

Readiness for Hospital Discharge in Primary Caregivers for Children with Acute Lymphoblastic Leukemia

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Abstract

Background Readiness for hospital discharge is essential to the treatment and rehabilitation. But until now, little is known about the existing status and affecting factors of readiness for hospital discharge in primary caregivers for children with acute lymphoblastic leukemia in China.

Methods A cross-sectional study of 253 leukemia patients including their family members from Nov 2016 to Aug 2017 was performed by convenience sampling and questionnaire survey.

Results The total score of readiness of primary caregivers is 157.36. Factors including periods of chemotherapy ($P<0.001$), complications ($P=0.019$), family economic situation ($P=0.023$), understanding of leukemia ($P<0.001$), objective supports ($P=0.004$), subjective supports ($P<0.001$), and availability of support ($P=0.045$) are main influences.

Conclusions

1. The readiness for hospital discharge in primary caregivers for childhood lymphoblastic leukemia patients is in an intermediate level, indicate that more efforts should be done in improving present situation, especially on the social support which got the lowest scores.
2. In induction remission period of chemotherapy with complications with poorer family economic state lacking knowledge about leukemia and with poor social support are possible factors leading to lower score in readiness for hospital discharge scale, which indicate that providing high quality family and primary caregiver assessment and discharge education throughout the hospitalization is the key to improve the readiness in nursing aspect.

Background

The incidence of acute lymphoblastic leukemia (ALL) is highest in children's malignant neoplasms. Approximately 3000 children in the United States are diagnosed with ALL every year[1]. Owing to the improvements in the efficacy of multiagent chemotherapy based on risk stratification, the survival rate of pediatric ALL has increased from less than 10–90% during the past four decades[2]. As children ALL is now a kind of curable disease, with the elevated survival rate, more labor-force and financial supports are needed during the long term chemotherapy process. As data shows in China, the average cost for success chemotherapy for a ALL child could reach 222800.67RMB, in which direct medical cost made a significant rate as high as 51.67%[3]. Besides of fearing of death, anxious and depress occurring from years-long caring and from heavy cost gradually became the major family mental burden nowadays. Data shows that the mean scores of self-rating anxiety scale (SAS) and self-rating depression scale (SDS) of family members who caring leukemia children were higher than those in controls. And these negative mental statuses would have serious impact on ALL children's treatment[4].

Chemotherapy is the primary treatment for patients with tumor. During the course of chemotherapy, patients stay in a defenseless status frequently. And limited medical resources could not keep ALL patients in hospital all the time. A telephone survey after first induction chemotherapy shows that among 418 patients, 251 (60.2%) occurred side effect after leaving hospital, and 12 in which had to go back to hospital for urgent treatment within 72 hours[5]. These situations gave the outpatients care an important role in ALL treatment.

Readiness for hospital discharge (RHDS) is an estimate for patients and their family members of being prepared or not prepared for hospital discharge, for further recovery and for returning to normal social activities. The estimate was based on the synthetic evaluation of patients' and family members' physical, psychological and social health conditions[6–8].

So, for patients with tumor, especially children with ALL, who would have longer chemotherapy duration and more rely on caring from family members, a good transition from hospital to family care is crucial to their survival. Based on this point, the readiness of hospital discharge in primary caregivers for ALL children should be valued, for it is the key to insure this smooth transition. Because of lack of relevant studies, our research is aim to find out the current situation of RHDS in main caregivers for children in different stages of leukemia treatment. And to analyze the possible impact factors. These data would help to modify discharge instructions, seek after more support from society and improve the overall leukemia survival rate in future finally.

Transition conditions including personal, communal and social factors and these factors could have positive or negative impact on the process and outcome of transition. In this study, personal factors including knowledge and preparation being in hospital, belief and attitude and social factors including socio-economic status and social supports are key research aspects.

Methods

This study was carried out according to the Declaration of Helsinki and was approved by the Ethical Committee of West China Second hospital Sichuan University and all methods were carried out in accordance with relevant guidelines and regulations. Informed consent was obtained from a parent and/or legal guardian. Totally 253 ALL patients in hospital aged 0-16 years including their family members from Nov 2016 to Aug 2017 were included. All subjects are clearly diagnosed by bone marrow morphology and immunophenotyping. Those who once requiring giving up treatment or whose data-integrity lower than 80% were removed.

Cross-sectional study was performed by convenience sampling and questionnaire survey. Information were collected under the agreement of the selected patients within 15-30 min at the bedside by using self-developed questionnaire of general and clinical characteristics of patient, self-developed questionnaire of general status of family and primary caregiver ,Chinese Version Weiss questionnaire of readiness of discharge scale[9] and Social support rating scale (SSRA)[10] for main caregivers.

All collected data was recorded by the form of database Epidata. Frequency and constituent ratio were used to describe enumeration data. And for describing quantitative data fitting normal distribution, mean and standard deviation were used.

Analyses were conducted using SPSS version 18.0. T test, variance analysis, minimum significant difference method (LSD method) and Pearson correlation analysis were performed to analysis general and clinical information of patients and their family. Comparisons were performed using chi-squared test or non-parametric test for categorical variables of general and clinical data and multiple linearity regression tests were performed for affecting factors. A P value ≤ 0.05 was considered statistically significant.

Results

Totally 264 questionnaires were sent out and took back afterwards, within which 253 questionnaires were accepted as valid (95.8%).

General and clinical characteristics of ALL patients

Totally 253 ALL children were included with median age of 6 year (aged from 1.08 to 15 yeas), with male to female ratio of 1.26, within which 78 were in induction period (30.8%), 108 were in consolidation periods (42.7%) and 67 were in intensification periods (26.5%). Totally 165 of 253 (65.2%) patients had complications during hospitalization, within which 66 (26.1%) patients were still not fully released from complications while discharge. Among these patients, 152 (60.1%) only had insurance of rural cooperative medical service. At the discharge, 188 (74.3%) were still with vein catheter.

General and clinical characteristics of ALL main caregivers

Totally 253 main caregivers for ALL children were included with median age of 32 year (aged from 23 to 60 yeas), most of who were Hans. More than half caregivers were farmers (127/253, 50.2%). Other information lists in Table 1.

Table 1
Information of main caregivers

Item		Number	Ratio (%)
Gender	male	46	18.2
	female	207	81.8
Kinship	mother	198	78.3
	father	40	15.8
	grandparents	15	5.9
marital status	married	244	96.4
	divorced	9	3.6
Habitation	urban area	79	31.2
	rural area	174	68.8
Family types	nuclear family	180	71.2
	kinship family	73	28.8
Education level	junior middle school or lower	131	51.8
	middle school	72	28.5
	college or higher	50	18.7
Occupation	farmer	127	50.2
	manual worker	10	4
	self-employed	34	13.4
	office worker	46	18.2
	teacher	14	5.5
	others	22	8.7
Financial status	completely satisfied	6	2.4
	almost satisfied	41	16.2
	partial satisfied	66	26.1
	hardly satisfied	94	37.2
	unsatisfied	46	18.2
Knowledge of ALL	completely understand	2	0.8
	almost understand	57	22.5

Item	Number	Ratio (%)
partially understand	105	41.5
do not understand	89	35.2

Results of RHDS

The total mean score of RHDS in main caregivers for ALL children was 157.36. The average score for each item was 7.15. Within all factors of RHDS scale, factor “Coping Ability” got the highest average score, while factor “Expected Support” got the lowest. Detailed score of each factor list in Table 2. In the item 1# “Ready to bring your children home”, 209 of 253 respondents (82.6%) chose “yes”. Among item 2# to item 23#, item 19# “Ability to perform medical treatments” got highest score while item 23# “Help with medical care” got the lowest score. Detailed each item (2# to 23#) sorted by score list in Table 3.

Table 2
Factors of RHDS for ALL main caregivers

Factor	Number of items	Total score (mean, SD)	Average score (mean, SD)
Factor 1: Personal Status	7	50.68,11.31	7.24,1.62
Factor 2: Knowledge	8	58.85,13.90	7.37,1.74
Factor 3: Coping Ability	3	24.99,4.42	8.33,1.47
Factor 4: Expected Support	4	22.84,9.94	5.71,2.36
Total	22	157.36,33.24	7.15,1.51

Table 3
Items of RHDS for ALL main caregivers

Item Number	Average score (mean)	Average score (SD)
19	9.16	1.39
7	8.75	1.8
18	8.5	1.73
10	8.39	1.91
6	8.38	1.92
14	8.26	1.96
3	8	2.02
12	7.78	2.17
11	7.71	2.04
13	7.71	2.19
20	7.49	2.31
5	7.47	2.09
17	7.33	2.18
2	6.87	2.25
9	6.66	2.14
15	6.47	2.65
4	6.05	2.05
21	5.99	3.26
22	5.96	3.19
16	5.87	2.73
8	5.16	2.93
23	3.4	3.1

Results of SSRS

The total mean score of SSRS was 42.17. After calibration which was used to make comparability during factors available, the objective support factors of SSRS got the lowest score. Detailed information lists in

Table 4.

Table 4
Factors of SSRS for ALL main caregivers

Factor	Items	Total Score	Score for ALL caregivers (mean, SD)	Calibrated Score (%) *
Subject support	1#,3-5#	32	24.41,4.66	76.28
Objective support	2#,6-7#	22	10.32,3.49	46.32
Support utilization	8-10#	12	7.44,1.96	62.00
Total		66	42.17,7.34	63.89

*: Calibrated Score = Mean Score for ALL caregivers/Total Score

Multi-factors analysis of RHDS

General linear regression was carried out for multivariate analysis. Variables were chosen based on the results of single factor analysis, including treatment phase, complications, vein catheter (with or without when discharging), habitation, occupation, financial status, knowledge degree, subjective support, objective support and support utilization. Within these factors, except vein catheter ($P = 0.077$), habitation ($P = 0.890$) and occupation ($P = 0.285$), others were all proved to be the independent factors to RHDS ($P < 0.05$). Detailed information listed in Table 5.

Table 5
Multi-factors analysis of RHDS

Variable	Assignment	Standard partial regression coefficient	t value	P value
Treatment phase	1 = induction period; 2 = consolidation period; 3 = intensification periods	0.382/0.35	6.569/4.338*	< 0.001
Complications	0 = none; 1 = exist during this hospitalization	-0.12	-2.366	0.019
Vein catheter	0 = without; 1 = with when discharging	-0.124	-1.778	0.077
Habitation	1 = urban area; 2 = rural area	-0.007	-0.138	0.89
Occupation	1 = manual worker; 2 = self-employed; 3 = office worker; 4 = famer; 5 = teacher; 6 = others	0.048	1.071	0.285
Financial status	1 = completely satisfied; 2 = almost satisfied; 3 = partial satisfied; 4 = hardly satisfied; 5 = unsatisfied	-0.11	-2.282	0.023
Knowledge degree	1 = completely understand; 2 = almost understand; 3 = partially understand; 4 = do not understand	-0.225	-4.303	< 0.001
Subjective support	calibrated scores	0.139	2.883	0.004
Objective support	calibrated scores	0.173	3.701	< 0.001
Support utilization	calibrated scores	0.095	2.017	0.045

*: induction period compared with consolidation period and intensification periods respectively.

Discussion

According to the results from questionnaire of readiness of discharge scale, the average total RHDS score in primary caregivers caring leukemia children was lower than that of lung cancer patients. In our survey, only 82.6% family believed that they were ready for discharge, which is lower than that of lung cancer (94.3%)[11] or surgical patients (93.0%)[12] indicating that the RHDS of primary caregivers for ALL children in China may not in a satisfied level.

The degree of understanding level about childhood ALL was proven to be independent affecting factors to RHDS. Based on our survey, there was a big difference in Knowledge score of RHDS between patients in local and in foreign developed countries. In our data, as high as 51.8% parents only have had middle school education or even poorer, while in foreign developed countries, more than 50% parents have had college education or better[13]. Lacking enough school education might hinder the enough medical information been obtained. Besides caregivers were undereducated, the shortage in nursing personnel could be another reason for poor knowledge level. In China, the ratio of nurses to patients is much less than that in most western countries[14]. So there were not enough labor-force could be devoted to improving health education effects.

Even in local, compared with other tumors, knowledge about childhood ALL still did not take any advantage. For ALL has much lower morbidity in total age group in China when compared with many solid tumors e.g. lung cancer or breast cancer, it was not paid enough attention like those solid tumors by public health administration, which leading to the poorer community services and diseases education. Even now, many parents still believe leukemia an incurable disease, and chose to give up as soon as been diagnosed. These might be an explanation for a large part of caregivers (35.2%) chose "Do not understand about leukemia" in survey, and also in Weiss questionnaire, the sixteenth items "Knowledge of resources" got a very low score (average 5.87). Therefore, improving the knowledge of childhood ALL by offering more and better hospital education and community services in a variety of ways might essential to improve RHDS.

Besides the knowledge about ALL, the treatment phase of chemotherapy was another affecting factor to RHDS. The induction phase is the first and the key period in ALL chemotherapy. In order to quickly removing ALL cells, in this period, the strongest drugs will be used intensively. It always a tough period in which children will not only suffer from side effects e.g. mucosa damage and hyperglycemia[15, 16] but also complications e.g. infection and hemorrhage[17, 18]. In this period, parents and their caregivers would more likely to get stress from many aspects[19] e.g. the fearing of treatment failure, anxious of high cost and sudden emerging complications. Compared with other phase, this phase is the first and shortest[20], which means the doctors or nurses would only have very little time to transfer essential disease information to caregivers and deal with their emotional stress effectively. The caregivers might also be short of time to get prepared mentally and/or economically.

Complications is one of the main lethal causes in childhood ALL. In our survey, during the treatment in hospital, as high as 65.2% patients experienced several kinds of complications, most of which was infection. Once complications happen, it not only always increases medical cost (longer stay in hospital, advanced antibiotics and more supportive treatment), but also may decrease survival. Therefore, the same as other tumors, complication is an important affecting factor to RHDS. To this concern, in order to improve RHDS, the proper chemical protocol arising from accurate diagnosis and grading is essential, for never too strong or too week protocol is the key to ensure smoothly through induction period and limit the complications. And off course, once complications occur, family without enough social supports or in poor economic condition might suffer more[21].

Lacking social support is a significant problem in childhood ALL caring in less developed country [22]. In our survey, except the twentieth item “emotional support at home”, other three items (twenty-first to twenty-third) of factor “Expected Support” got extremely low scores. Because of lacking enough social support from local community, volunteer agencies and medical institutions, family-unit is still the main economic and labor supporting sources for caregivers nowadays in China. According to questionnaire of general status of family and primary caregiver, a large part of patients belongs to kinship family (71.15%) and/or from rural area (68.77%). Connected by kinship, compared with that in nuclear family and/or in urban area, these caregivers are more easily to get help from family members or relatives nearby. But on another way, because these families might also have more elders and children to feed, have less income and less effective insurance from rural cooperative medical service[23, 24], most of the help they could get might be confined to mental comfort but not objective supports. So even there might be enough mental comfort, the heavier dependency burdens and poorer economic circumstances still made these parents often felling helpless. To this concern, providing more support by means of improving medical insurance systems and making rural medical service available for ALL patients would be essential to better RHDS.

To conclusion, owing to many limitations, RHDS of caregivers for childhood ALL patients is in an intermediate level in China. Based on our data, maybe the support, especially the objective support from society is most needed to improve RHDS. Although in the past decade, ALL have been already included in the medical insurance in China, but the lower reimbursement level and shorting of community services still make many of these families feel helpless. For the incidence of ALL is highest among children and by proper therapy, childhood ALL is now becoming a curable disease, government should pay more attention on ALL children and their family. Except objective support, knowledge about disease is another block. Besides community propaganda and education, education by doctors and nurses in hospital should play a major role. But limited by medical resources, bodies condition but not mental status is still the main consideration for discharge. So, how to make caregivers fully prepared mentally for discharge would become a big challenge for doctors and nurses, and should be always taken seriously during treatment course, especially in the first induction period. And even after leaving hospital, education from nursing still should go on by means of telephone or door-knocking. And finally, to successfully guarantee the curative effect, increase survival rate, decrease complications and shorten hospital stay by proper chemotherapy protocol performing and in-hospital nursing caring will always be the fundament for RHDS improving.

Conclusions

The readiness for hospital discharge in primary caregivers for childhood lymphoblastic leukemia patients is in an intermediate level. In induction remission period of chemotherapy,with complications with poorer family economic state with lacking knowledge about leukemia and with poor social support are possible factors leading to lower score in readiness for hospital discharge scale. More efforts should be done to provide high quality family and primary caregiver assessment and discharge education.

Limitation

Our study had three limitations. First, most data were from B-ALL children families, only a few T-ALL families were included. Second, this study was performed in a single center. Third, more cases should be obtained to insure more realistic conclusions.

Abbreviations

ALL acute lymphoblastic leukemia

SAS self-rating anxiety scale

SDS self-rating depression scale

RHDS readiness for hospital discharge

SSRA social support rating scale

Declarations

Ethics approval and consent to participate

This study was carried out according to the Declaration of Helsinki and was approved by the Ethical Committee of West China Second hospital Sichuan University and all methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Written informed consent for publication was obtained from all participants.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declared that they have **no** conflicts of interest to this work.

We declare that we do not have any commercial or associative interest that represents a conflict of interest in connection with the work submitted.

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Authors' contributions

BRL conceived and designed the study. FL and GZ performed the study and wrote the paper. XFZ gave general advice and checked data sources. All authors reviewed and edited the manuscript.

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