Article

How do Hematologists Communicate with Patients Suffering from Chronic Lymphocytic Leukemia?

Insights from the ERIC Pilot Study in Greece

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Abstract

Chronic Lymphocytic Leukemia (CLL) is a chronic hematologic malignancy with great heterogeneity and unpredictable clinical course. The European Research Initiative on CLL (ERIC), in the context of its CLL Patient Empowerment Program, conducted a study exploring hematologists' experience of communication. Thirty semi-structured interviews were conducted with hematologists caring for CLL patients in Greece. Inductive thematic qualitative analysis was employed revealing 3 major themes: (i) disclosure of information encompassing 'negotiating the level of disclosure', 'the power of cultural perceptions', 'fear of being held culpable', 'fear of patients' and own emotions'; (ii) medical-decision making which described 'balancing autonomy and beneficence', 'considering patients' preferences' and 'adhering to practice guidelines'; (iii) emotional support which included 'assessment of emotional distress', 'identifying and regulating patients' emotions' and 'maintaining a supportive relationship'. In conclusion, physicians are aware of the importance of communication and its potential impact on CLL patients. They use a wide range of communication strategies which serve the diversity of communication goals they

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must achieve. However, the majority have not received formal education on patient interactions. Present findings highlight the need for specific communication protocols, guidance and training that will empower physicians to overcome challenges, inherent to the nature of CLL.

Keywords

Chronic lymphocytic leukemia, medical information communication, medical decision making.

Hematologic malignancies comprise a group of diverse conditions currently on the rise in the Western world (Batista et al., 2017). Physicians treating patients with hematologic malignancies face a lot of communication challenges in everyday clinical practice and, thus, have a particular need for excellent communication skills (Christie & Glew, 2017). This is especially relevant considering that effective communication has been shown to enhance patients' psychological well-being, satisfaction with care and adherence to treatment, all of which can indirectly influence patients' health outcomes (Miller & DiMatteo, 2020; Street et al., 2009). More specifically, physicians who communicate compassionately, explain results and elicit concerns can positively impact the quality of life of patients with cancer (Kwan et al., 2013). Furthermore, physicians' signs of caring cannot only enhance trust in the provider (Lehmann et al., 2020a) but also reduce patients' psychological distress and need for information (Lelorain et al., 2012). Conversely, providing extensive medical information, without tailoring it to patients' corresponding preferences, has been found to negatively affect recall (Lehmann, 2020b). Overall, the quality and quantity of patient-physician communication is reported as a consistent predictor of patient adherence (Lin et al., 2017), while interventions aiming to improve the quality of communication have been successful in decreasing patients' anxiety and depression symptoms (Bernacki et al., 2019).

According to Epstein and Street's (2007) framework of '*patient-centered communication in cancer care*', physicians' and patients' communication behaviours in cancer healthcare settings is structured around six overlapping and interacting functions: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient self-management. Communication functions and behaviors may affect patient health outcomes directly—e.g. empathic communication can result in reduced pain (Howick et al., 2018)—or indirectly, through mediating outcomes. Improved access to care, the development of a stronger therapeutic alliance, increased social support, more effective patient emotional self-management, higher patient agency, increased patient knowledge and shared understanding, as well as patient-centered decision-making link effective communication with increased adherence, better quality of care and self-care, which facilitate healing and attenuate suffering (Epstein & Street, 2007).

Hematologists often do not have confidence in the communication skills training they have received, while many are dissatisfied with the degree of relevant training or the methods used (File et al., 2014). Clinical experience does not seem to improve physicians' communication skills (Fallowfield, 2010; Vries et al., 2014). It is therefore not surprising that effective communication continues to present a challenge for hematologists (Alexander et al., 2012; Chhabra et al., 2013). This is especially relevant considering that hematologists need to be able to break bad news,

support patients in emotionally charged situations, educate them about disease management and involve them in treatment decision making (Arnaoutakis et al., 2016).

Chronic lymphocytic leukemia (CLL) is a chronic hematologic malignancy which affects primarily individuals over 70 (DeSantis et al., 2014). Some patients are asymptomatic at the time of diagnosis whereas others exhibit symptoms and require treatment initiation soon after initial diagnosis. Asymptomatic patients are initially followed with watchful waiting, however, if disease progression occurs, they have to be treated with one or more lines of therapy, depending on treatment outcome (Hallek, 2019). Deferring treatment after cancer diagnosis is difficult for patients to understand and for physicians to explain and, therefore, CLL has been characterized as 'incurable, invisible and inconclusive' (Evans et al., 2012).

Against this background, ERIC, the European Research Initiative on CLL (<http://www.ericll.org/>) developed and launched its CLL Patient Empowerment Program in 2016. Its first goal was to conduct a needs' analysis of the two main actors of the healthcare interaction; namely, patients and physicians. Secondly, to develop materials, tools and initiatives for the empowerment of patients with CLL through information, self-management and support; by the same token, to empower physicians through education and training in communication skills within the current healthcare context. Thirdly, to implement and compare all of the CLL Patient Empowerment activities in different cultural contexts in Europe. The current study was conducted in the context of the first goal of the ERIC CLL Patient Empowerment Program and its aim was to explore hematologists' experience of communication with patients diagnosed with CLL.

Methods

Design

The current study employed qualitative methodology, in order to explore hematologists' experiences in-depth. Qualitative data were gathered via semi-structured face-to-face interviews with hematologists treating patients with CLL during 2016 and 2017.

Participants

Thirty in-depth semi-structured interviews ($N = 30$) were conducted with physicians affiliated to hospitals and hematology clinics in major cities all over Greece (Athens, Thessaloniki, Alexandroupolis, Larisa, Herakleion, Serres). Participants had between 2 and 32 years of active service ($M = 14.5$), while 4 were in hematology training and 1 had just retired. Eighteen were female and twelve were male. Purposeful sampling was used to intentionally select participants based on their ability to elucidate the specific experience under study (Robinson, 2014). Participants were CLL experts, namely practicing hematologists and hematologists in-training who specialize or are involved in the treatment of patients with CLL. Saturation was achieved at 28 interviews but data collection continued for 2 more interviews to ensure and confirm no new themes were emerging (Saunders et al., 2018). Individual participants were initially approached over the phone and none refused to participate.

Materials

The interview guide was developed drawing on the existing literature on the communication between hematologists and patients with hematological cancers (For the whole guide please see Appendix A). Study findings by Carey et al. (2012), Christie and Glew (2017), Alexander et al. (2012), and Chhabra et al. (2013) provided useful insights about the topics worth covering. These topics included the hematologists' experience of breaking bad news, communication of medical information, patient contact, treatment decision making, communication tools and training, psychosocial assessment and support. Specifically, Carey et al (2012) found that about half of their study participants (i.e. hematological cancer survivors) preferred a passive role in decision making. It was therefore decided to explore Greek hematologists' experience on decision making, how this is negotiated between parties and which factors might influence this decision. In the case of Alexander et al. (2012), findings revealed that unambiguous prognosis estimates for mortality or cure were given at least half of the study participants. Once again, this finding prompted us to explore the communication manner in which equivalent estimates are given by Greek hematologists. In the case of Chhabra et al (2013), initial consultations between physicians and hematological cancer patients were analysed and two types of language were distinguished; *deferential* which emphasized patient autonomy and *directive* which focused on physicians' recommendations. In the present study we decided to ask hematologists about the process they followed, how they checked for patients' understanding and strategies they used to aid comprehension. Finally, in the review by Christie and Glew (2017), it is mentioned that hematologists have a particular need for communication training but do not feel confident with their level of training in communication. This prompted our decision to explore Greek hematologists previous training, tools and level of confidence during difficult decision points throughout the disease course.

Data Collection

The interviews were conducted by one of the researchers (CK), who is a health psychologist and has extensive experience in qualitative research. The researcher had no prior relationship with participants before the study, they only knew about her professional background. The participating hematologist chose the place where the interview took place: hematologist's place or researcher's workplace. No one else was present at the time of the interview. Three interviews had to be conducted over the phone as the area participants were located in was remote and face-to-face contact would have been difficult to achieve. However, the researcher felt that this did not affect the rapport with the participants. Interviews took place in a private room, were audio-recorded and lasted from 20 to 60 minutes.

Ethical Issues

During recruitment, participants were informed about the purpose of the study, the organization hosting the research study, the study's procedure, their right to anonymity and confidentiality, their right to get informed about the findings after the end of the study and finally their right to withdraw from the study at any point without giving a reason. All participants gave their consent for

participation and audio recording of the interview discussion. Ethical approval for this study was obtained by the local Research Ethics Committee.

Analysis

Reflexive thematic analysis was employed to analyze the qualitative data (Braun & Clarke, 2006; Braun et al., 2018). First, the recorded interviews were transcribed verbatim. The transcribed interviews were thoroughly read by the principal researchers who conducted the analysis (CK, AX) to familiarize themselves with the data. Inductive coding was then performed on the semantic content on the data. Initially, coding was independently performed by the two researchers on the first two interviews. Following a discussion and agreement on the initial codes, preliminary themes and subthemes were constructed and researchers proceeded to work independently on the rest of the dataset. Both researchers worked on all interviews. When new concepts were met, these were once again discussed and coded. At the last stage of the process researchers reflected and discussed about the coded data, and constructed subthemes and themes from the initial codes. Subthemes and themes were further revised and refined during the writing process and appropriate extracts were used to support each theme (See Appendix B for the COREQ checklist for Qualitative Research). It is worth mentioning that the two principal researchers belong to different disciplines (medicine and psychology) and, thus, contributed complementary perspectives to the analysis. Both researchers are female and were employed as post-doctoral researchers at the Center for Research and Technology at the time of the study. Finally, the translation of extracts from Greek into English was also performed by the principal researchers. Disagreements on terminology and choice of wording were negotiated and resolved. Microsoft Word and Microsoft Excel were used for the management of codes and extracts.

Results

The analysis and interpretation of the study findings revealed three main themes; disclosure of medical information, medical decision-making and emotional support. A schematic representation of these themes is presented in Figure 1.

An important general observation is that none of the participants in this sample had ever received formal communication training within the context of their medical school or specialty training. In order to achieve all of the physician-patient communication functions, the majority adopted the techniques of senior physicians or developed their own through experience alone. One participant characteristically reports:

“Formally never. Our training took place in the context of our specialty training, observing and copying the hematologists, our professors, our mentors while in training”
(164_254-256/M, 8YEX)

Figure 1. Themes of Physicians' Communication with CLL Patients

Participants faced a number of communication challenges, of which the most important concerns the adaptability they have to show for effectively communicating with each and every patient about topics of such difficult nature in order to cater for a variability of ages, educational levels, capacities, values and attitudes. As a consequence, physicians frequently doubted their approaches. One participant muses on the impact of this gap in training:

“You cannot let such important issues be handled according to people’s intuition....as essentially that’s what we do, we cope with it, each one of us in accordance to his/her intuition and personality and that’s not always best ... it does not always help us make the right call ...” (177_270-272/F, 32YEX)

It should be noted at this point that all of the participating CLL experts also treated patients diagnosed with other hematologic malignancies. Although they shared their experiences of interaction with CLL patients specifically, some of the issues they quoted can be characterised as overarching in nature.

Disclosure of Medical Information

The theme of *disclosure of medical information* contains subthemes reveal the conditions under which physicians consider varying the level of disclosure as well as the fears they experience during the disclosure process.

Negotiating the Level of Disclosure. Almost all physicians felt uncomfortable delivering bad news such as initial diagnosis, relapse and poor prognosis. Their decision to fully or partly disclose as well as the approach and content of their disclosure was governed by their past experiences, their own moral compass, as well as the legal requirements of their profession and workplace context.

One participant characteristically describes the timepoints in the disease course that pose the greatest challenges:

“Definitely as a human being I find it hard to announce bad news, give a very bad diagnosis or tell relatives that things are not going well, it is much worse when I have to say we can’t hope for anything, we are at the final stage, these are always difficult points ...” (164_236-239/M, 8 YEX)

As a consequence, some physicians describe disclosing information only selectively:

“Truth is medicine which should be given only to those appropriate, to the extent appropriate and when appropriate” (166_408-409/M, 5YEX)

Physicians would often disclose to patients depending on their individual profile but also according to their explicit requests:

“When your patient is willing, communicative, intelligent and wants to know the truth, and it is necessary for him to be involved as a partner in your therapeutic effort, then he must know everything” (173_152-154/M, 22YEX)

However, even when sharing information with regards to the disease they completely avoided to offer numerical information i.e. percentage of survival, or expected time to relapse, or life expectancy in years. Instead, they would qualitatively describe the situation. For example:

“This is a dangerous disease that will require treatment many times, unlike infections that will only be treated once. Without appropriate treatment, this disease can be life threatening” (152_14-17/M, 24YEX)

Finally, many differentiated disclosure between patients and their families. One participant stated:

“To the patient I reply with optimism, to the family with numbers” (154_149-150/M, 11YEX)

The power of Cultural Perceptions. On conditions, physicians did not disclose the whole truth as this was not considered to be conducive to the patients’ benefit:

“I don’t think there is anyone in the Mediterranean region who wants to know that they have 6 months to live and this will help them in any way...I don’t believe it” (153_75-76/M, 18YEX)

Further, participants reported that they are often under pressure from the patients’ families to withhold the diagnosis from the patient. This is often against the physicians’ practice and communication principles. As one participant put it:

“The older the patient, the more likely it is that the relatives will come and say to you, don’t tell him, he is elderly, let’s not upset him” (158_105-107/F, training). Another participant said: “I have concluded that if you disclose the diagnosis to the patient at the

beginning, you have a better communication with him. But many times, I don't get to start off with everyone this way. In Greece, the family precedes, the carers invade and the patient is alone outside. Many times, you are asked not to disclose the diagnosis to the patient" (155_59-64/F, 12 YEX)

Conversely, other participants recognized the cultural context within which they are operating and respected the wishes of the Greek family, especially in the case of vulnerable patients. This physician recognizes the motivation behind the family's desires:

"The Greek family has its own protective mechanisms that are acceptable to me at least when it concerns very young or very elderly patients" (169_55-58, F, 14YEX)

Another physician recognizes a change in their own attitude overtime:

"Giving hope is more important than hiding the truth, in these cases one has to inform the relatives, in Greece the family is essentially like one person, it is a different approach than abroad so the relatives know but the patient ..." (151_76-80/F, 15YEX)

Fear of Being Held Culpable. Some participants mentioned that the diagnosis itself is difficult to communicate, however explaining both the consequences of treatment and, especially, the variability of outcomes present an even greater challenge. Fearing they might be blamed for any bad developments in the patients' health, they have to repeatedly stress that CLL is life threatening. According to their collective experience, the event of a death might leave them unsheltered to the relatives' anger, whose denial might not have allowed them to truly comprehend the gravity of the situation. The following passage illustrates a physician's thoughts on this issue:

"No matter how embarrassed I am to say it...we are now practicing 'defensive medicine' ... I am now so scared of criminal prosecution, I can sometimes exaggerate bad outcomes ... the first thing that comes to mind, is that they may not have realized that they might die ... There have been incidents when somebody died very quickly from the side effects of chemotherapy, and lawsuits ensued ... It is burdensome for your psychology, as you grow older anxiety slowly piles up on you" (144_114-122/F, 7YEX)

Fear of Patients' and Own Emotional Reactions. Some participants described their fears about the reactions of patients upon disclosure as well as their own reactions. This stemmed from their desire to deliver the news in a humane but professional manner. One participant said:

"What I'm afraid of is the reaction of others because someone can... be acquiescent, take it well, but some will express doubts about the situation, I will feel like I have not communicated it appropriately, and I caused the patient grief, or that he has not understood well enough what I have said, this is the most stressful part, how the patient will take it. I think I don't feel competent enough to feel fine ..." (148_56-62/M, 4YEX)

Another participant shared:

"If I think about this in an emotional way, something might slip out, or I may lose my cool and start crying and I don't want the patient to see me crying in front of him" (161_223-225/ F, training)

Others were concerned that the disclosure of a hematologic malignancy diagnosis will have a major impact on the patients' state of mind and this dictated to a large extent the manner in which they communicated it. One physician shared:

“Somebody might say you have to come out with it, explicitly and as it is, on the first day but I can't personally do that because I am thinking about that first evening and fear that they might make an attempt to take their own lives” (143_53-57/ F, 25YEX)

Medical Decision-Making

The present theme reflects the main factors determining the medical decision-making process thus creating a spectrum of eventualities of patients' level of involvement.

Balancing Autonomy and Beneficence. Physicians expressed a whole spectrum of views with regards to shared decision making which reflected their perception of their own role within the medical process and their beliefs about the appropriate level of patient involvement in therapeutic decisions.

For some physicians it was important that the selection of treatment was achieved through a transparent process as patient involvement is necessary for treatment acceptance and compliance. One participant mentioned:

“My opinion is that every man has a right to decide knowing that he suffers from a malignancy, has a certain life expectancy and everything that he will go through ... does he want to receive treatment causing hair loss or not for example, as it is my principle to co-decide treatment with my patient without lying to him” (166_94-97/ M, 5YEX)

Keeping the balance between respecting patients' rights (patient autonomy) and ensuring their well-being (principle of non-maleficence) while satisfying their own sense of duty and maintaining a strong work ethic presented a challenge for physicians. Different approaches of resolving this predicament emerged during discussions about shared decision making with participants. The following passage demonstrates one such approach:

“I believe in the patient's autonomy and if the patient insists on receiving something different than what I am proposing or recommending, I suggest a change of the attending physician or have them sign in their file that they are not accepting the treatment I have proposed” (166_246-249/ M, 5YEX)

A few described that they cannot support a choice of treatment they do not stand behind and, hence, resort to stirring patients towards a decision they feel is the best course of action

“... in my opinion we might think that we allow them to choose but actually we don't let them choose because it is the manner that we ourselves choose to inform and the way we present this information, it is completely subjective because this is the way I have perceived three different treatment options and certainly there is one I prefer ...” (176_219-224/F,10YEX)

Considering Patients' Preferences. Some participants pointed out that patients do not always want to take part in the decision-making process. It might be due to the lack of knowledge or the fear they are experiencing because of their disease but patients often do not want to voice an opinion and even the sheer prospect of contributing to a decision frightens them. One participant characteristically said:

“Usually, what you get from a patient to whom you have communicated the diagnosis of a serious disease is: doctor, I don't know and I put myself in your hands”
(162_209-211/F, 8YEX)

Nonetheless, the majority of physicians took into account patients' preferences when recommending a treatment. Certain therapeutic options for CLL require patients and families to adapt their daily life for the duration of the therapy. This held particular weight for physicians who understand the commitment required by patients and thus ensure patients are engaged in the decision-making process.

“I try to a certain extent, depending on his/her profile, wishes according to personality, lifestyle, place of residence, capability to come to the hospital for treatment all of these factors I try to take into account when I suggest 2 or 3 options so we can arrive at a decision together ...” (169_263-270/F, 14YEX)

Adhering to Practice Guidelines. A small group of physicians mentioned that their own clinical practice is governed by international guidelines to which they adhere and share with the patients. This is well illustrated in the following passage:

“If two different treatment options appear as equally valid, I always mention that, also according to recent recommendations, the patients need to participate in the therapeutic decision” (145_365-370/F, 9YEX).

Conversely, others voiced the opinion that treatment decisions are defined by treatment protocols within which there is no room for manoeuvring. One participant said:

“Because we work in a large clinic, there are protocols to follow ... so when we deviate this becomes an issue for discussion in the clinic board ... so we never give the choice to the patient ... I think ... I have always thought that this is not ethical ... for the patient to choose his own treatment ... meaning he does not have the knowledge ... that's why he trusts me ... we operate according to protocol” (144_207-213/F, 7YEX)

Emotional Support

The subthemes of the present theme reveal that physicians assessed patients for distress, regulated emotional responses and supported patients through a healing relationship. All participants acknowledged the importance of maintaining patients' physical and emotional wellbeing after the diagnosis and throughout the disease course of CLL. They also recognized their own role in the assessment of patients' emotional status and their support through emotional difficulties arising from the disease and its consequences. Most physicians adopted a holistic approach to care as they perceived patients' physical and emotional condition to be interlinked.

Assessment of Emotional Distress. Physicians did not formally assess patients for distress, however knew that patients were at risk at different key points during the course of their disease. Specifically, physicians shared their observations, namely that patients with CLL were suffering from anxiety at diagnosis and also in the event of relapse. Furthermore, that in the case of chronic conditions or long hospitalizations patients were at risk of depression.

With this in mind, physicians always started the consultation aiming to elicit information about the patients' emotional status first. One participant shared:

“Always the first question I myself ask in a consultation is how are you, how do you feel? How has your mood been? if you want to be informal, how are your spirits? If more formal, how have you been feeling during this time? Are you enjoying life? An initial general question that is quite exploratory and then while in conversation one thing leads to another” (164_117-121/M, 8YEX)

Physicians maintained the belief that patients could perceive true interest when expressed by their physicians. Therefore, they made an effort to remember issues patients mentioned had troubled or upset them so that they could bring them up in the next consultation and achieve some continuity. The following passage illustrates:

“What matters to the patient is to be interested in him as a whole on a human level, on both an emotional and social front; not just see him as a medical case. Be interested in the problems that his situation creates in his family and social environment” (142_188-191/F, 2YEX)

Physicians described that it was only through experience that they came to understand the importance of the emotional aspect of care and their own role in its provision. One participant describes:

“In the past, I was much stricter with my patients, not giving them the time they needed and not listening to their problem or the way they perceived their illness and especially the way it would affect their social, family and their professional life. Nowadays, I am devoting a lot of time to this aspect of the consultation ... because when you are younger you want to practice your therapeutic skills ... now I see that communicating with the patient is much more important than giving him the medical facts, you have to bring him close to you so that he feels he has someone who cares about him, someone who does not just care about curing the illness, but also cares about the patient's psychology” (151_27-35/F, 15YEX)

Identifying and Regulating Patients' Emotions. Physicians' first and foremost concern in the initial consultations was to alleviate patients' fear and emotional despair. They strived to gain patients' trust, establish rapport and avoid letting patients feel disheartened or burdened with negative emotions. Throughout the disease and especially at key timepoints (e.g. diagnosis, start of treatment, relapse) they found themselves dealing with patients' emotions through lengthy discussions.

The following passage demonstrates this:

“20-30% of patients who are chronically ill have some form of depression but we try to overcome it by talking with patients a lot, either within our daily routine, even on weekends we come in the clinic, when they see us, they always feel better, we have this communication, we don't treat them like whack on the head ‘you have this disease, you have to do this’ ... we have a rapport” (172_113-117/M,16YEX)

Observing emotional cues was essential to the identification of emotions and subsequent intervention by the physicians. One participant shared:

“I think you approach this according to the patient's psychological state and how he has received it (diagnosis). So if you see that the patient is feeling low...too low, you will accentuate the positive points ... for example ... it is very possible that everything will go well” (144_145-149/F,7YEX)

On many occasions, physicians described normalizing patients' emotions, namely validating a negative emotional response in the face of a grave health situation. One participant shares:

“I tell them ‘you are in the hospital and have been diagnosed with cancer, of course you are upset. You need help, there are simple medications that will help you at least get some sleep’ ... I acknowledge the emotion and then I call a specialist” (153_203-206/M,18 YEX)

The most important element of emotional regulation was the inspiration of hope. Physicians always made certain to give patients hope of a positive outcome. One physician shares:

“Let's say it's not going well, I tell my patients ‘we didn't have the response we wanted’, I always count myself in, ‘we didn't have the response we would like to have but there still room to do things’, I always leave a glimmer of hope even if I don't have hope myself ...” (143_178-182/F,25YEX)

Maintaining a Supportive Relationship. A minority of physicians described that they had the opportunity to refer patients to mental health specialists for counselling or therapy sessions within the hospital. In most cases, patients were assessed by liaison psychiatry services and prescribed anti-anxiety or anti-depressants. Few were offered counselling by psychologists and social workers who were part of hematology dedicated multi-disciplinary team. As such, physicians were often the only healthcare specialty supporting the patient and they were very much aware of the fact that patients derive a tremendous amount of emotional support from their relationship. Indeed, the relationship often traverses the strict patient-physician relationship boundaries.

“The relationship becomes a family one, a relationship between relatives, the patient makes you part of his life, because he meets you, you see each other again and again, he searches for you, he anticipates from you, he hangs on to you, he idolizes you, he deifies you ...” (162_173-176 /F,7YEX)

In closing, it is worth mentioning that physicians recounted using an array of techniques to in order to accomplish their communication goals with patients. For the purposes of this paper, these

have been grouped into three broad categories. The first is labeled 'Improving patients' health literacy' and strategies included aim to improve patients' comprehension, encourage empowerment and engagement. The second is labeled 'Provision of patient-centered care'; this group of strategies demonstrate the provision of care while responding to patients' needs by tailoring information, allowing time for adjustment and validating their autonomy. Finally, 'Emotional Cushioning' is a group of strategies aiming to provide reassurance, encouragement and demonstrate compassion while preparing patients for all eventualities. The above categories have not been matched to the current study's themes as none were exclusively used per theme. Instead, physicians used a mixture of strategies of the aforementioned communication strategies for an indicative list, please see Table 1.

Discussion

The current study examined the experience of 30 hematologists in Greece treating patients with CLL using qualitative interviews concerning communication in clinical practice. Hematologists' attitudes on important aspects of physician-patient communication were identified and explored. Analysis revealed three themes namely *disclosure of medical information*, *medical decision making* and *emotional support* which aligned with Epstein and Street's description of certain communication functions in the context of patient-centered communication in cancer care (Epstein & Street, 2007).

The theme of 'Disclosure of medical information' corresponded well with the 'exchanging information' communication function. This function emphasizes the importance for physicians to recognize patients' information needs, communicate information overcoming the barriers of health literacy and communicate prognoses accurately while maintaining hope. The theme comprised of a number of subthemes which focused on the physicians' challenges with communicating the right amount of information when communicating bad news and the influential power the cultural context has over such decisions. Furthermore, the fears that physicians might experience that might also drive their communication behaviors.

Medical decision-making corresponded well with the core communication function bearing the same label namely 'making decisions'. This function requires the physician to actively involve patients during the information exchange and deliberation making process. In the case of the present study's participants, it was apparent that adhering to practice guidelines and considering patient preferences were naturally primary concerns. However, participants were also concerned with balancing patient autonomy and beneficence. A whole spectrum of eventualities of patients' involvement resulted from the resolution of their internal battle.

Similarly, to Epstein and Street's (2007) 'responding to emotions', the present study's theme of emotional support comprised of the elicitation, identification and assessment of emotional distress and regulation of patients' emotions. Another aspect of the theme's description was maintaining a supportive relationship which demonstrated that hematologists were aware that the relationship itself constituted emotional support for the patients as it evolved over time. This aspect was reminiscent of another communication function namely 'fostering healing relationships'

which emphasizes the importance of rapport between physicians and patients as well as the agreement about mutual trust and expectations.

Table 1. List of Communication Strategies Used by Physicians with CLL Patients

	Strategy	Evidence
Improving patients' health literacy	Provide analogies	"I always offer this opportunity, I put it mildly, in many words, to describe to them that there is nothing wrong with visiting a mental health specialist, I usually give a parallelism we don't go to a physician only when we burning with high fever or when we can't drag our feet but we also go for a runny nose or a sore throat. In the same way, we don't go to the psychologist or psychiatrist only if we are crazy because that is the word that shocks, we go even when we are feeling a little anxious" (164_129-136, M, 8YEX)
	Provide metaphors	"While describing I might need to use an analogy, one that I often use comes to mind that the bone marrow is the factory producing the blood which circulates everywhere and the factory suffers damage" (162_75-78/F, 8YEX)
	Build on universal knowledge	"For each person, his disease is much like a fingerprint ... your disease is unique to you ..." (162_106-110/ F, 8YEX)
	Use of pictures	"I draw on the spot, the spleen, the lymph nodes, how the cells currently troubling us look like ..." (172_125-128/M,16YEX)
	Use of evidence	"I'm trying to show them so that they understand some of the lab results or other things that concern their disease, this is a technique to exercise courage, so that they get a grip of the disease and understand what they are achieving, how they can fight it, what their results are, I do it over and over again" (173_138_142/M, 22YEX)
Provision of patient centered care	Adaptation to patient's characteristics	"To a person who is advanced in age, you will choose to say a few things, when you have nothing to offer, you may not tell whole truth ..." (144_33-36/ F, 7YEX)
	Reduction to essential information	"You can see by the way they look at you that they cannot withstand a harsh word 'this is an incurable disease'" (151_70-73/F, 15YEX)
	Gradual disclosure	"Some insist on knowing from the beginning ... this is obvious and easy but when we see a reluctance to find out then we purposely leave things a little hazy and let them find out gradually" (173_95-98/M, 22YEX)

Table 1. List of Communication Strategies Used by Physicians with CLL Patients (*continued*)

Provision of patient centered care	Allow time and space	"I try to do it always, it's a good example we have from the UK, where in the end we say 'do you want to ask something?' 'Is there something you didn't understand?' when you have had time to think about it at home, write questions down and we'll talk about them next time" (169_93-96/F, 14YEX)
	Offer alliance	"I always make an introduction, in the end you are going to decide and we will not proceed with something you do not want to do. Even if you decide against what I am suggesting, we won't abandon you, we'll look at alternatives we can choose from. You always assure patients of this from the beginning" (150_424-427/ F, 19YEX)
Emotional cushioning	Balance realism and hope	"Speaking sincerely and giving real hope. Even for severe diseases because there are differences in survival depending on the success of the treatments. For us, these differences are meaningful" (153_99-101/ M,18YEX)
	Selective accentuation	"I will say that we have 80% of success, you never say 20% death rate, you focus on the positive" (173_110-111/ M,22YEX)
	Choice of wording	"In CLL, I will say 'chronic lymphocytosis' which I need to look into further...and once I have confirmed the diagnosis then I move on to the word 'leukemia' as this is what causes fear ..." (143_72-80, F,25YEX)
	Avoidance of emotionally charged words	"We say things like if his fate is such, if it is His will, if God wants to take him ..." (163_147-148/ F,22YEX)
	Plan of action	"I give patients a laid-out plan. People are relieved when you give them a plan of what they will need to do. I give them an overall perspective" (155_101-103/ F, 12YEX)

In line with previous research, our study revealed that the Greek socio-cultural context powerfully impacted the disclosure process as physicians often succumbed to or complied with the family's wishes to withhold the truth from the patients (Tsoussis et al., 2013). The practice of withholding information on diagnosis or prognosis is also common in several Asian and Southern European countries, despite a global trend towards full disclosure (Ni & Alræk, 2017). Undoubtedly, disclosure of a diagnosis of hematologic cancer, relapse or uncertain/unfavorable prognosis was a source of anxiety for a lot of physicians who described not only the emotional impact on patients but also their own responses to patients' display of distress. The aforementioned factors namely fear of causing psychological morbidity, family's requests of 'do not tell', contradiction between guidelines etc. have been described in the literature to constitute reasons for non-disclosure along with insufficient communication skills training (Ni & Alræk, 2017).

In an effort to reconcile their obligation of non-maleficence and their respect for patients' autonomy, the majority of physicians resorted to partial or gradual disclosure. This is possibly due to the fact that physicians typically have a long time to establish a deep relationship with patients suffering from CLL, something not always possible in the case of other hematological malignancies. Time allows for physicians to get a better sense of their patients, for the physician-patient relationship to establish and for the communicated information to get digested. Conversely, in other cultural contexts the disclosure process is approached in very different ways. For example, in a US study analyzing communication in encounters between 236 patients with hematologic malignancy and 40 hematologists, it was found that hematologists were providing quantitative estimates of mortality and cure to patients they saw for the first time in at least half of the encounters (Alexander et al., 2012).

The current study also shed some light into the dynamics of medical decision making from the physicians' perspective. Most participating physicians expressed the view that patients' preference is often not to get involved in treatment decisions. Indeed, the complexity of illness and treatment in hemato-oncology renders patients reluctant to actively participate in medical decisions (Christie & Glew, 2017; Ernst et al., 2011; Ernst et al., 2013). However, some studies suggest that the reason behind this is that patients might be just conforming to social roles which dictate yielding to physicians' authority (Chhabra et al., 2013; Frosch et al., 2012).

Other physicians in our study reported encouraging patient involvement in therapeutic decisions because they saw this involvement as a fundamental right to autonomy, essential for treatment compliance and in accordance with the latest practice guidelines. During the past few years, the evidence for patients wishing to actively participate in therapeutic decisions has been accumulating. Nevertheless, the extent to which this is true is unclear, mainly due to the variability of research findings from around the world. In the recent literature, an Australian study reported a modest 26% of hematologic cancer survivors ($n = 732$) wanting an active role in treatment decision making (Carey et al., 2012), while a similar survey from the Netherlands reported a much higher 62% of hematologic malignancy patients ($n = 458$) wanting to be actively involved (Rood et al., 2015).

Participants in the current study revealed that they were often required to regulate patients' emotions. More specifically, physicians permitted patients to show anger or grief and strived to promote hope and optimism. Emotional regulation, namely the process of identifying, responding and/or attempting to modify emotions, is one of the most important skills in effective social interaction, essential in the healthcare context (Kafetsios et al., 2014). Patients' emotional experience during medical consultations can influence their satisfaction with the provided care, adherence and health outcomes (Hall & Roter, 2011; Street et al., 2009).

Nevertheless, research shows that patients' emotions, inherent to the cancer disease course, remain unaddressed as physicians might not be able to identify and assess them. Moreover, physicians might choose not to address them fearing they will become emotionally involved in patients' distress or that valuable time will be lost from the consultation (Merckaert et al., 2005; Pollack et al., 2007;). Oncologists often miss opportunities to respond to emotional disclosures demonstrating empathy as they are more focused in 'solving the problem' underlying patients' emotions (Hsu et al., 2012). Furthermore, since they are trained to respond to biomedical concerns,

they are more comfortable reverting to a discussion on biomedical facts (Kennifer et al., 2009). Unfortunately, when intense emotions such as sadness, anxiety and fear are not recognized and treated, they can severely affect patients' quality of life in the long term (Merckaert et al., 2005). Furthermore, these feelings of sadness, anxiety and fear may cause patients to display physical symptoms or behavior which could be wrongly interpreted by physicians as CLL progression (e.g. fatigue, lack of appetite or weight loss) and drive them to erroneous decisions.

None of the physicians participating in the present study had ever received formal communication training either during their basic education or their specialization in hematology. In many healthcare contexts there is a prevailing assumption that the ability to communicate is going to develop 'on the job' through the experience gained from dealing with diverse and demanding situations (Christie & Glew, 2017). However, the majority of participating physicians thought that they would greatly benefit from communication training in the form of continuing professional education, in keeping with previous studies in the Greek context (Kyriopoulos et al., 2003).

Failing to acknowledge communication skills deficiencies and address them through supportive interventions can have devastating effects for both patients and physicians. Despite the professional satisfaction they are experiencing, caring for patients with cancer can be very distressing for physicians. Formidably, they are facing life and death decisions, administering different kinds of treatment (e.g., chemotherapy, targeted agents, immunotherapy, allogeneic transplantation), keeping up with scientific advances and dealing with existential questions on a daily basis (Shanafelt & Dyrbye, 2012). It is not surprising that the burnout syndrome, characterized by emotional exhaustion, depersonalization and loss of meaning is prevalent among oncologists (Shanafelt & Dyrbye, 2012). Lack of confidence in one's communication skills due to insufficient training has been proven to contribute to oncologists' burnout (Tanriverdi, 2013). This cannot only negatively affect the quality of their life but also the quality of care they provide (Salyers et al., 2017).

In conclusion, this study revealed that physicians managing patients with CLL in Greece are very conscious of the importance of communication and its potential impact on their patients' and their own lives. They use a wide range of communication strategies which serve the diversity of communication goals they must achieve in their clinical hemato-oncology practice and betraying the multi-faceted role they hold as educators, supporters, guides and healers etc. However, currently their practice is driven primarily by their personal attitudes and 'hands on' experiences, while also heavily influenced by their individual personality and intuition. Participants' experience of these communication functions and specifically their difficulties and concerns could inform future communication interventions along with other communication functions described by Epstein and Street (2007) such as 'managing uncertainty' or 'enabling self-management'. These functions may have not featured explicitly in this study's findings however are of great importance for hematologists to learn and/or practice. Considering that pitfalls in communication are common throughout the cancer care continuum (Back, 2020), our present findings highlight the need for specific communication protocols and training that will empower physicians to overcome challenges, inherent to the nature of CLL and hematologic malignancies at large. Indeed, the validity of this qualitative study's findings could be strengthened further, through the launch of a

national survey on communication for all physicians. The impact of such findings might set in motion a plan for the development of formal communication courses with the close collaboration of the country's medical schools.

Admittedly, this study is not without limitations. More specifically, one issue worth considering is the wide range of experience in years of participants included in the study. Since the focus of the present study was experience with CLL, we sought out to include participants reflecting the diversity of those practicing in this field in major centers in Greece in order to enrich our findings. However, we also realise that the experience of junior physicians might be somewhat different to seasoned physicians. Future work can focus on the experience and needs of young physicians whose communication style and strategies are not yet as established so that planned interventions addressing their specific needs might be even more effective. Another issue worth considering is the fact that participants drew on their experiences of interaction with patients with CLL, which has a number of distinctive characteristics, such as its chronicity, which allows clinicians to develop techniques such as *gradual disclosure* which are not feasible in other hematological malignancies of an acute nature. Another distinctive feature of CLL is that it might not require treatment at the point of diagnosis. However, literature shows that depression and anxiety are equally prominent in 'watchful waiting' as well as active treatment (Levin, 2006), a common experience for a number of other hematological malignancies. Therefore, although physicians shared their experiences specifically with CLL, some issues discussed, for example the process of *emotional regulation*, could be characterised as overarching in nature. Finally, this study is also limited by the fact that it was conducted with a national scope in mind. Indeed, the national perspective is gravely needed in order to identify specific issues in the healthcare and cultural context in question. Nevertheless, in order to overcome this limitation, ERIC is planning to explore physician-patient communication in the different countries and evaluate the specific need for communication protocols, guidelines and training.

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Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Conflict of Interest

The authors declare no conflicts of interest. All opinions presented in this manuscript belong to the authors alone and the support received from the medical companies listed in the funding section has in no way influenced their submitted work.

References

- Alexander, S. C., Sullivan, A. M., Back, A. L., Tulskey, J. A., Goldman, R. E., Block, S. D., Stewart, S. K., Wilson-Genderson, M., & Lee, S. J. (2012). Information giving and receiving in hematological malignancy consultations. *Psycho-Oncology*, 21(3), 297–306. <https://doi.org/10.1002/pon.1891>
- Arnaoutakis, K., Anders, M., & Berry, K. (2016). Simulating four essential conversations with hematology/oncology trainees: A qualitative evaluation. *Journal of Cancer Education*, 31(1), 55–62. <https://doi.org/10.1007/s13187-015-0847-7>
- Batista, J. L., Birmann, B. M., & Epstein, M. M. (2017). Epidemiology of hematologic malignancies. In M. Loda, L. A. Mucci, M. L. Mittelstadt, M. Van Hemelrijck, & M. B. Cotter (Eds.), *Pathology and Epidemiology of Cancer* (pp. 543–569). Springer. https://doi.org/10.1007/978-3-319-35153-7_29
- Bernacki, R., Paladino, J., Neville, B. A., Hutchings, M., Kavanagh, J., Geerse, O. P., Lakin, J., Sanders, J. J., Miller, K., Lipsitz, S., Gawande, A. A., & Block, S. D. (2019). Effect of the serious illness care program in outpatient oncology: A cluster randomized clinical trial. *JAMA Internal Medicine*, 179(6), 751–759. <https://doi.org/10.1001/jamainternmed.2019.0077>
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2018). Thematic analysis. In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences* (pp. 1–18). Springer. https://doi.org/10.1007/978-981-10-2779-6_103-1
- Carey, M., Anderson, A., Sanson-Fisher, R., Lynagh, M., Paul, C., & Tzelepis, F. (2012). How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Education and Counseling*, 88(1), 87–92. <https://doi.org/10.1016/j.pec.2011.12.014>. Epub 2012 Jan 31. PMID: 22296772
- Chhabra, K. R., Pollak, K. I., Lee, S. J., Back, A. L., Goldman, R. E., & Tulskey, J. A. (2013). Physician communication styles in initial consultations for hematological cancer. *Patient Education and Counseling*, 93(3), 573–578. <https://doi.org/10.1016/j.pec.2013.08.023>
- Christie, D., & Glew, S. (2017). A clinical review of communication training for haematologists and haemato-oncologists: A case of art versus science. *British Journal of Haematology*, 178(1), 11–19. <https://doi.org/10.1111/bjh.14606>
- DeSantis, C. E., Lin, C. C., Mariotto, A. B., Siegel, R. L., Stein, K. D., Kramer, J. L., Alteri, R., Robbins, A. S., & Jemal, A. (2014). Cancer treatment and survivorship statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(4), 252–271. <https://doi.org/10.3322/caac.21235>
- Epstein, R. M., & Street, R. L., Jr. (2007). Patient-centered communication in cancer care: Promoting healing and reducing suffering [monograph]. <https://doi.org/10.1037/e481972008-001>
- Ernst, J., Berger, S., Weißflog, G., Schröder, C., Körner, A., Niederwieser, D., Brähler, E., & Singer, S. (2013). Patient participation in the medical decision-making process in haemato-oncology—A qualitative study. *European Journal of Cancer Care*, 22(5), 684–690. <https://doi.org/10.1111/ecc.12077>

- Ernst, J., Kuhnt, S., Schwarzer, A., Aldaoud, A., Niederwieser, D., Mantovani-Löffler, L., Kuchenbecker, D., & Schröder, C. (2011). The desire for shared decision making among patients with solid and hematological cancer. *Psycho-Oncology*, 20(2), 186–193. <https://doi.org/10.1002/pon.1723>
- Evans, J., Ziebland, S., & Pettitt, A. R. (2012). Incurable, invisible and inconclusive: Watchful waiting for chronic lymphocytic leukaemia and implications for doctor–patient communication. *European Journal of Cancer Care*, 21(1), 67–77. <https://doi.org/10.1111/j.1365-2354.2011.01278.x>
- Fallowfield, L. (2010). Communication with patients after errors. *Journal of Health Services Research & Policy*, 15(Suppl. 1), 56–59. <https://doi.org/10.1258/jhsrp.2009.09s107>
- File, W., Bylund, C. L., Kesselheim, J., Leonard, D., & Leavey, P. (2014). Do pediatric hematology/oncology (PHO) fellows receive communication training? *Pediatric Blood & Cancer*, 61(3), 502–506. <https://doi.org/10.1002/pbc.24742>
- Frosch, D. L., May, S. G., Rendle, K. A., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Affairs*, 31(5), 1030–1038. <https://doi.org/10.1377/hlthaff.2011.0576>
- Hall, J. A., & Roter, D. L. (2011). Physician–patient communication. In H. S. Friedman (Ed.), *Oxford handbook of health psychology* (pp. 317–346). Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780195342819.001.0001>
- Hallek, M. (2019). Chronic lymphocytic leukemia: 2020 update on diagnosis, risk stratification and treatment. *American Journal of Hematology*, 94(11), 1266–1287. <https://doi.org/10.1002/ajh.23979>
- Howick, J., Moscrop, A., Mebius, A., Fanshawe, T. R., Lewith, G., Bishop, F. L., Mistiaen, P., Roberts, N. W., Dieninytė, E., Hu, X.-Y., Aveyard, P., & Onakpoya, I. J. (2018). Effects of empathic and positive communication in healthcare consultations: A systematic review and meta-analysis. *Journal of the Royal Society of Medicine*, 111(7), 240–252. <https://doi.org/10.1177/0141076818769477>
- Hsu, I., Saha, S., Korthuis, P. T., Sharp, V., Cohn, J., Moore, R. D., & Beach, M. C. (2012). Providing support to patients in emotional encounters: A new perspective on missed empathic opportunities. *Patient Education and Counseling*, 88(3), 436–442. <https://doi.org/10.1016/j.pec.2012.06.015>
- Kafetsios, K., Anagnostopoulos, F., Lempesis, E., & Valindra, A. (2014). Doctors' emotion regulation and patient satisfaction: A social-functional perspective. *Health Communication*, 29(2), 205–214. <https://doi.org/doi:10.1080/10410236.2012.738150>
- Kennifer, S. L., Alexander, S. C., Pollak, K. I., Jeffreys, A. S., Olsen, M. K., Rodriguez, K. L., Arnold, R. M., & Tulsky, J. A. (2009). Negative emotions in cancer care: Do oncologists' responses depend on severity and type of emotion? *Patient Education and Counseling*, 76(1), 51–56. <https://doi.org/10.1016/j.pec.2008.10.003>
- Kyriopoulos, J., Gregory, S., Georgoussi, E., & Dolgeras, A. (2003). Professional profile of national health service physicians in Greece and their self-expressed training needs. *Journal of Continuing Education in the Health Professions*, 23(2), 101–108. <https://doi.org/10.1002/chp.1340230207>

- Kwan, M. L., Tam, E. K., Ergas, I. J., Rehkopf, D. H., Roh, J. M., Lee, M. M., Somkin, C. P., Stewart, A. L., & Kushi, L. H. (2013). Patient–physician interaction and quality of life in recently diagnosed breast cancer patients. *Breast Cancer Research and Treatment*, 139(2), 581–595. <https://doi.org/10.1007/s10549-013-2569-z>.
- Lehmann, V., Labrie, N. H. M., van Weert, J. C. M., van Dulmen, S., de Haes, H. J. C. J. M., Kersten, M. J., Pieterse, A. H., & Smets, E. M. A. (2020a). Provider caring and structuring treatment information to improve cancer patients' recall: Does it help? *Patient Education and Counseling*, 103(1), 55–62. <https://doi.org/10.1016/j.pec.2019.07.011>
- Lehmann, V., Labrie, N. H. M., van Weert, J. C. M., van Dulmen, S., de Haes, H. J. C. J. M., Kersten, M. J., Pieterse, A. H., & Smets, E. M. A. (2020b). Tailoring the amount of treatment information to cancer patients' and survivors' preferences: Effects on patient-reported outcomes. *Patient Education and Counseling*, 103(3), 514–520. <https://doi.org/10.1016/j.pec.2019.09.024>
- Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2012). A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology*, 21(12), 1255–1264. <https://doi.org/10.1002/pon.2115>.
- Levin, T. (2006). Quality of life, depression and anxiety in chronic lymphocytic leukemia during phases of “watchful waiting” and active treatment. *Journal of Clinical Oncology*, 24(Suppl. 18), 6603–6603. https://doi.org/10.1200/jco.2006.24.18_suppl.6603
- Lin, C., Clark, R., Tu, P., Bosworth, H. B., & Zullig, L. L. (2017). Breast cancer oral anti-cancer medication adherence: A systematic review of psychosocial motivators and barriers. *Breast Cancer Research and Treatment*, 165(2), 247–260. <https://doi.org/10.1007/s10549-017-4317-2>
- Merckaert, I., Libert, Y., Delvaux, N., Marchal, S., Boniver, J., Etienne, A. M., Klastersky, J., Reynaert, C., Scalliet, P., Slachmuylder, J. L., & Razavi, D. (2005). Factors that influence physicians' detection of distress in patients with cancer: Can a communication skills training program improve physicians' detection? *Cancer*, 104(2), 411–421. <https://doi.org/10.1002/cncr.21172>
- Miller, T. A., & DiMatteo, M. R. (2020). Physician–patient communication. In K. Sweeny, M. L. Robbins, & L. M. Cohen (Eds.), *The Wiley encyclopedia of health psychology* (pp. 469–474). Wiley. <https://doi.org/10.1002/9781119057840.ch97>
- Ni, Y. H., & Alræk, T. (2017). What circumstances lead to non-disclosure of cancer-related information in China? A qualitative study. *Supportive Care in Cancer*, 25(3), 811–816.
- Robinson, R. S. (2014) Purposive sampling. In A. C. Michalos (Ed.), *Encyclopedia of quality of life and well-being research*. Springer. https://doi.org/10.1007/978-94-007-0753-5_2337
- Rood, J. A., van Zuuren, F. J., Stam, F., van der Ploeg, T., Eeltink, C., Verdonck-de Leeuw, I. M., & Huijgens, P. C. (2015). Perceived need for information among patients with a haematological malignancy: Associations with information satisfaction and treatment decision-making preferences. *Hematological Oncology*, 33(2), 85–98. <https://doi.org/10.1002/hon.2138>
- Salyers, M. P., Bonfils, K. A., Luther, L., Firmin, R. L., White, D. A., Adams, E. L., & Rollins, A. L. (2017). The relationship between professional burnout and quality and safety in healthcare: A meta-analysis. *Journal of General Internal Medicine*, 32(4), 475–482. <https://doi.org/10.1007/s11606-016-3886-9>

- Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Shanafelt, T., & Dyrbye, L. (2012). Oncologist burnout: Causes, consequences, and responses. *Journal of Clinical Oncology*, 30(11), 1235–1241. <https://doi.org/10.1200/JCO.2011.39.7380>
- Street, R. L., Jr., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling*, 74(3), 295–301. <https://doi.org/10.1016/j.pec.2008.11.015>
- Tanriverdi, O. (2013). A medical oncologist's perspective on communication skills and burnout syndrome with psycho-oncological approach (to die with each patient one more time: The fate of the oncologists). *Medical Oncology*, 30(2), 530. <https://doi.org/10.1007/s12032-013-0530-y>
- Tsoussis, S., Papadogiorgaki, M., Markodimitraki, E., Delibaltadakis, G., Strevinas, A., Psyllakis, M., Tabakaki, K., Drossitis, I., Kabourakis, A., Papadimitraki, E., Kryptos, S., Daskalakis, K., Fragiadaki, G., Zoumadaki, E., & Apostolakis, S. (2013). Disclosure of cancer diagnosis: The Greek experience. *Journal of the Balkan Union of Oncology*, 18(2), 516–526.
- Vries, A. M. M. D., Roten, Y. de, Meystre, C., Passchier, J., Despland, J.-N., & Stiefel, F. (2014). Clinician characteristics, communication, and patient outcome in oncology: A systematic review. *Psycho-Oncology*, 23(4), 375–381. <https://doi.org/10.1002/pon.3445>

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Appendices

Appendix A: Interview Guide

The purpose of this investigation is to learn more about your experience of treating patients with CLL. Specifically, to find out about your needs and concerns around communication within the context of physician-patient relationship. We would be grateful if you could help us by sharing your thoughts and personal experience with us. If you decide to take part, the researcher will come and see you at an appropriate time and place of your choice. During this meeting, the researcher will spend a short time asking you a few questions about your experience of treating patients with CLL. This should not take more than one hour of your time.

1. Can you describe your overall experience? /How would you rate it i.e. positively/negatively? (warm up)
2. What sort of contact do you have with CLL patients?
 - Frequency/duration
 - Kind
 - Patient / doctor's own initiative
3. Which communication channels do you keep open?
 - Email, phone etc.
4. What do you think CLL patients should know about their disease at the point of diagnosis? Where do your patients get further information from?
5. How do you communicate this to your patient?
 - Face to face, refer them to an internet site, etc.
6. How would you describe the process you follow? How do you ensure CLL patients' comprehension of important issues such as its chronic nature, lack of symptoms etc.?
 - Lecture, discussion etc.
7. In subsequent visits, what kind of assessment do you usually perform except monitoring of biomarkers?
 - Quality of life
 - Anxiety and depression

- Self-reported compliance
 - Social support
 - Illness perceptions
8. What sort of information do you elicit from your patients? / How important is this information for you?
 - Feelings, thoughts etc.
 - Information needs
 - Concerns
 9. What kind of feedback do you routinely give patients? / how?
 - e.g. molecular response
 10. How do you inform patients about the progression/bad prognosis of the disease? Is there information you might avoid sharing?
 - e.g. symptoms of relapse
 11. How do you reach decisions throughout the course of the disease? How would you ideally want this to happen?
 - Together
 - Primarily the physician's
 - Patient's preference
 12. What kind of tools do you use? / which ones in particular?
 - Decision-making trees, charts, leaflets
 13. How/when do you involve patients' family?
 14. Have you ever received formal communication training on announcing bad news?

Appendix B: COREQ 32 Item Checklist

No. item	Guide questions/description	Reported on page
Domain 1: Research team and reflexivity		
1. Interviewer/facilitator	Which author/s conducted the interview?	7
2. Credentials	What were the researcher's credentials?	7, 8
3. Occupation	What was their occupation at the time of the study?	8
4. Gender	Was the researcher male or female?	8
5. Experience and training	What experience or training did the researcher have?	7
6. Relationship with participants established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher?	7
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	7,8
Domain 2: Study design		
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study?	8
10. Sampling	How were participants selected?	5
11. Method of approach	How were participants approached?	6
12. Sample size	How many participants were in the study?	5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	6
14. Setting of data collection	Where was the data collected?	7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	7
16. Description of sample	What are the important characteristics of the sample?	5
17. Interview guide	Were questions, prompts, guides provided by the authors?	34-35
18. Repeat interviews	Were repeat interviews carried out?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20. Field notes	Were field notes made during and/or after the interview?	N/A
21. Duration	What was the duration of the interviews?	7
22. Data saturation	Was data saturation discussed?	5
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A

No. item	Guide questions/description	Reported on page
Domain 3: Analysis and findings		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	8
27. Software	What software, if applicable, was used to manage the data?	8
28. Participant checking	Did participants provide feedback on the findings?	N/A
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	9-18
30. Data and findings consistent	Was there consistency between the data presented and the findings?	9-18
31. Clarity of major themes	Were major themes clearly presented in the findings?	9-18
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	9-18