies inadvertently function to make certain groupings, like the San (and individuals like Dam), largely 'invisible' and thus 'unregulated' and not sufficiently provided for.

According to Health Unlimited (HU), the NGO contracted by the Namibian government to run DOTs, TB education and prevention programme in the Tsumkwe area, the San are not targeted by the government as a population group for health interventions. In terms of tuberculosis statistics they are rather subsumed under the health indicators for particular regions and districts. The State health services, being under-resourced and understaffed, contracted out the primary health care promotion function regarding tuberculosis in Otjozondjupa district to HU, but diagnostics remain the State's responsibility.

Apart from the logistical problems, the efficacy of TB tracing, prevention and control is affected by the inclusion of people with HIV/AIDS into the broad Namibian notified TB databases. Although the HIV prevalence among the San is low, among other groupings in Otjozondjupa region the co-infection of HIV/AIDS and tuberculosis is high and the prevalence of Multi-Drug Resistant tuberculosis (MDR) is rising (Sibeene, 2009). The main focus of the government is on HIV co-infection, where treatment is complicated. The target/risk groups are mostly not San and, as a result, the assumed State surveillance of the Ju/'hoansi is often patchy and incomplete.

To obtain information about the prevalence of tuberculosis among the San, one has to search under the health statistics of Health Unlimited. This international NGO focuses on 'indigenous people' or 'first people'. In the Otjozondjupa district HU nevertheless runs programmes inclusive of the whole population of the area because, for the Namibian government, the San have no more claim to health services and interventions than the rest of the population.

Currently the HIV prevalence in Namibia is between 20-22%, with about 64% of the aforementioned cases being co-infected with TB (USAID, 2009). Yet, in the case of the Ju/'hoansi, the HIV prevalence is low at about 3% (Lee & Susser, 2001; Susser, 2003). Co-infection of HIV/TB is even lower. While the San make up a very small percentage of the Namibian population (2% of 2 million people), the prevalence of TB is nonetheless very high. Rates of more than 1 500 TB cases per 100 000 people have been recorded for the San– one of the highest prevalence rates in the world (Health Unlimited, 2003). According to Wiesner (2003) more than 50% of adult deaths among the Ju/'hoansi is attributed to TB. The life expectancy for the San is approximately 22% lower than the national average and their mortality rate from TB an estimated 30% higher than the national average (Suzman, 2001). The prevalence of Multi-Drug Resistant tuberculosis is also rising among the San (Health Unlimited, 2003; Wiesner, 2003).

Structural inequality and 'culturalism'

Medical practitioner and anthropologist, Paul Farmer (1997, 1999) argues that there is a relationship between poverty, marginalisation and disease. Southern African research literature abounds with studies describing the issues that perpetuate the spread of tuberculosis and give rise to its high incidence (de Beer, 1984; de Villiers, 1991; Grange and Zumla, 1999; Packard, 1989; Strebel and Seagar, 1991; Wilson and Ramphele, 1989). Such factors include overcrowding, impoverishment, poor nutrition and being members of historically disadvantaged communities (Svavamve and Ehlers, 2008; Farmer, 1999; De Beer, 1994; Packard, 1989,).

Tuberculosis is a disease that marks social inequality, lack of power and poor or insufficient nutrition. A longitudinal study by Wiesner (2003) has shown that, over time, Ju/'hoansi communities have lost access to a great deal of land and environmental resources and they often suffer periods of great financial and environmental stress and of hunger. Not surprisingly the Human Development Index for the Ju/'hoansi San is less than half the national average, while their Human Poverty Index is more than double the national average. Per capita income of the San is reportedly the lowest among all language groups in Namibia, and the majority of the population lacks access to means of earning cash income. Food insecurity, landlessness, poor access to education, extreme scarcity and dependency heightens vulnerability to TB (Suzman, 2001; Wiesner, 2003). It is difficult for impoverished and marginalized people (like the Ju/'hoansi) to maintain their health. Farmer (1999) argues that it is precisely the conditions of structural inequality such as poverty, hunger, and oppression that predispose people to develop active TB.

The San are simultaneously nationally perceived as a group which, according to a spokesperson of the Department of Health, "clings to their culture and their way of life" (Interview). They are thus often represented by the State (and the media) in a way that Lock and Nguyen (2010) refer to as a 'culturalism', i.e. as "distinct and essentialized communities in the name of the respect for differences" (Fassin and Rechtman, 2005:348). Health care providers in our study frequently referred to the 'culture' of the Ju/'hoansi as problematic in relation to poverty and tuberculosis. For example, according to one health care worker the Ju/'hoansi "do not use their medicines correctly because of their culture, they believe plants can cure them (Interview). Another opined that "the San come to the hospital too late because they use their healers and take their (plant) roots" (Interview). Yet a third complained about the "backward ideas and practices" of the Ju/'hoansi and linked it to the high prevalence of TB amongst them (Interview). In this way the notion that 'culture' affects patient adherence can turn attention away from the social, economic and political basis of poor health among marginalized groups. Such 'culturalism' from health care providers involves a form of "decontextualised blaming of the patient" and puts the responsibility for treatment failure on the sufferer instead of the provider; thereby ignoring the influence of poverty, discrimination, and systemic injustice (Greene, 2004: 402, 403).

Understandings of TB that do not cohere with the medical view, are perceived by health care providers as erroneous 'culture and beliefs' – which, in turn, is viewed as problematic for TB education and treatment adherence. At the same time Ju/'hoansi sufferers, whether they are diagnosed with TB or suspect that they have it, interpret their signs and symptoms of ill health in the context of their own lives and circumstances as well as those of the community they live in. The San, even whilst they are portrayed in somewhat simplistic ways in the media and in institutional understanding, are not necessarily under the control of their own hegemonic "culture". They interact with, and are part of, wider national and global processes, reflect on their own lives and try to cope with ill health in a variety of ways (Lock and Nguyen, 2010:9).

The ambiguity of diagnostics

TB education for the San in Otjozondjupa is good. The health care workers are dedicated, many can speak Ju/'hoansi, and local people understand their message quite well. N//hoq'ma villagers can recite the causes and warning symptoms of TB. They know a lot about TB medication, what it involves, how it must be taken, the necessity of adherence to treatment, as well as the fact that TB and plant medicines should not be used simultaneously. At any given time, there are people in the village who are on TB treatment.

When villagers talked about this disease it was apparent that knowledge and information about tuberculosis is often represented as 'hard' and uncontestable.

For example, TB is caused by a 'bug' (mycobacterium) infection. It is curable through a strict regimen of four pharmaceuticals, which are taken for six months. There are certain factors which contribute to its spread, e.g. social circumstances, poor diet, smoking, coughing 'on' others, poor ventilation and sanitation, etcetera.

Yet, the diagnosis of TB was not straightforward. In this remote part of Namibia it is most often done through a sputum smear microscopy. Usually three sputums are taken consecutively and sent to the laboratory in Grootfontein, more than 200 kilometers away (mostly dirt road). This is the baseline test for TB, but according to the WHO its reliability can be between 35-53%. It is also the cheapest and thus most affordable test. Since there are no laboratory facilities in Tsumkwe or Mangetti, the two closest clinical facilities, Dam's sputum samples were sent to Grootfontein, and then to Windhoek. Namibia has few facilities with microscopy services or trained staff to do diagnostics (Zvavamwe, & Ehlers, 2008). This makes it difficult to ascertain whether a patient's sputum remains directly microscopic positive (DM+ve); thereby indicating that live TB bacteria are present in the sputum, and/or whether the patient is responsive to TB treatment. A further step in diagnostics is the sputum culture, which has to be done in the capital, Windhoek, which is about 700 kilometers away. It can take from six weeks to three months for the results to return. It is also expensive. Another possibility is an x-ray – this is done only in Grootfontein, but can also be confusing.

Thus, tuberculosis, its diagnosis and treatment is not necessarily clear-cut. TB is very much a social disease and is transmitted through interaction. In this regard research in South Africa has shown that the classic DOTs (directly observed treatment) approach, which focuses mostly on transmission and exposure between members of a household, potentially underestimates the wide circles of social relationships and interaction that people have in reality, and which exposes them to potential infection (Classen et al, 1999). Dam had visited other villages and could have been infected during this time, whilst simultaneously spreading his infection. The classic DOTs approach, however, focuses almost exclusively on 'new' infections.

In areas with high TB rates, many people are exposed to others who have infectious TB. Most of the time people who have been exposed do not develop full-blown TB. A person can also have a latent TB infection and accordingly has bacteria in his body, whilst remaining symptom free. In such a case the infection can only be detected through certain tests, e.g. a skin test, which is not so easily accessible in remote areas in Namibia. If an x-ray is taken, it will seem 'normal' (Temple et al, 2008).

Studies have also shown that TB recurs quite a lot, sometimes within 1-2 years, in people, like Dam, who had earlier been 'cured' of TB. This can be due to poor adherence, treatment failure or reinfection - the latter is defined as "a recurrent TB episode in which the strains of the separate episodes differed by more than four bands" (Verver et al, 2005: 1430). TB infection is thus not single event. According to Marais et al (2009:1):

In settings in which TB is endemic, the first infection is likely to occur in childhood but is unlikely to be a single lifetime event. In all likelihood, ongoing TB transmission within endemic communities causes repeated episodes of infection... results from recent molecular epidemiologic studies challenge the unitary concept of TB pathogenesis by providing definitive evidence that reinfection contributes substantially to the global TB disease burden. Studies using IS6110 fingerprinting have established that most infections causing active TB in adults from TB-endemic areas represent currently circulating strains that were recently transmitted, most often outside of the household. Studies also have shown that more than 50% of recurrent disease occurring in endemic settings results from reinfection.

The Namibinan national DOTs strategy prioritises people with pulmonary TB, since they can infect others. Yet, a person who has been cured, can still have pockets of TB bacteria which can become isolated in organs of the body, and which can, if a person's immune system declines, become active again. It is also possible to have TB of the glands, heart or another body part. Such cases are difficult to identify and diagnose and they may go untreated.

The experience of people like Dam was that it can take a long time to be diagnosed and to get started on treatment. Tuberculosis control programmes focus their efforts on patients with newly diagnosed TB, who are responsible for most of the disease burden. However, compared with new TB cases, people who have a history of TB (both disease episodes and treatment), like Dam, experience poorer treatment outcomes and a higher mortality rate. A person can also become infected with multiple strains of Mycobacterium tuberculosis (Richardson et al, 2002).

Pharmaceuticals

Tuberculosis treatment protocols are long in duration, involve a complex schedule, and can have side effects long after the initial symptoms of the disease have disappeared. (Greene, 2004: 402). What Dam did not understand, and the health care worker did not explain, was that people who have recurring TB are, in accordance with WHO guidelines, usually hospitalised for two months. This is because their treatment regimen also changes. According to a health care provider they usually receive Streptomycin injections for two months, as well as the four standard pharmaceuticals - Isoniazid, Ethambutol, Rifampicin, and Pyrazinamide. Then they go on a one month regimen of the latter four. Afterwards they continue for five to six months with Rifampicin, Isoniazid, and Ethambutol. The treatment regimen is accordingly much longer and more complicated than Dam had experienced in the past (Sonnenberg et al, 2009).

It is important to also consider the way in which the daily experiences of using TB medication, as well as its side-effects are understood. Many people find the idea of continuously taking treatment for subclinical disease difficult to accept

(Jackson, 1996). Sufferers might feel that the side-effects like of TB medication, like nausea, vomiting, fatigue, insomnia, discoloured urine, peripheral neuropathy and such, make them feel worse or might interpret it as indicative of another illness. Research has shown that, as a result, sufferers often adjust their dosages, the timing of the doses or discontinue treatment (Ibid; Shimada et al, 1995). Dam, however, had during his first two bouts of TB, strictly adhered to his treatment regimens. He was not averse to the pharmaceuticals – he resisted hospitalisation. He was also disillusioned about the fact that, whilst he maintained that he had TB, his disease remained medically unrecognised.

When Ju/'hoansi suspect that they have TB, but are undiagnosed, they search for other forms of treatment, e.g. they use medicinal plants – like Dam did. At this point I wish to turn to the aforementioned photograph of Dam next to the fire, drinking a medicinal plant. Since Dam, as well as his wife, family members and local healers (n/um kxaosi or owners of n/um – healing power) suspected that he had TB, he was treated with a variety of plants over time. This aspect will be discussed more fully in the next section.

Plant medicines

According to Chinsembu (2009) the use of African traditional medicines (ATM) is a contested terrain in Namibia. Although ATMs are utilised extensively in resource-poor settings, this practice is largely discouraged by staff working in health prevention and care programmes. It is believed that ATM can negatively affect the efficacy of pharmaceuticals, e.g. TB medication, or it may lead to discontinuation of treatment. Many Ju/'hoansi used medicinal plants to take care of their ailments, especially if they had no pills. Like pharmaceuticals, medicinal plants are imbued with meaning and form part of local healing knowledge and practices. Unlike pills, medicinal plants are 'alive' and part of the environment (Gibson & Oosthuysen, 2009).

It is of interest that, like most plant medicines, the aforementioned sourplum, is usually taken fresh from the veld. According to healers (*n/um kxaosi*) interviewed, the plant material is 'wet' and has healing/ spiritual power or energy called *n/um*. Plant medicines were used for different kinds of ailments, and depending on whether they were available in the area or not. *N/um* has to be heated up, but also has to be both given (by a healer or family member) and taken (by the sick person). *N/um* is shared (Gibson, & Oosthuysen, 2009). *N/um kxaosi*, who were observed, sometimes talked to the plants, either when collecting them, or during or after administering them. In interviews they stressed that the plants had to be 'thanked' and 'paid' for their sharing of *n/um*. Plants, humans, animals, insects, the sky, the soil, rain, wind etc. are part of nature (*Tsi* or *!ou*). Thus, whereas pills are objects, medicinal plants are much more. They have spirit or essence and are linked or entangled through the movement of *máq* - air, breath, wind, energy and vitality - between them, over time and through space (Low, 2009). Nani, an old and experienced healer tried to explain:

When you walk, you leave a *spoor* (a trail), animals leave a *spoor*, rain leaves a *spoor*... you can see from the *spoo*r what kind of rain was falling, hard rain, soft rain. Even plants leave a *spoor* – the grass drags on the ground, it falls in places, the seed falls, it rolls, the leaves, fall and blow around. You can see it was there. You leave a *spoo*r and the leaves or the grass or seeds, they blow over it, then you can see you shared that story, that place even long after(wards). The *máq* moves between us, we share it. Plants are alive, they have a power to live, they change the soil around them, they can affect animals, they protect themselves from humans from animals, they move their seeds, they can *trek* (migrate) to other places and grow there.

It would seem that plants have "power to grow themselves and be alive" (Rival & McKey, 2008:12), and arguably a certain 'agentivity' in relation to themselves (Barad, 2007:44; Rival& McKey, 2008). Study participants stressed that plants breathe, live, reproduce, feed, poison, defend against or hide themselves from predators. They 'drink', 'eat' and move in the air. They can travel across distance; can affect the environment, the kind of animals that may live there etc. Plants can be stronger or weaker, depending on where they grow. Through the movement and sharing of *máq,* i.e. essence/wind/ air, people, animals and plants interpenetrate and transform each other. Ultimately plant medicines are utilised because people like Dam are in distress and in need of relief.

It was possible to identify a number of plants that were used to treat suspected TB. Both Leffers (2003) and Leger (1997) have also recorded plant use among the Ju/'hoansi, but they did not explore the way in which plant medicines, efficacy or safety was understood. The latter two aspects, as well as the possibility of an adverse reaction between plant medicines and pharmaceuticals used to treat TB, are the main reason for the concern of health care providers. From study observations it seems that healers are, however, careful about the plants utilised and that they have their own understanding of efficacy. When a healer (*n/um kxao*) prepared an infusion of roots of the Horn pod tree (*Diplorhynchus condylocarpum*) for Dam, the former also drank some of the infusion, saying that it helped to prevent TB infection as well. It could thus be used as a prophylaxis. Dam drank the infusion in the morning and evening for two consecutive days, after which his symptoms disappeared. He started coughing again five days later. Once again he was given an infusion and the symptoms disappeared for two weeks. Mouse-eared combretum (*Combretum heroroense*) and African wattle (*Peltophorum africanum*) was also utilised over time to treat Dam. According to healers other plants used to treat TB-like symptoms include the camelthorn (*Acacia erioloba*), Bloodwood (*Pterocarpus angolensis*) and lavender tree (*Heteropyxis natalensis*). If symptoms disappeared for some time, the plant was perceived to be efficacious. While plants could be efficacious because of a placebo effect, some of them have also been found to have antimicrobial and/ or anti-inflammatory components (Green et al, 2010; Theo et al, 2009; van Vuuren, 2008).

Healers insisted that the treatment of each sick person had to be handled on an individual basis. They were certain the plants they used were safe because many healers before them had used it over time (Gibson, & Oosthuysen, 2009). The use of plant medicines was learned from other healers and such knowledge was transmitted orally. Xau, a healer, said sometimes the spirits showed him a new plant to use in his dreams. Whilst he was very familiar with the environment, and knew whether animals ate it; he tested it with his tongue for possible toxicity and drank the decoction himself. Xau's guidelines for safety were roughly the following: he broke the roots, leaves or bark (depending on how he was going to use it), rubbed it on his skin and even inside of his mouth. Sometimes he tested a 'new' remedy with his tongue and waited for a while. He chewed the plant and swallowed some of it. If it did not taste burny, astringent or bitter and/or he did not experience adverse effects within a day or so, he assumed that the plant was safe. If a plant did not seem to work, another one, which could be used for the same illness or for similar symptoms, was tried.

Some of the plants mentioned by the healers for TB treatment have been studied in other African countries and found to have anti-bacterial and anti-inflammatory properties (Green *et al*, 2010; McGaw *et al*, 2001; Okeleye *et al*, 2010). This indicates that more emphasis is needed on research on plants and plant material and its efficacy in TB treatment, especially since Africa does not have enough medicines in general and even a relatively well-resourced country like Namibia has pockets of acute infection, in this case by TB and MDR TB which is not directly linked to HIV/AIDS.

Conclusions

One of the aims of this paper was to illustrate how an overstretched health care system inadvertently contributes to the problem of tuberculosis because it is not always possible to diagnose, supply drugs, and counsel patients: this leaves them with little insight into the complexities of this disease and its treatment and without the necessary pharmaceuticals to do so. At the same time, the Namibian government cannot give higher priority to the San in relation to the rest of the population.

The paper explored tuberculosis in a small group among whom co-infection with HIV is low, whilst the government has to provide services for a wider population within which the opposite is true. Although the health system is geared to providing equal access and tries to display an equitable approach to testing for, diagnosing and dispensing treatment to some two million inhabitants across a vast land surface area; it means in actuality that the access to diagnosis, and thus treatment, is not equal for the already marginalised.

At the same time, the embeddeness of culturalism in the health care system diverts attention from the social, economic and political relationships with poor health. As most Ju/'hoansi speakers report, they are easily blamed for their poor TB outcomes. Ju/'hoansi patients are often held responsible when their TB treatment fails or when they develop resistance to TB drugs. Culturalism thus affects health outcomes and end up confusing, exasperating and even antagonising the sick.

In the absence of diagnosis local people turn to medicinal plants to treat their symptoms, yet this practice is frowned on and perceived as a form of 'cultural' undermining of the tenets of good medical practice, and in particular as subverting TB treatment. Nonetheless, some of the plants utilised by the healers and locals for TB treatment have been studied elsewhere and found to have anti-bacterial and anti-inflammatory properties. Healers also have their own understandings of efficacy and of safety in relation to plat medicines. This indicates that more emphasis is needed on research on plants and plant material and its efficacy in TB treatment, especially since Africa does not have enough medicines in general and even a relatively well-resourced country like Namibia has pockets of acute infection, in this case by TB and MDR TB which is not directly linked to HIV/AIDS.

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Of Remedies and Poisons: Recreational Use of Antiretroviral Drugs in the Social Imagination of South African Carers

***Fiona Larkan**
Department of Anthropology, National University of Ireland (NUI) Maynooth
E-mail address: fiona.larkin@nuim.ie

Brian Van Wyk
School of Public Health, University of the Western Cape, South Africa
E-mail address: branwyk@uwc.ac.za

Jamie Saris
Department of Anthropology, National University of Ireland (NUI) Maynooth
E-mail address: ajamie.saris@nuim.ie

Abstract

During an ethnographic study of barriers to, and compliance with, antiretroviral (ARV) treatment in the South Africa's West Coast region, our team came across a general sense amongst heath care providers that there was a lively illicit trade in antiretroviral medications. In itself, this is seen to be a barrier to adherence for many of their patients whose medication is traded to, or stolen by, drug dealers. Independent anecdotal evidence is emerging about this trade, though there has been little hard data verifying the existence of a recreational market for ARVs. While there are rumours that Efavirenz (some of whose side effects are hallucinogenic) is being used in the manufacture of crystal methamphetamine (locally 'tik'), such reports, in themselves, do not seem able to explain the ubiquity (and the confidence) of the belief in this trade amongst the health care providers with whom we have interacted. This paper explores aspects of the off-label trade of ARVs (as we have come to know it) and, as importantly, how rumor and knowledge of this trade has gained increasing currency in the social imagination of health and social care workers. This, we argue, could precipitate a real crisis in the Government's public rollout programme.

Keywords: Social Imagination, South Africa, antiretroviral treatment, Recreational drugs, HIV/AIDS

*Corresponding author – fiona.larkan@nuim.ie

Introduction

This paper concerns the reported off-label usage of Efavirenz (brand-named Stocrin in South Africa) and other antiretrovirals (ARVs) in the Western Cape Province of South Africa. We explore some of the evidence for this off-label usage, as well as how understandings of this usage have become embedded in what we call the social imagination of Health Care Workers in the area. Finally, we explore some of the implications of such reports for the antiretroviral programme rollout.

Globally, South Africa has the largest public-funded Antiretroviral Treatment (ART) programme, serving almost one million HIV-positive patients from 500 public health facilities across the country. In many respects, this system is considered the model for the rest of the Developing world. ARVs are available free of charge to any HIV-positive adult or adolescent who meets the criteria (below)[1]. However, despite the availability of ARV drug treatment through South Africa's public health system since 2004, two thirds of patients in need cannot or do not access treatment (WHO, 2007). A further proportion cannot or do not adhere to treatment once accessed.

A two-year ethnographic study has been underway in South Africa's West Coast region since January 2009, which seeks to understand barriers to access and adherence to ARV medicines. This study operates from the premise that such barriers, much like the diseases being treated, are the result of the complex intertwining of political, economic, social-cultural, gender, and biological factors.

The issue of an off-label trade of ARVs was first brought to the attention of researchers by home-based care workers who, it was found, would constantly introduce the topic in the context of more general discussions about social grants, poverty, crime rates and gang activities in the area. Given the serious implications such a trade could have not only on the biological outcomes of HIV-positive patients, but on future funding, it was felt that the topic merited further research. In particular it was felt that focus group discussions could explicate the extent and operations of any market that might exist and the supply and demand factors that fed any such trade.

Background

ARVs in South Africa are available free of charge to any HIV-positive adult or adolescent with a CD4 count of less than 200 (or <350 in the case of pregnant women or patients with TB); OR to anyone who has reached the WHO measured Stage IV of an AIDS-defining illness, irrespective of CD4 count; OR anyone with MDR or XDR TB irrespective of CD4 count (DoH, 2010). Prior to initiation on treatment (during what is known as the 'work-up' phase) patients need to meet psychosocial criteria as certified by an appropriate counsellor whose assessment is based both on interactions

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[1] *Different criteria apply for HIV-positive children, who were outside the scope of this study.*

with the client, and the formal and informal knowledge that they have about the client. It is the informal knowledge that counsellors gain about clients that gives opportunity for rumour, gossip and hearsay to be considered as part of the client's suitability for inclusion onto the programme. These criteria, which are specifically *not* intended to be exclusion criteria, are:

- Demonstrated reliability, i.e. has attended three or more scheduled visits to an HIV clinic.
- No active alcohol or other substance abuse.
- No untreated active depression.
- Disclosure: It is strongly recommended that clients have disclosed their HIV status to at least one friend or family member OR have joined a support group.
- Insight: Clients need to have accepted their HIV-positive status, and have insight into the consequences of HIV infection and the role of ARV treatment before commencing ARV therapy.
- Able to attend the antiretroviral centre on a regular basis (transport may need to be arranged for patients in rural areas or for those remote from the treatment site).

The recommended first line treatment regime for patients who meet the above criteria is also clearly defined in the national government guidelines. A central component of the first-line drug cocktail is a non-nucleoside reverse transcriptase inhibitor drug Efavirenz/Stocrin. Reported common side effects of Efavirenz/Stocrin include psychiatric symptoms such as insomnia, confusion, memory loss, and depression (Cespedes *et al*, 2006) and more serious symptoms such as psychosis may occur in patients with compromised liver or kidney function (Hasse *et al,* 2005; Louwenhaupt *et al,* 2007).

Methodology

The field site in which our ethnographic research project is underway includes three antiretroviral treatment (ART) clinics which serve a (largely rural) area of the Western Cape Province of some 450km radius. Up to 30 Primary Health Care (PHC) clinics feed into the three ART clinics. In addition, each ART clinic works with at least two non-governmental organisations (NGOs) which employ home-based carers to visit vulnerable patients in their homes to assess their needs and, crucially, to support them in their treatment regimen. Over a two year period thus far a team of researchers have conducted extended interviews with over 120 patients. Where patients gave their permission they were 'shadowed' by a research team member as they negotiated the treatment pathway and consulted with a range of nurses, doctors, adherence counsellors, treatment counsellors and home-based carers or community workers. In addition, many patients gave their permission to repeated interviews and visits to their homes for meetings with family members/friends or other members of their support network. Parallel to the patient interactions, repeated, extended semi-structured interviews were conducted with over 30 health workers including clinicians, nurses, pharmacists, counsellors and community care workers, all of whom were working within the public ARV rollout schemes. All interviews were conducted in the language of choice of the participant (usually English, Afrikaans or *isi*Xhosa, which are the three primary languages of the region), were digitally recorded, transcribed in full and translated into English which is the working language of the research team. Detailed field notes and field diaries were kept by the researchers and form part of the data.

Finally, multi-lingual focus group discussions which form the basis for this paper were held with two groups of home-based carers and community health workers – one in each of two ART sites. These discussions were conducted in English, Afrikaans and *isi*Xhosa as participants were encouraged to speak in whichever language they were most comfortable with. Although English was the common language of all present, it is rarely a first language. Researchers who were fluent in all three languages were present to translate immediately. Again, all discussions were digitally recorded, transcribed and translated into English.

Social Imagination

While there is some evidence for 'off-label' use of ARVs, we have been struck by how certainty of such use has begun to enter into what we call the social imagination of this Western Cape community of carers over the past 18 months to two years. But what do we mean by 'social imagination'? Broadly speaking the social imagination operates in the interstices between private thought and personal experience, and systemic forces ranging from trends in thought to structural conditions. In that sense, the social imagination can be seen to occupy the middle ground between individuals, and systems and structures. Mills (1959) saw social imagination primarily as *private individuals* making the connection between personal problems and the influence of broader social processes on those problems.

> '*When people [i.e. private individuals] cherish some set of values and do not feel any threat to themselves they experience well-being. When they [private individuals] cherish values but do feel them to be threatened, they experience a crisis – either as a personal trouble or as a public issue*' (Mills, 1959: 11).

We will show how this [imagined] crisis was evoked in health care workers, when their cherished values – a clear separation between 'medicine' and 'drugs', the necessity of a rigorous compliance to the health care regime, and valorisation of a therapy that potentially makes a deadly disease a liveable state – are all threatened by poor adherence among [some] patients.

Christens, Hanlin and Speer (2007) argue that although individuals within systems are the bearers of a social imagination, they are not entirely individually responsible for the views they hold, or for changing them. In common with them, we focus on the social imagination of the community 'with an emphasis on the role of cultural beliefs, ideology and shared understandings in shaping the views that individuals hold about the systems and societies of which they are a part' (p.230). In communities such as the community of carers we are discussing here, people 'imagine' their social surroundings in an elusive set of self-understandings, stories, images, and even rumours. These stories, images, rumours and ideas, are constantly reiterated, becoming one of the ways the community makes sense of the social order, thus in Taylor's words, "paving the way for common practices and a widely shared sense of legitimacy" (2004: 23). Such social imaginations create, sustain and re-define social order within an environment of serious inequalities, persistent resource scarcities, and large social gulfs between those rendering and those in receipt of services.

The recoding of ARVs away from 'wonder drug' and towards a 'dangerous substance that is being abused' seems to be of great concern. The close association that such diverse scholars as Derrida (1970) through Martin (2006) have observed in the Pharmacon between 'remedy' and 'poison' seems to be especially worrisome. The communities in receipt of ARVs often are struggling with a history of substance abuse amongst other legacies of generations of structural violence, which is seen by many staff members to be a significant barrier not just to treatment but to better life chances. Indeed, some clinic staff are the human filter that separates those who have substance abuse issues away from those who do not as part of 'working up' a patient for ARVs according to the protocol produced above. As some staff members verge on the puritanical in their desire to isolate an ARV patient from any alcohol or drug use, not just in their own life but also in their residence, it is not surprising that they imbue the misuse of ARVs in such strong moral terms.

Health Systems – the caring community:

With the advent of antiretroviral treatment for HIV and AIDS patients, the disease profiles and illness experiences for these patients changed – mostly for the better, though many psychosocial and economic challenges remain. A HIV-positive status changed from a sure death sentence to a chronic illness (or in best circumstances, condition). However, the delayed introduction of ART in public health care in South Africa and the effervescence of HIV-related stigma and discrimination, among other things, conspired to create denialism about HIV status in many communities – which in turn manifested in a refusal to test voluntarily for HIV. Many patients, with the exception of pregnant women and children, present at public health facilities only when they become symptomatic. In these cases, the widely reported benefits of HAART –

which is provided in SA – are curtailed. This renders HIV patients very dependent on a range of caregivers from primary health care workers to community-based carers, such as home-based carers who provide palliative care at home, and community health workers who improve the reach of the PHC clinic to provide adherence counselling and support to HIV/AIDS patients.

The health care system in South Africa is driven by the Alma Ata principles of the Primary Health Care Approach. The essence of this approach is that health care should give priority to the community's primary needs for health care and be responsive to community needs. In reality, however, very little outreach to the community served by the clinics is done by PHC staff themselves. Instead, this task is delegated to community health workers (CHWs). CHWs are lay people, usually from the particular community, who are trained to perform specific health related functions, without being professionally qualified to perform health care, and being compensated by what is regarded as an honorarium or stipend rather than a salary (Lewin *et al*, 2010). The creation of the cadre of CHWs was initially motivated by PHC staff being overloaded (Lehmann & Sanders, 2007). Mercurially though, it is widely reported in South Africa and Africa-wide that health workers tend to refuse to acknowledge the value of CHWs to the PHC system, and rather perceive them as doing the 'dirty work' in the community that *they* do not have time to do. The net result is tenuous, sometimes tense, relationship between health workers (professionals) and CHWs (lay people), where PHC staff are often distant from CHWs, while at the same time being very reliant on them to receive their 'intel' about the 'community', right down to intimate details of patient's domestic situation.

The system of home-based carers, on the other hand, was instituted in response to psycho-social needs of patients in the community. They support patients who are bed-ridden in their homes. They are not historically linked to the health care system, but employed by the Social Welfare department. The HIV epidemic in South Africa re-scaped, and brought into sharp relief, the notion of 'care' in communities, and it was soon clear that the delineation of HBC and CHW creates inefficiencies and their merger could render a more efficient service and perhaps even some cost-savings. HBCs through their supportive relationship with palliative patients in the community were seen most suited to provide adherence support to HIV and AIDS patients, but not only those who are bed-ridden. Current attempts are in place in SA to create one cadre called community-caregivers.

Stories of ARV off-label trade:

There have been several media reports of the use of Efavirenz/Stocrin as well as other ARVs for recreational purposes – whether to crush and smoke, (*BBC News* 8.12.2008) to add during the manufacturing process of crystal methamphetamine ('*tik*') (*Cape Argus* 20.05.2008), or to crush and add to *dagga* (cannabis) for smoking (locally known as *'whoonga'*) (*Mercury*, 21.6.2010).

The recreational use of ARV drugs was explored in focus group discussions with home based carers and community health workers. They related to us the plight of patients who are desperately dependent on the welfare grants they receive from government. These *temporary* disability grants are given to patients for a period of six months when they are declared unfit to work on the basis of their HIV status. After six months the status of the patient grant may be reviewed.

When patients are initially put on the ART they most often present with a WHO Stage III HIV illness, i.e. they have a CD4 count of less than 200. Patients are informed that they qualify for a grant as they are medically unfit to work. The CD4 count in itself does not render a patient medically fit/unfit to qualify for a grant. However, those with low CD4 counts in most cases experience a decline in their health – hence the reporting to the health setting. It is this concomitant factor that leads to the physician motivating for the disability grant on the basis of HIV defining illness. As the importance of the CD4 count is impressed on the patient in a variety of settings they come to believe, with some justification, that a CD4 count of 200 is a sort of magic marker that determines their eligibility for a welfare grant. Patient CD4 count is checked every three months. It is envisaged that this check would indicate whether current treatment is working; soon after ARVs are instituted CD4 counts can be expected to rise and viral load quashed down so low as to be undetectable. An increase in CD4 count would indicate that the person's immune system is getting stronger and HIV viral replication is suppressed. A stronger immune system would also indicate that the person is getting stronger (and potentially on the way to becoming economically productive).

Thus, the purpose of the disability grant is to aid HIV patients in recovery to become fit for gainful employment, but it is no secret that most HIV and AIDS patients in South Africa are battling unemployment and poverty. National unemployment, for example, stands at 40%[2], but in settings where we work it can range as high as 80%. For many HIV patients, therefore, the disability grants have in fact become a *de facto* poverty alleviation grant, used to sustain households rather than for treatment support, such as nutrition and transport to clinics. Re-application for the grant often coincides with the 2nd CD4 check and it is at this point that the patients reportedly begin to go off their ART schedule, in order to maintain their CD4 count below 200, believing this will extend the disability grant for another six months.

Our team entered a clinical context, then, where 'adherent to medication' was a complex idea, and one that could change over time. Incidences of ARVs leaking off the list were one genre of stories told about difficult patients. Thus the incidents we detail below about Efavirenz/ Stocrin being sold and used as recreational drugs, need to be understood within a broader context of anxieties about the use of ARVs by both staff

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[2] *Figure based on proportion of employed to working age population. www.statssa.gov.za/keyindicators/QLFS (accessed 11.9.2010)*

and patients. In addition to such stories, for example, ARV drugs are also known to be sold to patients who are ill but do not want to attend their clinic, or to those who simply don't trust clinic staff with maintaining confidentiality regarding their HIV status, and to patients who are illegal immigrants – HIV-positive but not eligible for free ARVs. In other words, off-label, but therapeutic usage of medication was also reported.

Two incidences of ARV leakage that we collected directly connected such misuse to criminality. The first report is of gangs standing outside the clinics, and robbing patients of their ARV drugs, which are then sold on the black market. This scenario reportedly took place in a township near the city:

At [another suburb] where they have an ARV clinic and then the gangs wait outside. When you go inside and then they know [that the] ARV clinic HIV patients are going in there. They'll rob you from your tablets when you come out.

A second reported incident related is of a former community health worker who was mugged and robbed of medication by gang members. The victim's colleagues were convinced that this man was targeted because he was known to be carrying medicines and that the muggers knew what they were looking for. Notably in this case, there is no specific mention of ARVs and the health worker was in fact carrying a wide range of medications. The connection between theft of medications and a recreational use of ARVs (rather than other types of medication) is one made by the carers themselves.

> … they take actually the whole bag because there's a… they know there's some drugs. Something in that they can use for drugs… And at that time the police was driving in the street so it actually happened at that moment and he caught the guy with the... medication. That was a whole bag full of medication because we must only take the medication. We must only take the people's medication home because some of the patients can't walk. But now what happened now, he had it at the clinic. They must come fetch their medication there.

In a third account, community health workers explained that patients would voluntarily sell a range of medications (including ARVs, asthma pumps and TB medication) either directly to non-registered patients, or to drug dealers, who in turn sell it on for therapeutic or recreational use.

> ...not only ARV... any medication because there's all ... they sell it to the drug dealers. I heard it this morning when I was looking for that aunty I think it was in your street…[gestures to a colleague] and one of the shop's owners told me themselves they working so damn hard and this patient when they get their medication they take it to the drug dealers…they are waiting for them there. Some of them are waiting for them there even for... from the TB medication also that's what happens.
>
> Yes even their...their asthma... their pumps they sell it for ten or thirty rand… sometimes also to people... to people who don't want to go to the clinic. I know

> about a patient of mine who's done this... I got a refusal from her husband and she isn't till today not my patient but they're staying in the same house so I would... I'm doing her blood pressure also but I know she's… selling it to a patient who also got asthma.
>
> Yes... they use it as a drug because... there are two houses close to me... where they use and sell drugs...and there they get the ARVs from the patients... and they sell it to the drug [dealers]... who sell the drugs... and then he pays that person and sells it again in pieces to others... And then young people also use it... they walk pass that house.

One of the doctors working in an ARV clinic reported a break-in at her office where ARV drugs were the only medications stolen. This was interpreted as evidence of a recreational market for Efavirenz/Stocrin. Since then regulations to prohibit the storage of sample medication in examination rooms have been introduced at the hospital.

Finally, Gerald (51) has reported being mugged and having his bag (which contained his medication) stolen when crossing an area of open ground en route home from the clinic. However, he emphasises that it is not only his medication that is stolen, but his mobile phone, his bag and anything of value on his person. The point he makes is clear - if someone mugs him, should he automatically assume it is for his medication which is carried in an anonymous plastic bag, or is he merely the unfortunate random victim of attack.

> They are stealing anything that you have on you... the medication is just in the bag when they steal it.

While none of these accounts involved direct observation of recreational use, these stories share some similarities. They clearly do not distinguish the ARVs according to their purported psychopharmacological effects – Efavirenz/Stocrin, for example is not being directly targeted. It is not clear, moreover, the precise black-market circuits these robberies are feeding: off-label therapeutic consumptions as detailed above, different therapeutic regimes (traditional/indigenous or faith-based) or recreational pleasure. Moreover, can muggings which result in the theft of medication always be interpreted as targeted attacks on the part of criminal gangs looking for ARVs for recreational use?

Only one participant reported directly experiencing the actual use of ARVs as recreational drugs. Mary (28) reports that her boy friend used to take her pills to (crush and) smoke them.

> So they gave him the… those white pills and the small brown ones, but he doesn't take them… He only went once and never again… There was one time he smoked my pills. *My* pills!… See, it's a little pill… a little white one [indicates to Efavirenz/Stocrin on wall chart]. He smokes it …
> But now I don't know why he smokes my pills. He can, he works, he can take

> money and buy drugs and smoke them. Because like I explained to him 'Darlene said to me they're very dangerous pills. So you mustn't drink my pills, and I mustn't drink your pills. Must just leave my pills alone.' No, then he showed me he knows better, he is going to smoke it now. Now I hide my pills at my mother 'n them.

Discussion

Our findings indicate two potentially serious issues in the public experience with respect to the massification of the ART programme. The first, a historically-rooted crisis of confidence in the public health system is illustrated by people (non-registered patients) who are aware that they are living with HIV but who would rather buy their medication from other patients than register as an ART patient in the public programme. The second, a crisis of resources in the lives of those in the public programme is reflected in stories of patients who risk their own health to obtain a welfare grant (supporting therapy ostensibly restoring their economic productivity) in order to support their households that are existing at the edge of scarcity.

Stories about ARVs leaking off the list are embedded in, and in some ways help the teller work their way through, this difficult context. The ways that this complex reality is refracted through stories about the recreational use of ARVs which stress selfish pleasure-seeking and inexplicable criminality, however, are worrisome for several reasons. First is the rhetorically powerful movement of ARVs from the realm of 'gifted wonder remedy' to 'selfishly consumed poison'. Antiretroviral drugs, when used as recreational drugs (rather than medicine) are just not 'matter out of place' but can become an index of the fecklessness of a whole community. The Gift is both spurned and misused by the Receiver, *and* such use has the potential to produce HIV strains that are resistant to Efavirenz (amongst other elements of HAART) within this community, which would render any future ART programme with limited and more expensive options. Secondly, the ART patients who are selling their medication, either to drug dealers or to other non-registered patients, are breaking compliance with the health care regimen. Partial adherence, in addition to bedevilling their own chances of recovery, also complicates their treatment regimen, thus requiring additional health care expertise at great expense and cost to the health services. This renders the ART patient as a person 'out of place', because he fits neither within the capabilities or expertise of the ART clinic, nor within the social order created by the health care system.

Here is where the nature of the global environment in which the South African health crisis and the South African response is embedded, intersects in potentially dangerous ways with local clinical understanding of non-compliance. The psychosocial criteria that patients have to meet before initiation on ART already provide the health care workers with the potential to limit access to ARVs to those patients that are suspected would not be compliant to the treatment regimen. The emergence of recreational use of ARVs in this social imagination has the potential to legitimise actions that are aligned with delaying access to treatment to yet more individuals who are clinically eligible. These delays make for, at best, sicker individuals beginning ARVs and, at worst, a death that was potentially avoidable. At the same time, Donor Organisations have yet another example of the intractability of giving aid to the feckless as it will only be abused or go astray leading to serious unintended consequences (a more serious HIV epidemic).

Off-label use of ARVs clearly is happening, but it is not occurring (even in the limited time that we have had a chance to investigate it) in a fashion that is amenable to explanation by logics invoking brain-chemistry or individual criminality. Further detailed ethnographic work would need to be conducted amongst the drug-using populations of the region to establish the existence and extent of recreational (ARV) drug use.

Instead these stories are embedded within the same context that structures the epidemic in the first place – a history of savage inequalities, of structured distrust of a medical system that did not always serve it poorest members well, and of individuals and communities forced to deal with scarcity as a result of their history of being at the sharp end of structural violence.

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Epistemological Issues in the Making of an African medicine: *Sutherlandia (Lessertia Frutescens)*

Olajide Oloyede
Research in Anthropology and Sociology of Health (RASH)
Department of Anthropology and Sociology
University of the Western Cape, Cape Town
E-mail: jide.oloyede@gmail.com

Abstract
The scientific clinical trial of the African traditional medicine, Sutherlandia (Lessertia frutescens) *forms an interface between the indigenous local knowledge of people living with Aids, traditional health practitioners and that of science and global health. Up till now, no cross-disciplinary studies have been done on epistemological questions concerning especially the knowledge and understanding of 'proof' of efficacy concerning an African traditional medicine. This paper draws together insights and analysis from the anthropology and sociology of health and healing in discussing the intersecting fields of knowledge and experience of pharmacology, phytotherapy and related fields, as well as that of biomedical and traditional health practitioners, and of research subjects involved in the making of clinical trials of* sutherlandia (lessertia frutescens) *in South Africa.*

Keywords: *South Africa, African medicine, bio-medicine, sutherlandia (lessertia frutescens) clinical trials.*

Introduction

Traditional herbal medicines, generally considered as naturally-occurring plant-derived substances with minimal or no industrial processing that have been used to treat illness within local or regional healing practices (Cravotto *et al*, 2010) receive significant attention in global health debates. This attention seems, of recent, to centre more on randomised clinical trials (RCT) of these medicines, which still remain the prevailing source of healing in most part of Africa with an estimated 80% of people using them.[1]

Generally, the standard call is for evidence-based research of herbal medicines in relation to quality, efficacy and safety, or in terms of well-defined close/effect relationships. The supporting evidence that is needed revolves chiefly around well-controlled clinical trials including placebo-controlled trials, where appropriate and, bioavailability and pharmacokinetic studies. Such trials tend to receive generous funding from governments, pharmaceutical companies and herbal entrepreneurs. For example, China, India, Nigeria and the US are said to have made substantial investments in traditional medicine (WHO, 2002). South Africa made the provision for the investigation of traditional medicines (Pefile, 2005) in its national drug policy, and, in several African countries, there is an active promotion of traditional medicines for the treatment of HIV and associated symptoms by Health Ministries (Morris, 2002, Mills *et al*, 2005).

However, as the ever-expanding literature shows, randomised clinical trials of traditional herbal medicines remain controversial especially its underlying assumptions: the power and superiority of its mode of evaluation of efficacy. Some consider clinical trials as epistemologically problematic rejecting the notion that herbal medical treatment can be evaluated by scientific methods (Mackenzie-Cook, 2006). The premise for this is that science-based medicine is considered reductionist, whereas traditional herbal medicine is vitalistic (Coulter and Willis, 2004) and as such, it is problematic to evaluate the efficacy of traditional plants according to the criteria of evidence-based science. In addition, efficacy and safety are often evaluated "with different point of views and filtered by different opinions according to the clinical or traditional experience in the various folk medicines in different European countries" (Calapai, 2008: 428 citing Mahady, 2001). These observations, one may argue, remain in the tradition of the ancient ruminations on the extent to which medicine is a science and an art, a duality which Montgomery, in her recent volume *How Doctors Think – Clinical Judgment and the Practice of Medicine*, noted as a reminder that medicine remains poorly defined. Others, who stress the politics in this medical epistemology, see it as an extension of the politics of knowledge domination by the West through the strengthening of the long-standing 'hegemony' of bio-medicine.

At the heart of this strengthening 'agenda' is the special room given to traditional herbal medicines – complementary and alternative medicines (CAM), a term that is considered as reflecting the hegemony and indeed suggests hierarchies of knowledge. An opposing view, of this politics of knowledge, is what can be termed the 'preservation stance'. In this view, it is held that indigenous medical knowledge must be protected and preserved and organisations such as the Dakar (Senegal)-based Association for the Promotion of Traditional Medicine (PROMETRA) dedicates itself to preserving and restoring African traditional medicine and indigenous science. There are those who disagree with this view dismissing traditional medicines on the ground that it is based on 'superstition and neocremancy', suggesting instead that herbal medicines should be 'co-opted' into bio-medical knowledge and researched for this purpose as they "would not only improve and demystify its therapeutic qualities" (Nyika, 2007: 25), but "provide validated information to traditional healers and patients on" their judicious use (Mills, et al, 2005: 1). Such a view, one must hasten to add, seeks to standardise and control that which hardly falls within biomedical modality of knowing.

In the pages to follow, the above issues are discussed within the general theme of knowledge, healing and medicinal plants drawing together insights and analysis from anthropology and sociology of health and healing. The literature on this is verse and it is not the objective here to attempt to cover the topics nor provide an authoritative review of the debate; my task is simply to present a relatively sustained examination and discussion of the more salient ones – the increasing clinical trials of herbal medicines as part of the 'movement' to give it a science base; the ethos of healing of traditional medicine and its incompatibility with the ethos of bio-medicine. The objective is to bring to the fore the dilemmas, difficulties, challenges in the quest for the treatment of chronic diseases in a context in which the vast majority rely on traditional herbal medicine but science and scientific methods are accepted as the major foundations for health care and biomedical knowledge inform health policy. The key point is: clinical trials' 'logic of refutation' would seem to provide, epistemologically, a partial knowledge of the efficacy and safety of traditional medicines based strongly on the traditional healing's 'logic of affirmation', which is readily dismissed by the former. Both require rigorous examination in the quest to establish a plant's efficacy; defining all potential warrants for medicine-making in clinical trials strengthens the efforts to structure hierarchies of knowledge that denote and devalue knowledge derived from anything other than rigorously conducted clinical research. It is an old call but given that there has not been any intellectual resolution that can serve as a platform on which biomedicine/traditional healing can jointly proceed to achieve optimal practice of medicine in the context described earlier, the current piece aims, modestly, to stimulate further philosophical inquiry for that purpose. The discussion draws also from an on-going 'conversation' with traditional health practitioners in a UWC-PEPFAR project[2] that brings together bio-medical and traditional health practitioners in dealing with HIV/AIDS as well as from phytotherapy, considered as a complementary approach to healing and preventing disease.

The paper is an outgrowth of an ongoing study of the philosophy and environment of clinical trials of *sutherlandia.* The discussion is structured as follows: the first section deals with herbs and the scientific testing of their safety and efficacy in the form of clinical trials. This is followed by the section in which traditional medical health system is discussed, specifically, its knowledge base. These sections set the context for a discussion of an African herbal plant, the *sutherlandia,* and the clinical trial of this plant is examined against the issues raised in the sections. These are all brought together in the last section which raises some questions with the purpose of showing the complexities of the making of a medicine in a context where most patients utilize the services of traditional healers.

Herbs for medicines and clinical trials of herbs

Generally, herbs can be any form of a plant or plant product including leaves, stems, flowers, roots and seeds. As such they are often perceived as 'natural' and thus somehow safe (Ernst, 2002).These plants can either be sold raw or as extracts, where they are mace rated with water, alcohol or other solvents to extract some of the chemicals. The resulting products contain dozens of chemicals, including fatty acids, sterols, alkaloids, flavonoids, glycosides, saponins, and others (Bent, 2008). However, many different side effects to herbs have been reported and recently reviewed (De Smet, 2002). A common toxity to herbal medicines involve pyrrolizidine, alkaloids, which are complex molecules found in certain plants that may be used or inadvertently added to herbal medicines. These alkaloids produce hepatotoxity through a characteristic veno-occulsive disease that may be rapidly progressive and fatal (Stickel, Patseuker and Scuppan, 2005). Yet, herbal medicines are reported to have no-side effects except in cases where the herbs are used with synthetic drugs. Some herbs, as De Smet (2002) notes are known to interact with pharmaceutical drugs. St John's wort, for example, is said to be the most notoriously interactive herbal product, and has been shown to interfere with numerous drugs metabolized by the cytothrome P-450 liver enzyme system, including protease inhibitors, chemotherapeutic agents and oral contraceptives (see, for example, Nebel *et al*, 1999; Prost *et al*, 2000).Some authorities note that many herbs, including Kava, Valerian and St John's wort, have the potential valerian to interact with anesthetic agent s and other drugs given in the perioperative period (Ang-Lee, Moss, Yuan, 2001). One must, however, state that the true frequency of side effects for most herbs is not known because they have not been tested in large clinical trials and also because surveillance systems are much less extensive than those in place for pharmaceutical products (Bent, 2008).

Some researchers consider herbal medicines as not fulfilling the requirements of well established medicinal use despite the long tradition of use. The adverse effects of phytotherapeutic agents are less frequently compared with synthetic drugs; however, well controlled clinical trials and numerous individual case reports have now confirmed that such effects do exist (Calixto, 2000). One cannot rule out the fact of the longstanding use of herbal medicines as a guarantee of their safety. At the same time, one cannot say that because of this, there safety and efficacy cannot be questioned. The question therefore is: what is the level of acceptable safety and efficacy? This question raises a general problem: the evaluation of efficacy. According to what criteria? Generally and principally, as has become quite known, it is according to the criteria of evidence-based medicine. As suggested by Calapai and Caputi (2007), the efficacy of medicinal plants can be tested in clinical trials much like synthetic drugs, although numerous methodological and logistical problems exist. The methodological issues include research design. There is a consensus that all human subjects research must 'maintain valid study designs', however, the characteristics of a valid research design would seem to be an issue. There is the argument, especially by those trained in biomedical methods of clinical investigation that the only valid source of knowledge regarding clinical efficacy must come from one type of research design: the randomised blind, placebo-controlled trial (Tilburt and Kaptchuk, 2007).This is considered a gold-standard and any deviation from it makes the research worthless.

There is an opposing view which suggests that the attempt to evaluate traditional therapies with biomedical methodologies, may fail to generate true knowledge since that knowledge itself depends on a scientific vocabulary that only makes sense within the concepts of biomedicine (Schaffner, 2002; Fabrega, 2002).They suggest that the "standard notions of experimental design criteria represents an imperialistic 'western' mode of thinking" (Schaffner, 2002, p7). Kaptchuk (2001) suggested that research on herbal medicines should typically employ experimental research designs such as the RCT, even if research tools are not perfect; they are, in fact considered the best methods for furthering knowledge. What we, therefore, have is that clinical trials of herbal medicines continue with its tradition of 'trials' – science's tradition. The trials maintain focus on safety and efficacy hardly showing interest in the cultural context of the use of such plants. What is the cultural context of the use of such plants? Of what benefit is the cultural context to the issue of efficacy and safety? In asking these questions, one is invariably asking questions of the knowledge base of traditional medical practice. What is this knowledge base? The answer is well-known as so much has been written; what can be done for the purpose of the discussion at hand is to present the core. This is done within the context of what can be considered as the traditional health system and this follows immediately.

Traditional Medical Practice and its knowledge base

Forster's (1976) notion of 'personalistic' serves as a useful starting point in describing the traditional medical system. In such a system, illness and misfortune can be caused by the purposeful manipulation of supernatural powers so that the religious and medical systems are intermeshed. Personalistic etiologies are based on the idea that the volition or the intervention of an extra-natural force causes misfortune. The treatment of personalistic illness is the specialty of the traditional healer who conducts healing ceremonies aimed at appeasing angered gods or spirits, or counteracting the influence of witches or others who possess the power to cause illness. On this point, one needs to point out that in as much as a deity, a human witch or sorcerer, or non-human agent such as an evil spirit or ancestor can use powers beyond those of everyday experience to harm living human beings or control their behaviour, the converse applies in that the same powers can be proactive and assure success in life to those who possess them. Given this, the medical practitioner in this system, referred to, generally as the traditional healer is "someone who is recognised by the community in which he {she} lives as competent to provide health care by using vegetable, animal and mineral substances and certain other methods based on social, cultural and religious background as well as the prevailing knowledge, attitudes and beliefs regarding physical, mental and social well-being and the causation of disease and disability in the community" (WHO, cited in Pretorious et al 1993). Obviously if such a person is responsible for disease and disability, then, he is a sorcerer, which then suggests that a sorcerer in this system is also considered a medical practitioner. This explains why the African traditional medical practitioner is various referred to as herbalist, native doctors, native healer, traditional doctor, medicine man, witch doctor, among others.

However, whether a healer or a sorcerer, a medical practitioner is an agent who is knowledgeable in culturally determined roles of procedure that can be used to control supernatural powers to bring about predetermined effects for self or client. The assumption is that these forces are part of a coherent interconnected universe in which acts of magic can project specific forces along pathways or connections between things to bring about desired goals. When there is interference with the cause of natural forces which results in action contrary to their 'natural programme', we can then say that there has been sorcery as Stevens (1996) also pointed out. It is important to note that Stevens (1996: 723) conceptually separate the forces of nature that can be magically programmed for a specific action from the powers of the anthropomorphised deities, ancestors, ghosts and spiritual beings that also inhabit the universe. Medical practitioners in personalistic systems are skilled in controlling natural forces and some also can capture the services of spirits. This is part of their very rich repertoire in preparing medicine. Included in this repertoire in some cultures are human images molded or carved from natural materials and used as conduits to channel the powers of nature toward cultural goals of 'magical mimesis' which, according to Taussig (1992), involves "*both* copy and substantial connection, *both* visual replication and material transfer" (Taussig, 1992: 8-14).

The making of medicine in this system is thus one in which the entire natural world is a source of power. Practitioners, therefore, incorporate plant and animal parts and other natural objects, as well as artefacts in varying combinations to draw upon the unique powers of each. The parts of plants and animals used tend to be what Rubin (1989) described as "signature elements". These include the leaves, roots of the plants, bark as earlier mentioned. In cultures where human figures are used as part of the making of medicines, such figures are more than mere imitations. As Wolff (2000) keenly observed, in the case of the place of human figures in the medicines of the Yoruba of South-western Nigeria, such figures are transformers that embody and channel the powers of the natural materials from which they are fashioned. In other words, he adds, enthusiastically, that the creation of the medicine figure is an act of embodiment with the intention of concentrating powers of nature for social goals. Most of these medicine figures must be further empowered, which was also noted by Wolff, before they fulfill their instrumental function. This can either be through putting them in contact with the additional magical ingredients and/or by having powers called into them through sacrifice and incarnations.

There are other similar practices in sub-Saharan Africa. Wolff (2000) notes that, one of the best documented traditions of the medical use of human images as power objects, is that of the Kongo. He writes that Kongo medical practitioners make *minkisi* figures with magical ingredients inserted into wood or applied as thick mantles to the surfaces. It is known that such figures, when carved in human form, can be charged with positive curative or protective forces or conversely with destructive powers to bring misfortune or disaster to enemies. We see this also in the role of *Esu* in Yoruba medicine (Oloyede, 1999). As Wolff (2000) was correct to point out, in the larger inventory of the Yoruba sculpture in which the human figure is the leitmotif, the carved and modeled human images in indigenous medicines form a small and obscure category. However, their use in making medicines is huge; yet, it is herbal plants that are central in making medicines. In this regard, traditional healers are skilled botanists and have great talent for locating plants with medicinal properties.

In the conversations with traditional health practitioners in an ongoing research that was referred to earlier, they point out that their preference for sourcing the plants remains the village groves, jungles and the generally wild. This is based upon the belief that wildly collected materials are more effective than planted ones. This point is very crucial in the making of herbal medicines. Interestingly, scientific studies, seem, to some extent to support this assertion. Medicinal properties in plants are due mainly to the presence of secondary metabolities that plants need in their natural environments under particular conditions of stress and competition, which perhaps would not be expressed under monoculture conditions. Active ingredient levels can be much lower in fast growing cultivated stocks. In wild populations, plants can be older due to slow growth rates and can have higher levels of active ingredients. This scientific explanation is culturally explained by traditional health practitioners as simply part of the healing power of nature and only those trained who possess the skill and knowledge are directed to the plants in their natural habitat. In fact most personalistic illnesses can be treated only by traditional healers because they know the proper rituals part of which include gathering the appropriate herbal plants. While one can presume that cultivated plants are likely to be somewhat different in their properties from those gathered from the natural habitats, it is also clear that certain values in plants can be deliberately enhanced under controlled condition of cultivation. This is a very crucial meeting point of traditional herbal medicine and biomedicine at which difficulty of '*togetherness*' somehow emerges. Most standard pharmacological evaluations of medicinal plants tend to support the use of traditional medicines but fall short of suggesting that efficacy must be culturally appropriate. Scientific clinical trials are supposed to provide 'proof' of efficacy and allow these medicines to be admitted into evidence-based medicines.

However, from the discussion in the earlier part of this section, what works in traditional herbal medicines would seem to include transcendent, transformational experiences, changing lived-body experience and the gaining of meaning. Traditional medical practitioners have in fact been referred to as "excellent psychologists" (Crawford and Lipsege, 2004) in that their therapy is so widely regarded as successful because psychosocial issues are addressed and as such the "meanings of sicknesss events become a social issue" (Goody, 1977) thus interpreted as structural microcosms of the society as a whole (Swedlund and Armelagos, 1990). Of what use, therefore, is the clinical trials of herbal medicines? Apart from the efficacy and safety issue, some have suggested that there are practical benefits because biomedical criteria can generate valuable new interpretations for comparative studies of human physiological processes, the ways in which such processes are perceived and the culture-specific behaviours that these perceptions produce. An example of this point would be Browner, Ortiz de Montellano and Rubel, (1988: 683). These authors developed a model for analyzing ethnomedical data independently as well as according to the standards of biomedicine.

The first step in their model is to identify the phenomena under investigation in emic terms. In the second step, one determines the extent to which the phenomena described can be understood in terms of biomedical concepts and methods. The third and final step is to identify the area of convergence and divergence between the emically described phenomena and their biomedical understandings. At this stage, biomedical concepts are used not to examine the phenomena in their own terms (as in the second step) but to see if they are consistent with biomedical assumptions. Etkin (1988) suggested how efficacy can be measured culturally in what is a seminal piece in this regard. He defines efficacy as "something that works by directly producing a set of required, culturally defined outcomes" (p30) and suggested that the key to any consideration of efficacy is the distinction between its emic and etic interpretations. The efficacy of medicinal plants may be judged in their ability to induce full remission of symptoms. One notes this particular point in the conversations with traditional healers on the UWC-PEPFAR project. The efficacy of medicinal plants is judged not so much because they have been in use for generations but their ability to induce full remission of symptoms. Physical signs such as fever salivation are important indicators that a plant has initiated the healing process.

Ortiz de Montellano and Browner (1985) both developed a method for assessing the efficacy of medicinal plants according to both indigenous understanding of their therapeutic effects and the standards of biomedicine. The first step in their method requires investigating informants' own understandings of illness aetiology to predict what medicines would be considered appropriate for their treatment. These ethnomedical data are then combined with data on chemical constituents, physiological effects and biomedical concepts that constitute 'confidence levels' for the efficacy of plant medicines. Level I comprise reported folk use. Multiple reports of use by populations widely dispersed through space, or persistent reports over long periods of time, increase the probability that a plant will exhibit pharmacological activity. Level II plants meet the criteria of Level I and show the desired activity of the isolated compounds or extracts in *in vitro* or *in vivo* tests. At Level III, plants satisfy Level II requirements and show a plausible biochemical mechanism by which the active constituents could exert the indicated physiological effect. Finally Level IV plants fulfill the criteria for Level III and have been clinically tested, or are commonly used in medicine. Information on a plant's level of confidence is then considered in the light of its emic evaluation of efficacy. This method would seem to go the distance in terms of understanding of the therapeutic effects of medicinal plants, but in practice, are clinical trials conducted along what is suggested? For this, we examine the clinical trial of a herbal plant using one of such trials at the South African Herbal Science and Medicine Institute (SAHSMI).

SAHSMI and the Clinical Trial of *Sutherlandia*

The South African Herbal Science and Medicine Institute (SAHSMI) based at the University of the Western Cape in Cape Town conducted what could be considered the first randomised double-blind, placebo-controlled trial of *sutherlandia* in healthy adults in the country. The Institute which houses the International Centre on Indigenous Phytotherapy Studies (TICIPS), a global centre on indigenous medicine funded by the National Centre for Complementary and Alternative Medicine (NCCAM) of the National Institutes of Health (NIH) in Washington, DC, USA., conducts clinical trials of herbal plants in collaboration with the School of Medicine at the University of Missouri in the US, the Nelson Mandela Medical School of the University of Kwazulu-Natal in Durban, South Africa, the Institute for Infectious Diseases and Molecular Medicine (IIDMM) of the University of Cape Town in South Africa, the Medical Research Council (MRC) of South Africa. This collaborative endeavour is rooted in biomedical culture in that what is sought in the clinical trials are evidence for efficacy and safety. Such evidence is informed by the idea that building a valid basis for knowledge in herbal medicine will require balancing two aspects of scientific validity: internal and external validity (Cravotto; Boffa; Genzini and Garells, 2010). Internal validity means that the research must reliably test hypothesized relationships between an intervention and outcome under controlled conditions. Internally valid research will typically try to answer a focused research question that is salient within the vocabulary and a method of scientific community at the time the research is conducted. External validity refers to the applicability of the research results to a target population outside the experimental conditions of the research study. External validity must always be weighed against the need for rigorous internally valid research.

The clinical trial of *sutherlandia,* a shrub that belongs to the Fabeca family, at SAHSMI was along this line (see Quinton *et al* 2007). *Surtherlandia* is principally constituted of L.-canavanine, a non-protein amino acid. Gericke *et al* (2001) note that there is about 30-40 mg of L-canavanine per dry gram of the *S. frutescens* leaf. Other principal constituents are GABA, and D-pinitol. The latter is a type of sugar 'found in many types of legumes and is classified as a chiro-inositol. It is also known as 3-O-methyl-D-chiro-inosotol, or 3-0-methyl-1,2,4 cis-3,5,6 *trans*-hexahydroxyl-cyclohexanol (Mills *et al*,2005) GABA (gabba-amino butyric acid) is both an amino acid and inhibitory neurotransmitter. It is found at levels of 14 mg per gram dry leaf of *S. frutescens* (Gerike *et al*, 2001). *Sutherlandia* is indigenous to South Africa and is widely used in the country as traditional medicines "since they were first adopted by the Khoi, San, and Nama peoples" (Johnson *et al*, 2007:0002). Like most traditional herbal medicines, its usage is not confined to the treatment of a single illness but several illnesses such as cancer, tuberculosis, diabetes, influenza, rheumatoid arthritis, osteoarthritis, peptic ulcer and in the current era of HIV/AIDs, some of the associated symptoms like nausea (Gericke *et al*, 2001; Dalvi, 2003; Johnson *et al*, 2007). The various names given to it by different ethnic groups in the country reflects its wide usage. We are told that it is referred to as *Unwele*, *Lerumo-lamadi*, *Unwele*, *kankerbos*, *kankerbossie* (Mills *et al*, 2005 citing Gericke et al, 2001; Dalvi *et al* 2003). *Sutherlandia* does not have any rules that govern its use like most herbal plants that are widely sold in the country. Consequently, the absence of any form of regulation has meant that the harmonization of its use could also be considered as an issue. Its importance for clinical trials lies, partly, in this.

The objectives of the clinical trials at SAHSMI were twofold: to conduct a pilot study of the safety of *sutherlandia* in healthy adults and secondly, to contribute to establishing procedures for ethical and *scientifically* {emphasis mine} rigorous clinical trials of African indigenous medicines. The design was a randomised, double-blind placebo-controlled trial of *sutherlandia* leaf: 12 participants were randomised to a treatment of 400mg capsules of *sutherlandia* leaf powder, 13 individuals were randomised to consume a placebo capsule, each receiving 180 capsules for the 3 months duration of the trial which was at the Tiervlei Trial Centre of the Karl Bremer Hospital in Bellville, Cape Town, South Africa. Clearly, what we see here is that when medicinal plants with biologically active constituents are the focus of study, biomedical researchers fail to consider the cultural contexts within which plants are used with the result that efficacy of a plant is misunderstood (Walstein and Adams, 2006). Can one say this of the scientists at SAHSMI. The scientists at SAHSMI will probably argue that they are aware of the cultural context and that given the challenges posed by the 'medication of HIV/AIDs crisis', effective crisis intervention is dependent on accurate assessment that directly translates into focusing treatment when it is needed. They will go on to point out that the philosophical basis of clinical trials at the Institute is not just about providing the evidence of the efficacy and safety of traditional medicines, rather, it is about enhancing the well-being of the patients' safety and cure of disease, which, keen observers would not hesitate to point out that, though commendable, is hardly different from what biomedical researchers would generally say. The scientists know very well that traditional as well as biomedicine is integral components of the health care delivery system in the country and indeed, in several African countries. One can suggest that that they will also know that the individual's interaction with other sectors of health care depends on how the health problem is perceived or sanctioned by the sick person and most importantly by relatives and close friends as shown by Crawford and Lipsege's exploratory study of the identification of psychological distress among the Zulu people in South Africa (2004). Depending upon the prevalent symptoms of illness, a person may choose to disregard an illness or heath problem, use treatment modalities known to the individual, friends or family or make decision to use services of a traditional medical practitioner or biomedical health practitioner (Tabi *et al*, 2006). Despite the 'cultural awareness' of the scientists at SAHSMI, there is still the difficulty of going beyond the narrow concern, as exemplified by clinical trials, with safety, efficacy and toxity of plants to a focus on how people use their knowledge of such plants – the uses to which people put their knowledge of the natural world and classification as it relates to their exploitation of it. This perhaps explains why SAHSMI sought anthropology and sociology in it's broad interdisciplinary understanding of herbal medicines and clinical trials.

Concluding Remark: Biomedical hegemony?

Biomedicine is charged in the wider critique of the continuing hegemonic domination of the West over all aspects of life outside the western world. This is not without foundation. In a penetrating piece on applied ethnobiology, Sillitoe (2006) notes that "the term ethnobiology did not come into use until the twentieth century. Naturalists have shown an 'interest' in local biological knowledge since the time Europeans started to explore the world from the fifteenth century onwards. Indeed this knowledge informed biological science from early on, as witnessed in the research by Linnaeus, who corresponded with people around the world, and Rumphius' work in Southeast Asia. In a sense, we can interpret this as ….. Europeans not only sought to understand the new regions they invaded but also were on the lookout for resources that they might profitably exploit engaging practices that today we should consider tantamount to biopiracy………. Those who engage in bio-prospecting, hoping for example, to find elsewhere plants with unknown medicinal or cosmetic properties, are also current-day descendants of this tradition, although from a humanistic perspective such work gives rise to worries about theft of others' knowledge". Would this explain the non-availability of the traditional healers' knowledge for scientific inquiry and its concomitant dismissal that it does not have scientific legitimacy?

It is very clear in the vast literature on traditional healing that in the 'clinical setting' of traditional healing, the encounter between the traditional healer and the patient is not necessarily between the two: both ancestors are involved. The clinical reasoning of the traditional healer is thus a multilayered process of the interaction in the clinical setting which reveals to the traditional healer certain 'signs' of which the bodily signs is a part and interpretations thereof, as well as the consultations with the ancestors for the understanding of the patient's 'disequilibrium' and what to do to bring it back to the state of 'equilibrium'. This epistemological complexity of understanding shows that what is 'prescribed' is specific to the patient as an individual person, not as a body and as such would hardly yield itself to the efficacy sought through clinical trials that are controlled, measured and regarded as valid. Traditional medical healing modality, one must emphasise, has withstood the test of time but, perhaps, not the test of science, which is still grappling with the mind-body interconnections. In the traditional healers' view, clinical trials may yield an understanding of the herbs but this is not equivalent to the understanding of the patient's state of 'person-disequilibrium'. To them, this cannot be ignored when talking about efficacy of herbs.

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This paper, as mentioned in the text, is an outgrowth of an ongoing project exploring the philosophy and environment of clinical trials of herbal plants at the South African Herbal Science and Institute (SAHSMI) at the University of the Western Cape. Some of the materials used for the discussion derive from my interaction with staff and students of the Institute as well as from a tape-recorded interview with the Director of the Institute, Prof Quinton Johnson.

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End Notes

[1] The traditional medicine system in Africa includes herbal remedies for specific diseases, folk knowledge, traditions and values, health behaviours and patterns.

[2] The UWC-PEPFAR-CDC Project 7 is specifically concerned with the training of traditional healers and biomedical health professionals in dealing with HIV/AIDS. It is an attempt to bring together both health practitioners within the context of a wider science-traditional medicine paradigms engagement/meeting.

The Marital Immigrant. Land, and Agricultue: A Malawian Case Study

Paul Kishindo
Chancellor College, University of Malawi, Zomba, Malawi
Email: paulkishindo@yahoo.co.uk

Abstract
The central and southern regions of Malawi predominantly follow matrilineal succession and inheritance and practice uxorilocal marriages. Women, rather than men, own the primary land rights. Colonial government officials and some Eurocentric scholars have argued that the system of uxorilocal marriages and female ownership of land rights are inimical to agricultural development principally because men lose the motivation to make long term investments in land which does not belong to them. This study of marital immigrants sought to investigate whether the location of land rights in someone other than themselves affected the way they viewed agriculture and made farm decisions. It found that while short term decisions are not affected, long term investments are influenced by perception of security, understood in terms of marital stability.

Keywords: *marital immigrant, uxorilocality, patrilineal system, matrilineal system, matrimonial village, maternal village.*

Introduction

Agriculture is the principal source of livelihood in Malawi. Almost 90% of all Malawian households can be labeled farming households (Republic of Malawi and World Bank 2007:44). Access to land is therefore regarded as a fundamental right. Several studies have established a link between access to land and rural poverty in the country. The National Sample Survey of Agriculture 1992/93, for example, showed that the poorest and most vulnerable households in the country were those owning less than one hectare of land (Malawi Government, 1993). The first Integrated Household Survey (HIS) in the country, carried out in 1998, confirmed the link between access to land and poverty. According to this survey, households cultivating less than 0.5 hectare contributed the majority of the poorest and most vulnerable households in the country (National Economic Council, 2000: 78).

The Malawi Land Act 1965[1] recognizes three categories of land: private, public and customary. Private land is defined as all land held, owned or occupied under a freehold or leasehold title, 'certificate of claim'[2], or registered under the Registered Land Act 1967; while public land is all land occupied, used or acquired by the government; customary land, on the other hand, is defined as all land, held or occupied under customary law. Customary law varies from one ethnic group to another. There are also local adaptations. Recent estimates put land held under customary tenure at about 66% of the country's total land area of 9.4 million hectares (Republic of Malawi and World Bank 2007:151). It is on customary land that most of the country's food production occurs as well as that of significant quantities of cash crops such as cotton, rice and burley tobacco.

Kinship ideology defines who has rights to customary land. In contrast to the patrilineal social systems of the northern region where primary rights belong to men and are passed on from father to sons, in the matrilineal social systems which predominate in the central and southern regions primary land rights belong to women and are passed from mother to daughters. Men live in their wives' villages and access land through them. Theirs are secondary rights whose continued enjoyment depends on the longevity of the marriage (see also Peter, 2010). Such uxorilocally married men known as *akamwini* (sing. *mkamwini*) in Chichewa, the national lingua franca, are in effect marital immigrants.

Women's possession of land rights at the expense of men has been blamed by some observers for the lack of agricultural development in Malawi because it is thought to remove from men the motivation to invest in the land (Kettlewell, 1965; Lamport-Stokes 1970; Rimmington, 1963; McLoughlin, 1972). As early as 1945, the colonial Director of Agriculture was advocating individual ownership of land as a means of doing away with what he viewed as the evil of the matrilineal system and its negative effects on agricultural development (Peters, 2010: 186). The Malawi Congress Party (MCP), which ruled the country from 1964 to 1994 shared this view and sought to discourage uxorilocal marriages among social groups which practised them. Resolutions to that effect were passed at the 1969 and 1971 party conventions (Nankumba and Machika 1988:29). However, neither the government nor the scholars who condemned uxorilocal marriages provided evidence directly linking them to lack of investment in agriculture. It was assumed that agricultural development could only occur through the agency of men, and ownership of land rights by them was a necessary condition. In spite of the efforts of colonial and post independence governments to discourage uxorilocal marriages, they are still practised widely in the southern region, although it is more common in the central region for uxorilocality and virilocality to coexist (see e.g. Takane, 2005: 103) Takane views this as an adaptive strategy employed by villagers in response to the increasing scarcity of land. The persistence of uxorilocal marriages suggests that those ethnic groups that practice them see some value in them that would be lost if they opted for alternative post-marital residence arrangements.

This paper examines the extent to which uxorilocal marriage affects men's ability to make important decisions on family holdings. It is based on interviews with 20 uxorilocally married men and 20 wives of such men in Kachenga Village, Balaka district, southern Malawi[3]. The participants were identified with the assistance of the group village head. The average period of residence in the village was 15 years, with the oldest having lived in the village for 54 years. Husbands and wives were interviewed separately to ensure that both parties expressed their views freely. The group village head was interviewed for his insights into land tenure rules and customs relating to marriage. Informal discussions were held with members of the village outside the named categories to supplement what was gathered from the participants of the study, and also to crosscheck some information. Visits were made to crop fields to see what crops were grown and the type of improvements that were made on the land. The information was collected during many visits to the site between September 2008 and March 2009, with the most recent made in July 2010.

The village

The Yao claim primacy of settlement in Kachenga village and constitute the dominant ethnic group. They are matrilineal. Descent is reckoned through a common ancestress. A group of sisters constitutes the core of the hamlet. The population of a hamlet is basically made up of sisters, their husbands and children (cf Mitchell, 1956: 145). Immigrants without affinal or kinship ties with the matrilineal core of the village can be found in some of the 13 hamlets that make up the village. They are integrated to a greater or lesser degree into Yao culture. The eldest brother of the sisters is usually the hamlet leader, although in two cases that role has been assumed by women. The hamlet leader does not always have to live in the hamlet, but must be available to handle important matters affecting it, for example, illnesses, marriages, deaths and disputes among members. It is largely for this reason that those who hold these positions tend to marry within walking distance of their villages.

Each hamlet has a specified area where its members have their crop fields. This land is deemed to be the corporate property of the matrilineage, and is held in trust for the group by the hamlet leader. In turn, the hamlet leader is answerable in matters of land and custom to the group village head, and ultimately to chief Kalembo. The territorial chief is traditionally known as the 'owner of the land' because the authority of village heads and hamlet leaders to distribute land is believed to emanate from him. Individual families are allocated parcels of land on which to grow crops. These allocations are made to women because 'women build the village'. This reflects the importance attached to women in matrilineal social systems. The essential fact is that women form the stable population in the village, while men are taken away from it by marriage and the search for employment opportunities.

Uxorilocal marriages are the norm, and early marriages are common. The men marry outside their own villages, while men from other lineages come into the village to marry women from the local matrilineages. Unlike in patrilineal social systems, no transfer of bride-wealth from the man to the woman's family is required to legitimate a marriage: the consent of the woman's maternal uncles and her mother are adequate (see also Kasmann and Chirwa, 1997: 6). Children are deemed to belong to their mother's matrilineage. A man's principal role in a marriage appears to be that of helping his wife fulfill her reproductive duty to her matrilineage. A special bond exists between a brother and sister; and an elder brother has authority over his sister and her offspring which often overrides that of the husband (see also Mitchell 1956:145; Peters 2010:184). A child may not be initiated or sent to school without the senior maternal uncle's approval. Cases were reported where sick women delayed going to hospital, with fatal consequences, because the brother with authority was away in his wife's village and could not give his timely consent. Mitchell (1956:144) observed that the principle of uxorilocal marriage is in conflict with the principle of male leadership of the matrilineage. In reality, however, this situation can be allayed through cross-cousin marriage which ensures that a man remains within the village, though in a different hamlet; or by marrying into a neighbouring village.

The operation of the uxorilocality principle ensures that the majority of adult male members of the local matrilineages are resident outside their maternal villages. Those who are resident in their maternal villages are likely to be those in-between marriages; those who inherited their mother's land when there were no female heirs; those in cross-cousin marriages; or those whose families had more land than female members need for their use (Peters 1997:205; Kishindo 2006:13). Unless they have no living sisters, nieces or grandnieces, men who reside in their maternal villages and cultivate land deemed to be part of lineal land risk being forced out by any of these female kin when they need land because the later have customary precedence. Lineal land used by men is in effect on loan to them by the female members. In land cases, customs weigh heavily in favour of the women.

However, in the specific conditions that allow men access to lineal land could lie the beginning of a new pattern of land acquisition which accommodates both male and female members of the matrilineage. The gap left by male members of the matrilineages is filled by marital immigrants. They help the matrilineages reproduce and replenish their membership; participate in community projects; and provide male labour and other resources for agricultural production.

Agriculture

Farming as in other parts of the country, is the major occupation in the village and it involves all ages. Farming practices are learned as part of the normal socialisation process. Cotton and burley tobacco are the two major cash crops in the village. Out of the 20 households studied, six grew cash crops: two grew tobacco and four grew cotton. There has not been an agricultural advisor in the area since 1973. This means that any new practices have to be learned through other means than the formal extension which has been severely affected by cessation of training of extension staff for much of the 1990s (which has not been explained by the Ministry of Agriculture), resignations and deaths. The reopening of the Natural Resources College is a hopeful sign that the situation might improve soon as its graduates get deployed to farming communities.

A major determinant of investment in land is the extent to which one feels secure on it. An individual is likely to invest in land if they feel certain that they will have use of it, or access to it, for long enough to enjoy the benefits of their investment. Abbot and Makeham (1981:143) argue that without security of tenure land users will only apply those inputs, or engage only in those activities that bring immediate benefits. Security of tenure on the other hand, emanates from formal legal title, or a community's recognition of one's rights to a specific piece of land and its willingness to protect them when they are threatened. A community's recognition of one's rights to a specific piece of land is particularly important in customary land tenure. Uninterrupted occupation and use over several generations, of the same piece or pieces of land in the village is believed to confer 'ownership' on the holder. Thus users of lineal land consider themselves owners of their parcels of land rather than mere right holders. They cannot be arbitrarily removed from their land by the village head, group village head or even the chief. When the village needed land for a community day secondary school, police post and a nutrition rehabilitation centre the group village head had to negotiate with the families that were the recognised owners. However, the villagers' understanding of ownership, based on uninterrupted occupation and use of a specified parcel of land, and community recognition of the family's or individual's right to remain on it, is at variance with that of some development theorists and international development agencies (see for example, Kameri-Mbote and Kindiiki 2008:179). The latter category of people believes that ownership of a piece of land must be signified by a formal document recognised by a court of law, and which gives exclusive rights to the holder. This, it is argued, is the basis of tenure security and agricultural development. Consequently World Bank supported agricultural development projects, for example, the Lilongwe Land Development Project and Community Based Rural Land Development Project included land registration and titling as a major component. The evidence, however, shows that land registration has not been successful because the process is cumbersome and its value is little understood (see for example, Kumwenda, 2010:72). Adams and Turner (2006) have argued that registration and titling programmes, where they have occurred in eastern and southern Africa, have not unlocked agricultural based economic growth. Instead they have often disempowered vulnerable people, especially women.

The enjoyment by men of access rights to their wives' land is dependent on the longevity of the marriage, which is in turn a function of the internal dynamics of the marriage and how well the two parties manage their relationship, often in the face of interference from the wife's mother or her brothers. Phiri (1983) found that marital insecurity among the matrilineal Chewa of the central region would be felt particularly in the first years of marriage as the newly-married man adjusted to the demands of his dual roles as husband and resident son-in-law. During discussions with the wives of marital immigrants it was established that failure to father children, laziness, failure to provide the basic needs of the family, repeated verbal and physical abuse of family members, and disrespect for a mother-in-law may be cited as causes for divorce. Divorce is usually effected when the maternal uncles of the wife and husband, who are the customary sureties to the marriage, agree that the two parties can no longer live together. The village court usually merely endorses the decision of the marriage sureties. Mother-in-law influence is said to be a frequent source of marital discord. It seems to be to the advantage of the resident son-in-law to maintain a mother-in-law's favour.

All the 20 marital immigrants acknowledged their 'stranger' status in the village and that the land they worked on belonged to their wives and their matrikin. The situation was accepted as the normal order of things. Farm work is shared by family members although women tend to take sole responsibility for seed selection, harvesting and storage of maize, the principal food crop. In addition to working on the family holding, the men are also expected to help out on the mother-in-law's holding if she is a widow or divorced. Hard working men tend to earn the praise of their wives and mothers-in-law, while lazy ones tend to be ridiculed. There is often competition among men married to sisters for praise, which sometimes leads to jealousy and conflict.

The relationship between men and women in relation to agriculture is one of mutual dependence: whereas men need women to access land, women need men to do the heavier farm work such as land preparation, and to procure farm inputs, especially fertilizer. In order to acquire the necessary cash the man is often compelled to engage in *ganyu*4on richer neighbours' holdings or non-farm income earning activities. Married women therefore have a potential advantage over their unmarried counterparts and are likely to have higher production outcomes. Kasmann and Chirwa (1997:8) in their study of a Yao community in Mulanje, southern Malawi, found that households with a husband were more likely to use fertilizer and hire additional labour than female–headed households, and consequently produce higher crop yields.

Farm decision-making

The family holding is an integral part of the household economy. It must produce the food the family needs as well as generate cash to meet the basic needs. Decisions regarding selection of seed for the next growing season and production of minor crops such as cowpeas and vegetables were deemed to be a female preserve. On the other hand, purchase of farm inputs, hiring of labour and disposal of income from the cash crops, were a male prerogative. The male prerogative over income from cash crops seems to be a universal cultural phenomenon in Malawi (Kasmann and Chirwa 1997:8; Republic of Malawi and World Bank, 2007:44). This prerogative sometimes comes into conflict with wives' expectation when the men use the proceeds of crop sales for purposes other than improving the living standards of the family. A common complaint of the women participants was that the men often spent proceeds of crop sales on beer rather than useful household items such as plates, pots and pails.

The overall picture that emerges is that while women own the land rights, men as heads of households are responsible for the most important agricultural decisions. The potential 'veto' by a woman who owns the land rights, however, seems to make men more willing to negotiate with their wives on important farm issues. In the two cases where part of the family holding was either sold, or rented out, the decision was made with the express approval of the wife. Such sale also had to be cleared with the hamlet leader for the reason that the land would transfer to non-kin. Transfer of land rights to non-kin has important implications for the needs of future generations.

Long term investments

Agricultural development requires both short-term and long-term investments. Chemical fertilizer and pesticides can increase crop yields on a piece of land several times over in an agricultural year. Other investments of a more permanent nature such as dams can make irrigation farming possible and raise the value of the land. Mc Loughlin (1972) and Abbot and Makeham (1981) argue that permanent improvements on the land are important indicators of security of tenure. Individuals are likely to invest in improvements whose benefits can be enjoyed only some time in the future if they are, or believe, they will be around to enjoy or access the benefits. Such improvements include dams, drainage ways, contour bunds and terraces. The creation of permanent structures on the land, however, assumes the possession of the relevant technical knowledge in addition to the perception of security. It is possible for one to enjoy security of tenure, yet lack the knowledge of innovations that can improve agriculture.

Observations of crop fields in the village did not show any evidence of permanent structures that could improve agriculture: for example, there were no water conservation works; and yet the area is prone to erratic rainfall. Interviews with our study participants, as well as informal discussions with members of the village community revealed that they were not aware of such technology. The lack of awareness was attributed to the absence of agricultural advisors and access to agricultural technical information. The question that arose was whether, if they had the relevant technical knowledge, they would build water conservation dams on the land they were cultivating, which in effect belonged to their wives. All the 20 marital immigrants indicated that they would if the structures could be demonstrated to improve crop yields. As people who depend on own-production for food security and income generation, any technology or practice that would raise crop yields was welcome. The decision to adopt such an innovation would, however, depend on the relationship that existed among the man, the wife and her matrikin especially her mother and brothers. Where the relationship was 'not good' it would not be advisable to embark on long-term projects as one may not enjoy the benefits. Rude behaviour by married women's brothers towards enterprising brothers-in-law is frequently a source of frustration. Out of the 20 marital immigrants, six had at one time or another during their stay in the matrimonial village experienced rude behaviour from brothers-in-law. Thus what might prevent men from investing in major or long term investments is not so much the fact that one does not have the rights to land but the behaviour of the people among whom one has to live. Where harmonious relations exist and one is respected, long term investments may be made. Banda (1991) noted a tendency among smallholder fish farmers in Zomba to locate their ponds on sites acquired in their maternal villages, although not necessarily on lineal land, in what was seen as an effort to escape from the jealousy and interference of brothers-in-law and fellow marital immigrants married into the same family. This sometimes involved taking the wife away from her village to reside in the husband's own village in what is termed *ulooka*. However, this course of action is possible only where one is assured of access to lineal land and confident that such access would not later be contested by female members of the matrilineage; or where the village head can make a special allocation out of unclaimed land.

Successful or enterprising marital immigrants tend to be resented by their less successful brothers-in-law because they are thought to be pompous and show off their success. This behaviour could partly be explained by the special relationship that exists between a brother and sister in Yao culture. A sister looks at her brother as protector and provider in times of need. A successful husband is able to meet his wife's and children's needs so that she does not have recourse to her brother's support. This capacity to meet the family's needs raises the woman's estimation of her husband's abilities, which in turn poses a threat to the brother-sister special relationship.

Conclusion

This study sought to examine the extent to which uxorilocal marriage affects marital immigrants' decisions in agriculture. The evidence shows that the fact that the man does not own the rights to the land he works does not prevent him from making the important decisions on the land. As head of household a man is expected to initiate innovations and make decisions that help the household achieve food security and generate a reasonable income from the land. The system of uxorilocal marriages and female ownership of land rights create conditions for greater consultation on important farm decisions between the two sources of authority in a household, especially those relating to land transfers.

While short-term investments do not pose a challenge to the marital immigrant, long-term projects do. The extent to which marital immigrants are willing to make long term investments in the matrimonial village is dependent on their perception of security in the village. In this context security is understood in terms of longevity of marriage. The behaviour of the wife, mother-in-law and other matrikin influence marital stability and ultimately whether one considers themselves integrated enough to feel like a permanent member of the village. Since women are critical to land access, and the behaviour of her matrikin create the conditions that may influence marital stability, it might be more useful to focus land-based development initiatives on them rather than men.

Endnotes

1 The act has been amended several times, notably in 1967 and 1972, to accommodate changing circumstances and development needs of the country.

2 'Certificates of claim' were granted by the first colonial governor to European settlers who had acquired land from African chiefs under various agreements before the declaration of protectorate status in 1891. The certificates conferred legitimacy to the acquisitions. The Land Act conferred freehold status on such land.

3 This is part of a larger study 'Agricultural Development in a Matrilineal Social System' in the Department of Sociology, Chancellor College, University of Malawi led by the author.

4 Piece-work done for a mutually agreed rate of pay. It is an important source of rural income.

Gender Inequality in the Division of Household Labour in Tanzania

Sheryl Feinstein
Augustus College, Sioux
Email: Sheryl.Feinstein@augie.edu

Rachel Feinstein
Texas A & M, USA
and
Sophia Sabrow
Department of Sociology
University of Colonne, Germany

Abstract
This study examined the gender norms and the language used for rationalising gender inequality regarding the division of household labour in Tanzania. Tanzanian university students and secondary students participated in interviews, focus groups, and surveys for this study. Findings suggest that Tanzanian men have very traditional expectations regarding gender roles while Tanzanian women have more progressive expectations. Some gender norms, including the expectation that women should be responsible for the children and should do more work than men overall, were demonstrated. Naturalisation, the attempt to justify an inequality such as sexism by claiming that the disparity is simply natural, was used to explain inequalities; as was minimisation, the attempt to justify an inequality by reducing the significance of the problem. Lastly, cultural sexism attempted to justify gender inequality by explaining the differences between genders as a result of cultural practices rather than sexism.

Introduction

Gender equality, usually considered a basic human right, has not been absolutely achieved in any country (Newman, 2006). A growing interest in this topic has encouraged organisations like the United Nations to research gender inequality internationally and to develop a mechanism for comparing the level of inequality in each country.

Using the 'gender empowerment measure' (GEM) to represent the inequality of opportunities for men and women in each country, the United Nations ranked the United States (US) 12th and Tanzania 159th out of 177 countries (UNDP, 2008). This significant disparity implies that women in the US participate much more in political and economic sectors of society than women living in Tanzania (Newman, 2006). Although the GEM noted a significant difference between the US and Tanzania's level of gender inequality, neither country demonstrated perfect equality. Furthermore, this indicator describes the gender inequality in quantitative terms of access to political power and economics; however, the GEM does not explain the degree of sexism involved in the gender norms of each society.

Sexism is an aspect of gender inequality that is perpetuated through gender norms. Healey explains that there are two types of sexism, hostile and benevolent. Hostile sexism includes agreement with negative stereotypes against women and "anti-minority group prejudice" whereas benevolent sexism is often "expressed as an apparently positive attitude of protection and affection" (2006:99). Although these forms of sexism are seemingly contradictory, Healey asserts that both types of sexism "promote stereotypical views of women and serve to justify and rationalise their lower status" (2006:99). When either form of sexism is used, individuals are expressing traditional attitudes towards gender norms. Although sexism can take many forms, and often works on a structural level, making it difficult to recognise at times, it cannot be overlooked in studying gender roles and the division of labour.

Consistently, research focusing on gender norms in various countries around the world demonstrates a difference between male and female responses. Often this is the most significant finding of research on gender norms. In general, males express "more traditional sex-role attitudes than females" (Rao & Rao 1985:607; Morinaga, Frieze, Ferligoj 1993:317).

There has been little research conducted on gender roles in Tanzania. However, a study by Susan Rogers focusing on village women in Tanzania in 1983, found that women were aware that they work more than men, but they were unable to change the situation. A local Tanzanian organisation conducted a study in 2006 reaffirming the idea that Tanzanian women are working harder than men (LCCB, 2006). One participant in this study explained that although both boys and girls work on the farm together, afterward "the girl would collect water, cook etc. while the boy is resting waiting for food" (2006: 17). The boys are taught how to become men and perform men's duties while "girls are socialised to perform 'mothers duties'" (2006:17). The Local Community Competence Building (LCCB) organisation in Tanzania describes the inequitable division of labour between boys and girls as "contributing to human rights violation and gender inequity" (2006:24). This study depicts some of the gender norms in Tanzania like the expectation that women will work harder and longer hours than men as well as serve the men. Based on this study, it is predicted that Tanzanian students will describe the women's work day as longer and involving more work than men's work day because of women's housework responsibilities.

The situation is further complicated by the control the men have over women's labour. The men are the supervisors and they also control the finances (Rogers, 1983). For these reasons women are further oppressed by their position as a labourer. Conflict theory would likely view the oppression of women as related to the alienation they experience. Women have little contact with other women who suffer the same problems, and they do not see the results of their labour (Appelrouth, 2007). Rogers explains that women do not come to a "full realisation of the implications" of their positions as labourers and they agree to these tasks "because of the ideals inculcated in [them] by social norms" (Roger,s 1983:37). Because of the disconnection women have between their labour and the financial rewards, they experience alienation and do not feel like their work has the same amount of meaning as it does for the men (Appelrouth, 2007). This study demonstrates how the gender norms that allow for extreme gender inequality are perpetuated due to the dominating role men play and the alienation, isolation, and lack of power women experience.

Methods

The Sample

This study was conducted using qualitative interviews, focus groups and surveys. In both the interviews and the focus groups, interactive conversations were guided and left open-ended (Babbie, 2005). Tanzanian students who were currently attending Tumaini University and secondary school students in Iringa Municipal were interviewed for the study. Fourteen university students and 14 secondary students were interviewed, half from each group were female and half were male. Additionally, two focus groups, one consisting of five female university students at Tumaini and one of five male university students, were conducted. Finally, 210 secondary students were surveyed. The participants' ages ranged from 17 to 30 years-old. This study focused on some of the most educated and thus most likely progressive members of Tanzanian society.

All of the interview participants were collected using a convenient sample. Normally focus groups are not based on random selection and therefore are not representative, because the purpose of these groups is to explore an issue rather than explain it (Babbie, 2005). For this reason, members of the focus groups did not need to be randomly selected for the data to be reliable. Students who were on university or secondary school campuses studying or talking with friends outside were asked to participate in the study either as an interviewee or a member of the focus group. Interviews with university students were conducted in English, while interviews with secondary students were done in Kiswahili.

Students at one government secondary school in Iringa were chosen to participate in the questionnaire. The school site was chosen because it was co-educational and students from the region attended, bringing in a broad perspective. All students in Form 4 took part in the study; 97 were male and 113 were female. The surveys were administered during class time, assuring a 100% return rate.

Measurement

Each interview began by asking the participants how they were raised differently from their siblings of the opposite sex, in order to determine whether the gender inequality that has previously been studied is apparent to local Tanzanians.

In order to receive specific responses it was necessary to probe participants, questioning them on differences in educational success, responsibilities around the house, rules, expectations for marriage, apparent respect from parents, apparent love from parents.

In order to identify the common verbal mechanisms used to rationalise the gender inequality in Tanzania, students were asked to explain why they believe the gender division of labour occurs the way it does in their country. For example, after students described their gender roles they were asked, "Why do you think your parents encouraged your sisters to cook and clean and your brothers to work outside?"

The focus groups were used to enhance the research on verbal mechanisms. However, the questions used in the focus groups were more specific and largely revolved around the gendered division of household labour. The primary purpose of the focus group was to determine the Tumaini University students' expectations in terms of gender roles in marriage.

Instructions for the questionnaire were given in Kiswahili, the students' native tongue. The questionnaire consisted of 30 multiple-choice items and was developed from responses gathered during the interview process. Questions probed into perceptions on the following topics: educational success, work responsibilities, rules, and expectations for marriage. The questionnaire was analyzed using descriptive statistics, responses were tallied and percentages were computed.

Conducting this research as two Americans and a German may have allowed for potential problems with the data. Although all of the university classes were taught in English and all students know the language well, a language barrier was still likely present to various degrees. The vocabulary or the accent may have made it difficult for the participants to correctly understand the questions. Or their responses may have been misunderstood, either in terms of hearing them correctly or interpreting the responses correctly.

Furthermore, there was no access to a recording device so the responses were written down as they were stated. This may have caused problems with accuracy. Only sporadic statements were written down word for word when time allowed.

Since research is not commonly conducted in Tanzania, students may have experienced discomfort throughout the interview process. Particularly, being questioned by white females may have intimidated some participants more. This could have made students feel compelled to use responses that they believed the researchers wanted to hear, therefore altering the validity of the data.

Results

Tanzanian Expectations for Division of Household Labour

Consistent with previous research, responses from Tanzanian men were very different with regards to their expectations for the division of household labour compared to the responses from Tanzanian women. Men had much more traditional expectations for future household gender roles than women, who had very egalitarian aspirations. For example, the men felt that there was no need to change the way labour is currently distributed since women see their jobs as their responsibility. One student explained, "Something that is culture is very difficult to change. It is hard to change. Women naturally themselves found that they are responsible to do those things. So far there is not a need to change because they see it as their responsibility."

However the women were adamant that men should help cook and do half of the housework. A female student summarised the feelings of other participants in the focus group by saying that it is okay for men and women to share the same chores "because we know we are all the same. They have the same brain, two hands. So everything I can do, a man can also do." Since the men do not see a problem even though the women explicitly state that they desire change, this clearly suggests that some form of miscommunication is occurring between the two genders. This miscommunication may be due to the men's desires to deny or ignore how the women are feeling or it could possibly come from an inability of the women to express their selves due to the strong traditional culture in Tanzania.

Tanzanian women seem to desire egalitarian households. There was strong agreement among the women in the focus group that sharing household responsibilities with their husbands was important and was how they were going to carry out their future marriages. One female student explained that the strict gender roles are "part of the culture, but as this time passes the men should help cook". She provided her perspective on sharing household chores, like cooking, saying that "It is happening, but mostly to educated families. In the indigenous family, men can't [cook]." This desire was present in many of the female university students I spoke with, which suggests that currently in Tanzania it may be expected for educated women to want egalitarian divisions of labour. However, one significant distinction between these findings is that most Tanzanian men did not express any feelings of responsibility for household chores. Instead, it can be implied from their responses that in Tanzania the gender norms are very traditional and men are not expected to take on household responsibilities despite the increasing responsibilities of women, nor are they expected to express egalitarian desires.

Despite the desires of Tanzanian women to have egalitarian households, results from the interviews demonstrate that this is not occurring. Instead, the gender norms in

Tanzania seem to encompass traditional roles for women, causing them to be responsible for all domestic duties. For example, all but one of the respondents from the interviews mentioned that the women were responsible for cooking or performing the 'kitchen duties' in their home. The one student who was raised in a more egalitarian household explained that her situation was very abnormal, and friends and relatives were shocked when her brothers would cook. She explained that her relatives are surprised by this because their culture "prohibit[s] men from going to the kitchen" and says that women are supposed to cook and clean. Other students expressed the same cultural prohibition of men in the kitchen as an explanation for the division of labour. One student in particular explained that he can count on one hand the number of times his father ever entered their kitchen. This division of labour would not necessarily contribute to inequality if it did not signify that women work harder and more often than men. However, this study found that the domestic tasks regarded as a woman's responsibility ensure that women work more than men. Survey respondents corroborated these findings; 0% of male and female participants believed that men should wash clothes, cook or take care of children, although many women believed that it should be the responsibility of both.

Although more women are receiving higher education and getting jobs outside of the house, they are still expected to take care of the household responsibilities, which further increase the amount of work women do in comparison to men. In fact, both male and female participants acknowledged that women work harder than men. A few male students explained that although their sisters have to be at school at the same time as themselves, the sisters have to wake up earlier to make breakfast and take care of the children. After school, both siblings have homework responsibilities but the women are still expected to do all of the housework, prepare the meals, and take care of younger siblings or their own children. In addition, five of the 28 students specifically stated that women work harder than men. Some students recognised the labour division as oppressive to women and unfair. And many students implied that women work more than men through their descriptions of the gendered responsibilities that they experienced growing up in their homes. These findings suggest that the gender norms in Tanzania include the expectation that women will take care of the household responsibilities even if it means working much harder and longer hours than men.

The gender norms regarding the division of labour seem to revolve around the needs of men. The rules fluctuate to benefit men depending on the particular situation. For example, many students explained that men are prohibited from the kitchen, but they also said that if the women of a household are absent or sick the men are no longer prohibited from cooking. One student explained that, "very rarely boys cooked" like when his mom was sick or the girls were all at school.

In other words, the culture is forgiving enough to allow men to feed themselves when it is essential, but not forgiving enough to give men and women equality. One female student further supported this idea when she explained that she and her sisters do the washing and cooking, but her brothers don't do these jobs if a girl is around-"just African culture. If [a] boy is doing something for a girl it's bad". Based on the interview data it was determined that Tanzanian women are expected to serve the men in their culture as part of the gender norms. Although, surprisingly, it was not uncommon for men and women interviewed to mention that the normal rigidity of the gender roles were deviated from when help was necessary.

During the focus group, it was revealed that the gender norms regarding the division of labour are not always as divided as Tanzanian married couples make it seem. A married college student in the group explained that some women who are very 'strong' are able to convince their husbands to help out around the house with the children, cooking, and cleaning. When other students in the focus group tried to qualify his statement by quickly pointing out that this is 'very rare', he continued to explain that it is not really as rare as they think. Living in Tanzanian culture, he said that if he were doing chores to help his wife he would "keep it as a secret because if [his] friends know there will be shame". He believes that men in about 50% of the married couples help their wives with household duties. This statistic is likely not accurate, but his perception of the situation as an insider in a marriage is interesting. Based on his statement, it is likely true that other Tanzanians are not aware of the real number of husbands who help their wives around the house.

Tanzanian students felt that child raising, cooking and cleaning were more natural for women, while doing outside work is not as natural for them. One student from the focus group explained that it is a good thing that women do not have to go out "looking for cows… It is somehow natural." He immediately continued by stating "for example, getting pregnant is something a man cannot do." Since these three lines were part of his continuous thought process, it appears that this student is using evidence of a biologically determined responsibility (getting pregnant) as support for the notion that women should be working inside rather than outside with animals.

During the male focus group, most of the men made it very clear that they believe they are superior to Tanzanian women. The Tanzanian male students said that many women use the term '*bwana*', which means Lord, to refer to their husbands. When the researcher smiled at this, the students assured them it was not a joke, but instead it refers to the 'high class' of man. One male student who was interviewed also explained that his sister and he were respected by their parents equally as children, but as they grow up girls are supposed to respect men. And one female student interviewed said that the reason men don't cook and clean is because "men think they are superior so they refuse".

This suggests that sexism is not heavily stigmatised in Tanzania. Furthermore, responses derived from the focus group give the impression that some Tanzanian students, particularly males, are proud of being sexist and claiming their believed superiority over women.

Language Used to Rationalise Gender Inequality

Bonilla-Silva developed frameworks that are commonly used by Americans to rationalise racism. Applying these to the issue of gender demonstrates how individuals use a similar process to rationalise gender inequality. Ferber used Bonilla-Silva's frameworks in examining the gender ideology of United States citizens. She was able to apply all four frameworks, naturalisation, minimization, cultural [sexism], and abstract liberalism to the gender ideology of the US, implying that Americans attempt to avoid sounding sexist despite the reality that gender inequality does indeed exist. By analyzing the data collected from Tanzanian university students, it is possible to determine whether a similar process of rationalisation is occurring in their culture as well. The results from Tanzanian students demonstrated that three out of the four frameworks are commonly used; naturalisation, minimisation, and cultural sexism.

Naturalisation:

Although Tanzanian women never spoke of their gendered chores as natural in the interviews or focus group, the men in the focus group did use this explanation for the inequality. The actual term 'natural' was used a couple of times throughout the focus group session. The students did not seem to have a specific explanation for the naturalness they assigned to women's responsibilities; they simply explained that they were 'somehow natural'. As previously noted, when questioned for specific explanations, students provided the concept of 'getting pregnant', which 'is something a man cannot do'. The students attempted to make the argument that other inside chores like cooking, cleaning, raising children, are naturally a woman's responsibility simply because one biological process, getting pregnant, is only physically possible for females. Using naturalisation as an explanation for all women's responsibilities, allows Tanzanians to feel justified in assigning more tasks to women.

Naturalisation was also used by participants when discussing the disparity in the amount of respect given to females and males. The male students in the focus group were asked how they would respond if their future wives wanted equal respect from them, or even demanded equal respect of them. A member of the male focus group plainly stated, "if you deserve to be respected I will respect you naturally." Respect should not be demanded, he firmly believed. Most of the other members of the focus group concurred with the notion that respect should not be demanded by women. His argument used naturalisation to deny the gender inequality that has been socially constructed and maintained in Tanzania. By claiming that people are either naturally deserving of respect or not, the student is attempting to excuse the general lack of respect towards women in Tanzania. Instead of the blame for this inequality resting on the shoulders of Tanzanian men, it belongs to nature. Furthermore, something that is natural cannot be changed through social action. In other words, the naturalisation of gender inequality allows for the continuation of the problem because it is supposedly beyond human decision.

Cultural Sexism:

During the interviews students used various explanations for the gendered division of labour in order to avoid explicitly saying that their chores are divided in a sexist way. Almost all students described the gendered division of labour as 'Tanzanian culture' or 'African tradition'. The word 'culture' or 'tradition' was used by nearly every student interviewed in order to explain the current household labour division. When asked to explain further, no one could give a thorough response. A female participant from the focus group explained that the division of household labour is "a form of culture. They [men] won't be respected by the community [if] women are up." Others attempted to explain culture's role by stating that the household labour division is something their ancestors had done, which is probably the reason their parents maintained the same gender roles and passed them on. Many students did not see the passing of these traditions as problematic or worthy of critiquing. In response to the question "Why do you think the culture is this way?" (Regarding the gendered labour division) one student casually said, "Maybe from the past but we don't know why we are doing this." Students explained the unequal division of household labour as being caused by tradition and culture rather than by sexism.

Minimisation:

Regarding the issue of respect, minimisation was used to rationalise sexist interactions. One female who was interviewed felt that she was given more respect than her brothers by her mother. However, when it came to her father, the brothers received more respect. She believed this was due to the fact that they are older than her. Since the father's role in the family and in society is more powerful and influential than that of her mother's, it is likely that 'earning' the father's respect is more meaningful than earning the mother's. Since this student seems to disregard the power differential between her mother and father, it is easy for her to rationalise the lack of respect she receives from her father as fair. After all, she is receiving more respect from her mother, so it is only fair that her brothers receive more respect for her father. By ignoring the significance of gender, she is able to minimise her own situation rather than acknowledging the sexism that is at work within the family structure.

This student also used another form of minimisation. She described her brothers as receiving more respect from her father due to their age. Some of the other female students also explained that their brothers were given more respect than themselves, but they believed this was an issue of age rather than gender as well. By focusing on ageism as the culprit, students are minimising the significance that sexism plays in their culture. This allows the sexism to continue because it goes unnoticed. On the other hand, one male student mentioned that his sisters received more respect than himself because they were older. This suggests that age sincerely plays a role in Tanzanian culture, but whether gender tends to override age or *vice versa* is not strongly demonstrated in this data.

Abstract Liberalism, the fourth framework of Bonilla-Silva's, is not present in the study on Tanzanian university students. Since abstract liberalism is an idea based on values of individualism and succeeding based on one's own merit, it likely fits with American culture better than Tanzanian. With a more communal style culture, Tanzanians likely disagree with the American "not in my backyard" motto, which describes the attitude that change is okay as long as it does not effect *my* life. The fact that Ferber was able to recognise all four frameworks being used in the US whereas this study found that Tanzanians only seem to use three of the frameworks, suggests that there is less stigmatisation of sexism in Tanzanian culture. This finding, is supported by the lack of inhibition Tanzanians felt towards talking about the superiority of men. If sexism is less stigmatised and therefore more socially acceptable in Tanzania than the US, Tanzanians do not need to deny or justify the gender inequality by using these frameworks. Since the frameworks are a way for individuals and societies to overlook and deny the reality of a problem like sexism, they should be more commonly used in countries where sexism is stigmatised although it continues to exist, like the United States.

Discussion

The difference between Tanzanian men and women's desires for the divisions of household labour helps explain why the transition to a more egalitarian division is not occurring. As the primary holders of economic and political power, men are ultimately the decision-makers regarding social expectations and norms. The dominating role of men was also demonstrated by their lack of attention to the egalitarian desires of women. By ignoring or disallowing the expression of women's opinions, men can continue promoting the same norms, values, and gendered divisions of labour that have historically benefited them.

Similarly, with the transition from women working solely inside the home to receiving more education and working at paid jobs, their responsibilities have now doubled. Rather than logically dividing the household labour equally between men and women, the cultural expectations have remained static, which promotes the continued privilege of men. The fact that neither females nor males denied that women indeed work harder than men suggests it is true that Tanzanian women are working more than their male counterparts. Since women are working harder than men, they are probably less capable of sparing energy to analyze their situation as the primary labourers with little payback, or to fight against this inequality. As Baxter pointed out, the overwhelming responsibilities of women decrease their ability to gain economic or political independence, and because of that they do not have the capabilities to effectively advocate against their situation (1997).

Another contribution to the continuation of disadvantageous gender norms, and division of labour in particular, is the perception of the situation compared to the reality. Tanzanian men were quick to assume that men have all of the control in a marriage and provide little assistance to their wives. However, one male student that was already involved in a marriage, along with many female students explained that the reality can be very different. They provided examples of women who made their husbands help with household duties. And these individuals perceived this marriage dynamic to be common, whereas other male students, who had not yet been involved in a marriage, perceived the situation to be strictly aligned with the cultural expectations. Although, neither perception can be generalised to describe the reality of what is actually occurring within Tanzanian marriages and homes, it can be determined from this study that the reality for many families is inconsistent from the perceptions of many individuals.

It is likely that the inconsistency between perceptions of the division of labour and the reality helps reinforce the *status quo*. Since men are the decision-makers and the privileged members of Tanzanian society, the majority of those men who have preconceived notions that the traditional gender roles are the norm, they will likely ensure that their expectations will be met. On the other hand the perception of many women that the gender roles are changing makes them content with the current situation. It also allows sexism to continue because the women do not see the need to fight against the situation.

Minimisation, naturalisation, and cultural sexism contribute to the problem of sexism by allowing the complexity of inequality to be overlooked. Instead of Tanzanians viewing the gendered division of labour as a social construction that privileges men most people see the division as being derived from natural processes or choices. Additionally, using culture and ageism instead of sexism to explain the gender inequality provides more forgivable explanations. These frameworks prevent people from focusing on the central problems leading to inequality, which often allows individuals to overlook inequality all together. Inevitably, the use of these frameworks perpetuates sexism and the inequality of the division of labour in Tanzania.

For future research on the gender norms and inequality in Tanzania it would be beneficial to collect data from a random sample of Tanzanian university students. This would allow for generalisable data. In addition, a larger sample would also be useful since it would make the data more reliable.

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SAVIOURS and SURVIVORS: Darfur, Politics and the War on Terror

Mahmood Mamdani

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Reviewed by
Lwalzi Siyabonga Lushaba
Political Science Department
Fort Hare University
Alive, 5700
Emal: taungnguru@yahoo.co.uk or llushaba@ufh.ac.za

In February 2003, the Durfur Liberation Front (DLF), later to change its name to Sudan Liberation Movement/Army (SLM/SLA), attached and seized the town of Gulu. In response, the Sudanese government launced a brutal counter insurgency. Even though a history of the conflict in Darfur extends a decade and a half earlier to 1987, it was the violence of the 2003 counterinsurgency which turned Darfur into an object of a concerted global campaign/discourse. Genocide and justice were two coordinates upon which hinged this global discourse. If the Save Darfur Coalition (SDC), western media and American officialdom christened the crisis genocide, the International Criminal Court (ICC) harped on justice – punitive justice, that is.

To validate the genocide claim, western organisations and their intellectual sponsors appealed to colonial historiography. From the intellectual labours of colonial historians had emerged a history of Sudan whose hallmark was the bifurcation of that society into settler Arab and native African (Zurga) races. Locked in a Hegelian dark past, went the logic of this historiography, native Africans signified stagnation to be liberated from it and civilized by settler races, in this case Arabs. 'Arabisation' within which Arab identity acquires an imperical status. Drawn to the present, this narrative impels us to this of the crisis in Darfur as conflict between imperial Arabs and subjugate native Africans.

In July 2008, the ICC indicated President Omar Hasan Ahmad al-Bashir for, amongst other crimes, conspiracy to commit genocide. For those captivated by the racialised narrative of imperialist Arab-Zurga relations handing over President al-Bashir to the ICC set both the inner and outer limits for justice.

In his timely book, *Saviours and Survivors,* Mahmood Mamdani, subtly but intensely persuades the reader to rethink many of the assumptions that have driven the post-2003 discussions of Darfur. The book is made all the more important by its significance beyond the theoretical. At an intellectual level, its major accomplishments are to dispel the myth that the people of Sudan have always been or are best categorised into members of different races, Arab and Zurga, to show that there is not singular history of Arab groups in Sudan, and lastly to marshal sufficient evidence behind the argument that slavery rather than being a foreign Arab institution, was largely a local Fur one (section 2). At level of praxis the book exposes, within the context of Darfur, the folly in the failure to transform the tribal world of natives – a subject of the author's earlier book *Citizen and Subject.* For weak African states there is in the post-Cold War humanitarian order a real risk of their sovereignty being subverted by the benevolent international community under the pretext of protecting vulnerable populations, the book similarly warns (pp. 271-300).

Setting this work apart from other on Darfur is the dexterity with which the author negotiates his way through grim facts of killing, death and human suffering without letting emotive and moral considerations obscure reason. From an incredible mass of evidence and an expansive array of sources, Mamdani weaves together a timeless treatise presented in accessible jargon without, however, compromising scholarly prescience. Composed of eight chapters, excluding the introduction and conclusion, the book is divided into three sections. The first section interrogates the origins and politics of the Save Darfur Coalition. From inception the SDC shared with official America a single-minded determination to label the conflict in Darfur 'genocide'. However, the number of those dead does not lend credibility to the claim (pp. 25-39). Neither does the United Nations International Commission on Inquiry on Darfur. In its January 2005 report it found that, "the Government of the Sudan has not pursued a policy of genocide… directly or through the militias under its control" (p. 42). Irrespective, the SDC and official America were not deterred. Why and what were the consequences thereof? These questions hold the author's intellectual gaze in the first section of the book.

The second section opens with a survey of two observable strands of Sudanese history-writing. Harold A. MacMichael, an accomplished British colonial administrator, best represents the views of the colonial school. For him, "the history of Sudan before colonialism involved and interaction between native and settler races, with Arab races domination – and civilizing – non-Arab natives" (p.86). Dominated by archaeologist and historically inclined anthropologists the second school, whose lead the author's follows, emerges as a critique of colonial historiography (p. 93). Studying the history of communities from below, the author maintains that there is not "one singular history of Arabs in Sudan but multiple histories" (p. 108). Contrast, for example, riverine Arabs who are settled peoples with Arabs of southern and northern Darfur who are cattle (the Baggara) and camel (the Abbala) nomads respectively. The end-results are multiple local histories; where, in riverine Sudan Arab is an identity of power whilst Darfur Arabs are marginal to power (p. 108).

British colonialists rationalised the shift toward a tribal system of property and governance, instituted under rubric of indirect rule, as a return to authentically African social informations. To refute the claim, the book traces the history of the Dar Fur Sultanate from around the mid-1600s with particular emphasis on the Keira dynasty. To consolidate its hold on power, the Keira dynasty took several measures which invariably led to the detribalisation of Dar Fur. These include; dismantling the old tribal land ownership structure and instituting in its place a new land ownership title known in Arabic as *hakura* given mostly to the new hold man (*fuqara*); promoting Islam as an alternative ideological system to kinship solidarity thereby welding together a wider transtribal Islamic community (*ummah*); and recruiting officers into the royal army and other institutions of control from the slave ranks meant to free the king from kin-based authority and power (00. 114-136). As a consequence when the Sultanate of Dar Fur collapsed after two-and-half centuries in 1874, Dar Fur was a detribalised community. It is the detribalised pre-colonial Dar Fur that the British would, against the flow of history, seek to retribalise (chapter 5). It is the retribalised society that successive post-colonial regimes reproduced rather than reform.

The last section of the book interrogates two tendencies within the western sponsored discourse on Darfur. First, is the depiction of the war in Darfur as if it was an exclusively north Arab versus south Zurga conflict. Indeed, the conflict was initially between darless camel nomads (Abbala) of the north and the dar-owning sedentary tribes of the south. But, to emphasise only the north-south is to silence the south-south axis of the conflict between dar-owning and darless cattle-nomad (Baggara) tribes of the south. On the balance of evidence this elision was neither coincidental nor driven by ignorance. Acknowledged, it posed the danger of unsettling the racialised Arab-Zurga dichotomy crucial to the genocide claim (pp. 231-243). Second, is the tendency to define justice in retributive terms as though all knowledge gained from theories of transitional justice and the experience of post-conflict societies like Rwanda and South Africa hold no lesson for Sudan (pp.282-288).

Four propositions sum up the book's major arguments: (a) the conflict in Darfur was not a racial one between Arab and Zurga; (b) its causes were numerous including a long environmental crisis which saw the desert encroaching onto northern Darfur thereby pushing Abbala tribes further south; (c) its brutality was a function, not of biology but, militarisation of the region during the Cold War (chapter 7); and (d) the solution to the crisis can neither be a military one nor a single-minded pursuit of justice to the exclusion of reconciliation (conclusion).

One, however, cannot fail to observe, perhaps with consternation, that once the discussion shifts to the post independence period, in the sixth chapter, the people below lose the agency. In a book which scores it's intellectual distinction by pleading the case for the insertion of multiple subaltern histories in the discourse on Darfur that suddenly the national, as opposed to multiple localities, become the loci of politics with every other development deriving its meaning of becoming explicable relative to it, is unsettling. Simply the question is, as various post-independence regimes in Khartoum reproduced the tribalised colonial Darfur that had the Keira dynasty been detribalised what were the ebbs and flow in the politics of the governed below?

Noting the effects of the British policy of governing the north and south Sudan as two distict cultural spheres Mamdani writes; "whereas the southern elite saw itself in parochial terms, as no-Arab and southern, the northern elite saw itself as Arab and national (that is, Sudanese)" (p.178). Policies pursued by the northern elite, which has dominated power since independence, including a *de facto* declaration of Islam as state religion and proclamation of Arabic as the official language, pose a challenge to the author's conception of a Sudanese national identity. What are the norms, boundaries, codes and symbols of this national Sudanese identity - are they ethnic, cultural, religious or civic/political? Or, simply, is being Sudanese tantamount to being an ethnic Arab, as the author implicitly suggests?