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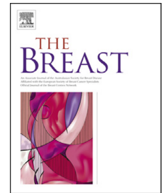

Viewpoints and debate

# Eliminating “ductal carcinoma in situ” and “lobular carcinoma in situ” (DCIS and LCIS) terminology in clinical breast practice: The cognitive psychology point of view

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ABSTRACT

There is evidence from the literature that the terms “ductal carcinoma in situ” and “lobular carcinoma in situ” (DCIS and LCIS) should be eliminated in clinical breast cancer practice and replaced with the new “ductal intraepithelial neoplasia” (DIN) and “lobular intraepithelial neoplasia” (LIN) terminology. The main purpose of the present article is to expand on this argument from a cognitive psychology perspective and offer suggestions for further research, emphasizing how the elimination of the term “carcinoma” in “in situ” breast cancer diagnoses has the potential to reduce both patient and health care professional confusion and misperceptions that are often associated with the DCIS and LCIS diagnoses, as well as limit the adverse psychological effects of women receiving a DCIS or LCIS diagnosis. We comment on the recent peer-reviewed literature on the clinical implications and psychological consequences for breast cancer patients receiving a DCIS or LCIS diagnosis and we use a cognitive perspective to offer new insight into the benefits of embracing the new DIN and LIN terminology. Using cognitive psychology and cognitive science in general, as a foundation, further research is advocated in order to yield data in support of changing the terminology and therefore, offer a chance to significantly improve the lives and psychological sequelae of women facing such a diagnosis.

Typology: Controversies/Short Commentary

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## Introduction

In breast cancer diagnosis, as in any type of cancer, communication is essential and the terminology used by physicians may have a profound impact on patients' lives [1]. Particularly relevant in this sense, the ductal carcinoma in situ (DCIS) and the lobular carcinoma in situ (LCIS) diagnoses have recently been raising concerns in the oncology field [2]. Both in DCIS and in LCIS, the term “in situ” is the Latin word indicating “in the original position” and it specifies that the abnormal cells have not invaded the basement membrane [3,4]. That means that diagnoses such as DCIS and LCIS do not signify ‘invasive’ breast carcinomas, but rather non-invasive, and they should be considered and communicated to patients in a different manner in order to differentiate the pathologies [5,6]. For this reason, the aim of our contribution is to highlight some considerations about the use of a new terminology for these two conditions. Even though the current discussion is predominantly related to DCIS, LCIS terminology also continues to be frequently used and should be equally considered for the reasons stated in this paper [6,7]. Our starting point is the debate recently published by Galimberti et al. [8]. In their article, Galimberti et al. argue the benefits of abandoning the DCIS and LCIS diagnoses in breast cancer and adopting new DIN (ductal intraepithelial neoplasia) and LIN (lobular intraepithelial neoplasia) classifications concerning ‘in situ’ cancer, in order to eliminate the misconceptions associated with the term carcinoma when related to a non-invasive disease.

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They emphasize that the need to clearly separate the so-called 'invasive' breast carcinomas from the so-called 'in-situ' carcinomas has been clear for some time now, but in their opinion the change is happening too slowly. They name several reasons for the definitive abandonment of the terms DCIS and LCIS and a permanent 'change of name'. Firstly, they stress the importance of eliminating the term 'carcinoma' when referring to DCIS/LCIS since it is not, in fact, cancer. In contrast to 'invasive' breast cancer, DCIS does not metastasize and a woman cannot die from the condition, unless it develops into invasive breast cancer [9] which, in most cases, is rare. Their second reason for the change to DIN and LIN terminology is due to the complexity of a DCIS/LCIS diagnosis. The diagnosis is challenging and confusing to both health professionals and patients and the ability to communicate related information is far from optimal. Research has shown that women with DCIS do not fully understand their diagnosis or the treatment options available to them. This is in part due to the terminology used to communicate information about the disease and the related implications and treatment options [10–16]. In addition, the confusion and lack of knowledge in women with DCIS often introduces unnecessary negative psychological effects resulting in difficult decision-making concerning their treatment options [8]. They suggest that by eliminating the anxiety-producing term 'carcinoma' from a condition that cannot metastasize, will reduce confusion in health care settings, as well as contribute to reducing adverse psychological reactions in patients.

In this paper, we argue that there is confusion and misperceptions linked to DCIS/LCIS diagnoses and we focus on the associated adverse psychological effects in DCIS/LCIS patients. In addition we take a cognitive psychology perspective and aim to discuss the need for further research in the field, as well as a change of terminology for the sake of increasing patients' understanding, satisfaction, and overall psychological adjustment related to their disease.

## Perceptions related to a 'carcinoma in situ: diagnosis among physicians and patients

Recent studies have focused on the confusion related to DCIS and LCIS in physicians, patients, and the general public [10–16]. Through this research, it has been found that there is a far from optimal approach that physicians sometimes use to disclose information to women with DCIS and LCIS, leading to disease confusion and poor decision-making. According to Kennedy et al. [17], one of the reasons for the inadequate exchange of information among physicians and patients is the misperceptions that physicians hold about DCIS and LCIS. Moreover, physicians hold a diverse awareness of the disease and they tend to use many different descriptive terms when communicating with patients about the diagnosis and the related treatment options [18]. In attempt to disentangle the confusion among physicians, there is a need for professionals in the field to delineate shared terminology in order to minimize the confusion associated with the explanation of the diagnosis. As physician confusion contributes to the inadequate exchange of information among physicians and patients, the majority of women diagnosed with DCIS and LCIS are also confused and misguided. As research sheds light on the misperceptions of 'carcinoma in situ' among physicians, the misunderstandings and confusion in patients has also been an important topic in the field of psycho-oncology.

## Psychological effects

### *Emotional impact*

Confusion and dissatisfaction with treatment decisions in women diagnosed with an 'in situ' diagnosis, such as DCIS and LCIS, have been linked to adverse emotional impact. Due to the use of the word carcinoma in their diagnosis, women are often misled about the extreme severity of their disease. In addition to this misperception, women are further proposed treatment options that indicate that their condition is not severe. This contradiction can therefore result in a treatment choice that does not satisfy the patient physically or emotionally. This is significant since lower levels of satisfaction with treatment choices have been found to be highly statistically associated with high levels of worry about breast cancer recurrence which in turn, have been found to effect women's mood [19–23]. Moreover, the stress caused by the perceived uncertainty and anxiety associated with DCIS and LCIS leads women to make uninformed decisions and to undergo the most aggressive and complete treatment possible, such as a mastectomy [18]. Furthermore, some studies report low satisfaction, a weak "fighting spirit," and a high feeling of helplessness/hopelessness in patients [24–26].

From a cognitive psychology perspective, it is important to note that the emotion that is felt during a specific moment guides people's cognition and behavior [27]. Emotional distress is considered a normal response around the time of cancer diagnosis and it causes significant levels of anxiety, depression [28–30]. For example, when feeling anxiety, fear or sadness, people tend to assign more weight to negative than to positive stimuli [30]. On this line, according to the affect heuristic [31], the negative meaning attached to the event of a DCIS/LCIS diagnosis affects the perceived risk and, as consequence, the patient's decision-making and the way he or she reacts to it. This is due the fact that a diagnosis of DCIS is perceived as an ominous diagnosis, because of the word "carcinoma" that acts as a strong reminder of "death" or "end". In this situation, women cannot avoid the emotional responses related with this word. On the contrary, DIN can be perceived differently. Leaving out the word carcinoma and replacing it by 'intraepithelial neoplasia', DIN allows for another meaning ruling out the death threat and all the emotional turmoil.

Coherently, with misinformation and skewed risk perceptions concerning the metastases of the disease and of prognosis, women with DCIS and LCIS have been found to experience similar psychological distress to women with early stage invasive breast cancer (EIBC) [32,33].

### *Cognitive processes impact*

As Galimberti and colleagues [8] strongly suggest a name change, others argue that there is no data to propose that a name change will have an effect on risk perceptions, anxiety/distress, or decision-making [25]. As we point out in this article, there is more to suggesting a name change to DCIS/LCIS than just due to the associated misperceptions and confusion among both professionals and patients. As research has shed light to the fact that women diagnosed with DCIS and LCIS have numerous unnecessary and adverse psychological effects, comparable to those of women with invasive breast cancer, the need for further research and a change in the medical field is vital. A cognitive psychology perspective can be taken in order to promote further research in the field with the purpose of understanding the importance of eliminating the word carcinoma from an "in situ" diagnosis. As much of women's psychological problems related to DCIS and LCIS are in part due to confusion as well as the decision-making processes accompanying their diagnosis, cognitive psychology can provide an explanation as to how important precise comprehension and clear communication between the physician and the patient really are. This is especially significant during important times such as during diagnosis and treatment decision-making. The moment of diagnosis is very demanding: it is a time in which women feel overwhelmed and

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