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A Study of Staged Differences in the Needs of Lymphoma Patients throughout the Service under the Care Perspective

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Abstract: Based on the perspective of caring, this study constructs a whole-cycle management programme for lymphoma patients, and systematically explores the pathway of patients' health management from diagnosis to recovery by integrating literature analysis, clinical practice research, and multidisciplinary experts' consensus. Focusing on the differentiated needs of patients, the study proposes a dual-track management framework of 'precise diagnosis and treatment standard' and 'humanistic care practice', and innovatively designs a multidisciplinary collaborative mechanism, an information-based follow-up platform, and a social support network. Through the role of 'care consultant', the programme connects the medical team with the individual needs of patients, strengthens treatment compliance and improves the quality of life, and provides a theoretical basis and practical reference for the optimization of the whole management mode of lymphoma patients.

Keywords: Lymphoma patients; Holistic management; Patient needs

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1. Introduction

Lymphoma is one of the common malignant tumours in China, with the incidence rate increasing year by year and showing a trend of youthfulness. Although advances in diagnostic and treatment technologies have significantly improved the survival rate of patients, the long treatment cycle and complex treatment methods still bring continuous pressure on patients physically and mentally [1]. Existing management models focus on the treatment of the disease itself, but it lacks dynamic attention to the needs of patients throughout the entire course of their illness, resulting in some of their needs not being responded to in a timely manner, which affects the overall effectiveness of treatment and quality of life [2]. Therefore, this study systematically analyses the differences in the core needs of lymphoma patients during the diagnosis, treatment, and rehabilitation stages from a caring perspective, to provide theoretical support for the construction of a more humanistic and caring whole-course management model.

2. Theoretical framework and research design

2.1. Theoretical foundation

From the individual-environment interaction perspective, the health ecology model highlights that patients' needs are shaped by both internal factors (physical and psychological) and external factors (family, healthcare system, and policy environment) [3]. It offers a dynamic framework to assess how lymphoma patients' needs align with available resources across different disease stages.

Meanwhile, patient empowerment theory emphasizes patients' active role in care through information, skills, and emotional support, enhancing their control, adherence, and quality of life [4]. This study applies the theory to explore patient demands for information, psychological care, and social support, supporting a doctor-patient co-managed model of care.

2.2. Research subjects and data sources

This study takes lymphoma patients admitted to a tertiary hospital in Hubei Province as the main research subjects. Inclusion criteria include: (1) Patients with lymphoma diagnosed by pathology; (2) Age 18–70 years old; (3) Conscious and with basic communication ability [5]. The exclusion criteria included: (1) Patients with severe organ dysfunction or mental illness; (2) Patients whose survival period was expected to be less than 6 months [6]. Finally, a total of 276 valid cases were included, and the patients were predominantly over 45 years of age (67.15%), with the time of diagnosis concentrated within 1 year (78.47%), and non-Hodgkin lymphoma accounted for 66.42% of the cases. Meanwhile, semi-structured interviews were conducted with 24 haematology staff (8 doctors and 16 nurses) with 2–35 years of working experience, covering junior, middle, and senior titles.

A mixed-method study was conducted from Jan 2023 to Feb 2024, using both paper and online questionnaires with a valid return rate of 98.56%. The survey covered patient demographics, perceptions of the management process, and needs assessment. Semi-structured interviews (15–30 minutes each) were conducted with 24 hematology staff (8 doctors [D1–D8], 16 nurses [N1–N16]) with 2–35 years of experience, focusing on practical experiences and suggestions for improving TMS implementation. Interviews were recorded, transcribed, and analyzed using NVivo12. Ethics approval was obtained, and informed consent was signed by all participants. The study included 276 lymphoma patients admitted to a tertiary hospital in Hubei Province. Inclusion criteria: pathologically diagnosed lymphoma, aged 18–70, conscious, and communicative. Exclusion criteria included: severe organ dysfunction, mental illness, or expected survival < 6 months. Most patients were over 45 years old (67.15%), diagnosed within 1 year (78.47%), and had non-Hodgkin's lymphoma (66.42%).

Data were collected from a mixed-method study (Jan 2023–Feb 2024), using paper-based and online questionnaires on patient demographics, management perceptions, and needs, achieving a valid return rate of 98.56%. Semi-structured interviews (15–30 minutes each) explored healthcare professionals' experiences and suggestions for TMS improvement, transcribed and analyzed via NVivo12. The study received ethics committee approval, and all participants provided informed consent to ensure compliance and privacy protection.

2.3. Criteria for the division of phases

2.3.1. Diagnostic period (0–1 month)

The time boundary is taken as the time from the first appearance of symptoms in patients to the pathological confirmation of the diagnosis and the formulation of the preliminary treatment plan [7]. This stage covers imaging examination, pathological biopsy, typing diagnosis, and the formulation of treatment plans, and it is the period when the patient's psychological impact is the most significant and the need for information is the most urgent [8]. The delineation is based on the clinical diagnosis and treatment pathway; 78.47% of patients are diagnosed within 1 year, and the staging assessment and treatment plan decision-making need to be completed within 1 month after the initial diagnosis.

2.3.2. Treatment period (1–6 months)

The treatment period is centered on receiving standardized chemotherapy, radiotherapy, or targeted therapy, covering 2–8 standard treatment cycles [9]. In this stage, patients face multiple challenges such as drug side effects, treatment compliance, and family economic pressure, and need to dynamically monitor physiological indicators and psychological status [10]. The division refers to the recommended treatment cycles in CSCO Lymphoma Guidelines 2024, and combines with clinical data showing that 51% of patients need to go through multiple hospitals to confirm the diagnosis, suggesting the importance of treatment consistency.

2.3.3. Rehabilitation phase (more than 6 months)

The starting point is to enter the follow-up monitoring after completing the standardized treatment, focusing on the prevention of recurrence, management of long-term complications, and promotion of social function recovery [11]. The quality of patient survival in this stage is closely related to long-term follow-up services, and 22.26% of patients have the need for a rehabilitation period of more than 3 years. The classification is based on the International Consensus on the Management of Survivors of Lymphoma, which emphasizes the need for continued attention to relapse risk and health behavior interventions for 5 years after the end of treatment [12].

3. Analysis of differences in demand by stage

3.1. Core demand in diagnostic period

In the diagnostic period, the service demand of lymphoma patients mainly focuses on the outpatient consultation session itself, with a lower reliance on the appointment and waiting process [13]. According to the data in **Table 1**, in the outpatient consultation session, 22.63% of the patients considered it very necessary, and 21.53% considered it relatively necessary, indicating that patients generally attach importance to the quality and efficiency of the services in the actual consultation process. For outpatient appointments and pre-admission appointments, although around 22% of patients said they needed it very much, more than 43% of patients chose 'not very much', indicating that the overall demand for appointment-based services was not prominent. Similar trends were observed for arrival and waiting procedures, with only 20.80 per cent of patients indicating 'very much' and 44.89 per cent 'not much'. These data suggest that patients are most concerned with obtaining effective, timely, and clear medical information and professional judgement during the diagnostic phase of the consultation process, rather than the process itself.

Table 1. Outpatient visits and examinations

	Very little	Not much	Fair	More	Very much
Outpatient Appointments	4.01%	43.43%	10.95%	19.34%	22.26%
Outpatient Visits	2.55%	45.99%	7.30%	21.53%	22.63%
Pre-admission Outpatient Appointments	2.92%	44.16%	6.93%	22.99%	22.99%
Arrival at Hospital, etc.	2.19%	44.89%	8.39%	23.72%	20.80%

The interviews further corroborated this focus on need. Healthcare professionals generally agreed that effective communication at the initial diagnosis stage plays a key role in patient understanding and treatment adherence, with D1 noting that ‘it is important to guide the patient himself to have a general understanding of his disease and an expectation of the prognosis’ and D6 emphasizing that “at the beginning of his diagnosis, if we can comprehensively and better inform him about the disease and popularize it with him”. This suggests that what patients urgently need during the diagnostic period is the transparent communication of information about the disease and support at the psychological level to help them build initial awareness and trust in the midst of the unknown and anxiety. In contrast, process services, such as appointment booking and waiting, are of lower priority during the diagnostic period, and more service improvement should be focused on improving the quality of interaction and the ability of scientific communication during face-to-face consultation.

3.2. Core demand in the treatment period

In the treatment period, patients’ demand for various services in the inpatient treatment process shows a high degree of concentration, especially in the key nodes such as admission confirmation and ward entry [14]. The data in **Table 2** shows that 26.28% of the patients think that they ‘need it very much’ in the service node of ‘notification and confirmation of hospital admission’, and as high as 26.64% of the patients think that they ‘need it very much’ in the service node of ‘arrival at the inpatient ward’. In the ‘arrival at the inpatient ward’ section, as many as 26.64% of patients chose ‘very necessary’, suggesting that patients are extremely concerned about communication and process confirmation in the early stages of hospitalization. Meanwhile, although 21.90% and 20.80% of the patients in the data considered ‘very necessary’ for the examination procedure and hospital waiting procedure respectively, more than 43% of the patients indicated that these procedures were ‘(not very necessary)’, indicating that the patients’ needs for functional processes are relatively balanced. This shows that patients’ needs for functional processes are relatively balanced, while the real focus is on the quality of service and smoothness of processes actually experienced during hospitalization. In addition, the data on information and communication needs show that about 24.82% of patients very much hope that healthcare professionals can explain treatment plans and side effect management in easy-to-understand language, reflecting the actual needs of patients for professional explanations and timely responses during the treatment period.

The interviews further reflected the important impact of treatment services on patients’ overall adherence to treatment and psychological support. By ‘providing patients with a clear description of the disease and treatment expectations at the initial consultation stage’, healthcare professionals help patients to develop correct perceptions and lay a foundation of trust for the successful implementation of the treatment period. In addition, the interviews also emphasized the care for patients’ financial burden and treatment outcome, indicating that during the treatment period, healthcare professionals not only focused on the quality of treatment, but also on providing personalized financial and psychological support to patients.

In **Table 3**, there is also a relatively high concentration of demand for ‘consistent standards of care’ and ‘continuous nursing guidance’ (26.28% and 24.45% of patients said ‘very much needed’, respectively), indicating that nursing care is not only focused on the quality of treatment, but also on providing personalized financial and psychological support to patients during the treatment period. “This shows that the quality and coordination of care services is an important part of improving patient satisfaction and treatment adherence. By optimizing communication and coordinating treatment and care services at all stages, healthcare professionals seek to build an integrated service system that focuses on medical technology and meets the emotional and economic needs of patients, thus truly reflecting the concept of holistic management from a caring perspective.

Table 2. Hospitalization treatment

	Very little	Not much	Fair	More	Very much
Waiting for inpatient admission	2.92%	43.80%	6.57%	25.91%	20.80%
Inpatient admission notification and confirmation call	2.55%	44.53%	5.47%	21.17%	26.28%
Blood test procedures	2.55%	43.07%	6.93%	25.55%	21.90%
Arriving at hospital and waiting for admission	3.65%	43.07%	6.57%	20.80%	25.91%
Admission to ward	4.01%	44.16%	5.47%	23.72%	22.63%
Arrival at inpatient ward	4.01%	43.07%	6.57%	19.71%	26.64%

Table 3. Treatment and nursing needs

	Very little	Not much	Fair	More	Very much
I expect a consistent standard of care at different stages of treatment	4.01%	38.69%	8.76%	22.26%	26.28%
I need healthcare professionals to provide ongoing nursing guidance during treatment	1.82%	36.86%	12.41%	24.45%	24.45%
I expect healthcare professionals to coordinate services at different stages of treatment	2.55%	35.40%	13.50%	26.28%	22.26%
I need healthcare professionals to provide rehabilitation guidance after treatment	1.82%	37.96%	9.49%	28.83%	21.90%
I expect healthcare professionals to provide advice on pain management	2.55%	35.77%	12.77%	27.01%	21.90%

3.3. Core needs in the rehabilitation phase

In the rehabilitation phase, the service focus of lymphoma patients gradually shifted from inpatient treatment to post-discharge continuity support and inter-agency co-management, showing a shift in the focus of needs [15]. The data in **Table 4** shows that in terms of discharge processing, only 28.10% of patients indicated that they needed the service ‘very much’, while as many as 43.07% of patients indicated that they needed it ‘not too much’. Similarly, at the point of ‘leaving the hospital’, 24.10% of patients indicated that they needed the service ‘very much’, while 43.07% of patients indicated that they needed it ‘not too much’. Similarly, 24.45% of patients indicated that they needed the service ‘very much’ at the point of ‘leaving the hospital’, while 44.89% indicated that they needed it ‘not too much’, reflecting the overall low demand of patients for discharge procedures. This phenomenon shows that the majority of patients have a basic understanding of and are able to adapt to the discharge process, but their real concern is the continuous medical support and health management after discharge.

Table 4. Discharge

	Very little	Not much	Fair	More	Very much
Discharge	3.65%	43.07%	6.20%	18.98%	28.10%
Leaving the hospital	2.92%	44.89%	6.57%	21.17%	24.45%

Most patients showed a strong demand for continuity and coordination in medical services (**Table 5**). Specifically, 28.83% indicated they "somewhat needed" and 21.17% "very much needed" continuous care, reflecting concerns about consistency across treatment stages. For coordination between different healthcare institutions, 25.18% expressed a strong need and 23.36% a moderate need, highlighting expectations for smooth inter-agency collaboration. Additionally, 25.91% of patients "very much needed" follow-up plans and guidance, while 27.37% emphasized the importance of timely updates to treatment records, showing that follow-up and information sharing remain key concerns during the rehabilitation phase.

Table 5. Service coordination and continuity requirements

	Not at all needed	Not much needed	Neutral	Somewhat needed	Very much needed
I need medical staff to ensure continuity of care	2.19%	35.40%	12.41%	28.83%	21.17%
I hope medical staff can coordinate services across different institutions	2.55%	36.50%	12.41%	23.36%	25.18%
I need medical staff to provide follow-up plans and guidance	2.19%	36.13%	12.77%	22.99%	25.91%
I hope medical staff can update my treatment records in a timely manner	1.46%	31.02%	16.79%	23.36%	27.37%

Interviews with healthcare professionals similarly highlighted practical dilemmas and professional reflections on services during the rehabilitation period. D4 mentioned that 'many patients may be lost behind just after the end of treatment', pointing out the risk of patients being easily disengaged from the management of the healthcare system after discharge. D3, on the other hand, bluntly stated that "follow-up is the most difficult, firstly, there has to be a person and then that person must also have a spirit of sacrifice", revealing the reality of the challenge of manpower investment in follow-up.

Nonetheless, healthcare professionals demonstrated a positive attitude towards continuous improvement of services during the recovery period, with some departments extending their health management services by setting up public numbers and conducting regular lectures. Especially in terms of updating and sharing treatment information as shown in **Table 6**, 27.37% of the patients said that they 'very much need' healthcare professionals to update their treatment records promptly, highlighting the high demand for transparent and continuous information services. Regarding follow-up planning and guidance, 25.91% were 'very necessary' and 22.99% were 'quite necessary', further confirming that the focus of rehabilitation services has clearly shifted to post-discharge care and extended services for chronic disease management. Therefore, from a caring perspective, the rehabilitation period should not be regarded as the end of medical services, but rather as a service re-linking stage that requires great attention and determines the quality and effectiveness of long-term health management for patients.

Table 6. Service coordination and continuity requirements

	Very little	Not much	Fair	More	Very much
I need healthcare professionals to ensure continuity of treatment services	2.19%	35.40%	12.41%	28.83%	21.17%
I want healthcare professionals to co-ordinate services between different healthcare providers	2.55%	36.50%	12.41%	23.36%	25.18%
I need healthcare professionals to provide follow up plans and guidance	2.19%	36.13%	12.77%	22.99%	25.91%
I want healthcare professionals to keep my treatment records up to date	1.46%	31.02%	16.79%	23.36%	27.37%

4. Management countermeasures under the perspective of care

4.1. Theoretical logic

Guided by the concept of whole-person health ("physical, mental, social, and spiritual"), lymphoma management requires a shift from disease-centered to patient-centered care. Integrating MDT and narrative medicine, the model combines clinical pathways with humanistic care through information sharing, psychological support, and social connection. The caring consultant bridges patients and the medical team, enhancing treatment adherence and quality of life, ultimately promoting a management model that unites medical precision with human warmth.

4.2. Staged intervention strategies:

4.2.1. Diagnostic period: Establishing the mechanism of 'stepped release of information'

Intervention in the diagnostic period is centered on progressive information transfer, and cognitive guidance and emotional comfort are achieved through the collaboration of doctors and nurses. During the first consultation, the nurse in charge uses layman's language to explain the characteristics of lymphoma, and combines graphic manuals and three-dimensional animation demonstrations to eliminate the patients' misunderstanding of "cancer = terminal disease". The attending physician informs the patients of the classification, treatment plan, and prognosis indexes in a graded manner after the diagnosis is confirmed by pathology, and at the same time, provides a standardized Diagnostic and Treatment Navigator's Manual to specify the examination process and time nodes. In response to patients' individual questions, the multidisciplinary team will conduct targeted Q&A within one week after diagnosis, and dynamically adjust communication strategies in combination with the emotional assessment of the counsellor to ensure the simultaneous advancement of information absorption and psychological adaptation.

4.2.2. Treatment period: constructing 'family-healthcare' collaborative symptom management

The treatment period focuses on symptom control and treatment adherence, and dynamic management is achieved through the empowerment of family caregivers and remote monitoring technology. The nursing team provides family members with training in symptom recognition, such as early warning signs of fever, and supplies an electronic "Symptom Log" for real-time documentation of chemotherapy-related reactions, including nausea and myelosuppression. Utilizing a mobile medical platform, a 24-hour direct symptom reporting channel is established, enabling patients or caregivers to report abnormal signs through visual descriptions or standardized assessment scales. Specialist nurses respond within two hours with graded interventions: green for consultation and guidance, yellow for outpatient evaluation, and red for emergency intervention. At the same time, a multidisciplinary support team was formed to discuss complex symptoms (e.g. neurotoxicity, immune-associated pneumonia) weekly by video conference, and personalized nursing video tutorials were simultaneously pushed to the family to form a closed-loop management of “symptom identification - professional intervention - family implementation”, to reduce the risk of unplanned hospital admission.

4.2.3. Rehabilitation: Implementing a ‘community embedded’ social support network

Rehabilitation management focuses on the reconstruction of social functions and long-term health monitoring, and connects medical resources and community services through a hierarchical diagnosis and treatment system. With community health service centers as the hub, a collaborative team of family doctors, specialist nurses and social workers has been set up to establish dynamic health records for patients, and carry out regular home follow-up visits (routine blood tests, assessment of immune function) and home care guidance (PICC maintenance, nutritional programmes). In collaboration with the civil affairs department and by integrating community resources, a “Lymphoma Rehabilitation Station” has been established to offer vocational training and psychological counselling services. Additionally, patients who have been in remission for over five years have been recruited to form a “Peer Support Group,” aimed at easing the anxiety of reintegration into society through shared experiences and mutual support. At the same time, a mobile rehabilitation management module has been developed, integrating data from smart bracelets (such as heart rate and step count) and a review reminder function. The system enables automatic alerts for abnormal indicators and allows one-click activation of a green referral channel to the nearest medical facility. This supports the construction of a three-tier linkage network connecting hospital, community, and family care.

5. Conclusion

Based on the pain points of clinical practice, this study constructed a patient-need-oriented lymphoma management programme, which deeply integrates humanistic care into the whole cycle of disease management. The program innovatively combines multidisciplinary collaboration mechanism and information technology, which not only ensures the standardization of diagnosis and treatment, but also realizes individualized health management through the role of caring consultant, and provides an operable practical path to enhance patients’ adherence to treatment and improve the quality of long term survival, which is of great value in promoting the transformation of China’s oncology patients’ management mode from “disease-centred” to “life-cycle care”.

Disclosure statement

The authors declare no conflict of interest.

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