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Contents

Foreword

Welcome to the latest edition of the International Journal of Clinical Skills (IJOCS), Volume 8, Issue 2, March 2014.

There is no doubt that high standards of communication by health care professionals can lead to better patient outcomes and satisfaction. Informed by theoretical perspectives from workplace learning, the Head of Clinical Communication at St George's Medical School, University of London, explores how clinical communication is taught, learned and practised. Is the clinical workplace the legitimate location for teaching and learning clinical communication? This interesting paper proposes a new way of understanding learning in this context.

Can bad news be delivered without destroying hope? Canadian researchers, Dr Lawrence Martis and Dr Anne Westhues, present an informative study which examines the process of breaking bad news in India. Physicians who ground their practice in a biomedical model of care are likely to adopt strategies that result in non-disclosure or partial disclosure of clinical bad news. However, a social determinant of health perspective helps physicians to use strategies to conserve hope among patients without withholding truth about their health condition.

The Trust Quotient and Johari window are tools that can help in understanding, measuring and improving trustworthiness. It follows that greater trust in health care professionals is associated with increased patient satisfaction and improved clinical outcomes. This paper describes a case scenario to illustrate the Trust Quotient and Johari window – tools which should be increasingly utilised by doctors and healthcare workers to measure and improve their trustworthiness.

As always, your feedback is invaluable for the continued development of the International Journal of Clinical Skills – the only peer reviewed international journal devoted to clinical skills. E-mail: feedback@ijocs.org

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Delivering bad news without destroying hope: the conceptions, concerns and actions of physicians in India

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Keywords

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Clinical communication

Abstract

Introduction:

Empirical knowledge on the relationship between bad news and hope can be a great resource for physicians caring for patients with life-limiting diseases. Although the extant literature sheds some light on interpersonal and psychological dimensions of clinical hope, it does not provide sufficient information on its sociostructural environments. Moreover, the literature is limited with regard to the hope-conserving practices of physicians in low and middle income countries, including India.

Methods:

A qualitative study was conducted to examine the process of breaking bad news in India. Analysis of the data collected through semi-structured interviews with 27 physicians working in four tertiary care hospitals in Karnataka province generated a grounded theory that explains the processes of creating competence for communicating bad news to patients and families without undermining their hope.

Results:

The processes related to preserving hope are discussed. Divergent views on the nature of bad news, its relationship to hope, the functions of hope, and strategies to promote hope when conveying bad news are presented. Physicians who perceived bad news and hope as mutually exclusive clinical realities, resorted to truth-avoidant strategies for conserving hope. Four such strategies were identified in the data: paternalistic silence, deception, masking and continuation of futile treatments. On the other hand, clinicians who believed that it is possible to preserve hope when delivering clinical bad news focused on attenuating both the medical and material ill-effects of life-limiting diseases. They employed a set of truth-integrative strategies such as phased disclosure, undoing of false hope, drawing on patients' resources, presenting team care, highlighting the positive, discussing care options, providing personal and social support, and arranging material / tangible support.

Discussion:

This study suggests that socioeconomic disparities and dysfunctional health care systems destroy hope as

as much as the bio-physical aspects of a life-limiting disease. It invites health care professionals to reconceptualize the relationship between bad news and hope by taking into account structural/systemic issues of health care provision and to employ suitable hope-conserving strategies, even when death is imminent or foreseeable.

Conclusion:

Physicians who ground their practice in a biomedical model of care are likely to adopt interactional strategies that result in non-disclosure or partial disclosure of clinical bad news. On the contrary, a social determinant of health perspective helps clinicians to use strategies that conserve hope among patients without withholding truth about their health condition. More studies on the sociostructural dimensions of hope are necessary to develop best practices on delivering bad news without destroying hope.

Introduction

The communicative competence of physicians is challenged most in the context of life-limiting diseases. In such situations, patients and families expect more information than in the case of curable or manageable health conditions [1] but estimating survival, level of functionality and treatment outcomes is seldom easy [2]. Managing the emotional disturbance of patients and families and involving them in planning care [3], and dealing with misunderstandings about prognosis and treatment goals [4], add to the complexities of clinical interactions. Central to these challenges is the problem of nurturing hope when delivering bad news to patients and families, or truth telling, a phrase used synonymously henceforth.

Bad news and hope are inextricably interrelated because bad news reduces hope about recovery or resolution of health issues that impact upon various aspects of life. Buckman [5] has implicitly referred to this inverse relationship by defining bad news as “any news that drastically and negatively alters the patient’s view of her or his future”. Similarly, Ptacek and Eberhardt [6] have highlighted the need for contextualizing clinical bad news in broader life prospects of a person because such information “results in cognitive, behavioral or emotional deficit in the person receiving the news and this lasts beyond the bad news encounter”. Bad news related to a life-limiting disease is seldom singular because a series of hope-curtailling events such as unfavorable diagnosis,

poor prognosis, treatment failures, functional impairments and impending death are likely to unfold during the disease trajectory. So, hope in the context of a life-limiting disease should not be treated merely as a psychological state of a person largely determined by the interactional skills of individual physicians. Rather, the role of the sociocultural and sociostructural environment should be examined to understand the concept of clinical hope and the process of preserving and promoting it. As a step towards balancing the predominant psychological and interpersonal outlook on hope in the extant literature, this article highlights its sociostructural dimension. It invites health care professionals to employ such strategies that ensure disclosure of bad news to patients and families without undermining their hope.

Review of literature

A good amount of knowledge on physicians’ perspectives and hope-conserving actions already exists and is useful for didactic and patient care environments across the globe. However, few studies have originated from low and middle income countries, particularly from India which is the second largest country with 1,210 million people [7] and is counted among top ten countries with ever increasing incidence of life-threatening and non-communicable diseases [8]. We were unable to find any studies that specifically explored the conceptions, concerns and actions of physicians in India with regard to nurturing hope among patients and families dealing with life-limiting diseases. General comments on physician’s views on the relationship between bad news and hope are found in a handful of Indian studies. For example, Yusuf and colleagues [9] examined the attitudes of 48 physicians working in a tertiary care hospital in Kashmir (India) and found that 94% of the participants believed that news about an unfavorable diagnosis should be disclosed reservedly, particularly if the information is to be shared with women. This study revealed that the fear of destroying hope influences truth telling behaviors of physicians; 56% of the participants said that they withheld bad news for fear of causing distress, depression and suicidal ideation among patients. Similarly Kumar and colleagues [10] reported that all 35 radiation oncologists who participated in their study dismissed the view that the condition of patients deteriorates or adversely affects survival if they come to know the hard truth. Although 32 participants preferred to disclose bad news to patients, 22 of them acknowledged that they usually hide the hard truth from patients on the behest of families. These findings suggest that there is conflict between physicians and families regarding the impact of hard truth or clinical bad news on hopefulness and the emotional state of

patients. Chattopadhyay and Simon [11] found that attitudes about disclosure are disease-specific, as well. For example, Indian society in general perceives cancer as a “disease without hope” and physicians are less likely to fully disclose bad news about cancer than diseases where there may be a realistic or at least perceived favourable prognosis. Based on these studies, we can surmise that truth telling behaviors of physicians in India are influenced by their personal views on its effects on hope, the wishes of family members, and social beliefs about life-limiting diseases. Unfortunately, none of these aspects are explained to the extent needed to guide clinical practice and medical education in India and internationally. Further, the influence of the sociostructural environment on clinical hope is almost completely neglected.

The research done in economically developed countries has shed light on the struggle faced by physicians about preserving hope when providing honest truth [3]. Several studies have shown that physicians who consider bad news and hope as antithetical constructs tend to withhold bad news from patients in order to protect them from emotional distress and hopelessness [12 – 17]. Studies have also revealed that instead of choosing between truth telling and sustaining hope, some physicians adopt an integrative approach by balancing the amount of hard truth and desired level of hope [18 – 22]. The vocabularies of hope rather than of deficits, a language of possibilities, achievable goals and a commitment to help the patient were found to generate and maintain hope among patients and families [23].

In conclusion, the existing literature informs us that there are divergent views and practices among physicians in both high and low income countries about sustaining hope when delivering clinical bad news. We found two major gaps in this knowledgebase. One is a lack of focus on the influence of sociostructural environments on hopefulness. A second is a lack of literature grounded in the experiences of physicians working in low and middle income countries, specifically in India. We hope that this study will bridge these gaps, improve clinical communication in India, and raise awareness among scholars and health care providers across the globe about the influence of systemic factors on the capacity of physicians to nurture hope when delivering bad news.

Methods

Research questions

Initially, this study was designed to explain the process of breaking bad news to patients with life-limiting diseases in India. During the course of the study, it became apparent that the process of creating communicative competence for breaking bad news was the core concern of the participants. The analysis of the data generated a theoretical framework for producing physicians capable of breaking bad news well. “Preserving hope” was one of the subcategories connected with communicative competence for truth telling and for the purpose of this article, the findings related to it are organized to answer the following questions: 1) How do physicians in India conceptualize hope in the context of life-limiting diseases? 2) How do their views influence truth telling behaviors? 3) What strategies do they employ to preserve or promote hope when delivering bad news to patients and families?

Approach to research

Grounded theory methodology is not only ideal for studying processes but also is a “method in process” [24]. It has evolved into many forms based on the epistemological and ontological perspectives of researchers that range from realism to relativism [25]. Glaser and Strauss [26], the originators of grounded theory methodology, did not subscribe to any particular ontological view. However, many of the guidelines provided by them correspond with critical realist-constructivist ontology, which allows researchers to explore the multiple meanings constructed by people about a single and somewhat mind-independent reality [27, 28]. This ontological standpoint allowed us to draw on the expertise of grounded theory scholars with divergent worldviews to examine the multiple meanings and actions of physicians that form part of the process of nurturing hope when delivering bad news to patients in India.

Sampling

Participants for this study were recruited at three tertiary care hospitals in Bangalore and one in Mangalore, two prominent cities of Karnataka province in India. An invitation letter was circulated to 49 physicians, asking them to contact the first author if they had at least two years of post-MBBS (Medical Bachelor and Bachelor of Surgery) clinical experience and were willing to share their experiences about breaking bad news to patients

and families. A consent form was sent to 41 physicians who showed interest in this study, but because of the saturation of categories only 27 physicians were interviewed. A purposive sampling procedure was used, inviting physicians from various medical specialties, and by gender, age and educational background to generate data with maximum variation of views and experiences concerning truth telling [29], and to have multiple comparison groups for generating a theory [30]. Grounded theory methodology emphasizes simultaneous data collection and analysis. As such, theoretical sampling procedures were followed to saturate the emerging categories. For example, the analysis of the data indicated that the capacity of physicians to deliver bad news and conserve hope may differ considerably when working in public, not-for-profit, and corporate (for-profit) hospitals. So the participants were asked to share their experiences at different hospitals rather than limiting themselves to their current location. During data analysis, the need to substantiate the views of physicians was observed and the sample was expanded to include physicians currently working in public and corporate hospitals as well as not-for-profit hospitals.

Data collection

Demographic information such as age, sex, academic qualifications, years of post-MBBS medical practice, location and type of hospital worked at previously, number of bad news events communicated in a week and completion of any training program related to clinical communication was obtained from each participant (Table 1). A field notes form was used to record observations and ideas that emerged during the planned interviews with the participants and unplanned encounters with other health care professionals, patients, researchers and administrators. The larger portion of the data was gathered through one hour semi-structured interviews with each of the 27 participants. Eight participants were contacted for a second time for about 10-15 minutes to obtain clarifications and additional information. All interviews were conducted in English and verbatim transcripts were prepared from the digital sound recordings and subsequently anonymized.

Table 1: Demographic characteristics

SEX	Male:	19 participants
	Female:	8 participants
AGE	Average:	42 years old
	Range:	26-63 years old
	Average:	18 years
	Range:	5-33 years
YEARS OF POST-MBBS MEDICAL PRACTICE	Cardiology / Chest Medicine:	3 participants
	General Medicine:	5 participants
	General Surgery:	3 participants
MEDICAL SPECIALTY OF PARTICIPANTS	Obstetrics & Gynaecology:	3 participants
	Nephrology:	2 participants
	Oncology:	5 participants
	Paediatrics:	3 participants
	Pain & Palliative Care:	2 participants
TYPE OF HOSPITAL EXPERIENCE	Worked only in public hospitals:	6 participants
	Worked only in not-for-profit hospitals:	7 participants
	Worked only in corporate hospital:	1 participants
	Worked in two or all three types of hospitals:	13 participants
NUMBER OF BAD NEWS EVENTS HANDLED IN A WEEK	1-10 events:	15 participants
	11-20 events	12 participants
ATTENDANCE AT FORMAL CLINICAL COMMUNICATION TRAINING	Yes:	11 participants
	No:	16 participants

Data analysis

The narrative data was analyzed as a two-level iterative procedure suggested by Glaser [30, 31] with the aid of NVivo (Version 9) qualitative data management software. The first level of analysis generated five substantive or conceptual categories through open coding and we identified “creating communicative competence” as the core category by means of selective coding procedures. During the open coding phase efforts were made to be open to all theoretical possibilities when labelling various actions and interactions in the data as concepts. Selective coding involved choosing a category that explained most of the perceptions, actions and interactions in the data [26]. The second level of analysis or theoretical coding involved using coding families suggested by Glaser [31] and Strauss and Corbin [32] for

expanding and assembling the conceptual categories into a theoretical structure by connecting categories with each other and with their properties [33].

A number of procedures were followed to ensure the quality of the emergent theory. For example, the codes were examined by three experienced researchers who independently checked the correspondence between the pieces of raw data coded under each category and its properties. The emergent theoretical framework was presented at two participating hospitals to obtain feedback from health care professionals on the interpretation of the data and to include their perspectives in the research results.

Research ethics

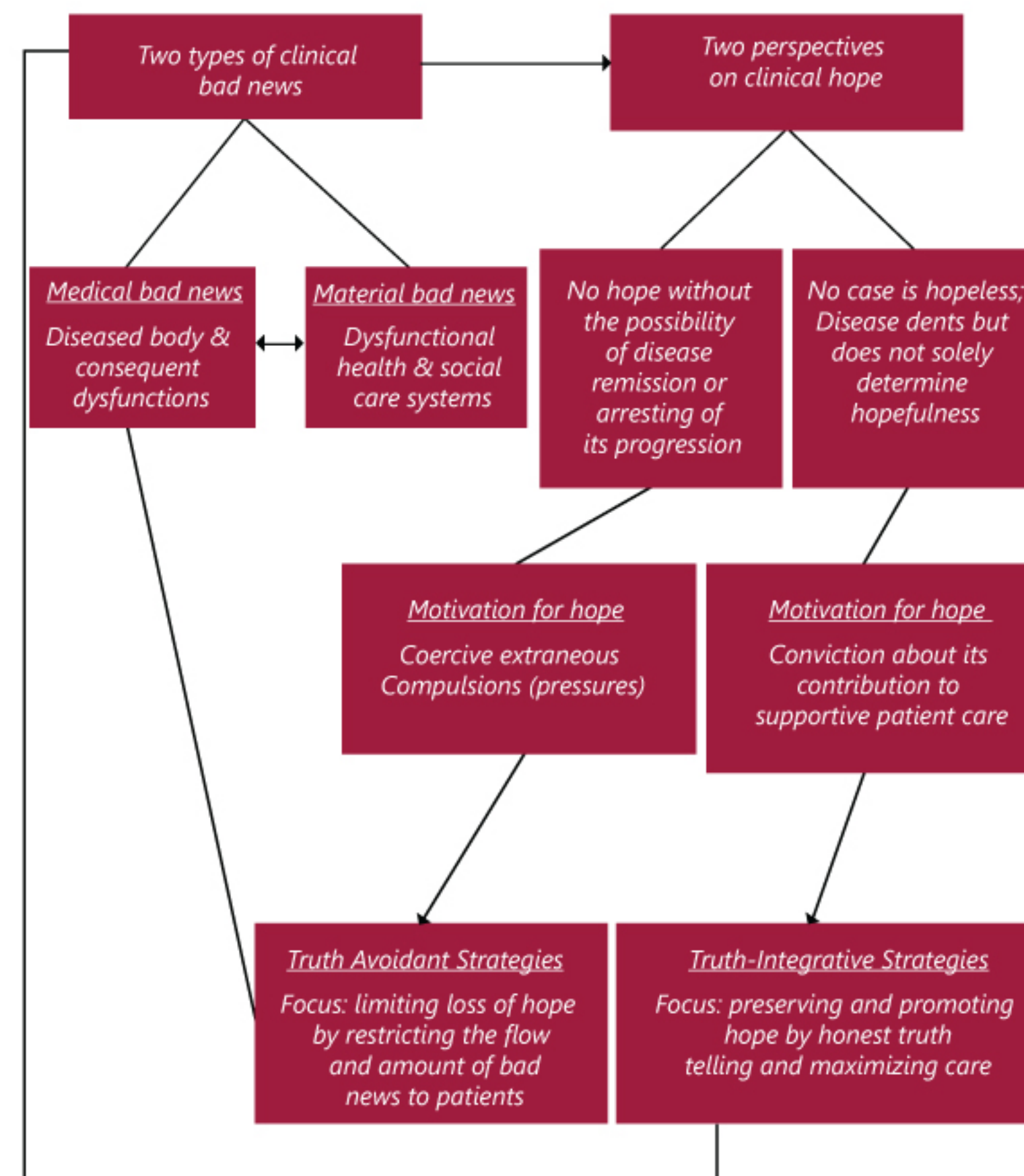
Prior to data gathering, the research proposal was approved by the Research Ethics Boards at Wilfrid Laurier University, Canada and St. John's National Academy of Health Sciences in India. The research was carried out in accordance with the Declaration of Helsinki [34] of the World Medical Association.

Results

Physicians' beliefs about the nature and scope of hope in the context of life-limiting diseases

The analysis of the data revealed that bad news related to life-limiting diseases is a causal condition for diminished hope among patients and their families but the bad news that adversely affects hope is always plural and multidimensional. It became evident that physicians' conceptions about hope and their hope-nurturing actions flow from a multidimensional concept of bad news. Two types of bad news were found in the data: 1) medical bad news; and 2) material bad news (Figure 1). The former refers to the information about diagnosis of a life-limiting disease, potential complications or treatment failures, bio-physical and psychosocial dysfunctions and threat to life expectancy. The second type of bad news suggests that unfavorable material and social circumstance create and compound the medical bad news. Material bad news included health-related exclusionary social beliefs and customs, socioeconomic disparities, a dysfunctional health care system and a lack of a social safety net, in particular the absence of universal health insurance.

Figure 1: Process related to delivering bad news without destroying hope



All physicians who participated in this study believed that clinical bad news adversely affects hopefulness among patients and their families. However, they shared different views about the nature and scope of hope in the context of life-limiting diseases. A few of them equated authentic hope with remission or at least the possibility of modifying the progressive trajectory of a disease. The following quote presents the view that hope is a contradiction if no cure or alternatives to biophysical dysfunction could be provided:

"I do not think anybody enjoys giving bad news, but in situations of breaking bad news about the diagnosis where there is treatment or cure, I do not feel very bad. We just assure them that there is a treatment for this and we are going to help you out. When it comes to end stage diseases, we feel really helpless that we are not able to do anything... Some people [family members] say that if [the patient is] terminally ill, we take the patient back home because they do not have any hope and we cannot give them any hope."

On the contrary, a majority of the physicians were of the opinion that it is possible to provide authentic hope even when options for curing or restoring the biophysical functioning are limited or do not exist. According to them, clinical hope is not contingent on a disease-free

existence but an attitude towards life in general and disease, debility and death in particular. So, avoiding absolutes and refraining from labelling patients as hopeless cases are fundamental to patient care.

"My feeling is that one should not give up hope until the last moment. Do our best and after that it's in God's hand... I have found many instances. I will tell you one instance: The child was very bad; we had given up hope. The child had convulsions because of 'brain infections'. We told them that this child is not going to live and even if she does, she is going to have blindness and deafness. All specialists we referred to - the ENT, Neurologist, Ophthalmologist and Neurosurgeons - they said it was a very bad prognosis; 'this child is going to be dependent'. But to our surprise, after about three weeks the child slowly improved, although she was not looking around or not listening, but she was able to feed herself. Six or seven months later one girl walked into the outpatient department and we failed to recognize her. 'Doctor, don't you remember me', said her father, 'The child you said (laughs)... now she is fully talking, walking, not blind, not deaf.' ... If you tell any patient that nothing can be done, it would be a traumatic experience."

Similarly, a surgeon illustrated his view that providing hope is not contingent upon cure:

"What I tell them about the stage four cancer and all, this has already reached stage four and has spread, cannot do much curing, but we can keep him comfortable, free of symptoms from which he is suffering, by giving palliative therapy, medical treatment, so that we keep him comfortable and suffering-free, pain-free, till he lives."

In brief, two conceptions about clinical hope emerged during the analysis of the data. According to one view, authentic hope is contingent on their ability to cure a disease or arrest its progression. On the contrary, most of the physicians contextualized hope in the totality of life rather than confining it to a diseased body. According to the first view, the type and severity of the disease determine the possibility of hope; the latter perspective suggests that disease severity invites both care providers and care consumers to redefine hope but does not preclude physicians from nurturing it.

Motivations for preserving hope

One would not expect to learn about hope-preserving actions from physicians who associate authentic hope with curing the disease or finding alternatives to biophysical debilities when they did not believe this was

possible. However, the analysis of the data revealed that physicians' actions and interactions do not always flow from their perceptions of hope because intervening factors either override or underscore their personal views. Even those who considered hope as a mirage in situations of a life-limiting disease reported that it was important to sustain hope when delivering bad news because: 1) Patients and families expect physicians to provide hope; 2) Failure to provide hope might trigger violence from patients and families; 3) It is necessary to avoid being considered incompetent; and 4) It avoids legal battles with care consumers. The following excerpt from an interview provides a glimpse into the pressure to preserve hope, even when the physician did not believe hope was warranted:

"In our country patients have a very different feeling towards their doctors. Sometimes, they think that they are gods; for them anything is possible. If I tell them, they cannot believe it and say, 'How can you say, that you cannot do it?'... Most often, in this hospital, by the time they come in, the patient has already gone to about three places or the person has been kept at home for two or three weeks and suddenly they expect miracles to happen."

Some physicians reported that the compulsion to preserve hope is higher in the context of young patients because family members become violent upon receiving harsh bad news about them. They also pointed out that people bring patients to a tertiary care hospital with high expectations and in particular they expect much from physicians working at corporate hospitals:

"Somehow, the people who can afford the treatment may seem to think that they can buy anything. So, sometimes, they say, 'We are ready to spend anything, to get medicine anywhere in the world, but this child must recover'. They are not willing to accept that in spite of everything, this child may not survive. So that is the challenge. These things happen in corporate hospitals. They seem to say that, 'I am paying you; so provide me what I want.'"

The motivations discussed above are extraneous to physicians and somewhat coercive. The comparative analysis brought forth a counter view held by a great majority of the physicians that hope is valued for its contribution to patient care processes, even when cure is unlikely. The following five functions of hope were identified:

(a) Hope is a universal need

Some physicians contextualized the relevance of hope in life as a whole rather than confining it to disease contexts because all human beings need hope. As this physician pointed out:

"If there is no hope for living or anything, I do not think that anybody would wish to do anything, isn't it? Everybody needs hope. I think, even a terminally sick patient, I do not think that she hopes to die. Whatever we see, even the very sick patient; I had my own grandmother, bedridden, paralyzed and she had cancer; in spite of that, she says, 'maybe if I live for another ten days, the other grandchild will come to visit me.' That is hope. Even in sickness, I think, everybody hopes to live".

(b) Hope prevents a sense of abandonment among patients

One physician asserted that information without hope hurts immensely but hope makes bad news a bit more palatable:

"From a patient's perspective, when you deliver a bad news, as long as you give him some hope, the patient has something grab onto. Instead, if you are going to tell him, (mumbles) 'you have got cancer and you are going to die' that is going to really hurt him so much. So, even when I tell them that you have the cancer, this is the kind of treatment... We can focus on the symptoms and we can manage without pain. So, I tell them of the components of best supportive care, but telling them that we are not able to cure, but the symptoms which are painful, we will address them. So, the goal of this is to tell them that we have not given up hope or we are abandoning you, even if you are talking about palliative care, we do it well. We won't give up on you. So, I think that helps... So, I think that hope is very important."

(c) People dealing with life-limiting diseases badly need hope

Often the disease and social beliefs about it force patients to perceive themselves as hopeless and a burden to others. Patients with stigmatized diseases in particular suffer hopelessness, not only due to the disease burdens but also because people around them transmit the message that their condition is hopeless. An oncologist emphasized the need to counter these messages with hope-nurturing actions and interactions that build clinical trust and compliance to treatment:

"So, that feeling hopeful is more important, I think. That will be the one thing where the patient gets confidence in you and then they will start really accepting our treatment because in our branch (oncology) accepting the treatment is very difficult aspect. They lose hope. If you come out with a, okay, you have cancer, 1000 people outside will say that there is no cure for it and you are going to die. So, if you don't give them hope, they'll think that it is waste to spend money, that you do this. So this is more important, give hope."

(d) Hope increases immunity and makes treatments effective

Some participants believed that hope not only generates a positive frame of mind among patients, but may have favourable bio-physical outcomes, as the following quote suggests:

"I feel that most of the diseases are diseases of the mind. If a person develops a positive attitude, maybe to some extent, the immune systems functions in a better way. Maybe, if hope is there, it is alright."

(e) Hope keeps patients in care

Some physicians commented that hope is necessary to ensure patients' adherence to treatments for extending their life-expectancy or enhancing the quality of life.

"I want my patients to come back to treatment, though not with me, but with anybody. So, I will give him that much information so that he will keep up with his treatment. He will go ahead with the hope because if he does not do any treatment ... I give you one example, one lady came to me. She had vocal muscle cancer... She badly needed surgery because that was her last chance... She did not buy into the treatment because, I feel, the information which was given to her might have broken her hope or may be, we were not sensitive enough with which she could have taken the treatment."

To summarize, irrespective of their beliefs about the nature of hope in life-limiting disease contexts, both extraneous pressures and awareness of the functions of hope in patient care processes motivated the physicians to address the hope-deficit situations caused by clinical bad news.

Strategies employed by physicians to preserve hope

Two kinds of strategies for preserving hope were identified in the data, which we distinguished as

'truth-avoidant' and 'truth-integrative' strategies. Physicians who associated hope with cure and felt pressured by factors extraneous to their personal viewpoint used a different set of tactics (truth-avoidant) compared to their counterparts who believed that one can have hope even when cure is not possible (truth-integrative). Physicians in the first group were concerned that bad news disclosure might kill hope and therefore tried to limit the flow of unfavorable information to patients and sometimes totally avoided truth telling. Physicians in the second group tried to preserve hope by reducing the ill-effects of bad news, rather than hiding distressful information. These divergent hope-conserving techniques are described below with some supporting extracts from interview data in tables 2 and 3.

Truth-avoidant strategies: limiting the flow of bad news to avoid loss of hope

Participants who equated hope with cure and felt pressured to provide hope focused on manipulating medical bad news to minimize the hope-deficit among patients and their families. They tried to manage the adverse effects of medical bad news on hope by restricting the flow and amount of bad news to patients. Four strategies were identified in the interviews:

1. Paternalistic silence: This strategy refers to blocking bad news, particularly truth about dark diseases such as cancer or a disease that has reached the terminal stage, with the belief that it is in the best interest of patients.

2. Deception (blatant lies): This strategy involves hiding the news about a serious disease by misleading the patients to believe that the disease symptoms were caused by some manageable chronic disease.

3. Masking / minimizing: Using language that minimizes the severity of the disease outcomes. For example, referring to cancer as a bad tumor.

4. Continuing futile treatments: Continuing to provide treatments known to be ineffective thereby creating a false sense of hope for a period of time.

Table 2: Truth-avoidant strategies: limiting the flow of bad news to avoid loss of hope

1. Paternalistic silence:

In fact, you might call the person back and say, 'You need only medicines now. We will see you after six months. You don't need surgery. We don't say, 'We can't do surgery,' instead we say, 'you don't need surgery now. You can come after six months and then we will evaluate you'. We send them back because we do not want to dash hopes.

I wouldn't like to tell the patient because however well you put it across, it depends on how the person takes it. Imagine a person not able to bear that and something happens and the family members will blame you that 'he would have lived for sometime'. If they tend to go into depression, I do not like to tell them without the consent of the family members.

2. Deception (blatant lies):

Just to tell you one more case, there was a young man with intestinal cancer. He was told that he has TB [Tuberculosis], because the relatives requested the doctor to tell him that it was just TB. Earlier he was tested for TB and was put on those tablets.

So right from my MBBS days, we have seen our professors and all that, they tell the patient: 'don't worry; nothing will happen. We will treat you; you will be fine. Go and call the attender [family member]'. And they tell the attender, 'see, sorry boss this is progressive disease. There is nothing much I can do about it. Just to keep him happy we have told this'. Probably, I have picked up those things. I never had the guts to go tell the patient, 'No, I am sorry you are going to die out of the disease.'

3. Masking / Minimizing:

If it is a cancer, definitely, I do not say it is a cancer, but I say it is a bad tumor, because the word itself, 'cancer' everybody knows, though it is a layman, everybody knows, it is a bad disease. So, we usually say that 'it does not look very nice tumor. If untreated, it might spread. It might come back later, but now we can do something to stop it.

Okay, a person is having a cancer and I am not telling that 'you have cancer'. I will tell him that you have a little serious disease and you require a long treatment, a different line of treatment. I will not tell him directly what it is.

4. Continuing futile treatments:

What we have done might not help the patient. The surgery by itself might not help the patients because, if you are looking at the malignancy, for example, it reached progressive point where after a point, tumor cannot be not arrested. However, we face some situations that we do it (surgery) anyway.

I do not know because I have never worked in a private hospital (laughs). There, I think it is little different about communicating bad news. I used to go as a consultant to some of the private hospitals, where I noticed that they do not like to have deaths in their hospitals, in a private hospital. So they usually try to keep the patient alive with 'faltu' [fake or useless] treatments and then refer them to either a government hospital or a bigger hospital just before death.

Truth-integrative strategies: managing the ill-effects of bad news disclosure

The many physicians who believed that bad news might dent, but not totally destroy hope, emphasized that both honestly conveying the distressful health information and preserving hope were equally important to clinical relationship. Rather than hiding bad news from patients as a way of conserving hope, they tried to integrate hard truth with hope-conserving interactions. As such they focused on providing material and social supports to counter the ill-effects of both medical and material bad

news on hope. Such physicians believed that providing more care rather than less bad news is the key to nurturing hope among patients and families. The following hope-nurturing strategies were identified during the analysis of the data and Table 3 summarizes quotes that support this analysis:

1. Phased disclosure: This strategy involves conveying honest and entire bad news in a caring fashion by breaking the information into small chunks and disclosing it at different stages of the disease trajectory. Instead of hiding the hard truth, physicians advocated with family members for the patient's right to know the truth about their health condition.

2. Undoing false hope: Physicians emphasized realistic hope by acknowledging the limitations of their professional capacity to cure or save life, by helping families recognize their limited financial resources, explaining the limits to the kinds of treatments and technologies their hospital could offer and by pointing out the gaps in medical science.

3. Drawing on patients' resources: There are many instances in the data to suggest that physicians assessed a patient's perspective on life as a whole (existential outlook), including views on disease and death. They gathered information on the educational, professional and financial background of the patient and his or her family and the level of family support to understand the level and sources of a patient's resilience. Subsequently, when breaking the bad news, they referred to the personal and relational resources of patients as a way of bolstering hopefulness.

4. Presenting team care: The participants tried to instill a sense of confidence in patients and families by presenting the expertise of the health care team. They engaged social workers and other health professionals in the care of the patient.

5. Highlighting the positive information: This strategy involves highlighting how the patient is functioning normally and healthily before discussing the problem areas or life-threatening. Often physicians drew patient's attention to success achieved in addressing some symptoms before providing information on non-responsive treatments.

6. Discussing care options: Physicians discussed the end of curative treatments and changes in treatment goals from cure to ensuring pain-free life. They discussed palliative care options and referred them to hospice or rehabilitation centres.

7. Providing personal and social support: Physicians tried to provide comfort to the patient and helped them to get connected with other patients and families who were experiencing the same illnesses.

8. Arranging material / tangible support: Many physicians expressed the belief that delivering bad news and communicating a sense of care should go hand in hand and therefore they personally or through social workers procured tangible supports such as travel assistance, food and free prescription drugs for low income patients.

Table 3: Truth-integrative strategies: managing the ill effects of bad news disclosure

1. Phased disclosure:

I always talk to the patient party and I will tell even though I will make it in two stages for that. I first mentally prepare them for eventuality: 'these are the possibilities we are thinking. It may be this child may have a treatable condition and there is the possibility of a condition we may not be able to treat this. But we are hoping for the best; we will tell you what the prognosis by tomorrow'. So, but we should be able to tell whatever the outcome comes. So I will always make different stages. I will prepare them mentally

As long as you can put a base line and not at the first instance I don't think you need to spill the entire beans to them. You need to take, you should know how much to tell. For example, you know there is a lump and you know it is malignant. Give them a thought and say 'we do think of malignancy and there is a possibility that it might not be'. He is already thinking in a process, could it be malignant and he is preparing himself.

2. Undoing false hope:

They think that doctor is there to cure, there is answer for everything; but we don't have answers to many things. There is a limit to which I can go and our medicines can work. Finally when we have to give up treatments, we say, 'we have tried our best but it did not work'. They accept it a little better. Of course there could be grief. Some of them may break down crying, but that's natural.

Same thing happened with this lady also. She asked me, 'what is this?' Then I said, 'it looks like there is some tumor in your stomach.' Then she paused and said, 'tumor means you cannot operate it and take it out?' I said, 'it is not in an operable stage right now. The surgery is very very risky.' So, she said, 'there is no other treatment for that?' I said, 'there are strong injections but because of your age, you would not be able to tolerate those injections' Then she asked me, 'then the tablets you are giving me, are they helpful in reducing the tumor?' I said, 'no, I am giving only to relieve your pain.' She got anxious and said 'so, you are saying that it is not curable?' I said, 'yes'.

3. Drawing on patient's resources:

I think, most of our population, is a religious minded, whatever may be their religion. They have faith in something. Though, I put it that you have done your best, you are doing your best, we are doing our best and we will continue to do our best, but that alone is not the thing. There is something more than that which determines. But that does not mean, we just stop doing whatever we can do; we should do best whatever is in our hands. There is something which not in our hands. So, prepare them that way.

Normally a mass in the pancreas is most of the time, 99% of the time, is malignant. So, we told her 'you require surgery. If it is possible to remove it we will or if we cannot remove it, then it least we try to relieve you of your jaundice... It was not difficult to encourage her probably, because the fact that she is [a prominent social figure] and another factor is that she is educated and had an idea of what it could be,

beforehand, the possibility at least. Her colleagues are there you know; lot of support is there. Lot of other people come to visit her; bring flowers, are around her all the time and they show lot of love.

4. Presenting team care:

So, I get other people involved, specially social workers and counsellors to keep on talking to them and also get other members of the family into the picture, because one person may deny and other person may accept it little more. Some of them may accept more than that. And that person will try to convince the other persons of the family, which is more effective than I trying to convince. So, taking help of other health care persons and other members of the family is much better.

We work as a team, as a department. So, we have to give these insights to the family that we are seeing them as not one person, but there are other members of the team. So, there are many people who are talking to them.

5. Highlighting the positive information:

I pick out the relatively good news from the bad news and I highlight that. So that may be the optimistic view.... So, every time they meet us with a report we talk to them; only few reports would be bad, but many would be normal and we say, this is normal, your heart is normal, your kidney functions are normal and that puts them in hope. So, all things are normal and this is only one wrong. So, we have to deal with this. So, every time we meet them we give them some hope and something of bad news also side by side.

Normally, what I do is that I tell the good news first among the bad news whatever is there. I told her that the surgery went well and your jaundice will come down. She had lot of itching because of the jaundice. I told her, 'you are recovering very quickly but then like I told you before, there was a tumor and it was not only in the pancreas but also in other places as well. We have taken a biopsy and that biopsy has come as cancer and once you recover from the surgery we can plan what we can do further to help you'.

6. Discussing care options:

Ultimately our goal is to give comfort to the patient, not to treat. We are just giving the comfort... What I tell them about the stage four cancer and all, this has already reached stage four and has spread, cannot do much curing, but we can keep him comfortable, free of symptoms from which he is suffering, by giving palliative therapy, medical treatment, so that we keep him comfortable and suffering-free, pain-free, till he lives.

So, people have to take the relatives into confidence and tell them: 'this is exactly what the entire picture looks like. You have your options and it is left to you how you want to go about this from now'. There are couple of things we need: we give them option A, option B and option C; either they leave him alone, probably, that is not the best choice; nobody wants to see a patient sinking right at all. We can palliate him by giving probably an alternative option, probably a diversion procedure something like that, which does not cure him of the disease, but takes care of the present problem of not being able to eat, or probably not being able to pass stools. We need to do something called a colostomy. That's how we start about counselling the patient. Telling the patient relatives about the disease proper, what is the progress of the disease and what is general outcome we look for, which comes at the end of, after the thorough investigation.

7. Providing personal and social support:

'Dubtheko thin ka sahara' (to the drowning, even the support of straw is helpful). In such times, everyday there is negative thing is told to you, even one person who comes and supports you and tells you that, come, I tell you, I will talk to you, or I tell you what needs to be done and they support this way.

Yes, not only giving the information to a particular patient about his or her diagnosis but also you are providing hope by telling them about available treatments and also by giving the examples from your previous cases to encourage them and make them understand and help them to overcome their trauma... Then you comfort them; tell them the incidence, how many children do get this kind of disease; if it's very rare disease or it's quite a common disease. Tell them if there is anybody else in the surrounding area you know has this disease, or anybody in that ward is there with similar disease. You try to include somebody with whom they can relate to. So, they feel little less stress. It is little easier to take the news because somebody else is also there in the same boat.

8. Arranging material / tangible support:

So, we have tried to address these issues by bringing in a patient nutrition program, which is funded by one of our wealthy patients. Then we have a poor patient's fund to offset some costs; we get medical social worker involved [in coordinating material support].

Those who are very poor, as I spoke to you about that 25 year old person, we have philanthropic organizations, they give the aid. We have been in very good terms with them. We tell such persons to go and meet with such organizations and see how much financial help they can get. Then we even tell them to meet the local persons such as members of parliament, members of legislative assembly, to approach chief ministers or prime ministers funds. But we keep these options only for the young persons who are breadwinners.

In conclusion, as illustrated in Figure 1, this study suggests that bad news in the context of a life-limiting disease emerges from both the biophysical condition and the sociocultural environment of patients which jointly undermine hope. Irrespective of whether authentic hope was associated with the possibility of curing a disease or considered possible in spite of poor disease outcomes, a number of personal and sociocultural factors motivated physicians to undertake actions and streamline interactions to address the inverse relationship between hope and bad news. Hence, some physicians handled this situation by manipulating the delivery of bad news (truth-avoidant hope-conserving tactics) but others faced this clinical challenge by providing maximum care, which required efforts to address both the medical and environmental aspects of bad news (truth-integrative hope-conserving strategies). Importantly, the latter type of interventions highlights the belief that bad news disclosure (truth telling) and clinical hope can co-exist.

Discussion

This study invites health communication scholars and health care professionals to reconceptualize the relationship between bad news and hope. A number of scholars such as Sonnenberg [35] have argued that there is an inverse relationship between hope and truth; as more truth is revealed, the amount of hope declines. However, the 'truth-integrative' hope-nurturing strategies identified by this study tell us that honest truth telling can be pursued because of the intrinsic value of such a clinical responsibility. Instead of masking bad news, or delivering bad news by informing the patient or family of what cannot be done, health care professionals can navigate them towards hope by providing them with social and material supports and laying out a plan for what can be and will be done. This approach leads all who deal with disease to value life [22]. Hope-nurturing strategies underline a belief that hard truth and hope can coexist and therefore health care professionals do not have to choose between the two. The majority of the

physicians interviewed believed that they should adopt truth telling and undertake actions to enhance hope because these are integral aspects of their clinical responsibility. In short, it is not the amount of bad news alone but lack of supportive hope-nurturing interventions or environments that makes life hard for patients and families dealing with life-limiting diseases in India.

This study emphasizes the need to extend the purview of the actions to promote hope beyond the usual clinical environment to communities. Traditionally, hope has been viewed as a psychological state of self-confidence about positive outcomes [23] or a motivational state and a cognitive process that involves goal setting, and directing energy and resources toward achieving the desired goal [36]. Gravlee [37] has distinguished hope from wishful thinking by pointing out that both concepts involve optimism, but the former relates to genuinely attainable goals. So hopefulness presupposes the ability to frame realistic goals and strategies to achieve them with a sense of confidence [23].

In the extant literature on truth telling, hope is conceptualized primarily as a mental state that enables patients and families to tolerate bad news and to undertake actions to redress the adverse outcomes of a disease. Several training programs on clinical communication have been designed to teach health care professionals the interpersonal communication skills for conserving hope among patients and families when delivering bad news. Previous research hardly addresses a sociostructural dimension of hope in clinical interactions related to life-limiting diseases. This study has emphasized the need for going beyond the psychological perspective on hope and a focus on communicative competence of individual professionals because bad news is not merely about diseased bodies but dysfunctional social structures and health care systems too. This study, however, emphasizes the value placed on the environmental or sociostructural dimension of hope by physicians in India and suggests that preserving hope does not depend merely on the interpersonal skills of health care professionals but very much on the availability of supportive structures. This study supports Freire's [38] call for pedagogy of hope, which acknowledges that training programs that seek to increase the capacity of individuals creates a false illusion of change unless such educational initiatives are accompanied by actions toward institutional change. Addressing the sociostructural aspect of clinical hope will help health care professionals, particularly those working in low and middle-income countries, to provide a better quality of care.

Conclusion

Hope is a crucial resource in any clinical care context because people who perceive themselves capable of coping with disease burdens are more likely to participate in care processes and report better health outcomes. The need for hope is even more intense when dealing with life-limiting diseases because often such patients are considered "hopeless cases". Besides the training initiatives to enhance physicians' knowledge about the relationship between bad news and hope, and equipping them with skills to preserve and promote hope, actions to create support systems for patients within clinical and community environments are necessary. More studies of this nature are needed in low and middle-income countries to balance the regional disparity in the literature, to produce practice guidelines to help health care professionals in these countries, and to enrich scholarship on clinical communication by further developing our understanding of the sociostructural dimension of clinical hope amidst bad news.

Declarations

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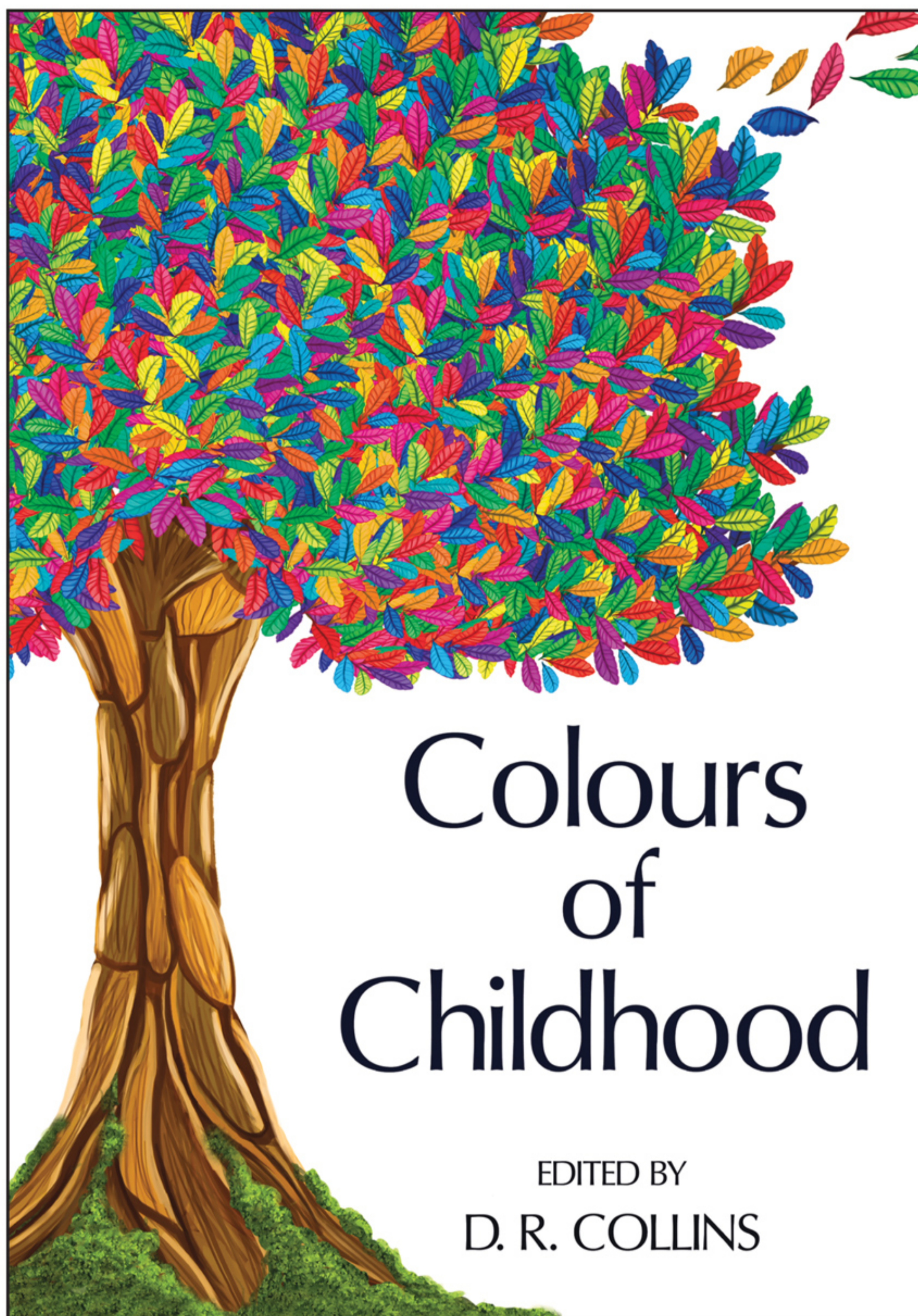
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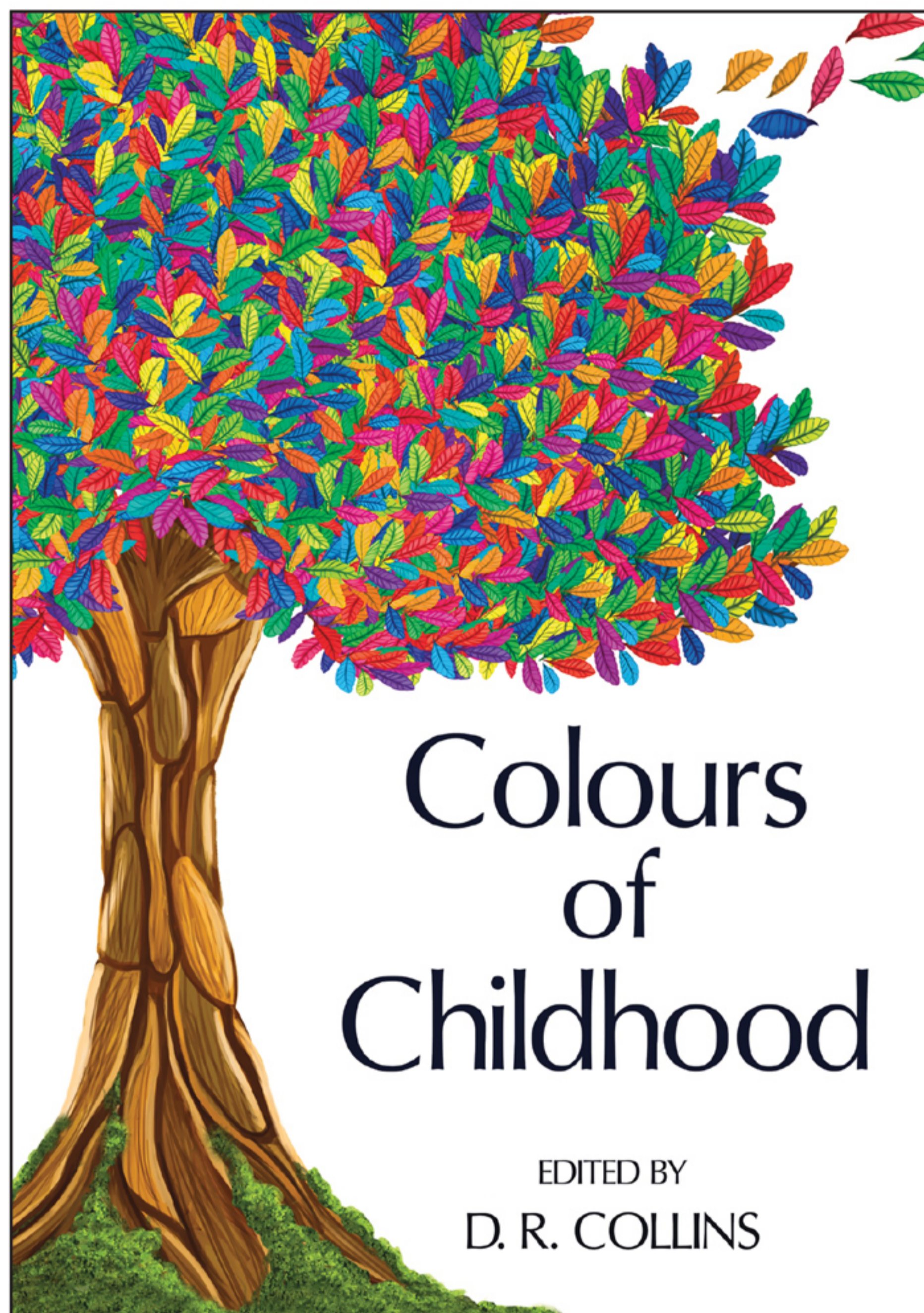
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