Counseling a Woman with DCIS

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Clinical Points

- Multivariate aspects of diagnosis and treatment of DCIS may cause in the woman confounding thoughts about its nature and conflicting decisions about the right treatment.
- Given the complexity of DCIS, the first communicative approach should be, namely, educational.
- In the diagnostic assessment, the lack of certainty and the need of additional investigation could cause the first failure of any effective communication.
- Where delay may arise, in order to reduce anxiety, a definite timetable should be set for each step of the process in terms of working days.
- Communication is only as good as the message received. Misinformation is as damaging to the psyche as no information at all.

13.1 Overview

For a woman with DCIS, the search for the *right* treatment may be a difficult journey through the medical system as regards the multivariate elements of the diagnosis as well of the treatment. In 1991 Melvin Silverstein, one of the greater researchers of DCIS, wrote these—still valid today—lines:

> Her agony came from the fact that mastectomy would be curative and it was hard to turn that down. A lesser procedure, while preserving her breast and her femininity, offered her somewhat less chance for a complete cure—but exactly how much less was unknown.

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> Perhaps only a small amount less. It didn't seem worth losing her breast for a few percentage points. Yet, maybe it was. It was the most difficult decision of her life. But medicine had failed her. The data upon which to base her judgment was weak, and we had shifted the burden of that judgment to her. [1]

Today we know a great deal more about DCIS, but it is still questionable whether the decision-making process is some easier. In the meanwhile a number of *right* treatments are flawed in some way with the result, even today, of confounding her thoughts and making her decision more difficult.

Is DCIS really a cancer? It is never easy to tell a patient that she has BC, and a number of questionable topics should be taken into account. A common understanding has been reached on the following statements.

- From a biologic point of view, DCIS is definitely a cancer.
- From a prognostic point of view, DCIS has, as a whole, a favorable but uncertain attitude.
- Surgical approach of DCIS is not commensurate with its gravity but with its extension.
- Radiotherapy is strongly recommended, though it may not always be necessary.

How DCIS can be perceived? A diagnosis of DCIS can provoke substantial psychological distress, partly because of the apparent ambiguity of having no manifest tumor but possibly having a very early form of BC that needs treatment. Generally perceptions about the risks of recurrence, metastasis, and death are the same as those of woman with early invasive BC. Moreover, also in case of very favorable DCIS, these perceptions are stronger in patients who believe they are at high risk due to familiarity. Even lack of full scientific certainty becomes a medical weakness in the management or control of the disease or nothing more than a way to concealing the truth.

Can the word cancer *be replaced*? In the population, the word *cancer* evokes the spectre of an inexorably lethal process. However, cancers are heterogeneous and include also indolent disease that causes no harm during the patient's lifetime, and better biology alone can explain better outcomes. Therefore, some clinicians suggested the use of the term *cancer* only for describing lesions with a reasonable likelihood of lethal progression if left untreated, while for some conditions like DCIS, the word *cancer* should not be in the name of diagnosis. However, the above implementation has many obstacles.

- Suggested changes may be a prescription for nosological confusion.
- Cancer is not a singular entity, it is not binary as suggested, and its aspects are highly heterogeneous and dynamic, reflecting a *continuum* of characteristic biological features that may change over time.
- The psychological consequences of changing the diagnosis for millions of people who already see themselves as cancer survivors are uncontainable. For better or worse, cancer is no longer just a diagnosis; it is an identity.

- Moreover, telling a woman who underwent surgery and years of hormone therapy for DCIS endured these treatments not for cancer but for an indolent lesion of epithelial origin may invalidate her experience.

It can be expected that even legal, insurance, psychological concerns will fail to correct this problem in the future. Just in case of molecular diagnostic tools that identify indolent or low-risk lesions were adopted and validated, it may be possible to reclassify such cancers as IDLE (InDolent Lesions of Epithelial origin) and to remove the word cancer.

The first approach should be educational. Even if the patient does not think of *breast cancer* as an inexorable disease, clinicians need (Fig. 13.1):

- To educate her that the term cancer encompasses a multitude of lesions of varying degrees of aggressiveness and lethal potential, but that is certainly not the case with DCIS, even if DCIS too has multivariate aspects.
- To emphasize to the patient that she has a *preinvasive* cancerous lesion, which at this time is not a threat to her life.
- To deal with the fear that the cancer has spread, having the ability to assure patient with DCIS that if no invasion was seen microscopically, the likelihood of systemic spread is essentially zero.
- The likelihood of local recurrence is more unpredictable but it may be kept under control.

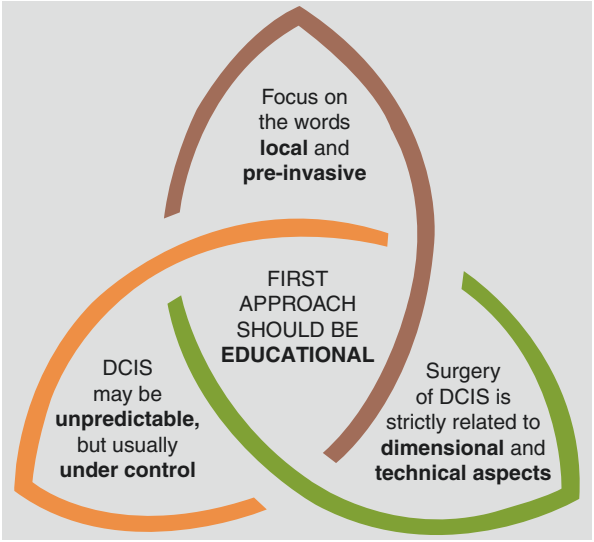

Fig. 13.1 Educational approach to DCIS

13.2 A Radiological Finding

The suspicion of a DCIS is mainly radiological, and much of it depends on the fulfillment of the diagnostic process before the counseling. Two types of stress may be noticeable. The first is the failure to reach at once a definitive diagnosis due to the need of additional investigations. The second stress is related to the length of an unavoidable delay.

13.2.1 The Need of Additional Investigations

Patients who have an equivocal result or require repeats should have a face-to-face consultation to clearly discuss the need for further tests and possible outcomes and a simple care plan put together. Believe it or not, the need of additional investigation is the first and most common cause of the failure of efficient communication between the diagnostic team and the woman. The forces encountered here are the unexpected present and the unpredictable future. Factors to be taken into consideration are predictability and prudence.

Predictability. In most cases, clinicians should not postpone counseling to the definitive results but prepare woman to the most likely outcome, within a reasonable range of lesions. On the other hand, it is well known they are able to intuitively consider all factors at all times, even while they are seeing the patient and formulating diagnostic hypothesis. This "reflection during action" is the process the doctor uses when dealing with specific, unique, uncertain, and complex situations. These are situations where knowledge is the major requisite, but also skills and attitudes, which make of medicine an art.

Prudence should have a big part in the above process. It refers mainly to subjective "physician-centered" knowledge and experience to make a medical diagnosis and devise a treatment plan. However, another component should be "patient-centered" and define the factors related to patient's psychology and sociology. For someone, this component is better called humanity but more simply is a professional duty.

13.2.2 The Length of Delay

At the slightest suspect of cancer, some women live the doubt as if the diagnosis were certain, and delays at any stage of the diagnostic process may result in anxiety for the woman, which sometimes may be considerable.

Where delay may arise, a definite timetable should be set for each step of the process in terms of working days (w.d.). According to Eusoma [2], quality assurance in the diagnosis of breast disease is guaranteed by the realization of the following indicators:

- Minimum standard for delay between mammography and result: 5 w.d. or less.
- Delay between result of imaging and offered assessment minimum standard: 5 w.d. or less.

- Delay between assessment and issuing of results minimum standard: 5 w.d. or less.
- Delay between decision to operate and date offered for surgery minimum standard: 15 w.d. or less, ideally 7–10 w.d.
- Moreover, 95% of women should receive full and adequate assessment in three appointments or less.
- Ninety percent of women with symptoms and signs strongly suggesting the presence of any kind of cancer should be seen within 2 weeks of referral, and agreed protocols should be in place to facilitate this.

Besides time frames, the radiologist should be present in the clinic at the time when a woman has her mammogram so that any necessary further investigation (e.g., magnification or spot compression views, ultrasound examination) can be performed without delay. As far as possible, the woman should be informed of the result of her examination before she leaves the clinic and of the need for any necessary further investigation to be performed.

For patients who undergo needle biopsy, both written and verbal information should be provided. All patients who undergo needle biopsy should be provided with a definite appointment or other agreed arrangement for communication of the biopsy result, within 5 working days, so they can arrange to be accompanied by family/friend if they wish.

The failure of the assessment process to make a definitive diagnosis of either a benign or a malignant condition is an undesirable outcome of assessment and further increases anxiety. For this reason, the use of early recall for a repeat examination at a time shorter than that normally specified for a routine follow-up is to be avoided.

Women must be informed of time limit to expect results and should be provided with written information at appropriate stages in the diagnostic procedure. However, information regarding the likelihood of malignancy being present should not be given via telephone or letter. Such information should be given verbally to the woman, preferably in the presence of a relative or a nurse counselor.

Many feel that radiologist should provide the woman diagnostic details of the assessment. Obviously information, upon which the following decisions are based, should have consistent evidence shared by other members of the team. It is just information, while definitive conclusions should be postponed to the final stage and drawn by the multidisciplinary team (MDT).

13.3 A Proven Diagnosis of DCIS

Communication has been defined an extraordinary opportunity, a key clinician skill, a basic need, and a fundamental aspect of care. Moreover, for the clinicians communication opportunities and skills are associated with less burnout and work-related stress. Despite these mutual advantages, most physicians have little training in communication and little interest to improve it. Just because communication in

DCIS is multifaceted, it is therefore more rewarding. Clinicians may also maintain their doubts but have a chance to demonstrate how to move inside them. Ultimately, in oncological cases, the aspects of communication most valued by patients are those that help patients and their families feel guided, build trust, and support hope.

Communicating the diagnosis takes time, and it should be ensured that sufficient time and support is provided for this. Moreover, the patient should be given their results possibly in the presence of a breast care nurse and any relative/carer/friend that they wish to have at the consultation.

Lines of behavior toward woman with histologically proven diagnosis of DCIS are:

- Assure that she has a minimal less common lesion, not comparable with nodular ones.
- Point out that the kind of surgery, thought limited, is related to technical matters.
- Inform that she is likely going to need some additional treatment, which may include surgery, radiation therapy, hormonal tablets, or some combination.
- Reassure that treatments do not include chemotherapy, that her hair will not fall out, and that it is highly unlikely that she will die from this lesion.
- Point out that a careful clinical follow-up will be required.

As in any medical counseling essentials are: treat the patient as a unique person; address her formally; make eye contact with him/her. It is important to show respect but also to tighten a therapeutic alliance founded on transparency, empathy, trust, and kindness. Sometimes conflicting or undesirable results need to be given by an appropriately trained senior clinician who has experience and training in breaking bad news.

It is worthwhile to remember that communication, even if real, has a strong individual component since it is 20% what the doctor knows and 80% how they feel about what they know. Moreover, communication is very little based on words; tone of voice and body language account for much more. The communication of the distinctive features of the DCIS is very difficult, and it is not always about being proper but it is about being effective. Finally, effective communication is only as good as the message received (Fig. 13.2).

Different people have different needs for information, and these may change with the many facets of DCIS. Some women find that gathering information helps them cope with their diagnosis and treatment. Much information is now available to patients, and many resources are directed at trying to prevent or ameliorate psychological stress. Guiding patients to well-established websites (to select previously) and information resource centers might ameliorate anxiety. However, this may entail a significant hazard in case of misinformation, as damaging to the psyche as no information at all.

Communication should be developed in order for the patient to comprehend and agree. Sometimes words can be as hard as stones, and each caregiver should therefore calibrate their speech to avoid confusion, anxiety, fear, or depression.

Fig. 13.2 Some facts about effective communication [3]

For this reason, communication should also take account of a large number of verbal faux pas that some women are not willing to tolerate. Among the several behaviors to avoid include blocking, lecturing, collusion, and premature imprudent reassurance [4].

- *Blocking* occurs when a patient raises a concern but the physician either fails to respond or redirects the conversation. For example, a woman with BC might ask, "How long do you think I have?" To which the doctor responds, "Don't worry about that." It is important to recognize the mechanisms related to blocking because they are the reasons why the physician typically fails to elicit the range of patient concerns and consequently is unable to address the most important ones.
- *Lecturing* occurs when a physician delivers a large chunk of information without giving the patient a chance to respond or ask questions.
- *Collusion* occurs when patient hesitates to bring up difficult topics and the physician does not ask her directly—a *don't ask, don't tell* situation.
- *Premature* (imprudent) *reassurance* occurs when physician responds to patient concern with reassurance before exploring and understanding the concern.

On the contrary, virtuous behaviors to cultivate are also a number. Some of these:

- *Ask-tell-ask*. Always ask about the patient's understanding of the issue. *How do you see your health?* Tell the patient in straightforward language what you need to communicate—the bad news, treatment options, or other information. Stop short of giving a long lecture or huge amounts of detail. Information should be

provided in short, digestible chunks. A useful rule of thumb is not to give more than three pieces of information at a time. Do not use medical jargon. Ask the patient if she understood what was said. In few cases and without any pressure, consider asking the patient to restate what was said in her own words.

- *Tell me more*. Ask the patient if they need more information or if all their questions are being answered. Ask about how they feel about what has emerged and its meaning.
- *Respond to emotions*. Approaching the person with kindness is key to helping. However, in cases of problematic relationships, covering emotional responses involves naming, understanding, respecting, supporting, and exploring the emotional response and consequently the need for nursing or psychological support.

Some women are more demanding. In the belief they are at high risk of invasive BC, they may continue to feel distressed also following a diagnosis of very favorable DCIS. It is important to precisely, and sometimes again and again, address these (mis) perceptions at the initial consultation. On the contrary, some women do not ask for clarifications for many reasons: are afraid or ashamed of their ignorance; are fearful of being pushy, ill-timed; are afraid for wasting health workers' time; and wish to remain in denial because the reality is painful to face. *Good doctors have to try to hear the silent ones*, according to one line by Paul Celan. Everyone praises the silent ones for their reserve, but their inscrutability may conceal deep thinking, a seal of superiority, and even a psychological block. Every woman is a person who is fighting a battle you too know little about. Do not make believe to know the unknown, and be respectful and kind is mandatory.

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