Histol Histopathol (2025) 40: 297-306

Histology and Histopathology
From Cell Biology to Tissue Engineering

REVIEW Open Access

Risk perception of patients with ductal carcinoma *in situ* (DCIS) of the breast and their healthcare practitioners: The importance of histopathological terminology, and the gaps in our knowledge

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Summary. Despite ductal carcinoma *in situ* (DCIS) being a non-obligatory precursor of invasive breast carcinoma, its diagnosis generates substantial psychological distress. The limited knowledge about the natural history of DCIS contributes to the insufficient transmission of information about DCIS to patients and the general population. The uncertainty about the progression risk to invasive carcinoma hampers adequate communication by clinicians. Breast cancer-related mortality after a DCIS diagnosis is low. However, several studies have demonstrated that DCIS patients generally overestimate the risk of developing loco-regional recurrence or dying from breast cancer. Various factors contribute to this perceived risk. Despite the lack of infiltrative growth, DCIS is treated similarly to invasive breast cancer, with surgery, radiotherapy, and hormonal therapy. Additionally, the term 'carcinoma' in DCIS provokes anxiety. Incorrect risk perception by physicians may result in overtreatment.

Here, we provide an overview of epidemiologic data on mortality after DCIS. We discuss the impact of the term "ductal carcinoma *in situ*" on patients' and physicians' perceptions of risk. The available evidence is mostly limited to patients within the Anglosphere. Recent studies, and European studies in particular, are scarce. We identify this as an area of interest for future large-scale European studies. We discuss the potential value of the "ductal intraepithelial neoplasia" (DIN) terminology, introduced in 1998. Although replacing the concept of "DCIS" with the DIN terminology is unlikely to solve the entire problem of risk overestimation, it could be the first step to optimize doctor-patient communication and alter the current risk perception.

Key words: Ductal carcinoma *in situ*, Breast, Risk perception, Psychological distress, Breast cancer diagnosis

Introduction

Ductal carcinoma *in situ* (DCIS) of the breast is a proliferation of neoplastic epithelial cells confined to the ductal-lobular system, without infiltrative growth into the surrounding fibroadipose stroma (Graff, 2010; Partridge et al., 2012). Neoplastic cells of DCIS and invasive breast cancer share a similar morphology and, therefore, both entities are semantically distinguished from one another by the addition of the words '*in situ*' and 'invasive' (Allred, 2010). This morphological similarity is illustrated by fine needle aspiration cytology samples, wherein it is virtually impossible to discriminate *in situ* from invasive carcinomas due to a lack of histological context (Graff, 2010; Vicks et al., 2024). DCIS represents a non-obligatory precursor of invasive carcinoma; some lesions are assumed to remain indolent, whereas others can progress to invasive breast cancer, which is potentially lethal (Tavassoli and Sakorafas, 2009; Allred, 2010). The main purpose of

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www.hh.um.es. DOI: 10.14670/HH-18-806

Abbreviations. ADH, atypical ductal hyperplasia; DCIS, ductal carcinoma *in situ*; DIN, ductal intraepithelial neoplasia; FEA, flat epithelial atypia; IDLE, indolent lesions of epithelial origin; UDH, usual ductal hyperplasia.

DCIS treatment is thus to prevent the development of invasive breast cancer and its associated risk of distant metastases (Boughey et al., 2007; Chiorescu et al., 2021). Most DCIS patients are therefore treated with surgery and adjuvant radiotherapy and/or hormonal therapy upon diagnosis, which prevents the study of the natural behavior of their tumors. Because of these immediate medical interventions, it is as yet impossible to predict which DCIS lesion will become an invasive carcinoma and which one will not (Van Bockstal et al., 2020). This uncertainty impedes efficient communication between healthcare professionals and patients about their disease, and results in substantially distorted risk perception. In the present review, we provide a non-exhaustive overview of the epidemiological data on DCIS-related mortality and the current evidence regarding the risk perception of DCIS patients and their doctors. We identify areas of interest for future quality-of-life and risk perception studies. Finally, we discuss the semantics of this enigmatic disease by focusing on the potential impact of a change toward "ductal intraepithelial neoplasia" terminology.

DCIS-related mortality

Per definition, DCIS is not a lethal disease as the neoplastic cells are still confined within the basement membrane of the mammary ductal-lobular system and cannot give rise to distant metastases (Davey et al., 2011). DCIS-related mortality is therefore caused by ipsilateral recurrence as invasive breast cancer, which can metastasize. Pathological features of DCIS associated with a high risk of death from breast cancer are large tumors and positive or unclear surgical margins (Wadsten et al., 2017). As the risk of breast cancer-related death after a DCIS diagnosis depends on the recurrence risk, and the invasive recurrence risk in particular, it is also determined by the type of surgery (Erbas et al., 2006) (Table 1 (Cuzick et al., 2011; Wapnir et al., 2011; Giannakeas et al., 2018; Mannu et al., 2020; Alaeikhanehshir et al., 2024)). The locoregional recurrence risk is higher after a lumpectomy than a mastectomy, presumably because of the higher risk of incomplete resection (Veronesi et al., 2002; Abdulla et al., 2023). Adjuvant radiotherapy after lumpectomy approximately halves the locoregional recurrence risk, regardless of the DCIS grade (Wapnir et al., 2011; Wickerham and Julian, 2013). Since the long-term breast cancer-specific survival after a DCIS diagnosis is approximately 97-98% (Table 2 (Wapnir et al., 2011; Narod et al., 2015; Giannakeas et al., 2018; van Maaren et al., 2018; Mannu et al., 2020)), the surgical treatment of DCIS aims to prevent progression to invasive carcinoma, and the adjuvant radiotherapy and hormonal therapy aim to reduce the locoregional invasive recurrence risk (Javid et al., 2014; Sanders et al., 2014; Giannakeas et al., 2020). Interestingly, recently published long-term follow-up data from an English population-based cohort study demonstrated that the risk of invasive breast cancer and breast cancer death is higher in patients with non-screen-detected DCIS than in patients with screen-detected DCIS (Mannu et al., 2020, 2024). Although mastectomy was associated with a lower risk of invasive breast cancer than breast-conserving treatment with or without adjuvant radiotherapy, the breast cancer-related mortality was not significantly different between these treatment subgroups among women with non-screen-detected

Table 1. Cumulative incidence of subsequent ipsilateral invasive breast cancer in a non-exhaustive selection of large-scale studies, according to DCIS grade, type of surgery and adjuvant treatment.

Reference	Period	Country and/or study population	Study cohort size	5-year CI of subsequent IBC	10-year CI of subsequent IBC	15-year CI of subsequent IBC	20-year CI of subsequent IBC
Alaeikhanehshir et al., 2023	2005-2015	Netherlands Cancer Registry	14.419 women	LO: • Grade I/II: 3.3%; • Grade III: 5.3% LRT: • Grade I/II: 1.6%; • Grade III: 2.1%	LO: 7.1%; • Grade I/II: 7.1%; • Grade III: 6.1% LRT: 3.1%; • Grade I/II: 2.7%; • Grade III: 3.2%		
Giannakeas et al., 2018	1998-2014	SEER database Canada	100.000 women	LO : 5.3% M : 0.6%	LO: 9% M: 1.4%	LO: 11,4% M: 1.8%	
Mannu et al., 2020	1998-2014	England	36.878 women	8.3%		LO: 9.4% LRT: 7.1% M: 2.8%	15.6%
Cuzick et al., 2011	1990-1998	UK, Scotland, Australia and New Zealand	1694 women		LO: 10%; LRT: 4%; LTAM: 9%; LRT +TAM: 3%		
Wapnir et al., 2011	1985-1990 and 1991-1994	USA NSABP B-17 trial and NSABP B-24 trial	813 women and 1799 women			LO: 19.4%; LRT: 8.9% (B-17); LRT + Placebo: 10% (B-24); LRT + TAM: 8.5%	

DCIS, ductal carcinoma in situ; CI, cumulative incidence; IBC, invasive breast cancer; LO, lumpectomy only; LRT, lumpectomy with radiotherapy; M, mastectomy; TAM, tamoxifen; LTAM, lumpectomy + tamoxifen.

DCIS (Mannu et al., 2024).

Psychological distress and risk perception in DCIS patients and the general population

In the early years of 2000, similar levels of psychological distress in DCIS patients and invasive breast cancer patients were observed, characterized by insomnia, unhappiness, and nervousness (Rakovitch et al., 2003). DCIS patients seemed to have a comparable health-related quality of life and well-being compared to invasive breast cancer patients (van Gestel et al., 2007). More recently, Gregorowitsch et al. demonstrated a significantly increased high-risk depression score in DCIS patients than in invasive breast cancer patients. Similar levels of anxiety and health-related quality of life were observed in both groups, despite physicians' knowledge about the frequent misconception of DCIS patients, as well as improved access to (digital) information for patients as compared with the early years of 2000 (Gregorowitsch et al., 2018).

This increased psychological burden could be caused by the lack of knowledge about the natural history of DCIS. Since it is impossible to accurately predict which DCIS lesion can progress to invasive carcinoma in case of active surveillance, this uncertainty causes nearly all patients to be treated upon diagnosis (Carrera and Payne, 1999; Javid et al., 2014). Such a 'one size fits all' approach likely results in overtreatment, although it is currently unknown to what extent. These uncertainties about disease progression and the appropriate treatment could affect the communication of healthcare professionals, generating confusion among both patients and their caregivers.

Only 6% of the general population in the USA confirmed having already heard about DCIS in 1997 (Schwartz et al., 2000). These findings were confirmed in Victoria, Australia, by Davey et al., who reported that 91% of DCIS patients had never heard of DCIS before their diagnosis (Davey et al., 2011). Women without cancer history overestimate their probability of dying from breast cancer within 10 years by more than 20-fold, demonstrating the lack of information in the general population (Black et al., 1995; Rakovitch et al., 2003). An Australian mixed-method study conducted in the general population showed that the awareness and knowledge about DCIS are very limited, despite a high level of screening participation (Nickel et al., 2023). More recent data on the knowledge about DCIS of the general population are lacking, especially beyond the Anglosphere.

Similar observations were made among DCIS patients, notwithstanding that these women had already been informed by healthcare professionals about their disease. Curiously, Rakovitch et al. observed that women diagnosed with DCIS answered a questionnaire about their disease and risk perception more accurately than women with invasive breast cancer, and they were more frequently able to identify DCIS in pictures, however, they still overestimated their own risk for local recurrence and breast cancer-related death (Rakovitch et al., 2003). Nevertheless, De Morgan et al. showed that 63% of DCIS patients who responded to their questionnaire thought DCIS could metastasize, 43% worried about dying from DCIS, 66% worried about developing invasive breast cancer in the same breast and, 75% feared invasive breast cancer in the opposite breast (De Morgan et al., 2011b). van Gestel et al. observed that patients struggled to answer an open question about the description of DCIS (van Gestel et al., 2007). The limited knowledge about their disease, as well as many misunderstandings, likely influences the

Table 2. Breast-cancer specific mortality after a diagnosis of DCIS, based on a non-exhaustive selection of large-scale studies.

Reference	Period	Country	Population size	5-year BC-specific mortality	10-year BC-specific mortality	15-year BC-specific mortality	20-year BC-specific mortality
Narod et al., 2015	1988-2011	SEER database Canada	108.196 women		1.1%		3.3%
Giannakeas et al., 2018	1998-2014	SEER database Canada	100.000 women	0.4%	1.2%	2%	
Mannu et al., 2020	1998-2014	England	36.878 women		1.2%		3.8%
Van Maaren et al., 2018	1999-2012	Netherlands Cancer Registry	12.256 women				Grade I: 0.7% Grade II: 1.3% Grade III: 1.6% Grade unknow: 2.7%
Wapnir et al., 2011	1985-1990 and 1991-1994	USA NSABP B-17 trial and NSABP B-24 trial	813 women (B-17) 1799 women (B-24)			LO: 3.1% LRT : 4.7% (B-17) LRT+ placebo: 2.7% (B-24) LRT+ TAM: 2.3% (B-24)	

DCIS, ductal carcinoma in situ; BC, breast cancer; LO, lumpectomy only; LRT, lumpectomy with radiotherapy;TAM, tamoxifen.

misperception of the risk of local recurrence and breast cancer-related mortality associated with DCIS.

Risk perception by healthcare professionals

The gaps in the knowledge concerning DCIS also affect medical caregivers. Partridge et al. performed the first evaluation of physician perception and management approach to DCIS: 63% of physicians were convinced that DCIS constitutes no or only a slight risk to overall long-term health. Interestingly, physicians' risk perception was influenced by the number of breast cancer patients they cared for, with fewer patients resulting in a larger estimated impact on patients' general health (Partridge et al., 2008). These heterogeneous opinions could explain the difficulty in finding universal and unambiguous terminology, as well as the diverse disease management. Given the variable terminology used to define and explain DCIS to patients, the confusion and inaccurate risk perceptions of patients are not surprising (Partridge et al., 2012). An alternative solution consists of healthcare providers explaining systematically all words of ductal carcinoma in situ, with an emphasis on "*in situ*" (Pravettoni et al., 2016).

Influence on decision-making and treatment

The treatment decision-making process for patients was considered difficult by 64% of physicians, and 42% considered it to be more complicated for DCIS than for invasive breast cancer (Partridge et al., 2008). Additionally, around half of the physicians found DCIS more difficult to explain to patients than invasive breast cancer (Kennedy et al., 2009). Choosing the appropriate treatment as part of shared decision-making is laborious in a context of poorly understood disease: patients feel worried about doing not enough as well as being too aggressive (De Morgan et al., 2011b; Rosenberg et al., 2022). Healthcare practitioners play a key role in this decision-making process, as they can – consciously or unconsciously – influence women with their preferred treatment through their communication and, in particular, through the terminology used (Davey et al., 2011; Nickel et al., 2017; Rosenberg et al., 2022).

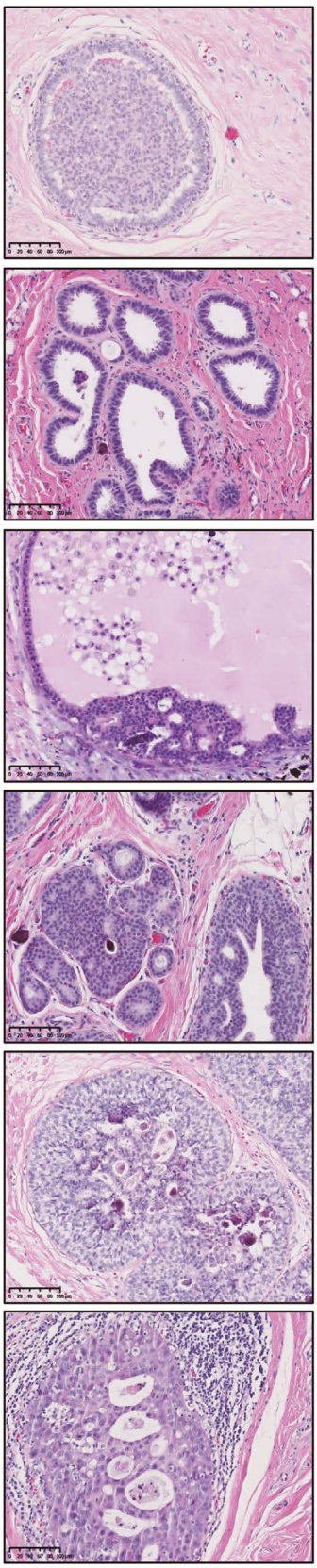
As we mentioned before, DCIS treatment is comparable to treatment of early invasive breast cancer, despite its non-invasive nature (Carrera and Payne, 1999; Rosenberg et al., 2022). Both diseases also share common risk factors and a common detection mode (Allred, 2010; Groen et al., 2017). Several reports illustrated that treatment choice substantially contributes to women's fear and confusion: how can we reconcile the need for mastectomy for DCIS patients, while some invasive breast carcinomas are treated with wide local excision? (Graff, 2010; Fallowfield et al., 2014). For instance, lobular carcinoma in situ (LCIS) generally causes less concern because it is treated less aggressively, although it shares almost the same name as DCIS (Partridge et al., 2012).

Last but not least, the current misperception about the risks associated with DCIS, as well as the uncertainty about disease progression, likely cause difficulties with study accrual in the ongoing active surveillance trials LORIS, LORD, and COMET (Wheelwright et al., 2023). These difficulties resulted in a modification of the study protocol of the LORD trial, modifying its randomized design into a patient's preference trial (Schmitz et al., 2023). Because of the difficulties with recruitment and the subsequent protocol modification, it is questionable whether the active surveillance trials will be able to provide the expected answers.

A matter of semantics?

In the past three decades, healthcare professionals have questioned the legitimacy of the term 'ductal carcinoma *in situ*' but no concrete progress has been made so far. Several studies have demonstrated that both patients and healthcare professionals are confused about whether DCIS should be considered cancer or not (Kennedy et al., 2008, 2009; Partridge et al., 2012; Rosenberg et al., 2022). Despite DCIS having a better prognosis than invasive breast cancer, most patients overestimate their own risk of recurrence (both local and distant) and breast cancer-related death, which is often estimated to be almost the equivalent of the risk associated with invasive breast cancer (Rakovitch et al., 2003; van Gestel et al., 2007 Partridge et al., 2012; Rosenberg et al., 2022).

The DCIS communication aid, developed by De Morgan et al. in Australia to facilitate disease understanding among patients, states that "DCIS is not breast cancer as we commonly understand it" (De Morgan et al., 2011a). The question is: what is the common understanding of DCIS? What is the population's perception of DCIS compared with invasive breast cancer? The available evidence is mostly limited to the Anglosphere. As DCIS and invasive breast cancer are frequently regarded as similar, a DCIS diagnosis can provoke substantial agony. The current confusion and fear might partially be provoked by the term 'carcinoma' and indicates the need for an alternative. In 1998, for the first time, Tavassoli introduced the concept of 'Ductal Intraepithelial Neoplasia' (DIN) (Fig. 1 (Tavassoli, 1998, 2005; Bechert et al., 2016; Jakub et al., 2017; Marques et al., 2019; Takada et al., 2020; Vicks et al., 2024)). Inspired by the term "mammary intraepithelial neoplasia" (MIN) suggested in 1991 by Rosai et al., DIN was classified into three grades: DIN1, DIN2, and DIN3, corresponding to low, intermediate, and high-grade (Rosai, 1991). DIN1 was subsequently divided into DIN1a (equivalent to usual ductal hyperplasia, UDH), DIN1b (equivalent to so-called flat epithelial atypia, FEA, and atypical ductal hyperplasia, ADH), and DIN1c (comprising low-grade DCIS) (Tavassoli, 1998; Galimberti et al., 2013). Others feel that the subclassification of DIN1 is overly complicated and could be removed (Wachter et al., 2009). The DIN1



DIN terminology	Old terminology	Upstaging risk
UDH	UDH	1.9%
DIN 1a	FEA	8.2%
DIN 1b	ADH	11.3-24.5%
DIN 1c	DCIS Grade 1	7.4-35.7%
DIN 2	DCIS Grade 2	10.7-35.7%
DIN 3	DCIS Grade 3	18.6-65%

Fig. 1. Photomicrographs of the various types of ductal intraepithelial neoplasia (DIN), their synonyms, and their estimated risk of being associated with invasive breast cancer on subsequent resection when diagnosed in a biopsy. Upstaging risk is based on the literature (Tavassoli, 1998, 2005; Bechert et al., 2016; Jakub et al., 2017; Marques et al., 2019; Takada et al., 2020; Vicks et al., 2024). Hematoxylin and eosin stain. Original magnification 200x. ADH, atypia ductal hyperplasia; DCIS, ductal carcinoma *in situ*; DIN, ductal intraepithelial neoplasia; FEA, flat epithelial atypia; UDH, usual ductal hyperplasia.

subgroups were subsequently modified into DIN1a representing FEA, DIN1b representing ADH with a size cut-off of ≤2 mm, and DIN1c representing DCIS grade 1 with a size cut-off of >2 mm, with UDH being excluded from intraductal neoplasia (Bechert et al., 2016).

Some researchers argue that the terms "invasive" or "infiltrating" can be eliminated because these concepts are inherent to the word "carcinoma" (Veronesi et al., 2009). Alternatively, "indolent lesions of epithelial origin" (IDLE), 'abnormal cells', "nodule", or "borderline breast disease" have been proposed as alternatives for DCIS (Masood, 2015; Esserman and Varma, 2019) with varying success (Fig. 2 (Tavassoli, 1998; Kennedy et al., 2009; Fallowfield et al., 2014; Masood, 2015; Esserman and Varma, 2019)). None of these terms has ever consistently replaced the name 'DCIS'. Nevertheless, many women would prefer a terminology that excludes the term "cancer" (Nickel et al., 2015).

Pros and cons for a change of name

Nowadays, it seems paramount to emphasize the difference between "invasive" and "*in situ*" carcinoma for breast cancer patients in general, and for DCIS patients in particular (Pravettoni et al., 2016). The implementation of the DIN classification would be a major step forward in patient-oriented care for several reasons.

Advantages

The message conveyed by the 'DIN' name is more in line with the definition of DCIS. "Neoplasia" more clearly expresses the presence of abnormal cells without being marred by an invasive concept, often associated with the 'cancer' word. Removing the word "carcinoma" from DCIS should reduce anxiety among patients. In particular, it should lower the fear of distant metastases, as DCIS itself is not a life-threatening disease (De Morgan et al., 2011a,b; Partridge et al., 2012). Since DCIS treatment aims to prevent the evolution toward invasive breast cancer (De Morgan et al., 2011a), one cause of the suspected overtreatment could originate in the overestimation of the risk of developing invasive breast cancer. This overestimated risk for *in situ* lesions likely generates an overestimation of the potential benefits of various medical interventions (Rakovitch et al., 2003). Omer et al. demonstrated the impact of the terminology on treatment decisions. They described DCIS using different terms such as "non-invasive cancer", "breast lesion" and "*abnormal cells*" to women of the general population. When DCIS is described as a high-risk factor rather than cancer, more than 65% of women did not choose surgery (Omer et al., 2013).

A name change would also be advantageous for medical professionals, to increase consistency with precursor lesions in other organs. "Intraepithelial neoplasia" is currently used for precursor lesions of epithelia in the cervix, vulva, vagina, penis, anus, prostate, and pancreas (Partridge et al., 2012).

Potentially practical difficulties

Some authors claim that, before changing the name of a disease, a new concept or discovery has to be present to support the need for such new terminology (Partridge et al., 2012). Omitting the term "cancer" could cause the loss of certain "advantages" of being considered a cancer patient in society, such as healthcare reimbursement issues, and access to prolonged follow-up and specialized care facilities.

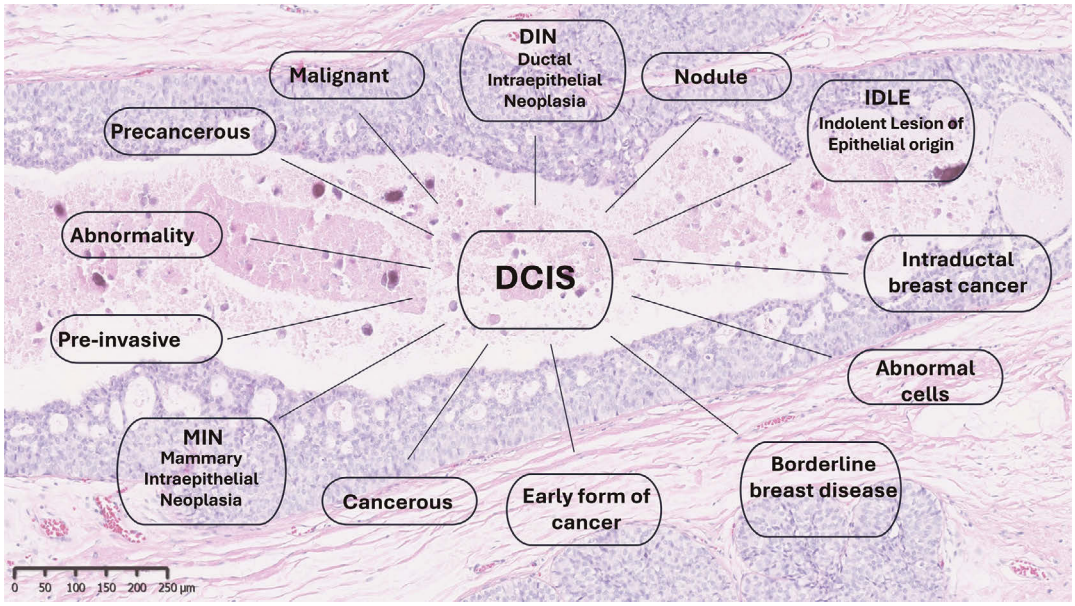


Fig. 2. Alternative names for ductal carcinoma *in situ* (DCIS) mentioned in reports on risk perception of DCIS patients and their caregivers. (Tavassoli, 1998; Kennedy et al., 2009; Fallowfield et al., 2014; Masood, 2015; Esserman and Varma, 2019)

Additionally, changing the name of DCIS, which is already very well-established, could create confusion among patients and practitioners (Esserman and Varma, 2019). Every innovation encounters adaptation difficulties: postponing the introduction of an alternative terminology such as the DIN classification might occur due to fear of change. Partridge et al. proposed a multi-phase method for this transition, comprising interdisciplinary discussion about the choice of the name. This is followed by the inclusion of the alternative terminology (such as DIN) in parentheses after DCIS in pathology reports; subsequently changing the order of the terms with DCIS in parentheses after DIN, and finally only using DIN in pathology reports (Partridge et al., 2012).

Some authors highlight the possibility of reducing diagnostic interobserver variability by the introduction of the new terminology, by avoiding the distinction between low-grade DCIS and ADH, as both lesions could just be classified as DIN1 (Tavassoli, 2005; Tavassoli and Sakorafas, 2009; Partridge et al., 2012). However, the issue of inter-observer variability for DCIS grading is unlikely to be solved by a name change as the DIN classification still requires DCIS grading (Van Bockstal et al., 2021), with DIN1c comprising DCIS grade 1, DIN2 corresponding to DCIS grade 2, and DIN3 corresponding to DCIS grade 3 (Galimberti et al., 2013). The DIN classification is therefore unlikely to solve the problems caused by categorizing the biological spectrum of cytonuclear atypia, which remains a challenge, even among experts (Dano et al., 2020).

Additionally, the DIN classification could insinuate the possibility of breast cancer progression from low to high-grade DIN, before becoming an invasive breast carcinoma, which has been rejected for more than a decade (Lopez-Garcia et al., 2010). Strikingly, several studies state that most DCIS will never progress to invasive breast carcinoma. This hypothesis is often postulated, but on which basis? Alternative hypotheses could be formulated, such as: "every DCIS can progress to an invasive lesion, as long as one waits long enough". This viewpoint postulates that all DCIS will harbor at a given time, all the necessary molecular modifications to allow intraductal neoplastic cells to cross the basement membrane and infiltrate the surrounding fibroadipose stroma. The only parameter required might be time. As long as the results of active surveillance studies are not available, we will not be able to clarify the uncertainty about the progression risk of so-called low-risk DCIS.

Despite the different terminology, healthcare providers will still be obliged to discuss the different treatment modalities. A different terminology does not solve the problem of the uncertainties on the spontaneous progression of DCIS to invasive breast cancer, nor will it reduce the psychological distress to zero. Even when the name changes to DIN, providers have to inform patients about the knowns and unknowns of this disease, without forgetting to mention the risk, prognosis, treatment, and potential side effects (Wachter et al., 2009). Critics, therefore, postulate that it is more important to improve the risk stratification of patients instead of pursuing a name change (Graff, 2010). Developing other tools to reduce anxiety due to a DCIS diagnosis also seems crucial. The treatment decision-making process, essential in the support of DCIS patients, could be assisted by DCIS communication aids that specify how to communicate about this non-invasive lesion and its good prognosis while using visual support materials (De Morgan et al., 2011a).

Conclusions

Since the introduction of the DIN terminology in 1998, many discussions have followed, but few or no actual changes have been performed. Despite several decades of lack of progress on this subject, the discussion remains a hot topic, especially because the current risk perception prevents women from participating in active surveillance trials (Schmitz et al., 2023; Wheelwright et al., 2023). Modifying DCIS into "ductal intraepithelial neoplasia" could help to reduce the psychological distress currently experienced by many patients. This alternative terminology could potentially diminish the presumed overtreatment, which originates in an overestimation of the risk of dying from breast cancer among patients and their caregivers.

Most studies about risk perception among DCIS patients were performed in the Anglosphere, and recently performed large-scale studies are scarce. We identify the lack of European studies as an area of interest for future exploration. Such a study could also be an opportunity to increase the knowledge of the general population about DCIS. Future surveys should investigate the perception of DCIS and its recurrence risk both in the general population, patients and healthcare professionals. Changing terminology might represent an important step in influencing risk perception among DCIS patients. However, one of the most important challenges for clinicians and pathologists remains; the identification of reliable biomarkers to assess the aggressiveness of DCIS. Accurate prediction of the biological behavior of DCIS will automatically decrease the uncertainty surrounding this yet enigmatic disease, resulting in personalized treatment and a more appropriate risk perception.

Funding information. J. Riggi received a research mandate from the not-for-profit organization Fondation Saint-Luc (Brussels, Belgium).

C. Galant is supported by the 'Fonds Gaëtan Lagneaux' (Fondation Saint-Luc, Brussels, Belgium).

M.R. Van Bockstal received a postdoctoral clinical mandate (2019-089) from the not-for-profit organization 'Foundation Against Cancer' (Brussels, Belgium) and is supported by the 'Fonds Gaëtan Lagneaux' (Fondation Saint-Luc, Brussels, Belgium).

Conflict of Interest. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

Abdulla H.A., Rajab B., Hammad M. and Alrayes A. (2023). Risk factors for positive margins in breast-conserving surgery. Cureus 15, e38399.

Alaeikhanehshir S., Schmitz R.S.J.M., Van Den Belt-Dusebout A.W., Van Duijnhoven F.H., Verschuur E., van Seijen M., Schaapveld M., Lips E.H., Wesseling J. and Grand Challenge PRECISION Consortium. (2024). The effects of contemporary treatment of DCIS on the risk of developing an ipsilateral invasive Breast cancer (iIBC) in the Dutch population. Breast Cancer Res. Treat. 204, 61-68.

Allred D.C. (2010). Ductal carcinoma *in situ*: terminology, classification, and natural history. J. Natl. Cancer Inst. Monogr. 2010, 134-138.

Bechert C., Kim J.-Y., Tramm T. and Tavassoli F.A. (2016). Co-expression of p16 and p53 characterizes aggressive subtypes of ductal intraepithelial neoplasia. Virchows Arch. 469, 659-667.

Black W.C., Nease R.F. Jr and Tosteson A.N. (1995). Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. J. Natl. Cancer Inst. 87, 720-731.

Boughey J.C., Gonzalez R.J., Bonner E. and Kuerer H.M. (2007). Current treatment and clinical trial developments for ductal carcinoma *in situ* of the breast. Oncologist 12, 1276-1287.

Carrera C. and Payne S. (1999). Ductal carcinoma *in situ* (DCIS) of the breast: The need for psychosocial research. Psychooncology 8, 538-545.

Chiorescu A., Fredholm H., Sackey H.I. and Fredriksson I. (2021). Local recurrence after treatment of ductal carcinoma *in situ*: A comprehensive overview. Chirurgia 116, S128-S135.

Cuzick J., Sestak I., Pinder S.E., Ellis I.O., Forsyth S., Bundred N.J., Forbes J.F., Bishop H., Fentiman I.S. and George W.D. (2011). Effect of tamoxifen and radiotherapy in women with locally excised ductal carcinoma *in situ*: long-term results from the UK/ANZ DCIS trial. Lancet Oncol. 12, 21-29.

Dano H., Altinay S., Arnould L., Bletard N., Colpaert C., Dedeurwaerdere F., Dessauvagie B., Duwel V., Floris G., Fox S., Gerosa C., Jaffer S., Kurpershoek E., Lacroix-Triki M., Laka A., Lambein K., MacGrogan G.M., Marchió C., Martinez D.M., Nofech-Mozes S., Peeters D., Ravarino A., Reisenbichler E., Resetkova E., Sanati S., Schelfhout A.M., Schelfhout V., Shaaban A.M., Sinke R., Stanciu-Pop C.M., Stobbe C., van Deurzen C.H.M., Van de Vijver K., Van Rompuy A.-S., Verschuere S., Vincent-Salomon A., Wen H., Bouzin C., Galant C. and Van Bockstal M.R. (2020). Interobserver variability in upfront dichotomous histopathological assessment of ductal carcinoma *in situ* of the breast: the DCISion study. Mod. Pathol. 33, 354-366.

Davey C., White V., Warne C., Kitchen P., Villanueva E. and Erbas B. (2011). Understanding a ductal carcinoma *in situ* diagnosis: patient views and surgeon descriptions. Eur. J. Cancer Care 20, 776-784.

De Morgan S.E., Butow P.N., Lobb E.A., Price M.A. and Nehill C. (2011a). Development and pilot testing of a communication aid to assist clinicians to communicate with women diagnosed with ductal carcinoma *in situ* (DCIS). Support Care Cancer 19, 717-723.

De Morgan S., Redman S., D'Este C. and Rogers K. (2011b). Knowledge, satisfaction with information, decisional conflict and psychological morbidity amongst women diagnosed with ductal carcinoma *in situ* (DCIS). Patient Educ. Couns. 84, 62-68.

Erbas B., Provenzano E., Armes J. and Gertig D. (2006). The natural history of ductal carcinoma *in situ* of the breast: A review. Breast Cancer Res. Treat. 97, 135-144.

Esserman L.J. and Varma M. (2019). Should we rename low risk cancers? BMJ 364, k4699.

Fallowfield L., Matthews L., Francis A., Jenkins V. and Rea D. (2014). Low grade ductal carcinoma *in situ* (DCIS): how best to describe it? Breast 23, 693-696.

Galimberti V., Monti S. and Mastropasqua M.G. (2013). DCIS and LCIS are confusing and outdated terms. They should be abandoned in favor of ductal intraepithelial neoplasia (DIN) and lobular intraepithelial neoplasia (LIN). Breast 22, 431-435.

Giannakeas V., Sopik V. and Narod S.A. (2018). A comparison of two models for breast cancer mortality for women with ductal carcinoma *in situ*: an SEER-based analysis. Breast Cancer Res. Treat. 169, 587-594.

Giannakeas V., Sopik V. and Narod S.A. (2020). Association of a diagnosis of ductal carcinoma *in situ* with death from breast cancer. JAMA Netw. Open 3, e2017124.

Graff S. (2010). Ductal carcinoma *in situ*: should the name be changed? J. Natl. Cancer Inst. 102, 6-8.

Gregorowitsch M.L., van den Bongard H.J.G.D., Young-Afat D.A., Pignol J.P., van Gils C.H., May A.M. and Verkooijen H.M. (2018). Severe depression more common in patients with ductal carcinoma *in situ* than early-stage invasive breast cancer patients. Breast Cancer Res. Treat. 167, 205-213.

Groen E.J., Elshof L.E., Visser L.L., Rutgers E.J.T., Winter-Warnars H.A.O., Lips E.H. and Wesseling J. (2017). Finding the balance between over- and under-treatment of ductal carcinoma *in situ* (DCIS). Breast 31, 274-283.

Jakub J.W., Murphy B.L., Gonzalez A.B., Conners A.L., Henrichsen T.L., Maimone S. 4th, Keeney M.G., McLaughlin S.A., Pockaj B.A., Chen B., Musonza T., Harmsen W.S., Boughey J.C., Hieken T.J., Habermann E.B., Shah H.N. and Degnim A.C. (2017). A validated nomogram to predict upstaging of ductal carcinoma *in situ* to invasive disease. Ann. Surg. Oncol. 24, 2915-2924.

Javid S.H., Fang L.C., Korde L. and Anderson B.O. (2014). Renaming ductal carcinoma *in situ*: would removing "carcinoma" reduce overtreatment? J. Natl. Compr. Canc. Netw. 12, 599-602.

Kennedy F., Harcourt D. and Rumsey N. (2008). The challenge of being diagnosed and treated for ductal carcinoma *in situ* (DCIS). Eur. J. Oncol. Nurs. 12, 103-111.

Kennedy F., Harcourt D. and Rumsey N. (2009). Perceptions of ductal carcinoma *in situ* (DCIS) among UK health professionals. Breast 18, 89-93.

Lopez-Garcia M.A., Geyer F.C., Lacroix-Triki M., Marchió C. and Reis-Filho J.S. (2010). Breast cancer precursors revisited: molecular features and progression pathways. Histopathology 57, 171-192.

Mannu G.S., Wang Z., Broggio J., Charman J., Cheung S., Kearins O., Dodwell D. and Darby S.C. (2020). Invasive breast cancer and breast cancer mortality after ductal carcinoma *in situ* in women attending for breast screening in England, 1988-2014: population based observational cohort study. BMJ 369, m1570.

Mannu G.S., Wang Z., Dodwell D., Broggio J., Charman J. and Darby S.C. (2024). Invasive breast cancer and breast cancer death after non-screen detected ductal carcinoma *in situ* from 1990 to 2018 in England: population based cohort study. BMJ 384, e075498.

Marques L.C., Marta G.N., De Andrade J.Z., Andrade D., De Barros A.C.S.D. and Andrade F.E.M. (2019). Is it possible to predict underestimation in ductal carcinoma *in situ* of the breast? Yes, using a simple score! Eur. J. Surg. Oncol. 45, 1152-1155.

Masood S. (2015). A call for change in the diagnosis and treatment of

patients with ductal carcinoma *in situ*: An opportunity to minimize overdiagnosis and overtreatment. Breast J. 21, 575-578.

Narod S.A., Iqbal J., Giannakeas V., Sopik V. and Sun P. (2015). Breast cancer mortality after a diagnosis of ductal carcinoma *in situ*. JAMA Oncol. 1, 888-896.

Nickel B., Barratt A., Hersch J., Moynihan R., Irwig L. and McCaffery K. (2015). How different terminology for ductal carcinoma *in situ* (DCIS) impacts women's concern and management preferences: A qualitative study. Breast 24, 673-679.

Nickel B., Barratt A., Copp T., Moynihan R. and McCaffery K. (2017). Words do matter: a systematic review on how different terminology for the same condition influences management preferences. BMJ Open 7, e014129.

Nickel B., McCaffery K., Jansen J., Barratt A., Houssami N., Saunders C., Spillane A., Rutherford C., Stuart K., Robertson G., Dixon A. and Hersch J. (2023). Women's views about current and future management of ductal carcinoma *in situ* (DCIS): A mixed-methods study. PLoS One 18, e0288972.

Omer Z.B., Hwang E.S., Esserman L.J., Howe R. and Ozanne E.M. (2013). Impact of ductal carcinoma *in situ* terminology on patient treatment preferences. JAMA Intern. Med. 173, 1830.

Partridge A., Winer J.P., Golshan M., Bellon J.R., Blood E., Dees E.C., Sampson E., Emmons K.M. and Winer E. (2008). Perceptions and management approaches of physicians who care for women with ductal carcinoma *in situ*. Clin. Breast Cancer 8, 275-280.

Partridge A.H., Elmore J.G., Saslow D., McCaskill-Stevens W. and Schnitt S.J. (2012). Challenges in ductal carcinoma *in situ* risk communication and decision-making: report from an American Cancer Society and National Cancer Institute workshop. CA Cancer J. Clin. 62, 203-210.

Pravettoni G., Yoder W.R., Riva S., Mazzocco K., Arnaboldi P. and Galimberti V. (2016). Eliminating "ductal carcinoma *in situ*" and "lobular carcinoma *in situ*" (DCIS and LCIS) terminology in clinical breast practice: The cognitive psychology point of view. Breast 25, 82-85.

Rakovitch E., Franssen E., Kim J., Ackerman I., Pignol J.P., Paszat L., Pritchard K.I., Ho C. and Redelmeier D.A. (2003). A comparison of risk perception and psychological morbidity in women with ductal carcinoma *in situ* and early invasive breast cancer. Breast Cancer Res. Treat. 77, 285-293.

Rosai J. (1991). Borderline epithelial lesions of the breast. Am. J. Surg. Pathol. 15,209-221.

Rosenberg S.M., Gierisch J.M., Revette A.C., Lowenstein C.L., Frank E.S., Collyar D.E., Lynch T., Thompson A.M., Partridge A.H. and Hwang E.S. (2022). "Is it cancer or not?" A qualitative exploration of survivor concerns surrounding the diagnosis and treatment of ductal carcinoma *in situ*. Cancer 128, 1676-1683.

Sanders J.B., Loftin A., Seda J.S. and Ehlenbeck C. (2014). Psychosocial distress affecting patients with ductal carcinoma *in situ* compared to patients with early invasive breast cancer. Clin. J. Oncol. Nurs. 18, 684-688.

Schmitz R.S.J.M., Engelhardt E.G., Gerritsma M.A., Sondermeijer C.M.T., Verschuur E., Houtzager J., Griffioen R., Retèl V., Bijker N., Mann R.M., van Duijnhoven F., Wesseling J. and Bleiker E.M.A. (2023). Active surveillance versus treatment in low-risk DCIS: Women's preferences in the LORD-trial. Eur. J. Cancer 192, 113276.

Schwartz L.M., Woloshin S., Sox H.C., Fischhoff B. and Welch H.G. (2000). US women's attitudes to false positive mammography results and detection of ductal carcinoma *in situ*: cross sectional survey. BMJ 320, 1635-1640.

Takada K., Kashiwagi S., Asano Y., Goto W., Morisaki T., Takahashi K., Fujita H., Takashima T., Tomita S., Hirakawa K. and Ohira M. (2020). Factors predictive of invasive ductal carcinoma in cases preoperatively diagnosed as ductal carcinoma *in situ*. BMC Cancer 20, 513.

Tavassoli F.A. (1998). Ductal carcinoma *in situ*: introduction of the concept of ductal intraepithelial neoplasia. Mod. Pathol. 11, 140-154.

Tavassoli F.A. (2005). Breast pathology: rationale for adopting the ductal intraepithelial neoplasia (DIN) classification. Nat. Clin. Pract. Oncol. 2, 116-117.

Tavassoli F.A. and Sakorafas G.H. (2009). 'Ductal carcinoma *in situ* of the breast'- Is it time to replace this term by 'ductal intraepithelial neoplasia of the breast'? Onkologie 32, 218.

Van Bockstal M.R., Agahozo M.C., Koppert L.B. and Van Deurzen, C.H.M. (2020). A retrospective alternative for active surveillance trials for ductal carcinoma *in situ* of the breast. Int. J. Cancer 146, 1189-1197.

Van Bockstal M.R., François A., Altinay S., Arnould L., Balkenhol M., Broeckx G., Burguès O., Colpaert C., Dedeurwaerdere F., Dessauvagie B., Duwel V., Floris G., Fox S., Gerosa C., Hastir D., Jaffer S., Kurpershoek E., Lacroix-Triki M., Laka A., Lambein K., MacGrogan G.M., Marchiò C., Martinez M.-D.M., Nofech-Mozes S., Peeters D., Ravarino A., Reisenbichler E., Resetkova E., Sanati S., Schelfhout A.-M., Schelfhout V., Shaaban A., Sinke R., Stanciu-Pop C.M., van Deurzen C.H.M., Van de Vijver K.K., Van Rompuy A.-S., Vincent-Salomon A., Wen H.Y., Wong S., Bouzin C. and Galant C. (2021). Interobserver variability in the assessment of stromal tumor-infiltrating lymphocytes (sTILs) in triple-negative invasive breast carcinoma influences the association with pathological complete response: the IVITA study. Mod. Pathol. 34, 2130-2140.

van Gestel Y.R.B.M., Voogd A.C., Vingerhoets A.J.J.M., Mols F., Nieuwenhuijzen G.a.P., van Driel O.J.R., van Berlo C.L.H. and van de Poll-Franse L.V. (2007). A comparison of quality of life, disease impact and risk perception in women with invasive breast cancer and ductal carcinoma *in situ*. Eur. J. Cancer 43, 549-556.

van Maaren M.C., Lagendijk M., Tilanus-Linthorst M.M.A., De Munck L., Pijnappel R.M., Schmidt M.K., Wesseling J., Koppert L.B. and Siesling S. (2018). Breast cancer-related deaths according to grade in ductal carcinoma *in situ*: A Dutch population-based study on patients diagnosed between 1999 and 2012. Eur. J. Cancer 101, 134-142.

Veronesi U., Cascinelli N., Mariani L., Greco M., Saccozzi R., Luini A., Aguilar M. and Marubini E. (2002). Twenty-year follow-up of a randomized study comparing breast-conserving surgery with radical mastectomy for early breast cancer. N. Engl. J. Med. 347, 1227-1232.

Veronesi U., Zurrida S., Goldhirsch A., Rotmensz N. and Viale G. (2009). Breast cancer classification: Time for a change. J. Clin. Oncol. 27, 2427-2428.

Vicks E., Mason H., Perez Coulter A., Niakan S., Friedrich A., Cho R. and Casaubon J. (2024). Increased risk of upstage when combinations of breast lesions of uncertain malignant potential are found on core needle biopsy: The need for surgical excision. Am. J. Surg. 227, 6-12.

Wachter D.L., Beckmann M.W. and Hartmann A. (2009). Ductal carcinoma *in situ* - do we really need a new nomenclature? Onkologie 32, 158.

Wadsten C., Garmo H., Fredriksson I., Sund M. and Wärnberg F. (2017). Risk of death from breast cancer after treatment for ductal carcinoma *in situ*. Br. J. Surg. 104, 1506-1513.

Wapnir I.L., Dignam J.J., Fisher B., Mamounas E.P., Anderson S.J., Julian T.B., Land S.R., Margolese R.G., Swain S.M., Costantino J.P. and Wolmark N. (2011). Long-term outcomes of invasive ipsilateral breast tumor recurrences after lumpectomy in NSABP B-17 and B-24 randomized clinical trials for DCIS. J. Natl. Cancer Inst. 103, 478-488.

Wheelwright S., Matthews L., Jenkins V., May S., Rea D., Fairbrother P., Gaunt C., Young J., Pirrie S., Wallis M.G., Fallowfield L. and LORIS Trial Management Group (2023). Recruiting women with ductal carcinoma *in situ* to a randomised controlled trial: lessons from the LORIS study. Trials 24, 670.

Wickerham D.L. and Julian T.B. (2013). Ductal carcinoma *in situ*: a rose by any other name. J. Natl. Cancer Inst. 105, 1521-1522.

Accepted September 3, 2024