ISSN 2307-8960 (online)

World Journal of *Clinical Cases*

World J Clin Cases 2021 August 26; 9(24): 6964-7291

Published by Baishideng Publishing Group Inc

World Journal of Clinical Cases

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The *WJCC* is now indexed in Science Citation Index Expanded (also known as SciSearch®), Journal Citation Reports/Science Edition, Scopus, PubMed, and PubMed Central. The 2021 Edition of Journal Citation Reports® cites the 2020 impact factor (IF) for *WJCC* as 1.337; IF without journal self cites: 1.301; 5-year IF: 1.742; Journal Citation Indicator: 0.33; Ranking: 119 among 169 journals in medicine, general and internal; and Quartile category: Q3. The *WJCC*'s CiteScore for 2020 is 0.8 and Scopus CiteScore rank 2020: General Medicine is 493/793.

RESPONSIBLE EDITORS FOR THIS ISSUE

Production Editor: *Ji-Hong Liu*; **Production Department Director:** *Yu-Jie Ma*; **Editorial Office Director:** *Jin-Lei Wang*.

NAME OF JOURNAL
World Journal of Clinical Cases

ISSN
ISSN 2307-8960 (online)

LAUNCH DATE
April 16, 2013

FREQUENCY
Thrice Monthly

EDITORS-IN-CHIEF
Dennis A Bloomfield, Sandro Vento, Bao-Gan Peng

EDITORIAL BOARD MEMBERS
https://www.wjgnet.com/2307-8960/editorialboard.htm

PUBLICATION DATE
August 26, 2021

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https://www.wjgnet.com/bpg/gerinfo/242

STEPS FOR SUBMITTING MANUSCRIPTS
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World Journal of Clinical Cases

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World J Clin Cases 2021 August 26; 9(24): 7043-7052

DOI: 10.12998/wjcc.v9.i24.7043

ISSN 2307-8960 (online)

ORIGINAL ARTICLE

Retrospective Study

Patients' awareness about their own breast cancer characteristics

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Author contributions: Li YY designed and developed the whole project and organized collaborators to finish this survey, modified the original article, completed the statistical work, and was charge of manuscript submission; Geng C contributed to the preparation, creation, and presentation of the work of the original research group, helped the corresponding author do the project administration, and was charge of communication of all hospitals; Lu GJ took the survey and collected the data of patients from Weifang city when he worked in Shandong An Qiu People's Hospital then; Zhu J took the survey and collected the data of patients from Foshan city.

Institutional review board statement: The study was reviewed and approved by the Department of Breast and Thyroid Surgery Institutional Review Board (No. SWYX2021-090).

Informed consent statement: All study participants, or their legal guardian, provided informed written consent prior to study enrollment.

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Abstract

BACKGROUND

Patients' knowledge about the characteristics of their own cancer could be an important factor for understanding treatment regimens and adhering to therapies. However, to date nothing is known about the awareness among Chinese breast cancer patients about the characteristics of their own tumors.

AIM

To investigate how much knowledge that Chinese breast cancer patients have about their tumor characteristics and the impact of health and education literacy on the acquisition of such information.

METHODS

The survey was administered to patients who were diagnosed with breast cancer from 2017 to 2019 in three hospitals in China, and who came in for regular follow-up on an outpatient basis. We collected responses from 226 respondents who were asked about their cancer characteristics (stage, grade, and estrogen receptor status and human epidermal growth factor receptor 2 status of the cancer), and evaluated the correctness by comparing with their medical records. Logistic regression was used to assess the probability of knowing and of correctly answering questions. We also analyzed the association between our findings and the level of the patient's education and their health literacy.

RESULTS

Conflict-of-interest statement: The authors have no conflicts of interest to declare.

Data sharing statement: No additional data are available.

Manuscript source: Unsolicited manuscript

Specialty type: Medicine, research and experimental

Country/Territory of origin: China

Peer-review report's scientific quality classification

Grade A (Excellent): 0
Grade B (Very good): B
Grade C (Good): 0
Grade D (Fair): 0
Grade E (Poor): 0

Received: April 22, 2021
Peer-review started: April 22, 2021
First decision: May 24, 2021
Revised: May 25, 2021
Accepted: July 5, 2021
Article in press: July 5, 2021
Published online: August 26, 2021

P-Reviewer: de Azambuja E
S-Editor: Gao CC
L-Editor: Wang TQ
P-Editor: Li X

Overall, 20.80% to 57.96% of the patients reported knowing about the characteristics of breast cancer; of these, 10.18% to 46.46% reported these characteristics correctly. Education, age, and health literacy were all significantly associated with awareness rate, and with the level to which this information was accurate.

CONCLUSION

Breast cancer patients in China know little about their disease, and better education aimed at improving their knowledge about cancer characteristics is urgently needed. The low level of awareness could represent a deficiency of communication between surgeons and patients, which may be one of the reasons why medical disputes occur in China.

Key Words: Breast cancer; Awareness; Characteristics; Health literacy; Education

Core Tip: Breast cancer patients in China have very poor knowledge about their own disease. Better education of individuals with breast cancer in China is critically needed. We highly recommend that Chinese physicians provide additional information about the disease to patients, which might promote better treatment adherence and lead to improved doctor-patient relationships.

Citation: Geng C, Lu GJ, Zhu J, Li YY. Patients' awareness about their own breast cancer characteristics. *World J Clin Cases* 2021; 9(24): 7043-7052
URL: https://www.wjgnet.com/2307-8960/full/v9/i24/7043.htm
DOI: https://dx.doi.org/10.12998/wjcc.v9.i24.7043

INTRODUCTION

Breast cancer is one of the most common malignancies in women worldwide and is the leading cause of cancer-related deaths in women[1]. Comprehensive knowledge about cancer can improve healthy behaviors; such knowledge is also positively correlated with more regular cancer screening, earlier diagnosis of cancer, and treatment adherence[2-5]. Despite these benefits, previous studies show that general knowledge about breast cancer is poor and is mainly focused on understanding risk factors, pathogenesis, and treatment options[6-8]. It is critical that breast cancer patients understand the characteristics of their own cancer, including the stage of the tumor and its hormone receptor and human epidermal growth factor receptor 2 (HER2) status; such knowledge can lead to a better understanding of treatment principles — such as trastuzumab therapy for HER2-positive breast cancer and endocrine therapy for hormone receptor-positive breast cancer — and ultimately to better treatment adherence[9].

Historically, the incidence of breast cancer in China has been low, but data from national screenings point to a sharp rise in recent years[10]. Breast cancer alone was estimated to account for 15% of all new cancers in Chinese women in 2015[11]. Despite this trend, our earlier data show that 81.4% of women aged 25-70 years in eastern China have poor awareness about breast cancer[12]. In 2015, Freedman *et al*[13] reported racial/ethnic disparities in patients' knowledge about their own breast cancer characteristics in the United States and noted that breast cancer patients in general have poor knowledge about their own tumors. However, to our knowledge, similar studies have not been conducted in China, where most of the world's population live.

Here, we designed and administered a survey, aimed at determining breast cancer patients' knowledge about their own cancer, and the extent to which this information is correct. We also sought to analyze whether education and health literacy influence the associations.

MATERIALS AND METHODS

Study population

Patients included in the study were diagnosed with stage 0 to IV breast cancer from 2017 to 2019 at Shandong Provincial Hospital Affiliated to Shandong University, Maternal and Child Care Service Hospital of Foshan City, Guangdong, and Shandong Anqiu People's Hospital. Patients had undergone primary surgery, and lived in Shandong province and Guangdong province, which together have a population of 190 million residents. Of the 236 patients who were approached about participating, 8 refused to participate, while 226 accepted.

Survey

Participants were asked about their general information, including marital status, the highest level of educational attained, household income, insurance coverage, and self-reported level of health literacy. They were also asked about their cancer characteristics [tumor stage, tumor grade, axillary lymph nodes status, estrogen receptor (ER) status, progesterone receptor (PR) status, and HER2 status] and treatment intervention (chemotherapy, radiotherapy, endocrine therapy, and trastuzumab therapy). All questions included the option of answering "I do not know". Health literacy was assessed *via* three questions, as described by Shinden *et al*[9]. Medical information about patient tumor characteristics and treatment interventions was also collected from hospital records by investigators.

Variables of interest

We surveyed whether patients were aware of their cancer characteristics including tumor stage, tumor grade, ER status, and HER2 status, and the correctness of knowing about their cancer characteristics was also examined. Knowledge about cancer characteristics was defined as providing an answer (correct or incorrect) to the questions; the correctness of patients' knowledge about their own cancer characteristics was defined as the answer that matched the data collected from medical records.

Statistical analysis

The demographic characteristics of respondents, their knowledge, and the accuracy of their knowledge are presented as percentages. Logistic regression analysis was used to determine the probability of knowing and correctly answering questions about stage, grade, ER status, and HER2 status as a function of the patients' age, marital status, level of education, health insurance, and health literacy. Results are considered statistically significant if $P < 0.05$. Odds ratios with 95% confidence intervals were also calculated. SPSS16.0 was used for all data analyses.

RESULTS

Survey results are listed in Table 1. Overall, 57.96% of the patients reported that they knew their disease stage, 20.80% reported that they knew their tumor grade, 47.35% reported that they knew their ER status, 38.05% reported knowing their PR status, and 34.96% reported knowing their HER2 status (Table 2). Moreover, 61.95% of patients were correct in their knowledge of their own disease stage, 10.18% reported their correct tumor grade, 46.46% reported their correct ER status, 35.40% reported their correct PR status, and 32.30% reported their correct HER2 status (Table 3).

Further analysis of the data on knowledge about cancer characteristics revealed that, relative to those in the < 50 years group, patients in the 50-59 year and also in the 60-69 year groups consistently had less knowledge about the disease stage and ER status and HER2 status of their tumor, although most did know about their tumor grade; however, there was no statistically significant difference in level of knowledge about their own condition between patients in the ≥ 70 years group and the < 50 years group. Increases in years of education (education up to junior high school, senior high school, and university or above *vs* primary school or below) were correlated with level of knowledge about disease stage, tumor grade, ER status, and HER2 rose greatly. Lower reported health literacy also was associated with reduced knowledge about their cancer condition. Levels of knowledge about their cancer were not statistically different in patients who were married or had health insurance from those in patients who were not married or did not have health insurance, except with regard to their ER status (Table 4).

Table 1 Characteristics of surveyed patients

Characteristic	No.	Percentage (%)
Age at diagnosis, yr		
< 50	129	57.08
50-59	66	29.20
60-69	31	13.72
≥ 70	6	2.65
Marriage status		
Married	215	95.13
Unmarried or other	8	3.54
Educational attainment		
Primary school or below	55	24.34
Junior high school	78	34.51
Senior high school	63	27.88
University or above	31	13.72
Household income		
< 50000 Yuan	81	35.84
50000-100000 Yuan	53	23.45
100000-200000 Yuan	68	30.09
≥ 200000 Yuan	20	8.85
Insurance coverage		
Yes	196	86.73
No	28	12.39
Tumor stage		
0	7	3.10
I	79	34.96
II	83	36.73
III	48	21.24
IV	10	4.42
Tumor grade		
Low grade	31	13.72
Middle grade	157	69.47
High grade	36	15.93
Axillary lymph nodes status		
Metastasis	92	40.71
No-metastasis	132	58.41
ER		
Positive	171	75.66
Negative	54	23.89
No-detection	1	0.44
PR		
Positive	155	68.58
Negative	71	31.42

No-detection	0	0.00
HER2		
Positive	63	27.88
Negative	154	68.14
No-detection	7	3.10
Chemotherapy		
Yes	209	92.48
No	18	7.96
Trastuzumab therapy		
Yes	15	6.64
No	210	92.92
Radiotherapy		0.00
Yes	78	34.51
No	148	65.49
Endocrine therapy		
Yes	174	76.99
No	52	23.01
Health literacy, mean ± SD	3.36 ± 0.98	

ER: Estrogen receptor; PR: Progesterone receptor; HER2: Human epidermal growth factor receptor 2; SD: Standard deviation.

Table 2 Knowing about their cancer characteristics for surveyed patients

"Knows" characteristic	No.	Percentage (%)
Know stage		
No	91	40.27
Yes	131	57.96
Know grade		
No	169	74.78
Yes	47	20.80
Know ER status		
No	99	43.81
Yes	107	47.35
Know PR status		
No	119	52.65
Yes	86	38.05
Know HER2 status		
No	122	53.98
Yes	79	34.96

ER: Estrogen receptor; PR: Progesterone receptor; HER2: Human epidermal growth factor receptor 2.

Regarding the data on "Correct Report" of characteristics, patients in the 50-59 years and 60-69 years group consistently had less accurate knowledge about their disease stage, ER status, and HER2 status, relative to patients in the < 50 years group; the exception was with regard to knowledge about their tumor grade; however, the

Table 3 Correct knowledge about their cancer characteristics for surveyed patients

Characteristic	No.	Percentage (%)
Correct stage		
Don't know or incorrect	140	61.95
Correct	81	35.84
Correct grade		
Don't know or incorrect	189	83.63
Correct	23	10.18
Correct ER status		
Don't know or incorrect	100	44.25
Correct	105	46.46
Correct PR status		
Don't know or incorrect	123	54.42
Correct	80	35.40
Correct HER2 status		
Don't know or incorrect	127	56.19
Correct	73	32.30

ER: Estrogen receptor; PR: Progesterone receptor; HER2: Human epidermal growth factor receptor 2.

accuracy of knowledge in the over 70 years group was not statistically different from that in the < 50 years group. In addition, a university degree (or higher education degree) was consistently associated with patients having more accurate information about their cancer condition, compared to those with education only up to primary school or less. Those who had an education up to senior high school had more accurate knowledge about their disease stage, ER status, and HER2 status, and those with education only up to junior high school displayed greater accuracy in knowing their disease stage, compared to those with primary school (or below) education. Lower reported health literacy was associated with lower accuracy about patients' own condition, with the exception of their HER2 status. No statistical differences were observed in the accuracy of patients' knowledge about their condition in the context of their marital status and health insurance: The one exception was that there was a positive association between being married and having an accurate knowledge about their own HER2 status, and between having health insurance and having accurate knowledge about their disease stage and ER status (Table 5).

DISCUSSION

A patient's knowledge about his/her cancer can encourage healthy behavior and improve treatment adherence. Compared to that in developed countries, patients' knowledge about their own breast cancer is very poor in the Chinese population, and the lack of awareness of this disease has already had a serious impact on cancer screening and early cancer diagnosis in China[14]. In the present survey, we observed that a high percentage of patients in China had no knowledge about their cancer or were not able to correctly report their cancer information. Compared to the American breast cancer patients included in the study by Freedman *et al*[13], the population that we surveyed had much less information about their own cancer, with the exception of knowing whether the tumor is HER2-positive. Our analysis showed that lower level of education, older age, and lower health literacy in patients were associated with less knowledge about one's own tumor.

Our results underscore the need for more work aimed at enhancing Chinese patients' knowledge about their own cancer. Providing comprehensive knowledge of breast cancer treatments, such as trastuzumab therapy for HER2-positive breast cancer or endocrine therapy for hormone receptor-positive breast cancer, can help patients

Table 4 Models for knowing about their cancer characteristics for surveyed patients

	"Knowing" analysis [odds ratio (95% confidence interval)]			
	Stage	Grade	ER status	HER2 status
Age at diagnosis, yr				
< 50	1	1	1	1
50-59	0.48 (0.26-0.91)	1.56 (0.77-3.14)	0.49 (0.26-0.92)	0.37 (0.19-0.74)
60-69	0.34 (0.15-0.79)	0.32 (0.07-1.43)	0.23 (0.09-0.60)	0.24 (0.08-0.68)
≥ 70	0.45 (0.09-2.35)	1.90 (0.33-10.97)	0.20 (0.02-1.98)	0.24 (0.03-2.19)
Marriage status				
Married	1	1	1	1
Unmarried or other	0.68 (0.17-2.79)	1.22 (0.24-6.25)	2.79 (0.55-14.16)	4.79 (0.94-24.39)
Educational attainment				
Primary school or below	1	1	1	1
Junior high school	3.36 (1.60-7.05)	5.02 (1.39-18.11)	2.10 (0.96-4.59)	3.05 (1.12-8.29)
Senior high school	5.18 (2.34-11.47)	5.22 (1.43-19.12)	4.07 (1.80-9.21)	8.41 (3.09-22.88)
University or above	7.26 (2.62-20.15)	7.30 (1.82-29.30)	7.41 (2.58-21.29)	17.08 (5.22-55.92)
Insurance coverage				
Yes	1	1	1	1
No	2.28 (0.92-5.62)	0.96 (0.36-2.52)	15.25 (3.51-66.21)	1.77 (0.78-4.01)
Health literacy				
Average	0.44 (0.31-0.62)	0.57 (0.41-0.79)	0.68 (0.50-0.92)	0.68 (0.50-0.93)

ER: Estrogen receptor; HER2: Human epidermal growth factor receptor 2.

understand the rationale underlying a particular treatment for their conditions, which may in turn lead to a better understanding of the disease and better decisions about and adherence to treatment[15,16]. Unfortunately, many providers fail to provide patients with basic education about their disease and treatments.

The factors that contribute to this lack of education process are not known. After assessing a patient's characteristics, health care providers should find an effective way to transmit information about the disease to patients. In this exploratory analysis, we showed that 57.96% of the patients claimed that they are aware of the stage of their own cancer, but the rate of correct knowledge was only 35.84%. The stage of cancer is the issue of most concern for cancer patients at the time of diagnosis. However, the method for tumor classification takes into consideration tumor size and lymph node status, which might be complicated for patients to appreciate, especially due to a lack of accuracy of their knowledge. We also observed that the rates of Know ER and Correct ER were higher than those for other cancer characteristics, which may be related to the use of hormone therapy for patients with ER-positive cancers, and general treatment can increase general breast cancer knowledge[17,18]. The rates of Know HER2 and Correct HER2 were lower than the corresponding values for ER, perhaps because of the high incidence of HER2-positive breast cancer in China. The rate of Correct HER2 was comparable to that of Know HER2, which may be because trastuzumab therapy for HER2-positive patients was very expensive and was not covered by national health insurance in most parts of China. In addition, the tumor grade is less of a factor than other characteristics in making the decision for which clinical treatment to use. Our results confirm that the rates of Know grade and correct grade were lower than those for other characteristics.

Our findings indicate an association between a lower awareness rate and correct rate and lower educational attainment or poor health literacy. In addition, a lower level of knowledge and accuracy about one's own condition was also associated with higher age, but this association did not hold for patients who were ≥ 70 years old; however, because we included only six patients in the ≥ 70 years group, the data were insufficient to draw a firm conclusion for this group. Limited health literacy, including

Table 5 Models for correctness of knowing about their cancer characteristics for surveyed patients

	"Correctness" analysis [odds ratio (95% confidence interval)]			
	Stage	**Grade**	**ER**	**HER2**
Age at diagnosis, yr				
< 50	1	1	1	1
50-59	0.35 (0.18-0.70)	0.81 (0.30-2.23)	0.46 (0.24-0.86)	0.45 (0.23-0.88)
60-69	0.32 (0.12-0.84)	0.31 (0.04-2.47)	0.20 (0.07-0.54)	0.30 (0.10-0.86)
≥ 70	0.55 (0.10-3.13)	3.71 (0.62-22.17)	0.20 (0.02-1.98)	-
Marriage status				
Married	1	1	1	1
Unmarried or other	0.53 (0.10-2.69)	1.14 (0.13-9.68)	2.88 (0.56-14.61)	5.46 (1.07-27.79)
Educational attainment				
Primary school or below	1	1	1	1
Junior high school	3.83 (1.52-9.65)	2.42 (0.48-12.21)	2.19 (0.99-4.87)	2.59 (0.94-7.09)
Senior high school	4.96 (1.94-12.71)	2.86 (0.57-14.47)	3.91 (1.72-8.90)	7.14 (2.63-19.43)
University or above	10.18 (3.47-29.84)	6.56 (1.26-34.09)	9.73 (3.23-29.36)	12.00 (3.78-38.09)
Insurance coverage				
Yes	1	1	1	1
No	2.54 (1.14-5.70)	0.59 (0.13-2.65)	15.80 (3.64-68.62)	1.59 (0.71-3.56)
Health literacy				
Average	0.66 (0.49-0.88)	0.51 (0.33-0.79)	0.73 (0.54-0.98)	0.76 (0.56-1.04)

ER: Estrogen receptor; HER2: Human epidermal growth factor receptor 2.

in the older age group and in those with a lower educational level, was found to be correlated with poor health[19,20], which indicates the necessity for pertinent identification and development of appropriate interventions by providers. In the exploratory analyses, the rates of Know ER and Correct ER were associated with patient insurance coverage; however, this correlation may be due to a greater acceptance of hormone therapy in ER-positive patients, who are more likely to be covered by insurance.

CONCLUSION

In summary, our survey results show that breast cancer patients in China have very poor knowledge about their own cancers. Better education of individuals with breast cancer in China is critically needed. We highly recommend that Chinese physicians provide additional information about the disease to patients, which might promote better treatment adherence and lead to improved doctor-patient relationships.

ARTICLE HIGHLIGHTS

Research background

Patients' knowledge about the characteristics of their own cancer could be an important factor for understanding treatment regimens and adhering to therapies.

Research motivation

To date nothing is known about the awareness among Chinese breast cancer patients on the characteristics of their own tumors.

Research objectives

We aim at determining how much knowledge that Chinese breast cancer patients have about their tumor characteristics and the impact of health and education literacy on the acquisition of such information.

Research methods

The survey was administered to patients who were diagnosed with breast cancer from 2017 to 2019 in three hospitals in China, and who came in for regular follow-up on an outpatient basis. We collected responses from 226 respondents who were asked about their cancer characteristics (stage, grade, and estrogen receptor status and human epidermal growth factor 2 status of the cancer), and evaluated the correctness by comparing with their medical records. Logistic regression was used to assess the probability of knowing and of correctly answering questions. We also analyzed the association between our findings and the level of the patient's education and their health literacy.

Research results

There were 20.80% to 57.96% of the patients who reported knowing about the characteristics of breast cancer; of these, 10.18% to 46.46% reported these characteristics correctly. Education, age, and health literacy were all significantly associated with awareness rate, and with the level to which this information was accurate.

Research conclusions

Our survey results show that breast cancer patients in China have very poor knowledge about their own cancers.

Research perspectives

We highly recommend that Chinese physicians provide additional information about the disease to patients, which might promote better treatment adherence and lead to improved doctor-patient relationships.

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