Chronic pain after breast cancer surgery

By Dr Julie Bruce

Breast cancer is the commonest cancer affecting women and surgery is the main treatment, either to the breast and/or the underarm area. There are two main types of breast operation, mastectomy (removal of the whole breast) or removal of the cancerous lump, called lumpectomy or breast-conserving surgery. The lymph nodes in the armpit can also be affected and it is common for women to also have a procedure for partial or complete removal of lymph nodes.

How common is it?
One of the first UK studies of chronic pain after mastectomy was conducted in Scotland in 1999. Over 400 women were surveyed at three years after breast cancer surgery and 43 per cent reported pain in the chest and upper arm. Many women reported problems with everyday activities, such as lifting bags, turning the steering wheel when driving and doing household tasks. For some women, the painful symptoms had started fairly soon after their operation; for others, symptoms had started later, possibly relating to radiotherapy and chemotherapy treatment.

Six years later, we resurveyed the women reporting painful symptoms to find out whether they had recovered. About half of women with pain at three years were, by then, pain-free but half still had the pain (on average seven to nine years after their mastectomy). Of those still with pain, they reported that they had ‘learned to live’ with their painful symptoms – many had tried alternative therapies.

We have since conducted another Scottish study to understand more about the type of pain experienced both before and after breast cancer surgery. We assessed another 400 women before their breast cancer operation, very few reported chronic pain in the breast and upper body. After surgery, over half of women reported moderate to severe intensity acute postoperative pain in the first week. We know that this pain was not a continuation of any existing pain. We found that of the 400 women surveyed, those who had more severe acute pain after surgery were more likely to have chronic pain at four and nine months after their operation. This suggests that if we could better control and treat acute postoperative pain, we may reduce the proportion of women experiencing chronic painful symptoms.

Nerve and phantom pains
Women with neuropathic pain (nerve pain) use terms such as ‘stabbing’, ‘burning’, ‘tingling’, ‘shooting pain’ or ‘numbness’. Surgeons may have to dissect branches of the main nerve running
through the underarm when removing the tumour and surrounding tissue – this is unavoidable, but may be partly responsible for some persistent symptoms.

Although neuropathic pain is the most common type of pain reported after breast cancer surgery, some women also experience phantom breast pain. Phantom pain is pain that seems to come from an amputated limb, breast or other body part. Phantom sensations after mastectomy might not involve pain, but there are reports of 17 per cent of patients six years after surgery having phantom breast pain.

What are the risk factors?
Certain groups of women may be more at risk from chronic pain after their breast surgery than others.

Firstly, younger women do seem to be at greater risk of chronic pain than older women – this has been found after many different operations. This finding might be partly explained by the fact that younger people are often more active and are working, thus having persistent pain could have a greater impact on their daily life compared to older people who are often less active. Or it may relate to nerve and tissue changes (how we react to pain) as we get older.

There is emerging evidence to show that women with other chronic pains are at greater risk of having chronic pain after their surgery. This may include people who suffer from such conditions as chronic low back pain, irritable bowel syndrome, migraine, fibromyalgia and perhaps several other conditions as well. Changes in the nervous system may well lie behind many of these conditions. There is also a new area of pain research exploring pain genetics, suggesting that some people may be more susceptible to pain conditions than others.

It is entirely expected that women will be very worried and fearful of their future when faced with a cancer diagnosis and impending surgery. Women who are very anxious and worried about their operation are at greater risk of acute and chronic postoperative pain – so excessive worry and anxiety is a risk factor. This has been found with other operations, not just breast cancer. Preoperative preparation is vital; for example, a clear explanation about the operation and recovery process setting out the risks (and benefits) should be undertaken as standard practice.

Finally, one of the strongest and most consistent risk factors for chronic post-surgical pain is the severity of acute postoperative pain in the days and weeks after an operation. Treatment and adequate control of acute postoperative pain immediately after surgery is very important and may ‘dampen’ the pain response, preventing longer term symptoms. Again, there is emerging evidence to suggest that women reporting pain with neuropathic characteristics (such as stabbing, tingling, numbness) in the early postoperative period may be at greater risk of having these symptoms persist in the longer term.

Treatment
Long term pain after breast cancer surgery is treated in much the same way as other post-surgical pain. Refer to the leaflet ‘Chronic Pain after Surgery’ for more details.

Better understanding
An earlier version of ‘Chronic Pain after Surgery’ reported widespread misdiagnosis of pain after breast surgery, with many women being labelled as having ‘emotionally-derived pain’. This negative,
unhelpful labelling clearly reflects a lack of knowledge: there are now many articles from around the
world reporting that painful symptoms after breast cancer surgery are common, disabling and can
be challenging to treat.

Indeed, one of the largest studies ever conducted was undertaken in Denmark, where almost every
breast cancer surgery patient in the country was followed-up two years after their operation. The
research team found that out of over 3200 women, half still had pain in more than one area related
to their operation and 58 per cent reported sensory disturbances, such as numbness or sensitivity to
touch. Overall 25 per cent of women had moderate to severe pain two years after their surgery. The
study also revealed that many women suffering symptoms were under-treated and had poor pain
relief and symptom control. This was a hugely important study and was published in the Journal of
the American Medical Association (JAMA), one of the highest ranking medical journals – this has
helped to increase recognition and raise awareness of the condition amongst doctors and healthcare
professionals.

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