Effect of education on quality of life of family caregivers of children with leukemia referred to the Oncology Clinic at Kerman's Afzali-Poor Hospital (Iran), 2012

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Objective. To investigate the impact of education on the quality of life of parent of children with leukemia referred to the oncology clinic at Kerman's Afzali-Poor hospital (Iran). Methodology. This was an interventional study with 80 parents of children with leukemia; all of the caregivers were mothers and were included in the research. They were chosen using the convenience sampling method and categorized randomly into two groups (intervention and control, each with 40 participants). Research tools included demographic information and Quality of Life (QoL) scale (a specific form for first-degree family caregivers of patients with leukemia). Questionnaires were applied at the beginning of the research and after three months; this second evaluation coincided in the study group with the end of the intervention. The intervention lasted four sessions of 45- to 65-minute classes, with lectures and question and answer sessions, educational booklets, and posters in groups with 4 - 6 members. **Results**. In the first evaluation, mean QoL scores in the study and control groups were 224.9 and 225.7, which, after three months changed to 338.2 and 226.7, respectively. T-test verified these increases (p<0.05) in quality of life in the intervention group. Conclusion. According to the effectiveness of the education on the parent's quality of life, it is recommended to implement consulting and educational programs for parents, especially parents of children with leukemia, to promote care, reduce anxiety, and consequently, enhance quality of life.

Key words: Quality of life; Education, nursing; Leukemia; parents.

Efecto de la educación en la calidad de vida de los cuidadores familiares de menores con leucemia referidos a la Clínica Oncológica en el hospital Afzali-Poor en Kerman (Iran), 2012

Objetivo. Investigar el impacto de la educación en la calidad de vida de padres y madres de menores con leucemia referidos

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a la clínica de oncología del hospital Afzali-Poor en Kerman (Irán). Metodología. Estudio intervencional con 80 padres de menores con leucemia; todos los cuidadores de familia fueron madres y se incluyeron en la investigación. Fueron seleccionados utilizando el método de muestreo por conveniencia y asignados aleatoriamente en dos grupos (intervención y control, cada uno con 40 participantes). Las herramientas de investigación incluyeron información demográfica y la escala de calidad de vida (formulario específico para familiares de primer grado de consanguinidad cuidadores de menores con leucemia). Las encuestas se aplicaron al inicio de la investigación y luego de tres meses; esta segunda evaluación coincidió en el grupo de estudio con el final de la intervención. La intervención se hizo en cuatro sesiones de clases de 45 a 65 minutos, con conferencias y sesiones de preguntas y respuestas, cartillas educacionales y afiches en grupos con 4 - 6 integrantes. Resultados. En la primera evaluación, las puntuaciones promedio basales de calidad de vida en los grupos de estudio y control fueron 224.9 y 225.7, que, luego de tres meses cambiaron a 338.2 v 22.7. respectivamente. La prueba t verificó estos incrementos (p<0.05) en calidad de vida en el grupo de intervención. Conclusión. Según la efectividad de la educación sobre la calidad de vida de los padres, se recomienda implementar programas educacionales y de consultoría para los padres, específicamente los padres de menores con leucemia, para promover cuidados, reducir ansiedad y, en consecuencia, mejorar la calidad de vida.

Palabras clave: calidad de vida; educación en enfermería; leucemia; padres.

Efeito da educação na qualidade de vida dos cuidadores familiares de menores com leucemia referidos à Clínica Oncológica no hospital Afzali-Poor em Kerman (Iran), 2012

Objetivo. Pesquisar o impacto da educação na qualidade de vida de pais e mães de menores com leucemia referidos à clínica de oncologia do hospital Afzali-Poor em Kerman (Irã), Metodologia. Estudo intervencional com 80 pais de menores com leucemia; todos os cuidadores de família foram mães e se incluíram na investigação. Foram selecionados utilizando o método de amostragem por conveniência e atribuídos aleatoriamente em dois grupos (intervenção e controle, cada um com 40 participantes). Ferramentas de investigação incluíram informação demográfica e a escala de qualidade de vida (formulário específico para familiares de primeiro grau de consanguinidade cuidadores de menores com leucemia). As enquetes se aplicaram ao início da investigação e depois de três meses; esta segunda avaliação coincidiu no grupo de estudo com o final da intervenção. A intervenção durou por quatro sessões de classes de 45 a 65 minutos, com conferências e sessões de perguntas e respostas, cartilhas educacionais e cartaz em grupos com 4 - 6 integrantes. Resultados. Na primeira avaliação, as pontuações média de qualidade de vida nos grupos de estudo e controle foram 224.9 e 225.7, que, depois de três meses mudaram a 338.2 e 226.7, respectivamente. A prova t verificou estes incrementos (p<0.05) em qualidade de vida no grupo de intervenção. Conclusão. Segundo a efetividade da educação sobre a qualidade de vida dos pais, recomenda-se implementar programas educacionais e de consultoria para os pais, especificamente os pais de menores com leucemia, para promover cuidados, reduzir ansiedade e, em consequência, melhorar a qualidade de vida.

Palabras chave: qualidade de vida; educação em enfermagem; leucemia, país.

Introduction _

Childhood cancer is an increasing and prevalent type of chronic disease worldwide.¹ Leukemia is one of the most common cancers in children under 15 years of age and represents 25% of all cancers in children.² Like other chronic diseases,

it causes many physical and mental problems for the caregivers, who are mainly parents,³⁻⁶ and makes parents show various levels of anxiety, shock, depression, disappointment, and denial during initial stages of the diagnosis of childhood disease. 4,7,8 These issues can remain with them for years after the disease is controlled and may be transferred to the child patient and other healthy children in the family. 4,7,9 At the time of child's diagnosis of leukemia, the family is confronted with challenges, such as conflict and role ambiguity and sense of helpless, job loss, disruption, disorder in interpersonal relationships, inability in engaging in individual, family, and social and other activities. 9,10 Quality of life (QoL) decreases in the children and the family members of children diagnosed with leukemia. 11

A study was carried out with 739 members of cancer patient families by the Behavioral Research Center of the American Cancer Society, which reported high levels of mental stress associated to disorder in dimensions of physical, mental, and social performance. In a study, Yamazuki¹² compared the quality of mothers' life with and without leukemic children: he found that dimensions of quality of mothers' life with leukemia children were low in five areas, particularly in physical and mental dimensions. Although the role of parents is considered in recent years, quality of their life has not been assessed overall, and there was a little focus on carrying out proper educational interventions to promote the quality of life of family caregivers - especially parents of leukemic children. 13 Given that one of the ways to improve QoL is by implementing educational interventions for parents to face the effects and consequences of childhood disease and to restrain them for a life with better quality.¹⁴ Results of implementing the interventions are parents' empowerment, which should be targeted through nurse-family cooperation, emphasizing on reducing hazardous factors and improving QoL. Nurses should mostly rely on positive family capacities. 15 Therefore; this study aims to determine the effect of education on QoL of parents with leukemic children.

Methodology ___

The current interventional research was conducted in Afzali-Poor Hospital in Kerman (Iran) in 2012,

It is a main center providing services for leukemic children in southern Iran. The research sample consisted of 80 parents with children with leukemia, who are randomly categorized into two groups of test and control (40 persons in each group). Study inclusion criteria were parents who had leukemic children and child's age was in the range of 7-10 years, have minimum literacy, no record in using previous consulting systems, filling in a specific form for informed consent by samples, and exclusion criteria were lack of cooperation of parents with the researcher. Data collecting tools included two parts: the first contained demographic information and the second was a reliable and validated QoL scale (a specific form for the home, first-degree relevant caregivers of leukemia patients) by Ferrell and Grant¹⁶ that includes 37 items. In this tool, questions about QoL dimensions are set into four dimensions: physical, mental, social, and spiritual. This scale scored from zero to 10. In 16 questions, zero score represents the worst situation and 10 stands for the best condition for that person. In the remaining 21 questions, zero score is the best mode. Hence, there is a direct relation between measurement scale in the first 16 questions and overall score of QoL, and an inverse relation in the other 21 questions. The overall score is calculated by adding scores of questions: unfavorable quality = 0-123 points, 124-246 = partly favorable, and247-370 = favorable quality.

The QoL scale was translated into Persian, backtranslated to its original language, and again translated to Persian, and approval was acquired from scientific referees. The questionnaire was examined for validity by 10 medical and nursing professors, whose suggestions and review comments were applied in the tool. The questionnaire's validity was also studied by using the test-retest method among 10 participants. Cronbach's Alpha was calculated at 0.87. Samples were selected by using convenience and available sampling based on entry conditions. Then, a research assistant, who learnt how to fill out the questionnaire, accomplished QoL questionnaires through interviews with parents of both interventional and control groups. Next, test and control groups were specified by random allocation, as the first member was randomly assigned to the test or control group and the other participants were divided between both groups, alternatively, so that each group had 40 members.

To heed ethical issues in research, as well as prevent possible errors, completed questionnaires were codified. After that, the intervention was applied to test group. Intervention was in the form of education and educational booklets. Education, implemented by the researcher, included three sessions of educational class taking 45 - 60 minutes, held as lecture or question and answer (Q&A) sessions in 4 – 6-member groups. The following matters were presented to parents in these sessions: appropriate and required information about leukemia and its remedy, effects of the disease on family and ways to cope with them (session 1); ways to communicate with the child, impacts of the disease on various dimensions of the child's life, how to mitigate them, and promote the child's quality of life (session 2); and how to care for the sick child in the hospital and at home (session 3). According to the parents' academic education and their level of understanding, other teaching aids such as posters were employed, enough time was spent to ensure full comprehension by the participants. Regarding the severe need for these parents to gain information about the disease and care for their children, they endeavored to learn all of educational matters in these three planned sessions. In addition, after each instructional session, the parents in the test group received instructional booklets containing necessary information, as teaching aids to review their possible questions in the booklet. Again, two months after completing the intervention, the QoL questionnaire was completed by a researcher by interviews with the parents in both test and control groups. Data collected were analyzed by SPSS software (v.11) and by using analytic and descriptive statistics. P-value equal to 0.05 was set as level of significance. The current study also took into account ethical considerations.

Results

Based on the study's findings, mean ages were 34.1 and 34.8 years for mothers, 46.8 and

44.6 years for fathers, and 9.5 and 9.3 years for children in study and control groups, respectively. Sixty-five percent of children sampled in the test group and 72% of the children sampled in the control group were males. Among the fathers, 60% in the test group and 50.6% in the control group were self-employed, and most of the mothers were homemakers (95.6%) in both groups. The academic educational level for most of the fathers (74.2% in both groups), and most of mothers (73.5% in the study group and 77.6% in the control group) was elementary. Generally, independent t and Chi-square tests showed no difference in the demographic attributes of both groups.

The results show that the overall QoL score was 224.9 for the study group and 225 for the control group. However, after two months of intervention, this score reached 338.2 in the study group and 226.7 in the control group. Independent t-test confirmed no significant statistical difference between both groups with respect to scores of the four QoL dimensions, as well as total QoL score (p<0.05), while after educating this difference became significant (Table 1). The QoL scores and the score differences in both groups, before and after intervention, are compared in Table 2. In the test group, average scores increased for all QoL dimensions after training. The highest increase occurred in the mental dimension with an average difference of 49.9 and the least increase took place in the physical dimension with an average difference of 15.7. These findings also show that the social dimension remained almost the same in the control group after intervention (average difference of 0.4±0.0), the mental and spiritual dimensions increased slightly (average score differences 0.9 ± 4.2 and 8.6 ± 1.0 for mental and spiritual dimensions, respectively), while the physical dimension mitigates (average difference 6.3±1.0). Total QoL score difference is 56.6±29.2 before and two months after training the study group, while this number is 18.1±0.9 for the control group. Paired t-test shows that increases in QoL dimensions scores in the study group are significant, while it does not validate changes in QoL scores of the control group. Furthermore, independent t-test shows that there is a statistically significant difference between the two groups after two months of education versus

the difference of QoL dimensions scores, as well as overall QoL score (p < 0.05) (Table 2).

Table 1. QoL mean (±SD) score for parents with leukemic children referred to Kerman's Afzali-Poor Hospital before training and two months after training in both study and control groups

| Time | Before int | tervention | n Value | After int | | |
|----------------|------------------|------------------|---------|-----------------|------------------|---------|
| QoL dimensions | Study | Control | p-Value | Study | Control | p-value |
| Physical | 26.3 ± 6.7 | 25.8± 7.1 | 0.76 | 42.0 ± 3.8 | 7.1 ± 24.8 | < 0.001 |
| Mental | 96.4 ± 7.9 | 97.3 ± 3.2 | 0.91 | 146.3 ± 5.1 | 98.±0 3.6 | < 0.001 |
| Social | 55.3 ± 10.7 | 55.9 ± 11.8 | 0.83 | 86.6 ± 2.3 | 55.9 ± 11.8 | < 0.001 |
| Spiritual | 46.8 ± 9.9 | 46.9 ± 9.9 | 0.95 | 63.1 ± 2.4 | 47.9 ± 9.8 | < 0.001 |
| Overall QoL | 224.9 ± 24.1 | 225.7 ± 24.3 | 0.89 | 338.2 ± 7.8 | 226.7 ± 23.8 | < 0.001 |

Table 2. QoL mean (±SD) score change before and after intervention in both test and control groups for parents with leukemic children referred to Kerman's Afzali-Poor Hospital

| Study | | Control | | | | Difference | Difference before | | |
|----------------------------|-----------------------------|--------------------|---------|------------------------|--------------------|-------------|--|---|-------------|
| Group QoL dimensions | Before interven- tion | After intervention | p-Value | Before intervention | After intervention | p- Value | before and after inter- vention for study group | and after intervention for control group | p- value |
| Physical | 26.3± 6.7 | 42.0± 3.8 | <0.001 | 25.8± 7.11 | 7.11± 24.8 | 0.81 | 15.7± 5.9 | 6.3± 1.0 | <0.001 |
| Mental | 96.4± 7.9 | 146.3± 5.1 | <0.001 | 97.0± 3.2 | 98.0± 3.6 | 0.09 | 49.9± 7.2 | 4.2± 0.9 | <0.001 |
| Social | 55.3 ±10.7 | 86.6± 2.3 | <0.001 | 55.9 ± 11.8 | 55.9± 11.8 | 0.44 | 31.3± 10.9 | 0.4± 0.0 | <0.001 |
| Spiritual | 46.8± 9.9 | 63.16± 2.47 | <0.001 | 46.9± 9.9 | 47.9± 9.8 | 0.57 | 16.3± 10.5 | 8.6 ±1.0 | <0.001 |
| Overall QoL score | 224.9 ±24.1 | 338.2± 7.86 | <0.001 | 225.7± 24.3 | 226.7± 23.8 | 0.83 | 56.65 ± 29.7 | 18.1± 0.9 | <0.001 |

Discussion

According to the results, the overall average QoL score of parents of children with leukemia is partly desirable (224.9 in the test group and 225.7 in the control group). Our results are consistent with those reported by Fatokian *et al.*,¹⁵ where more than four-fifths of the samples have a partly desirable or undesirable physical situation and

only 15.7% of the samples have a desirable physical situation, which could stem from lack of social support. To resolve it, caring roles and tasks should be divided between the parents.¹⁷

According to the findings of the current research, QoL scores of the parents studied with respect

to physical conditions, for the study and control groups before intervention, were 26.3 and 25.8, respectively, increasing to 42.1 and 24.8, respectively, two months after intervention. Results of the assessment prior to intervention show lack of information in many dimensions. In comparison, the average overall QoL score increased to 338.2 for the study group and 226.7 for the control group after two months of training. Independent t-test shows no significant statistical difference between the two groups before training in terms of overall QoL score and its quadruplet dimensions; after training, this statistical difference become significant.

Average scores increased for all dimensions in the test group. Many studies have discussed undesirable effects of a sick child in the family on QoL, physical and mental health of parents, and influence of education on QoL of family caregivers for chronic diseases;2,13,15,18,19 results demonstrating positive effects of education on child patient caregivers. Klassen et al., 20 studied 513 parents seeking to assess the effect of caring for children with cancer on health-related QoL, showing that parents of children with leukemia have poor QoL, agreeing with the current research. The authors suggest educational intervention for parents as a part of remedial programs for children with leukemia. In a comparative study, Yamazaki¹² also compared QoL of mothers of children with cancer and mothers of children with non-cancerous disease in Japan; average QoL scores were poor in five of eight areas, and the maximum weaknesses were in mental, physical, and social performances.

Based on our results, the overall QoL scores of all samples were partly favorable before intervention. In contrast, the scores enhanced obviously in all areas after two months of training, especially in mental health, with the average difference reaching 49.9 in the study group and 4.2 in the control group. These results are consistent with those reported by Khanjani et al., 18 who studied the effects of educating parents on how they should care for children with cerebral palsy on QoL of 25 family caregivers. In this research,

QoL scores were higher three months after accomplishing training than scores before getting education in three areas. This change in physical and emotional roles were outstanding (p<0.001); 50.6 and 31 ± 2 , respectively. It is noteworthy that chronic diseases have their unique attributes and effects on the family. Therefore, taking care of mentally retarded and disabled children causes less decreases in scores of physical and mental health dimensions; while, in cases of children with cancer it leads to more fear, anxiety, and mental problems in caregivers.

Reviewing other studies, it was revealed that educated mothers caring for mentally retarded children leads to attitude improvements and better adaptation compared to before training.²¹ Sanjari et al.,22 argue that diagnosing and curing cancer require the diseased children and their parents to understand how they should deal with stressful aspects of the disease. Given that parents often take on preparing the daily needs of children, they can use coping procedures to get over the issues.²³ It is also suggested that nurses and responsible persons can contribute in promoting QoL of diseased children and their families by providing them with consulting services and developing and executing documented educational programs to help them to learn proper coping methods.²¹ Results of another study in Kerman reveal that 94.1% of research centers employ reliance and belief in God as a coping method.²³ In a study seeking to investigate compatibility methods and experiences of fathers of children with leukemia, researchers found that, for most fathers. compatibility approaches included gaining knowledge, receiving aid from others, problemresolving methods, and using religious beliefs.²⁴

In the current research, social status remains unchanged even after training in both groups. In other research, 3.5% of the participants have a desirable social status, and 3.4% have undesirable spiritual and mental conditions. ¹⁵ Research results demonstrate that social supports are among the least used sources in families, stemming from the fact that people do not accept direct help due to cultural circumstances. Therefore, this duplicates

the importance of institutions reinforcing and supporting patients and their families to effectively adapt to problems. Thus, sufficient social support can improve their adaptive skills and have a direct effect on improving QoL;²⁵ hence, it is suggested that required facilities be provided for them through social-supportive and welfare services, and nurses should be familiar with the services and introduce them to the caregivers.

Conclusion _

Given that parents of children suffering from leukemia need more attention than parents of children enduring other diseases, it is necessary to include supportive programs for parents in the child's remedial program immediately after diagnosing the disease. Research results show that education affects the quality of life of parents, particularly in the mental dimension. According to the parents' role in caring for children, it is recommended to present programs to promote the mental health level of families with children with leukemia in addition to remedial care. Additionally, nurses can provide families with information about support systems and consulting services available in society, and considering their accessible sources, facilitate utilizing these services for them and help to improve their quality of life.

According to our findings, participants need physical, mental, and –particularly- social supports. Thus, it is suggested that the Ministry of Healthcare contributes in providing costly medicine required by cancer patients and in taking care of these patients at home for the caregivers by providing them with social, supportive, and welfare services such as improving health insurance.

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