Chapter 9

Social Reintegration and Rehabilitation for Fistula Patients

Most patients will be able to return to their homes and families and live a normal life following successful fistula surgery. However, we know that many fistula patients have lived in isolation for many months to years and have been shunned by their families and friends and may need time to reintegrate back into society. Several may believe their fistula has been attributed to charms, witchcraft or bad luck.

Many fistula patients are young in age, still girls rather than women and become detached from their families and friends due to the stigma of having had a fistula. Most have a limited education and are often isolated after losing their job, being separated or divorced from their partner or husband and source of income. In addition, they will almost certainly have lost the baby that caused the fistula as either a stillbirth or early neonatal death. Very few will have had the opportunity to witness the burial of their baby due to being hospitalised after a difficult postnatal period.

The majority of fistula patients have a low level of education and are unemployed, hence the need for rehabilitation to empower them to integrate back into society. In some countries there are government policies that include protocols for reintegration and rehabilitation for women who have suffered from fistula.

Social reintegration helps fistula survivors to reconnect with their families and friends through programmes that involve counselling and activities to develop new skills to enable them back into the workplace and to generate an income for themselves.

Trained counsellors play an invaluable role in helping many of these women come to terms with the dreadful experience and stigma they have endured from having had a fistula. Time is needed to listen to their stories and to appreciate what they have been through. It is important that they understand what caused their fistula using charts or a model to help illustrate the process of obstructed labour and fistula formation.

Equally important is that they acknowledge that fistula has nothing to do with witchcraft, charms or bad luck and that it is completely preventable with timely access to trained medical personnel.

Rehabilitation activities empower women by helping them develop skills that allow them to earn a living and to rejoin their families. Some of the activities taught in reintegration and rehabilitation programmes include teaching the women to knit or sew and to make hand crafts that they can sell. Baking, soap-making and candle-making are also taught, as is animal husbandry where they can learn how to look after animals, such as goats or chickens, to help raise an income (Figure 71).

Figure 71 Cured patients involved in a reintegration project

These women should be encouraged to resume a normal life and to meet a new partner if their husband or partner has left them and, after a period of time, to try again for a family if that is their wish.

Secondary infertility

Many fistula patients find their menstrual periods do not return following delivery. There is no clear evidence as to why this occurs, but many have experienced severe illness due to the nature of fistula formation. Sepsis, significant weight loss and depression are common features following fistula injury causing a stress reaction in the body. Some may be affected by Sheehan syndrome, which is a hormone imbalance caused by necrosis of the anterior pituitary, whilst others may suffer from Ashermann syndrome, which causes destruction of the lining of the uterus.

There are a few women who will have had a hysterectomy after the birth but may be unaware that this has happened. Some will fail to menstruate

due to their cervical canal being closed, which may have happened during surgery, making them unable to conceive.

However, most women will become sexually active again in time and should be advised to use contraception to delay conception for at least a year following fistula repair. The use of contraception will help reduce the fear they may have of a future pregnancy after the experience they have been through. A few may choose not to be sexually active again, as they are unable to overcome their fear of sex, whilst some may find sexual intercourse too painful (dyspareunia) following fistula repair. Sexual intercourse may also not be possible if the patient has vaginal stenosis (narrowing of the vagina), which may lead to further rejection and stigma.

Elective caesarean section should be offered for all women who have had fistula repair surgery to reduce the risk of any reoccurrence. Stillbirth rates are reported to be high for fistula survivors. There also appears to be an increased risk of miscarriage following fistula repair.

Fistula prevention

Primary prevention of fistula is the most important step in fighting fistula. All women should be seen frequently in the antenatal period and a birth plan discussed with them. Women should be encouraged to deliver their babies with skilled birth attendants, such as midwives, at health centres or hospitals and to attend for regular antenatal care.

Reducing delay in getting to hospital is a priority for women with obstructed labour. All women in pregnancy should be encouraged to plan and save some money for transport when labour begins. Emergency transport vehicles need to be in place for early referral of obstructed cases.

Educating midwives and traditional birth attendants on early signs of obstructed labour will help with prevention of fistula. Perhaps an easy message to educate the traditional birth attendants is that no woman in labour should see the sun setting twice during delivery and to seek advice early to avoid problems.

Routine use of partograms in obstetric care allows obstructed labour to be detected early and improves maternal and newborn health outcomes.

Following a prolonged labour with no urinary leakage, it is advised to leave a Foley catheter in place for 10–14 days. With a fresh VVF (i.e. within the first 3–4 weeks post-delivery), a Foley catheter should be left *in situ* for 4–6 weeks. Some small fistulas will heal completely with decompression of the bladder, and others will reduce in size, making the repair easier. Caesarean sections and gynaecological operations should be performed by competent surgeons using good lighting.

There is a need for enhanced surveillance in areas where fistula rates are high to advise government policies to help improve maternal outcomes. Specialist fistula treatment centres are needed to provide optimal care in treating, reintegrating and rehabilitating women with fistula.

Eradication of obstetric fistula requires safe delivery services with competent midwives using partograms and timely referral in the case of obstructed labour to an emergency obstetric centre for swift caesarean section by a competent surgeon. Launched in 2013, 23rd May each year is observed as the International Day to End Obstetric Fistula. This day is marked to raise awareness of obstetric fistula and mobilise support from around the globe to help eradicate this debilitating condition.

Avoidance of 3rd and 4th-degree tear

Perineal trauma, including 3rd and 4th-degree tears, tends to follow a fast delivery. This can be avoided with a slow controlled birth. If the mother delivers with a midwife present, the midwife can flex the baby's head, supporting the perineum as the head is slowly crowning and then delivering.

Perineal massage during the second stage of labour and warm compresses may help to make the perineum more supple, which may facilitate the delivery and is practiced in some centres.

However, reducing tears during labour is dependent on the availability of trained midwives and skilled delivery techniques. In rural areas, there is often a lack of trained midwives or a very high patient-to-midwife ratio.

Fistula champions

Fistula champions are women who have suffered from obstetric fistula and return home to their communities as advocates and agents of change to raise awareness on prevention of obstetric fistula and help

identify other fistula patients who can access treatment. They need a small amount of training to equip them with the skills to raise awareness in their community.

Ethical considerations in nursing fistula patients

The nature of obstetric fistula is such that it leaves women incontinent of urine and/or faeces and unable to work or care for themselves, often being cared for by their mother or closest relative. Fistula patients are usually in their childbearing years, 18–45 years, with very little formal education, making them some of the most vulnerable members of society.

However, it is important to remember there may be older women in their 70s and 80s presenting for fistula surgery who have been living with a fistula for 40–50 years. These women can benefit from a successful repair and should not be turned away because of their age.

Obstetric fistulas persist in the world's most disadvantaged communities, where women have limited rights and opportunities.

The professional codes of conduct and ethics for nurses around the world follow similar principles and should be adhered to by all nurses. For example, in Uganda, the code of conduct for nurses emphasises the importance of human rights, including a person's right to dignity and respect, which are integral components of nursing care.

When caring for fistula patients, it is paramount that all nurses adhere to the professional code of conduct. Due to many of the patients' low level of literacy this may mean taking time to explain carefully what the proposed treatment/operation and recovery period entail. As important members of the fistula care team, nurses play a critical role, helping to make treatment decisions, while respecting the decisions their patients make.

All patients need to be cared for and supported during their hospital stay, whether it be daily monitoring of vital signs, wound checks, catheter checks or just generally checking they are OK and not in any pain. Privacy should be maintained when carrying out intimate procedures with patients, using screens around beds and respecting the patients' dignity and right to privacy.

The days and weeks after patients have had surgery and are ambulating around the ward with their catheters draining while their repair heals is a good time to spend with them and get to know them on an individual basis. This gives nurses time to truly connect with the patients, know their story and be able to explain what has happened to them. It is also a good time to reinforce, so they understand, that their injuries have not been caused by witchcraft, charms or bad luck.