

# Informing Severely Ill Patients: Needs, Shortcomings and Strategies for Improvement

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## Keywords

Patient information · Communication · Palliative care · Early integration · Advanced cancer · Shared decision-making

## Summary

The scope of palliative care has expanded gradually over the last decade. Provision of palliative care is not restricted to the last months of life as in some out-dated concepts. It addresses the needs of severely ill patients in all care settings (in- and outpatients, home care, hospices). Particularly in the last years, the value of integrating palliative care early in the disease trajectory of life-threatening and incurable diseases has become increasingly acknowledged. In order for patients to fully benefit from the concept of early integration of palliative care, they need to be provided with information tailored to their disease trajectory. For example, patients and relatives need to know how symptoms such as pain, depression, fatigue, breathlessness, or anxiety can be alleviated. The patients' knowledge and understanding will support the coping process, improve comfort and enhance patient participation and autonomy. Since information needs are highly individual and vary throughout the course of the disease, an interactive approach of assessing the patients' needs and responding to them adequately is mandatory. In this article, the information needs of advanced cancer patients and their families are explained, shortcomings of the present information concepts are discussed, and an integrative approach to responding to patients' information needs throughout the care pathway is advocated.

## Schlüsselwörter

Patienteninformation · Kommunikation · Palliative Versorgung · Frühe Integration · Fortgeschrittener Krebs · Gemeinsame Entscheidungsfindung

## Zusammenfassung

Das Verständnis von Palliative Care hat sich im letzten Jahrzehnt gewandelt und erweitert. Verglichen mit älteren, mittlerweile überholten Konzepten sollte sich Palliative Care nicht auf die Betreuung von stationären Patienten in den letzten Lebensmonaten beschränken. Vielmehr sollte sie dezidiert medizinische sowie psychosoziale Bedürfnisse von schwer kranken Patienten in allen Behandlungssettings (stationär, ambulant, häuslich, Hospiz) berücksichtigen und den Patienten frühzeitig im Krankheitsverlauf angeboten werden. Das Potenzial dieser «early integration of palliative care» bei lebensbedrohlichen bzw. nicht heilbaren Erkrankungen findet auch in Deutschland zunehmend Anerkennung. Um sicherzustellen, dass Patienten die therapeutischen Möglichkeiten von Palliative Care optimal ausschöpfen können, benötigen sie und ihre Familien ausreichend Informationen. Zum Beispiel sollten sie wissen, was gegen belastende Symptome wie Schmerz, Depression, Erschöpfung, Luftnot oder Angst getan werden kann. Dieses Wissen unterstützt den Coping-Prozess, fördert das subjektive Wohlbefinden, gibt Sicherheit und verbessert die Partizipation und Patientenautonomie deutlich. Da die Informationsbedürfnisse individueller Natur sind und im Verlaufe der Erkrankung variieren, ist eine interaktive Herangehensweise notwendig, um die Bedürfnisse einschätzen und individuell auf sie reagieren zu können. In diesem Artikel stellen wir die Informationsbedürfnisse von schwer betroffenen Krebspatienten sowie ihren Familien dar und stellen einen integrativen Ansatz für die individuelle und zielgerichtete Patienteninformation sowie deren Integration in den Behandlungspfad vor.

## Introduction

Dealing with severe illness is challenging for both patients and families. Many questions and uncertainties arise concerning emotional, physical, social, spiritual and technical issues. Especially in advanced stages of cancer, the patient is highly vulnerable and prone to lose self-confidence and control. Providing personalized information for patients through the cancer care continuum facilitates the coping process, improves patient comfort and enhances patient choice. However, information needs often remain unmet [1–4], resulting in unrelieved symptoms and distress and unnecessary hospitalizations [5, 6]. In particular, patients report substantial information deficits on therapeutic options, goals of treatment, impact of cancer on daily life, and management of symptoms of the disease [3, 6, 7]. Tracking down the necessary and relevant information is challenging for most patients although there is an abundant choice of printed and online information that has to be assessed [8]. Additionally, the multidisciplinary approach of cancer care and its specialization and fragmentation bear the risk of discontinuity as well as lack of and inconsistency of patient information [9]. In this article, we point out information needs of severely ill cancer patients and their families, discuss shortcomings in meeting information needs and present an integrative approach to responding to patient information needs.

## Information Needs

### *Content: How Many Details Are Requested?*

Many studies report that patients suffering from cancer generally want to be kept well informed about treatment options and the progress of their illness, be it positive or negative [10–13]. This does not imply that full disclosure of information at any time is appropriate: In stressful situations, some patients may prefer to avoid certain information, as has been reported by recently diagnosed patients [14] and by patients with poor prognosis [2, 15, 16]. Both seeking information and avoiding it are strategies to cope with the cancer experience. Coping describes the dynamic process of dealing with a demanding situation and can be either satisfactory or unsatisfactory [17]. The outcome of coping depends (a) on the individual's judgment of the situation and (b) his appraisal of resources he can use to adapt and reestablish equilibrium [17]. Knowledge can foster successful coping as the patient may (a) appraise a situation as less threatening because he knows what to expect and/or (b) sees an option for affecting the outcome. Information can help people to feel in control, to reduce fears and to manage daily life. However, if the message is too threatening and little can be done to influence it, e.g. when therapy fails and a malignant disease progresses, the patient and his family may not be ready to bear it right away but need time and emotional support to accept it [18]. Information needs are

context dependent and vary throughout the cancer care continuum and between individuals [4, 18–22]. What patients want to know does not necessarily correspond to what health care professionals think they want to know [23–25]. The challenge for health care professionals is to find out the patient's actual information preferences and to respond adequately, and not to base their information on personal assumptions.

Uncertainty about the future is very stressful for the patient. Therefore, in advanced disease, information on the course of the disease, the prognosis and on therapeutic options to influence progression is a key issue for severely ill patients [2, 26] and their caregivers [2, 18]. Being informed on what to expect can reassure family members while their perception of uncertainty is more frightening than reality [18]. Understanding the prognosis can help patients to decide on further therapy, especially when they have to choose between life-extending therapy and comfort care [27]. However, the wish for full disclosure of prognosis of patients with advanced cancer is ambiguous: Some patients prefer full disclosure while others do not [23, 26, 28]. Considering their end of life, patients want to know if pain will be relieved and who will provide ongoing care [26]. However, information needs go far beyond medical issues as the cancer experience affects all dimensions of life, i.e. physical, emotional, social and spiritual aspects. Patients expressed the need to know how their disease will affect their everyday life and the lives of their family members, how to pay for their care, and how to write a will [26]. Family caregivers involved in end-of-life care at home have a great need to learn about the practical issues of caring for their loved one: They need to learn about medication and pain management, physical symptoms and comfort, nutrition, personal hygiene and excretion, positioning, technical equipment, availability of local support, and emergency measures [29]. Once they have accepted that death is inevitable, they address the need to learn more about the dying process [18].

### *Process of Information: What is Valued as Helpful?*

The relationship and interaction between patient, family and health care professionals have considerable importance in finding out and meeting the patient's needs [22, 30]. Health care professionals are valued as the preferred source of information [20, 21]. Patients and families value the process of information sharing as just as relevant as the content [18, 22]. The way information was provided influenced subsequent conversations and the way information was perceived: If patients perceived a trusting relationship to their physicians in previous talks, they were more confident in consecutive visits, even with health care professionals they had not met before [22]. Patients specified requirements for sensitive information sharing: They wanted the health care providers to be honest [22, 26], to convey hope [22, 26], to speak in plain language [22], to be empathic [22], to give them enough time during the discussion [22] and to pace the amount of information to what they can assimilate [22].

### *Patient Information to Enhance Self-Care*

Patients and families cannot anticipate the whole spectrum of information needed to manage illness and daily life. Their perspective on information needs should be the focus of attention, but must be completed by the health care professionals' point of view. One example is pain management. Many people have misconceptions about pain and pain management and avoid talking about pain because they are afraid of taking pain killers [31, 32]. They need to know about modern pain management strategies to make better use of pain therapy and to participate actively [33, 34]. Orem's Self-Care Theory can serve as a theoretical framework to define patient information needs [35, 36]. Orem proposed that individuals in principle are able and willing to initiate and perform self-care to maintain life, health and well-being [35]. However, illness or therapy can change self-care demands, and the patient may need appropriate information and training to fulfill these demands [35]. Research shows that patients who received special education can improve their self-care activities and develop more effective strategies to successfully manage therapeutic side effects, pain and other burdening symptoms [37–39].

### **Shortcomings**

Although the importance of providing professional patient information has been recognized for many years, the quality of information-giving still requires improvement. Deficits are most prominent in the following areas of information giving.

#### *Structure*

As far as 'structure' is concerned, transsectoral health care delivery, specialization and lack of continuity throughout the cancer care continuum impede a trusted relationship between health care professionals and patients. The resulting loss of information bears the risk of patients falling through the cracks. Lack of resources, like time constraints [40] and scarcities in formal training of health care professionals, directly affect the clinician-patient encounter. So far, lack of formal assignment of patient information, i.e. defining roles and responsibility of health care professionals, planning, and documenting needs assessment, has led to a rather ad hoc, unsystematic patient information process. Asymmetry of information and knowledge and the health care professionals' dominance impede successful information sharing and shared decision making. In this context, the use of the concept 'informed consent' is questionable.

#### *Process*

The process of providing patient information has been described as not effective in several ways. Health care professionals tend to ask inhibitory instead of facilitative questions. Open questions which encourage and enable the patient to

disclose his concerns are often avoided [41]. Physicians employ a rather medico-professional-oriented terminology that is difficult to understand for many patients [40, 42]. Moreover, physicians rarely check what patients have understood [43]. Patients withhold their concerns and questions because of lack of time [40] and interviewing style: If health care professionals do not explicitly prompt the patients to talk about emotional and social issues, the patients will not expect that the physicians are responsible for these issues and retain their worries [24]. Therefore, many patient concerns remain hidden and needs remain unmet, not only in the inpatient chemotherapy setting [44] but even in the hospice setting [24]. Additionally, physicians are rather reluctant to offer information on prognosis, especially in advanced cancer [25].

### **Strategies for Improvement**

We now discuss strategies for improvement relating to optimizing the *structure* of health care service and improving the *process* of information-giving.

#### *Structure*

Structure comprises health care policies, rules and legislations, management strategies of health care services, infrastructure, workflow management, formal and informal teaching programs, and allocation of resources. The World Health Organization [45] proposed standards for hospitals to establish patient information within the concept of Health Promotion that can serve as a template to improve structure on the organizational basis. They specify the organizations' responsibility to stipulate a management policy for health promotion activities, to identify responsibilities and to allocate resources, in order to ensure competencies of staff and patient information throughout the care pathway and after discharge [45]. A manual is available to guide implementation and evaluation of these standards [46].

#### *Process*

Characteristics of the process of information-giving relate to the way it is performed, i.e. where and when it takes place, who delivers the information, and what methods (i.e. personal communication styles, leaflets, patient/proxy workshops) of communication are employed. Within this scenario, the interaction of health care professionals with patients and families is a pivotal element as it significantly affects their emotional response, understanding and coping. More engagement in face-to-face communication is recommended by national commissions (Sachverständigenrat für die Konzertierte Aktion im Gesundheitswesen, National Institute for Clinical Excellence, National Cancer Institute [19, 47, 48]). Relevant features of information-sharing are (table 1): 'building a trustful relationship', 'supportive listening', 'effective interviewing', 'helping the patient to find out his priorities', 'helping the

**Table 1.** Recommendations for effective patient information (based on [3, 5, 18, 19, 22, 41, 49–54])

Building a trustful relationship	be honest
Supportive listening	non-directive, person-centered, empathic approach use open questions be sensitive to the cues of the patient help the patient to find out his priorities encourage patients and families to express their questions and concerns
Actively address information needs concerning prognosis and end-of-life issues	–
Help the patient to set priorities	learn about the individual context and values the best medical option is not necessarily what is in the best interest of the patient
Ensure understanding	employ everyday language, avoid medical jargon accept that patients may not always be able to process information because he or she might be emotionally overwhelmed or may suffer from symptom load or drug-induced restraint constantly check what he or she understood and whether or not the information is perceived as helpful summarize the provided information to structure the conveyed message and point out results of the conversation

patient to understand' and 'sharing power' [3, 5, 18, 19, 22, 41, 49–54].

The patients' perception of a trustful relationship is one that is characterized as feeling connected, understood and acknowledged as well as being convinced that the clinician is committed to their best interest [19, 55]. Supportive listening requires a non-directive, person-centered, empathic attitude and sensitivity to the cues of the patient [49]. Effective interviewing aims at encouraging patients and families to express their questions and concerns, as they need support especially when asking about prognosis and end-of-life issues [3]. Using open questions helps the patient to display his point of view and feelings and become more involved [41]. Eliciting psychosocial issues as well as physical complaints and cultural or socioeconomic aspects is necessary to understand the individual context [19, 41]. Learning about the individual context and values is a premise to help the patient find out his or her priorities. The best medical option is not necessarily what is in the best interest of the patient [51]. For example, if a patient is completely occupied with the management of social problems, like the care of his/her children or parents, he or she might decide against a certain medical regimen. Helping the patient to understand the necessary information and comprehend the available support requires employing everyday language and avoiding medical terminology, to avoid misunderstandings and an increase in the asymmetry of knowledge and power [19, 22, 52]. Cancer patients may not always be able to retain and process information because they may be emotionally overwhelmed [50] or impaired in their cognitive capability. Therefore, it is necessary to constantly check what they have understood and whether the information is helpful [18]. Summarizing information can organize and structure the conveyed message and point out results of the conversation. 'Sharing power' implies a participative approach, thus offering opportunities for patient participation at all stages of the disease [19].

Several tools are available to facilitate and ascertain information-giving during daily routine and throughout the cancer care continuum. Osse et al. from the Netherlands [56] developed a clinical tool that addresses informational needs of palliative care patients, including information about treatment possibilities and side effects, physical symptoms that can be expected, nourishment, alternative healing methods, sexuality, euthanasia (as it is relevant in the Netherlands because of the national legislation), agencies who provide help, and medical (e.g. technical) aids. This tool assesses problems with consultations, physical symptoms, and social and financial issues [56]. To assist the patients' and caregivers' enquiries during physician consultations, question prompt lists to propose potentially relevant questions to the patient have been valued as helpful by patients [3, 57, 58]. Two studies documented an increase in the number of questions asked during physician-patient or physician-caregiver encounters and an enhancement of discussions about end-of-life issues [3, 57].

Since many questions and concerns of patients deal with end-of-life issues, symptom relief, and patterns of decline, early integration of palliative care can provide a comprehensive approach to respond to psychosocial, physical, and spiritual information needs [59]. Research shows that patients who participated in early palliative care demand less aggressive therapy and report better symptom control and quality of life [60, 61]. Thorough assessment of the patients' individual (information, physical, psychosocial, and spiritual) needs, values and priorities as well as an adequate response (open communication) to these needs may have contributed to these findings. 'Shared care' concepts with palliative care teams may also reduce caregiver burden and workload throughout the course of the disease since psychosocial care can be very demanding, especially in times of crisis. Palliative care offers support in coping throughout the cancer care continuum and can be integrated into all settings of care, i.e. in the community, at home, in nursing homes and hospitals [62].

To improve continuity and consistence of information throughout the care continuum and across disciplines, professions and settings, van Wersch et al. [9] developed a multidisciplinary care protocol for breast cancer patients that outlines information goals of each party involved. It was valued as useful by patients and health care providers to coordinate patient information and improve coherence throughout the entire course of care [9]. At the Center of Integrated Oncology (CIO) at the University Hospitals of Cologne and Bonn, a cross-sectional care protocol is being developed that identifies patient information needs and links them to the clinical care pathway. Information options that can be offered to patients at various stages of the care pathway include patient seminars, web-based center-specific care information, and information leaflets. The latter target various cancer topics and can increase knowledge and recall [39, 63]. There is still little proof of acceptability and effectiveness of patient information leaflets in later stages of cancer. Print media, prompt lists and protocols are valuable when they assist the information process rather than replace interpersonal information [63, 64].

### Limitations

Communication and information needs strongly depend on the cultural background [65]. The concepts presented in this review, however, mostly lack validation for the German language and culture. Moreover, as for other communicative and psychosocial interventions, randomized controlled trials or large cohort studies of the approaches discussed here are scarce. Therefore, the level of evidence to support the use of these concepts is limited.

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### Conclusions

Providing patient information throughout the process of the disease is an indispensable component of health care professionals' duties when caring for patients with cancer. The therapeutic merits that come along with successful patient-centered information cannot be underestimated (increase of the patients' quality of life and control, reduction of therapeutic side effects and unnecessary hospitalizations, etc.). Yet, individualized and thorough provision of information is challenging. Therefore, on the structural level, health care services should be better educated to ensure effective patient information and counseling throughout the care continuum. Apart from conveying such interactional skills, patient information may be enhanced by cooperation with administrative structures to provide written and/or online information, closely cooperating with a palliative care program that is integrated very early in the course of incurable progressive disease.

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