

Significant Impact of Cutaneous T-Cell Lymphoma on Patients' Quality of Life

Results of a 2005 National Cutaneous Lymphoma Foundation Survey

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BACKGROUND. Cutaneous T-cell lymphoma (CTCL) can have a profound impact on a patient's health-related quality of life; however, little is known about its actual impact. The authors evaluated patients' perspectives on the impact of CTCL on physical functioning, lifestyle, emotional well being, and satisfaction with treatment.

METHODS. A 4-page, self-administered questionnaire was mailed and made available online in March 2005 to the entire United States membership of the Mycosis Fungoides Foundation (n = 930 members). Outcome measures were patients' perspectives on the psychosocial impact of CTCL and the management of their disease.

RESULTS. The response rate was 68%, and 93.6% of respondents were white. The majority of respondents had mycosis fungoides (89%). Respondents were bothered by skin redness (94%) and by the extent of symptoms that affected their choice of clothing (63%). For most patients, the disease had a functional impact, rendering them tired or affecting their sleep. Health distress was reported by almost all respondents, with 94% reporting that they worried about the seriousness of their disease and 80% worrying about dying from the disease. Sixty-two percent of respondents reported that their disease made them feel unattractive, 85% reported that their treatment made their disease seem more manageable, but 61% reported that they felt burdened financially by their disease.

CONCLUSIONS. The high response rate and patients' responses to the survey provided compelling evidence that patients believed CTCL had a profound and severe impact on their functioning, emotional, and social well being. A striking health distress was prevalent in almost all respondents. Although the majority of patients reported that treatments made their disease more manageable, a significant proportion reported that they felt burdened financially by their disease.

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Cutaneous T-cell lymphoma (CTCL) refers to a group of lymphoproliferative disorders characterized by clonal accumulation of neoplastic T-lymphocytes in the skin.¹ In the United States, nearly 20,000 individuals have CTCL, and there are approximately 1200 new diagnoses each year. The most common form, mycosis fungoides (MF), can cause severe suffering with adverse affects across multiple dimensions of health-related quality of life (HRQOL).^{2,3} MF is often a chronic disease, and multiple therapies are available, each with varying side-effect profiles. Those patients with MF who pro-

gress to the tumor stage or who have the leukemic variant, Sézary syndrome, often die of their malignancy. There have been few studies of the impact of MF and other CTCL on patients' HRQOL, and no studies have included more than a relatively small series of patients.

For these reasons, we conducted a survey to measure HRQOL in patients with CTCL as well as their perceptions of their CTCL treatment. In 2005, we partnered with the Mycosis Fungoides Foundation, which subsequently was renamed The Cutaneous Lymphoma Foundation (The Foundation). This is an independent, nonprofit patient advocacy organization that is dedicated to supporting patients with cutaneous lymphomas by promoting awareness and education, advancing patient care, and facilitating research.

We developed a survey that was administered by The Foundation to its members in the United States with CTCL. The survey evaluated patients' perspectives regarding the impact of CTCL and its treatment on their lifestyle, occupation, emotional health, and social condition. We observed that patients frequently reported significant adverse impacts of CTCL on several aspects of their life, including increased health distress, and that CTCL adversely affected their role function.

MATERIALS AND METHODS

The survey was developed by the research team and submitted to the Board of The Foundation for review. The study design and survey were reviewed and approved by the Institutional Review Board at Boston University. The 4-page, self-administered survey was piloted initially for clarity, readability, and time to complete. The final survey was mailed by The Foundation to the entire patient membership in the United States ($n = 930$ patients) in March 2005 and was made available online to those members in the United States who preferred to complete an online survey. Follow-up postcard reminders were sent 1 month later to increase response rates. Surveys were completed anonymously either online or on paper and were sent back in a self-addressed envelope. Completed surveys were coded and entered into a computer with double entry of random subsamples.

The survey content included questions on demographics, incidence and severity of CTCL, type of CTCL, psychosocial impact, symptoms, awareness of available therapies, therapies received, perceived treatment effectiveness and awareness, and access to The Foundation website. It was designed to capture the essentials of CTCL patients' experience with their disease, their perceptions, and their awareness of available therapies.

For the current analysis, data records from paper surveys were combined with records from online surveys of those respondents who indicated residence in the United States (US Foundation membership). The complete data file was analyzed using SAS software (version 9.1). Frequency distributions of survey questions were obtained for the overall sample and in subsets that were defined by disease stage. Differences between groups were evaluated by using chi-square tests and Student *t* tests. In addition, we performed an exploratory factor analysis to uncover the latent structure or dimensions of HRQOL as measured by the set of variables in our survey. For this analysis, we used Proc Factor in SAS with Varimax rotation, limiting the analysis to factors with Eigen values >1.0 . Internal consistency of identified factors was evaluated by computing Cronbach α correlations. Based on this analysis, unit-weighted factor scores were computed and standardized with values ranging from 0 (worst) to 100 (best) for comparisons by stage and other variables.

RESULTS

Demographics

In total, 309 surveys were returned in self-addressed envelopes, and 321 surveys were completed online, for an overall response rate of 67.7%. Fifty-five percent of respondents were women, and 45% were men. Respondents were predominantly white (white, 93.6%; African American, 4.3%). The median age of survey respondents was 57 years. The median age at onset of symptoms was 46 years, and the median age at diagnosis was 53 years. Among all respondents, 56.6% had an income $> \$60,000$, and 73.2% had completed some level of college.

There were some differences between respondents who completed the survey on paper and those who completed it online (Table 1). Respondents who used the Internet tended to be older (61 years vs. 55 years), more often were white (96.3% vs. 90.9%), and were older at the onset of symptoms (48 years vs. 43 years) and at diagnosis (54 years vs. 51 years). Other differences were small and were not significant.

The majority of respondents had MF (89%). Patients with Sézary syndrome comprised 4% of respondents. Patients with a CD30-positive lymphoproliferative disorder represented 2% of respondents. The majority of respondents indicated that they were bothered by itching (88%), scaling (83%), or skin redness (94%). Pain was another important symptom, with 41% of respondents reporting some pain and 13% reporting "quite a bit" to "very much pain."

TABLE 1
Cutaneous T-Cell Lymphoma Survey: Comparison of Paper Respondents vs. Internet Respondents in the United States

Variable	Paper respondents	Internet respondents	P
Age, y			
Mean (SD)	54.4 (12.2)	60.9 (13.4)	<.001*
Median	55	61	
Age at diagnosis, y			
Mean (SD)	50.1 (12.3)	54.2 (14.2)	<.001*
Median	51	54	
Age at symptoms, y			
Mean (SD)	42.9 (15)	48.2 (16.3)	<.001*
Median	43	48	
Female gender (%)	52.4	55	NS [†]
White race (%)	90.9	96.3	.006 [†]
Income ≥\$60K (%)	57.5	52.9	NS [†]
Some college (%)	73.8	73.6	NS [†]

SD indicates standard deviation; NS, nonsignificant.

* *t* test.

[†] chi-square test.

The extent of symptoms affected choice of clothes in 63% of respondents.

Respondents were asked to indicate the stage of their disease, but only 33% gave answers that could be used reliably to assign stage. Among the 245 respondents who had classifiable answers, 174 respondents (80.0%) reported stage IA to IIA disease, 43 respondents (17.6%) reported stage IIB/III disease, and 6 respondents (2.4%) reported stage IV disease.

Functional Impact of CTCL

Overall, respondents reported a serious impact of CTCL on their functioning (Table 2). For at least 66% of respondents, their disease made them tired. CTCL affected their ability to meet the needs of their family, interfered with their job, resulted in missed days of work, limited their normal daily activities, and had a significant impact on their social interactions. The ability to sleep was another key aspect of their functioning, with 66% of respondents reporting that CTCL affected their sleep.

Psychosocial Impact of CTCL

A significant psychosocial impact was reported (Table 3) with the themes of depression, frustration, anger, embarrassment in many respondents; worries about disease seriousness in almost all respondents (94%); and death in a majority of respondents (80%). Although 39% of respondents reported that their disease made them feel ashamed, 62% felt that their disease made them unattractive. For close to 30% of

TABLE 2
Activities of Daily Living Affected Negatively by Cutaneous T-Cell Lymphoma in the United States Survey

About your disease	Percentage of respondents		
	Not at all	A little bit/somewhat	Quite a bit/very much
Interferes with job	54.8	30.8	14.4
Limits family activities	57.7	31.4	10.9
Interferes with keeping a job	73.7	14.8	11.5
Missed work or school	45.1	40.7	14.2
Limits daily activities	49.8	36.2	14.0
Forced to stay in bed	74.5	18.8	6.6
Makes you tired	34.4	41.9	23.8
Tend to stay at home	61.8	24.7	13.5
Affects your social life	52.3	32.6	15.2
Affects your desire to be with people	59.2	27.3	13.5
Affects how well you sleep	40.1	38.6	21.3
Feel financially burdened	39.5	40.7	19.8
Content with your current QOL	16.7	33.3	50.0

QOL indicates quality of life.

TABLE 3
Psychosocial Activities Affected by Cutaneous T-Cell Lymphoma in the United States Survey

About your disease	Percentage of respondents		
	Not at all (disagree)	A little bit/somewhat (somewhat agree)	Quite a bit/very much (agree)
Worried about dying	19.9	56.4	23.8
Worried disease may be serious	6.3	56.4	37.4
Makes you feel depressed	27.4	53.0	19.7
Feel frustrated about disease	13.4	48.1	38.5
Feel ashamed about disease	59.9	30.3	8.7
Feel angry about disease	36.6	43.2	20.3
Satisfied with coping	28.5	57.2	14.3
Interferes with sex	(52.7)	(23.0)	(24.3)
Feel unattractive	(37.0)	(39.1)	(23.9)

respondents, their disease had been mistaken for an infectious/contagious condition (data not shown). Furthermore, in 47% of respondents, their disease interfered with their sex life, and 47% of respondents reported that CTCL affected how close they could be with a loved one (data not shown). With regard to coping skills, more than 25% of respondents were not satisfied with how they were coping with their disease.

Treatment of CTCL

The majority of respondents reported that they were satisfied with the treatments they received (82%). In

TABLE 4
Exploratory Factor Analysis

Item	Role function	Health distress	Treatment satisfaction	Symptoms	Emotions
Role function					
Disease interferes with your job or school	82.1				
Disease prevents you from meeting family needs	79.7				
Miss work or school because of medical visits	77.3				
Disease limits your normal daily activities	77.1				
Disease interferes with keeping a job or staying in school	75.1				
Disease forces you to stay in bed	73.3				
Stay at home because of your skin disease	71.2				
Disease affects your social life	66.9				
Disease affects your desire to be with people	63.3				
Disease makes you tired	63.2				
Disease affects how well you sleep	55.2	40.1			
Bothered by pain	53.4				
Disease affects how close you can be with those you love	47.7				41.7
Feel financially burdened by the cost of treatments	40.1				
Content with your current quality of life	40.1				
Health distress					
Worry that your disease may be serious		75.7			
Worry about dying from your disease		75			
Feel angry about your disease		58.2			
Satisfied with how you are coping with your disease		50.6			
Disease makes you feel depressed	42.4	64.1			
Feel frustrated about your disease		64.1			
Treatment satisfaction					
Satisfied with the treatments you have received			83.9		
Satisfied with the effectiveness of your current treatment			80.4		
Feel that the treatments make your disease more manageable			72.8		
Feel you need a more aggressive treatment			63		
Satisfied with the explanations from your physicians			57.3		
Physician treating your disease communicates well with you			55.4		
Symptoms					
Bothered by skin redness				64.3	
Bothered by scaling				57.9	
Bothered by itching				53.9	
Disease affects your choicer of clothes				44.5	
Emotions					
Disease makes you feel ashamed					62.1
Feel embarrassed by your disease					60
Disease makes you feel unattractive					45.0
Feel you have been treated unfairly by service establishments					44.4
Feel supported by your family and friends					41.1
Disease interferes with your sex life					40.4
Factor loadings*					
Variance explained	7.23	4.28	3.33	2.81	2.22
Standardized α coefficient	.94	.91	.85	.79	.73
Sample mean [†]	74.1	57.9	66.3	48.3	71.8
Standard deviation	23.9	25.9	25.1	25.4	23.4

*Presents factor loading scores (limited to scores > 40).

[†] Factor scores are standardized to range from 0 (worst) to 100 (best).

total, 85% of respondents felt that their treatment made their disease more manageable. The majority of respondents (93%) reported that the physician treating their disease communicated well about their

disease and progress, and 84% were satisfied with the explanations they had received from their physicians about their disease. Patients were less content with treatment effectiveness, because approximately

TABLE 5
Factor Scores by Stage of Disease

	Early stage (N = 196)*		Late stage (N = 49)		t Test of difference; P
	Mean	SD	Mean	SD	
Role function	79.1	17.9	60.4	26.2	< .001
Health distress	57.7	24	39.8	23.6	< .001
Treatment satisfaction	66	24.2	54.6	25.4	.006
Symptoms	52.9	22.1	31.4	19.2	< .001
Emotional well being	7.4	22.1	53.3	24.7	< .001

SD indicates standard deviation.

* Early Stage indicates stages IA to II; Late Stage, stages IIB, III, and IV. There was insufficient information on the remaining patients to assign stage.

25% of respondents reported that they were either “not satisfied” or “not sure” how effective their treatment was at the time of survey completion. With regard to treatment aggressiveness, 28% of respondents felt that they needed a more aggressive treatment, and 36% were “not sure.” Only 8% of respondents felt that they had been treated unfairly. A majority of respondents (61%) felt financially burdened by their disease.

Types of Treatment

For all therapies, approximately 66% of respondents commented on their use. More than 75% of respondents had received topical steroids and, of those, 65% reported that they were helpful. Nitrogen mustard, which was received by approximately 50% of respondents, was reported as helpful by 50% of those recipients. Carmustine had been received by <10% of respondents, and most recipients (89%) reported that it was not beneficial. Less than 25% of respondents had received topical retinoids, and close to 50% of those recipients reported that they were helpful. Approximately 33% of respondents had received narrowband ultraviolet light, and, of those, approximately 66% of recipients reported that it was helpful. Psoralen with long-wavelength ultraviolet light (PUVA) had been received by 42% of respondents and was reported as helpful by 75% of those recipients. Less than 10% of respondents had received electron beam therapy, and, of those, 39% of recipients reported that it was helpful. Oral bexarotene had been received by close to 10% of respondents and, of those, 42% of recipients reported that it was beneficial. Both extracorporeal photopheresis and subcutaneous interferon were received by <10% of respondents and, of those, approximately 33% Of recipients reported that those treatments were help-

ful. Oral methotrexate also was received by <10% of respondents, but <25% of those recipients reported that it was beneficial. The fusion toxin therapy, denileukin diftitox, was received by very few respondents (<3%) and reportedly was helpful in only 9%. Close to 10% of respondents received chemotherapy, and >33% of those recipients reported that it was helpful.

Factor Analysis

The exploratory factor analysis identified 5 factors (Table 4). Based on the component items in each factor, they were labeled as role functioning, health distress, treatment satisfaction, symptoms of disease, and emotional well being. All 5 factors performed well with distinct patterns of items based on factor-loading scores and explained variances. All 5 factors also showed good internal consistency with high standardized α coefficients.

Unit-weighted factor scores were computed and contrasted in respondents classified by disease stage (Table 5). A strong association was evident with substantially lower scores (worse HRQOL) in respondents with late-stage disease. Differences in factor scores between the groups ranged from a 50% standard deviation for treatment satisfaction, a 75% standard deviation for role function and health distress, and a nearly 100% standard deviation for symptoms and emotional well being. Factor scores in respondents without sufficient information to classify by stage did not differ significantly from the scores in respondents who had early-stage disease.

DISCUSSION

Several key findings emerge from this national survey, which was conducted within a well defined, representative CTCL population. The response rate of 68% offers a relatively unbiased picture of the impact of CTCL on patients' HRQOL. The magnitude of the response provides clinicians with valuable insights into patients' perceptions of the impact of CTCL on their lives and the manageability of their disease. To date, no studies or surveys adequately had documented the disruption that patients with CTCL experience in their daily lives. To our knowledge, the current study is the first to document the extent to which CTCL has an impact on patients' lives. The most significant aspect of this impact is the health distress reported by almost all respondents, with 94% of all respondents reporting that they worried about the seriousness of their disease and 80% reporting that they worried about dying from the disease. A majority also reported that they felt frustrated with their dis-

ease, angry, and depressed. This health distress probably has been underestimated by those who care for patients with CTCL. Our previous results suggest that the disease has an impact on emotional well being that is related mostly to disease stage.²⁻⁵ Emotional well being includes anger, sadness, depression, embarrassment, frustration, and worries of disease worsening and death.⁵ It is clear that all of these emotions are relevant to the HRQOL of patients with CTCL. It is noteworthy that 2 skin conditions with no connotation of cancer, atopic dermatitis and psoriasis, reportedly affect HRQOL by heightening psychological distress.⁶ This distress, in turn, may affect the outcome of dermatologic treatments. Particularly in patients with psoriasis, it has been observed that psychological distress results in an unfavorable outcome in the response to PUVA.⁷ Adding cognitive behavior therapy to standard treatment improved the clinical severity of psoriasis.⁸ Given our findings and the literature on psoriasis, additional research is needed in this area, because it is likely that psychological distress affects the outcomes of patients with CTCL, possibly in a similar manner to that observed in patients with psoriasis. An important question that our data raise in patients with CTCL is whether the "cancer connotation" affects HRQOL more deeply compared with the impact of atopic dermatitis and psoriasis on HRQOL. The visibility and symptoms associated with the cutaneous manifestations of CTCL are major contributors to HRQOL, but there are no data on this additional cancer impact. It is tempting to postulate that the cancer connotation would add further to health distress in CTCL; however, research in this area is needed to clarify that hypothesis patients with CTCL.

The emotional impact of CTCL on patients' lives clearly has been underestimated in our daily assessment of patients and in clinical trials enrollment. Only 1 large, published Phase III clinical trial of denileukin diftitox included HRQOL-specific and additional CTCL-specific questions.⁹ To date, there has been no national standard assessment of CTCL patients' emotional well being. Our survey suggests that questioning patients about their overall health, including emotional, role function, and psychosocial health, would shed light on the exact impact of their disease on their well being. The work of Mary-Margaret Chren has highlighted the relevance of improving patients' overall care, with the patient report representing a vital part of their disease evaluation.¹⁰ In light of the serious impact of CTCL on patients' emotional well being, HRQOL assessment should be incorporated as a routine part of the evaluation of patients with CTCL and of their enroll-

ment in clinical trials. In other cancers, the measurement of HRQOL has been a major focus of research for close to 25 years. HRQOL research has provided insight into the management of breast, prostate, and colorectal cancers. For example, in the primary management of breast cancer, HRQOL measurements provided information that was useful in selecting optimal treatment when 2 medical options had equivalent medical outcomes.¹¹

A surprising finding in the current study was the proportion of respondents (close to 66%) who reported that symptoms affected the choice of their clothing. A large majority of respondents (>80%) were bothered by itching, scaling, or skin redness. Pruritus was much more common than expected (88% of respondents reported this symptom). Pain also was significant. In evaluating patients with CTCL, physicians principally have focused on objective clinical findings, extent of lesions, type of lesions (patch, plaques, tumors), presence of lymph nodes, and flow cytometry results; however, they probably are unaware of the patients' perspective and how the location of lesions (i.e., on the face or other visible areas) can have a major impact on patients' HRQOL.

Another major impact of CTCL is that of role function. CTCL causes significant disruption in the lives of patients. For approximately 66% of respondents, the disease made them tired or affected their sleep. For at least 50% of respondents, it interfered with their daily activities, and 55% of respondents had missed work or school. In total, 43% of respondents felt that their disease prevented them from meeting the needs of their family. These results were striking, and we did not expect to observe such an impact on role function, because 80% of respondents who provided information about their disease stage had early-stage MF. Role function may be affected by the disease or by the treatment itself. Our representative national survey highlights not only a tremendous impact on role function but indicates an unappreciated financial burden of the disease in 61% of respondents. In light of the chronicity of CTCL, financial coverage of medication should be addressed when discussing prognosis and choice of therapies with all patients.

The psychological impact of CTCL also was enormous, with 62% of respondents reporting that their disease made them feel unattractive. Close to 50% of respondents reported feeling that their disease interfered with their sex life or affected how close they could be with a loved one. A significant proportion of respondents also reported that their disease had been mistaken for an infectious/contagious condition, and many felt ashamed of their disease. Overall,

our survey results point to a tremendous psychosocial impact of CTCL. Although, to date, we have used weighted skin scores to assess for clinical severity of disease, our survey data suggest that incorporating patients' perspectives will be relevant, because treating their skin may not necessarily translate into the treatment of what physicians have perceived as "their disease." Acknowledging the many facets of their debilitating skin condition, including the physical, psychological, emotional, and financial aspects, will be relevant toward improving patients' overall health. Our colleagues who work with psoriasis patients have recommended⁷ that encompassing a holistic approach to the treatment of chronic inflammatory skin diseases will be a first step toward improving patients' lives.

With regard to treatment, the majority of respondents reported that they were satisfied with treatments received and explanations given and that the treatments and explanations made their disease more manageable. The majority of respondents also reported that the physician treating their disease communicated well about the disease. These findings are important, because they indicate that, to a certain point, current therapies are making the disease more manageable for patients. However, >25% of our respondents reported feeling that the treatment of their disease was not aggressive enough. This finding suggests that physicians should discuss carefully patients' treatment expectations and their desire and tolerance for more aggressive therapies given the side-effect trade-offs.

The exploratory factor analysis of questions from our survey yielded useful and promising results. The 5 factors that were identified in this analysis, role functioning, health distress, treatment satisfaction, disease symptoms, and emotional well being, capture the salient aspects of the disease on quality of life as perceived by patients. These factors performed well with good internal consistency, and their validity is supported further by the relatively large decrements observed for patients with late-stage disease. These differences also indicate the profound impacts of advanced CTCL on various aspects of HRQOL.

There are limitations to our survey. We did not capture the data on nonrespondents with regard to gender, race, or income. We did not have a representative group of African Americans with CTCL, although previous data suggested that blacks are twice as likely to be afflicted as whites.¹² It is possible that African Americans with CTCL do not have the same access as well educated whites to patient-advocacy organizations like The Foundation. Foundation members, who self-selected themselves to complete

our survey, may not be completely representative of the CTCL population of the United States. Future studies on the impact of CTCL on HRQOL should include a larger representative group of African-American patients with CTCL. We also did not have adequate representation from other racial origins (e.g. Hispanics), and future studies should capture those data. Because our respondents included a predominantly educated population, our findings may not be generalizable to the entire American CTCL population. However, it is also possible that the impact of CTCL on the HRQOL of respondents with lower socioeconomic status would have been greater, possibly as a result of lack of awareness of The Foundation and its mission of "promoting awareness and education, advancing patient care, and facilitating research." In our survey, approximately 66% of respondents did not provide information on their disease stage. However, we observed that factor scores among respondents who did not have sufficient information to be classified by disease stage did not differ significantly from the factor scores among respondents who had known early-stage disease, suggesting that the respondents with unknown disease stage may have had early-stage disease. Because the survey was conducted with The Foundation, it is possible that patients who had no knowledge of The Foundation may have had different demographics or may have responded differently to our survey, as postulated above for African-American patients with CTCL. However, the breakdown of types of CTCL among patients who responded was similar to that in international data bases of patients (that is, the majority have MF). Although, even with a breakdown of CTCL types similar to the breakdown in national data bases, the impact of HRQOL may have been different.

Our survey assessed respondents at a single time point, and this may be viewed as another limitation. In this regard, 1 respondent commented as follows: "This survey takes only a snapshot in time, and the response (at least to my thinking) depend greatly on one's current status. My responses on some questions would have differed quite a bit only a couple months ago—when undergoing different treatment with different results—and I found myself struggling with which answer to give. This, once again, points out the unpredictable ups and downs of this disease." However, in the U.S. Food and Drug Administration's Draft Guidance on Patient Reported Outcome Measures,¹³ it is stated that "It is usually better to construct items that ask patients to describe their current state than to ask them to compare their current state with an earlier period or to attempt to average their experience over a specified period of

time." Thus, assessing respondents at a single time point does not appear to represent a limitation.

In conclusion, to our knowledge, our national survey is the first ever to document in great detail the extent to which CTCL can impact patients' lives. Health distress was reported by almost all respondents, psychological well being was affected severely, symptoms had an impact on patients' choice of clothes, and most respondents had a significant disruption in their role function. The information gained from this survey should help stimulate future research on HRQOL in patients with CTCL and the incorporation of HRQOL instruments into their routine care with the ultimate objective of improving their lives.

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