



Breast Cancer Survivors Report Similar Concerns Related to Return to Work in Developed and Developing Nations

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Abstract

Aim To determine whether breast cancer survivors (BCS) at work following the diagnosis and/or treatment of breast cancer, in a rapidly developing country such as China experience similar to return to work challenges as reported in nations with established return to work (RTW) policy and procedures for employees with cancer. **Methods** Semi-structured interviews were conducted with 16 BCS who returned to work following diagnosis and/or primary cancer treatment. An Interpretative Phenomenological Analysis was used to investigate responses. **Results** Three recurring themes emerged: (1) challenges at work related to residual effects of diagnosis and/or primary treatment; (2) positive and negative responses from employers and/or supervisors; and (3) positive and negative responses from co-workers/colleagues. Although several participants experienced a high level of workplace support, there was a subgroup that did report challenges related to symptom burden, cognitive limitations, and both positive and negative responses by employers and co-workers were reported. **Conclusions** Findings indicate similar challenges in BCS who RTW during and/or following cancer treatment in both rapidly developing and developed nations. Results suggest that regardless of the existence of workplace policies and practices related to RTW for workers with a history of cancer, a subgroup of BCS experience similar challenges when returning to work. These findings highlight the international nature of RTW challenges and suggest the need for more global efforts to develop and evaluate workplace interventions to assist with these similarities.

Keywords Breast cancer · Cancer survivors · Return to work · Phenomenological analysis · Workplace support · Symptom management

Introduction

Breast cancer is one of the most common cancers among women throughout the world. More specifically, in China there has been an annual increase in breast cancer diagnoses

of 3% [1] and a current rate of 59.7/100,000 in major metropolitan areas [2]. Women tend to be diagnosed with breast cancer at a younger age than in developed countries in China [3]. The median age of diagnosis and treatment in China tends to be about 48 years; 10 years younger than is typical in western counterparts [4]. This median age suggests that many patients are diagnosed and treated while still at working age. While survival rates have increased globally [5, 6] there has been a marked increase in the number of long-term breast cancer survivors (BCS) in China [7].

The average sick leave for those diagnosed with breast cancer in western countries is 1 year [8] although wide variations in return to work (RTW) rates have been observed. In terms of BCS in China, a survey of 1466 BCS reported that 57% of cases remained at home to “recuperate following surgery” for the duration of their lives and others returned to work an average of 21 months following diagnosis [9]. While a more recent study from China reported that <20% of working-age breast cancer patients RTW in the city of

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Beijing [10]. The proportion of Chinese women returning to work is smaller and the time from diagnosis to RTW tends to be longer than that of developed countries [11]. It is unclear if there are specific problems experienced related to RTW by BCS following diagnosis and primary treatment for breast cancer in China as the country continues to place a high value on increased productivity [12]. It is currently unclear whether the BCS experience at work during and/or following primary treatment in a country considered a rapidly developing nation with a strong emphasis on work function differs from more developed countries also with a focus on productivity but also with long standing policies and procedures designed to assist employees with various medical illnesses return to and remain at work.

Almost two decades of research on cancer and work conducted in developed countries have reported that a number of demographic [13–15], treatment [13, 16], symptom [13], and workplace [17–19] related factors are associated with lower rates of RTW [13], work sustainability [20], and work functioning [21] in BCS back at work. These variables include age, education, income, marital status, dose and type of chemotherapy exposure, lymphedema, depression, fatigue, cognitive impairment, non-physical job type, flexible working hours, emotional support from friends, family members, and co-workers [13, 15, 18], high job demands, and lack of support from co-workers and employers. Research on factors associated with work sustainability in a diverse group of cancer survivors have also shown that workplace problems, including reports of being poorly treated, passed over for promotion, discriminated against and not provided with any type of accommodation were significantly and directly related to a number of negative work outcomes [20].

This research indicates that challenges to RTW and work sustainability exist in some with a history of breast cancer. An early study conducted in the United States on newly diagnosed breast cancer patients reported that both perceived employer discrimination and lack of accommodation were independently related to RTW at 12 and 18 months [22]. A more recent longitudinal study in the Netherlands that followed a diverse group of cancer survivors at work for 6, 12 and 18 months noted that while work function and symptom burden (fatigue, depressive) improved over the initial 18 months back at work following treatment; higher levels of fatigue, depressive symptoms and cognitive limitations at work were negatively related to work functioning throughout this 18 month period. In contrast, higher levels of work functioning were related to higher levels of supervisor support and a greater number of working hours [21].

The present study was conducted to describe the experiences of those with a history breast cancer returning to work in a rapidly developing nation. If evidence emerges indicating BCS in China experience a similar set of challenges to those supported by quantitative and qualitative literature

from a diverse set of nations [13, 15, 17–20], perhaps it is time to consider a generic set of experiences related to return to work, despite variations in cultures, histories of economic development and work place protections for those with cancer. There may be a subgroup of breast cancer survivors with a history of breast cancer diagnosis and treatment at work who experience similar challenges related to work world wide. Such a finding would add further support for a more global effort to prevent and manage these work-related challenges. Retrospective interviews of the experiences of woman with breast cancer who during and/or following their diagnosis or treatment for breast cancer in China actually returned to work were conducted.

Methods

Participants

Purposive sampling was used to select participants. While a total of 18 breast cancer patients were recruited two patients refused to participate in the interviews. One was reluctant to be recorded, while it was unclear why the second patient refused the interviews. Participants included patients on ($n=2$) and off ($n=14$) primary treatment. At the time of the interviews all 16 participants returned to paid employment at the same organizations prior to diagnosis. Inclusion for recruitment were: (i) primary diagnosis of breast cancer (stages I-III) with no other cancers as determined by medical records, (ii) between 18 and 60 years of age, (iii) working at the time of diagnosis, (iv) returned to work at interview, and (v) fluent in Mandarin. We recruited participants from both the inpatients at discharge and the breast cancer outpatient clinic at a tertiary general hospital in Beijing.

Procedure

All participants completed a face-to-face, semi-structured, interview. Interviews were analyzed following the procedure of Interpretative-Phenomenological Analysis (IPA) [23]. All interviews were performed face-to-face by the first author in a quiet location convenient to the survivor [generally at their home ($n=6$) or workplace ($n=10$)]. All interviews were audio-recorded with consent. The interview lasted an average of 40 min, ranging from 31 to 58 min.

Data Collection

A semi-structured, interview was developed for this study that included open-ended questions such as: “Can you tell me your working experiences after returning to work after breast cancer?”, followed by probing questions such as “Please explain more”, and “Can you give an example?”, based on the

response of the BCS. Interviewing skills were required, such as active listening and asking open-ended questions without hidden presumption, building rapport and trust. The specific goal of the interview was to elicit the BCS's account of their experience after a RTW. During the interview, nonverbal information (such as body language, facial expressions, and gestures) was also noted and integrated into the transcript. RTW was defined as return to former paid employment after sickness absence following a breast cancer diagnosis and treatment.

Data Analysis

All aspects of the research study were sensitive to context, rigor, transparency, and impact [24]. As for sensitivity to context, word-by-word quotes and comments related to body language throughout the analysis process gave the participants a voice and let researchers trace back to explanations [25]. Each transcript was analyzed in its entirety prior to analyzing the next transcript [26], which allowed for a certain level of rigor [25]. Transcripts were read multiple times to ensure a complete understanding of the transcript and notes related to observations and reflections were completed.

Emergent themes were transformed from notes. Seeking connections and clustering themes was the next stage allowing for the grouping of themes. Results were discussed with a second member of the research team to facilitate consistency/reliability. Some themes were discarded and others further elaborated on. Recurring themes among all transcripts were identified. All themes were compared, with particular attention to convergent and divergent characteristics. Analysis did not stop until commonalities and differences between participants became clear. Finally, several super-ordinate themes were identified that also described the participant's experience.

Results

Participants

The BCS were between 30 and 53 years of age, with an average of 42.8 ± 6.8 years. Time to return-to-work was from 1 month to 24 (average = 9.3, median = 8.5) months after breast cancer diagnosis. At interview, time back to work ranged from 3 to 48 months (median = 18 months). Participants' characteristics are presented in Table 1.

Themes

Three major themes were identified: (1) experiencing work-related challenges; (2) response from employers (supervisors); and (3) response from colleagues or co-workers. These experiences were reported by those

Table 1 Demographic, work and clinical characteristics of the participants (n = 16)

Variables	n (%)
Age (years) [mean (SD) (range)]	42.8 (6.8) (30–53)
Educational level	
Junior high school	1 (6.25)
Senior high school	3 (18.75)
Junior college/diploma	3 (18.75)
Undergraduate/bachelor degree	9 (56.25)
Marital status	
Unmarried	2 (12.5)
Married	12 (75.0)
Divorced	2 (12.5)
^a Occupational categories	
Professional/technical/managerial	12 (75.0)
Clerical/sales	2 (12.5)
Services	2 (12.5)
Stage of cancer	
Stage I	2 (12.5)
Stage II	10 (62.5)
Stage III	4 (25.0)
Treatment type	
Surgery	3 (13.1)
Surgery + Chemotherapy	6 (7.3)
Surgery + Radiotherapy + Chemotherapy	7 (34.7)
Time from diagnosis to RTW (months)	
≤ 12 months	12 (75.0)
> 12 and ≤ 24 months	4 (25.0)
Duration at work post diagnosis (months)	
≤ 12 months	8 (50.0)
> 12 and ≤ 24 months	1 (6.3)
> 24 and ≤ 48 months	7 (43.8)

SD Standard deviation

^aBased on the dictionary of occupational titles by U.S. Department of Labor

working in government positions and private companies either during treatment or following primary treatment (majority) for breast cancer. A summary of such themes and subthemes are provided in Fig. 1.

Experiencing Work-Related Challenges

This theme is concerned with how cancer or treatment-related symptoms and functional limitations that were experienced affect the survivor's ability to adapt to work. Thirteen of the sixteen survivors reported such challenges coincident with RTW. This theme included physical and cognitive challenges.

Fig. 1 Experiences described related to returning to work among woman with breast cancer during and following primary treatment

Theme 1: Experiencing work-related challenges

Physical limitations

Cognitive limitations

Theme 2: Response from employers/supervisors

Support from Employers/Supervisors

Accommodating efforts

Economic support

Cohesion

Supportive comments

Negative Reactions from Employers/Supervisors

Bullying

Lack of empathy

Overprotection

Expectations of abrupt return to pre-cancer expectations

Theme 3: Response from co-workers

Positive Support from Co-workers

Supportive behaviors

Positive feedback (verbal, non verbal)

Negative Reactions from Co-workers

Troublesome behavior

Lack of sensitivity

Physical Limitations

Physical weakness (fatigue, lack of stamina) and treatment side effects (symptoms of menopause, affected limb discomfort) were reported when at work. A few interviewees experienced a decline in physical stamina that disqualified them for their job.

“I thought I was going to die after continuous working, I sweated a lot with numb legs...as if my body was not my own...difficult to work a whole day.”
Nurse

“I was weak at work, especially in the afternoon, I sweated a lot.” Returned to work during chemotherapy.

Financial manager

“...It was hard to complete meeting memos...and my arm ached after typing a long time...” Head nurse

Cognitive Limitations

The cases also identified a number of cognitive challenges while at work, including declining memory, slow reactions, difficulty in concentration, and frequent cognitive errors (e.g., misnaming someone). All survivors who

received chemotherapy identified some type of cognitive challenge after returning to work. Teachers, financial staff and clinical nurses tended to be most affected.

“...memory was really bad...if not preparing lessons in advance an accident would occur...that is, I would forget the word...it was also really difficult to prepare examples for class.” Returned to work 18 months following surgery. Teacher

“...I couldn't concentrate...I could only concentrate on working for a while.” Returned to work during chemotherapy. Financial staffer

Response from Employers/Supervisors

This theme refers to the attitude and behavior of employers/supervisors and the emotional responses of survivors. All survivors indicated both positive and negative experiences in the workplace.

Support from Employers/Supervisors

Most survivors experienced instrumental and social support from supervisors that included accommodation efforts, economic support, supportive comments, and overall improvement in the work environment.

Accommodating Efforts When back at work, most BCS received accommodations from supervisors in terms of reduced hours, flexible schedules, gradual increase in hours and duties, time off for medical appointments, increase in staff or greater sharing workloads with co-workers, delaying deadlines, changing specific duties and creating a more pleasant or safer work environment or work transfer. Managers sought to accommodate BCS's abilities and reduce stress.

“After I became ill, the employer provided staff to share my work tasks...let me arrange my working hours according to my own physical condition, going or not going to workplace, also I decided how long I worked.” Returned to work during chemotherapy. Corporate finance supervisor

“I did not have contact with chemical reagents as before...I was so happy for the new working environment.” Returned to work 8 months after diagnosis. Laboratory technician

Economic Support Survivors reported supervisors provided them the same or relatively higher salary regardless of lower working productivity than before.

“...they also considered my financial situation... never gave me less than before...” Returned to work 16 months after diagnosis. Financial Cashier

“I got twenty or thirty percent of the bonus rather than nothing, the employer showed consideration for me.” Returned to work 9 months after surgery. Mid-level manager

Cohesion This subtheme reflected an individual's specific expectation for interconnection at work. A supportive team atmosphere in the workplace, created by managers, improves relationships and benefits the team.

“My employer said we should help each other... shouldn't have negative thoughts or actions about return.” Middle-level manager reassigned un-supportive co-workers leaving others who did provide support. Returned to work 1 month after surgery. Clerk

Supportive Comments Many BCS experienced supportive comments of understanding, attention, and approval from managers. This category tended to refer to communicating with empathy often seen as a base for acceptance. It specifically refers to a manager's understanding of: (1) a survivor's suffering from breast cancer, (2) reduced work ability, (3) the personal need for work, and (4) the acknowledgement that new needs must be accommodated.

“...every time the principal saw me he would ask ‘how you felt recently...let me know if you need anything’, which let me believe that he cared about me.” Teacher
“The employer had a talk especially with me, asked me about my condition and the operation, assessed the situation, told me not worry about job...this comforted me for a while...” Clerk

Negative Reactions from Employers/Supervisors

Although all survivors experienced certain types of support from employers, five survivors also described negative experiences including inadequate support, over-protection, support weaning, or actually being fired. Each of these cases had negative psychological experiences including lack of acceptance, not being understood, inconsiderate behavior of supervisors, inappropriate reassignment, and being pitied. These were related to consideration of termination.

Bullying “...One employer who was also a co-worker came up and told me, you got breast cancer now, I will find an excuse to fire you...this made me upset then...” Clerk

Lack of Empathy Survivors mentioned lack of empathy and understanding by a supervisor can influence work-

place support. Task-oriented and autocratic supervisors who ignored survivors and their real needs were interested in productivity or pressured work attendance and worsened survivors' RTW experiences.

"...When I moved to a new post, my old supervisor said didn't I take care of you? I didn't assign you to night shifts..." RTW 8 months after surgery. Nurse
 "I was in such a desperate position...many times I wanted to stand on the tallest building of the hospital, such a huge hospital, how could they not accommodate me?" Nurse

Overprotection Several survivors reported that they felt being over-protected by supervisors or employers, which made them lose self-esteem and self-value.

"The employer did not let me do this, did not let me do that...I felt I was such a stupid idiot because I could do nothing then." Returned to work 1 month after surgery. Clerk
 "...they all regarded me as a dying patient as if I was not going to survive the next several days...as if I was somehow not normal ...I could not accept this and felt they did not respect me." Returned to work during chemotherapy. Clerk

Expectations of Abrupt Return to Pre-cancer Expectations Some survivors indicated that supervisors' support decreased over time or disappeared when encountered a new supervisor in work. Invisible symptoms (e.g., fatigue, cognitive problems, adaptation) caused supervisors to overestimate survivors' capacities.

"Told me requirements for you and others were identical...no difference...had meeting before 8:00 am, I must leave home at five o'clock. Certainly, I could not keep up...was criticized at every morning meeting...I was in a particularly bad mood...I thought this supervisor was really bad...drove me almost crazy." Returned to work during chemotherapy. Clerk
 "Little by little, the workload assigned to others was reassigned. They said because you looked so good, people around me thought you could work just as before..." Mid-level manager

Response from Co-workers

Co-workers' reactions were related to both positive and negative work experiences. Both extremes in attitude and behavior occurred. Many survivors experienced practical or instrumental support and spiritual encouragement from

coworkers, including both supportive behaviors and positive communication or feedback.

Positive Support from Co-workers

Supportive Behaviors Most survivors experienced support from co-workers in terms of sharing of tasks and flexibility or latitude in work performing certain tasks.

"My co-workers did not let me lift heavy objects, they were there to help me, and they did not let me get tired. They were willing to offer a helping hand whenever they could." Returned to work 8 months after diagnosis. Laboratory technician
 "My co-workers would help me type, if I have a lot of tasks at one time." Returned to work 1 month after surgery. Head nurse

Positive Feedback (Verbal, Non Verbal) One survivor reported being inspired by co-workers' feedback related to her appearance.

"Customers...company co-workers, supervisors...their appreciating and admiring eyes, gave me a lot of confidence." Mid-level manager

Negative Reactions from Co-workers

Six out of 16 survivors reported negative attitudes, evaluations, and hostility from co-workers. Lack of attention and understanding appeared to lead to difficulties in collaborating with co-workers.

Troublesome Behavior Several survivors experienced negative reactions from co-workers regarding the very idea that those with cancer RTW and they tended to keep a certain distance from them or look at them strangely.

"No one talked to me, they stayed far away from me. If I do see them they just say hello in a hurry...as if they were afraid of me...I felt very lonely...I did not want to work any longer." Corporate finance supervisor
 "I could feel that kind of glance, you know? The eyes...I cannot tell you how I felt at that time...definitely uncomfortable, you know." Returned to work 9 months after diagnosis. Mid-level manager

Lack of Sensitivity Lack of knowledge of cancer and its adverse effects made it very difficult for co-workers to know the actual needs of survivors. Co-workers might unintentionally make work emotional or physically more difficult through words or actions.

"...a former co-worker said, 'hey, you got lucky you do not need to work the night shift, you found a positive

situation out of misfortune...’ how could this be called lucky? I had cancer. That’s my misfortune...” Nurse
 “There was that type of co-worker...when you could not lift heavy object, she just let you do that type of thing.” Nurse

Discussion

The findings of this study indicate that BCS who return to the workplace in China report employment challenges related to residual symptoms including fatigue, functional changes (e.g., cognitive limitations at work) and problematic communication or interactions involving employers, supervisors and co-workers. These findings indicate that BCS face similar workplace challenges in Chinese workplaces as in other workplaces with a longer history of workplace protections for workers with chronic illness [27] and perhaps more experience with employees with a history of breast cancer. The results also highlight the importance of a supportive, flexible and accommodating workplace [28–31].

Symptoms reported by BCS have been related to performance decline [32–34]. Even BCS on an average of 4 years post diagnosis report greater work limitations when compared to a non-cancer comparison group [35]. These challenges were experienced in certain BCS in the current sample and can be best conceptualized as an aspect of short and long term effects of diagnosis and treatment [27, 36]. Supervisor support as observed in the present study is another commonality consistent with the global literature [37]. It is well known that support of supervisors can facilitate the process of RTW in cancer survivors [28], yet there can be a strong bias against cancer survivors returning to work. The mechanism behind the positive effect of supervisor support can be as simple as such support can impact the cancer survivors’ perception of their own work ability or self-efficacy [38] at this period represents time when understandably many BCS may be especially vulnerable or particularly sensitive to such responses.

BCS reported negative experiences with employers/supervisors ranging from inadequate or no support, to bullying, to situations where the BCS thought there was too much support. Prior research has indicated that workplace problems, including discrimination (e.g., being passed over and absence of workplace accommodations), are significantly and directly related to both perceived work ability and work sustainability [20]. Poor work support has also been associated with lower work ability among a mixed group of survivors post primary treatment [39]. Also, workers experiencing lower social support when diagnosed changed work more frequently than workers with higher social support [40]. Therefore this negative response by co-workers and/or employer/supervisors can be counterproductive.

The potential reasons for this can be many. One is that the BCS’s need for support is not prioritized or even considered. Although supportive work environments were viewed as helpful, the specific needs of individuals do differ [41]. When provided with more risk- stratified interventions such as individualized accommodations, cancer patients are better able to return to work [41, 42] and keep their jobs [42]. Some BCS in the present study reported problems related to “excessive support”. Similar overprotective reactions have been related to lower self-esteem and self-efficacy at work [43] which can interfere with efforts to achieve greater levels of self management upon returning to work.

Bullying behavior from employers were also reported and, as expected, resulted in negative emotions and poorer psychological health [44]. In workplaces where the RTW or accommodation process is seen as an “unnecessary managerial burden”, it is difficult for managers to determine the best course of action [45, 46]. The view that this effort represents an “unnecessary managerial burden” could very well lead to bullying behavior on the part of managers, other negative interactions with management, and the decision to eventually leave the workplace by BCS.

It must be acknowledged that some employers may not want cancer survivors to RTW because the perceived or actual difficulty these employees have meeting requirements of specific work tasks. Research that examines the experiences, attitudes and behaviors of managers/employers in such circumstances, while complicated, is necessary for the identification for underlying processes related to successful RTW and generating solutions. A UK study [30] reported that while managers had favorable attitudes towards supporting cancer survivors in the process of RTW there were some managers who perceived the requirements to make appropriate work accommodations for survivors were just too complicated and burdensome. These managers also harbored negative attitudes regarding the individual’s ability to work and meet the demands of the job [30]. These findings indicate a genuine need to generate innovative, low cost, effective and easy to implement accommodations for many of these patients.

Related evidence of a negative perception of workers with some type of limitation has also been reported in a survey of human resources and line managers from Midwest USA [47]. These employer representatives indicated they were not “overly enthusiastic” with potential employees who experience various types of disabilities including those with cancer or a history of cancer. These managers viewed employees with a history of cancer and its treatment as “unreliable and not very productive” [47]. A qualitative study from Canada found that employers held very contrasting views about employees with a history of cancer [48]. In the Netherlands, while there is a legislative framework with clear guidelines and a focus on supporting the RTW

process of sick-listed employees [49], a qualitative study of 30 employers reported that they need easily accessible information and decision-making skills to support cancer survivors in their RTW efforts [50]. If it is made too difficult to get such information, motivation for RTW on the part of supervisors will vary.

Participants in the present study also reported negative reactions from co-workers. It has been observed that among all work related factors, lack of support from co-workers and employers emerge as a primary barrier for BCS's decision to remain at work [51]. One possible explanation for such negative reactions may relate to the "workplace norm" of equal workload sharing, and result in co-workers actually discouraging the return of cancer survivors [52]. It is also possible that over-interpretation of negative experiences due to cancer survivors' heightened sensitivity and suspiciousness [53] can facilitate non productive "friction" between the BCS and their workplace. Support for this hypothesis would imply that certain interventions directed at such sensitivity may be helpful and should also be evaluated.

The present study indicates that despite cultural differences and health and workplace policy variations, certain physical, cognitive, emotional, and interpersonal challenges can be reported related to return to work following a breast cancer diagnosis and treatment [54]. The global literature on return to work and the work experience in a subgroup of cancer survivors (breast and others) [55–57] suggests that some common underlying mechanism maybe operational in workplaces in many nations of the world. A potential common factor among workplaces may be the legitimate expectation of a certain level of work productivity among those at work. The challenges reported by BCS in the global literature indicate have been associated with lower work productivity again observed in only a sub group of BCS. Efforts to return or accommodate these levels of productivity to some threshold level of acceptability to all involved rather than simply continue the status quo may provide a win-win situation for survivor and employer.

The current findings suggest that effective interventions to prevent or attenuate residual symptoms and functional limitations through some combination of cancer survivor rehabilitation, workplace accommodation, along with efforts to improve workplace support (supervisors and co-workers) may improve a number of short and long term work outcomes important to BCS and employers at some global level. While improvements in symptom burden and work function typically occur over time, problems do persist in select cases even when this improvement or return to pre-treatment levels occurs. It is important to recall that despite such recovery, symptom burden (fatigue, depressive symptoms) and cognitive problems in the context of work continued to be related to poorer work function at 18 months [21]. The types of interventions mentioned above may not

only enhance short-term RTW and work sustainability but improve longer term outcomes for both the cancer survivor and employer. It remains curious why after early publications of the existence of these problems in cancer survivors at work have existed for over 20 years ago (e.g., mismatched workplace support, discrimination, bullying) the problems continue to be experienced across the globe.

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Compliance with Ethical Standards

Conflict of interest The authors have no conflict of interest to declare.

Ethical Approval All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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