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Prognostic Awareness in Terminally Ill Cancer Patients: A Narrative Literature Review of the Processes Involved

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Abstract: High prognostic awareness (PA) is seen by many as a threat to terminal patients' psychological well-being. Whether this concern is supported by evidence or not is still a matter of discussion, given the heterogeneity of existing findings. This ambiguity points to the importance of considering contextual processes involved in the relationship between high PA and psychological outcomes, as a possible mediator and moderator mechanism. Aiming to capture a holistic image of the relationship between PA and the psychological experiences of patients, we adapted a narrative method to synthesize and discuss patient-related (physical symptoms, coping strategy, spirituality) and external (family support, received medical care) processes as potential explaining mechanisms.

Keywords: psycho-oncology, cancer, prognosis, awareness, palliative care, terminal care

Introduction

As the paternalistic model of the physician-patient relationship is gradually being replaced with the models that promote patient-centered care and an individualized approach, information disclosure to patients is becoming one of the core values of modern medicine. However, delivering news about diagnosis and prognosis to patients – a particularly delicate responsibility that physicians carry – becomes especially challenging when the news is bad.¹ In fact, delivering a terminal prognosis is the most difficult conversation for oncologists.² Physicians may find it easier to have a conversation about the extent of the disease or treatment goal.³ This is expected, as while discussing terminal prognosis, doctors typically share information related to life expectancy and survival rates. To assist medical professionals in handling such delicate discussions, ASCO guidelines^{4,5} have been developed on patient-clinician communications. Nevertheless, regardless of the professionalism with which the prognosis is communicated, receiving such information about one's own life may come with significant psychological distress to which patients react differently. The extent to which patients are aware of their terminal prognosis or shortened life expectancy is referred to as prognostic awareness (PA).⁶ In several studies,^{7–16} PA is assessed through the structured and semi-structured interviews. Patients are typically asked a general question about their condition (eg “what do you know about your condition?”) and more detailed follow-up questions. The answer of the patient is later coded to establish whether the patient is aware of the prognosis or not and what is the level of awareness. Other studies^{17–21} use questionnaires to measure patients' insight into prognosis. One example of such questionnaires is a Prognosis and Treatment Perceptions Questionnaire (PTPQ)²² that measures patients' perceptions about: 1) the likelihood of cure, 2) the importance and helpfulness of knowing about prognosis, 3) the primary goal of cancer care, 4) preference for information about treatment, and 5) satisfaction with the quality of the information received about prognosis and treatment.

The accuracy of PA may depend on a number of factors.⁶ Whether a patient has high PA (a more accurate awareness of prognosis) may depend on the physician's delivery of the prognosis²³ as well as the patient's readiness to accept the

received information.²⁴ A recent meta-analysis²⁵ reports that only about half of the cancer patients fully understand their prognosis. Moreover, a lower level of PA is more prevalent in male participants,²⁶ those with lower education levels, and elderly patients.^{27,28} In addition, depending on age and life expectancy, patients differ in their preferences on whether to receive prognostic information or not.²⁹

One of the most significant differences in PA has been observed across countries. According to a recent systematic literature review,²⁵ PA was found to be highest in Australia, followed by East Asia, North America, southern Europe, and the United Kingdom. This may be due to the traditions, beliefs, and practices rooted deeply in different cultures and translated into medical practice. In the Anglo-Saxon and Northern European countries patient autonomy and access to medical information are prioritized.²⁵ Conversely, in the Asian countries, southern Europe, and United Kingdom it is more common to withhold poor prognosis from patients in an attempt to protect them from the distress it may cause, patients' relatives are often the ones who oppose truth-telling. Inducing additional emotional distress and depriving patients of hope is one of the most common concerns underlying information withholding.³⁰ Hence, information disclosure is still seen by many as a threat to patients' psychological well-being. The question of to what extent breaking "bad news" releases patients from the burden of uncertainty and helps them cope and to what extent it leaves them hopeless has been increasingly acknowledged and addressed in a growing literature. Many studies have taken steps in broadening our understanding of whether there is any evidence to support the common concern about patients' psychological well-being when confronted with prognosis.

In association with PA, three main psychological variables are discussed in the literature: (1) anxiety,^{7–11,17–19,26} (2) depression,^{7–9,12,13,19,20,22,26,31} and (3) quality of life.^{14–16,19,21,22,26,32–36}

Literature on PA and its association with anxiety, depression, and quality of life of terminally ill cancer patients provides heterogeneous evidence.³⁷ While some of these studies report PA to be associated with low anxiety, depression, and high quality of life,^{9,12,26,33} others report the opposite.^{19,21,22} These differences may be due to numerous processes that could contribute to the impact of PA on these psychological outcomes.

Aims

Building on the literature, in this review we focus on some key contextual processes, both internal and external to the patients, that can explain the relationship between the PA and the three outcomes mentioned above. By doing so, we aim to understand under which conditions some patients benefit from high PA, while others experience increased psychological distress due to it.

To capture the overall context of this matter, a narrative approach was adapted in line with the guidelines provided by Demiris and colleagues.³⁸ Thus, the search strategy for recruiting the reviewed papers did not follow a strict protocol.

Contextual Processes Involved in the Relationship Between PA and Psychological Variables

In response to our aim, in the following sections, we describe the abovementioned contextual processes and the role they play in the lives of terminally ill cancer patients. Some of these processes are related to patients themselves (physical symptoms, coping strategy, spirituality) and others are external (received medical care, family support).

Patient-Related Processes

Physical Symptoms

Impaired physical condition is one of the difficulties that terminally ill cancer patients have to face. The deteriorated physical state is related to the sensation of pain, as well as the perceived loss of independence. Notably, these two important indications of an approaching end might increase the PA of the patients. They can also cause serious psychological distress. Therefore, a patient in pain or in need of regular physical assistance might have a high PA as well as an impaired mental state. However, the latter may be due to the changes and sensations that follow the physical symptoms, rather than PA itself. For instance, it has been shown that PA is associated with increased anxiety and a shorter survival period.²¹ Authors suggested that there may be a way in which patients sense the progression of their

disease and with it, the shortened survival. It is probable that patients with shorter survival have more salient physical discomfort, which forces them to face the reality and acknowledge the approaching death. In this case, it may be that it is the physical pain that causes psychological distress, rather than PA.

A qualitative study conducted with British patients¹² reported that patients were most likely to experience psychological distress if they had physical symptoms. Such physical discomfort was reported to be the main factor to compromise psychological well-being. In addition, patients with deteriorating physical condition expressed their concern about the loss of freedom and increased dependency on their caregivers. This, according to the authors, even though most aware patient groups do experience the highest rates of psychological distress, awareness of prognosis does not itself cause depression. Instead, physical symptoms and the concerns accompanying these symptoms might be the cause of compromised psychological well-being.

Therefore, it may be difficult to draw conclusions about PA and the psychological impact it has on patients without considering such an important contextual factor as the physical condition of the patient.

Coping Strategy

Emotional responses such as misery, depression, and frustration are common following the disclosure of a terminal diagnosis,³⁹ and the way in which these responses are dealt with and processed over time may depend on the coping strategy that a patient adopts. In other words, the relationship between PA and psychological well-being may change over time and this change may be moderated by the adopted coping strategy.

Evidence for the moderating effect of coping strategies has been provided in a recent study.¹⁹ Patients with a higher PA showed a worse quality of life, higher levels of depression and anxiety. Interestingly, this relationship was moderated by the coping style and positive reframing (reframing information in such a manner that would emphasize something good in what is happening) of the given information. The active coping style conveys taking active steps and increasing one's effort in trying to execute a coping attempt in a stepwise manner.⁴⁰ It was associated with lower levels of depression and higher quality of life among patients who had high awareness of their terminally ill condition, rather than those who named "curing their cancer" to be the main goal of their physicians (an indication that the terminal patients had low PA).

Another important factor to consider is whether patients develop acceptance of their prognosis over time or deny it. Acceptance coping strategy implies accepting and acknowledging negative circumstances the way they are, even if it does not fit one's desire.⁴⁰ This strategy has been suggested as an explanatory variable of the positive change in the emotional state following receiving a prognosis in a recent study.²⁶ Initially, participants who were more aware of their prognosis had higher levels of both depression and anxiety. Interestingly, in 12 weeks of follow-up analysis authors observed that aware patients showed significant improvement on these scales; in other words, their initial distress decreased over time. According to the authors, this decrease in the level of psychological distress within aware patients may be due to acceptance of the terminal status of one's illness. Acceptance of prognosis, they conclude, may need to be developed over time. Similarly, in a recent multi-country study in Asia⁴¹ the relationship between higher awareness of the prognosis and anxiety and depressive symptoms was moderated by the acceptance of illness. Acceptance showed to improve the psychological outcomes of the patients. The importance of acceptance of prognosis has been outlined in other studies as well, in which this variable was studied more directly. Evidence shows that those patients who have adopted acceptance coping strategy deal better compared to those who experience denial or self-blame.^{42,43} It is important to note though that denial is a complex construct and requires a careful examination and cautious interpretation when it comes to coping, in some cases, it may have a positive effect on dealing with bad news. The denial coping strategy is the contrary to acceptance coping strategy and it represents the refusal to accept the truth about an event that is happening in real life.⁴⁰ Denial can serve as a defense mechanism when confronted with information that is too distressing to be processed right away.⁴⁴ Newly diagnosed cancer patients, for instance, often go through the denial phase, and at the initial stages, this may not be associated with increased anxiety or depression.⁴⁵ Therefore, denial itself may not be related to impaired psychological health. However, at a later stage (eg terminal stage), when medical decisions have to be made, a coping strategy such as denial can rob patients of the ability to make optimal choices. For example, denial has been shown to be one of the main barriers to referral to palliative care.⁴⁶

Another coping strategy that may be adopted by both patients and their physicians is avoidance, which is thoroughly discussed in the Problematic Integration (PI) theory by Babrow.⁴⁷ The theory focuses on two important aspects of human experience: the perception of the likelihood for some event to happen (probabilistic orientation; expectation) and the value that we attribute to this event (evaluative orientation; desire). A patient with a terminal diagnosis has a subjective perception of the likelihood of approaching death (“What are my chances of survival?”), at the same time, they also have their subjective value judgment for this event (“how good or bad would it be to die?”). According to Babrow, probabilistic and evaluative orientations affect each other. For instance, the expectation of death may affect the meaning a person attributes to it; or, the desire to keep on living may affect the perception of the likelihood that one might die. Our experience is based on the integration of these two orientations. When this integration is problematic (expectation and desire conflict) uncertainty may drive both patients and medical professionals to avoid confrontation with the prognosis. This could mean focusing on alternative curative treatments instead of allowing life to end; postponing the conversation about life-sustaining treatments from the doctors’ side; and the satisfaction with this delay from the patients’ side.⁴⁸ Instead of blaming patients, physicians, or the healthcare system, the PI theory acknowledges the discrepancy between expectation and desire which makes the conversations about terminal illness problematic and drives both doctors and patients to adopt an avoidance coping strategy. As a result, communication between patients and doctors is portrayed as a process in which they negotiate and create knowledge and values.

In summary, coping strategies together with the timing in which they are adopted can have explanatory value in the relationship between PA and psychological health. How patients cope may either help them acknowledge their terminal state or hinder their ability to tolerate the medical information, which in turn impacts the medical decisions they make and consequently their health-related quality of life. Therefore, the type of coping strategy is associated with the level of PA and it may impact whether this awareness draws them into hopelessness or gives them a sense of agency as decision-makers.

Spirituality

When faced with one’s own death, spirituality may become most salient and relevant than it has ever been in an individual’s lifetime. Spirituality represents the search for meaning in life and a connection with the transcendent.⁴⁹ How people psychologically process the forthcoming death may significantly depend on how they conceptualize it and the meaning they give to it. Studies show that spirituality can have a protective role on cancer patients’ psychological well-being,⁵⁰ this role is played out by providing patients with a sense of meaning and peace.⁵¹

The relationship between PA and spirituality has been previously discussed. It has been shown that patients in the terminal phase of illness have increased spirituality compared to healthy people or patients without the terminal condition.⁵² This finding suggests that being faced with death increases people’s spiritual tendencies, facilitates the search for meaning, and may evoke reevaluation of one’s outlook on life and death. Additionally, spirituality may impact a person’s openness to accept the prognosis. High PA has been shown to be associated with high spiritual tendencies, this was the case, especially for religious aspects of spirituality.⁵³ This may be due to the belief in the afterlife which is one of the core fundamentals of many religions. Such belief may reduce the fear, arm patients with hope, and result in better coping.

Furthermore, when it comes to the relationship between spirituality and PA, the phenomenon of faith healing may be interesting to consider. Faith healing is sometimes chosen as an alternative treatment option outside of bio western medicine. It represents the practice of treating illness through prayers, rituals, and the exercise of faith.⁵⁴ In a recent study conducted in Ghana,⁵⁵ researchers deduced that the trust in faith healers and positive perception of them is quite high. Faith healers reported that they provide flexibility in terms of location and time to people and that this could be one of the reasons why people are prone to approach them more freely. For some, faith healing is also the first port of call for the treatment of the disease.⁵⁶ This might lead to delayed treatment-seeking and delayed contact with the medical healthcare professional, which may result in adverse outcomes.⁵⁵ For this reason, it has been suggested that faith healers and formal medical institutions could consider working in tandem.^{55,56} This strategy could be useful for preventive and curative purposes, although the literature lacks insights on the relationship between faith healing and the PA of terminal patients. Another aspect of spirituality that may favor the well-being of a patient is the sense of belonging and support from the

religious community. A recent study⁷ conducted with Italian patients showed that extrinsic spirituality (ie, the participation in religious practices that are shared with the community) predicted high prognostic awareness and moreover, awareness was associated with lower levels of anxiety and depression. Authors suggest that extrinsic spirituality may be associated with higher levels of awareness because having a sense of belonging, receiving support from the religious community, sharing one's feelings and fears favors the awareness and acceptance of the terminal prognosis. Hence, spirituality not only provides an individual with a new outlook but may as well translate into social support.

Current studies suggest different mechanisms through which spirituality favors PA and the psychological well-being of terminally ill individuals. Overall, it can be stated that spirituality is one of the important contextual factors that have to be considered when discussing the psychological experiences of patients with advanced cancer.

External Processes

Family Support

Aside from the social support that patients receive from different communities that they belong to (eg the religious communities discussed in the previous section), an important part of the support and care that they receive comes from their family members and their presence and effort are an important component of what is referred to as a good death.⁵⁷ The support and involvement from family members are needed for ensuring that patients receive high-quality care and that their wishes are respected and considered (eg choosing to die at home rather than in the hospital). The perceived lack of emotional support from the family strongly predicts patients' depression.³¹

Interestingly, the difficulty of communicating with family members has been associated with low levels of PA and increased anxiety.¹⁷ Patients sometimes sense that their family members are withholding information in order to protect them.³⁴ A recent study⁵⁸ found a significant prognostic discordance in patient-caregiver dyads. Specifically, in over 24% of studied dyads patients reported their condition as non-terminal while their caregivers considered the diagnosis to be terminal. Similarly, while the caregivers show more accurate PA, this is not associated with the patient's own PA.⁵⁹ Patients' perception of being protected by withholding the information has been associated with the increased need to have more open discussions with the family.³⁴ Besides openness in communication, the congruence of opinions between the patients and their caregivers is an important aspect of end-of-life decisions. For instance, it has been shown that the patient-caregiver congruence on the preferred place of death significantly impacts the quality of life of terminally ill cancer patients.³³

However, the complexity of the relationship between perceived support and psychological well-being shall not be underestimated, as perceived social support does not always predict better psychological outcomes. Terminally ill patients often perceive themselves as a burden to their family members and caregivers.³³ The perception of support and care may direct patients to focus on the unbalanced nature of the relationship between them and their close ones, with the former always being the recipient of care and the latter always being the provider.⁶⁰ Such a violation of reciprocity may impair the psychological state of patients, feeling of being a burden to the family may result in a lower quality of life and depression.⁶¹ Therefore, the relationship between perceived support and the emotional struggles of the patients is nuanced. To recreate the balance, it may be helpful to allow terminally ill patients to contribute to the well-being of others. It has been suggested that patient contributions in the forms of time, gifts, or sharing knowledge with others are important elements in achieving a sense of a good death.⁵⁷

Overall, open communication with the family is not just one of the key points toward high PA, but it may also contextualize this awareness in a way that emotionally benefits the patients. In particular, perceived emotional support from the family may help patients manage the end-of-life period and assist them in making decisions such as the treatment received or the place of death. It is important though that through communication patients' perception of being a burden to their loved ones is reduced and they maintain a sense of their social function despite the limitations of their physical condition.

Received Medical Care

When discussing the psychological and physical well-being of patients in their terminal stages, it is of utmost importance to consider the type of medical care they receive. Palliative care offers relief and is aimed at increasing the quality of life

of terminally ill patients, by meeting their physical, psychological, practical, and social needs, as opposed to curative care which aims to cure the disease and sets recovery as its goal.⁶²

It has been shown that those patients who are assigned to palliative care develop a higher PA, compared to those who receive solely standard oncology care⁶³ as well as significantly improve quality of life and mood over time.⁶⁴ This may be due to the fact that effective communication with the patient is one of the fundamental aims of palliative care and due to this communication, patients have the opportunity to take part in medical decision-making. Adopting an active role allows patients to develop more understanding of their medical condition. Patients who are involved in medical decisions are nearly four times more likely to be aware of their cancer diagnosis.⁸ Moreover, involving patients in medical decisions based on their role preferences predicts satisfaction and lower levels of treatment-related decisional regret.⁶⁵

As for terminally ill cancer patients, awareness of one's prognosis can significantly impact end-of-life decisions. For instance, patients with high awareness of their prognosis are less likely to choose aggressive treatment such as chemotherapy.⁶³ PA also allows patients to make choices regarding future possible interventions. A good example of this is do-not-resuscitate (DNR) consent signed by a patient that instructs the healthcare team not to perform cardiopulmonary resuscitation (CPR) if the patient's heart stops beating. DNR consents allow patients to remain at home at the moment of death, instead of exhaling their last breath in the hospital.¹¹ Even though it is still common for DNR orders to be placed late in the process and its practice still differs across countries,^{11,66} DNR orders promise to be one of the important facilitators of shared decision-making at the end of life.

Aside from impacting end-of-life decisions of terminal patients, PA is important within itself and may have different effects based on the meaning the patients attribute to it. In this sense, psychotherapeutic work that is often included in palliative care plays a tremendous role.⁶⁷ There are multiple therapeutic approaches currently applied to assist terminal patients. While all of them aim at improving the psychological well-being of patients, based on the theoretical background of these approaches, each of them focuses on diverse aspects of patients' experiences. For example: meaning-centered psychotherapy⁶⁸ was developed based on the works of Viktor Frankl and it includes interventions that are designed to guide individual in their existential journey of finding meaning and significance in the approaching death; cognitive-existential group psychotherapy⁶⁹ is following six general goals including reframing negative thoughts and enhancing problem solving and coping, aspects that are crucial in dealing with terminal prognosis; dignity therapy⁷⁰ was created in response to the fact that terminal patients suffer not only due to upcoming death but also due to the loss of dignity and therefore giving them the tools to manage this challenge and to feel heard is prioritized in the approach; Last but not least, managing cancer and living meaningfully (CALM)⁷¹ is an approach developed by Gary Rodin that aims at assisting patients in confronting their fears and allowing oneself to feel vulnerable while maintaining the sense of meaning and purpose. One concept of CALM that is especially relevant for PA is "double awareness".⁷² CALM intervention helps individuals stay engaged in the world while becoming aware of the approaching death. In this sense CALM addresses both domains that are relevant for terminal patients: life and death. Generally, all of these therapeutic approaches confirm that among psycho-oncologic interventions PA and the meaning it carries for patients is considered. Overall, based on the current literature, it may be proposed that there is a bidirectional relationship between receiving palliative care and high PA: (1) The choice of palliative care and referral to it from the patients' side points to a more aware state.⁴⁶ It indicates that patients acknowledge their incurable state and are able to shift their focus from recovery to more realistic goals, such as reducing suffering and considering their care preferences at the end of life. (2) Being the recipient of palliative care further develops patient awareness of the survival time span and the nature of prognosis,⁶³ as patients are encouraged to attribute a meaning to their prognosis and cope with it accordingly. Additionally, the communication between the healthcare team and patients are prioritized and patients are often asked about their preferences in reference to a different end of life choices.

Therefore, in addition to other external factors, the medical care that patients receive is an important key in understanding whether patients will develop high PA and if they will, whether it will benefit their psychological well-being and quality of life.

Discussion

Full information disclosure to patients has been advocated in Western countries for many years now and over time it has become a favored medical practice that is considered to be ethically correct, as it directs physicians to honor patients by keeping them informed and involved in the medical process.^{73,74} One of the important factors that foster patient involvement is receiving clear explanations concerning the medical condition.⁷⁵ Nevertheless, this outlook is not internalized and adopted equally all over the world. Many view PA as a threat to patients' mental health and their fighting spirit. This concern translates into withholding medical information from the patients, which may be a questionable practice, given the abovementioned ethical values that modern medicine holds. The conflict between the guidelines of information disclosure and concern for the patients' well-being has been the focus of discussion in the last decades.

Our aim was to categorize and discuss the individual and external processes that may better explain the association between PA and psychological outcomes. In the literature, three main psychological variables discussed in relation to high PA are depression, anxiety, and quality of life. In relation to these three variables, there is substantial evidence for both positive and negative associations with high PA. As a result, while some of the studies suggest PA to be beneficial for psychological well-being, others provide evidence that reinforces the perception of disclosing bad news as a threatening factor.

In this review, we identified some common contextual processes recurring in the literature. The two main categories that were discussed covered: (1) patient-related processes, which included physical symptoms, coping strategy, and spirituality; (2) external processes, which included family support and received medical care. By doing so, we thus provided a more detailed picture of the complex relationship between PA and psychological outcomes, identifying some important explaining mechanisms. Moreover, by addressing factors such as adaptive coping strategy, spirituality, and received support, this review highlights the importance of sociocultural and humanistic aspects of patient care, rather than solely following a "disease-based" model of medicine that focuses on impairments (eg increased depression and anxiety; compromised quality of life). To our knowledge, this is the first review providing a comprehensive analysis of the circumstances that play a supportive role in the terminal patients' mental state when they are faced with a prognosis. We consider this aspect of our contribution of high importance, as it has the potential to play an explanatory role in understanding the reasons behind the negative and positive associations between PA and psychological variables that are reported in the literature.

Limitations

This review, however, is subject to some limitations, mostly due to the literature under examination. Even though most of the studies provided evidence-based findings in relation to contextual processes, in some of them, these processes have been part of the authors' interpretation of results, rather than factual data. This was particularly true for correlational studies, in which the causal direction between variables cannot be established. Therefore, part of the existing literature only assumes a possible causal direction from PA to psychological outcomes. Despite this limitation of the current studies, the heterogeneity of findings suggests nevertheless that the concerns that underly information withholding may represent much more than just the prevailing cultural beliefs. Hence, the relevance and importance of contextual processes that shed more light on the association between PA and the mental state of the patients are indisputable.

Another limitation is that not all of the 3 psychological outcomes (anxiety, depression, quality of life) are discussed under each contextual process (physical symptoms, coping strategy, spirituality, received medical care, family support). This is the case since not all 3 of them are researched concerning all processes included here. However, considering our main aim, this limitation is not critical. We pursued to analyze under which conditions some patients benefit from high PA, while others experience increased psychological distress due to it. The evaluation of each of the 3 psychological variables included in this study indicates whether patients benefit from high PA or experience increased psychological distress due to it, therefore including all 3 of them in relation to all contextual factors is not crucial.

Conclusions

The issues identified and examined in this review may have important theoretical and practical implications. At a theoretical level, it shed light on the possible mediator and moderator mechanisms of the relationship between PA and psychological outcomes in terminally ill cancer patients. We thus invite future studies to further explore other contextual variables that have not been previously considered but might have an important explanatory value in the complex dynamic of becoming aware of the forthcoming death and the psychological processes that follow this realization.

At a more practical level, this review may serve doctors as well as caregivers in understanding which factors should be considered when disclosing prognosis, what could serve patients in dealing with bad news and what could threaten their psychological well-being on the contrary. This can contribute to the general aim of developing more efficacious and tailored supportive interventions for cancer patients.

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Disclosure

The authors declare that there is no conflict of interest.

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