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ORIGINAL ARTICLE

Exceptional patients and communication in cancer care—are we missing another survival factor?

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Abstract
Objective There is increased awareness of the issue of exceptional survival beyond expectations among cancer patients with poor prognosis, and researchers are starting to look closely at this phenomenon. In this study, we explored the perceptions of these "exceptional patients" as to their understanding and insight into their unusual experience.
Methods We used a qualitative approach consisting of in-depth, open-ended interviews with exceptional patients in two locations, Texas and Israel, from 2007 to 2014. The interviews were audio-recorded and qualitatively analyzed, and gave rise to illness narratives entailing detailed descriptions of patients experience over the course of their disease and treatment. A qualitative content analysis focusing on contextual meaning was utilized.
Results Twenty-nine patients participated in our study. The mean years since diagnosis was 9.55 years (range, 4–23 years). All patients had received conventional treatment, including surgery, chemotherapy, and radiation therapy. One of the prevailing themes in these interviews was related to the patient-doctor relationship. Most participants mentioned that the support they received from one or more physicians was a crucial factor for their exceptional survival.
Conclusion The significance of patient-doctor relationship in cancer survival requires further research. This research is especially important as it adds to the current trend of patient centered care and points to the added value of relationship between health providers and patients. This relationship, as perceived by these exceptional patients, can be a factor that adds to improved survival in cancer care.

Keywords Exceptional patient · Exceptional physician · Cancer survival · Remarkable recovery · Patient-doctor communication · Cancer care · Cancer prognosis

Affiliation 1 relates to data collected at 2007–2009 for Dr Frenkel

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Introduction

Nearly 14 million cancer survivors are living in the USA. Owing to advances in early detection and treatment, approximately two thirds of people diagnosed with cancer are expected to live at least 5 years after diagnosis [1]. With the aging of the population and the continued advances in technologies to detect cancer early and treat it effectively, including improvements in radiation and chemotherapy regimens, surgical techniques, biological modalities, and gene therapy, the number of individuals living years beyond a cancer diagnosis can be expected to continue to increase.

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Unfortunately, not all patients are cured, and as mentioned above, one third of patients diagnosed with cancer will not survive 5 years after diagnosis. Patients with advanced lung cancer or pancreatic cancer, for example, still have a grim 5-year survival rate of less than 15 %. On the other hand, among patients with such a dismal prognosis, some survive much longer than expected. These patients are considered "exceptional patients." These patients survive for extended periods that cannot be explained by the nature of their disease or treatment. The defining criteria of the exceptional patient are controversial. Gotay defined "an exceptional survivor as a cancer patient who is alive when the probability is less than 25 % of living for 5 or more years, for a given type and stage." [2].

Despite the well-documented occurrence of this phenomenon [3–26], few studies have attempted to explain the factors that promote exceptional survival.

Several mechanisms for exceptional survival have been proposed. Some focus on complementary therapies, changes in nutrition, or nutritional and herbal supplements [4–8]; others focus on physiological characteristics, including immunological factors, the elimination of carcinogens or antigens, factors suppressing angiogenesis or promoting tumor necrosis or apoptosis, or genetic and epigenetic factors; and others focus on psychological characteristics of the patients [3–5, 8, 16, 18–20, 22–26].

On the other hand, in the past decade, the medical community has been increasingly interested in the value of patient-doctor communication and how this communication affects the disease process. Most of the literature concentrates on the improvement of patients' quality of life with improved patient-doctor communication [27–35]. However, no data are available to determine whether improved patient-doctor communication affects the survival of cancer patients.

With increased awareness of exceptional survival among these patients with a poor prognosis, researchers are starting to look closely at this phenomenon. The National Cancer Institute is leading an initiative aimed at discovering why some patients experience such exceptional survival**.** This initiative includes plans to carry out molecular profiling in tissue samples from exceptional survivors of cancer [25].

We approached exceptional survival from a more subjective perspective. We explored the perceptions of exceptional patients and their understanding of their unusual experience. To obtain these perceptions, we conducted a qualitative study in two separate locations, USA and Israel.

Methods

We used a qualitative approach consisting of in-depth, open-ended interviews using a narrative approach with exceptional patients and their family members. [36, 37] Illness narratives can give detailed descriptions of a patient's experience over the course of an illness or treatment. Working with narrative techniques requires dialogical listening to the narrator (the patient) and reflexive monitoring of the act of interpretation [36, 37, 38]. The qualitative approach seeks "to understand." It opens up the investigation to understand the patient's experience and may help explain a specific phenomenon.

We deemed this approach, now widely used in the context of health care, as most appropriate to capture the perceptions and experiences of exceptional patients. This project was approved by the Institutional Review Boards of the institutions that were involved in the study.

Setting and recruitment

The overall study period was 2007 to 2014. In the first stage of the study, completed in a major oncology center located in Houston, Texas, from 2007 to 2010, patients were recruited to the study through referrals from their oncologist; in the second stage of the study, from 2011 to 2014, patients were recruited in Israel only, through a regional population registry. All patients' medical records were evaluated by an independent external oncologist to verify that these patients had an exceptional disease course.

Data collection

Narrative interview techniques were used to elicit a reflective account of patients' experience according to what the patients felt was important to discuss [36–8]. The main question was open-ended: "Tell me about your experience of having an exceptional disease course." Patients were directed to elaborate on the way the experience changed their lives (if at all), their understanding of the prognosis, lifestyle changes, conceptions of exceptional survivorship, use of complementary or alternative medicine, their rationalization (if any) of their exceptional status and to what (if anything) they attributed their survival.

Data analysis and interpretation

We used qualitative content analysis that focused on contextual meaning. In each location, experienced qualitative researchers examined the interview transcripts independently and identified common categories, themes, and subthemes for cross-validation. Except in two cases, the analyses were done in the patients' native language, which was either English or Hebrew; two of the interviews were translated into Hebrew from Russian, which was the patients' native language.

Results

Participants

Twenty-nine exceptional cancer patients were identified during the two data collection stages of the study. In the first component, 14 participants were identified by oncologists from a leading oncology center as being exceptional survivors. In the second component, we used a population registry in one region of over 600,000 people to identify additional 15 exceptional patients who survived advanced lung cancer or pancreatic cancer with expected prognosis of less than 15 % 5-year survival.

Majority of patients had advanced breast cancer, pancreatic adenocarcinoma, and advanced lung cancer. The mean years since diagnosis was 9.55 years (range, 4–23 years) (Data is summarized in Table 1).

All patients had received conventional treatment, including some combination of surgery, chemotherapy, and radiation therapy. We identified several leading themes in these interviews, and the most prevalent theme in the interviews in both components of the study, both in the USA and Israel, was related to the patient-doctor relationship, which is the focus of this report.

"*Because of you I am alive*"

Several participants mentioned the importance of the support they received from the medical team, especially the physician, as a crucial factor for their exceptional survival. The patient's relationship with an individual physician was a critical element and the focus of much discussion. The physicians mentioned in this report were both male and females without any specific gender predominance.

These patients described a very complicated relationship with their healthcare providers. Although each patient's experience was different, these experiences shared some basic patterns and basic elements. The narratives typically described a vilified, incompetent physician who did not seem to care about the patient, or did not communicate with the patient. This vilified physician was contrasted with the savior-physician who was described as both omniscient and omnipotent, both sensitive to the patient's emotional needs and decisive. One patient was very clear about her physician, "because of Doctor G I am alive". One patient's partner was careful to find his wife "the best doctor" because he believed that doctors are the most important component in healthcare. He believed that a specific doctor was responsible for saving his wife. He defined a good doctor as one who likes the job, who asks about how patients feel and who shows concern.

One patient mentioned that her physician treated "each patient as if he was his only patient, as if he was his or her son." She also believed that the attitude of the physician is at least as important as his medical knowledge. Another patient described the oncologist as having "a demeanor about him that is frank, is straightforward. He doesn't pull any punches, but his demeanor while he's doing that gives you a sense of calmness." Another stated "They look at me as [name] and not as a medical record number."

Qualities of the physician

Communication patterns were crucial in these patients' relationships with their physicians. Patients typically compared several physicians who had treated them and described several attitudes and characteristics of good physicians (Table 2).

Compassion One of the most important qualities that patients mentioned was the physician's compassion. One patient expressed gratitude for her physician and "his calm, quiet, compassionate nature." One patient speaks of her doctor as an "angel" not in religious context but rather as being "amazing" (specifically, not being aggressive in terms of treatment choices and having a special type of intuition, knowledge, and experience). She describes her doctor as "first league," in that he was warm and caring. Another patient mentioned her own exceptional, "out of this world" doctor. She describes the surgeon who treated her as an "angel" with "hands of an angel." She mentions the way he treated her: bringing her coffee (prepared the exact way her late husband used to), sitting next to her bed, stroking her, wetting her lips. He is the only one she trusts; he is "more than a father, more than a brother". One patient and her partner said that she would not be alive if they had not met her exceptional doctor.

Availability Several patients mentioned that the physician did not appear rushed when talking with them and was always available via phone or email. "You always felt that he was there for *you*." Many physicians established their availability with their patients as reported by these statements: "if you need me, call me or shoot me an email…if you're in pain, don't suffer," "if ever you have any questions call me… call me if you need anything." An explicit invitation for the patient to contact the physician was crucial, as it opened the communication for patients when they felt scared or nervous. Physicians who indicated their openness and availability were regarded highly by the patients: "like they really were honestly there for you, I always felt like when I was there that I was in their hands." Patients felt that their physicians acted more like a concerned friend than a doctor, "we feel like we are old friends, he is overweight but always cares if I carry more weight than he does…".

Honesty Honesty was coupled with a sense of care, compassion, and hope. One patient remarked, "[the doctor] didn't say, 'okay, you're dying.' He said 'we don't know, I've got other patients who have had the same situation that you've got' and one patient had been [diagnosed] 7 years and she was still

Table 1 Demographics and diagnosis data for cancer patients who survived (USA $n = 14$; Israel $n = 15$)

	Number of patients USA	Number of patients Israel
Gender		
Male	4	6
Female	10	9
Age		
<44	1	0
44–55	4	0
55–81	8	15
Marital status		
Married	12	10
Divorced/widow	1	5
Single	1	0
Mean number of years since diagnosis (range 4–23 years)	11	8.2 yrs
Cancer diagnosis		
Breast	7	0
Pancreas	1	7
Lung		8
Colo-Rectal	2	0
AML	2	
Thyroid	1	
Cervical	1	
Advanced disease	14	15
Treatment received		
Chemotherapy	14	9
Radiation	9	2
Surgery	9	11
BMT	4	0

Table 2 Characteristics of the exceptional doctor

1.	Professional
2.	Asking about the patients' feelings
3.	Determined and decisive
4.	Compassionate
5.	Has a sensitive and personal approach that shows concern
6.	Available
7.	Makes the patient feel as if the patient is a close friend
8.	Close, attentive listening
9.	A sense of calmness
10.	Internal cheerfulness combined with being present
11.	Sense of humor
12.	Thinks "out of the box"

The exceptional physician does not have to have all these characteristics but should adopt one of these forms of sensitivity, which can make a large difference in the patient's perception of the quality of care

doing fine…it didn't dwell on the death part of it so much, but he gave me hope."

Sensitive and calm One patient described her physician's sensitive communication style; this physician provided information that was "frank, straightforward…but his demeanor while he's doing that gives you a sense of calmness." "I will forever be grateful to Dr. W. and his staff for his calm, quiet, compassionate nature." "…he just has a demeanor about him that is frank, is straightforward. He doesn't pull any punches, but his demeanor while he's doing that gives you a sense of calmness…."

Other patients mentioned that their doctor gave hope and spoke calmly and professionally, which showed understanding to patient's emotional state. Several patients commented on their physician's good sense of timing in giving the right amount of information, especially in the beginning "good about giving me the information as I needed it or as I brought it up," and "good doctors that know exactly only what you want to hear… that you don't want to know everything."

Decisive Some patients described their physician as both sensitive and decisive, which made them trust their doctor and follow every order to the letter. One patient mentioned "I am going to the one that decides, if it is the head of the department, this is the person I will go to". Another patient referred to the issue of decisiveness as a critical component, "I considered my doctor as a super- doctor, he had some combination of intuition, knowledge, but mostly decisiveness." Another patient noted "I haven't always wanted to hear what my doctor said; but I've always trusted him to make the best decision."

Internal cheerfulness combined with being present Several patients commented that their exceptional physician had an internal cheerfulness that was combined with a sense of being present. As one patient mentioned, "He was always cheerful and happy and answered all your questions. He didn't rush out of the room, like he had some place else he needed to be. You always felt like he was there for you." Another patient mentioned a similar quality in her exceptional physician: "My husband and I liked to make jokes and stuff, so, [my doctor] would joke with us too… My doctor just seemed so upbeat… which makes you feel upbeat."

Discussion

In this study, we identified and interviewed exceptional cancer patients. These patients were diagnosed with an advanced stage of different types of cancer and experienced unexplained prolonged survival time, given the nature of their disease or treatment. We explored with these individuals their perceptions of factors that might explain their enhanced survival.

An important theme in the interviews was related to patient-doctor interactions. Patients identified an exceptional physician who was a major factor in their unusual survival. Our data suggest that certain characteristics in the patient-doctor relationship and a physician's unique qualities might play a major role in cancer patients' survival.

Previous studies on exceptional cancer patients have speculated about many factors that might prolong survival, including dietary changes, immune system enhancement, spiritual awakening, behavioral changes, and a change in personal attitude [3–5, 8, 16, 18–20]. To explain exceptional cancer survival, researchers often look for a magic pill [4–7]; unfortunately, this magic pill has never been found.

It is well known from multiple previous studies that social support is mentioned as an important factor to healing and a significant survival factor [39–45]. In long-term studies of populations, strong family and community connections reduce the risk of developing cancer and weak social connections reduce survival [39–41].

In our study, patients identified their connections with their physician as a significant factor in their survival experience.

These exceptional patients repeatedly mentioned that among their physicians, there was one exceptional physician. This physician thought "outside of the box" or even was situated as an outsider to the healthcare system. Several patients and their families perceived these exceptional physicians as responsible for saving the patient from death and other patients accorded their physician as very important to their survival. In the first cohort where patients were found through a physician referral, one might argue that physicians who have particularly good or close relationship with these patients may be biased as to whom they recommend to the study. This assumption is dissolved in the second cohort where the patients were identified through a population registry where the physicians did not have any role in the selection of patients and similar finding was found.

The exceptional physician was described as professional and determined, with a sensitive and personal approach. These physicians were able to develop a personal communication pattern with their patients, combining compassion with close, attentive listening, which enabled patients to express themselves. The exceptional physician managed to communicate about the things that mattered to patients. Thus, being an exceptional physician is not just about being nice; exceptional physicians are attentive and flexible enough to espouse the patient's psyche, social position, value system, and emotional status. The physician does not have to have multiple traits but rather should adopt one of these forms of sensitivity, which makes a large difference in the patient's perception of the quality of care (Table 2). This is one area in which additional research is needed to uncover which physician characteristics may be most important to patients.

Patients in the study did not relate to their physicians as "Gods," but rather emphasized the excellent relationship they had with their practitioners, as an essential ingredient in their survival. Even though most physicians recognize that their relationships with patients can have healing effects, relational skills are rarely studied systematically and are often consigned to the unscientific and mystified "art" of medicine [42]. A study that was designed to explore this question and identify a core set of healing skills from the "healers" perspective was conducted in Vanderbilt University Medical Center [42]. This study was conducted with 50 practitioners who were selected by their peers as being healers. These practitioners mentioned that they take time to be with their patient, they listen, they let the patient explain, they do the little things that are important to their patients, and they share authority, and are committed. These findings are very similar to the findings we gathered in our study from the patients' perspective about their physicians.

Our previous reports conducted at The University of Texas MD Anderson Cancer Center [22, 23] focused on these patients' broader perceptions of the factors in their exceptional survival experience and did not focus specifically on the relationship between the patient and an individual physician as an element of exceptional survival. While patients in these reports described several attitudes and characteristics of physicians, some of the most important qualities that were helpful and important in their survival process hinged on the compassion and communication abilities of the physician.

To the best of our knowledge, no study has focused on the direct relationship between patient-doctor communication and exceptional survival. One study of patients with non-small cell lung cancer showed that supportive care improved survival, but this study did not show a direct causal relationship between survival and improved communication processes [27].

Our study supports previous assumptions that improved communication in cancer care can affect health outcomes [28–30]. The value of patient-doctor relationships and the quality of physicians' communication with their patients has been discussed in many forums and publications [28–32]. It is commonly perceived that patients get well, at least in part, because they believe in the power of modern medicine and expect to feel relief when they see physicians they trust. Previous studies emphasize the importance of communication in cancer care with the perception that communication may influence clinical outcomes [43, 44].

Although the relationship between physicians' communication and patient outcomes has been actively researched for 30 years, studies have focused predominantly on patient satisfaction, quality of life, and adherence to treatment [28–30].

However, growing evidence shows that communication can affect directly the patient's psychological symptoms, as well as physical and emotional well-being [45]. Results from

empirical studies show that indeed physician behavior can result in significant health benefits for patients [31–34].

Patients reported reduced anxiety and depression as well as increased hope when physicians were empathic, gave clear information, discussed questions and feelings, were reassuring, and were open about the diagnosis and prognosis [32, 34]. However, studies in cancer care that focus on the relationship between physician behavior and patient outcomes are relatively limited, and data regarding the effect of physicians' behavior on survival are not available.

In our study, patients did not ascribe their survival to medication; they did not mention a magic pill that made the difference in their survival. Rather, they emphasized the unique relationship that they had with their exceptional physicians. In many cases, these exceptional patients believed that their exceptional physician rescued them from death.

The capacity of one human to heal another and the healing relationships that evolve have been the subject of intense interest for healthcare providers [35]. Indicators of a strong therapeutic alliance include mutual trust, coordinated and continuous healthcare, and the patient's perception of feeling respected and cared for. The physician-patient alliance is enhanced when physicians are optimally informative and show empathy with the patient's circumstances, when patients have an opportunity to express their concerns, and when patients receive consistent messages and coordinated care from the clinical team [28, 29].

We interviewed 29 exceptional patients who survived cancer that has very poor prognosis, for this study. We are making claims that are not statistical but rather qualitative. As a qualitative study, such findings are not generalizable but focus on a deeper understanding of the phenomenon.

It seems that these patients' experiences and the lessons obtained from their survival trajectory are important enough to mention. This research is noteworthy as it adds to the current trend that emphasizes patient-centered care and enhances the added value of unique relationship between health providers and patients. The findings do provide some essential insights into the issue of patient-doctor communication that has clinical applicability. Additional qualitative studies and further quantitative research with a larger sample are warranted.

This suggested relationship, as perceived by these exceptional patients, might be another factor that adds to improved survival in cancer care, and healthcare practitioners, residency and fellowship educators might need to be aware of these findings. Leaders of health care education should consider mentioning this issue into forums of discussion that might enlighten students and health professionals in understanding patient-centered care and the value of communication and healing.

The importance of patient-doctor relationships for cancer survival requires further research and exploration as this issue might raise the likelihood that unique patient-doctor relationship might affect healing and survival outcomes.

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Compliance with ethical standards

Competing interests The authors declare that they have no competing interests.

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