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ORIGINAL RESEARCH ARTICLE

Hope in cancer patients: the relational domain as a crucial factor

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ABSTRACT

Aims and background: Hope is crucial for patients with cancer. We explored the determinants of hope in patients with cancer using a questionnaire administered over the course of 1 day to an unselected sample of patients at an Italian cancer center.

Methods: A team of oncologists, statisticians, and chaplains developed a questionnaire with medical, psychological, spiritual, and religious content. A cross-sectional study was conducted on 320 patients who answered the questionnaire.

Results: In the group of participants, 92.8% had a religious belief. Women, patients with limited formal education, and believers were more hopeful. Patients placed trust in God, their partners and children, scientific research, and doctors. On univariate and multivariate analysis, hope was found sensitive to patients' sharing their experiences with others (including family and friends), their positive perception of the people around them, and their relationship with doctors and nurses.

Conclusions: If validated in further studies, these results support the notion that a patient with cancer's sense of hope is sensitive to the quality of relationships with caregivers. This may be important to health care organization and resource allocation.

Keywords: Hope, Pastoral care, Psycho-oncology, Quality of life, Spirituality

Introduction

Efforts to humanize medical care are being made at numerous cancer institutes in an effort to deal holistically with patients' clinical, psychological, and social issues. Spiritual and religious issues may be included as well. Indeed, meeting the spiritual needs of patients is increasingly seen as relevant to appropriate patient-centered care. Research has demonstrated that spiritual or religious practices are resources that can help patients to cope better with disease and suffering (1, 2). A correlation between hope and quality of life has been reported, and hope has been included among the aspects of quality of life measured in patients with various neoplasms (3, 4).

Clinical practice and the medical literature suggest that hope is a crucial issue for both patients and caregivers (5, 6). Hope is not easy to define and measure, however. Generally speaking, "hope" may be defined as the "expectation of, or belief in the fulfillment of something," but in a medical sense, and in oncology in particular, hope means a great deal more. On a simple, intuitive level, it is generally recognized

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that hope is a fundamental need of human life. Losing hope may worsen a patient's condition, and vice versa (7, 8). There are studies in the literature on the effects of hopelessness, and attention has focused mainly on hope in the sense of the absence of despair (9). Various studies have been carried out, particularly in the palliative care setting, with a view to identifying strategies for dealing with the onset of despair and depression (10). In the last 2 decades, hope has been attracting a growing interest. Ad hoc questionnaires (11) and psychometric tools (12) have been designed to measure and assess this construct.

We investigated what and how patients hoped in a cohort of cancer patients interviewed on a typical day at the Istituto Nazionale Tumori in Milan, which is a comprehensive cancer center serving as a reference center for patients from all over Italy.

Since Italy is mainly a Christian country, the theoretical model used to shape our questionnaire was Christian (13), but hope is interpreted as depending not only on religious aspects, but also on psychological, spiritual, and relational matters (14). We consequently assumed that we might use the tool to investigate the matter of hope effectively in non-Christians and nonbelievers.

Methods

Questionnaire

To investigate hope from an integrated perspective, the study relied on the use of a self-administered questionnaire developed by a team of physicians, statisticians, and chaplains operating in various settings, including medical oncology, hematology, clinical psychology, hospital management, biomedical research, statistics, and pastoral care. An initial set of questions was prepared to shed light on the various aspects of hope in its medical, psychological, spiritual, and religious dimensions. The questions were the outcome of a multidisciplinary team's discussions to identify items most likely to be important to patients. These questions were then jointly reviewed and reduced in number by the team to reasonably limit the time it would take patients to complete the questionnaire.

A preliminary version of the questionnaire was administered to a pilot group of people from various social and cultural backgrounds. This exercise prompted some rewording and further reduction of the questions. The final version of the questionnaire consists of 26 items (supplementary Tab. I. Available online at www.tumorijournal.com). The first 13 have to do with patient characteristics; items 14 to 24 include a variable number of subitems (from 3 to 17) for assessing hope on a Likert scale, so as to quantify its qualitative aspects (15); and items 25 and 26 have to do with the importance that patients attribute to certain professional figures and care settings.

Study procedures

The study was conducted using a cross-sectional design, after obtaining the approval of the hospital's National Cancer Institute of Milan independent ethical committee. The questionnaires were administered on April 18, 2012.

TABLE I - Medians and interquartile ranges for mean answers to questions based on scores of 1-8[a] (groups Q16, Q18, Q19, Q23, Q24)

	Median	Interquartile range
Group Q16: "How do you imagine hope and the feelings it gives you?"	2.9	1.3-5.0
Group Q18: "What do others mean to you?"	7.6	6.4-8.0
Group Q19: "How do others see you?"	7.2	6.0-8.0
Group Q23: "Thinking back to my past, I feel …"	6.7	5.7-8.0
Group Q24: "Right now I feel …"	6.3	5.3-8.0

[a]A high score for groups Q18-Q24 and a low score for group Q16 are indicative of a strong sense of hope.

In all, 22 units took part in the study, comprising 6 medical oncology/radiotherapy units, 12 surgical units, and 4 outpatient clinics. To have the questionnaires distributed and collected, we selected and trained members of involved units and volunteers from the Italian League Against Cancer (Lega Italiana per la Lotta Contro i Tumori) at the outpatient clinics. These operators were asked to explain the purpose of the study to patients, provide instructions on how to fill out the questionnaire, obtain participants' informed consent, administer the questionnaires, and collect them after ensuring patients' compliance with the following inclusion criteria: (1) written informed consent to the treatment of personal information; (2) age over 18 years; (3) sufficient language skills and sociocultural level to understand the questionnaire; (4) medical conditions enabling the patient to read, understand, and answer the questionnaire; (5) no evidence of mental disorders or cognitive impairments.

To ensure confidentiality, the questionnaires contained no personal details. All collected data were input in an electronic database and checked for completeness and consistency before undergoing statistical analysis. Questionnaires containing answers to at least 50% of the questions were considered acceptable.

Statistical methods

Descriptive analyses were run, based on conventional statistics such as means (± standard deviation) or medians (interquartile ranges) for continuous variables, and frequency tables for categorical variables.

As a preliminary step, a principal components analysis was carried out on the answers to questions 14-24 in the questionnaire. Subsequent analyses were then conducted on selected items (scored on a Likert scale) considered the most representative of the spiritual and/or religious perspective, or on the means by group of the subitems scored from 1 to 8 (reversing the scores for unfavorable items so that they could be added to the favorable items).

The associations between the answers in the questionnaire and the patient's main characteristics were tested with

the Kruskal Wallis test. In particular, the following clinical characteristics were considered: status (inpatient or outpatient), sex, age, formal education, religiosity, and stage of disease.

We then specifically investigated the influence on a patient's hope of their personal religious beliefs, their trust in medicine, and their relationships with other people. To do so, we first selected the items in the questionnaire that represented these factors best (supplementary Tab. II. Available online at www.tumorijournal.com). Considering the items that directly assessed a patient's hope, we created an index ranging from 0 (no hope) to 1 (strong hope) that marked a patient's overall degree of hope. The index reflected the weighted average of each patient's answers to each question (and subitem), after appropriate score reversing to make higher scores always represent a stronger degree of hope.

By further pooling the questions representing religious beliefs, trust in medicine, and relationships with other people, we created 14 new variables (supplementary Tab. III. Available online at www.tumorijournal.com) that we used for a subsequent analysis. The aim of these variables was to summarize the main factors belonging to the 3 macroareas (religious beliefs, trust in medicine, and relationships with other people) that could have influenced a patient's degree of hope. A global score (not bound within the 0-1 interval)

TABLE II - Answers to questions by patient characteristics significantly influencing the distribution

	Answer[a]								p Value[b]
	A		B		C		D		
	No.	%	No.	%	No.	%	No.	%	
14D: "Knowing I'm not alone gives me hope"									
Sex									0.007
F	128	81.5	26	16.6	1	0.6	2	1.3	
M	92	68.7	31	23.1	5	3.7	6	4.5	
Formal education									0.010
Up to 8th grade	95	84.1	14	12.4	2	1.8	2	1.8	
Up to 13th grade	88	73.9	25	21.0	3	2.5	3	2.5	
University degree or higher	40	63.5	19	30.2	1	1.6	3	4.8	
Religiosity									<0.001
Practicing believer	137	83.5	24	14.6	-	-	3	1.8	
Nonpracticing believer	80	71.4	24	21.4	5	4.5	3	2.7	
Nonbeliever	8	40.0	9	45.0	1	5.0	2	10.0	
15H: "When I die I hope to see my loved ones again"									
Formal education									<0.001
Up to 8th grade	101	86.3	8	6.8	5	4.3	3	2.6	
Up to 13th grade	101	83.5	10	8.3	4	3.3	6	5.0	
University degree or higher	35	59.3	14	23.7	4	6.8	6	10.2	
Religiosity									<0.001
Practicing believer	148	89.7	13	7.9	3	1.8	1	0.6	
Nonpracticing believer	88	75.9	17	14.7	8	6.9	3	2.6	
Nonbeliever	2	12.5	2	12.5	1	6.3	11	68.8	
20C: "I pray for other patients too"									
Sex									<0.001
F	63	38.9	62	38.3	26	16.0	11	6.8	
M	29	22.1	45	34.4	33	25.2	24	18.3	
Formal education									0.011
Up to 8th grade	47	40.2	41	35.0	18	15.4	11	9.4	
Up to 13th grade	32	27.1	45	38.1	25	21.2	16	13.6	
University degree or higher	14	22.2	22	34.9	18	28.6	9	14.3	

To be continued

TABLE II - Continued

	Answer[a]								p Value[b]
	A		B		C		D		
	No.	%	No.	%	No.	%	No.	%	
Religiosity									<0.001
Practicing believer	68	41.0	70	42.2	26	15.7	2	1.2	
Nonpracticing believer	26	22.0	38	32.2	33	28.0	21	17.8	
Nonbeliever	1	6.7	-	-	2	13.3	12	80.0	
21B: "My religious belief increases my will to combat my disease"									
Status									0.009
Inpatient	98	56.0	47	26.9	16	9.1	14	8.0	
Outpatient	50	40.3	42	33.9	20	16.1	12	9.7	
Formal education									0.001
Up to 8th grade	71	60.7	28	23.9	12	10.3	6	5.1	
Up to 13th grade	56	46.7	39	32.5	15	12.5	10	8.3	
University degree or higher	19	31.7	22	36.7	9	15.0	10	16.7	
Religiosity									<0.001
Practicing believer	104	61.9	46	27.4	12	7.1	6	3.6	
Nonpracticing believer	41	35.0	42	35.9	24	20.5	10	8.5	
Nonbeliever	2	15.4	1	7.7	-	-	10	76.9	
22D: "Knowing that others pray for me makes me feel better"									
Status									0.039
Inpatient	92	15.1	61	33.9	14	7.8	13	7.2	
Outpatient	52	40.6	46	35.9	18	14.1	12	9.4	
Sex									0.004
F	88	53.7	53	32.3	13	7.9	10	6.1	
M	54	38.8	51	36.7	19	13.7	15	10.8	
Religiosity									<0.001
Practicing believer	103	60.6	55	32.4	8	4.7	4	2.4	
Nonpracticing believer	38	32.2	50	42.4	20	16.9	10	8.5	
Nonbeliever	2	11.1	2	11.1	4	22.2	10	55.6	

The associations were statistically significant in the case of the following variables: status vs items 21B, 22D; sex vs items 14D, 20C, 22D; formal education vs items 14D, 15H, 20C, 21B; religiosity vs items 14D, 15H, 20C, 21B, 22D.
[a]Key to answers: 14D, 21B: A = completely agree, B = partially agree, C = partially disagree, D = totally disagree; 15H, 22D: A = a lot, B = quite a lot, C = a little, D = not at all; 20C: A = always, B = often, C = rarely, D = never.
[b]p Value, Kruskal-Wallis test.

was calculated for each variable. The score corresponded to the answer to a question when the variable depended on a single question, or it was the weighted average of several answers to questions belonging to the same variable.

A univariate analysis was run to establish the correlation between each new variable and the degree of hope. Spearman correlation coefficient was calculated for discrete variables, while one-way analysis of variance was used for categorical variables. Variables showing a significant correlation with the degree of hope were then inserted in a multivariate linear regression model to assess which of them independently influenced a patient's hopefulness.

The statistical analyses were run using SAS software, assuming statistical significance for 2-sided p values below the conventional threshold of 5%.

Results

Overall analysis

In all, 320 patients could be analyzed, 185 of them inpatients (57.8%) and 135 outpatients (42.2%). The response rates were 63.1% for inpatients and 24.5% for outpatients. Supplementary Table IV (available online at www.tumori-

TABLE III - Median scores for patients' trust[a] in various figures and settings

Figure/setting	Median[b]
Spouse	10
Children	10
God	10
Scientific research	10
Physicians	10
Nurses	9
Volunteers	8
Medication	8
Health system	8
Friends	8
Relatives	8
Religion	8
Psychologist	7
Chaplain	7
Mass media	6

[a]Degree of trust on a scale from 0 (none) to 10 (total).
[b]The list is arranged in declining order of the median values first, then of the arithmetical means (not shown).

journal.com) summarizes the characteristics of the sample of patients: 92.8% were believers, either practicing (54.4%) or nonpracticing (38.4%), while the proportion of nonbelievers was 7.2%. The inpatient and outpatient groups were comparable in terms of age, formal education, and religiosity. The group had a higher prevalence of women (54% vs 46%). Overall, around 20% of patients reported experiencing little or no hope (question 14A).

Figure 1 shows the answers given for the items (scored on a Likert scale) judged to be the most relevant for the purposes of our research.

Table I shows the means by group for the subitems quantified with scores from 1 to 8.

Table II shows the associations between the answers given in the questionnaires and the patients' characteristics (inpatient/outpatient status, sex, formal education, and religiosity). A stronger sense of hope tended to be associated with female sex, a limited formal education, and a greater degree of religiosity.

Concerning question 26, designed to measure the patients' trust on a scale from 1 to 10 (Tab. III), scores were highest for their trust in God, their partners, their children, scientific research, and their doctors, while slightly lower scores were returned for nurses, and the lowest scores were reached for mass media. The psychologist and the hospital chaplain were awarded the same degree of trust.

Factors influencing a patient's hope

Univariate analysis (Tab. IV) showed that almost all factors relating to relationships with other people had a significant influence on a patient's degree of hope. The more patients shared their experience and suffering with others, the more they were hopeful (var Other 1, p<0.001). Patients who perceived others positively (var Other 2, p<0.001) and did not feel they were a burden or problem for people around them (var Other 3, p<0.001) were more hopeful. A stronger degree of hope was also associated with a greater degree of trust in other people, including friends, volunteers, and the chaplain (var Other 5, p<0.001), and of trust in the help that could come from others (var Other 6, p = 0.002). Considering medicine as a science, the more hopeful patients trusted more in the people caring for them (var Med 2, p = 0.01) than in medicine per se (var Med 3, p = 0.069), despite high hopes being placed in therapies and care (p<0.001). Finally, trust in religion was the only factor in the area of religious beliefs that correlated with a stronger sense of hope (var Rel 5, p = 0.032).

Multivariate analysis (Tab. IV) showed that the therapy and care that patients received (var Med 1, p = 0.019), combined with being able to share their experience with others (var Other 1, p<0.001) and having a positive perception of other people (var Other 2, p = 0.019), were factors that gave patients a stronger sense of hope.

TABLE IV - Univariate and multivariate analyses of factors influencing patients' hope relating to the 3 macro-areas of religious beliefs, trust in medicine, and relationships with other people

		Univariate analysis p[a]	Multivariate analysis p
Religious beliefs			
Declared religious belief	Rel 1	0.44	-
Faith	Rel 2	0.29	-
Life after death	Rel 3	0.17	-
Religion in suffering	Rel 4	0.31	-
Trust in religion	Rel 5	0.03	0.96
Sharing with others	Others 1	<0.001	<0.001
Relationships with others			
The perception the patient has of other people	Others 2	<0.001	0.027
The perception the patient imagines others have of him/her	Others 3	<0.001	0.27
Praying for others	Others 4	0.065	-
Trust in others	Others 5	<0.001	0.79
Help coming from other people	Others 6	0.002	0.16
Trust in medicine			
In medical treatments	Med 1	<0.001	0.019
In medical personnel	Med 2	0.01	0.48
In medicine as a science	Med 3	0.069	-

[a]Rel 1, Others 6, and Med 1 were analyzed using one-way analysis of variance; all the others were analyzed using linear correlation analysis (Spearman coefficient).

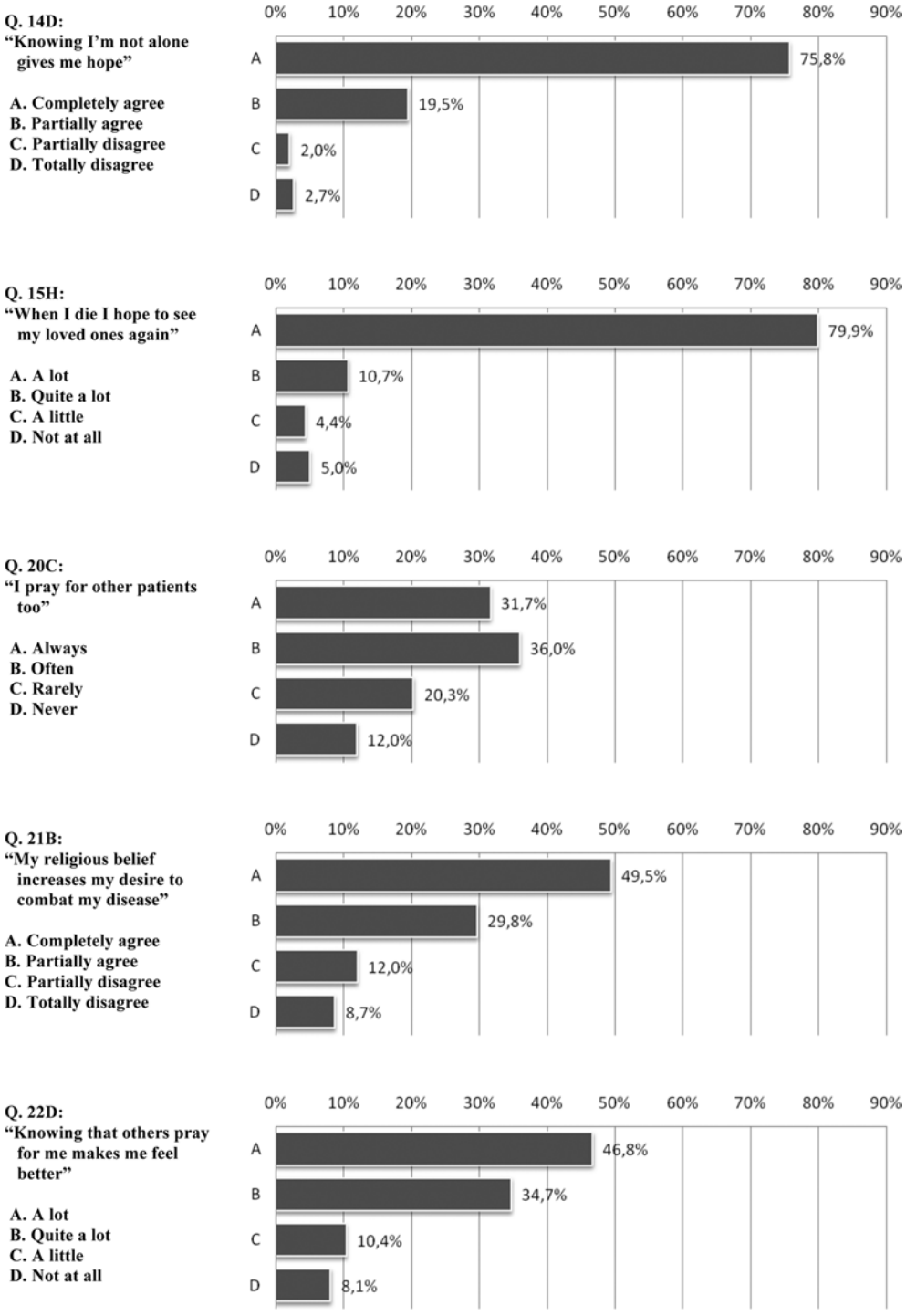

Fig. 1 - Answers for some of the relevant items scored on a Likert scale.

Conclusions

The aim of this study was to characterize the concept of hope in a population of 300-plus patients with cancer, investigating what and how patients hope using a quantitative and measurable tool. A major finding of our study is that patients with cancer's hope correlated with the degree of trust they placed in caregivers, their ability to share their experience with others, and their feeling of having mutual human relationships.

We can assume that hope is a value, provided it does not amount to an unrealistic optimism (which might stem from patients receiving misleading information or lacking awareness). By and large, hope does not coincide exclusively with trust in one's future. Hope can well be related to temporary goals, such as having a treatment that succeeds for a while, or better pain control. In our study, this emerges from answers to our questionnaire such as "I hope to get better," "I hope to get no worse," "Hoping helps me feel less physical pain," and the like.

Hope is a critical issue in patients with cancer. There have been reports on how hope can enhance a patient's capacity to adapt to severe disease (5, 16). Hope is important for terminally ill patients as well (17). Having hope has been found to correlate with better pain tolerance, better quality of life, positive coping, resilience, and higher self-esteem (18), whereas hopelessness has been associated with fear, psychological distress, physical deterioration, and poor compliance.

In patients with a dismal prognosis, hope is classically seen as having to do with religious faith and the spiritual domain (hoping to be saved, to go to heaven, to be rejoined with loved ones, to give sense to life). Religious aspects emerged from answers such as "thanks to my religious belief I feel a sense of hope," "I don't think life ends with death," "I pray for the doctors and nurses who care for me," "My religious belief increases my motivation to fight the disease," "Praying makes me feel less lonely." Paying attention to patients' spiritual needs can be seen as a resource for supporting hope in cancer hospitals. Measures taken to provide spiritual support should focus on safeguarding patients' entitlement to respect for their spiritual and/or religious needs (19).

Our study would suggest that there are other aspects of hope that are not related to the religious or spiritual domains, however. Our findings indicated that a significant amount of hope has to do with relationships (being valued, feeling loved and supported, not feeling a burden to others, not being lonely). These feelings were covered by a number of answers, such as "Knowing that others remember me makes me feel better," "I hope my loved ones will continue to stand by me," "I feel good when I succeed in sharing my positive experiences," "My family is very supportive," "The people caring for me (doctors, nurses) give me a lot of hope," "Other people are important to me." The more patients see their relationships with others in a positive light, the stronger their sense of hope. In brief, good relationships (between patients and healthcare personnel, and between patients and their families and friends) are associated with higher hopes. Nobody ever hopes alone, but always with others, and for others (14).

Our study has some limitations, such as the relatively limited size of the sample and a possible selection bias pertaining mainly to the self-selection of patients able and willing to answer a questionnaire. On the other hand, the questionnaire was proposed over the course of a single day to patients with different types of cancer and different levels of disease severity, both at the outpatient clinic and in the wards, all factors that should reduce the selection bias. Of course, this meant that our study could not record changes in patients' level of hope over time, but the aim of this effort was exploratory. In fact, the questionnaire has yet to be validated and this will need to be done in a next step. This will involve validating the tool and re-assessing our results, particularly in different sociocultural and religious settings, on larger samples, in other cultural contexts, and readministering the questionnaire to explore variations over time.

Our present results are nonetheless worth reporting for their value in clinical practice. If relationships are crucial, measures aiming to strengthen patients' relationships with physicians and nurses could improve the patients' sense of hope. It is vitally important to create opportunities to nurture patients' trust and hope by striving to ensure good patient-doctor relationships. Relationships and trust are not static, but dynamic constructs: trust is not given once and for all, it has to be maintained. It is important to ensure that doctors are sufficiently aware that communications and relationships must be managed properly, even though this takes time and effort. This concept can be relevant for health care organization and resource allocation: hospitals need to be organized so as to enable relationships to happen, by suitably adjusting the workload or the numerical ratio of doctors to patients.

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