

Optimizing Discharge Planning to Enhance Caregiver Knowledge and Self-Efficacy in Parents of Children with Cancer Undergoing Chemotherapy

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ABSTRACT

Childhood cancer poses significant challenges for families, particularly in settings where access to treatment and supportive care is limited. Children undergoing chemotherapy require repeated hospitalizations, creating disruptions in family routines and increasing caregiver burden. Discharge planning has been shown to strengthen caregiver readiness, improve continuity of care, and reduce unplanned visits. Knowledge and self-efficacy are essential components of caregiver competence and influence decision-making, adherence, and stress management. This study aimed to evaluate the effect of optimized discharge planning on caregiver knowledge and self-efficacy among parents of children with cancer undergoing chemotherapy. A quantitative pre-experimental one-group pre-posttest design was used involving 35 caregivers selected through purposive sampling. Researcher-developed Guttman-scale questionnaires measured knowledge (20 items) and self-efficacy (25 items), both validated and reliable. The intervention consisted of structured discharge planning delivered from admission to discharge, including assessment, education on cancer, chemotherapy, and management of treatment side effects. Pre-test data were collected at admission, and post-test data at discharge. Analysis employed descriptive statistics and the Wilcoxon signed-rank test. Results showed significant improvements in caregiver knowledge (mean increase from 76.28 to 81.57; $p = 0.007$) and self-efficacy (mean increase from 70.40 to 80.91; $p = 0.000$). Gains were observed across all components of knowledge and self-efficacy, and no respondent experienced a decline. In conclusion, optimized discharge planning effectively enhances caregiver knowledge and self-efficacy in pediatric oncology settings, underscoring the importance of structured educational support during hospitalization and transition to home care.

Keywords: childhood cancer; caregiver; discharge planning; knowledge; self-efficacy; chemotherapy

INTRODUCTION

Cancer is a long-term chronic illness that affects a substantial number of individuals in contemporary society. The experience of cancer influences not only the diagnosed individual but also the entire family system, particularly in cases involving children with cancer [1]. Childhood cancer, defined as malignancy occurring in individuals aged 0–14 years, remains a leading cause of mortality among children worldwide [2]. More than 80% of childhood cancer cases occur in low- and middle-income countries, where access to adequate diagnostic and treatment services is often limited [3]. Childhood cancers constitute a heterogeneous group of malignancies with diverse patterns of occurrence, etiologies, treatment modalities, supportive care needs, survival outcomes, and risks of acute toxicities and long-term complications [4]. Cancer is the most common cause of disease-related death among children outside the neonatal period [5].

Children diagnosed with cancer frequently require repeated hospitalizations, which disrupt daily activities and alter family routines [6]. Moreover, children and adolescents undergoing cancer treatment experience numerous symptoms and discomforts resulting from both the disease and its therapies [7]. Cancer treatment, particularly chemotherapy, is prolonged, aggressive, and associated with significant adverse effects that may diminish the child's quality of life and increase the burden on families who must sustain long-term treatment needs [8]. Parents or caregivers often describe the diagnosis and treatment process as one of the most stressful periods of their lives [9]. Consequently, optimal discharge planning is essential to prepare both the child and caregiver for independent management of health needs at home.

Effective discharge planning initiated at the time of hospital admission can shorten the length of stay, enhance communication between nurses, children, and caregivers, and facilitate the identification of patient needs and preferences [10]. Discharge planning also prepares patients and caregivers for home-based care, coordinates follow-up services with nearby facilities, and reduces emergency department visits prior to subsequent treatment cycles [11]. In some cases, discharge planning enables children and caregivers to make informed decisions regarding continuation or cessation of medications and supportive care, particularly in palliative contexts [12]. Because most caregivers of children with cancer are mothers, psychological challenges are common, as mothers often experience emotional shifts and lifestyle changes following their child's diagnosis and treatment. Therefore, improved knowledge through education and emotional support is needed to strengthen caregiver self-efficacy [13].

Knowledge refers to familiarity, awareness, or understanding of facts, information, descriptions, or skills acquired through experience or education by observing, discovering, or learning [14]. Knowledge can be delivered using engaging methods and media to facilitate comprehension and enhance cognitive functioning, which in turn may influence self-efficacy [15]. Adequate knowledge shapes self-efficacy by enabling individuals to make informed decisions, select appropriate treatment options, and adhere to medication regimens. Self-efficacy has been identified as a strong mediator of health-promoting behaviors [16].

Self-efficacy is an individual's judgment or confidence regarding their ability to perform specific tasks and achieve desired outcomes. Children with low self-efficacy tend to avoid tasks perceived as demanding, whereas those with higher self-efficacy demonstrate greater motivation to complete tasks [17]. Self-efficacy fosters belief and confidence in one's ability to act successfully and accomplish goals [18]. A study conducted at the Children's Hospital affiliated with Ain Shams University and the pediatric oncology unit at the National Cancer Institute affiliated with Cairo University involving 50 respondents found that caregivers who received discharge planning demonstrated improved knowledge and practices related to child care, experienced lower anxiety levels, and were better able to manage distress during the child's illness [9].

Based on this phenomenon, the present study aims to examine the optimization of discharge planning in relation to caregiver knowledge and self-efficacy among parents of children with cancer undergoing chemotherapy.

METHODS

The study was carried out in the pediatric hemato-oncology inpatient unit of a national tertiary referral hospital during the period in which children with cancer were admitted for scheduled chemotherapy cycles. This setting was selected because caregivers remain closely involved in

daily care activities throughout hospitalization, allowing the research team to observe changes in knowledge and self-efficacy before and after the intervention. The research employed a quantitative pre-experimental design using a one-group pre-posttest approach. This design was chosen to explore causal effects by observing a single cohort of participants prior to and following the administration of an intervention, without comparison to a control group. Through this approach, the study aimed to capture measurable changes attributable to the discharge planning intervention.

The subjects of the study were caregivers of children diagnosed with cancer who were hospitalized specifically for chemotherapy. Participants were recruited using purposive sampling, in which caregivers were selected based on predetermined criteria relevant to the study objectives. Eligible caregivers were those who served as the primary caregiver of a child undergoing chemotherapy, had no cognitive or hearing impairment, and accompanied a child admitted for chemotherapy. Caregivers of children who were critically ill or who died during hospitalization were excluded. Sample size estimation using G*Power with an effect size of 0.55 and a power of 85% indicated a minimum of 32 participants; anticipating a 10% dropout rate, the final sample consisted of 35 caregivers.

The independent variable in this study was the discharge planning intervention. The intervention was implemented immediately after the pretest and consisted of a structured sequence of activities, beginning with an initial assessment of caregiver needs, followed by tailored education on childhood cancer, chemotherapy protocols, and management of treatment-related side effects. This educational support was integrated into routine nursing care throughout the child's hospitalization and continued until the day of discharge, when caregivers received the child's medical summary. The dependent variables were caregiver knowledge and caregiver self-efficacy. These outcomes were measured using researcher-developed questionnaires based on the Guttman scale. The knowledge questionnaire contained 20 items divided into two domains, understanding of cancer and chemotherapy protocols each scored 5 for "yes" and 0 for "no." The self-efficacy questionnaire consisted of 25 items across three domains: stress management, decision-making, and positive attitude, each scored 4 for "yes" and 0 for "no." Total scores for each instrument reflected the overall level of knowledge and self-efficacy. Instrument validity testing on 30 respondents showed r-values exceeding the r-table value of 0.36 for all items, while reliability testing yielded Cronbach's alpha values of 0.75 for the knowledge questionnaire and 0.78 for the self-efficacy questionnaire.

Data collection began with the administration of the pretest at the time of the child's admission. Caregivers completed both questionnaires before receiving any educational intervention. Afterward, the discharge planning intervention was delivered throughout the hospitalization period. The posttest was conducted on the day of discharge, immediately after caregivers received the child's medical resume, using the same instruments to assess changes in knowledge and self-efficacy. All collected data were checked for completeness, coded systematically, and entered into a statistical database. Data processing involved scoring each questionnaire according to predefined criteria and generating total scores for each variable. Descriptive statistics were used to summarize participant characteristics, while inferential analysis was conducted to compare pre- and post-intervention scores. Statistical tests appropriate to data distribution were applied to determine whether the discharge planning intervention produced significant improvements in caregiver knowledge and self-efficacy.

RESULTS

Characteristics of caregivers

A total of 35 caregivers of children with cancer participated in this study. None of the respondents dropped out, and all caregivers were mothers of the hospitalized children. Their characteristics, including age, educational level, prior experience caring for a child with cancer, and number of children are presented in Table 1. The caregivers' ages ranged from 20 to 52 years, with a mean age of 34.46 years, indicating that most respondents were in early adulthood. The number of children under their care ranged from 1 to 5, with a mean of 2.54. Educational background was predominantly at the secondary level, with 13 respondents completing junior high school and 14 completing senior high school or vocational school. Only two respondents held a bachelor's degree. Most caregivers (88.6%) had prior experience caring for a child with cancer, while four respondents (11.4%) had no such experience.

Pre-test and post-test scores of knowledge and self-efficacy

Table 2 shows an increase in post-test scores for both caregiver knowledge and self-efficacy. The total knowledge score increased to a mean of 81.57, with mean improvements of 3 points in understanding cancer and 2.29 points in chemotherapy procedures. Self-efficacy also

Table 1. Distribution of demographic characteristics of respondents

Demographic variable	Frequency	Percentage
Age: mean (standard deviation)		
Number of children: mean (standard deviation)	17	85
Education		
Elementary school	6	17.1
Junior high school	13	37.1
Senior high school	14	40.0
Bachelor degree	2	5.7
Experience caring for a child with cancer		
Yes	31	88.6
No	4	11.4

Table 2. Distribution of pre-test and post-test scores for caregiver knowledge and self-efficacy

Variable	Mean	Standard deviation
Knowledge (pre-test)		
Understanding cancer	38.14	8.23
Chemotherapy procedures	38.14	8.83
Total knowledge score	76.28	16.24
Knowledge (post-test)		
Understanding cancer	41.14	5.01
Chemotherapy procedures	40.43	4.75
Total knowledge score	81.57	8.02
Self-efficacy (pre-test)		
Stress management	26.48	6.65
Decision-making	8.80	2.70
Positive attitude	34.34	7.42
Total self-efficacy score	70.40	16.23
Self-efficacy (post-test)		
Stress management	30.51	3.89
Decision-making	10.51	2.18
Positive attitude	39.03	3.64
Total self-efficacy score	80.91	7.58

Table 3. Optimization of discharge planning on caregiver knowledge and self-efficacy

Variable	Mean rank	z value	p value
Knowledge			
Negative rank	0		
Positive rank	9		
Ties	26		
Total	35		
Self-efficacy			
Negative rank	0		
Positive rank	17		
Ties	18		
Total	35		

improved across all components, with increases of 4.03 points in stress management, 1.71 points in decision-making, and 4.69 points in positive attitude, resulting in a total post-test mean of 80.91.

Effect of discharge planning on knowledge and self-efficacy

The Wilcoxon signed-rank test demonstrated that optimized discharge planning significantly improved both caregiver knowledge and self-efficacy. Knowledge increased with a mean rank of 0.00 ($p = 0.007$), while self-efficacy increased with a mean rank of 0.00 ($p = 0.000$). Nine caregivers showed improved knowledge, while 26 maintained the same level between pre-test and post-test; none experienced a decline. For self-efficacy, 17 caregivers demonstrated improvement, 18 remained unchanged, and none showed a decrease following the intervention.

DISCUSSION

The characteristics of caregivers participating in this study encompassed age, educational attainment, prior experience in caring for a child with cancer, and the number of children under their responsibility. The respondents' ages ranged from 20 to 52 years, representing a span from early to middle adulthood. Individuals within this age range generally possess the cognitive maturity to think rationally, draw upon accumulated life experiences, and demonstrate a nurturing disposition toward family members. They also tend to exhibit greater tolerance toward others and are capable of making independent decisions, all of which may help alleviate the burden associated with caregiving responsibilities [20]. The caregivers in this study were responsible for between one and five children, including the child currently undergoing treatment. This finding aligns with previous research examining caregiver anxiety, role strain, and distress, which identifies the number of children in the household as an important characteristic influencing caregiver functioning and psychological load [21,22].

Educational attainment among respondents was predominantly at the secondary level. This pattern differs from findings reported in a study involving 186 caregivers at the Pediatric Hematology-Oncology Department of the Mississippi Medical Center, where higher education levels were more common, including 48 respondents with associate degrees and 73 with bachelor's degrees [23]. In the present study, most caregivers had prior experience caring for a child with cancer, with only four respondents lacking such experience. This observation is consistent with research on family caregivers, which suggests that parents who have previously cared for a child with cancer tend to develop stronger support systems, enhanced psychosocial and spiritual resources, and more hopeful outlooks regarding their child's health trajectory [24].

The analysis revealed that some respondents did not exhibit increases in knowledge or self-efficacy at post-test, although none experienced a decline. Several factors may explain this pattern. First, the predominance of secondary-level education among respondents may have influenced their ability to assimilate new information. Prior studies indicate that educational level is closely associated with knowledge acquisition; individuals with higher educational attainment generally demonstrate greater capacity to understand and retain information provided during educational interventions [25]. Second, the age distribution of respondents, spanning early to middle adulthood may also have contributed to variations in knowledge gains. Age can influence caregivers' ability to process information due to physical conditions, cognitive load, and family responsibilities. Younger caregivers often exhibit more rational decision-making and may carry lighter family burdens compared to older caregivers, potentially facilitating better information uptake [20]. Third, the number of children under a caregiver's responsibility may contribute to caregiver burnout, particularly among those managing multiple dependents. This is supported by research involving 332 caregivers, which found that both the number of children and the age of the child with cancer significantly affect caregiver anxiety and distress levels [22].

The findings of this study demonstrate that optimized discharge planning significantly enhances caregiver knowledge and self-efficacy among parents of children undergoing chemotherapy. These results are consistent with a study involving 138 caregivers, which showed that structured education and training effectively improved caregiver self-efficacy in managing cancer-related care [26]. Similarly, research involving 54 caregivers reported that educational interventions significantly increased both knowledge and self-efficacy in managing cancer-related pain [27]. The degree of uncertainty experienced by parents regarding care needs during chemotherapy varies across treatment phases. Care requirements, including infection control, dietary management, daily activities, and prognosis tend to intensify during the initiation and active phases of treatment compared to the post-treatment phase. This underscores the need for tailored educational programs designed to provide practical support to parents throughout the treatment continuum [28].

Systematic education and information delivery within discharge planning can reduce length of stay and unplanned visits among pediatric hematology-oncology patients [29]. Therefore, healthcare facilities are encouraged to implement discharge planning through interprofessional collaboration to minimize medical errors and prepare caregivers for the transition from hospital to home care [11]. In pediatric hematology-oncology settings, discharge planning must adhere to established standards to ensure continuity of care, facilitate coordination between inpatient and outpatient services, and reduce barriers during subsequent admissions [30]. For newly diagnosed pediatric cancer cases, discharge planning should be initiated early, structured comprehensively, and aligned with educational standards. Nurses play a central role in executing discharge planning and ensuring its effectiveness [31].

The findings of this study carry important implications for improving the quality of nursing care, particularly in enhancing child comfort, caregiver knowledge, and caregiver self-efficacy. For nursing education, the results may inform curriculum development by integrating evidence-based discharge planning content to prepare graduates capable of delivering high-quality, evidence-driven interventions. For healthcare facilities, the study provides a reference for optimizing discharge planning in pediatric inpatient units. For the broader community, the findings offer updated information that may strengthen community participation in supporting families managing childhood cancer. Future research may explore emerging phenomena such as the development of pediatric hematology-oncology discharge planning formats, the effectiveness of discharge planning on length of stay (LOS), readmission rates, and patient satisfaction.

This study employed a pre-experimental one-group pre-posttest design, which limits external validity and lacks a control group, thereby restricting generalizability. Additionally, the study did not develop a specialized discharge planning format for pediatric hematology-oncology, nor did it measure length of stay or readmission events following discharge. These limitations highlight opportunities for further investigation in future research.

CONCLUSION

Optimizing discharge planning was shown to effectively improve caregiver knowledge and self-efficacy among mothers of children with cancer undergoing chemotherapy. These findings provide updated evidence to strengthen the quality of pediatric oncology nursing care, particularly through structured and continuous discharge planning that equips caregivers for home-based management after hospitalization. The results also highlight the importance of integrating systematic education into routine nursing practice to enhance caregiver readiness during treatment transitions. Further research using more complex methodologies and robust designs is needed to examine the broader impact of discharge

planning, including its effectiveness in reducing length of stay and lowering readmission rates among pediatric cancer patients receiving chemotherapy.

Ethical consideration, competing interest and source of funding

-Ethical approval for this study was granted by the Research Ethics Committee of the Faculty of Nursing, Universitas Indonesia (Approval No. KET-097/UN2.F12.D1.2.1/PPM.00.02/2023). All participants provided informed consent, and principles of confidentiality, anonymity, and voluntary participation were upheld throughout the research process.

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REFERENCES

1. Aburn G, Gott M. Education given to parents of children newly diagnosed with acute lymphoblastic leukemia: A narrative review. *J Pediatr Oncol Nurs*. 2014;28(5):300–5.
2. Fitzmaurice C, Abate D, Abbasi N, Abbastabar H, Abd-Allah F, Abdel-Rahman O, et al. Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 29 cancer groups, 1990 to 2017: A systematic analysis for the Global Burden of Disease Study. *JAMA Oncol*. 2019;5(12):1749–68.
3. Cotache-Condor C, Rice HE, Schroeder K, Staton C, Majaliwa E, Tang S, et al. Delays in cancer care for children in low-income and middle-income countries: Development of a composite vulnerability index. *Lancet Glob Health*. 2023;11(4):e505–15.
4. Spector LG, Pankratz N, Marcotte EL. Genetic and nongenetic risk factors for childhood cancer. *Pediatr Clin North Am*. 2015;62(1):11–25.
5. Malkin D. The hereditary basis of childhood cancer. *Hered Basis Child Cancer*. 2021;1(1):1–8.
6. Enskär K, Darcy L, Björk M, Knutsson S, Huus K. Experiences of young children with cancer and their parents with nurses' caring practices during the cancer trajectory. *J Pediatr Oncol Nurs*. 2020;37(1):21–34.
7. Linder LA, Hooke MC. Symptoms in children receiving treatment for cancer—Part II: Pain, sadness, and symptom clusters. *J Pediatr Oncol Nurs*. 2019;36(4):262–79.
8. Lustberg MB, Kuderer NM, Desai A, Bergerot C, Lyman GH. Mitigating long-term and delayed adverse events associated with cancer treatment: implications for survivorship. *Nature Reviews Clinical Oncology*. 2023 Aug;20(8):527–42.
9. Bahy El-din Mohamed A, Ibrahim Abd Al-Moniem I, Shalaby L, Elsayed Hassan S. Effect of discharge plan for children undergoing chemotherapy and their caregivers on improving practice and coping pattern. *Egypt J Health Care*. 2019;10(1):102–16.
10. Holland DE, Man KLG, Ms PMC, Ms GMR, Dnp PKM, Ms LMM. Identifying hospitalized pediatric patients for early discharge planning: A feasibility study. *J Pediatr Nurs*. 2015;30(3):454–62.
11. Rasku T, Kaunonen M, Thyer E, Paavilainen E, Joronen K. The core components of community paramedicine-integrated care in primary care setting: a scoping review. *Scandinavian journal of caring sciences*. 2019 Sep;33(3):508–21.
12. Pollock K, Wilson E, Caswell G, Latif A, Caswell A, Avery A, Anderson C, Crosby V, Faull C. Family and health-care professionals managing medicines for patients with serious and terminal illness at home: a qualitative study. *Health and Social Care Delivery Research*. 2021;9(14):1–62.
13. Tan R, Koh S, Wong ME, Rui M, Shorey S. Caregiver stress, coping strategies, and support needs of mothers caring for their children who are undergoing active cancer treatments. *Clin Nurs Res*. 2020;29(7):460–8.
14. Mardiana N. The correlation between knowledge and intention with self-efficacy of pregnant women to attend antenatal care at healthcare. *J Nurs Educ Pract*. 2017;3(7):99.
15. Nastiiti EM. Relationship between first aid knowledge among school-aged laypersons and self-efficacy in handling injury cases: A systematic review. *J Kesehat Dr Soebandi*. 2020;8(2):148–53.
16. Mun MY, Hwang SY. Development and evaluation of a web-based learning course for clinical nurses: Anticancer chemotherapy and nursing. *Korean J Adult Nurs*. 2020;32(4):364–73.
17. Permana R, Sabirin F, Feladi V. Effect of self-efficacy and prior knowledge on students' skills. *J Educ Teach Learn*. 2016;1(2):76–82.
18. Karima NM, Nuraeni A, Mirwanti R. Knowledge and self-efficacy on "first responder" in giving first aid. *J Nurs Care*. 2019;2(1):17–22.
19. Polit DF, Beck CT. *Essentials of nursing research: Appraising evidence for nursing practice*. 7th ed. Philadelphia: Lippincott Williams & Wilkins; 2017.
20. Puspitasari S. Gambaran beban caregiver keluarga pada pasien kanker di rumah singgah Yayasan Kanker. Thesis. UIN Syarif Hidayatullah Jakarta. 2017;47–55.
21. Kusumadewi AR. Negosiasi peran yang dilakukan orang tua sebagai caregiver yang memiliki anak penderita kanker. Thesis. UNAIR. 2019;1–7.
22. Toledano-Toledano F, Luna D, Moral De La Rubia J, Martínez Valverde S, Bermúdez Morón CA, García MS, et al. Psychosocial factors predicting resilience in family caregivers of children with cancer: A cross-sectional study. *Int J Environ Res Public Health*. 2021;18(2):1–13.
23. Ramsey LH, Graves PE, Sharp KMH, Seals SR, Collier AB, Karlson CW. Impact of race and socioeconomic status on psychologic outcomes in childhood cancer patients and caregivers. *J Pediatr Oncol Nurs*. 2019;41(6):433–7.
24. Wijayanti T. Pengalaman orangtua dalam merawat anak kanker. *J Keperawatan*. 2021;13(1):213–26.
25. Adi Rizka, Iskandar SA. Analysis of the relationship between education level and knowledge on chemotherapy adherence in breast cancer patients at Cut Meutia General Hospital, North Aceh. *J Ilm Mns Kesehat*. 2023;6:69–77.
26. Hendrix CC, Bailey DE, Steinhauser KE, Olsen MK, Stechuchak KM, Lowman SG, et al. Effects of enhanced caregiver training program on cancer caregivers' self-efficacy, preparedness, and psychological well-being. *Support Care Cancer*. 2016;24(1):327–36.
27. Kizza IB, Muliira JK. Influence of a home-based education intervention on family caregivers' knowledge and self-efficacy for cancer pain management in adult patients within a resource-limited setting. *J Cancer Educ*. 2019;34(6):1150–9.
28. Park M, Suh EE, Yu SY. Uncertainty and nursing needs of parents with pediatric cancer patients in different treatment phases: A cross-sectional study. *Int J Environ Res Public Health*. 2021;18(8):82–8.
29. Rahim MQ, Griffin J, Hege K, Mueller EL. Right on schedule: Improving the rate of clinic appointments scheduled prior to hospital discharge. *Pediatr Qual Saf*. 2022;7(1):22–8.
30. Kurian T, Stranges E, Czerlanis C. Inpatient hematology and oncology using standardized discharge processes. 2021;1(1):50–6.
31. Hockenberry M, Haugen M, Slaven A, Skeens M, Patton L, Montgomery K, et al. Pediatric education discharge support strategies for newly diagnosed children with cancer. *Cancer Nurs*. 2021;44(6):E520–30.