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Indwelling experience and coping strategies of upper arm infusion ports in patients with cancer: a qualitative study

Yawen Wang ,[1,2] Xiyi Wang,[3] Xiaoxia Qiu[1,2]

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[1]School of Nursing, Xuzhou Medical University, Xuzhou, Jiangsu, China
[2]Department of Oncology, Shanghai Jiao Tong University School of Medicine Affiliated Renji Hospital, Shanghai, China
[3]School of Nursing, Shanghai Jiao Tong University, Shanghai, China

Correspondence to
Xiaoxia Qiu;
qiuxiaoxia1003@163.com

ABSTRACT

Objectives The upper arm infusion ports have been proven to be advanced and safe, but the experience from the perspective of patients is lacking. This study explored the indwelling experience and coping strategies of upper arm infusion ports in patients with cancer.

Design Qualitative exploratory study.

Setting This study was conducted between May 2021 and August 2021 at a level III-A general hospital in Shanghai, China.

Participants The participants, who are patients with cancer implanted with the upper arm infusion ports, included 10 women and 6 men, and the average age was 54.4±8.3 years old.

Methods Data were selected from semistructured in-depth interviews and analysed by thematic analysis.

Results There were 10 descriptive topics and 4 analytical topics in 2 parts. The indwelling experience includes positive experience (treatment benefit, life convenience) and negative experience (physical discomfort, social anxiety, psychological distress). Coping strategies include emotional-focused strategies (self-acceptance, avoidance and self-protection) and problem-focused strategies (information seeking, functional exercise and remove as soon as possible).

Conclusion The infusion port in the upper arm is beneficial to the safety and quality of life of patients with cancer. At the same time, there are challenges in physical, psychological and social adaptation. Patients respond with some measures, but obstacles may arise during implementation.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The qualitative study used to explore the experiences and coping strategies of upper arm infusion ports in patients with cancer shows us special points.
⇒ The semistructured interviews provided participants with time and direction to elaborate on their experiences and strategies about upper arm infusion ports.
⇒ Although our hospital is a large comprehensive medical centre and our patients come from all over China, this is still a single-centre study, and there are some results that should be interpreted with caution when in different cultural backgrounds.

INTRODUCTION

Totally implantable vascular access devices (TIVADs) are the completely implanted infusion devices, consisting with a port and a long catheter.[1] TIVADs are safe for continued infusion chemotherapy because they could reduce the risk of drug extravasation and prevent the stimulation of drugs on blood vessels, which improve the quality of life of patients with cancer during long-term intravenous treatment.[2]

TIVADs included the chest wall ports, the upper arm ports and others according to different implantation sites. In 2016, the infusion port implanted in the upper arm was first recommended by the Infusion Society as an alternative intravenous access for chemotherapy in patients with cancer.[3] Compared with chest wall ports, the upper arm port can reduce the risk of haemothorax, pneumothorax and pinch-off syndrome, and can provide comfort and privacy benefits for patients.[4 5] A large retrospective cohort clinical study in Italy[6] also demonstrated that the upper arm port using the peripherally inserted central catheter (PICC) insertion method can be considered as safe and reliable as other TIVADs, even with a lower risk of catheter-related thrombosis.

However, aside from these medical problems, patients may need to face psychological and social problems, which will affect their quality of life. Generally speaking, understanding the patients' perspective on healthcare is a fundamental requirement of contemporary health service delivery and essential condition to patient-centred care.[7 8] In recent years, to a lesser extent, the impacts of TIVADs on the quality of life, satisfaction and tolerability have been assessed through some quantitative surveys.[9–11] What is more, previous research showed that kinesiophobia, the fear of limb movement after TIVAD implantation, was common in patients with cancer, and it was closely related to the subjective experience of daily activities.[12]

But the specific experience of patients with the upper arm port and possible reasons behind related behaviour are less well understood. We should pay attention to the psychological experience, emotional changes and coping styles of patients with cancer during indwelling time of the upper arm port in order to carry out appropriate interventions.

This study aimed to illuminate the experience and coping strategies of patients with the upper arm infusion port by the qualitative research. In order to gain more complete information, the patients included were all prepared to remove their ports. We hope that the study will provide us with guidance to further formulate targeted interventions that can help our patients improve their self-management and quality of life during catheter indwelling time.

METHODS

This was a qualitative study using semistructured interviews. The Standards for Reporting Qualitative Research[13] was used to ensure quality reporting of this qualitative study.

Participant selection and setting

From May to August 2021, 16 patients were interviewed in a level III-A general hospital in Shanghai by purposive sampling method.

Inclusion criteria: (1) ≥18 years old; (2) diagnosed with cancer and undergoing long-term chemotherapy; (3) were implanted the upper arm infusion port; (4) signed informed consent voluntarily; (5) prepared to take the port out as planned. The exclusion criteria were patients having communication difficulties, severe psychiatric disorders or cognitive problems. The sample size was determined based on data saturation, which meant data collection was continued until there were no new discoveries.[14 15] Three additional interviews were completed to ensure no new information could be touched, after the first saturation—13th interview.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Interview outline

According to the research purpose, the outline interview was developed by the research team based on a review of the literature and discussion. Two patients were selected for the pre-interview. Based on the pre-interview, the question 'Do you think the different indwelling positions (chest wall/arm) of the infusion port have any influence on you?' was added to the outline (table 1).

Table 1 Semistructured question guide

Research categories	Questions
Indwelling experience	(1) Do you think the different indwelling positions (chest wall/upper arm) of the infusion port have any influence on you?; (2) What is the impact of the upper arm port on your social activities, work or daily life?; (3) How do you view these impacts?
Coping strategies	(4) What measures have you taken to deal with these impacts?; (5) Why do you want to take out the port?

Data collection

The interviews were conducted in a separate, undisturbed room in the hospital, where patients could not be interrupted or overheard by attending physicians, nursing staff or other patients to ensure that patient privacy was maintained. All interviews lasted approximately 10~45 min and were conducted by the same researcher. The whole interview was audio recorded, and notes were taken as a backup, including key parts such as facial expressions and body language. The interviews were transcribed at the end of each day, and patients were required to confirm and sign to make our text consistent with their ideas. Information on the gender, age and diagnosis of cases was extracted from clinical charts.

Data analysis

Subject analysis[16 17] was used to analyse the interview content. Combined with the research purposes—'indwelling experience' and 'coping strategies'—the two researchers first read each interview text and independently coded it. Then, a team meeting was held with the participation of the third researcher and the first two researchers. We contrasted differences and similarities of different coding, and extracted meaningful and similar ideas to build descriptive themes. The themes were updated after each interview using the same method. Finally, the researchers summarised the existing and newly generated descriptive topics, identified the connections between them, refined, defined and formed the analytical themes.

Quality control

The researchers were trained in qualitative research methods and skills before conducting the interview. The different backgrounds and perspectives of the researchers gave breadth to the analysis.[18] All data were collected and analysed individually and collectively by all researchers, and the consensus on the analysis result was reached after full discussions.[19] The interview data were confirmed by the interviewees.

RESULTS

General information

Ten women and six men, with an average age of 54.4±8.3 years, participated. The indwelling time of infusion port

Table 2 Characteristics of the participants

Demographic characteristics	N (%)	Mean±SD
Age (years)		54.4±8.3
Sex		
Man	6 (37.5)	
Woman	10 (62.5)	
Level of education		
Less than high school	2 (12.5)	
High school	5 (31.3)	
University degree and above	9 (56.3)	
Religion		
None	14 (87.5)	
Christianity	1 (6.3)	
Buddhism	1 (6.3)	
Diagnosis		
Gastric cancer	4 (25.0)	
Breast cancer	3 (18.8)	
Lung cancer	3 (18.8)	
Ovarian cancer	2 (12.5)	
Colon cancer	2 (12.5)	
Bladder cancer	1 (6.3)	
Endometrial cancer	1 (6.3)	
Catheter-related complications		
None	14 (87.5)	
Thrombosis	1 (6.3)	
Shoulder dysfunction	1 (6.3)	
Indwelling time (days)		282.1±242.7

ranged from 115 days to 1072 days. Table 2 shows the demographic and clinical features of the sample.

Two main themes were identified based on the findings—(1) 'indwelling experience' was formed by two subthemes: 'positive experience' and 'negative experience'; (2) 'coping strategies' also contained two analytical topics: 'emotional-focused coping' and 'problem-focused coping' (see table 3 for details).

Indwelling experience

Positive experience

Treatment benefit

Interviewees recognised the role of transfusion port in protecting blood vessels: 'The port can protect blood vessels' (S15), especially for patients with poor vascular conditions: 'I have to implant this catheter, I think it is necessary for me, my veins are very thin' (S5).

Life convenience

Respondents believed that compared with PICC and chest wall port, the upper arm port is not only convenient for daily life without frequent maintenance, but also conducive to the protection of privacy: 'I feel good. Their PICCs have to be maintained every 7 days. Especially in winter, it's not convenient to get dressed' (S7). 'I chose it to be implanted in my arm so that others cannot find it. I kept my illness from my parents' (S1). 'I said to many other patients that it must be best to implant the upper arm port. It is also convenient to take a shower and maintain' (S13). 'Short clothes will be dressed in summer. I think that kind (chest wall port) will not look good on the chest' (S12).

Negative experience

Physical discomfort

Limb dysfunction developed after the implantation of the upper arm port. Some patients reported decreased comfort, including pain and numbness that may not last for a long time but may recur: 'Sometimes I feel a little pain, especially on cloudy days. I feel like something was pulling me' (S2). A part of respondents think the upper arm port limited normal activity or sports: 'I don't dare to use my arm normally. I think I need to take it out so that I can exercise normally' (S12). 'I think I can't swim because of this. That makes me very sad' (S10). 'My understanding is I can't lift heavy objects, nor can I be hit by others' (S11). For patients with breast cancer, the upper arm port means bilateral constraint: 'One hand (breast cancer side) already cannot do anything, and now the other hand cannot be used because of this (arm port). That's too bad' (S8).

Social anxiety

Patients feel uneasy about the role function changes due to the upper arm port implantation: 'Without this (arm port), I can move easily. I won't let them surround me all the time. After all, everyone will be tired' (S1). Patients worried about privacy exposure caused by the upper arm port and increased social distancing to keep safe: 'When wearing short sleeves, someone asked me what this is' (S11). 'I'm still nervous if someone touches me, well, I choose to keep some distance' (S16).

Psychological distress

The upper arm port puts psychological pressure on patients. It reminds patients of the fact that they are sick: '… Someone said to me that you don't take it out, it can be in your body for life. I said I did not want to have this disease all my life. I want to return it' (S5). Patients may be accompanied by safety anxiety, which refers to worries and fears caused by unknown events and results, such as the pain caused by the implantation and the complications caused by the upper arm port: 'Although the operation is small, it still endured two operations, after all' (S12). 'Because I am still in the recovery period, I will be careful. What if the port splits? I'm done. I suffered so much' (S10). 'At that time, the information from doctors and nurses was too much. I was thoroughly confused!' (S8). In addition, patients have fear of movement due to safety anxiety: 'I dare not move for fear of problems' (S3). Cultural background also brings pressure on patients: 'The old people should have their dentures fixed when

Table 3 Themes, subthemes and meaning units identified during analysis

Categories	Themes	Subthemes	Meaning units
Indwelling experience	Positive experience	Treatment benefit	Protect the blood vessels
		Life convenience	Avoid frequent maintenance
			Protection of privacy
	Negative experience	Physical discomfort	Pain
			Limb movement limitation
			Complications
		Social anxiety	Increased social distance
			Body image disorder
			Role change
		Psychological distress	Sense of disease indication
			Safety anxiety
			Fear for arm movement
			Culture background
Coping strategies	Emotional-focused coping	Self-acceptance	Self-attribution
			Compare with PICC/chest port
			Spiritual relief
			Divert attention
		Avoidance and self-protection	Reduced arm movement
			Avoid touching or talking about the port
	Problem-focused coping	Help with information	Seek information support
		Functional training	Try to do some training
		Remove as soon as possible	Remove as soon as possible

PICC, peripherally inserted central catheter.

they leave, otherwise they will have no teeth after reincarnation. I think that it is not good to keep my port inside when I leave' (S5).

Coping strategies

Emotion-focused coping

Self-acceptance

With more convenience obtained in the process of use, the interviewees actively adjusted their cognition of the upper arm port and were willing to recommend it to other patients: 'I think it is quite convenient. The PICCs have to be maintained every week. It was winter then, and it was not convenient to wear clothes.' Religious belief also plays a positive role: 'This is not superstition. It can help you become more calm and more open-minded' (S13). Some interviewees will choose self-attribution: 'I think everyone's body constitution may be different from others. I am very sensitive all the time. I dare not touch it' (S8). Some respondents participated in daily activities actively after implantation to divert attention: 'I travelled with my family. I have to carry a suitcase. I would have a rest if I got tired' (S10). 'I made myself busy so that I could pay less attention to my port' (S11). A young male respondent said he still insisted on exercises for better rehabilitation: 'I still played basketball, exercised, every day, did push-ups, just hoping to get better.'

Avoidance and self-protection

Due to various reasons, such as the fear of complications, patients hold a conservative attitude towards unknown things and take avoidance measures for self-protection: 'I tried to hold things in my left hand' (S11), deliberately concealing the fact of the infusion port to protect the privacy of the disease: 'I said a button was eaten accidentally when I was a child, and it slipped to here (fingering her port)' (S5).

Problem-focused coping

Help with information

Seeking information is a common coping strategy. Interviewees took the initiative to get the information related to the upper arm port, including asking for help from medical staff: 'At the beginning, I felt uncomfortable, so I also called the head nurse' (S3), and expressed satisfaction with the good medical support system: 'Everything is well. I have the phone number, so I can directly ask questions' (S14). One respondent chose to search for information online: 'I will go to Baidu and Tik Tok to read relevant science popularization' (S2). Some consult a fellow patient or a friend who has similar experience: 'All patients say that (PICC) is easy to be infected so they choose the upper arm port' (S3). But some respondents were unable to obtain consistent answers from medical

staff when they had questions. 'In one place, I was allowed to do many things. But in the other place, the doctor and nurses told me I must be careful. I heard two versions' (S11).

Functional training

The respondents actively tried arm movements and self-management during the indwelling period: 'I do square dancing every day to wave my arm in order to prevent thrombosis' (S8). 'After I found this problem (shoulder mobility disorder), I tried to train my arm, and then it seemed that I could raise my hand a little bit. I raise my hands a few more times a day when I find that I can raise them after more exercises' (S1).

Remove as soon as possible

Most interviewees choose to take out the upper arm port as soon as possible after the treatment, so as to declare the phased victory of the disease, end the bad psychological experience and free the arm to return to life: 'I have always wanted to take it out after chemotherapy because I always feel something in my body. And I couldn't measure blood pressure on this arm (with port). It's always better to take it out' (S7).

DISCUSSION

Indwelling experience

Benefits and recognition

Our study is indicating that the primary concern is put on helping infusion treatment, consistent with the research results of Ryan *et al*.[20] A study[21] showed that 92% of respondents reported that venous access devices improved their quality of life. However, Goossens *et al*[22] found that only 8% of patients reported an improvement. This may be because patients did not understand the meaning of the term 'quality of life' in the open-ended questionnaire they filled out, or the researchers did not give them a clear reference point. A randomised trial by Biffi *et al*[23] compared three different approaches and found that central vein placement appeared to have no effect on quality of life and psychological distress in patients with cancer. A study of patients with breast cancer showed that a more subtle, aesthetically pleasing scar, such as in the triangular thoracic groove, was associated with higher cosmetic satisfaction.[24] We also found most patients believe that the upper arm port is more convenient to use and conducive to privacy protection compared with other infusion tools, such as PICC and chest ports, which is worth promoting. This implies that the port implantation site, not the vein placement, has an impact on the quality of life of patients with cancer, which was supported by the study of Burbridge and Goyal[4] who also found that the upper arm port had higher patient satisfaction in this respect compared with chest ports.

Change and confusion

Scholars have found that long-term use of catheters will cause a series of problems, including changes in body perception and the sense of shame,[25] which has been confirmed in this study. In addition, we found that patients have fear of arm movement, body anxiety and maladjustment to family and social role changes. At the same time, cancer diseases bring huge pressure to patients[26]; the inherent correlation between the upper arm port and cancer diseases increased this psychological pressure. From our study, the upper arm port reminds patients the cancer, and they are concerned that complications may affect their health or interrupt treatment. Psychological problems and potential mental disorders not only reduce the quality of life, but also have a negative impact on treatment compliance and prognosis.[27] Further attention should be paid to this problem in clinical practice.

Coping strategies

Various ways of self-acceptance

Self-acceptance refers to positive self-awareness, which means that individuals can flexibly view self-related events in life, and are willing to understand and unconditionally accept all their characteristics, and understand their objectivity and positive values correctly,[28 29] which are beneficial to patients to balance their survival needs and the impact of the upper arm port on life. People often adopt a combination of strategies to cope with the problems.[30] To adjust themselves, respondents take methods including self-ascribing, contrast experience of the upper arm port with PICC and chest wall port, spiritual counselling, diversion and others, which help them recognise the role and advantages of the upper arm port, complete self-acceptance and achieve harmonious coexistence with the port.

Avoidance responses need to be viewed objectively

Avoidance is an emotion-oriented coping strategy,[26] and is often regarded as negative coping that is not conducive to adaptation.[31] Nonetheless, our interview found that its impacts on patients need to be viewed objectively.

On the one hand, patients with cancer are more sensitive to the evaluation from others related to the disease, and the stigma makes them more resistant to the events that expose the privacy of the disease, so they may take measures to conceal the indication of the disease shown by arm ports.[32] Meanwhile, as coping methods are rooted in social environment such as culture and class,[33] the fear of cancer and funeral culture in traditional Chinese society may also promote patients' avoidance. However, this avoidance does not necessarily bring negative effects, which may be related to the sense of security and self-esteem that can be provided to patients in a short time.

On the other hand, we found that some patients had limited arm activities in order to preserve the catheter or simply because there was a foreign body inside the arm. Some patients were even afraid to raise their hands above their heads. Moderate physical exercise is beneficial to patients with cancer,[34] and helps reduce the incidence of upper arm thrombosis caused by infusion port.[35] This reminds us that we need to consider patients' feelings

and actual physical state, and realise that cancer diseases and drug treatment themselves will have limitations on patients' activities.[36] We should avoid excessive restrictions on patients during education, so as to reduce patients' anxiety and fear of the upper arm indwelling port.

Obstacles in obtaining professional information

Patients actively try self-management to adapt, but some approaches, especially seeking information from professionals, are obstructed. Consistent with other studies,[16 37] interviews showed that patients lacked information related to the upper arm port, and different patients had different information needs at different stages. Respondents received information support from medical staff, network and peers, but the information may be heterogeneous or even misleading, which is not conducive to doctor–patient trust building and patient decision-making. Cooke *et al*[38] also found that patients noticed these inconsistencies, and what is more, patients paid more attention to maintenance. At the same time, this study found that the knowledge from peer supporters was not recognised by all patients, especially those who were highly educated. More information provided by peer supporters is from their own perspective so objectivity and correctness cannot be ensured, which may have a negative impact on patients' decision-making. Parás-Bravo *et al*[25] believe that clear and accurate personalised information provided by professional teams may be more beneficial to patients in some cases.

LIMITATIONS

There are some limitations to this study. First, although our hospital is a large comprehensive medical centre and our patients come from all over China, this is still a single-centre study. Another limitation is that we considered only the perspectives of adult patients and not those of paediatric patients.

CONCLUSION

The upper arm infusion port provides safe and convenient treatment for patients with cancer, as well as brings negative experiences related to physiological and life changes. Patients seek balance between survival and living through emotion-focused coping and problem-focused coping, but there are some obstacles in the implementation of coping measures such as help with information. It is time to pay more attention to patient experience in subsequent clinical trials and researches.

We need to listen to patients' responses and learn from their experiences, improve communication and health education, and, if possible, build patient follow-ups. In another way, we could strengthen professional exchanges and promote the introduction and practice of standards and consensus, so as to help improve the quality of life of patients with indwelling upper arm infusion ports.

Contributors All authors contributed to study design and analysis. All interviews were conducted by YW. XW and YW read each interview text and independently coded it. XQ participated in the follow-up discussion. YW drafted the first manuscript. All authors read and approved the final manuscript. XQ is responsible for the overall content as guarantor.

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Patient consent for publication Not required.

Ethics approval This study involves human participants and was approved by the Shanghai Jiaotong University School of Medicine, Renji Hospital Ethics Committee (reference number: RenjiEthics2017148). In accordance with the Declaration of Helsinki, the interviewees understood the purpose and method of this interview and voluntarily signed informed consent. Participants could opt out at any stage of the study.

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ORCID iD

Yawen Wang http://orcid.org/0000-0002-4435-8480

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