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Cognitive complaints and supportive care needs in Chinese cervical cancer survivors: a qualitative study

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Title: Cognitive complaints and supportive care needs in Chinese cervical cancer survivors: a qualitative study

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Abstract

Objectives: This study aims to explore perceived cognitive complaints and relevant supportive care needs in Chinese cervical cancer survivors after primary cancer treatment.

Design: This study utilized a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Setting: This study was conducted in a secondary cancer care center, located in South China.

China.

Participants: 31 women with cervical cancer after primary cancer treatment, aged 18-60 years old, were purposively selected using non-random sampling procedures.

Results: A total of 31 cervical cancer survivors joined this study. Of that total, 20 women (64.5%) reported cognitive complaints after cancer treatment. The most common complaint was loss of concentration (n=17, 54.8%). Perceived contributing factors to these cognitive complaints included chemotherapy (n=15, 48.4%), and aging (n=8, 25.8%). These cognitive problems most commonly impacted their daily living (n=20, 64.5%). Common supportive care needs include symptom management strategies (n=11, 35.5%), and counseling services (n=8, 25.8%).

Conclusion: This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for preventing, and providing supportive care services, such as educational and counseling services, to reduce cognitive impairment in women with cervical cancer.

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Strengths and limitations of this study

- This is one of the first published studies exploring cognitive complaints in Chinese cervical cancer survivors, which is an understudied population.
- 'Doing nothing' as a common coping strategy for cognitive complaints, which has cultural implications in a Chinese population.
- This study, as a pilot, only recruited study participants at a single medical center, which could limited the transferability of study findings.

Keywords Cervical cancer. Survivors. Cognitive complaints. Supportive care needs.

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Introduction

Cervical cancer is the second most common cancer, followed by breast cancer, among women in China.[1] Due to medical advancements in early detection and the possibility of curative cancer treatment,[2] the five-year relative survival rate of cervical cancer in mainland China is up to 69% for all stages.[1] As more cervical cancer survivors are living longer after curative treatment, late effects of cancer treatment are becoming increasingly common.[3] One such long-term and late effect is neurocognitive, which has emerged as a significant problem affecting cervical cancer survivors.[4,5]

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Cognitive complaints often refer to cognitive impairment or cancer-related cognitive impairment.[6,7] Other studies have described this as chemotherapy-related cognitive dysfunction, colloquially named 'chemo brain' or 'chemo fog'.[8,9] Cognitive complaints have the potential to significantly impact both social and occupational functioning, interfering with the ability to carry out normal daily activities, all of which in turn contributes to lower quality of life (QOL) in cancer survivors.[4,6,10] Cognitive complaints have been reported in approximately 40% of patients prior to any cancer treatment, and as many as 75% of patients indicate some degree of cognitive impairment during the period of active cancer treatment. Finally, cognitive complaints are still present in up to 60% of long-term cancer survivors.[6] In a study conducted in mainland China, female cancer survivors with an average of 2.79 years post primary treatment reported higher levels of cognitive limitations, significantly reducing their work productivity and global QOL.[7]

There are quantitative research approaches employed to explore cognitive complaints and related supportive care issues among cancer survivors,[4,12] and these researchers have proposed that quantitative cognitive measures are more objective and reliable than qualitative exploration of cognitive problems in cancer survivors.[13,14] However, other researchers argued that there are inherent difficulties with a quantitative approach, in terms of fully appreciating cognitive complaints by cancer patients.[4,15] Qualitative research studies would enable us to identify the presence of cognitive symptoms that quantitative approaches cannot detect, either by self-reported cognitive measures or neurocognitive tests.[15] In addition, qualitative in-depth interviews could provide information about how cognitive impairment impacts cancer patients' QOL, and could allow researchers to obtain rich information about numerous coping strategies to ameliorate cognitive dysfunction symptoms, as well as develop intervention strategies.[15]

Therefore, there is a need for a qualitative study to explore perceived cognitive complaints and relevant supportive care needs in cervical cancer survivors after primary cancer treatment. A clear understanding of cognitive complaints experienced by cervical cancer survivors, through qualitative in-depth interviews, could aid health care providers in developing targeted interventions, as well as in providing relevant supportive care services for alleviating the extent and impact of cognitive complaints in cancer survivors.[16]

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Methods

Design

This study utilized a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Study sample

All study participants were recruited from the Gynecological Oncology Unit in a cancer hospital. This study obtained ethical approval from the hospital's ethics committee. Inclusion criteria were: women who were at least 18 years old, with a primary diagnosis of cervical cancer, who had completed their primary cancer treatment of surgery, radiation therapy or chemotherapy. Exclusion criteria included potential psychiatric disorders, previous cancer history, or traumatic brain injury.

Study procedure and qualitative interviews

After obtained written consents, eligible participants were invited to participate in a semi-structured interview, and complete a socio-demographic sheet. This sheet was used to collect information on demographic and clinical characteristics, including age, education level, marital status, stage of tumor, type of cancer treatment received, and time since completion of primary cancer treatment.

The interviews were conducted face-to-face at the in-patient ward's meeting room. All interviews utilized an interview guide composed of the following open-ended questions: 1) Compared to before your cancer diagnosis, tell us about the overall change in your cognitive abilities? For example, perceptions of understanding what people say to you, thinking of the right word when responding to others, feeling confident in completing a task or taking on new tasks? 2) What do you think the common contributing factors to any cognitive changes might be? 3) How about these perceived cognitive changes impact your daily life or work ability? 4) How do you deal with these changes, in other words, what types of coping strategies do you use as a result of any cognitive change you might be experiencing? 5) What types of supportive care services you

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would like to seek from health care providers to help you cope with cognitive complaints? Each interview lasted 30 to 45 minutes, and was recorded by a digital recorder and transcribed verbatim.

Data analysis

Qualitative interview data were transcribed for producing a verbatim transcript. Qualitative content analysis was used to identify and organize these verbatim data into clusters and categories.[17] Two researcher members independently conducted content analysis. For any disagreement with interpretation of clusters or categories, a third research member was involved in the discussion process for establishing consensus.

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Results

A total of 31 women with cervical cancer who had completed primary cancer treatment joined this study. Socio-demographic and clinical characteristics are listed in Table 1. The mean age was 45.06 (9.61), ranging from 19 to 57 years old. More than half of the participants had lower education levels (n=17, 54.8). All of these women were currently unemployed or on medical leave, as the mean duration of time since completion of primary cancer treatment was 1.22 (1.08) months. Almost all of the participants were married (n=29, 93.5%). Nearly half were at an early disease stage (n=14, 45.2%). Over 90% of the women had had surgery (n=28, 90.3%), more than half had had chemotherapy (n=17, 54.8%), and 12 women had undergone radiation therapy (38.7%).

Among the 31 cervical cancer survivors, 20 (64.5%) reported cognitive complaints after cancer treatment. Eleven women identified no cognitive changes, compared with pre-cancer diagnosis. Major categories emerged from the data including cognitive complaints, perceived contributing factors, impacts of cognitive problems on women's daily lives, health outcomes and work capabilities, coping strategies and supportive care needs from health care providers are shown in Table 2. The most common complaint was loss of concentration (n=17, 54.8%), followed by memory problems (n=15, 48.4%). Other common cognitive complaints included difficulties in learning new things, language issues (finding the right word to respond in everyday conversations), and a slowed rate of information processing.

The participants identified several factors that they believed were contributing to their cognitive complaints including chemotherapy (n=15, 48.4%), side effects of cancer and other treatment such as surgery or radiation therapy (n=12, 38.7%), and aging (n=8, 25.8%). These cognitive complaints had negative impacts on their daily lives, sleep and rest (n=20, 64.5%). Two participants indicated their cognitive function had seen negligible change, but their physical health had deteriorated significantly after cervical cancer diagnosis. While those women who were on medical leave at the time of data collection, two women indicated they were planning to leave their jobs due to loss of concentration and slowed information processing capacity.

As shown in Table 2, the most commonly used coping strategies were memo writing (n=15, 48.4%), and self-adjustment (n=14, 45.2%). Other coping strategies include "doing nothing" and organization of their environment. In addition, one woman sought acupuncture as an alternative therapy for her cognitive problems, as she had been told by her physician that there was no effective medication for cognitive impairment thus far. Chinese cervical cancer survivors describe a variety of supportive care needs, such as the need for education on common signs and

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symptoms of cognitive impairment and effective treatment therapies (n=11, 35.5%), providing counseling service to family members (n=8, 25.8%), and information on further rehabilitation services (n=7, 22.6%). Two women expressed the need for peer support, and suggested that health care providers could organize a peer support service for patients starting from the diagnosis stage onward. Several patients indicated that their health care providers had never mentioned cognitive impairment issues, and only mentioned this when patients asked about cognitive problems that appeared during cancer treatment.

By a synthesis of these qualitative findings, a preliminary cognition model among cervical cancer survivors after cancer treatment is illustrated in Figure 1. Cognitive complaints are multifactorial in nature, and contributing factors include demographic characteristics, biological factors, psychological distress, disease stage and cancer therapies.

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Discussion

This is one of the first published studies exploring cognitive complaints in Chinese cervical cancer survivors, while there is accumulating evidence documenting cognitive impairment issues among cancer survivors, mainly dominated by breast cancer survivors.[18] The prevalence of cognitive complaints among Chinese cervical cancer survivors was 64.5%, which is consistent with previous research.[6] Yet since this study, as a pilot, adopted a small and non-random sample, epidemiological studies are needed to further quantify the prevalence, impact and extent of cognitive complaints in this study population.[19]

Concurring with previous research evidence, chemotherapy and the side effects of cancer are the most common factors associated with cognitive complaints.[4,7] This study identified that cervical cancer survivors perceive that aging is a likely contributing factor in cognitive impairment. These participants took "aging as a normal process of cognitive decline," and viewed cognitive impairment as a process that could not be changed. In their coping strategies, this is the reason that some women did nothing to try to cope with their cognitive complaints. 'Doing nothing' as a common coping strategy for cognitive complaints could be related to the Chinese Taoist philosophy: "Accepting the fact that a situation cannot be changed, and telling oneself that one should do little, as things will be all right at the end of the day".[20] Hence, coping strategies of doing nothing and self-adjustment could help these survivors maintain a sense of calm when facing difficulties cannot be changed.

As in previous studies,[4,6,7] findings from this study also revealed that cognitive complaints had a variety of consequences that impacted daily living, QOL, physical and psychological health, and work capabilities. While research into the relationship between cognitive functioning and work ability is still in its infancy,[21] returning to work is a critical milestone for many survivors, since work plays a key role in one's psychological, economic, and social wellbeing.[22] If cancer survivors were able to obtain individualized support and work-related adjustments from their employers, they would be more likely to continue working.[23] Hence, cognitive complaints in cancer survivors generate numerous supportive care requirements, not just in the workplace, but also from health care providers.

Common supportive care needs from health care providers include providing information about common signs of cognitive symptoms and management strategies, effective treatment therapies and possible rehabilitation services, in order to manage cognitive problems. Although many health care providers may gloss over the issue of patient cognitive complaints, believing they have no curative treatment to offer patients,[22] findings from a meta-analysis indicate that

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neuropsychological interventions (cognitive rehabilitation, cognitive training and neuromodulation strategies) can improve cognitive function in cancer survivors.[24] Additionally, behavioral intervention strategies (increasing physical activities and fostering supportive social relationships) could be helpful in improving cognitive function among cancer survivors.[12]

By a synthesis of these study findings, a preliminary cognition model for cervical cancer survivors after cancer treatment was established, to provide a theoretical underpinning for the perception of cognitive complaints, contributing factors, mediating factors, and the consequences of cognitive impairment in this study population. This model may be able to inform and stimulate further intervention studies. Certainly, this preliminary cognition model of cervical cancer survivors after cancer treatment can be continuously refined by further empirical research investigations. Overall, this model illustrates coping strategies at a personal level by self-adjustment or by doing nothing; and supportive care services, such as educational and counseling services for family members by health care providers could mediate the extent of the consequences of cognitive impairment. In addition, participants felt a great need for support, such as peer support, from diagnosis onwards, as well as for information on available rehabilitation services and counseling, to modulate the degree of cognitive complaints. Consequently, cognitive complaints exert negative effects on their daily living, QOL, work capability, and physical and psychological health.

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Limitations and implications for future research

There are two limitations in this study. Firstly, this study, as a pilot, only recruited study participants at a single medical center, and the sample size could not be representative of this population in general, although this study primarily offers significant insights into perceived cognitive complaints, contributing factors and consequences of cognitive impairment in cervical cancer survivors. Secondly, this study utilized a cross-sectional design and included study participants on the completion of primary cancer treatment in a short period of time. Future longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum.

Conclusion

This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for preventing, and providing supportive care services, such as educational and counseling services, to reduce cognitive impairment in women with cervical cancer.

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Competing interests: The authors declare no conflicts of interest.

Ethics approval: This study was approved by the Medical Ethics Committee of Hunan Cancer Hospital.

Data sharing statement: No additional data are available.

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Table 1 Demographic and clinical characteristics (N=31)

Variables	Mean (SD)	n (%)
Age (years) (range)	45.06 (9.61) (19-57)	
Education levels		
Primary school or below		17 (54.8)
High school		3 (9.7)
College		7 (22.6)
University or above		4 (12.9)
Employment status		
Employed but on medical leave		15 (48.4)
Unemployed or retired		16 (51.6)
Marital status		
Married		29 (93.5)
Divorced		2 (6.5)
Disease stage		
Stage IA		14 (45.2)
Stage IB-IIA		15 (48.4)
Stage IIB-IVA		2 (6.5)
Types of treatment		
Surgery		10 (32.3)
Surgery + chemotherapy		8 (25.8)
Surgery + radiation therapy		2 (6.5)
Surgery+radiation+chemotherapy		8 (25.8)
Radiation or chemotherapy		3 (9.7)
Time since completion of primary treatment (months) (range)	1.22 (1.08) (0-5)	

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Table 2 Major categories from the qualitative content analysis (N=31)

Categories	n (%)	Quotes from participants
Cognitive complaints		
Lost concentration	17(54.8)	*It's difficult to focus on a conversation or when reading newspapers or books. My biggest problem is lack of concentration*
Easily forgetting things or information told by others	15 (48.4)	*My memory changed a lot after chemotherapy; when I meet my friend on the road, I can't even remember her name. Sometimes, nurses tell me information about the illness, and I can't even remember what they have just told me*
Feeling it's hard to understand new things	7 (22.6)	*When I was reading some books, I saw the words, but I could not make sense of the words, even reading the same sentence several times.*
Difficulties in finding right word in general conversation	4 (12.9)	*When I speak with someone in general conversation, it's hard for me to find the right words*
Slowing down in working efficiency, compared with how they used to be	2 (6.5)	*I was used to being well organized in my work and daily life, but now it's hard to get back all those abilities, and work has slowed down a lot*
Perceived causing factors		
Relating to chemotherapy	15 (48.4)	*Even during chemotherapy, I found that my memory changed a lot. Now I have completed the whole cycle of chemotherapy, and more and more memory impairment has appeared*
Side effects of cancer and its treatment	12 (38.7)	*I believe lots of physical examinations, such as CT at the time of diagnosis, the use of analgesics, and the surgery procedure are all related to my cognitive problems*
Aging	8 (25.8)	*Maybe due to my age, my memory is worse and I've started forgetting things quickly*
Psychosocial issues	3 (9.6)	*Having to deal with too many sources of stress, such as the financial issues related to medical treatment*
Relating to immune function	2 (6.5)	*After I got this disease and received this series of cancer treatments, my immune*

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		function was destroyed, so my memory problems are partly due to this
Coping strategies		
By writing memos	15 (48.4)	*Writing down important things, use of diaries or phone reminders to organize daily tasks*
Self-adjustment and by relaxation techniques	14 (45.2)	*Asking myself to focus on one task at a time. When disturbed by other things or people, I'll adjust myself and refocus on what I was doing. By reading, or listening to music for focus*
Doing noting	6 (19.3)	*Now I can do nothing for this problem (cognitive impairment), as this may be due to my age; with older age, cognitive decline appears naturally. Other patients believe these cognitive problems are reversible and may get better gradually*
Environment organization	2 (6.5)	*To keep important personal belongs such as keys, eyeglasses, mobile phone in a fixed place*
TCM such as acupuncture	1 (3.2)	*Doctors told me there were no effective drug therapies for this problem, so I tried acupuncture*
Supportive care needs from health care providers		
Providing common symptoms of cognitive impairment and its effective therapies	11 (35.5)	*It's great for doctors and nurses to tell me common signs or symptoms of cognitive impairments, and provide intervention therapies to treat these problems*
Providing counseling services to family members	8 (25.8)	*It's hard for me to remember so much information. Health care providers should provide educational information and more counseling service to my family members*
Need information about possible rehabilitation service	7 (22.6)	*After hospital discharge, where should I seek further rehabilitation service for cognitive problems, or these problems can recover gradually*
Offering peer support networks	2 (6.5)	*At the time of diagnosis and during cancer treatment, I felt so worried. I need to connect with women who have had a similar experience, in order to share coping*

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		strategies
Impacts on		
Daily lives	20 (64.5)	*Sometimes, when people talk with me, I immediately forget what they were talking about, or when I'm doing things and people interrupt me, I'll forget what I want to do*
Quality of life	9 (29.0)	*This disease and its treatment have severely impacted all aspects of my life and left me feeling overwhelmed. Now I have poor memory, a slowed thinking process, and a large financial burden as a result of the medical costs, causing tension in my family relationship*
Psychological health	5 (16.1)	*Sometimes my brain becomes blank, and it seems my memory could not come back, so I felt so frightened and scared*
Work capability	3 (9.6)	*I have to leave my job, due to my body image now, during and after chemotherapy I lost a lot of hair, and I can't work for very long, I can only work for a short period of time, then I have to rest*
Physical health conditions	2 (6.5)	*Cognitive function changes were not obvious, but my health condition was a lot worse;, before the cancer diagnosis, my health was OK. But now my sleep is not good, my immune system is much weaker, and due to the loss of physical energy I can't work too long and need to take a break after working for just a short while*

Abbreviation: TCM, traditional Chinese medicine

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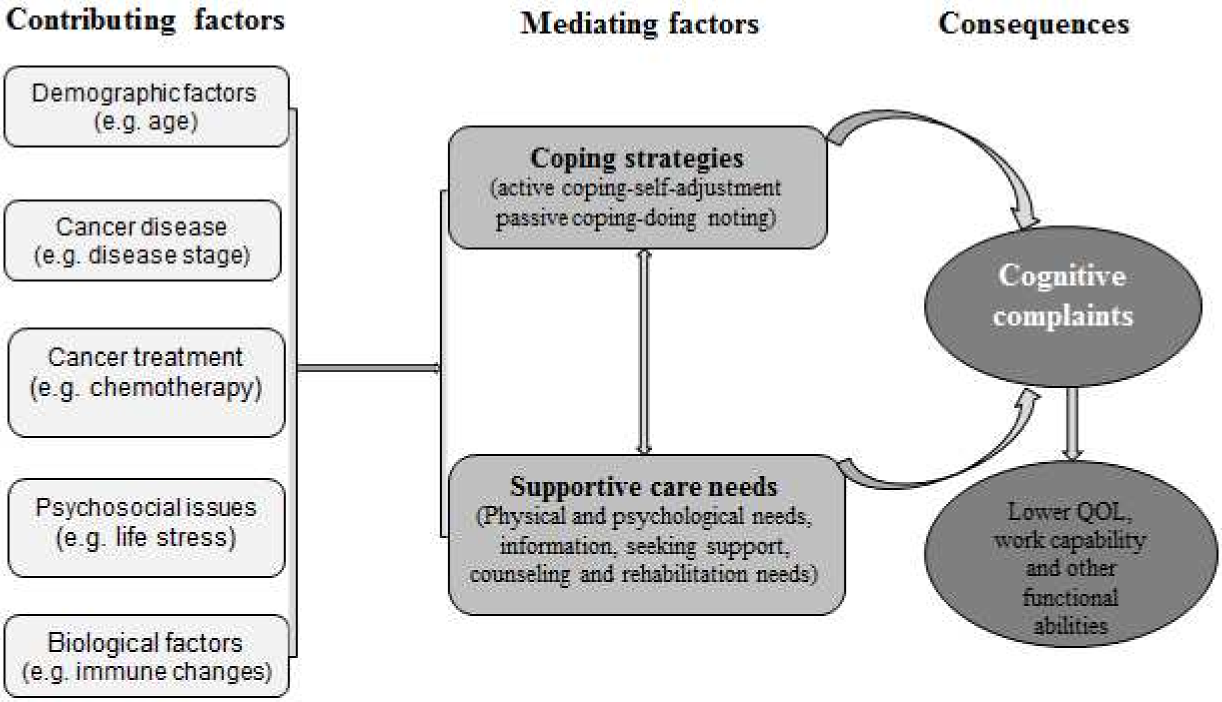
Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment



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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

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Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	7
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	N/A
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	N/A
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	7
		(c) Consider use of a flow diagram	7
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	7
Outcome data	15*	Report numbers of outcome events or summary measures	8
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8
		(*b*) Report category boundaries when continuous variables were categorized	8, Table 2
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	9
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	10-11
Generalisability	21	Discuss the generalisability (external validity) of the study results	10-11
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Cognitive complaints and supportive care needs in Chinese cervical cancer survivors: a qualitative study

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Title: Cognitive complaints and supportive care needs in Chinese cervical cancer survivors: a qualitative study

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Abstract

Objectives: This study aims to explore perceived cognitive complaints and relevant supportive care needs in Chinese cervical cancer survivors after primary cancer treatment.

Design: This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Setting: This study was conducted in a secondary cancer care centre located in South China.

Participants: 31 women with cervical cancer after primary cancer treatment, aged 18-60 years old, were purposively selected using non-random sampling procedures.

Results: A total of 31 cervical cancer survivors joined this study. Of that total, 20 women (64.5%) reported cognitive complaints after cancer treatment. The most common complaint was loss of concentration (n=17, 54.8%). Perceived contributing factors to these cognitive complaints included chemotherapy (n=15, 48.4%), and aging (n=8, 25.8%). These cognitive problems most commonly impacted their daily living (n=20, 64.5%). Common supportive care needs include symptom management strategies (n=11, 35.5%), and counselling services (n=8, 25.8%).

Conclusion: This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for prevention, and the provision of supportive care services, such as educational and counselling services, to reduce cognitive impairment in women with cervical cancer.

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Study strengths and limitations

- This qualitative study fully identified common cognitive complaints and supportive care needs, as well as how these complaints and unmet needs impact patients' QOL. The study also obtained information about coping strategies to ameliorate cognitive complaints.
- A major strength of this qualitative study was its use of the COREQ checklist for guidance and to ensure rigour.
- This preliminary study only recruited study participants at a single medical centre, which could limit the transferability of study findings.
- This study included study participants who had completed primary cancer treatment in a short period of time; longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum.

Keywords Cervical cancer. Survivors. Cognitive complaints. Supportive care needs.

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Introduction

Cervical cancer is the second most common cancer, followed by breast cancer, among women in China.[1] Due to medical advancements in early detection and the possibility of curative cancer treatment,[2] the five-year relative survival rate of cervical cancer in mainland China is up to 69% for all stages.[1] As more cervical cancer survivors are living longer after curative treatment, late effects of cancer treatment are becoming increasingly common.[3] One such long-term and late effect is neurocognitive, which has emerged as a significant problem affecting cervical cancer survivors.[4,5]

Cognitive complaints often refer to cognitive impairment or cancer-related cognitive impairment.[6,7] Other studies have described this as chemotherapy-related cognitive dysfunction, colloquially named 'chemo brain' or 'chemo fog'.[8,9] Cognitive complaints have the potential to significantly impact both social and occupational functioning, interfering with the ability to carry out normal daily activities, all of which in turn contributes to lower quality of life (QOL) in cancer survivors.[4,6,10] Cognitive complaints have been reported in approximately 40% of patients prior to any cancer treatment, and as many as 75% of patients indicate some degree of cognitive impairment during the period of active cancer treatment. Finally, cognitive complaints are still present in up to 60% of long-term cancer survivors.[6] In a study conducted in mainland China, female cancer survivors with an average of 2.79 years post- primary treatment reported higher levels of cognitive limitations, significantly reducing their work productivity and global QOL.[11]

There are quantitative research approaches employed to explore cognitive complaints and related supportive care issues among cancer survivors,[4,12] and these researchers have proposed that quantitative cognitive measures are more objective and reliable than qualitative exploration of

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cognitive problems in cancer survivors.[13,14] However, other researchers have argued there are inherent difficulties with a quantitative approach, in terms of fully appreciating cognitive complaints by cancer patients.[4,15] Qualitative research studies would enable us to identify the presence of cognitive symptoms that quantitative approaches cannot detect, either by self-reported cognitive measures or neurocognitive tests.[15] In addition, qualitative in-depth interviews could provide information about how cognitive impairment impacts cancer patients' QOL, and could allow researchers to obtain rich information about numerous coping strategies to ameliorate cognitive dysfunction symptoms, as well as develop intervention strategies.[15]

Therefore, there is a need for a qualitative study to explore perceived cognitive complaints and relevant supportive care needs in cervical cancer survivors after primary cancer treatment. A clear understanding of cognitive complaints experienced by cervical cancer survivors, through qualitative in-depth interviews, could aid health care providers in developing targeted interventions, as well as in providing relevant supportive care services for alleviating the extent and impact of cognitive complaints in cancer survivors.[16]

Methods

Design

This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

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Study framework

This study was guided by the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers.[17] This model consists of three key components: antecedents (cancer diagnosis and cancer treatment), mediators (physiologic, psychosocial and situational factors), and consequences (quality of life and functional ability).[17] While this model is named chemotherapy-related cognitive impairment, recent evidence indicates that cancer itself is also related to cognitive impairment.[6] As suggested by Myers, when researchers learn more about the physiological and psychological aspects of cognitive impairment, this model will require refining.[17]

Study sample

All study participants were recruited from the Gynaecological Oncology Unit in a cancer hospital. This study obtained ethical approval from the hospital's ethics committee. A purposive sampling was drawn to recruit eligible informants. Inclusion criteria were: women who were at least 18 years old, with a primary diagnosis of cervical cancer, who had completed their primary cancer treatment of surgery, radiation therapy or chemotherapy. Exclusion criteria included potential psychiatric disorders, previous cancer history, or traumatic brain injury.

Study procedure and qualitative interviews

After obtaining written consent, eligible participants were invited to participate in a semi-structured interview, and complete a socio-demographic sheet. This sheet was used to collect information on demographic and clinical characteristics, including age, education level, marital status, stage of tumour, type of cancer treatment received, and time since completion of primary cancer treatment. Qualitative interviews were guided by a narrative epistemology so as to

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facilitate informants in providing narrative accounts of their perceived experience.[18] The interviewer was an experienced research nurse who was not the staff nurse in the research setting of the Gynaecological Oncology Unit, and the data collection method was by written narrative, so that the interviewer's beliefs, biases or preconceptions would have no influence on the direction of the interviews. The interviewer only remained in the meeting room to take field notes, in order to obtain any emerging thoughts to guide data analysis.

The interviews were conducted face-to-face at the in-patient ward's meeting room. All interviews utilised an interview guide composed of the following open-ended questions: 1) Compared to before your cancer diagnosis, tell us about the overall change in your cognitive abilities? For example, perceptions of understanding what people say to you, thinking of the right word when responding to others, feeling confident in completing a task or taking on new tasks? 2) What do you think the common contributing factors to any cognitive changes might be? 3) How do these perceived cognitive changes impact your daily life or your ability to work? 4) How do you deal with these changes? In other words, what types of coping strategies do you use as a result of any cognitive changes you might be experiencing? 5) What types of supportive care services would you like to seek from health care providers to help you cope with any cognitive complaints? Each interview lasted 30 to 45 minutes, and was recorded by a digital recorder and transcribed verbatim. Data saturation was achieved much earlier than the final sample size of 31 patients with cervical cancer, as data collection and analysis were performed simultaneously in an iterative process.[19]

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Data analysis

Qualitative interview data were transcribed to produce a verbatim transcript. During the entire data analysis process, the researcher consciously separated herself from those biases, in order to be open to the information shared by study participants. NVivo 11 qualitative software (http://www.qsrinternational.com/nvivo-product/nvivo11-for-windows) was applied to organise and code the verbatim transcript. Qualitative content analysis was used to prepare, organise, and report the data.[20] A three-step content analysis process was followed: "*1) The verbatim transcript was organised into meaning units (such as words, phrases, sentences, or paragraphs that conveyed similar content deemed important to understanding the patients' experiences). 2) The meaning units were coded and categorised. 3) The abstraction process was guided by Myers's conceptual model and continued until primary themes were identified.*[20]

Two research members conducted content analysis independently. For any disagreement with the interpretation of clusters or categories, a third research member was involved in the discussion process, in order to establish consensus. To ensure the study findings were accurately reflecting informants' truly perceived experience of cognitive changes. Three women were invited to check the final verbatim transcript for the purpose of collecting participants' feedback and validation. The consolidated criteria for reporting qualitative studies (COREQ) checklist was applied to guide this study and ensure study rigour (Appendix 1).[21]

Results

A total of 50 patients with cervical cancer were approached, with 31 agreeing to participate in this written narrative interview. The women who did not agree to join this study had no interest

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in participating in any research. Their characteristics in terms of age, cancer stage and treatment types were comparable to the patients who completed written interviews. Of the 31 participants, 20 women (64.5%) reported cognitive complaints after cancer treatment. The socio-demographic and clinical characteristics of women with cognitive impairment are listed in Table 1. The mean age was 46.40 (9.80), ranging from 19 to 57 years old. More than half of the participants had lower education levels (n=11, 55.0). All of these women were currently unemployed or on medical leave, as the mean duration of time since completion of primary cancer treatment was 1.70 (1.03) months. Almost all of the participants were married (n=19, 95.0%). Only two women were in an advanced stage of disease (n=2, 10.0%). Most women had had surgery (n=18, 90.0%), more than half had had chemotherapy (n=11, 55.0%), and 12 women had undergone radiation therapy (38.7%).

Major categories that emerged from the data included cognitive complaints, perceived contributing factors, impacts of cognitive problems on women's daily lives, health outcomes and work capabilities, coping strategies and supportive care needs from health care providers are shown in Table 2. The most common complaint was loss of concentration (n=17, 54.8%), followed by memory problems (n=15, 48.4%). Other common cognitive complaints included difficulties in learning new things, language issues (finding the right word to respond in everyday conversations), and a slowed rate of information processing.

The participants identified several factors that they believed were contributing to their cognitive complaints, including chemotherapy (n=15, 48.4%), side effects of cancer and other treatment, such as surgery or radiation therapy (n=12, 38.7%), and aging (n=8, 25.8%). These cognitive complaints had negative impacts on their daily lives, sleep and rest (n=20, 64.5%). Two participants indicated their cognitive function had seen negligible change, but their physical

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health had deteriorated significantly after their cervical cancer diagnosis. While ten women who were on medical leave at the time of data collection, two women indicated they were planning to leave their jobs due to loss of concentration and slowed information processing capacity.

As shown in Table 2, the most commonly used coping strategies were memo writing (n=15, 48.4%), and self-adjustment (n=14, 45.2%). Other coping strategies include "doing nothing" and organisation of their environment. In addition, one woman sought acupuncture as an alternative therapy for her cognitive problems, as she had been told by her physician that there was no effective medication for cognitive impairment thus far. Chinese cervical cancer survivors describe a variety of supportive care needs, such as the need for education on common signs and symptoms of cognitive impairment and effective treatment therapies (n=11, 35.5%), providing counselling service to family members (n=8, 25.8%), and information on further rehabilitation services (n=7, 22.6%). Two women expressed the need for peer support, and suggested that health care providers could organise a peer support service for patients starting from the diagnosis stage onward. Several patients indicated that their health care providers had never mentioned cognitive impairment issues, and only mentioned this when patients asked about cognitive problems that appeared during cancer treatment.

Based on the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers (2009), and in combination with a synthesis of these qualitative findings, a refinement cognition model among cervical cancer survivors is illustrated in Figure 1. Cognitive complaints are multifactorial in nature, and contributing factors include demographic characteristics, biological factors, psychological distress, disease stage and cancer therapies.

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Discussion

This is one of the first published studies exploring cognitive complaints in Chinese cervical cancer survivors, while there is accumulating evidence documenting cognitive impairment issues among cancer survivors, mainly dominated by breast cancer survivors.[22] The prevalence of cognitive complaints among Chinese cervical cancer survivors was 64.5%, which is consistent with previous research.[6] Yet since this study, as a preliminary, adopted a small and non-random sample, epidemiological studies are needed to further quantify the prevalence, impact and extent of cognitive complaints in this study population.[23]

Concurring with previous research evidence, chemotherapy and the side effects of cancer are the most common factors associated with cognitive complaints.[4,7] This study identified that cervical cancer survivors perceive aging as a likely contributing factor in cognitive impairment. These participants took “aging as a normal process of cognitive decline,” and viewed cognitive impairment as a process that could not be changed. Consistent with previous studies,[17,24] participants in this study also reported that symptoms of worry, fatigue and pain seem to be related to cognitive impairment.

The patient experience of cancer-related changes in cognition may be the commonalities of the phenomenon across tumour types,[25] as this study did not find unique cognitive deficits in women with cervical cancer. Yet this study did identify some unique cultural issues for Chinese women in terms of coping strategies for cognitive impairment. Some women did nothing to try to cope with their cognitive complaints. ‘Doing nothing’ as a common coping strategy for cognitive complaints could be related to the Chinese Taoist philosophy: “Accepting the fact that a situation cannot be changed, and telling oneself that one should do little, as things will be all right at the

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end of the day".[26] Hence, coping strategies of doing nothing and self-adjustment could help these survivors maintain a sense of calm when facing difficulties that cannot be changed.

As in previous studies,[4,6,7] findings from this study also revealed that cognitive complaints had a variety of consequences that impacted daily living, QOL, physical and psychological health, and work capabilities. While research into the relationship between cognitive functioning and work ability is still in its infancy,[27] returning to work is a critical milestone for many survivors, since work plays a key role in one's psychological, economic, and social wellbeing.[28] If cancer survivors were able to obtain individualised support and work-related adjustments from their employer, they would be more likely to continue working.[23] Hence, cognitive complaints in cancer survivors generate numerous supportive care requirements, not only in the workplace, but also from health care providers.

Common supportive care needs from health care providers include providing information about common signs of cognitive symptoms and management strategies, effective treatment therapies and possible rehabilitation services, in order to manage cognitive problems. Although many health care providers may gloss over the issue of patient cognitive complaints, believing they have no curative treatment to offer patients,[29] findings from a meta-analysis indicate that neuropsychological interventions (cognitive rehabilitation, cognitive training and neuromodulation strategies) can improve cognitive function in cancer survivors.[30] In particular, a recent Cochrane review indicates that cognitive training may be effective in improving patients' cognitive function, as well as quality of life.[31] Additionally, behavioural intervention strategies (increasing physical activities and fostering supportive social relationships) could be helpful in improving cognitive function among cancer survivors.[12]

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By a synthesis of these study findings, a preliminary cognition model for cervical cancer survivors after cancer treatment was established, to provide a theoretical underpinning for the perception of cognitive complaints, contributing factors, mediating factors, and the consequences of cognitive impairment in this study population. This model may be able to inform and stimulate further intervention studies. Certainly, this preliminary cognition model of cervical cancer survivors after cancer treatment can be continuously refined by further empirical research investigations. Overall, this model illustrates coping strategies at a personal level by self-adjustment or by doing nothing; and supportive care services, such as educational and counselling services for family members by health care providers could mitigate the extent of the consequences of cognitive impairment. In addition, participants felt a great need for support, such as peer support, from diagnosis onwards, as well as for information on available rehabilitation services and counselling, to modulate the degree of cognitive complaints. Consequently, cognitive complaints exert negative effects on their daily living, QOL, work capability, and physical and psychological health.

Limitations and implications for future research

There are two limitations in this study. Firstly, this preliminary study only recruited study participants at a single medical centre, and the sample size could not be representative of this population in general, although this study primarily offers significant insights into perceived cognitive complaints, contributing factors and consequences of cognitive impairment in cervical cancer survivors. Secondly, this study utilised a cross-sectional design and included study participants on the completion of primary cancer treatment in a short period of time. Future longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum. As suggested by Myers,[25] qualitative studies do provide valuable

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information to healthcare professionals about the impact that cognitive changes have on cancer patients' QOL and daily function. Understanding cancer patients' experience of cognitive impairment, their coping strategies and supportive care needs could help healthcare professionals develop interventions to prevent, mitigate, and treat the cognitive sequelae of cancer and its treatment therapies.[25]

Conclusion

This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for prevention, and providing supportive care services, such as educational and counselling services, to reduce cognitive impairment in women with cervical cancer.

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Table 1 Demographic and clinical characteristics of participants with cognitive impairment

Variables	Mean (SD)	N=20, n (%)
Age (years) (range)	46.40 (9.80) (19-57)	
Education levels		
Primary school or below		11 (55.0)
College		6 (30.0)
University or above		3 (15.0)
Employment status		
Employed but on medical leave		10 (50.0)
Unemployed or retired		10 (50.0)
Marital status		
Married		19 (95.0)
Divorced		1 (5.0)
Disease stage		
Stage IA		7 (35.0)
Stage IB-IIA		11 (55.0)
Stage IIB-IVA		2 (10.0)
Types of treatment		
Surgery		5 (25.0)
Surgery + chemotherapy		5 (25.0)
Surgery + radiation therapy		2 (10.0)
Surgery+radiation+chemotherapy		6 (30.0)
Radiation or chemotherapy		2 (10.0)
Time since completion of primary treatment (months) (range)	1.70 (1.03) (1-5)	

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Table 2 Major categories from the qualitative content analysis (N=31)

Categories	n (%)	Illustrative quotes from participants
Cognitive complaints		
Lost concentration	17(54.8)	*It's difficult to focus on a conversation or when reading newspapers or books. My biggest problem is lack of concentration*
Easily forgetting things or information told by others	15 (48.4)	*My memory changed a lot after chemotherapy; when I meet my friend on the street, I can't even remember her name. Sometimes, nurses tell me information about the illness, and I can't even remember what they have just told me*
Feeling it's hard to understand new things	7 (22.6)	*When I was reading some books, I saw the words, but I could not make sense of the words, even when I read the same sentence several times.*
Difficulties in finding right word in general conversation	4 (12.9)	*When I speak with someone in general conversation, it's hard for me to find the right words*
Slowing down in working efficiency, compared with how they used to be	2 (6.5)	*I was used to being well organised in my work and daily life, but now it's hard to get back all those abilities, and work has slowed down a lot*
Perceived causing factors		
Relating to chemotherapy	15 (48.4)	*Even during chemotherapy, I found that my memory changed a lot. Now I have completed the whole cycle of chemotherapy, and more and more memory impairment has appeared*
Side effects of cancer and its treatment	12 (38.7)	*I believe that a lot of physical examinations, such as CT at the time of diagnosis, the use of analgesics, and the surgery procedure are all related to my cognitive problems*
Aging	8 (25.8)	*Maybe due to my age, my memory is worse and I've started forgetting things quickly*
Psychosocial issues	3 (9.6)	*Having to deal with too many sources of stress, such as the financial issues related to medical treatment*
Relating to immune function	2 (6.5)	*After I got this disease and received this series of cancer treatments, my immune*

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		function was destroyed, so my memory problems are partly due to this
Coping strategies		
By writing memos	15 (48.4)	*Writing down important things, use of diaries or phone reminders to organise daily tasks*
Self-adjustment and relaxation techniques	14 (45.2)	*Asking myself to focus on one task at a time. When disturbed by other things or people, I'll adjust myself and refocus on what I was doing. By reading, or listening to music for focus*
Doing nothing	6 (19.3)	*Now I can do nothing for this problem (cognitive impairment), as this may be due to my age; with older age, cognitive decline appears naturally. Other patients believe these cognitive problems are reversible and may get better gradually*
Environment organisation	2 (6.5)	*To keep important personal belongs such as keys, eyeglasses, mobile phone in a fixed place*
TCM such as acupuncture	1 (3.2)	*Doctors told me there were no effective drug therapies for this problem, so I tried acupuncture*
Supportive care needs from health care providers		
Providing common symptoms of cognitive impairment and its effective therapies	11 (35.5)	*It's great for doctors and nurses to tell me common signs or symptoms of cognitive impairment, and provide intervention therapies to treat these problems*
Providing counselling services to family members	8 (25.8)	*It's hard for me to remember so much information. Health care providers should provide educational information and more counselling services to my family members*
Need information about possible rehabilitation service	7 (22.6)	*After hospital discharge, where should I seek further rehabilitation service for cognitive problems, or can these problems recover gradually*
Offering peer support networks	2 (6.5)	*At the time of diagnosis and during cancer treatment, I felt so worried. I need to connect with women who have had a similar experience, in order to share coping*

		strategies
Impacts on		
Daily lives	20 (64.5)	*Sometimes, when people talk with me, I immediately forget what they were talking about, or when I'm doing things and people interrupt me, I'll forget what I want to do*
Quality of life	9 (29.0)	*This disease and its treatment have severely impacted all aspects of my life and left me feeling overwhelmed. Now I have poor memory, a slowed thinking process, and a large financial burden as a result of the medical costs, causing tension in my family relationship*
Psychological health	5 (16.1)	*Sometimes my brain becomes blank, and it seems my memory could not come back, so I felt so frightened and scared*
Work capability	3 (9.6)	*I have to leave my job, due to my body image now, during and after chemotherapy I lost a lot of hair, and I can't work for very long, I can only work for a short period of time, then I have to rest*
Physical health conditions	2 (6.5)	*Cognitive function changes were not obvious, but my health condition was a lot worse; before the cancer diagnosis, my health was OK. But now my sleep is not good, my immune system is much weaker, and due to the loss of physical energy I can't work too long and need to take a break after working for just a short while*

Abbreviation: TCM, traditional Chinese medicine

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Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment

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Appendix 1 Consolidated criteria for reporting qualitative studies (COREQ) checklist

COREQ items	Descriptions
Domain 1: Research team and reflexivity	
1. Interviewer/facilitator	The third author conducted the interview
2. Credentials	The researcher is nursing professor and holds Master degree of Nursing
3. Occupation	Clinical nursing researcher at the time of the study
4. Gender	Female
5. Experience and training	The researcher works for clinical researcher for more than 5 years with qualitative research training
Relationship with participants	
6. Relationship established	Working relationship was established prior to study commencement
7. Participant knowledge of the interviewer	Participants know about the researcher for doing the research
8. Interviewer characteristics	Described at page 7 from line 1 to line 6 in the manuscript.
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory	Methodological orientation underpinning the study was content analysis and was guided by a conceptual model by Myers (2009) (page 6, line 1-9)
Participant selection	
10. Sampling	Purposive sampling described at page 6, line 12-13.
11. Method of approach	Participants approached by face-to-face
12. Sample size	31 participants in this study
13. Non-participation	19 participants refused, reasons described at page 8 line 22, to page 9 line 1.
Setting	
14. Setting of data collection	Hospital's meeting room (page 7, line3)
15. Presence of non-participants	Nobody else present besides the participants and researchers (page 8, line 5-6)
16. Description of sample	Table 1.
Data collection	
17. Interview guide	Consisting of 7 open-ended questions and was pilot tested in a participants (page 7, line 8-17)
18. Repeat interviews	None
19. Audio/visual recording	N/A. as this study collected data by written narratives
20. Field notes	Yes, at page 7, line 5-6
21. Duration	30-45 minutes (page 7, line 17)
22. Data saturation	Yes, described at page 7, line 18-20
23. Transcripts returned	Transcripts were returned to three participants for comments or correction (page 8, line 14-16)

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Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	Twenty copies of data coded
25. Description of the coding tree	None.
26. Derivation of themes	Themes were derived from the data (Table2)
27. Software	Nvivo 11 was used to manage the data (page 8, line 4)
28. Participant checking	Three participants checked the final transcript of this study (page 8, line 14-16)
Reporting	
29. Quotations presented	Table 2.
30. Data and findings consistent	There was consistency between the data presented and the findings.
31. Clarity of major themes	Major themes clearly presented in the findings (Table 2)
32. Clarity of minor themes	Any diverse cases was resolved during the stage of data analysis.

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Title: Cognitive complaints and supportive care needs in Chinese cervical cancer survivors: a qualitative study

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Abstract

Objectives: This study aims to explore perceived cognitive complaints and relevant supportive care needs in Chinese cervical cancer survivors after primary cancer treatment.

Design: This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Setting: This study was conducted in a secondary cancer care centre located in South China.

Participants: 31 women with cervical cancer after primary cancer treatment, aged 18-60 years old, were purposively selected using non-random sampling procedures.

Results: A total of 31 cervical cancer survivors joined this study. Of that total, 20 women (64.5%) reported cognitive complaints after cancer treatment. The most common complaint was loss of concentration (n=17, 85.0%). Perceived contributing factors to these cognitive complaints included chemotherapy (n=15, 75.0%), and aging (n=8, 40.0%). These cognitive problems most commonly impacted their daily living (n=20, 100%). Common supportive care needs include symptom management strategies (n=11, 55.0%), and counselling services (n=8, 40.0%).

Conclusion: This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for prevention, and the provision of supportive care services, such as educational and counselling services, to reduce cognitive impairment in women with cervical cancer.

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Study strengths and limitations

- This qualitative study used written qualitative responses as means of data collection, so this method is more cost-effective and less time-consuming due to no requiring transcription.
- Additional strength of this study is that written qualitative responses might overcome the barrier of dialects, as Chinese people even within the same province typically speak many different Chinese dialects, so the written form is understandable across these dialect groups.
- This preliminary study only recruited study participants at a single medical centre, which could limit the transferability of study findings.
- This study included study participants who had completed primary cancer treatment in a short period of time; longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum.

Keywords Cervical cancer. Survivors. Cognitive complaints. Supportive care needs.

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Introduction

Cervical cancer is the second most common cancer, followed by breast cancer, among women in China.[1] Due to medical advancements in early detection and the possibility of curative cancer treatment,[2] the five-year relative survival rate of cervical cancer in mainland China is up to 69% for all stages.[1] As more cervical cancer survivors are living longer after curative treatment, late effects of cancer treatment are becoming increasingly common.[3] One such long-term and late effect is neurocognitive, which has emerged as a significant problem affecting cervical cancer survivors.[4,5]

Cognitive complaints often refer to cognitive impairment or cancer-related cognitive impairment.[6,7] Other studies have described this as chemotherapy-related cognitive dysfunction, colloquially named 'chemo brain' or 'chemo fog'.[8,9] Cognitive complaints have the potential to significantly impact both social and occupational functioning, interfering with the ability to carry out normal daily activities, all of which in turn contributes to lower quality of life (QOL) in cancer survivors.[4,6,10] Cognitive complaints have been reported in approximately 40% of patients prior to any cancer treatment, and as many as 75% of patients indicate some degree of cognitive impairment during the period of active cancer treatment. Finally, cognitive complaints are still present in up to 60% of long-term cancer survivors.[6] In a study conducted in mainland China, female cancer survivors with an average of 2.79 years post- primary treatment reported higher levels of cognitive limitations, significantly reducing their work productivity and global QOL.[11]

There are quantitative research approaches employed to explore cognitive complaints and related supportive care issues among cancer survivors,[4,12] and these researchers have proposed that quantitative cognitive measures are more objective and reliable than qualitative exploration of

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cognitive problems in cancer survivors.[13,14] However, other researchers have argued there are inherent difficulties with a quantitative approach, in terms of fully appreciating cognitive complaints by cancer patients.[4,15] Qualitative research studies would enable us to identify the presence of cognitive symptoms that quantitative approaches cannot detect, either by self-reported cognitive measures or neurocognitive tests.[15] In addition, qualitative in-depth interviews could provide information about how cognitive impairment impacts cancer patients' QOL, and could allow researchers to obtain rich information about numerous coping strategies to ameliorate cognitive dysfunction symptoms, as well as develop intervention strategies.[15]

Therefore, there is a need for a qualitative study to explore perceived cognitive complaints and relevant supportive care needs in cervical cancer survivors after primary cancer treatment. A clear understanding of cognitive complaints experienced by cervical cancer survivors, through qualitative in-depth interviews, could aid health care providers in developing targeted interventions, as well as in providing relevant supportive care services for alleviating the extent and impact of cognitive complaints in cancer survivors.[16]

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Methods

Design

This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Study framework

This study was guided by the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers.[17] This model consists of three key components: antecedents (cancer diagnosis and cancer treatment), mediators (physiologic, psychosocial and situational factors), and consequences (quality of life and functional ability).[17] While this model is named chemotherapy-related cognitive impairment, recent evidence indicates that cancer itself is also related to cognitive impairment.[6] As suggested by Myers, when researchers learn more about the physiological and psychological aspects of cognitive impairment, this model will require refining.[17]

Study sample

All study participants were recruited from the Gynaecological Oncology Unit in a cancer hospital. This study obtained ethical approval from the hospital's ethics committee. A purposive sampling was drawn to recruit eligible informants. Inclusion criteria were: women who were at least 18 years old, with a primary diagnosis of cervical cancer, who had completed their primary cancer treatment of surgery, radiation therapy or chemotherapy. Exclusion criteria included potential psychiatric disorders, previous cancer history, or traumatic brain injury.

Study procedure and qualitative interviews

After obtaining written consent, eligible participants were invited to participate in a semi-structured interview, and complete a socio-demographic sheet. This sheet was used to collect information on demographic and clinical characteristics, including age, education level, marital status, stage of tumour, type of cancer treatment received, and time since completion of primary cancer treatment. Qualitative interviews were guided by a narrative epistemology so as to

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facilitate informants in providing narrative accounts of their perceived experience.[18] The interviewer was an experienced research nurse who was not the staff nurse in the research setting of the Gynaecological Oncology Unit, and the data collection method was by written narrative, so that the interviewer's beliefs, biases or preconceptions would have no influence on the direction of the interviews. The interviewer only remained in the meeting room to take field notes, in order to obtain any emerging thoughts to guide data analysis.

The interviews were conducted face-to-face at the in-patient ward’s meeting room. All interviews utilised an interview guide composed of the following open-ended questions: 1) Compared to before your cancer diagnosis, tell us about the overall change in your cognitive abilities? For example, perceptions of understanding what people say to you, thinking of the right word when responding to others, feeling confident in completing a task or taking on new tasks? 2) What do you think the common contributing factors to any cognitive changes might be? 3) How do these perceived cognitive changes impact your daily life or your ability to work? 4) How do you deal with these changes? In other words, what types of coping strategies do you use as a result of any cognitive changes you might be experiencing? 5) What types of supportive care services would you like to seek from health care providers to help you cope with any cognitive complaints? Each interview lasted 30 to 45 minutes, and was recorded by a digital recorder and transcribed verbatim. Data saturation was achieved much earlier than the final sample size of 31 patients with cervical cancer, as data collection and analysis were performed simultaneously in an iterative process.[19]

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Data analysis

Qualitative interview data were transcribed to produce a verbatim transcript. During the entire data analysis process, the researcher consciously separated herself from those biases, in order to be open to the information shared by study participants. NVivo 11 qualitative software (http://www.qsrinternational.com/nvivo-product/nvivo11-for-windows) was applied to organise and code the verbatim transcript. Qualitative content analysis was used to prepare, organise, and report the data.[20] A three-step content analysis process was followed: "*1) The verbatim transcript was organised into meaning units (such as words, phrases, sentences, or paragraphs that conveyed similar content deemed important to understanding the patients' experiences). 2) The meaning units were coded and categorised. 3) The abstraction process was guided by Myers's conceptual model and continued until primary themes were identified.*[20]

Two research members conducted content analysis independently. For any disagreement with the interpretation of clusters or categories, a third research member was involved in the discussion process, in order to establish consensus. To ensure the study findings were accurately reflecting informants' truly perceived experience of cognitive changes. Three women were invited to check the final verbatim transcript for the purpose of collecting participants' feedback and validation. The consolidated criteria for reporting qualitative studies (COREQ) checklist was applied to guide this study and ensure study rigour (Appendix 1).[21]

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Results

A total of 50 patients with cervical cancer were approached, with 31 agreeing to participate in this written narrative interview. The women who did not agree to join this study had no interest in participating in any research. Their characteristics in terms of age, cancer stage and treatment types were comparable to the patients who completed semi-structured interviews. Of the 31 participants, 20 women (64.5%) reported cognitive complaints after cancer treatment. The socio-demographic and clinical characteristics of women with cognitive impairment and without perceived cognitive impairment are listed in Table 1. From Table 1, the demographic/clinical characteristics of women with and without perceived cognitive impairment were comparable.

Major categories that emerged from the data included cognitive complaints, perceived contributing factors, impacts of cognitive problems on women's daily lives, health outcomes and work capabilities, coping strategies and supportive care needs from health care providers are shown in Table 2. The most common complaint was loss of concentration (n=17, 85.0%), followed by memory problems (n=15, 75.0%). Other common cognitive complaints included difficulties in learning new things, language issues (finding the right word to respond in everyday conversations), and a slowed rate of information processing.

The participants identified several factors that they believed were contributing to their cognitive complaints, including chemotherapy (n=15, 75.0%), side effects of cancer and other treatment, such as surgery or radiation therapy (n=12, 60.0%), and aging (n=8, 40.0%). These cognitive complaints had negative impacts on their daily lives, sleep and rest (n=20, 100%). Two participants indicated their cognitive function had seen negligible change, but their physical health had deteriorated significantly after their cervical cancer diagnosis. While ten women who were on medical leave at the time of data collection, two women indicated they were planning to leave their jobs due to loss of concentration and slowed information processing capacity.

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As shown in Table 2, the most commonly used coping strategies were memo writing (n=15, 75.0%), and self-adjustment (n=14, 70.0%). Other coping strategies include “doing nothing” and organisation of their environment. In addition, one woman sought acupuncture as an alternative therapy for her cognitive problems, as she had been told by her physician that there was no effective medication for cognitive impairment thus far. Chinese cervical cancer survivors describe a variety of supportive care needs, such as the need for education on common signs and symptoms of cognitive impairment and effective treatment therapies (n=11, 55.0%), providing counselling service to family members (n=8, 40.0%), and information on further rehabilitation services (n=7, 35.0%). Two women expressed the need for peer support, and suggested that health care providers could organise a peer support service for patients starting from the diagnosis stage onward. Several patients indicated that their health care providers had never mentioned cognitive impairment issues, and only mentioned this when patients asked about cognitive problems that appeared during cancer treatment.

Based on the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers (2009), and in combination with a synthesis of these qualitative findings, a refinement cognition model among cervical cancer survivors is illustrated in Figure 1. Cognitive complaints are multifactorial in nature, and contributing factors include demographic characteristics, biological factors, psychological distress, disease stage and cancer therapies.

Discussion

This is one of the first published studies exploring cognitive complaints in Chinese cervical cancer survivors, while there is accumulating evidence documenting cognitive impairment issues

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among cancer survivors, mainly dominated by breast cancer survivors.[22] The prevalence of cognitive complaints among Chinese cervical cancer survivors was 64.5%, which is consistent with previous research.[6] As this study was a preliminary study and adopted a small and non-random sample, so epidemiological studies are needed to further quantify the prevalence, impact and extent of cognitive complaints in this study population.[23]

Concurring with previous research evidence, chemotherapy and the side effects of cancer are the most common factors associated with cognitive complaints.[4,7] This study identified that cervical cancer survivors perceive aging as a likely contributing factor in cognitive impairment. These participants took "aging as a normal process of cognitive decline," and viewed cognitive impairment as a process that could not be changed. Consistent with previous studies,[17,24] participants in this study also reported that symptoms of worry, fatigue and pain seem to be related to cognitive impairment.

The patient experience of cancer-related cognitive impairment may be the commonalities of the phenomenon across tumour types,[25] as this study did not find unique cognitive deficits in women with cervical cancer. Yet this study did identify some unique cultural issues for Chinese women in terms of coping strategies for cognitive impairment. Some women did nothing to try to cope with their cognitive complaints. 'Doing nothing' as a common coping strategy for cognitive complaints could be related to the Chinese Taoist philosophy: "Accepting the fact that a situation cannot be changed, and telling oneself that one should do little, as things will be all right at the end of the day".[26] Hence, coping strategies of doing nothing and self-adjustment could help these survivors maintain a sense of calm when facing difficulties that cannot be changed.

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As in previous studies,[4,6,7] findings from this study also revealed that cognitive complaints had a variety of consequences that impacted daily living, QOL, physical and psychological health, and work capabilities. While research into the relationship between cognitive functioning and work ability is still in its infancy,[27] returning to work is a critical milestone for many survivors, since work plays a key role in one's psychological, economic, and social wellbeing.[28] If cancer survivors were able to obtain individualised support and work-related adjustments from their employer, they would be more likely to continue working.[23] Hence, cognitive complaints in cancer survivors generate numerous supportive care requirements, not only in the workplace, but also from health care providers.

Common supportive care needs from health care providers include providing information about common signs of cognitive symptoms and management strategies, effective treatment therapies and possible rehabilitation services, in order to manage cognitive problems. Although many health care providers may gloss over the issue of patient cognitive complaints, believing they have no curative treatment to offer patients,[29] findings from a meta-analysis indicate that neuropsychological interventions (cognitive rehabilitation, cognitive training and neuromodulation strategies) can improve cognitive function in cancer survivors.[30] In particular, a recent Cochrane review indicates that cognitive training may be effective in improving patients' cognitive function, as well as quality of life.[31] Additionally, behavioural intervention strategies (increasing physical activities and fostering supportive social relationships) could be helpful in improving cognitive function among cancer survivors.[12]

By a synthesis of these study findings, a preliminary cognition model for cervical cancer survivors after cancer treatment was established, to provide a theoretical underpinning for the perception of cognitive complaints, contributing factors, mediating factors, and the consequences

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of cognitive impairment in this study population. This model may be able to inform and stimulate further intervention studies. Certainly, this preliminary cognition model of cervical cancer survivors after cancer treatment can be continuously refined by further empirical research investigations. Overall, this model illustrates coping strategies at a personal level by self-adjustment or by doing nothing; and supportive care services, such as educational and counselling services for family members by health care providers could mitigate the extent of the consequences of cognitive impairment. In addition, participants felt a great need for support, such as peer support, from diagnosis onwards, as well as for information on available rehabilitation services and counselling, to modulate the degree of cognitive complaints. Consequently, cognitive complaints exert negative effects on their daily living, QOL, work capability, and physical and psychological health.

Limitations and implications for future research

There are two limitations in this study. Firstly, this preliminary study only recruited study participants at a single medical centre, and the sample size could not be representative of this population in general, although this study primarily offers significant insights into perceived cognitive complaints, contributing factors and consequences of cognitive impairment in cervical cancer survivors. Secondly, this study utilised a cross-sectional design and included study participants on the completion of primary cancer treatment in a short period of time. Future longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum. As suggested by Myers,[25] qualitative studies do provide valuable information to healthcare professionals about the impact that cognitive changes have on cancer patients' QOL and daily function. Understanding cancer patients' experience of cognitive impairment, their coping strategies and supportive care needs could help healthcare professionals

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develop interventions to prevent, mitigate, and treat the cognitive sequelae of cancer and its treatment therapies.[25]

Conclusion

This study adds new insights into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints would subsequently facilitate the development of relevant therapeutic interventions for prevention, and providing supportive care services, such as educational and counselling services, to reduce cognitive impairment in women with cervical cancer.

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Ethics approval: This study was approved by the Medical Ethics Committee of Hunan Cancer Hospital.

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Table 1 Demographic and clinical characteristics of participants with cognitive impairment and without cognitive impairment

Variables	Mean (SD) / (%)	
	With reported cognitive impairment (n=20)	Without reported cognitive impairment (n=11)
Age (years) (range)	46.40 (9.80) (19-57)	43.45 (12.08) (19-56)
Education levels		
Primary school or below	11 (55.0)	5 (45.5)
College	6 (30.0)	5 (45.5)
University or above	3 (15.0)	1 (9.0)
Employment status		
Employed but on medical leave	10 (50.0)	7 (63.6)
Unemployed or retired	10 (50.0)	4 (36.4)
Marital status		
Married	19 (95.0)	10 (90.9)
Divorced	1 (5.0)	1 (9.1)
Disease stage		
Stage IA	7 (35.0)	4 (36.4)
Stage IB-IIA	11 (55.0)	6 (54.5)
Stage IIB-IVA	2 (10.0)	1 (9.1)
Types of treatment		
Surgery	5 (25.0)	3 (27.3)
Surgery + chemotherapy	5 (25.0)	4 (36.4)
Surgery + radiation therapy	2 (10.0)	0 (0.0)
Surgery+radiation+chemotherapy	6 (30.0)	2 (18.2)
Radiation or chemotherapy	2 (10.0)	2 (18.2)
Time since completion of primary treatment (months) (range)	1.70 (1.03) (1-5)	1.63 (1.20) (1-5)

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Table 2 Major categories from the qualitative content analysis (N=20)

Categories	n (%)	Illustrative quotes from participants
Cognitive complaints		
Lost concentration	17(85.0)	*It's difficult to focus on a conversation or when reading newspapers or books. My biggest problem is lack of concentration*
Easily forgetting things or information told by others	15 (75.0)	*My memory changed a lot after chemotherapy; when I meet my friend on the street, I can't even remember her name. Sometimes, nurses tell me information about the illness, and I can't even remember what they have just told me*
Feeling it's hard to understand new things	7 (35.0)	*When I was reading some books, I saw the words, but I could not make sense of the words, even when I read the same sentence several times.*
Difficulties in finding right word in general conversation	4 (20.0)	*When I speak with someone in general conversation, it's hard for me to find the right words*
Slowing down in working efficiency, compared with how they used to be	2 (10.0)	*I was used to being well organised in my work and daily life, but now it's hard to get back all those abilities, and work has slowed down a lot*
Perceived causing factors		
Relating to chemotherapy	15 (75.0)	*Even during chemotherapy, I found that my memory changed a lot. Now I have completed the whole cycle of chemotherapy, and more and more memory impairment has appeared*
Side effects of cancer and its treatment	12 (60.0)	*I believe that a lot of physical examinations, such as CT at the time of diagnosis, the use of analgesics, and the surgery procedure are all related to my cognitive problems*
Aging	8 (40.0)	*Maybe due to my age, my memory is worse and I've started forgetting things quickly*
Psychosocial issues	3 (15.0)	*Having to deal with too many sources of stress, such as the financial issues related to medical treatment*
Relating to immune function	2 (10.0)	*After I got this disease and received this series of cancer treatments, my immune*

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		function was destroyed, so my memory problems are partly due to this
Coping strategies		
By writing memos	15 (75.0)	*Writing down important things, use of diaries or phone reminders to organise daily tasks*
Self-adjustment and relaxation techniques	14 (70.0)	*Asking myself to focus on one task at a time. When disturbed by other things or people, I'll adjust myself and refocus on what I was doing. By reading, or listening to music for focus*
Doing nothing	6 (30.0)	*Now I can do nothing for this problem (cognitive impairment), as this may be due to my age; with older age, cognitive decline appears naturally. Other patients believe these cognitive problems are reversible and may get better gradually*
Environment organisation	2 (10.0)	*To keep important personal belongs such as keys, eyeglasses, mobile phone in a fixed place*
TCM such as acupuncture	1 (5.0)	*Doctors told me there were no effective drug therapies for this problem, so I tried acupuncture*
Supportive care needs from health care providers		
Providing common symptoms of cognitive impairment and its effective therapies	11 (55.0)	*It's great for doctors and nurses to tell me common signs or symptoms of cognitive impairment, and provide intervention therapies to treat these problems*
Providing counselling services to family members	8 (40.0)	*It's hard for me to remember so much information. Health care providers should provide educational information and more counselling services to my family members*
Need information about possible rehabilitation service	7 (35.0)	*After hospital discharge, where should I seek further rehabilitation service for cognitive problems, or can these problems recover gradually*
Offering peer support networks	2 (10.0)	*At the time of diagnosis and during cancer treatment, I felt so worried. I need to connect with women who have had a similar experience, in order to share coping*

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		strategies
Impacts on		
Daily lives	20 (100)	*Sometimes, when people talk with me, I immediately forget what they were talking about, or when I'm doing things and people interrupt me, I'll forget what I want to do*
Quality of life	9 (45.0)	*This disease and its treatment have severely impacted all aspects of my life and left me feeling overwhelmed. Now I have poor memory, a slowed thinking process, and a large financial burden as a result of the medical costs, causing tension in my family relationship*
Psychological health	5 (25.0)	*Sometimes my brain becomes blank, and it seems my memory could not come back, so I felt so frightened and scared*
Work capability	3 (15.0)	*I have to leave my job, due to my body image now, during and after chemotherapy I lost a lot of hair, and I can't work for very long, I can only work for a short period of time, then I have to rest*
Physical health conditions	2 (10.0)	*Cognitive function changes were not obvious, but my health condition was a lot worse; before the cancer diagnosis, my health was OK. But now my sleep is not good, my immune system is much weaker, and due to the loss of physical energy I can't work too long and need to take a break after working for just a short while*

Abbreviation: TCM, traditional Chinese medicine

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Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment

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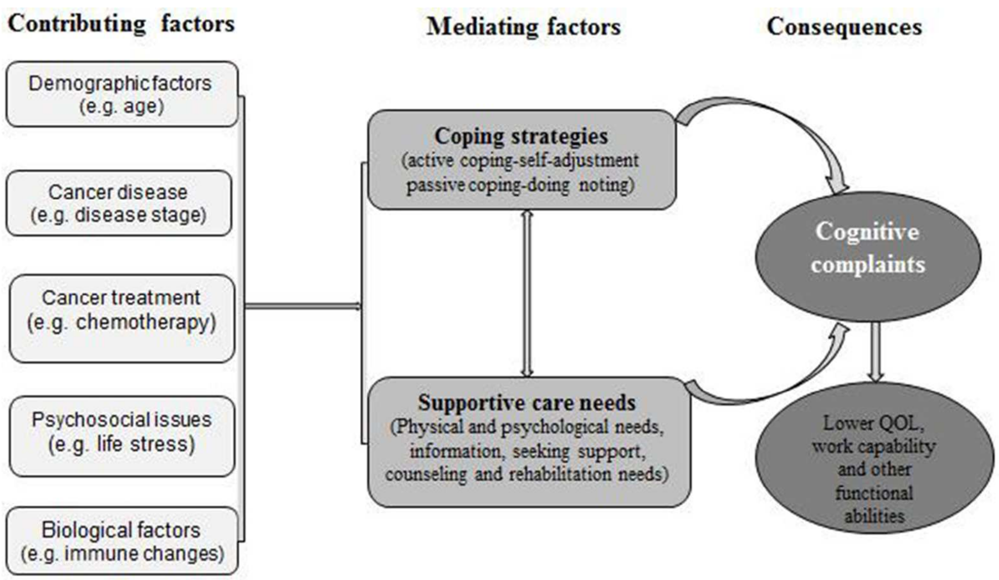

Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment
Figure 1

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Appendix 1 Consolidated criteria for reporting qualitative studies (COREQ) checklist

COREQ items	**Descriptions**
Domain 1: Research team and reflexivity	
1. Interviewer/facilitator	The third author conducted the interview
2. Credentials	The researcher is nursing professor and holds Master degree of Nursing
3. Occupation	Clinical nursing researcher at the time of the study
4. Gender	Female
5. Experience and training	The researcher works for clinical researcher for more than 5 years with qualitative research training
Relationship with participants	
6. Relationship established	Working relationship was established prior to study commencement
7. Participant knowledge of the interviewer	Participants know about the researcher for doing the research
8. Interviewer characteristics	Described at page 7 in the manuscript
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory	Methodological orientation underpinning the study was content analysis and was guided by a conceptual model by Myers (2009) (page 6)
Participant selection	
10. Sampling	Purposive sampling described at page 6
11. Method of approach	Participants approached by face-to-face
12. Sample size	31 participants in this study
13. Non-participation	19 participants refused, reasons described at page 8 to page 9
Setting	
14. Setting of data collection	Hospital's meeting room (page 7)
15. Presence of non-participants	Nobody else present besides the participants and researchers (page 8)
16. Description of sample	Table 1.
Data collection	
17. Interview guide	Consisting of 7 open-ended questions and was pilot tested in a participants (page 7)
18. Repeat interviews	None
19. Audio/visual recording	N/A. as this study collected data by written narratives
20. Field notes	Yes, at page 7
21. Duration	30-45 minutes (page 7)
22. Data saturation	Yes, described at page 7
23. Transcripts returned	Transcripts were returned to three participants for comments or correction
Domain 3: analysis and findings	
Data analysis	

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24. Number of data coders	Twenty copies of data coded
25. Description of the coding tree	None
26. Derivation of themes	Themes were derived from the data (Table2)
27. Software	Nvivo 11 was used to manage the data
28. Participant checking	Three participants checked the final transcript of this study
Reporting	
29. Quotations presented	Table 2
30. Data and findings consistent	There was consistency between the data presented and the findings.
31. Clarity of major themes	Major themes clearly presented in the findings (Table 2)
32. Clarity of minor themes	Any diverse cases were resolved during the stage of data analysis.

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Title: Cervical cancer survivors' perceived cognitive complaints and supportive care needs in mainland China: A qualitative study

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Abstract

Objectives: This study explores Chinese cervical cancer survivors' perceived cognitive complaints and relevant supportive care needs after primary cancer treatment.

Design: This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Setting: This study was conducted at a secondary cancer care centre located in South China.

Participants: 31 women with cervical cancer after primary cancer treatment, ages 18-60, were purposively selected using non-random sampling procedures.

Results: A total of 31 cervical cancer survivors joined this study. Of that total, 20 women (64.5%) reported cognitive complaints after cancer treatment. The most common complaint was loss of concentration (n=17, 85.0%). Perceived contributing factors to these cognitive complaints included chemotherapy (n=15, 75.0%), and aging (n=8, 40.0%). These cognitive problems most commonly impacted daily living (n=20, 100%). Common supportive care needs included symptom management strategies (n=11, 55.0%), and counselling services (n=8, 40.0%).

Conclusion: This study adds new insight into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese cervical cancer survivors. Improved understanding of cognitive complaints could subsequently facilitate the development of relevant therapeutic interventions for prevention; as well as the provision of supportive care services, such as educational and counselling services, to reduce cognitive impairment in women with cervical cancer.

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Study strengths and limitations

- This qualitative study used written responses as a means of data collection, which is a more cost-effective and less time-consuming method, as it does not require transcription.
- An additional study strength is that written qualitative responses could overcome the Chinese dialect barrier, as Chinese people, even within the same province, typically speak many different dialects. The written language is understandable across all dialect groups.
- This preliminary study recruited participants at a single medical centre, which could limit the transferability of study findings.
- This study included participants who had completed primary cancer treatment within a short time frame; longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum.

Keywords Cervical cancer. Survivors. Cognitive complaints. Supportive care needs.

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Introduction

Cervical cancer is the second most common cancer, followed by breast cancer, among women in China.[1] Due to medical advancements in early detection and the possibility of curative cancer treatment,[2] the five-year relative survival rate of cervical cancer in mainland China is up to 69% for all stages.[1] As more cervical cancer survivors are living longer after curative treatment, the late effects of cancer treatment are becoming increasingly common.[3] One such long-term and late effect is neurocognitive, which has emerged as a significant problem affecting cervical cancer survivors.[4,5]

Cognitive complaints often refer to cognitive impairment or cancer-related cognitive impairment.[6,7] Other studies have described this as chemotherapy-related cognitive dysfunction, colloquially named ‘chemo brain’ or ‘chemo fog’.[8,9] Cognitive complaints have the potential to significantly impact both social and occupational functioning, interfering with the ability to carry out normal daily activities, all of which in turn contributes to lower quality of life (QOL) for cancer survivors.[4,6,10] Cognitive complaints have been reported in approximately 40% of patients prior to any cancer treatment, and as many as 75% of patients indicate some degree of cognitive impairment during the period of active cancer treatment. Finally, cognitive complaints are still present in up to 60% of long-term cancer survivors.[6] In a study conducted in mainland China, female cancer survivors with an average of 2.79 years post-primary treatment reported higher levels of cognitive limitations, significantly reducing their work productivity and global QOL.[11]

Quantitative research approaches are employed to explore cognitive complaints and related supportive care issues among cancer survivors,[4,12] with researchers proposing that quantitative cognitive measures are more objective and reliable than qualitative exploration of cognitive

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problems in cancer survivors.[13,14] However, other researchers have argued there are inherent difficulties with a quantitative approach, in terms of fully appreciating cancer patients' cognitive complaints.[4,15] Qualitative research studies would enable us to identify the presence of cognitive symptoms that quantitative approaches cannot detect, either by self-reported cognitive measures or neurocognitive tests.[15] In addition, qualitative in-depth interviews could provide information about how cognitive impairment impacts cancer patients' QOL, and could allow researchers to obtain rich information about numerous coping strategies to ameliorate cognitive dysfunction symptoms, as well as develop intervention strategies.[15]

Therefore, there is a need for a qualitative study to explore perceived cognitive complaints and relevant supportive care needs of cervical cancer survivors after primary cancer treatment. A clear understanding of the cognitive complaints experienced by cervical cancer survivors, through qualitative in-depth interviews, could aid healthcare providers in developing targeted interventions, as well as in providing relevant supportive care services to alleviate the extent and impact of cancer survivors' cognitive complaints.[16]

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Methods

Design

This study utilised a qualitative research design. A semi-structured interview was used to probe cervical cancer patients' perceived cognitive complaints and supportive care needs.

Study framework

This study was guided by the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers.[17] This model consists of three key components: antecedents (cancer diagnosis and cancer treatment), mediators (physiologic, psychosocial and situational factors), and consequences (quality of life and functional ability).[17] While this model is described as chemotherapy-related cognitive impairment, recent evidence indicates that cancer itself is also related to cognitive impairment.[6] As suggested by Myers, when researchers learn more about the physiological and psychological aspects of cognitive impairment, this model will require refining.[17]

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Study sample

All study participants were recruited from the Gynaecological Oncology Unit in a cancer hospital. This study obtained ethical approval from the hospital's ethics committee. A purposive sampling was drawn to recruit eligible informants. Inclusion criteria were: women who were at least 18 years old, with a primary diagnosis of cervical cancer, and who had completed their primary cancer treatment of surgery, radiation therapy or chemotherapy. Exclusion criteria included potential psychiatric disorders, previous cancer history, or traumatic brain injury.

Study procedure and qualitative interviews

After obtaining the ethical approval, the participants were recruited from the hospital's gynaecological inpatient department. The third author assessed the eligibility of participants. The eligible women were invited to the hospital's meeting room for completing the semi-structured interview individually. These eligible participants were asked to participate in a semi-structured interview, and complete a socio-demographic sheet. This sheet was used to collect information on demographic and clinical characteristics, including age, education level, marital status, tumour stage, type of cancer treatment received, and time since completion of primary cancer treatment. Qualitative interviews were guided by a narrative epistemology in order to encourage participants to provide narrative accounts of their perceived experience.[18] Researcher characteristics: The third author, who conducted the interview, is a nursing professor who holds a Master of Nursing degree. All researchers in this study have been conducting clinical research for more than five years, and all have qualitative research training. The interviewer was an female experienced research nurse who was not a staff nurse in the research setting of the Gynaecological Oncology Unit, and the data collection method was by written narrative, so that the interviewer's beliefs, biases and preconceptions would have no influence on the direction of the interviews. No non-participants were present in in the interview, and the interviewer only remained in the meeting room to take field notes, in order to capture any emerging thoughts to guide data analysis.

The interviews were conducted face-to-face in the in-patient ward’s meeting room. All interviews utilised an interview guide comprised of the following open-ended questions: 1) Compared to before your cancer diagnosis, tell us about the overall change in your cognitive abilities? For example, your perceptions of understanding what people say to you; thinking of the right word when responding to others; and feeling confident about completing a task or taking on new tasks. 2) What do you think the common contributing factors to any cognitive changes might be? 3) How do these perceived cognitive changes impact your daily life or your ability to work? 4) How do you deal with these changes? In other words, what types of coping strategies do you use as a result of any cognitive changes you might be experiencing? 5) What types of supportive care services do you need from healthcare providers, to help you cope with any

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cognitive complaints? Each interview lasted 30 to 45 minutes, and was recorded by a digital recorder and transcribed verbatim. Data saturation was achieved much earlier than the final sample size of 31 patients, as data collection and analysis were performed simultaneously in an iterative process.[19]

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Data analysis

Qualitative interview data were transcribed to produce a verbatim transcript. During the entire data analysis process, the researcher consciously separated herself from personal biases, in order to be open to the information shared by study participants. NVivo 11 qualitative software (http://www.qsrinternational.com/nvivo-product/nvivo11-for-windows) was applied to organise and code the verbatim transcript. Qualitative content analysis was used to prepare, organise, and report the data.[20] A three-step content analysis process was followed: "*1) The verbatim transcript was organised into meaning units (such as words, phrases, sentences or paragraphs that conveyed similar content deemed important in understanding patients' experiences). 2) The meaning units were coded and categorised. 3) The abstraction process was guided by Myers's conceptual model and continued until primary themes were identified.*[20]

Two research members conducted content analysis independently. In case of any disagreement with the interpretation of clusters or categories, a third research member was involved in the discussion process, in order to establish a consensus. To ensure the study findings were accurately reflecting informants' truly perceived experience of cognitive changes, three research participants were invited to check the final verbatim transcript for the purpose of collecting participants' feedback and validation. The consolidated criteria for reporting qualitative studies (COREQ) checklist was applied to guide this study and ensure study rigour (Appendix 1).[21]

Results

A total of 50 patients with cervical cancer were approached, with 31 agreeing to participate in this written narrative interview. Those who did not join this study had no interest in participating

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in any type of research. Their characteristics in terms of age, cancer stage and treatment types were comparable to the patients who completed semi-structured interviews. Of the 31 participants, 20 women (64.5%) reported cognitive complaints after cancer treatment. The socio-demographic and clinical characteristics of women with cognitive impairment and without perceived cognitive impairment are listed in Table 1. From Table 1, the demographic/clinical characteristics of women with and without perceived cognitive impairment were comparable.

Major categories that emerged from the data – which included cognitive complaints; perceived contributing factors; the impact of cognitive problems on women's daily lives, health outcomes and work capabilities; coping strategies; and patients' supportive care needs from health care providers - are shown in Table 2. The most common complaint was loss of concentration (n=17, 85.0%), followed by memory problems (n=15, 75.0%). Other common cognitive complaints included difficulties in learning, language issues (finding the right words in everyday conversations), and a slowed rate of information processing.

The participants identified several factors that they believed were contributing to their cognitive complaints, including chemotherapy (n=15, 75.0%), side effects of cancer and other treatment, such as surgery or radiation therapy (n=12, 60.0%), and aging (n=8, 40.0%). These cognitive complaints had negative impacts on daily life, sleep and rest (n=20, 100%). Two participants indicated their cognitive function had seen negligible change, but their physical health had deteriorated significantly after the diagnosis of cervical cancer. While 10 women were on medical leave at the time of data collection, two women indicated they were planning to leave their jobs due to loss of concentration and slowed information processing capacity.

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As shown in Table 2, the most commonly used coping strategies were memo writing (n=15, 75.0%), and self-adjustment (n=14, 70.0%). Other coping strategies included "doing nothing" and organisation of their environment. In addition, one woman sought acupuncture as an alternative therapy, after her physician told her there was no effective medication for cognitive impairment thus far. Chinese cervical cancer survivors describe a variety of supportive care requirements, such as patient, as well as family education, on the common signs and symptoms of cognitive impairment; along with effective treatment therapies (n=11, 55.0%); counselling for family members (n=8, 40.0%); and information on further rehabilitation services (n=7, 35.0%). Two women expressed the need for peer support, and suggested that healthcare providers could organise a peer support group for patients starting from the diagnosis stage onward. Several patients indicated that their healthcare providers had never mentioned the potential for cognitive impairment, and only addressed this when patients asked about cognitive problems that appeared during cancer treatment.

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Based on the conceptual model of chemotherapy-related changes in cognitive function proposed by Myers (2009), and in combination with a synthesis of these qualitative findings, a new cognition model among cervical cancer survivors is illustrated in Figure 1. Cognitive complaints are multifactorial in nature, with contributing factors that include demographic characteristics, biological factors, psychological distress, disease stage and cancer therapies.

Discussion

This is one of the first published studies exploring cognitive complaints among Chinese cervical cancer survivors, while there is accumulating evidence documenting cognitive impairment issues among cancer survivors, mainly dominated by breast cancer survivors.[22] The prevalence of cognitive complaints among Chinese cervical cancer survivors was 64.5%, which is consistent with previous research.[6] As this study was preliminary and adopted a small and non-random sample, epidemiological studies are needed to further quantify the prevalence, impact and extent of cognitive complaints in this study population.[23]

Concurring with previous research evidence, chemotherapy and the side effects of cancer are the most common factors associated with cognitive complaints.[4,7] This study identified that cervical cancer survivors perceive aging as a likely contributing factor to cognitive impairment. Study participants considered "aging as a normal process of cognitive decline," and viewed cognitive impairment as a process that could not be changed. Consistent with previous studies,[17,24] study participants also reported that worry, fatigue and pain all seem to be related to cognitive impairment.

The patient experience of cancer-related cognitive impairment may be the commonality of the phenomenon across tumour types,[25] as this study did not find unique cognitive deficits in women with cervical cancer. However, this study did identify unique cultural issues for Chinese women seeking coping strategies for cognitive impairment. Some women did nothing to try to cope with their cognitive complaints. 'Doing nothing' as a common coping strategy for cognitive complaints could be related to the Chinese Taoist philosophy: "Accepting the fact that a situation cannot be changed, and telling oneself that one should do little, as things will be all right at the end of the day".[26] Hence, a coping strategy of doing nothing and self-adjustment could help these survivors maintain a sense of calm when facing difficulties that cannot be changed.

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As in previous studies,[4,6,7] this study's findings also revealed that cognitive complaints had a variety of consequences that impacted daily living, QOL, physical and psychological health, and work capabilities. While research into the relationship between cognitive functioning and work ability is still in its infancy,[27] returning to work is a critical milestone for many survivors, since work plays a key role in psychological, economic, and social well-being.[28] If cancer survivors were able to obtain individualised support and work-related adjustments from their employer, they would be more likely to continue working.[23] Hence, cognitive complaints in cancer survivors generate numerous supportive care requirements, not only in the workplace, but also from healthcare providers.

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Common supportive care needs that patients require from healthcare providers include the provision of information on the common signs of cognitive impairment, as well as management strategies, effective treatment therapies and possible rehabilitation services, in order to manage cognitive problems. Although many healthcare providers may gloss over the issue of patient cognitive complaints, believing they have no curative treatment to offer patients,[29] findings from a meta-analysis indicate that neuropsychological interventions (cognitive rehabilitation, cognitive training and neuromodulation strategies) can improve cognitive function in cancer survivors.[30] In particular, a recent Cochrane review indicates that cognitive training may be effective in improving patients' cognitive function, as well as their quality of life.[31] Additionally, behavioural intervention strategies (increasing physical activity levels and fostering supportive social relationships) could be helpful in improving cognitive function among cancer survivors.[12]

Through a synthesis of these study findings, a preliminary cognition model for cervical cancer survivors after cancer treatment was established, to provide a theoretical underpinning for the perception of cognitive complaints, contributing factors, mediating factors, and the consequences of cognitive impairment in this study population. This model may be able to inform and stimulate further intervention studies. Certainly, this preliminary cognition model of can be continuously refined through further empirical research investigations. Overall, this model illustrates coping strategies at a personal level, through self-adjustment or by doing nothing. Additionally, supportive care services, such as education and counselling for family members, could mitigate the consequences of cognitive impairment. In addition, participants felt a great need for support, including peer support, from diagnosis onwards, as well as for information on available rehabilitation services and counselling, in order to modulate the degree of cognitive complaints. For survivors of cervical cancer, cognitive complaints exert negative effects on daily living, QOL, work capability, and physical and psychological health.

Limitations and implications for future research

This preliminary study has two limitations. First, this study only recruited participants at a single medical centre, and the sample size could not be representative of this population in general. This study primarily offers significant insights into perceived cognitive complaints, contributing factors and consequences of cognitive impairment in cervical cancer survivors. Second, this study utilised a cross-sectional design and included participants who had completed primary cancer treatment within a short period of time. Future longitudinal research should be conducted to identify the trajectory of cognitive complaints over the cancer care continuum. As Myers suggested,[25] qualitative studies provide valuable information for healthcare professionals on the impact of cognitive changes on cancer patients' QOL and activities of daily living. Understanding cancer patients' experience of cognitive impairment, their coping strategies and supportive care needs could help healthcare professionals develop interventions to prevent, mitigate, and treat the cognitive sequelae of cancer and its treatment therapies.[25]

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Conclusion

This study adds new insight into the growing body of research on cognitive complaints by cancer survivors, in particular Chinese survivors of cervical cancer. Improved understanding of cognitive complaints could subsequently facilitate the development of relevant therapeutic interventions for prevention, as well as for the provision of supportive care services such as education and counselling, to reduce cognitive impairment in women with cervical cancer.

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Competing interests: The authors declare no conflicts of interest.

Ethics approval: This study was approved by the Medical Ethics Committee of Hunan Cancer Hospital.

Data sharing statement: No additional data are available.

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Table 1 Demographic and clinical characteristics of participants with cognitive impairment and without cognitive impairment

Variables	Mean (SD) / (%)	
	With reported cognitive impairment (n=20)	Without reported cognitive impairment (n=11)
Age (years) (range)	46.40 (9.80) (19-57)	43.45 (12.08) (19-56)
Education levels		
Primary school or below	11 (55.0)	5 (45.5)
College	6 (30.0)	5 (45.5)
University or above	3 (15.0)	1 (9.0)
Employment status		
Employed but on medical leave	10 (50.0)	7 (63.6)
Unemployed or retired	10 (50.0)	4 (36.4)
Marital status		
Married	19 (95.0)	10 (90.9)
Divorced	1 (5.0)	1 (9.1)
Disease stage		
Stage IA	7 (35.0)	4 (36.4)
Stage IB-IIA	11 (55.0)	6 (54.5)
Stage IIB-IVA	2 (10.0)	1 (9.1)
Types of treatment		
Surgery	5 (25.0)	3 (27.3)
Surgery + chemotherapy	5 (25.0)	4 (36.4)
Surgery + radiation therapy	2 (10.0)	0 (0.0)
Surgery+radiation+chemotherapy	6 (30.0)	2 (18.2)
Radiation or chemotherapy	2 (10.0)	2 (18.2)
Time since completion of primary treatment (months) (range)	1.70 (1.03) (1-5)	1.63 (1.20) (1-5)

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Table 2 Major categories from the qualitative content analysis (N=20)

Categories	n (%)	Illustrative quotes from participants
Cognitive complaints		
Lost concentration	17(85.0)	*It's difficult to focus on a conversation or when reading newspapers or books. My biggest problem is lack of concentration*
Easily forgetting things or information from others	15 (75.0)	*My memory changed a lot after chemotherapy; when I meet my friend on the street, I can't even remember her name. Sometimes, nurses tell me information about the illness, and I can't even remember what they have just told me*
Feeling it's hard to understand new things	7 (35.0)	*When I was reading books, I saw the words, but I could not make sense of the words, even when I read the same sentence several times.*
Difficulties in finding right word in general conversation	4 (20.0)	*When I speak with someone in general conversation, it's hard for me to find the right words*
Slowing down in working efficiency, compared with how they used to be	2 (10.0)	*I was used to being well organised in my work and daily life, but now it's hard to get back all those abilities, and work has slowed down a lot*
Perceived causing factors		
Relating to chemotherapy	15 (75.0)	*Even during chemotherapy, I found that my memory changed a lot. Now I have completed the whole cycle of chemotherapy, and more and more memory impairment has appeared*
Side effects of cancer and its treatment	12 (60.0)	*I believe that a lot of physical examinations, such as CT at the time of diagnosis, the use of analgesics, and the surgery procedure are all related to my cognitive problems*
Aging	8 (40.0)	*Maybe due to my age, my memory is worse and I've started forgetting things quickly*
Psychosocial issues	3 (15.0)	*Having to deal with too many sources of stress, such as the financial issues related to medical treatment*
Relating to immune function	2 (10.0)	*After I got this disease and received this series of cancer treatments, my immune*

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		function was destroyed, so my memory problems are partly due to this
Coping strategies		
By writing memos	15 (75.0)	*Writing down important things, use of diaries or phone reminders to organise daily tasks*
Self-adjustment and relaxation techniques	14 (70.0)	*Asking myself to focus on one task at a time. When disturbed by other things or people, I'll adjust myself and refocus on what I was doing. By reading, or listening to music for focus*
Doing nothing	6 (30.0)	*Now I can do nothing for this problem (cognitive impairment), as this may be due to my age; with older age, cognitive decline appears naturally. Other patients believe these cognitive problems are reversible and may get better gradually*
Environment organisation	2 (10.0)	*To keep important personal belongs such as keys, eyeglasses, mobile phone in a fixed place*
TCM such as acupuncture	1 (5.0)	*Doctors told me there were no effective drug therapies for this problem, so I tried acupuncture*
Supportive care needs from healthcare providers		
Providing common symptoms of cognitive impairment and its effective therapies	11 (55.0)	*It's great for doctors and nurses to tell me about common signs or symptoms of cognitive impairment, and to provide intervention therapies to treat these problems*
Providing counselling services to family members	8 (40.0)	*It's hard for me to remember so much information. Healthcare providers should provide educational information and more counselling services to my family members*
Need information about possible rehabilitation service	7 (35.0)	*After hospital discharge, where should I seek further rehabilitation service for cognitive problems? Or can I gradually recover from these problems?*
Offering peer support networks	2 (10.0)	*At the time of diagnosis and during cancer treatment, I felt so worried. I need to connect with women who have had a similar experience, in order to share coping*

		strategies
Impacts on		
Daily life	20 (100)	*Sometimes, when people speak with me, I immediately forget what they were talking about, or when I'm doing things and people interrupt me, I'll forget what I wanted to do*
Quality of life	9 (45.0)	*This disease and its treatment have severely impacted all aspects of my life, and have left me feeling overwhelmed. Now I have a poor memory, slowed thinking process, and a large financial burden as a result of the medical costs, causing tension in my family relationship*
Psychological health	5 (25.0)	*Sometimes my brain becomes a blank, and it seems my memory is not coming back, so I feel really scared*
Work capability	3 (15.0)	*I have to leave my job, due to my body image now, during and after chemotherapy I lost a lot of hair, and I can't work for very long, I can only work for a short period of time, then I have to rest*
Physical health conditions	2 (10.0)	*Cognitive function changes were not obvious, but my health condition was a lot worse; before the cancer diagnosis, my health was OK. But now my sleep is not good, my immune system is much weaker, and due to the loss of physical energy I can't work too long and need to take a break after working for just a short while*

Abbreviation: TCM, traditional Chinese medicine

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Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment

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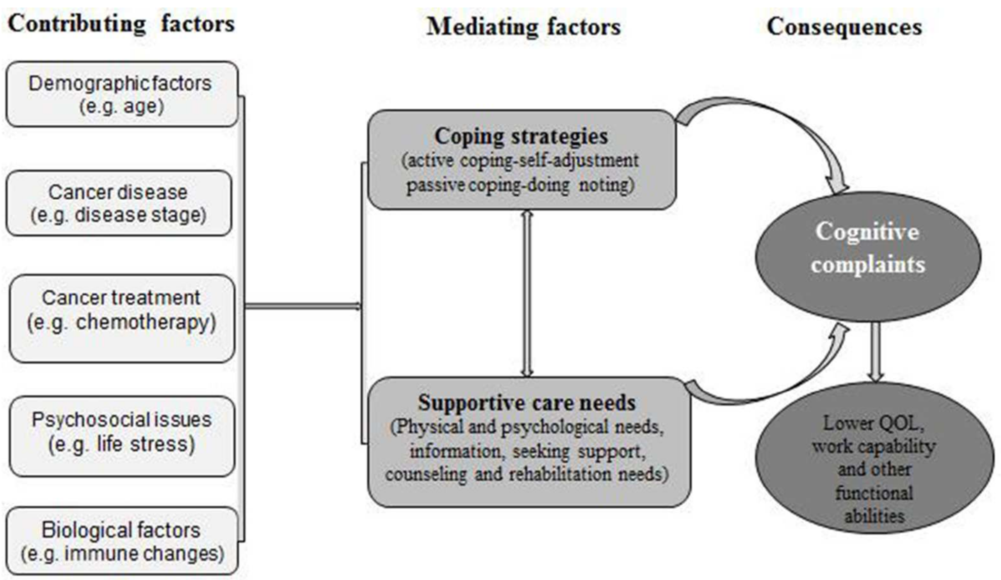

Fig. 1 A preliminary cognition model among cervical cancer survivors after cancer treatment
Figure 1

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Appendix 1 Consolidated criteria for reporting qualitative studies (COREQ) checklist

COREQ items	**Descriptions**
Domain 1: Research team and reflexivity	
1. Interviewer/facilitator	The third author conducted the interview (page 7, line 118)
2. Credentials	The researcher is nursing professor and holds Master degree of Nursing (page 7, line 118-122)
3. Occupation	Clinical nursing researcher at the time of the study (page 7, line 119-120)
4. Gender	Female (page 7, line 121)
5. Experience and training	All researchers work for clinical research for more than 5 years with qualitative research training (page 7, line 119-120)
Relationship with participants	
6. Relationship established	Working relationship was established prior to study commencement
7. Participant knowledge of the interviewer	Participants know about the researcher for doing the research
8. Interviewer characteristics	Described at page 7 in the manuscript (line 118-121)
Domain 2: study design	
Theoretical framework	
9. Methodological orientation and Theory	Methodological orientation underpinning the study was content analysis and was guided by a conceptual model by Myers (2009) (page 6, line 96-103)
Participant selection	
10. Sampling	Purposive sampling described at page 6, line 96-103
11. Method of approach	Participants approached by face-to-face
12. Sample size	31 participants in this study (page 8, line 161)
13. Non-participation	19 participants refused, reasons described at page 8 (line 162) to page 9 (line 163)
Setting	
14. Setting of data collection	Hospital's meeting room (page 7, line 124)
15. Presence of non-participants	Nobody else present besides the participants and researchers (page 7, line 124)
16. Description of sample	Table 1.
Data collection	
17. Interview guide	Consisting of 7 open-ended questions and was pilot tested in one participant (page 7, line 127-136)
18. Repeat interviews	None
19. Audio/visual recording	N/A. as this study collected data by written narratives
20. Field notes	Yes, at page 7, line 124

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21. Duration	30-45 minutes (page 7, line 136)
22. Data saturation	Yes, described at page 7, line 137-139
23. Transcripts returned	Thirty-one copies of transcripts returned (page 8, line 161)
Domain 3: analysis and findings	
Data analysis	
24. Number of data coders	Two research members coded the data (page 8, line 152)
25. Description of the coding tree	None
26. Derivation of themes	Themes were derived from the data (Table2)
27. Software	Nvivo 11 was used to manage the data (page 8, line 144-146)
28. Participant checking	Three participants checked the final transcript of this study (page 8, line 155-157)
Reporting	
29. Quotations presented	Table 2
30. Data and findings consistent	There was consistency between the data presented and the findings
31. Clarity of major themes	Major themes clearly presented in the findings (Table 2)
32. Clarity of minor themes	Any diverse case was resolved during the stage of data analysis

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