QOL-E

HEALTH-RELATED QUALITY OF LIFE

This study includes patients with Myelodysplastic Syndrome (MDS) and explores their perception of experiences they have had with their health and disease.

Your participation is very important for us. Your responses may improve treatment in all patients that need therapy for MDS. It will take about 10 minutes to complete the questionnaire.

PERSONAL DATA PROTECTION

All information that may permit an identification of the participants in this study will be kept strictly confidential, will be used only for the purpose of the study and will not be disclosed for any reason without previous written consent, unless requested by Law.

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

1. Answer the question by circling **one** answer.

Example: (Mark the appropriate answer)

		YES	NO
a.	Have you been in a submarine?…….		√

2. If you are not sure about the right choice for your answer, mark the closest match and write a comment in the left margin.

3. If necessary, you can ask the dedicated Staff for assistance.

THANK YOU FOR YOUR PARTICIPATION IN THIS STUDY

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INTRODUCTION

1) In general, you would say that your health is:

Excellent	Good	Acceptable	Poor

2) Compared to a month ago, your health is:

Improved	The same	Worse	Much Worse

PHYSICAL WELL-BEING

3) In the last week, some daily activities may have been limited by your health, such as:

		I find it very difficult	I find it partially difficult	It is not difficult at all
A	Performing heavy activities (for example, running, jumping, etc.)			
B	Climbing stairs			
C	Lowering myself			
D	Taking care of myself (washing, dressing, feeding myself)			

FUNCTIONAL WELL-BEING

4) In the last week, what problems have you had in daily activities because of your health?

		Yes	No
A	I got very little done		
B	I had more fatigue doing my work		

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5) During the last week was it difficult for you to stay awake during the daytime?

Always	For many hours	For a few hours	Never

SOCIAL OR FAMILY WELL-BEING

6) According to you, are the following statements true or false?

		True	I do not know	False
A	My present condition interferes too much with my life			
B	I feel oppressed by my disease			
C	I feel that I am a burden for my family			

7) Your health is an impediment for you to keep a paid job (whether you are of retirement age or not).

True	False

8) In the last week, was sexual arousal a problem for you?

Never	Rarely	Sometimes	Often

DISTURBANCES, RELATED TO THE DISEASE

9) In the last week, how much did fatigue get in the way with your daily chores?

Not at all	A little	A lot	Extremely

10) In the last week, how much fatigue did you have?

Not at all	A little	A lot	Extreme

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11) In the last week, how much did the following problems disturb you?

		Not at all	A little	A lot	Extremely
A	Headache				
B	Palpitations (i.e., heart pounding)				
C	Difficulty in taking care of yourself				
D	Being bedridden				

12) During the last week, did you get enough sleep?

Always	Often	Rarely	Never

13) During the last week, did shortness of breath while climbing the stairs disturb you?

Never	Sometimes	Often	Very often

14) What effects of the disease disturb your daily life?

		No, not at all	A little bit	Yes, extremely
A	Being dependent on transfusions			
B	Not being able to do house chores			
C	Not being able to travel			
D	Being dependent on the hospital, doctors and/or nurses			
E	Stress and worry because of the disease			
F	The effect on your sex life			
G	Side effects of treatment			

Notes:

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