

Quality of life in cancer patients

HERBERT JANIG, WOLFGANG PIPAM and RUDOLF LIKAR

A study of 487 cancer patients in the province of Carinthia (Austria) investigated potential correlations between patients' subjective impressions of quality of life, their state of health and the location of tumour. Neither gender or age, nor the duration of the pain or the illness had any significant effect on quality of life. However, subjective impressions of quality of life depended very strongly on the location of tumour and the intensity of pain. Physical problems were felt to be less important than psychological problems and inadequate role functioning as a result of the cancer or its treatment. Thus activities carried out as a matter of course before the illness were no longer possible in the usual manner. Consequently, the milder the pain, the better the participants felt about their quality of life and the less they felt burdened by their symptoms, and vice versa. Those patients in whom pain had recently diminished in intensity and frequency considered their quality of life and state of health to be much better than those who were suffering more frequently and intensively from pain. For patients suffering from cancer-related pain, both therapeutic and psychosocial support should be provided so that they can cope with their illness more successfully.

The concept of quality of life is gaining in importance in medicine and psychology. Nowadays medical and psychological services are increasingly judged on the basis of the subjective benefits they provide for patients. As a result of increasing patient orientation in the health services, it is becoming ever clearer that "objective" criteria may be important when judging whether treatment has been effective or not but that they no longer suffice. Indeed, patients' subjective points of view are gradually being paid more attention. Ultimately, extending the range of factors used to judge the success of treatment, here in connection with cancer, must also be seen in the light of the realization that economic resources in the health service cannot be increased indefinitely (Köck, 1996).

In this connection, quality of life is either understood to be a general concept or a specific psychological construct which measures individual health-related or illness-related aspects of quality of life (Krizmanić, Kolesarić & Janig, 1994). At present, however, it is not based on one single homogenous theoretical model and, accordingly, the basic theoretical assumptions vary widely so that practically

every published quality-of-life questionnaire is based on its own theoretical model. The authors of such questionnaires generally agree that quality of life is a multifactorial construct, but the dimensions they employ vary considerably, ranging from physical ailments, social environment, basic mood, interpersonal relationships, group affiliation and general perception of health to vitality, etc.

Research into quality of life has been strongly but not exclusively stimulated by oncological research (Petermann & Krischke, 1994). In comparison with older methods (e.g. Karnovsky Performance Index, Knippenberg & Schmid, 1991; Spitzer Index, Spitzer et al., 1981), the procedures used today are based on more solid theoretical foundations. They include, for example, the quality-of-life profile for the chronically ill (PLC) by Siegrist, Broer & Junge (1996), the SF-36 state-of-health questionnaire (Bullinger & Kirchberger, 1998), the Munich list of dimensions for quality of life (MLDL) by Ludwig (1991), the scales covering quality of life (SEL) by Averbeck et al. (1997), and the EORTC questionnaire for quality of life in cancer patients (Aaronson et al., 1993).

Despite the increasing incidence of cancer, pain therapy for cancer patients is not considered adequate (Bernatzky et al., 1999; Ensink et al., 1998; Hanekop et al., 1998). This also applies to their psychological care, although it is well known that psychosocial support for cancer patients increases their quality of life and can also increase their life expectancy (e.g. Küchler et al., 1998). Quality of life can be seen as a central construct by which

Herbert Janig, Department of Psychological Basic Research, University of Klagenfurt, Universitätsstraße 65, A-9020 Klagenfurt, Austria. E-mail: herbert.janig@uni-klu.ac.at (Correspondence concerning this article should be sent to this address); Wolfgang Pipam, Rudolf Likar, Pain Clinic at Klagenfurt General Hospital, St. Veiter Straße 47, A-9020 Klagenfurt, Austria.

the success of psychological and nursing care can be measured (Schumacher et al., 1996; Padilla et al., 1990; Ferrell et al., 1996).

Efforts to obtain representative data on the quality of life of cancer patients gave rise to the present study as the well-known quality-of-life studies generally report on data relating to randomly chosen samples of in- and outpatients (see the review written by Krischke, 1995). The results of this study make it possible to give general statements on subjective impressions of quality of life in cancer patients as a basis for carefully directed pain therapy.

METHODS

Since 1987, a Cancer Register has been maintained at Klagenfurt General Hospital for the Austrian province of Carinthia (560,000 inhabitants). It includes all medical data for cancer patients who are being treated in hospitals or private practices. Every year the data of almost 2,000 patients are added to the register.

A sample of 3,272 cancer patients was taken from the Cancer Register. They were sent a questionnaire by post which was to be answered anonymously. The survey took place between May and December 1998 and covered the whole area of Carinthia. An accompanying letter explained the importance of the survey in improving medical and psychological pain therapy.

Out of the 3,272 questionnaires sent by post, 1895, or 57.9%, were returned. Of these 1895 returned questionnaires, 674 (35.5%) had been filled in, while 722 of them had the remark "deceased", 356 the remark "unknown"

and 145 the remark "no longer at this address" or "not taken", adding up to 64.5% of the total number of questionnaires returned. In the end, 487 (25.7 %) of the returned questionnaires proved to have all the details, including the diagnosis, and were included in the present study.

The questions on *quality of life* were from EORTC QLQ-C30, Version 2.0 (1997; Aaronson et al., 1993). The questionnaire consists of 30 items to be answered on scales ranging from 2 to 7. Five functional scales, a global health status scale (GHS) and nine symptom scales were then computed. In detail they cover:

Function Scales

Physical Functioning (PF): difficulties on physical exertion or when walking, help when performing daily routines; *Role Functioning (RF)*: disruptions at work or to leisure activities; *Emotional Functioning (EF)*: worries, irritability, strain, depression; *Cognitive Functioning (CF)*: difficulties concentrating and remembering; *Social Functioning (SF)*: the effects on family life and contacts with friends due to physical condition;

Global Health Status (GHS): general state of health, incl. any restrictions;

Symptom Scales: *Fatigue (FA)*; *Nausea and Vomiting (NV)*; *Pain (PA)*; *Dyspnoea (DY)*; *Insomnia (SL)*; *Appetite Loss (AP)*; *Constipation (CO)*; *Diarrhoea (DI)*; *Financial Difficulties (FI)* due to physical condition or medical treatment.

The *types of cancer diagnosed* which were reported by the participants were divided into six different groups based on medical criteria. In all, 17.2% of the participants

Table 1

Characteristics of the sample

Diagnosis	DIG			URO M		URO F		MAMMA			SKIN			ENT			Total		
Gender	m	f	t	m	f	f	m	f	t	m	f	t	m	f	t	m	f	t	
Age	70.7	68.8	69.8	64.7	62.7	61.2	64.2	64.5	64.4	62.7	56.0	59.4	65.9	62.1	63.6				
Time since diagnosis			55	61	81	62			64			63			64				
<i>n</i>	48	36	84	79	72	141	14	31	45	33	33	66	174	313	487				
Total (%)			17.2	16.2	14.8	29.0			9.2			13.6			100				

Note: DIG - patients with cancer of the digestive organs (e.g. oral cavity, stomach, small intestine); URO M - men with cancers of the urogenital system (e.g. kidneys, testes, prostate gland); URO F - women with cancers of the urogenital system (e.g. kidneys, urinary bladder, uterus, cervix); MAMMA - women with breast cancer; SKIN - cancer of the skin, bone or haemopoietic organs; ENT - cancer in the aerea of ENT (e.g. tonsils, larynx)

had cancer of the digestive organs (e.g. oral cavity, stomach, small intestine, large intestine, rectum, abbreviated with DIG), 16.2% were women with cancers of the urogenital system (e.g. kidneys, urinary bladder, uterus, cervix; URO F), 14.8% were men with cancers of the urogenital system (e.g. kidneys, testes, prostate gland, URO M), 29% of the participants were women with breast cancer (MAMMA, 9.2% had cancer of the skin, bone or haemopoietic organs (e.g. areas of the skin, bone marrow; SKIN) and 13.6% were in the area of ENT (e.g. tonsils, larynx; ENT). Nineteen participants with lung cancer were not included in subsequent calculations because the incidence was too low (see Table 1).

In addition, the patients were asked to state their age, gender, time since diagnosis and any disruptions to their lives experienced as a result of pain. They were also asked to report the thoughts and feelings which repeatedly accompanied them in their illness.

On average the participants had been diagnosed with cancer 64 months, or around 6 years, previously. While diagnoses of cancer of the digestive organs only went back four and a half years on average, women with urogenital cancers had known the diagnosis for much longer than six years. All other cancer patients in the survey had been diagnosed from six to six and a half years previously.

RESULTS

Quality of life and state of health

The cancer patients in the survey assessed their cognitive and physical functioning to be generally better than their emotional, social and role functioning. In other words, they felt that they were restricted in their daily lives and leisure activities and could no longer pursue these in their usual manner. Three out of five stated that they had difficulties on physical exertion (when carrying a heavy shopping bag, for example) while two out of five found it difficult to go for a longish walk. Every tenth subject even had difficulties taking a short walk outside the house and had to spend most of the day in bed or in a chair or was dependent on help for their everyday routine (eating, washing, using WC).

The cancer patients in the survey assessed their subjective impression of their general state of health to be 59.6 (on a scale of 0 to 100). A quarter of them considered their state of health to be "very good" or "excellent" while nine percent classified it as "bad" or "very bad". The differences between the individual groups were not significant (see Table 2).

In general, the patients appeared not to suffer too much from their symptoms. They had few problems with their digestive system, such as nausea, vomiting, constipation, diarrhoea or appetite loss. The financial burdens arising from the illness were considered to be greater, as was shortness of breath. The greatest problems were caused by pain, as well as by tiredness, weakness and sleeplessness (see Table 2). Two out of three participants felt that their lives were "moderately" to "very strongly" affected by pain.

The symptoms of sleeplessness and diarrhoea turned out to show the greatest and very significant differences between the various groups. Women with breast cancer, men with urogenital cancer, patients with cancer of the skin or bone and ENT cancers were clearly affected the least by diarrhoea. This contrasted very significantly with female patients with urogenital cancers and patients with cancer of the digestive tract: both of these groups suffered from diarrhoea to a significantly greater extent. Patients with ENT cancers suffered from disturbed sleep significantly less frequently than women with breast cancer and patients with cancer of the digestive organs.

Men suffering from urogenital cancers suffered significantly less often from tiredness than patients with cancer of the digestive tract and those with skin or bone cancer.

The duration of illness had absolutely no influence on quality of life. Not a single variable in the quality-of-life scales proved to correlate significantly with the duration of illness. The patients' age had only a limited effect on their quality of life, the only relevant domain being physical functioning. The older the patients were, the more they considered their physical functioning to be hampered. Correlations between age and role functioning, general state of health and the symptoms of tiredness and disturbed sleep were significant but extremely small (see Table 3).

Pain change

Just how important less or no pain is for a high subjective quality of life assessment can be illustrated by a comparison of two extremes: the group in which pain had recently become weaker and less frequent ($n=91$) and the group of those patients who were experiencing pain more frequently and intensively ($n=111$) (see Table 4).

Both groups were similar in terms of age and the duration of illness ($t(200) = -0.89, p = .38$; $t(200) = -1.18, p = .24$) but differed in all quality-of-life dimensions. Those patients with less intensive and less frequent pain consistently considered their physical functioning, role functioning and social functioning to be better than those in whom pain had recently increased in frequency and intensity ($t(200) = 2.2$ to 4.1 ; $p = .03$ to $.00$).

Table 2
Diagnosis and Quality of Life

	DIG		URO F		URO M		MAMMA		SKIN		ENT		Total		F	p
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD		
PF	70.2	29.2	71.6	28.9	81.4	23.6	71.6	24.0	73.8	30.7	77.6	26.1	73.8	26.8	2.02	.08
RF	57.9	34.8	62.2	35.8	66.4	30.6	56.1	32.7	58.1	37.2	68.7	30.9	60.8	33.6	1.89	.09
EF	58.9	28.9	60.2	30.6	69.6	25.6	59.5	30.2	62.4	30.1	61.5	30.5	61.5	29.5	1.38	.23
CF	71.6	26.9	70.0	31.3	75.0	28.5	72.9	27.1	71.5	31.3	70.5	28.9	72.1	28.5	.31	.91
SF	65.3	35.5	66.0	36.8	67.4	33.6	66.5	33.3	70.7	35.9	72.2	31.0	67.5	34.1	.45	.81
GHS	57.2	22.3	57.1	25.2	62.8	23.2	59.0	24.0	63.1	22.9	61.0	24.8	59.6	23.8	.88	.50
FA	48.8	30.6	44.7	33.2	36.1	30.6	44.2	31.7	48.9	30.6	42.3	31.7	44.1	31.6	1.56	.17
NV	12.7	22.5	14.3	26.5	9.7	20.1	10.4	20.8	9.6	16.9	13.1	23.7	11.6	22.0	.61	.69
PA	42.5	36.8	42.8	36.3	30.6	31.4	42.4	34.8	46.7	34.7	37.4	35.9	40.5	35.2	1.75	.12
DY	25.0	30.6	36.3	35.5	27.8	33.6	33.8	36.9	28.9	33.8	34.8	36.2	31.5	34.6	1.35	.24
SL	51.2	38.2	46.0	37.1	35.2	35.8	50.6	37.7	40.7	39.5	31.8	34.3	44.2	37.7	3.86	.00
AP	17.5	29.5	16.0	29.6	13.4	27.2	15.1	28.6	20.7	32.0	17.2	31.1	16.2	29.3	.43	.83
CO	24.2	34.5	19.0	31.0	17.6	31.6	21.7	34.0	20.7	34.3	26.7	29.4	20.3	32.6	.58	.71
DI	23.0	31.0	16.5	31.5	8.3	22.2	5.7	17.3	8.1	19.0	8.1	21.9	11.4	24.9	6.78	.00
FI	25.4	35.3	23.2	33.9	24.5	35.8	29.1	35.8	20.0	32.1	23.2	34.1	25.2	34.8	.65	.66

Note: PF - Physical Functioning, RF - Role Functioning, EF - Emotional Functioning, CF - Cognitive Functioning, SF - Social Functioning, GHS - Global Health Status, FA - Fatigue, NV - Nauseau, Vomiting, PA - Pain, DY - Dyspnoea, SL - Insomnia, AP - Appetite Loss, CO - Constipation, DI - Diarrhoea, FI - Financial Difficulties due to physical condition or mediactal treatment

Table 3
Coefficients of correlations among age, time since diagnosis, pain and quality of life

	PF	RF	EF	CF	SF	GHS	FA	NV	PA	DY	SL	AP	CO	DI	FI
Age	-.34**	-.13*	.07	-.09	.01	-.23**	.15**	.09	.16**	.03	.16**	.11	.11	.11	-.06
Time of diagnosis	-.05	-.07	.05	.00	-.05	-.03	.03	.05	.09	.04	.04	.02	.03	.05	.06
Pain intensity	-.56**	-.68**	-.57**	-.45**	-.56**	-.65**	.70**	.48**	—	.48**	.49**	.42**	.38**	.19**	.43**

Note: ** $p < .01$; * $p < .05$

PF - Physical Functioning, RF - Role Functioning, EF - Emotional Functioning, CF - Cognitive Functioning, SF - Social Functioning, GHS - Global Health Status, FA - Fatigue, NV - Nauseau, Vomiting, PA - Pain, DY - Dyspnoea, SL - Insomnia, AP - Appetite Loss, CO - Constipation, DI - Diarrhoea, FI - Financial Difficulties due to physical condition or mediactal treatment

Table 4
Pain Change and Quality of Life

Pain had recently become...	n	PF	RF	EF	CF	SF	GHS	FA	NV	PA	DY	SL	AP	CO	DI	FI
weaker and less frequent	91	74.5	59.5	56.1	71.2	72.0	56.5	46.2	13.9	41.8	33.3	47.3	15.8	22.7	12.5	27.5
more frequent and intensive	111	65.4	49.8	53.1	65.9	52.7	48.6	55.5	17.6	61.3	43.5	55.6	24.6	26.7	15.0	35.1
<i>t</i>		2.46*	2.16*	.77	1.29	4.08**	2.52**	-2.17*	-1.01	-4.24**	-2.07*	-1.57	-2.01*	-.80	-.66	-1.45
<i>p</i>		.02	.03	.44	.20	.00	.01	.03	.32	.00	.04	.12	.05	.43	.51	.15

Note: ** $p < .01$; * $p < .05$

PF - Physical Functioning, RF - Role Functioning, EF - Emotional Functioning, CF - Cognitive Functioning, SF - Social Functioning, GHS - Global Health Status, FA - Fatigue, NV - Nausea, Vomiting, PA - Pain, DY - Dyspnoea, SL - Insomnia, AP - Appetite Loss, CO - Constipation, DI - Diarrhoea, FI - Financial Difficulties due to physical condition or medical treatment

Table 5
Disruptions by Pain

Activity/Need	Cancer		Gender		Satisfaction with Pain Therapy			
	<i>n</i>	%	χ^2	<i>p</i>	χ^2	<i>p</i>		
Occupational/Household-Activities	217	44.6	34.4	.00	16.4	.00	13.0	.00
Other Physical Activities	192	39.4	5.0	.41	0.0	.96	7.4	.03
Mental Activities	50	10.3	2.7	.74	3.5	.06	8.2	.02
Social Activities (Family, Friends)	44	9.0	9.8	.08	0.9	.35	1.8	.40
Appetite	51	10.5	14.5	.01	2.1	.14	8.1	.02
Motivation	142	29.2	1.7	.89	0.0	.91	10.1	.01
Sexual Drive	101	20.7	18.9	.00	20.3	.00	2.4	.30
Falling asleep	97	19.9	13.6	.02	2.3	.13	8.8	.01
Sleeping through the Night	206	42.3	6.0	.31	5.1	.03	9.3	.01
Sum of Answer (apprx. 2, 3 answer for each subject)	1100							

Subjective impressions of the general state of health in patients with little and infrequent pain were much better than for the other patients ($t(200) = 2.5, p = .01$).

The burden placed on patients by their symptoms was also significantly different in these two groups: patients with little and infrequent pain suffered significantly less from tiredness and shortness of breath and had a much better appetite. For all other symptoms - nausea, vomiting, sleeplessness, constipation, diarrhoea and financial problems - there were also differences in favour of the patients who were less affected by pain but these differences were not significant.

Disruptions

Around two fifths of the patients in the survey admitted that they felt pain disrupted their personal and working lives as well as other physical activities. Almost one third felt they had less motivation and zest for life. Every fifth patient considered their sexual drive to be lower and had difficulties falling asleep. In contrast two out of five stated that they had problems sleeping through the night. The fewest problems cropped up in connection with appetite, social activities and mental activities: only one in ten in the survey felt that they were affected in this respect.

The disruptions experienced by the patients did not only depend on gender but also on the type of cancer and general satisfaction with the pain therapy they were undergoing. Women felt themselves to be affected in their activities at work and in the home significantly more frequently than men. In contrast, men felt that their sexual needs were affected significantly more frequently, they suffered significantly more frequently from not being able to sleep through the night and tended to feel more affected in their mental activities than did women.

Women with breast cancer suffered significantly more frequently from not being able to perform activities at work and in the home in the manner to which they were accustomed, while men with urogenital cancers and patients with cancer of the digestive organs were not affected so frequently. Appetite loss was most frequently associated with ENT patients, those with cancer of the digestive organs and women with urogenital cancers. Men with urogenital cancers, breast cancer patients and those with skin or bone cancer complained on reduced sexual activity significantly more frequently.

General satisfaction with pain therapy (provided by doctors, psychologists and others) played a very important role in the extent to which patients considered their lives to be disrupted: the more satisfied they were with their pain therapy, the less frequently they felt their lives to be disrupted, with two exceptions: social activities with family, friends and others, and limited sexual activity did not correlate with the patients' satisfaction with pain therapy at all.

Thoughts and feelings

When asked to state which thoughts and feelings they had in connection with their illness, 217 out of 487, or 44.6% of all patients in the survey, mentioned pain. More than one third (36.4%) of these answers was related to fears of a relapse, e.g.: "When pain occurs, I think of the possibility of new tumours growing and I'm afraid"; "I'm always worried about metastases growing"; "I often wonder whether another tumour might not be growing somewhere else"; "I'm afraid that the cancer will come back".

More than every fifth response (22.1%) was related to worries about impaired functioning which had already arisen or which was expected to arise, e.g.: "I could end up in a wheelchair one day"; "I won't be able to walk"; "My legs will give up on me"; "I'm afraid of not getting enough air"; "How long will I be able to continue getting dressed on my own?".

Around 15% of the replies were related to psychological problems ("loneliness"; "depression"; "fear of death"; "fear of the future"; "a feeling of helplessness"; "insecu-

rity") or directly to pain, e.g.: "I often wonder whether the pain will always be there"; "Does the pain ever go away again?"; "Can the pain get any worse?"; "What if the pain can't be treated?".

Every ninth response (11.1%) concerned family or social aspects: "worries about my job"; "worries about my family"; "worries about my children"; "worries about my son's future"; "won't be able to look after my handicapped child".

DISCUSSION

Men with urogenital cancers clearly felt that their physical functioning was better than other cancer patients did. They also felt less tired and gave the general impression that they suffered less from symptoms than the other patients in the survey.

Women with urogenital cancers reported that they suffered from diarrhoea more frequently, as did patients with cancer of the digestive organs. Women with breast cancer clearly experienced fewer disruptions to their role functioning than ENT cancer patients and suffered to a much lesser extent from no longer being able to carry out daily routines in the manner in which they were accustomed. They did mention disturbed sleep, just like patients suffering from cancer of the digestive organs, but stated that they suffered from diarrhoea less frequently than others.

Patients with ENT cancers could not do as much in their daily and leisure activities but suffered less frequently than others from disturbed sleep or diarrhoea, which are typical symptoms for patients with cancer of the digestive organs and women with urogenital cancers.

Patients with different diagnoses presented a different picture relating to subjective impressions of their quality of life and the extent to which their symptoms bothered them. It appeared that there was a great burden on cancer patients suffering from pain whose role and emotional functioning was affected as a result. While physical and cognitive functioning was not affected so clearly, the patients reported that they were not (no longer) in a position to carry out daily routines and leisure activities which they had obviously used to do, giving rise to major psychological problems. These could be connected with the difficulty of giving up old habits or getting used to the new way of life resulting from the illness. Objective clinical findings often have very little to do with subjective states of health, indicating the necessity for psychological and physical after-care (Weinrich & Sommer, 1996).

Apart from the fact that the older the patients were, the more they considered their physical functioning to be af-

ected, neither subjective impressions of quality of life nor state of health correlated with the patients' age or the duration of their illness. Obviously the "well-being paradox" (Staudinger, 2000) also applies to cancer patients, namely that many people feel well even under adverse circumstances.

In contrast, there were clear correlations between present pain and quality of life: the less pain suffered, the better patients felt in their physical, social, emotional, cognitive and role functioning and the less they were affected by other symptoms. The lower the pain, the better they considered their state of health to be and vice versa.

The stronger the pain, the more frequently the patients suffered from various symptoms, such as nausea, vomiting and tiredness, and the more they felt their daily lives to be affected. In contrast, their age and the duration of their illness had little or no effect on the stress caused by their symptoms.

For those who stated that they now had less frequent and less intensive pain than before, the quality of life and general state of health was clearly better than for those who suffered pain more intensely and frequently. Not only the actual illness but also the treatment of cancer causes pain and adds to patients' fears in many cases (Schmidt-Luggen, 1998).

In addition, the "mere" diagnosis of having cancer suffices to act as a stress factor; patients feel that they have been left alone, that they have not been given enough information, that they are not aware of which alternative forms of treatment are open to them. Indeed, quite a few patients slide into an acute crisis as a result of the diagnosis - and the way it has been conveyed - rather than as a result of the actual illness, and are hardly able to find their way out of this crisis without the help of other people.

Many cancer patients are plagued by their fears of a relapse, metastases and impaired functioning but also by worries about their own and their families' futures. However, the degree of fear or optimism has a decisive influence on quality of life (Graul, 1995). Not least for this reason, one of the most urgent tasks for psychological pain therapy is its contribution to reducing fear. The second major problem is largely caused by inadequate communication between doctors and patients. Most doctors have had no training and little practice in how to break bad news to their patients and provide them with the necessary information.

Less pain means more psychological agility, emotional stability, greater self-validity and a better subjective impression of one's state of health, which in turn have positive effects on the success of the treatment and healing process. Tumour pain always has a bio-psycho-social genesis, therefore neurosurgical, anaesthesiological and medical procedures alone are not enough when removing tumours

and relieving pain (Hanekop et al., 1998). Instead, accompanying psychosocial support should also be offered so that patients can cope with the associated psychological and social problems more easily. In addition, psychological training should be provided for those doctors who deal with cancer patients so that they can understand the psychological implications of being diagnosed with cancer and so that they can offer patients the support that they might need before they actually need it.

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