Evaluation of a nurse-led management program to complement the treatment of adolescent acute lymphoblastic leukemia patients

Hailong Lin, RN [a], Shiyan Zhou, RN [b], Dongxiu Zhang, RN [a], Leting Huang, RN [b,*]

[a] Department of Pediatrics, The Second Affiliated Hospital of Wenzhou Medical University, Wenzhou, Zhejiang Province, China
[b] Department of Hematology, The Second Affiliated Hospital of Wenzhou Medical University, Wenzhou, Zhejiang Province, China

ARTICLE INFO

ABSTRACT

Purpose: To evaluate a nurse-led management model of adolescent acute lymphoblastic leukemia (ALL) patients and improve their psychological care and quality of life.

Methods: Seventy-three adolescent ALL patients participated in an open, controlled clinical trial and were randomized into a nurse-led management model group (n = 36) and a doctor-led management model group (n = 37). Two assessment questionnaires were administered to assess and compare the 2 models during a 1.5-year follow-up period: the hospital anxiety and depression scale (HADS) questionnaire was administered at 6 different time points, and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) at 3 different time points.

Results: There were no differences in anxiety and depression between the groups according to the first-administered questionnaire (the mean anxiety and depression scores of the nurse-led group were 14.2 ± 4.1 and 10.8 ± 2.7, respectively; those of the doctor-led group were 13.8 ± 3.8 and 10.6 ± 2.2, respectively). However, repeated measures analysis of variance detected differences in subsequent HADS-based scores as a function of time between the 2 groups ($p < 0.05$). Moreover, the Holm–Sidak's multiple comparisons tests showed that patients of the nurse-led group had significantly decreased mean anxiety scores compared to those in the doctor-led group at the third and subsequent sessions, as well as in mean depression scores from the second session onwards (all $p < 0.05$). According to the last-administered EORTC QLQ-C30 questionnaire, there were statistical differences in cognitive, emotional, social, and quality of life scales between the 2 groups (all $p < 0.05$), but not in role and physical scales (all $p > 0.05$).

Conclusions: It is necessary to offer unique cognitive, psychological, and behavioral management models to adolescent ALL patients that are tailored toward their age group. Strengthening such management is more conducive to alleviating or even reversing psychological problems, and to improving patients' quality of life while ensuring complication-free follow-up periods.

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1. Introduction

Acute lymphoblastic leukemia (ALL) is a blood disease characterized by overproduction and accumulation of immature white blood cells (WBCs), which are also known as lymphoblasts (Frei & Sallan, 1978; Hunger & Mullighan, 2015). Symptoms include fever, increased risk of infection (particularly bacterial infections such as pneumonia), tendency to bleed, and increased fatigue, anemia, pallor, and headache (Hunger & Mullighan, 2015). The annual incidence in the People's Republic of China has remained stable for decades at approximately 1 per 100,000 individuals; 25–30% of those afflicted are adolescents (Zhang et al., 2014). The disease involves complex manifestations that can lead to a variety of symptoms. While various treatments including chemotherapy, immunotherapy, and hematopoietic stem cell transplantation are applied, post-induction therapy and long-term follow-up are often managed by a community-based oncologist in collaboration with a treatment team (Mandrell, 2009). Although reasonable treatment plans for adolescent patients are offered in China, management of home care and psychological counseling appears to be insufficient. This impacts the effect of treatment, and patients may also experience anxiety and depression during this period (Mandrell, 2009). To that end, a randomized controlled trial (RCT) was conducted to evaluate the efficacy of a model designed to guide the practice of nurse-led adolescent ALL management in the community in Wenzhou City, China.

* Corresponding author at: Department of Hematology, The Second Affiliated Hospital of Wenzhou Medical University, 109th Xueyuanxi Road, Wenzhou, Zhejiang Province, China. Tel.: +860577-88002716.
E-mail address: windflakelin@163.com (L. Huang).

2. Materials and methods

The RCT was conducted at the Department of Hematology and Oncology, the Second Affiliated Hospital of Wenzhou Medical University, China, and was approved by this institution's ethics review committee (number: 20,140,088). Eighty ALL cases newly diagnosed between January and December, 2014, were included in this study; the mean patient age was 13 years. Forty patients in the study group received ALL care guided by the nurse-led model; the remaining 40 patients received care guided by the traditional doctor-led model. All patients received complete induction therapy before being subjected to intensification protocols followed by maintenance therapy. The doctor-led model included optional follow-ups with physical examinations, laboratory tests, and pharmacological treatments by oncologists; subjects also responded to the Hospital Anxiety and Depression Scale (HADS) and the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) questionnaires. Care using the nurse-led model included nurse-administered follow-ups with physical examinations, laboratory tests, and pharmacological treatments by oncologists, in addition to nurse-led psychological support of patients (such as psychological assessment and intervention), evaluation using the HADS and EORTC QLQ-C30 questionnaires, and home care support. This nurse-led management model included the following instructions: 1. Stress management skills, such as slow breathing; 2. Helping patients manage their problems, including listing, selecting, and defining a problem, followed by brainstorming and choosing strategies most likely to help while adopting an action plan; 3. Improving patients' moods by encouraging them to get re-involved in fun, task-oriented activities despite having low morale; 4. Strengthening social support, including encouraging some patients to share difficulties and feelings with others they trust, while motivating others to use resources available from trusted people (such as tools or knowledge required to accomplish a task); and 5. General well-being, including continuing to practice learned skills after completing the intervention (Rahman et al., 2008). The care model was terminated if a patient's condition became critical, or if the patient was lost to follow-up.

Common symptoms and adverse events (including serious adverse events) recorded in this study included generalized anemia, dizziness, fatigue, bruising, infection, breathlessness, bone or joint pain, vomiting, liver damage, and renal damage (Hunger & Mullighan, 2015). Patients receiving doctor-led care accepted pharmacological treatment from an oncologist at the time of optional follow-up, while those receiving nurse-led care accepted pharmacological treatment from an oncologist at the time of nurse-administered follow-ups. The latter patients also received nurse-led education and consultation about home care; home visits were conducted if necessary (Fig. 1).

Psychological distress is often associated with leukemia, and adolescent ALL patients are generally at increased risk of anxiety and depression (Bryant et al., 2015; Jarden et al., 2013). Depressive symptoms can be as debilitating as the ALL itself, and can significantly affect patients' daily function. Patients with excessive distress regarding their symptoms tend to have even more anxiety and depression; thus, the psychological intervention by the nurse-led group in this study was designed to relieve depression. Patients of the doctor-led group were also able to discuss their depressive symptoms with a psychologist if they so desired. The intervention involved pilot testing and trial methodology, needs assessment, evidence-based theoretical underpinning, setting of objectives, and designing plans of action, and consisted of 6 sessions that took place over 1.5 years. Additional sessions were added if necessary. Patients described symptom details and personal circumstances in the first session, according to which assessments were reported in the subsequent sessions.

HADS was used to assess the anxiety and depression of the adolescent patients. The questionnaire consists of anxiety and depression subscales, each of which contains 7 items (subscale range, 0–3). Patient scores were obtained by summing up the subscales, yielding values of

0–21. The results were divided into 3 categories: scores of 0–7 signified no anxiety/depression, 8–10 referred to mild–moderate anxiety/depression, and 11–21 referred to moderate–severe anxiety/depression (Cavaleri et al., 2009). The anxiety and depression of patients who were primarily diagnosed through HADS were further investigated, and psychological intervention using the problem-management plus model was prescribed; this model reduces symptoms of depression, increases self-reliance, and increases hope in patients. The model program includes 3 group sessions of approximately 90 minutes, held on a quarterly basis, that address "causes", "symptoms" and "treatments and courses" as well as the necessary discussions (Snaith, 2003). Each intervention has 2 main components, a 30-min group session for acquiring information about anxiety and depression, and problem management during the remaining time. The informational part includes gathering data on (1) symptoms, epidemiology, and course of depressive disorders; (2) cause of illness; and (3) treatment of illness and depressive disorders. Problems are then categorized as solvable, unsolvable, and unimportant; this allows patients to prioritize and invest in solving only those problems that are critical to their well-being. The HADS questionnaire was re-administered each quarter just prior to the next intervention session.

Patients also regularly answered the EORTC QLQ-C30 questionnaires to assess their quality of life, which is a core measure for clinical cancer researchers (Luckett et al., 2011). The EORTC QLQ-C30 consists of 5 multi-item function scales, including role (RF), physical (PF), cognitive (CF), emotional (EF), and social (SF); it also incorporates a 2-item global quality of life scale (QL). Additionally, the questionnaire includes 3 multi-item symptom scales for nausea and vomiting (NV), fatigue (FA), and pain (PA), as well as 6 single-item symptom scales for appetite loss (AP), dyspnea (DY), insomnia (SL), constipation (CO), diarrhea (DI), and financial impact (FI). The questionnaire incorporates a 4-point response format including "not at all", "a little", "quite a bit" and "very much"; the global QL scale has a 7-point response format.

In such investigations, information on patients' symptoms in the nurse-led group is offered to physicians to obtain the necessary treatments; patients in the doctor-led group obtained treatment during outpatient follow-up based on their disease manifestations. All patients received in-hospital care, but patients of the nurse-led group received follow-up support in the home as well (transitional care), for which relatives and caregivers received training. Effective transitional care included accurate medication reconciliation and comprehensive nurse–patient communication. The former aimed to improve the delivery of outcome-based patient care and to reduce hospital readmissions. The latter was central to achieving optimal transition of care, such as symptom management, and also included palliative care, telehealth services, and home visits. The EORTC QLQ-C30 was re-administered every 6 months.

2.1. Statistical analysis

Data processing and statistical analysis were performed using the SPSS 17.0 statistical software package; samples were compared using the t-test or chi-square test. Repeated measures analysis of variance (RMANOVA) followed by Holm–Sidak's multiple comparisons tests were also employed.

3. Results

3.1. Demographic and clinical characteristics

Seven cases (4 in the nurse-led group and 3 in the doctor-led group) were lost to follow-up or discontinued participation in the study, either because of entering a critical period or relocation to another city for therapy. Thus, there were ultimately 36 patients in the nurse-led group and 37 in doctor-led group. Most of the patients were male (63.0%). The average patient age was 13.1 ± 1.7 years. Other than