



Background

Many women with low-risk forms of DCIS incorrectly believe they have invasive breast cancer due to the word “carcinoma”, which means cancer. This causes unnecessary anxiety and reduces quality of life. We aimed to identify how to improve communication about low-risk DCIS.

Methods

To identify ideal labels, language, and other strategies to improve communication, we: (1) summarized prior research, (2) interviewed women who had DCIS and physicians who interact with affected women, and (3) interviewed patients with other low-risk lesions (bladder, cervix, prostate) and physicians who care for them.

Interview participants

Patients (n=27)		
<i>Low-risk lesion discussed</i>		
Breast (DCIS)		12
Bladder/cervix/prostate		15
<i>Age (years)</i>		
< 50	5	
50+	17	
<i>Ethno-cultural group</i>		
Caucasian/White	17	
Non-Caucasian/White	10	
<i>Province</i>		
Ontario	20	
Non-Ontario	7	

Physicians (n=28)		
<i>Low-risk lesion discussed</i>		
Breast (DCIS)	15	
Bladder/cervix/prostate	13	
<i>Specialty</i>		
Family physician	5	
Obstetrician/Gynecologist	4	
General Surgeon	3	
Pathologist	2	
Urologist	2	
Urologic Oncologist	2	
Gynecologic Oncologist	1	
Radiation Oncologist	1	
Radiologist	1	
<i>Province</i>		
Ontario	13	
Non-Ontario	15	

Label Preferences

Patients and physicians disagreed about label preferences

Label Category	Patients	Physicians
<u>Abnormal</u> (abnormal, atypical)	<ul style="list-style-type: none"> – Easy to understand – Alleviates anxiety – Appropriate when first learning of diagnosis 	<ul style="list-style-type: none"> – Too general – Requires explanation
<u>Precursor</u> (stage 0, pre-cancer)	<ul style="list-style-type: none"> – Suggests cancer – Prompts anxiety 	<ul style="list-style-type: none"> – Suggests not cancer so alleviates anxiety – Let’s patients know they need treatment/follow-up
<u>Cancer</u> (non-invasive cancer, DCIS)	<ul style="list-style-type: none"> – Suggests advanced cancer – Prompts shock and anxiety 	<ul style="list-style-type: none"> – Learned in training – Matches what patients see elsewhere (medical records) – Let’s patients know they need treatment/follow-up

Recommendations to improve communication

Patients and physicians agreed on approaches needed

Language	Other Strategies
<ul style="list-style-type: none"> – Use non-triggering labels preferred by patients – Use plain/lay language to explain the diagnosis – Note the condition is common – Explicitly state it is not cancer – Describe lesion as the low end of a spectrum of types of cells – Explain why treatment is needed 	<ul style="list-style-type: none"> – Use visual aids to help explain the diagnosis (e.g. pictures, models) – Lengthen visits for enough time to discuss diagnosis/answer questions – Provide take home information – Refer patients to other sources of information (e.g. online) – Connect patients with support groups or services