Campaign to End Fistula with special focus on Ethiopia – A walk to beautiful[1] Is there a role for ultrasound?

Christian Pállson Nolsøe, MD PhD
Herlev Hospital, University of Copenhagen, Denmark

Young Mother by Christian Pállson Nolsøe

Yea, though I walk through the valley of the shadow of death…
Psalm 23,4 (King David of Israel 1000–970 BC)

"In an unequal world, these women are the most unequal among unequals"[2]

Introduction

A scourge from time long past that we thought removed from the surface of the earth has affected humanity again, or more correctly, part of humanity. A misery so all-embracing that it is incomprehensible to people of the Western world is everyday reality for hundreds of thousands of young women in Africa and other parts of the developing world. A disease by the somewhat strange name of obstetric fistula (OF), also known as rectovaginal or vesicovaginal fistula,[1] afflicts more than two million women in low-resource countries and the most remote parts of the world, while at the same time is totally absent in high-income countries.[3]

A fistula by definition is a false exit from cavities or tubular structures inside the body to the outside world or in-between internal structures that arises due to disease or physical damage. An obstetrical fistula is either a connection between the rectum and the vagina that allows stool to pass unhindered or a connection betwen the urinary bladder and the vagina that allows urine to pass. The term 'obstetric' derives from the fact that these fistulae are caused by tissue damage due to prolonged labour. To the vast majority in the West it is not even known. However, anyone who has ever visited a medical history museum will probably recall the horror by which one was struck when observing the instruments used for cutting up the (almost always dead) fetus in case of obstructed labour, and with little doubt, at the same occasion thought these doctors must have been some kind of monsters. Little did we know that the condition which called for the use of these cruel instruments still exists and affects thousands of birth-giving women, mainly in Sub-Saharan Africa and South Asia every day. Only the instruments, luckily, are no longer in use, but neither is the modern alternative available in these parts of the world. This very, very unlucky scenario causes the unbelievable suffering of millions of women through the complications of OF. Of course today in the West, treatment would involve the timely help of a midwife and, if necessary, a caesarian section performed by an obstetrical surgeon.

With this prologue, I wish to emphasise that being a young girl or an adolescent woman living in rural areas of contemporary Africa may very likely mean exposure to several forms of negative discrimination that inevitably decreases odds for leading a prosperous and happy life. Obstetric fistula especially afflicts impoverished girls and women living in remote regions without adequate medical services. Affecting the most powerless members of society, it touches issues related to reproductive health and rights, gender equality, poverty and adolescence.

Aim

Obstetric fistula[2] is a classic example of how gender discrimination may manifest itself in Africa and this has become especially evident in Ethiopia through the fantastic work done at the Addis Ababa Fistula Hospital. In other words, the scope of this article is OF in general and how this can be viewed from an Ethiopian angle in particular. This is also an excellent opportunity to showcase discrimination due to lack of education, funding and personal empowerment in the local community and how this may come to play a crucial role in very real situations. This inequity is evident in many aspects of daily life and influences vital areas such as economy, age, religion and above all gender. I hope with this article to present the problem, describe the major players as I see them, the actions and efforts they engage in and finally to analyse and discuss the future. I will build my case with an emphasis on the work of Reginald and Catherine Hamlin as it is told by themselves and reported and communicated in various ways by others. Their efforts jumpstarted the fight against OF. It took 40 years – so perhaps "tumble-started" would be the more correct metaphoric term.

Deliniation of the subject

I believe a historical overview is necessary to understand the present status but in realisation of the vastness of the subject I have chosen to limit the scope of this synopsis to cover merely a few of the many international aid organisations and non government orgainisations (NGOs) that are actively participating in the process today. Undoubtedly, one of the biggest and most influential organisations involved is the United Nation Population Fund (UNFPA) whose Campaign to End Fistula launched in 2003 is at the problem's coalface. Just to give an idea of the scale of this humanitarian effort the list of partners and sponsors involved – 89 in total – can be found at http://www.endfistula.org/public/pid/7439.

It is of course impossible even to list the achievements of all these players, however, aside from UNFPA I will to some extent involve in the analysis efforts made by organisations and institutions such as the Hamlin Fistula International and Addis Ababa Fistula Hospital, The Fistula Foundation and the Worldwide Fistula Fund.

Presentation of the problem

Of all the morbid conditions that can befall a woman following labour, suffering an OF is one of the most debilitating and devastating. In describing the terrible consequences of the condition Catherine Hamlin in her autobiography *The Hospital by The River*[4] gives a heartbreaking insight into the life and fate of one victim of OF in the remote northern region of Ethiopia:

"Ambaye visited several villages on an outreach trip to Gondar. In one, she and the team were led to a dilapidated hut away from the others. The whole structure was leaning to one side and looked as though it was about to collapse. Inside, crouched in the dark, downcast and listless, was a young woman, Anawa. She told them she had been married at 12 and was pregnant at 13. After a long labour her child was born dead, and she was left with a double fistula, incontinent of urine and bowel contents.

'What about your husband?' enquired Ambaye.

Tears welled up and trickled down her cheeks. 'He destroyed me and then he left'.

Amawa's mother looked after her until she sadly died, leaving her daughter to endure her affliction alone. She had been told there was a hospital in Addis Ababa where she could be cured, but she did not have the bus fare. When the outreach team found her she had been in this condition for 12 years. They arranged for her to go to a local hospital where Ambaye operated successfully." p 257

Amawa is a typical OF patient. She is pregnant before her body and pelvic bones are fully developed. She is poor and lives in rural Ethiopia, many kilometers and days of travel by bus away from qualified obstetric service.

Obstetric fistula – what is it, and how does it affect daily life?

Obstetric fistula is a complication of obstructed labour, an unfortunate condition that occurs in 5% of live births and is one of the major causes of maternal mortality and morbidity. For every maternal death it is estimated that 20 women suffer damage due to complications of obstructed labour and of these OF is one of the most common and certainly most dreaded injuries. Obstetric fistula is a hole in the birth canal caused by damage to the walls of the vagina when the presenting part of the baby, usually the head, causes the soft tissues to be impacted and compressed towards the mother's pelvic bones. This results in critical decrease in blood supply, leading eventually to tissue necrosis and subsequently an opening to adjacent organs, i.e. fistula formation. Most frequently the hole is between the vagina and the urinary bladder i.e. a vesicovaginal fistula but it can also form between the vagina and the rectum in which case a rectovaginal fistula is the result.

In both instances the contents of the organ will unfortunately flow unhindered to the vagina and involuntarily to the outside world. This of course results in the most offensive, humiliating but also uncontrollable odour being emitted. The continuous urinary and/or faecal dribbling excoriates the adjacent genital areas resulting in painful rashes and skin wounds. Often this constant leaking and unbearable stench is confused with venereal disease or interpreted by the village people as punishment from the gods for misbehavior or adultery on the woman's part, and soon she may find herself abandoned by her husband and rejected by her community.

As if this was not enough suffering, the woman also finds herself mourning the loss of her baby because in most of these cases the child is stillborn, even worse she may never bear another child. Her condition very often prevents sexual relationship and even if her husband was still interested she may often experience inability to become pregnant due to vaginal damage or amenorrhea.

It is crucial to notice that obstructed labour always ends! In rural Africa obstructed labour may often result in death or significant physical damage to the mother, her baby – or both. Furthermore when the mother survives obstructed labour only to develop an OF, statistically the baby is stillborn in more than 90% of cases.[5]

Most OF occur among women living in poverty in cultures where a woman's status and self-esteem may depend almost entirely on her marriage and ability to bear children. Despite this withering impact on the lives of thousands of girls and young women OF has largely been neglected, even in the parts of the world where it is most frequent.

Epidemiology and socioeconomic consequences.

It is estimated that two to three million young women live with untreated OF in sub-Saharan Africa and South Asia and each year, between 50,000 to 100,000 new women worldwide develop

OF.[6–8] A simple calculation can tell us that at the world's current capacity to repair fistula, it would take at least 200 years to clear the backlog of patients, provided that there are no more new cases. However, in the face of 100,000 new cases per year, the reality is that the need for treatment of OF will never be met at the present pace. On the contrary, numbers will keep increasing.

Looking at Ethiopia solely, the numbers do not present a more optimistic scenario. Ethiopia has a population of more than 85 million and estimated three million births per year and is one of the poorest countries of the world with five physicians and two midwives per 100,000. Information from UNFPA. Available at http://www.unfpa.org/sowmy/resources/docs/country_info/profile/en_Ethiopia_SoWMy_Profile.pdf Accessed 11th January 2013. By comparison these figures for Denmark are 5.6 million population, 60,000 births and 366 physicians per 100,000. In Ethiopia[3] alone an estimated 100,000 women need OF surgery and every year about 8900 new cases are added. This means even with a reported surgical capacity of 2500 patients per year at Addis Ababa Fistula Hospital, the world's largest fistula-only-facility, the outlook is bleak and in essence 6400 new cases are added to the backlog each year. However, those patients who make it to this Hamlin-founded facility or an equally successful hospital where OF repair is performed can expect a more than 90% cure rate.[9]

Tragically, the cost of saving the lives of one of these abysmally poor women by a surgical fistula repair is stunningly low by Western standards. At reported rates of $US300–600 in different places in Africa, this would not cause any considerable trouble for most people in Europe, and actually, in most places both surgery and all additional costs of the fistula hospital are covered by charity funding from government programs or NGOs.

However, in most cases speculation over the cost of the surgical treatment itself is not what prevents the OF patients from seeking help. Foremost, this is caused by something as banal as lack of knowledge. Patients or rural people in general simply do not know the condition can be cured and when they find out the next insurmountable obstacle is another, to westerners seemingly, very simple problem: How do we get there? The nearest road in many places in Ethiopia and the rest of rural Africa the may be one or two days' walk and after that there are hours and maybe days by bus to the fistula facility. But the biggest hindrance may actually be the bus fare!

In the meantime, women who experience this, theoretically speaking, both preventable and curable condition continue to suffer constant incontinence which often leads to social isolation, skin infections, kidney disorders and even death if left untreated. Leading life as social outcasts, these women rely on begging or the random mercy of relatives and friends. Even in the event of a successful operation, their social status may still be threatened and since many have been abandoned by their husbands or divorced, an OF treatment program will have to include social and socioeconomic rehabilitation in order to be truly successful. In other words the operated women should receive some kind of work training, education or employment opportunity, and not just sent off home.

Obstetric fistula can almost completely be avoided by delaying the age of first pregnancy till the bony structure of the girl is mature and by timely access to quality obstetric care including educated attendance at birth and availability of emergency cesarean section when obstructed labour cannot be relieved by vaginal birth. In addition, general improvement of nutritional status and education will both greatly enhance the odds for an uncomplicated pregnancy and labour.

Medical community awakening and international outreach

Because OF affects some of the most marginalised groups in society i.e. young, poor and uneducated or even illiterate girls and adolescent women in rural areas and remote parts of Africa and South Asia, it has remained a more or less 'hidden' condition. And hidden they have been, these miserable women have been hidden by their family and neighbors because of the smell and perhaps the fear of bewitchment, hidden by themselves out of shame and hidden by the international medical community due to negligence. Thankfully, they are not as hidden anymore.

Campaign to End Fistula and UNFPA

An increasing number of newly launched initiatives are published and broadcasted on different media. One such initiative is a short documentary movie with the title *Hidden no longer*. This film tells the story of four women from French speaking countries in Western Africa and is part of the United Nation Population Funds Campaign to End Fistula. It can be accessed online at http://www.endfistula.org/public/pid/7447?feedEntryId=24552.[10] If you have the attention of the UN you are truly hidden no longer. And if they dedicate an entire campaign to your purpose alone and to help cure your ailment exclusively, other people may think you walk in the light.

Happily, the problem of OF is hidden no longer. It is strange how a condition can be totally erased from the collective memory just because it no longer occurs in one's own backyard. No more than 150 years ago, the curse of OF was equally frequent in the western world as it is today in countries like Ethiopia. However, it was eradicated from the list of diseases that threaten women of today's high-income societies due to general improvement in standard of life and in particular public health and modern obstetrical services. Today, OF is practically never encountered by medical professionals in the rich part of the world. This is probably also the reason why it has taken so long to mobilise anew the international medical community as well as international aid organisations and NGOs. However, what was started by Catherine and Reginald Hamlin back in Addis Ababa in the 1960s is now finally bearing fruit.

The United Nations Population Fund in 2003 launched its Campaign to End Fistula initiative with an almost endless list of partners spread out over the world. In short the UNFPA's mission can be expressed as "to deliver a world where every pregnancy is wanted, every birth is safe and every young person's potential fulfilled". Thus, the Campaign to End Fistula appears to be naturally contained within the UNFPA's scope and is in accordance with the Millennium Development Goals (MDG) set up by their mother-organisation the UN itself, especially *MDG 2: Promoting gender equality and empowering women* and *MDG 5 Improving maternal health*.

The campaign has succeeded in drawing attention to the issue of fistula on multiple levels[11]and must continue to do so if the goal of ending fistula worldwide will be reached within a reasonable time, whatever that may be defined as. No doubt the task is big, very big, but the needs are even bigger. Fulfillment of the aim will call upon

participation on all levels from policymakers and health officials over affected communities and individuals to the public in general.

The Campaign has made remarkable progress and presently in conjunction with its approximate total of 89 partners, is working in 50 countries across Africa, Asia and the Arab region. Ending fistula worldwide will demand political interventions, additional resources, and strengthened collaboration between governments, their partners and society.

In each country, the campaign focuses on the three key areas prevention, treatment and rehabilitation. The goals of a mission this magnitude can only be achieved by effective, flexible and wholehearted collaboration in between a multitude of partners. This is probably also the explanation for the length of the Campaign-to-End-Fistula-list. A few selected partners are described in some detail in the next sections, in particlular Hamlin Fistula International because it is the original body involved in the treatment of OF. The Fistula Foundation and Worldwide Fistula Fund are also noted as they belong to what might be labeled "premier league" fistula NGOs in Africa plus they are both very visible when surfing the net for information.

Background and Hamlin Fistula International

The contemporary rediscovery of OF must be solely attributed to Australian/New Zealander couple Drs Catherine Hamlin and her late husband Reginald who arrived in Ethiopia in 1959 on a short term contract to start a midwifery school but found themselves entangled in the overwhelming problem of OF. In 1959 they founded the Addis Ababa Fistula Hospital which has been a huge inspiration for new OF facilities in other places in Africa and South Asia. This was the world's first, and for many years, only medical center dedicated exclusively to providing free OF surgery.[12] The facility[13] to this date has operated on more than 34,000 women suffering from childbirth injuries. They also co-founded an associated non-profit organisation, Hamlin Fistula, to raise funding for continued OF work.

In her autobiography *The Hospital by The River: a story of hope*[4] that was published in 2001 and went on to become an international best seller, Catherine Hamlin tells the story of their life and mission. Her book attracted huge attention and drew international aid organisations' focus on the developing countries' very limited capacity to help the many sufferers of OF. In the book, Catherine Hamlin frames the scenario and the Hamlins' commitment by quoting the parting line of the doctor they were replacing: *"The fistula patients will break your heart"* p 10.

As it turns out the Hamlins' endeavour has had influence not only on the world of obstetrics and public health but has also put its mark on public opinion, inspiring an award-winning film[1] and best-selling literature.

Catherine Hamlin has been described as a modern day Mother Teresa by *New York Times* columnist Nicholas Kristof two times Pulitzer Prize winner and co-creator of the Half the Sky movement. She appeared in January 2004 on the Oprah Winfrey television show and this was followed up in December 2005 by another episode for her show where Oprah Winfrey travelled to the Addis Ababa Fistula Hospital and filmed the interview on location. She has received many medical and honorary distinctions and in 2009 she was awarded the highly esteemed Right Livelihood Award, also called the alternate Nobel Prize.[14]

She can even put the Australian-born Crown Princess Mary of Denmark on the list of celebrities that promote her cause since the Crown Princess became UNFPA patron as of June 2010 where she participated in the Women Deliver Conference and met with fistula survivors at her first official mission. Much more importantly though, the Crown Princess continues to promote the quest against OF suffers such as when she recently appeared in the Danish magazine *Billedbladet* with multiple articles on her visit in Mozambique November 2011.[15] Here among other duties as UNFPA patron, she visited a fistula hospital in Beira and participated in the clinical rounds. During her visit she delivered this very straightforward address to the public: "It is my hope that the stories of these fistula survivors will help inform and create greater understanding of what a fistula is, and that families, communities and leaders will do their part to prevent new cases in the country". Through her great visibility in the press, not neglecting the tabloid part of it, the Crown Prince Mary's advocacy of the OF cause in the broad media is of tremendous value to increasing the knowledge of this terrible disease.

Another very similar but probably much more widely known example is the film cited in the title of this article *A Walk to Beautiful* by Steven Engel http://www.youtube.com/watch?v=3w-fOmovijc.[1] This feature-length Emmy award-winning movie draws attention to the dreadful situation endured by innumerable women suffering with OF in Africa and in the case of *A Walk to Beautiful*, especially in Ethiopia. The film tells the stories of five Ethiopian women with OF who fight, rather than find, their way to the Addis Ababa Fistula Hospital and the free treatment offered to them at this facility. For some of the women this journey took years of unnecessary suffering, because they could easily have been cured from the very start, or better yet, have avoided the ailment altogether had the proper maternal health care and community knowledge been available. The film also can be regarded as a tribute to Drs Catherine Hamlin and her late husband Reginald Hamlin in as much as the Addis Ababa Fistula Hospital was founded by them and still, at age 89, has Dr Catherine Hamlin operating as a fistula surgeon on a weekly basis.

Along the same line of thinking is the value of publicity that derives from best-selling fictional literature. In the *New York Times* bestseller *Cutting for Stone*[16] debut author Abraham Verghese narrates a beautiful and yet dramatic story about a pair of twins, Marion and Shiva Stone, born in Ethiopia before the revolution as a result of the forbidden and secret love between a beautiful Indian nun and a harsh British surgeon. Orphaned at birth by their mother's death due to obstructed labour, and their father's disappearance in shame, they are brought up by doctors at the missionary hospital called 'The Mission', where they were born. Bound together by a shared fascination with medicine, the lives of the twins as well as the place and time of the story reflect the entire scenario of OF as experienced in real life by the Hamlins. Their mother dies from obstructed labour and both her sons relate to the one disease she most likely would had suffered had she survived i.e. OF. One twin bears the name Marion, coincidentally the name of the surgeon regarded by many as the father of fistula surgery, 20th century American physician Marion Sims.[7] The other twin, despite not being a medical doctor by education and exam becomes a world famous fistula surgeon, reflecting the fact that dedicated and skilled persons can be trained to master OF treatment, or at least,

handle important aspects thereof. This could greatly enhance the future prospects of establishing surgical centers in Ethiopia and the rest of Africa to treat the many thousands of OF patients. The character Shiva has a real life equivalent, in *The Hospital by The River* we learn of Mamitu, once an OF patient herself, who stays on after her cure and becomes a competent fistula surgeon. She was even awarded the Gold Medal of the Royal College of Surgeons together with the Hamlins, which is a tremendous honour. Finally, as a curiosum, the name of the fictional hospital in the novel is 'Mission' and the Hamlins never hide that they were working out of Christian charity.

Hamlin Fistula International was founded by Drs Reginald and Catherine Hamlin in 1974 and oversees the Addis Ababa Fistula Hospital including a long-term care facility at this hospital, plus five mini-hospitals geographically spread out in rural areas of Ethiopia, to help overcome the problem of transportation. In addition, women with severe fistula injuries, who cannot be cured completely, receive an opportunity to lead a meaningful life. Seventeen kilometres outside Addis the rural village Desta Mender ('Village of Joy' in Amharic) has been built to provide a home for chronic patients, providing rehabilitation and training in income-generating activities to allow these women to continue life with dignity despite their disabilities. Some of the girls even receive training to become nurse-aides themselves. All services and treatment at these facilities are provided free of charge. Fundraising issues relating to OF repair surgery is also overseen by the organisation.

A midwifery school was established in 2007 to educate skilled birth attendants, and these maternal health workers are expected to greatly help reduce the number of new fistula patients. The hospital also provides training to medical students, local health workers, and international specialists. The Addis Ababa Fistula Hospital has a 120-bed capacity, but allegedly, at times has two patients in some beds. The facility treats more than 2500 women on an annual basis and works closely with them to support their transition back to society. More than 34,000 patients have been treated to date. The organisation also maintains a database to support ongoing research, technique development, and publication. Partner organisations in eight countries including Australia and New Zealand, fundraise and raise awareness about fistula. Most of these organisations have their own website that can be accessed individually and while it seems the main Hamlin Fistula International website at www.hamlinfistula.org has ceased updating information as of 2009 the others have not. The best overview of these sister organisations within the Hamlin Fistula International is found at the UK site www.hamlinfistulauk.org where links to the others are easily found. The easiest access to a newsletter directly from Catherine Hamlin herself containing the latest information about OF work in Ethiopia is at the Australian website www.hamlin.org.au (all three websites accessed 12th January 2013).

Some other NGOs

The Campaign to End Fistula has a total of 90 partners covering a range of organisations such as NGOs, non-profit organisations, international service organisations, corporations, teaching institutions, medical associations and religious communities plus a number of individual independent state governments aside from the UN itself. The entire list can be found at their website. Below is a short run down of two of the main hands-on organisations dedicated to helping fistula patients.

The Fistula Foundation – www.fistulafoundation.org – is dedicated to eradicating OF by raising awareness of the condition and raising funds for fistula repair, prevention, and educational programs worldwide. They claim, "We believe that no woman should have to suffer a life of shame and isolation for trying to bring a child into the world". The foundation started out in 2000 as a fundraising organisation to support solely the work done at the Addis Ababa Fistula Hospital, which American founders Richard Haas and daughter Shaleece had visited and found compellingly competent and compassionate in their help to OF patients.

From there the movement seems to have grown by itself and in 2009 the Fistula Foundation broadened its mission to fight fistula worldwide. However, it has remained the largest supporter of the Hamlin Fistula Hospital in Ethiopia for the last five years, allowing it to provide free OF repair to any woman in need coming to the hospital. Today, the foundation supports OF programs in a total of 18 countries spread out over Sub-Saharan Africa and South Asia making this NGO the largest private charitable foundation supporting fistula treatment globally.

In 2012, The Fistula Foundation was able to include four new countries in their program; Nepal, Somaliland, Zambia and Pakistan. Also in 2012, a new tool in the fight against OF was launched. In a three-way endeavour with Direct Relief International, UNFPA and The Fistula Foundation, the world's first Global Fistula Map was created. This web-based interactive map can be accessed online at http://www.globalfistulamap.org and displays fistula treatment centers across Africa. It is an initial effort toward a comprehensive fistula care map and it is met with great expectations as it can possibly guide NGOs to better channel funds to sites and organisations that have the greatest capacity to provide fistula treatment.

The Fistula Foundation also helped sponsor Engel Entertainment's *A Walk to Beautiful* the stunning film about OF and the care provided at Addis Ababa Fistula Hospital.

The Worldwide Fistula Fund (WFF) is a NGO founded in 1995 by Dr L Lewis Wall initially under the name of The Worldwide Fund for Mothers Injured in Childbirth. It was re-launched as the easier-to-remember Worldwide Fistula Fund in 2003. The WFF has focused on helping OF treatment, prevention and rehabilitation in western Africa, particularly Niger. The WWF opened The Danja Fistula Center last February in this extremely poor French speaking country and expects to provide OF repair and additional help to 2500 women within the next five years. In addition, the facility will function as a training and research centre for medical professionals. The intention is to replicate this Center in other developing nations. This newly built facility has 42 beds and the operating theatre is capable of accommodating three simultaneous operations. Like the Addis Ababa centre the Danja Fistula Center is special in that it treats OF exclusively. This allows the medical team to excel in OF surgery and provide excellent care to these women even in the context of limited resources. The WWF was also a sponsor of *A Walk to Beautiful*.

Medical ultrasound and obstetric fistula

Despite the fact that ultrasound scanning is by far the most frequently used diagnostic medical imaging modality worldwide in evaluation of both the female pelvis and the fetus, only very

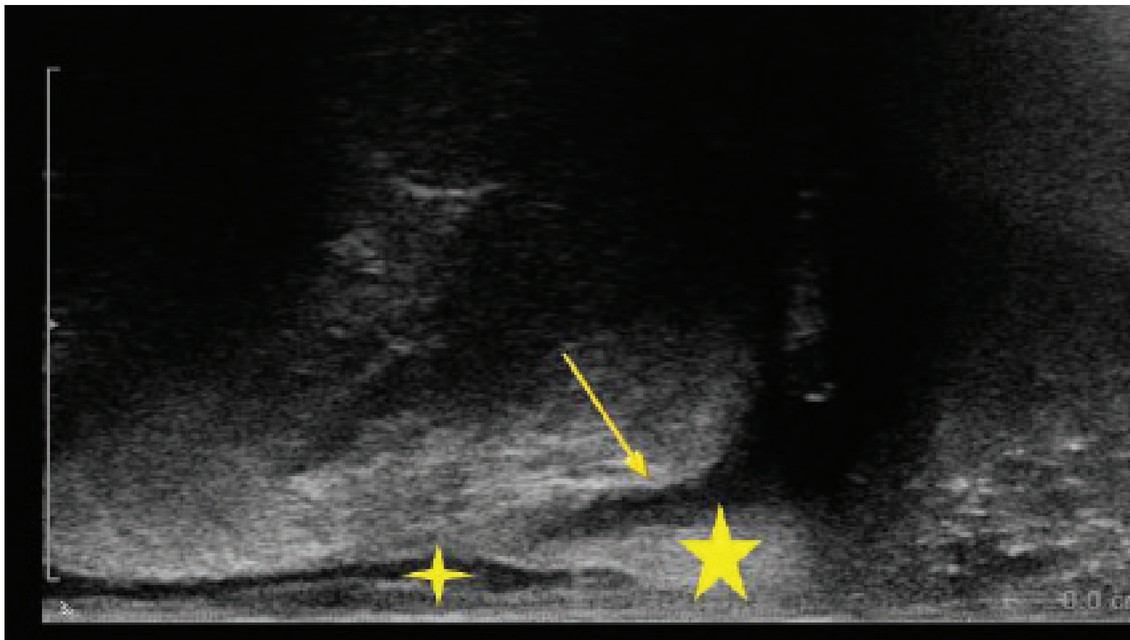
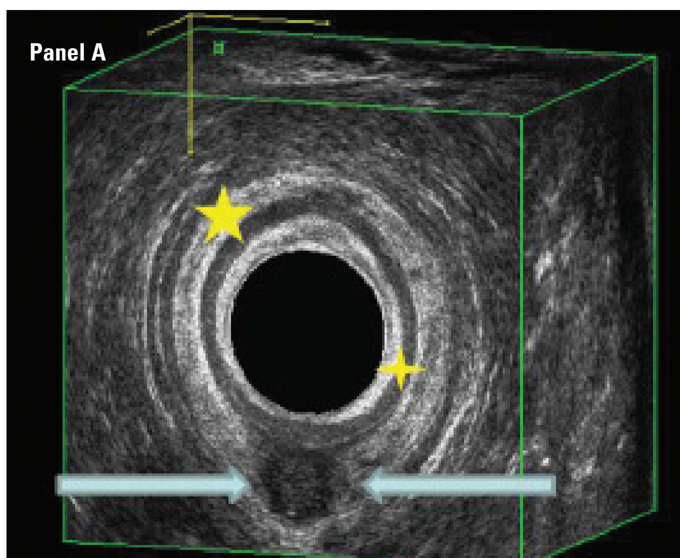


Figure 1: Trans rectal ultrasound examination with linear array, sagittal image showing a trans-sphincteric perianal fistula (arrow) extending from anal canal cranially through the usually echorich external sphincter (large five-pointed star) to skin surface at nates. Small, four-pointed star indicates internal sphincter with its usual echopoor appearance.



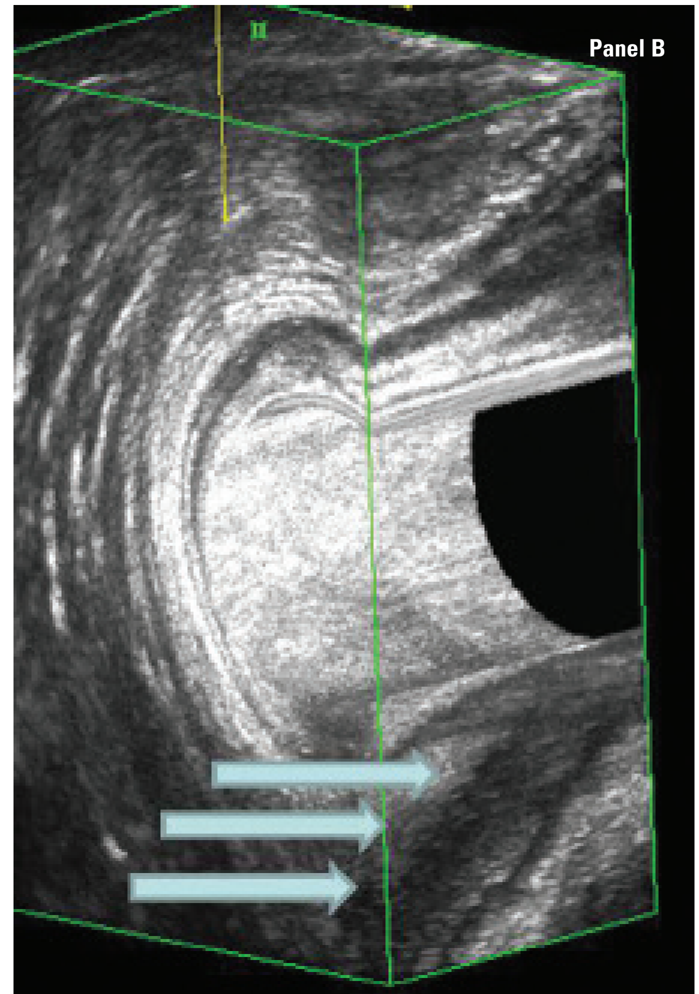


Figure 2: Trans rectal ultrasound examination examination with 3D reconstruction of an intersphincteric perianal fistula. Panel A: Transverse section with arrows pointing to fistula situated posteriorly at 6 o'clock. Large five-pointed star indicates external sphincter which is seen as an outer, echorich and somewhat thick ring. Smaller four-pointed star indicates internal sphincter which appears as an inner, echopoor and thin ring. Panel B: Demonstrates 3D reconstruction of perianal fistula showing is extent and direction from anal lumen towards skin surface.

limited experience has been reported regarding the use of ultrasound in diagnostic work up or prevention of OF.[17–19]

No doubt one reason for this oversight is the disease no longer exists in the Western medical science setting, so naturally no efforts were made to improve the diagnostic tools to work it up.

Another equally valid and unsettling reason is the extreme shortage of any kind of medical imaging including ultrasound in Africa and other third world countries where OF is frequently encountered.

Transrectal ultrasound (TRUS) plays an important role in the diagnostic work up of perianal fistula and the technique is often also used by the surgeon during operation.[20,21] There is no reason to believe this valuable contribution to planning and treatment

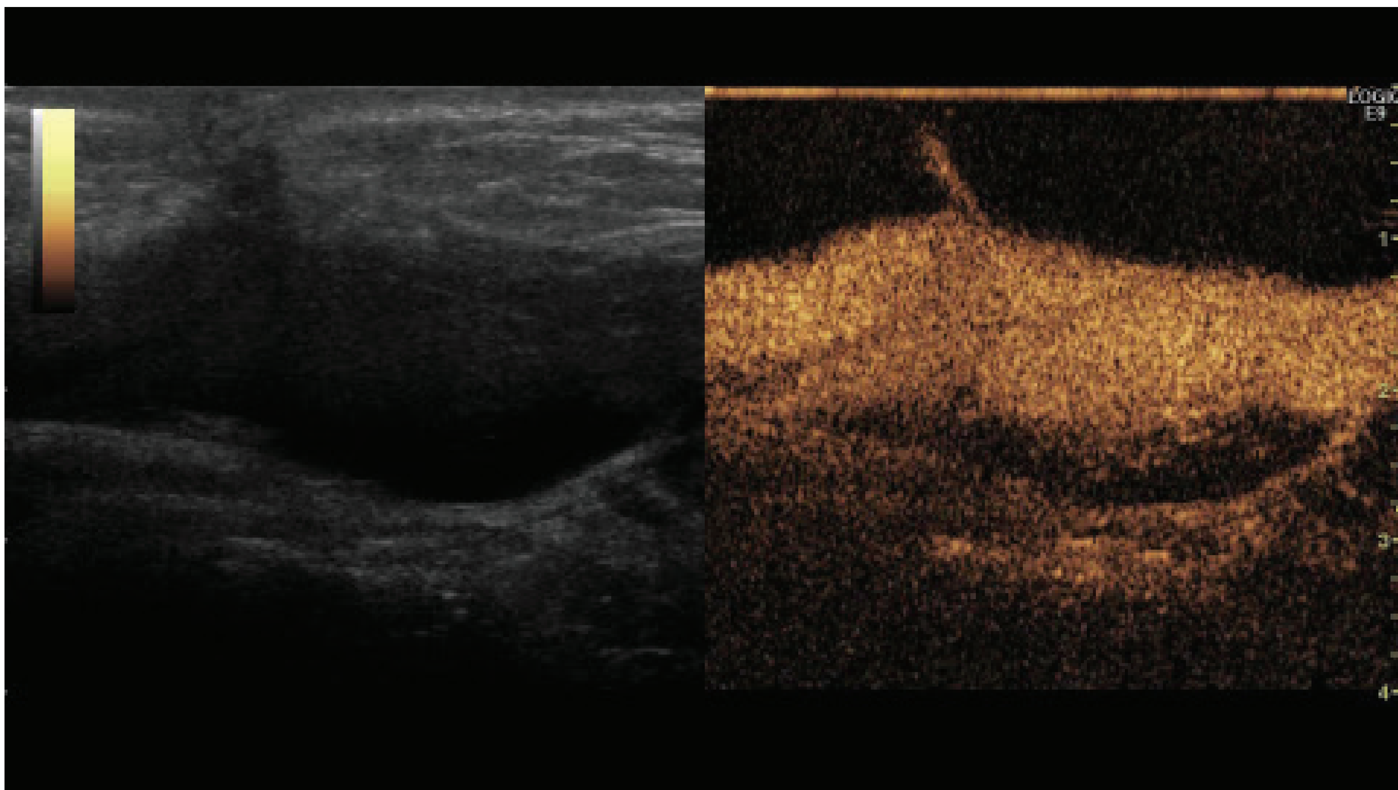


Figure 3: Contrast enhanced ultrasound fistulography ultrasound image of a contrast enhanced ultrasound examination of a fluid collection in the abdominal wall obtained with simultaneous dual display technique. The picture to the left is a fundamental i.e. "normal" ultrasound scan and the picture to the right is a second harmonic scan obtained at the exact same place and time. Both scans are obtained using low mechanical index setting to avoid bursting the bubbles in the contrast agent, which accounts for the darker than usual appearance. The abdominal wall fluid collection communicates to the skin via a narrow fistula and ultrasound contrast agent Sonovue[R] has been injected in the skin opening. Because Sonovue[R] is the only source in the image plane to give rise to second harmonic signals the contrast agent stands out clearly visualised on the dark background of tissue without signals. The subcutaneous fistula and the fluid collection itself are easily depicted in the harmonic image with its content of bright contrast agent whereas in the fundamental image the fistula cannot be differentiated from its surrounding oedematous tissue.

cannot be extended to cover OF, rather, as illustrated by the encouraging results reported in the two small series dealing with transvaginal and contrast enhanced colour Doppler ultrasound, respectively, it could be of great use.[18,19]

While the results of abdominal ultrasound scanning were rather discouraging[17] with only 29% of fistulae identified, changing technique to the transvaginal approach dramatically increased the retrieval rate to an impressive 100%.[19] Gold standard in both series was surgery. Despite the small numbers in both studies it does not come as a surprise that endoluminal scanning is much more sensitive than abdominal scanning and this actually corresponds well with the personal experience of this author as well as with the above-mentioned literature on similar conditions such as perianal fistula.

Conventional abdominal ultrasound cannot routinely be expected to visualise vesicovaginal fistula (VVF) or rectovaginal fistula (RVF). Usually artifacts due to bowel gas may obscure the image, plus the fistulae may be small in diameter and thus difficult to visualise, especially if the urinary bladder cannot be filled with fluid due to leaking. However, with endoluminal ultrasound scanning technique whether by use of the transvaginal or the transrectal route, one may take advantage of high frequency transducer technology plus the proximity of the organs and structures in question. This approach is essential for the excellent visualisation of fistula with TRUS and may even be taken to a higher level of understanding of the extent of disease involvement by use of 3D technology as exemplified in Figure 1 and 2.

A further refinement of ultrasound examination is ingeniously described by Volkmer, *et al.*[19] in their paper on colour Doppler with use of contrast media. The paper dates back to 2000 and much has happened in the field of contrast enhanced ultrasound (CEUS) since then, however the mere idea of visualising OF by use of ultrasound contrast has actually not been developed much further despite three generations of CEUS guidelines published since then, and most medical specialties have identified and reported one or more CEUS application.[22–25]

CEUS for visualisation of fistula is of special interest for the diagnostic work up of OF and can be performed either by use of catchers to instillate the contrast agent Sonovue (Bracco SpA, Milan, Italy) or by intravenous injection of the agent. In both instances imaging of the fistula can be performed by means of endoluminal or transperineal ultrasound scanning.[25] In my personal experience with CEUS fistulography which is in areas other than OF, I have found it a promising tool that convincingly demonstrates both the direction and extent of the fistula as well as the underlying cavity, if any (Figures 3 and 4).

Without doubt, the combined use of CEUS and endoluminal

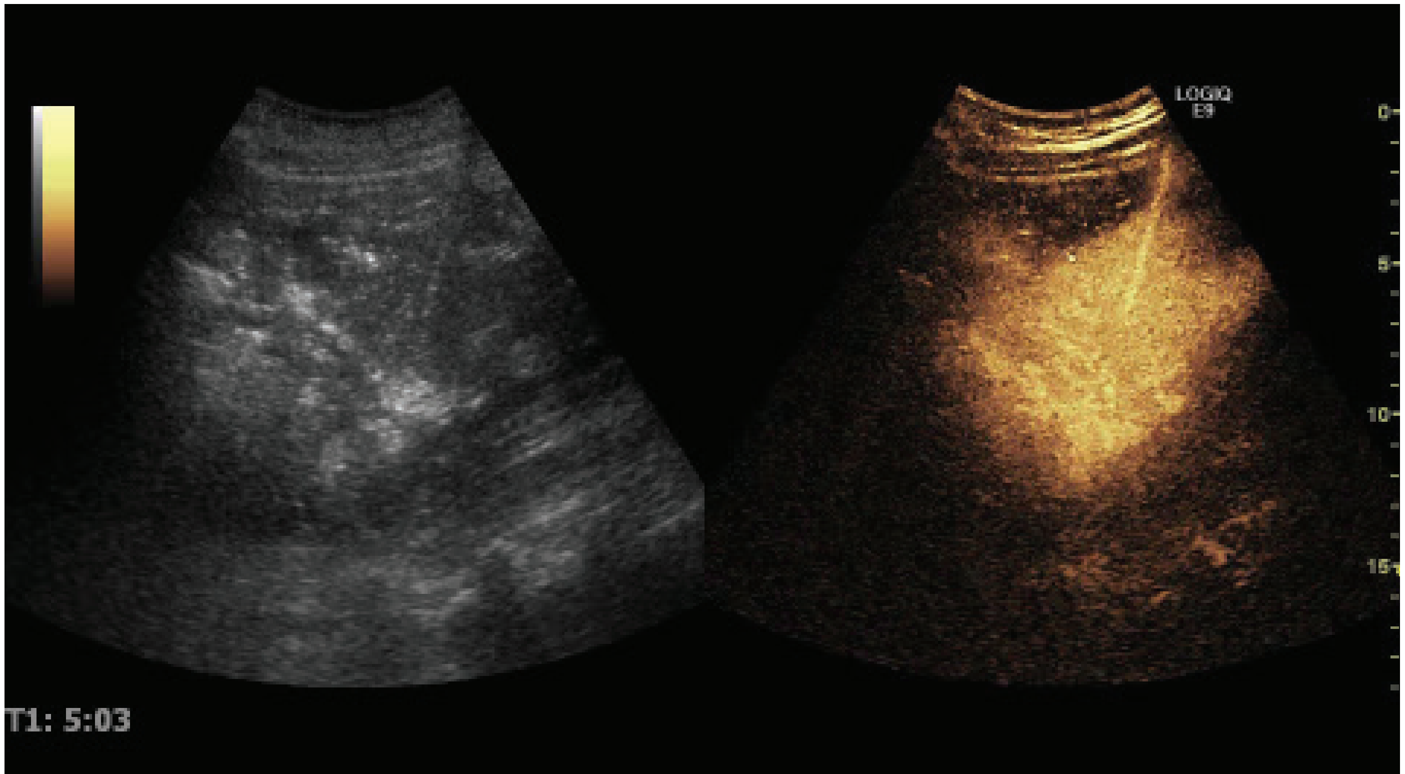


Figure 4: CEUS fistulography on catheter. Ultrasound image of a contrast enhanced ultrasound examination of a fluid collection in the pancreatic region on a patient with acute pancreatitis obtained with simultaneous dual display technique. As is the case with Figure 3 the picture to the left is a fundamental i.e. "normal" ultrasound scan and the picture to the right is a second harmonic scan obtained at the exact same place and time. Both scans are obtained using low mechanical index setting to avoid bursting the bubbles in the contrast agent, which accounts for the darker than usual appearance. A 7.5 F pigtail catheter has been inserted under ultrasound guidance and Sonovue^R ultrasound contrast agent is injected through the catheter. In the harmonic image to the right, both catheter and cavity is filled with a solution of Sonovue^R and stands out clearly delineated as opposed to the fundamental image to the left where it is difficult to outline both cavity and catheter.

ultrasound has the potential to become an effective tool in diagnostic work up of OF as well as an instrument during the surgical repair per se.

A completely different use of ultrasound imaging with regard to OF is the potential to identify pregnant women at risk of acquiring OF. This is the aim of a recently established project headed by the NGO *One by One* http://www.onebyoneproject.net (accessed 7th March 2013) in which ultrasound is utilised as a screening tool to predict factors predisposing to obstructed labour such as, for instance, immature pelvic bony configuration. If this hypothesis can be proven, then ultrasound may have a dramatic impact on the prevalence of OF by preventing obstructed labour and thus also preventing new cases of OF by bringing the potential new cases to the attention of professional birth assistance before problems occur.

As has been outlined in this short section about ultrasound and OF there may be a potentially huge positive impact of ultrasound imaging on several aspects of OF. However, one very crucial prerequisite is lacking: ultrasound is not available in the vast majority of places where it is needed the most.

As a matter of fact, no imaging modalities are available in many places in Africa and the third world in general. Bringing ultrasound to rural areas in Africa, where presently no medical imaging modality whatsoever is available, would greatly enhance the medical care in general including OF.

Ultrasound equipment has many advantages that make it the modality of choice if one were to bring medical imaging to the third world. It is portable to an extent where the newest miniature scanners may be carried in your pocket instead of your backpack, it is without radiation and can be powered by batteries or a portable power generator. The cost is low compared to other techniques. It is the ultimate modality for guidance of intervention, and if used in combination with CEUS there is no concern regarding kidney and liver function. And finally, the professional ultrasound community has the manpower, the connections and the know-how to set up telemedicine ultrasound facilities in rural areas on different locations in Africa, but there is a shortage of funding for equipment.

Presently, ultrasound emerges as the only modality that realistically speaking has the potential to overcome all foreseeable obstacles of introducing new high technology imaging technique to rural Africa. As I see it, ultrasound could produce everyday miracles for the often extremely poor people of rural areas for a limited amount of funding plus a manageable amount of technical support by using low- to mid-end ultrasound equipment.

Future aspects and conclusions

Obstructed labour always ends. In an affluent country like Denmark it ends when the woman is released by forceps delivery or cesarean section. In a poor country such as Ethiopia the unbearable pain may continue for days on end, up to five to six days. The baby dies after one to two days of labour but cannot be

born until the skull has fallen in so much that vaginal passage is possible and then the, by now macerated, little body can be expelled. That is if the mother is not already long dead. If she lives, her misery has not come to an end, it may have just started as she has acquired a fistula.

Typically she is very young, she may be only thirteen. Shortly before she had been at the brink of her life's meaning, now it has all just ended. The dripping, the unpleasant smell, the displeasure of her next of kin, forsaken by neighbours and friends, abandoned by her husband. Alone – so desperately alone. And yet, far from unique, by no means. Rather, on the contrary, one among many, one out of three million, who has done nothing wrong, and yet has been cast out and despised. Viewed as if bewitched, punished by the gods or suffering a self-inflicted disease of venereal kind. Just a girl. Barely an adolescent by Western standards. Found of no value, considered a burden to her community, no money herself, no future to dream of, no nothing.

It is easy to build up indignation towards this kind of thinking, this kind of behaviour and this kind of society. What an outrageous unrighteousness. What an injustice towards adolescent women in general and pregnant girls in particular. What ever happened to maternal health care? Where are the men in these kinds of societies and how can they lead their lives with this attitude?

Blame them we may think. And we are right to think so because of this obvious discrimination, this appalling gender and age inequality. But we are wrong to blame only them. Blame us! Blame ourselves and blame on the Western world and the overwhelmingly rich societies that thrive here. What about the obvious monetary inequality between their societies and our societies. Who are to be blamed for this if not us? We have the money; we have the power to change and to empower the weak of the developing world, the women, the young, the pregnant. It is up to us, just as much as it is to the women, their men and their societies.

Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me.

Psalm 23, 4 King James Bible (Cambridge Ed.) AD 1611

They who suffer OF find no easy comfort, and it may be difficult or impossible for them to say in their hearts the full length of Psalm 23 verse 4.

Having said that however, it is important to acknowledge the enormous efforts made so far and the fantastic results achieved for the many thousands OF patients healed or in the process of healing in Ethiopia, on the African continent and elsewhere in the developing world.

Thanks to the work of the Hamlin doctors, the wide array of NGOs and various charities and not to forget all the many voluntaries and employees behind, there is now a strong awareness of the gravity of the situation and magnitude of the problem plus at the same time a large number of OF repair programs on-going, newly inaugurated or in the pipeline where the need is most acute. Work is progressing along three main routes: prevention, treatment and rehabilitation.[26]

Prevention

The most effective way to prevent fistula must include delaying marriage as well as pregnancy at least until the girl is sexually mature and her body and especially the bony structure of the pelvis is ready. We must also ensure that skilled birth attendants and emergency obstetric care is available to all women in labour. Both of these approaches will call upon community-based measures of radical nature to change traditional thinking and doing. In addition, prevention also entails improving the health condition and nutritional status of women of reproductive age and tackling more general approaches such as underlying social and economic inequities to empower women and girls, enhance their life opportunities, and increase access to quality maternal health care services including family planning.

Treatment

Most people get involved in the movement against OF because they see the actual need and suffering from real persons they encounter in real life or through publicity initiatives by NGOs or the like. There is of course also a paramount wish from any patient with OF to be cured. The average cost of fistula treatment – including surgery, post-operative care and rehabilitation support – is a modest $US450. This of course is an overwhelming amount of money to most rural Africans and in particular to the typical OF patient. However, to most westerners it represents an absolutely manageable sum, and initiatives whereby donors agree to pay for individual patients (as with The Fistula Foundation) may represent an effective means of increasing treatment sponsoring.

All partners involved with the Campaign to End Fistula have treatment as one of their main goals and the Campaign supports all areas of treatment, from training doctors in fistula surgery to equipping and upgrading fistula centers. All involved want to increase the number of patients treated and cured. The Global Fistula Care Map represents one new thinking to reach that goal, and indeed increasing treatment may call upon our best in terms innovative ways of thinking. Sometimes the key to increasing treatment is entrepreneur-funded work such as building operative facilities and providing equipment. Sometimes the key is education, teaching fistula sufferers what fistula is and where they can go for free treatment. Sometimes the solution is funding surgeons' salaries or supplies. Sometimes the key is simply paying for transportation. Unbelievable as it may sound, some OF patients are unable to receive the almost always free treatment provided by most fistula facilities simply because they cannot afford the ticket for the two-day bus trip to the fistula hospital. And none of their relatives can, or will, pay the bus fare for them.

Rehabilitation

If the OF patient, despite the odds, makes it to the hospital and undergoes a successful fistula repair and convalescence the anguish is not yet over. Fistula treatment goes way beyond repair of the physical hole in a woman's vagina. Many patients and especially those who have lived with the condition for years will need emotional, economic and social support to fully recover from their ordeal. This is why most OF programs include in their activities help to achieve social reintegration. In addition some, like the WFF, provide services to help post-operative patients via vocational training, literacy initiatives and other skills training to empower them after surgery and may also offer help with

microfinance opportunities. Rehabilitation also means working with the community the woman will return to, counseling the woman herself or her husband and relatives can be helpful to ensure the former OF patient is accepted back into society without being stigmatised.

As has been described previously, a simple calculation will show that for Ethiopia, despite an impressive number of as many as 3500 OF patients receiving free surgery every year, the total number of 100,000 presently in need of care will continue to increase by a little more than 5000 per year. Looking at the bigger picture, reliable figures covering the whole world are not available. However, using the Global Fistula Care Map the estimate is depressing to view: 100,000 new cases each year, 15,000–20,000 operated and a backlog of two million.

Despite all that is being done, the OF problem will not go away but rather will grow. In view of these aspects for the future there can be no doubt that innovative thinking is required.[27,28] Unusual situations call upon unusual methods.

While researching this project, reading literature, surfing the net and watching or listening to broadcast and other media I have encountered some unusual methods that I believe could greatly further the Campaign to End Fistula. Africa, poorest among poor as this continent is, has one thing in abundance: mobile phones and wireless access. This I have witnessed myself travelling to Africa on several occasions but also is evident from available information on contemporary Africa. Africans have mobile phones, not all of them maybe, but a lot have. And they have good internet access. It has been said that Africa has the potential to become the first example of a larger population to skip classroom education entirely and make a wireless jump from ignorance to qualified via mobile phones or tablets.

At http://www.endfistula.org/public/cache/bypass/pid/7447?feedEntryId=23015 (accessed 13th January, 2013) the Campaign to End Fistula gives its idea of an innovative use of mobile technology in the OF battle. As mentioned above, many patients are deprived of free fistula repair due to lack of funds for the bus ride. In this short documentary by Lisa Russell it is shown how this can now easily be overcome by use of mobile phone technology. The Campaign makes a contract with a rural area 'fistula ambassador' in the vicinity of the bus route. This ambassador handles the bus fare for OF patients and gets reimbursed via mobile phone money transfer. The technology can be extended to cover regular funding by third party persons from abroad, and thus perhaps help increase the funding altogether.

Another project along this line of thinking is the One Laptop Per Child (OLPC) concept for Ethiopia http://wiki.laptop.org/go/OLPC_Ethiopia (accessed January 13th) that was launched recently and the preliminary amazing results reported by the end of 2012 with the headline *OLPC Project Puts Tablets In The Hands Of Formerly Illiterate Children With Amazing Results.* Allegedly, some children learned to read just by continuously and in community playing with a tablet they were given. If 5–6-year-old children can achieve this kind of improvement, indeed so can young women and their husbands. Tablets and laptops are extremely popular and sought after in Africa and if they can be had as a gift with an obligation such as 'learn-or-give-it-back' chain lock, or the like, I would not be surprised if education about maternal care could be smuggled in this way. And if this works, then why not try influence and change rural area community opinion on the issues discussed in the present synopsis. Reportedly, these devices cost as little as $US100.

Finally, a closing remark on community knowledge and how to encourage community engagement and stimulate positive changes in favor of women's rights. This is generally accepted as a key issue[29]. Tostan at www.tostan.org (accessed January 13th) recently proposed an innovative way to change traditional discriminative thinking and possibly harmful traditional practices. Tostan which means 'breakthrough' in the Wolof language is a community-based educational organisation in West Africa that works to increase women's age at marriage through holistic education and development activities. By discussing human rights and responsibilities, democracy, and health the Tostan program teaches the free right to marriage and negative health consequences to early labour. As a consequence, participating communities have begun to end the traditional practice of child marriage and forced marriage.

This paper is about those who walk alone, may we help them 'Walk to Beautiful'.

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