Prevalence and determinants of depression among caregivers of children with leukaemia in Iraq

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Abstract

Background: Depression in caregivers of leukaemic children is usually overlooked and hence missed, as doctors mostly focused on patient's evaluation and condition. Early attention to symptoms of depression may help to prevent the development of a more serious depression over time.

Aims: This study was conducted to estimate the prevalence, assess severity and identify determinants of depressive disorder among caregivers of children with leukaemia in Baghdad, Iraq, 2014.

Methods: This cross sectional study was conducted on a convenience sample of caregivers of 250 leukaemia children aged <15 years admitted to Child Welfare Teaching Hospital, Baghdad, Iraq. Socio-demographic variables were collected and the presence of depressive disorder was assessed using the Arabic Version of Beck Depression Inventory II (BDI-II); those with a score of >16 were considered depressed.

Results: The prevalence of depression was 72% (95% CI: 66–77.5%); classified to 18.9% having borderline clinical depression, 36.7% moderate depression, 27.8% severe depression and 16.7% extreme depression. Presence of depression was significantly higher among younger age caregivers, disease duration of >12 months and frequent hospital admission.

Conclusions: The high prevalence of depression among care givers of leukaemia patients urge health care professionals to pay more attention to the psychological aspects of the families of leukaemia patients and ensure referring them for psychiatric support.

Keywords: depressive disorders, caregivers, leukaemia, determinants, Iraq

Citation: Lutfi NM; Al Lami F. Prevalence and determinants of depression among caregivers of children with leukaemia in Iraq. East Mediterr Health J. 2019;25(6):385-393. https://doi.org/10.26719/emhj.19.005

Received: 19/04/15; accepted: 11/01/18

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Introduction

Leukaemia is the most common malignant neoplasm in childhood, accounting for about 31% of all malignancies among children less than 15 years of age (1). In Iraq, the latest figures indicate a total leukaemia rate of 4.18 per 100 000 among boys, and 2.07 per 100 000 among girls during 2008–2009 (2). Since the late 20th century, the overall survival rate of Acute Myeloblastic Leukaemia (AML) has improved and reached 45–60% (3), while the 5-year survival rate for children diagnosed with Acute Lymphoblastic Leukaemia (ALL) rose from 84% during 1990–1994 to 90% during 2000–2005 (4).

A diagnosis of leukaemia reverberates around the family and has implications for all, not just the diseased child (5), and marks the beginning of social and psychological devastation for the whole family especially the mother. The length and intensity of the treatment can be as distressing as the disease itself, negatively affecting their functionality as parents and in turn the child's ability to handle the treatment (6). This makes children with leukaemia and their families require long-term help and support from various agencies, including the primary health care team.

The term family caregiver refers to an unpaid family member, friend or neighbour who provides care to an individual that has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing to taking medication (7). Care giving also involves a great deal of emotional support that may include listening, counseling and companionship (8). Today, one of the all-too silent health crises is caregiver depression. Early attention to symptoms of depression may help to prevent the development of a more serious depression over time (9), although stigma and lack of awareness of mental disorders lead to under-use of available mental health services (10).

It has been found that the younger the caregiver, the higher stress she or he experiences (11). The most important concern of the families was the provision of the necessary time and expenses (12). Parents of children with cancer suffered greater financial hardship than parents of children with other serious illness (13). Having other children to be looked after is an additional role for the caregiver that requires time and energy. The most time- and energy-consuming task performed by parents are the provision of emotional support to the ill child and supporting other children (14). Decrease in contact with others and planned activities and decreased time for social activities predicted distress in cancer caregivers (11). Continuation of a normal life is difficult for both the child and the mother due to economic burdens, problems at work, and restriction of social life (15).

Caregivers need a range of support services to remain healthy, improve their caregiving skills and remain in their caregiving role. Support services include information, assistance, counseling, respite, home modifications or assistive devices, caregiver and family counseling, and support groups (9). A lot of studies evaluated the psychiatric impact of different chronic diseases on the patients themselves, but little is known about this problem among the caregivers, and even less in Iraq. The objectives of this study were to estimate the prevalence, assess severity and identify determinants of depression among caregivers of children with leukaemia in Children Welfare Hospital, Baghdad, Iraq, 2014.

Methods

This cross-sectional study was conducted on a convenience sample of caregivers of 250 leukaemia children aged <15 years admitted to Child Welfare Teaching Hospital during March–June, 2014, and who accepted to participate. For each leukaemic child, the primary care giver accompanying the child was included. Verbal approval was granted from all participants.

Data collection

All information was obtained from the caregivers using a questionnaire that was filled through direct interview and gathered socio-demographic data of the caregiver (age, sex, residence, employment status, marital status, educational level, income, relationship to the patient and counts of other children to be looked after) and the disease status of the leukaemic child (age of onset of disease in years, duration of disease in months, and number of hospital admissions). Assessment of presence and severity of depression among caregivers were evaluated using the Arabic version of Beck Depression Inventory II (BDI-II) questionnaire. This questionnaire is the most frequently used screening instrument in clinical work and research on depression (16-19), created by Aaron T. Beck, and consists of 21-multiple choice survey measuring the mood of the participants for the previous two weeks. It was also proved useful for measuring the severity of depression (17). The easy applicability and psychometric soundness of this scale have popularized its use in a variety of samples and in health care setting worldwide (20).

The scores obtained from each question ranges from 0-3, the total score was calculated and it measures the presence and severity of cognitive and somatic symptoms of depression on a scale from 0-63. A score of 0-16 is considered normal, 17-20: borderline clinical depression, 21-30: moderate depression, 31-40: severe depression and over 40: extreme depression (19). A score of ≥17 is considered depression.

Statistical analysis

Statistical Package for Social Science (SPSS 19) was used for data entry and analysis. Chi square test (X²-test) of independence was used to test association between categorical data. Logistic regressions analysis was used to

identify the independent risk factors of depression (as outcome variable), with calculation of the Odds Ratio (OR) and its 95% Confidence Interval (CI). Statistical significance was considered whenever *P*-value was equal or less than 0.05.

Results

A total of 250 caregivers (all were females) were included. The age range was 18–54 years, the mean age (±standard deviation) was 34 (±8.7) years. Caregivers living in Baghdad represent 56.8%, the remaining were from other governorates. The majority of caregivers were housewives (88.4%, 221), and 92% (229) were married. (Table 1)

Secondary school and primary school graduates constituted 37.6% (94) and 36% (90) respectively, while illiterate represents 18.4% (46). Caregivers with inadequate income level were 58.4% (146). Mother caregivers constituted the vast majority (88.8%, 222), while grandmothers and aunts constituted the remaining 11.2% (28). Caregivers who were caring for 3+ children constituted 57.2% (143) and those with no other children to care for constituted 11.6% (29) (Table 1).

The proportion of studied children who developed leukaemia under five years old was 60% (150) (Table 2). The mean age (±SD) was 4.4 (±2.3) years. The duration of leukaemia of more than 12 months was reported in 35.6% (89) of leukaemic children. Leukaemic children who had 6+ hospital admissions constituted 36% (90), and those mitted for the first time constituted 31.2% (78) (Table 2).

According to the results of BDI-II questionnaire, 72% (180) of the study sample has depression; 95% CI 66.0–77.5%. Around 37% (92) of those with depression had moderate depression, followed by those having severe depression (27.8%, 70). Only 16.7% (42) had extreme severe depression.

The prevalence of depression was highest among youngest age group (<30 years = 80.6%, 83) and decrease with increasing age to reach 55.2% (32) among the oldest age group (40+ years). The association between age and depression was statistically significant (P = 0.003) (Table 1).

The prevalence of depression among currently married caregivers was 73.8% (169). Being married was significantly associated with depression (P = 0.036). Also, the prevalence of depression was significantly higher among caregivers with 3+ other children to be looked after (87.3%, 112) compared to 58.6% (17) for those with no other children to look after (P = 0.029) (Table 1).

The prevalence of depression was significantly higher among caregivers of leukaemic children with duration of leukemia of more than 12 months (87.6%, 78) as compared to those with the duration of \leq 12 months (63.4%, 102) (P = 0.000) (Table 2).

The prevalence of depression was highest at the two extreme categories of number of hospital admission; 79.5% (62) for those with first admission and 82.2% (74) for those with more than six admissions. The association

Research article EMHJ - Vol. 25 No. 6 - 2019

Table 1: Distribution of the study group by depression and selected socio-demographic variables

Socio-demographic	Depressed		Not dep	ressed	Total		X ²	P Value
variables	N=180	%	N=70	%	N=250	%		
Age group (years)								
<30	83	80.6	20	19.4	103	41.2	12.0	0.003
30-39	65	73.0	24	27.0	89	35.6		
40+	32	55.2	26	44.8	58	23.2		
Residence								
Baghdad	102	71.8	40	28.2	142	56.8	0.005	0.95
Other governorates	78	72.2	30	27.8	108	43.2		
Employment status								
Housewife	156	70.6	65	29.4	221	88.4	1.884	0.17
Currently employed	24	82.8	5	17.2	29	11.6		
Marital status								
Currently married	169	73.8	60	26.2	229	91.6	4.377	0.036
Divorced/widowed/ single	11	52.4	10	47.6	21	8.4		
Educational level								
Illiterate	30	65.2	16	34.8	46	18.4	5.062	0.17
Primary school	60	66.7	30	33.3	90	36.0		
Secondary school	74	78.7	20	21.3	94	37.6		
Vocational (institute/university)	16	80.0	4	20.0	20	8.0		
Income								
Adequate	71	68.3	33	31.7	104	41.6	1.229	0.27
Inadequate	109	74.7	37	25.3	146	58.4		
Relationship to the patient								
Mother	162	73.0	60	27.0	222	88.8	0.931	0.33
Grandmother/aunt	18	64.3	10	35.7	28	11.2		
No. of other children to be looked a	ıfter							
0	17	58.6	12	41.4	29	11.6	7.1029	0.029
1-2	51	65.4	27	34.6	78	31.2		
3+	112	87.3	31	12.7	143	57.2		

Table 2: Distribution of the study group by depression and selected disease characteristics

Disease Characteristics	Depressed		Not depressed		Total		X ²	P Value
	N=180	%	N=70	%	N=250	%		
Age of onset (years)								
<5 years	109	72.7	41	27.3	150	60.0	0.083	0.77
5+ years	71	71.0	29	29.0	100	40.0		
Duration of leukaemia (month)								
< 12 months	102	63.4	59	36.6	161	64.4	16.769	<0.0001
>12 months	78	87.6	11	12.4	89	35.6		
Count of hospital admissions								
First admission	62	79.5	16	20.5	78	31.2	20.517	<0.001
2-5	44	53.7	38	46.3	82	32.8		
6+	74	82.2	16	17.8	90	36.0		

between number of hospital admissions and depression was statistically significant (*P* <0.001) (Table 2).

A cross-classification was made for caregivers with severe/extreme depression versus moderate/borderline depression by a number of socio-demographic variables and disease status of the leukaemic children. Severe/extreme depression was significantly higher among youngest age group (< 30 years) (61.4%, 51) (P < 0.001); those with inadequate income level (51.4%, 56) (P = 0.02); and being mothers (46.9%, 76) (P = 0.046). (Table 3) The prevalence of severe/extreme depression was significantly higher among caregivers of leukaemic children whose age of onset of leukaemia was below 5 years old (50.5%, 55) (P = 0.044) (Table 4).

Logistic regression analysis was applied considering the presence of depression as the outcome variable; and the socio-demographic and disease status variables as independent variables in the model. The model was statistically significant and able to accurately predict group membership according to the outcome (depressed vs. not depressed) with an accuracy level of 78.4%. Three explanatory variables had a statistically significant association with the risk of having depression. These variables were:

- age; youngest age group (<30 years) with Odds Ratio
 (OR) =6.69; 95% Confidence Interval (CI): 1.91-22.77
 (P=0.003);
- disease duration; >12 months' duration with OR=6.225;
 95% CI: 2.399-16.150 (P=0.000); and
- number of hospital admission; first admission with OR =9.17; 95% CI: 1.67–49.13 (P=0.01) (Table 5).

Table 3: Distribution of depressed group by severity of depression and selected socio-demographic variables

Socio-demographic variables	Borderline disease / moderate depression		Severe/extreme depression		Total		X ²	P Value
	N=100	%	N=80	%	N=180	%		
Age group (years)								
<30	32	38.6	51	61.4	83	46.1	18.494	<0.001
30-39	44	67.7	21	32.3	65	36.1		
40+	24	75.0	8	25.0	32	17.7		
Residence								
Baghdad	55	53.9	47	46.1	102	56.6	0.255	0.61
Other governorates	45	57.7	33	42.3	78	43.3		
Employment status								
Housewife	87	55.8	69	44.2	156	86.6	0.022	0.88
Currently employed	13	54.2	11	45.8	24	13.3		
Marital status								
Currently married	92	54.4	77	45.6	169	93.8	1.399	0.24
Divorced/widowed/single	8	72.7	3	27.3	11	6.1		
Educational level								
Illiterate	13	43.3	17	56.7	30	16.6	3.016	0.39
primary school	34	56.7	26	43.3	60	33.3		
Intermediate/secondary school	42	56.8	32	43.2	74	41.1		
Vocational (institute/university)	11	68.8	5	31.3	16	8.8		
Income								
Adequate	47	66.2	24	33.8	71	39.4	5.377	0.02
Inadequate	53	48.6	56	51.4	109	60.5		
Relationship to the patient								
Mother	86	53.1	76	46.9	162	90.0	4.0	0.046
Grandmother/aunt	14	77.8	4	22.2	18	10.0		
Count of other children to be look	ed after							
0	11	64.7	6	35.3	17	9.4	2.630	0.26
1-2	32	62.7	19	37.3	51	28.3		
3+	57	50.9	55	49.1	112	62.2		

Table 4: Distribution of depressed group by severity of depression and selected disease characteristics

Disease Characteristics	Borderline disease / moderate depression		Severe/extreme depression		Total		X2	P Value
	N=100	%	N=80	%	N=180	%		
Age of onset (years)								
<5 years	54	49.5	55	50.5	109	60.5	4.048	0.044
5+ years	46	64.8	25	35.2	71	39.4		
Duration of leukemia (month)								
< 12 months	59	57.8	43	42.2	102	56.7	0.499	0.48
>12 Months	41	52.6	37	47.4	78	43.3		
Count of hospital admissions								
First admission	33	53.2	29	46.8	62	34.4	3.902	0.14
2-5	30	68.2	14	31.8	44	24.4		
6+	37	50.0	37	50.0	74	41.1		

Table 5: Logistic regression model with the risk of having depression as the dependent (outcome) variable and selected explanatory variables

	Partial OR	95% Confidence Interval OR	P Value	
Age				0.008
Youngest age group (<30 years) compared to oldest age group (40+ years)	6.69	1.91 - 22.77	0.003	56.7
30-39 years age group compared to oldest age group (40+ years)	2.51	0.82 - 7.46	0.1	43.3
Duration of the disease				<0.0001
Duration of disease (>12 month) compared to (<12 months)	6.225	2.399-16.150	<0.0001	56.7
Count of hospital admissions				0.006
First admission compared to very frequent admissions (6+)	9.17	1.67 - 49.13	0.01	56.7
2-5 admissions compared to very frequent admissions (6+)	0.88	0.34 - 2.24	0.79	
30-39 years age group compared to oldest age group (40+ years)	2.51	0.82 - 7.46	0.1	43.3
Other independent factors adjusted for, but having no statistically significan	nt association with the	outcome.		

P (Model) <0.001; Overall predictive accuracy = 78.4%

Discussion

Global and domestic media reports have emerged since the 1990s, highlighting the high cancer rate in Iraq. The incidence rate of all types leukaemia has risen substantially in children less than 15 years old (21). Most of the studies about caregiver depression were conducted in western countries, which may be different from elsewhere (7).

In this study the prevalence of depression based on BDI-II score was much higher than the prevalence reported in Iraq Mental Health Survey (IMHS), 2006–2007. The life time prevalence of any mental disorder in IMHS was 18.8% and Major Depressive Disorder (MDD) was the second most common disorder (7.2%) after anxiety disorders (13.8%). The 12-month prevalence of any disorder was 13.6%; 21.9% of them considered serious and MDD was the most common disorder among this group (51%) with no significant sex difference (22). In Iraq

Family Health Survey, around 35.5% of respondents were considered as having significant "psychological distress". The prevalence was higher among females (40.4%) than males (30.4%) (23). Among attendees of primary healthcare centres in Baghdad, the prevalence of mental illness and depression was 36.8% and 18.3%, respectively (24). Lower figures were reported in Nassiyriah City, south Iraq, where the prevalence of mental illnesses was 18% and the prevalence of depression was 10.8% (25).

The high prevalence of depression among caregivers in this study is consistent with a study in Pakistan, 2014, on mothers with children having cancer where 78% of the mothers were depressed (20); the majority had mild depression (69%). A similar high prevalence of depression was noted in a study in Turkey, 2009, on mothers of children with leukaemia where 88% of mothers had depression, but the majority had major depression (61.5%) (26). In the Islamic Republic of Iran, a study conducted in

2014 showed a high prevalence of depression (91%) among caregivers of children with cancer; the majority had mild depression (69%) (16). In Korea, 2013, the prevalence of depression among family caregivers of cancer patients was 82.2%, with the majority reporting mild depression (40.4%) (27).

The prevalence of depression was high among the youngest age group of caregivers, which is consistent with Mathews et al., 2003 (11) study and a study done in Turkey in 2011 (28), and may reflect the inadequate experience of young mothers. The high prevalence of depression among caregivers with large number of other children to look after is similar to findings of studies conducted in Turkey, 2011 (28), and the United States of America, 2006 (29). Additional parenting role increases distress experienced by the caregiver.

Disease duration of more than 12 months was a significant risk factor for caregiver depression. Similar findings were reported in a study conducted in Sweden, which showed that mothers of children of newly diagnosed cancer, in active cancer and 1-year post diagnosis, reported more depressive symptoms than mothers of children undergoing active cancer therapy (30). The prevalence of depression was highest at the two extreme categories of number of hospital admissions. The first admission represents the time of shock, and more than six admissions represent the period of intensive chemotherapy. Some children need more frequent hospital admissions because they have frequent myelosuppression (31).

Severe/extreme depression was highest among the youngest age group; a finding consistent with a Turkish study (28) which also found that the younger the age of the caregiver the higher his/her level of depressive symptoms. Also, severe/extreme depression was more among those with inadequate income level. Family income was associated with caregiver depressive symptoms and the majority of depressed caregivers belong to the low socioeconomic class (28,32). Mothers were more likely to have severe/extreme depression than non-mother caregivers due to the heavy emotional burden imposed on the mother of a leukaemic child, and other responsibilities that have to be managed by the mother for other children, her husband and house management. Also, severe/extreme depression was

higher among mothers caring for children who develop the disease below 5 years of age. Emotional trauma and fear about the child's future could be behind this finding.

In this study, only the mothers of children with leukaemia were included, since the age limit of patients admitted to the paediatric hospitals in Iraq is 15 years and consequently, for cultural reasons, only mothers or other female caregivers are allowed to stay with the patients. Many studies conducted in other countries had included fathers and mothers of children diagnosed with leukaemia and other cancers. These studies, which included systematic review and meta-analysis, revealed higher prevalence of different types of mental disorders such as depression, anxiety and post-traumatic stress disorders among mothers as compared to fathers (32–38). Still, few studies did not show such a gender difference (39–41).

Limitations

As this was a cross-sectional study, any casual relationships cannot be inferred. Also, most of the caregivers in this study were unemployed; this had made the comparison by employment not feasible. Lastly, estimating the adequacy of family income was subjective and depended on the caregivers' responses.

Conclusion

The prevalence of depressive disorders among caregivers of leukaemic children was quite high, particularly among young mothers caring for children with disease duration of more than a year and those with frequent hospitalization. Health care professionals need to pay more attention to the psychological aspects of the families of leukaemia patients and ensure provision of psychosocial counseling and support as part of the overall management. The Iraqi Ministry of Health needs to take the initiative for the provision of comprehensive psychosocial support to the families caring for patients with chronic diseases and disabilities. Nursing schools can play a pivotal role in developing a cadre specialized in the provision of this type of support.

Acknowledgments

The study reported in this manuscript has been implemented after approval of the Ministry of Health, Iraq, and the Iraqi Board of Medical specialization.

Funding: None

Competing interests: None declared.

Prévalence et déterminants de la dépression chez les aidants d'enfants atteints de leucémie en Iraq

Résumé

Contexte : La dépression chez les aidants d'enfants leucémiques est souvent négligée et donc non diagnostiquée, les médecins se concentrant la plupart du temps sur l'évaluation et l'état des patients. Une attention précoce accordée aux symptômes de la dépression pourrait permettre de prévenir le développement d'un stade plus avancé de cette affection.

Objectifs: La présente étude a été conduite dans le but d'estimer la prévalence, d'évaluer la sévérité et d'identifier les déterminants des troubles dépressifs chez les aidants d'enfants atteints de leucémie à Bagdad (Iraq) en 2014.

Méthodes: La présente étude transversale a été réalisée sur un échantillon de commodité de 250 aidants d'enfants leucémiques âgés de moins de 15 ans admis au Centre hospitalier universitaire pour la protection de l'enfance à Bagdad. Les variables socio-démographiques ont été recueillies et la présence de troubles dépressifs a été évaluée à l'aide de la version arabe de l'Inventaire de dépression de Beck II (BDI-II). Les répondants ayant un score supérieur à 16 étaient considérés comme dépressifs.

Résultats: La prévalence de la dépression était de 72 % (IC à 95 %: 66 %-77,5 %), parmi lesquels 18,9 % ont été diagnostiqués en dépression clinique limite, 36,7 % en dépression modérée, 27,8 % en dépression sévère et 16,7 % en dépression extrême. La présence de cette affection était significativement plus élevée parmi les aidants plus jeunes ; elle durait généralement plus de 12 mois et nécessitait des hospitalisations fréquentes.

Conclusions: La prévalence élevée de la dépression parmi les aidants de patients leucémiques doit inciter les professionnels de la santé à accorder une attention plus soutenue à l'état psychologique des familles des patients et à s'assurer qu'elles soient orientées en vue de bénéficier d'un soutien psychiatrique.

معدل انتشار الاكتئاب بين القائمين على رعاية الأطفال المصابين بسرطان الدم (اللوكيميا) والعوامل المحددة له في العراق

نور محمد لطفي، فارس العلمي

الخلاصة

الخلفية: عادة ما يتم إغفال الاكتئاب لدى القائمين على الرعاية ومن ثمَّ لا يُلاحظ، حيث يركز الأطباء في الغالب على تقييم المريض وحالته. ويساعد الانتباه المبكر لأعراض الاكتئاب على الوقاية من تطوره إلى اكتئاب أكثر شدة على مدار الوقت.

الأهداف: أُجريت هذه الدراسة لتقدير معدل انتشار الاضطراب الاكتئابي وتقييم شدته وتحديد العوامل المحددة له بين القائمين على رعاية الأطفال المصابين بسر طان الدم في بغداد، العراق، ٢٠١٤.

طرق البحث: أُجريت هذه الدراسة المقطعية على عينة عشوائية من القائمين على رعاية ٢٥٠ طفلاً مصابًا بسرطان الدم تقل أعهارهم عن ١٥ عامًا والذين أُدخلوا إلى المستشفى التعليمي لرعاية الأطفال، بغداد، العراق. كها مُجمعت المتغيرات الاجتهاعية والسكانية، وتم تقييم وجود الاضطراب الاكتئابي باستخدام النسخة العربية من التنقيح الثاني لمقياس بيك للاكتئاب (BDI-II)؛ واعتُبِر الأشخاص الذين حصلوا على أكثر من ١٦ نقطة مصابين بالاكتئاب.

النتائج: بلغ معدل انتشار الاكتئاب ٧٢٪ (٦٦٪ ٥٠ /٧٧٪ ٩٥ CI:)؛ حيث تم تصنيفهم إلى ١٨,٩٪ مصابين بالاكتئاب السريري الحدودي، و٧, ٣٦٪ مصابين باكتئاب متوسط الشدة، و٨, ٢٧٪ مصابين باكتئاب حاد، و٧, ١٦٪ مصابين باكتئاب شديد. وكانت نسبة الاكتئاب مرتفعة بشدة بين القائمين على الرعاية الأصغر سنًا، حيث امتدت فترة المرض لأكثر من ١٢ شهرًا وتكرر دخولهم إلى المستشفى.

الاستنتاجات: يدعو معدل الانتشار المرتفع للاكتئاب بين القائمين على رعاية الأطفال المصابين بسرطان الدم العاملين الصحيين إلى إعطاء مزيد من الاهتمام للجوانب النفسية لعائلات المصابين بسرطان الدم وضهان إحالتهم للحصول على الدعم النفسي.

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