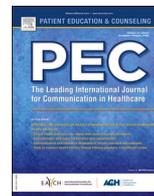




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Personalizing precision medicine: Patients with AML perceptions about treatment decisions

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ABSTRACT

Background: This study aims to explore patients' with acute myeloid leukemia perceptions about precision medicine and their preferences for involvement in this new area of shared decision-making.

Methods: Individual semi-structured interviews were conducted in Finland, Italy and Germany (n = 16). The study population included patients aged 24–79 years. Interviews were analyzed with thematic content analysis.

Results: Patient's perceived lack of knowledge as a barrier for their involvement in decision-making. Treatment decisions were often made rapidly based on the patient's intuition and trust for the physician rather than on information, in situations that decrease the patient's decision capacity. The patients emphasized that they are in a desperate situation that makes them willing to accept treatment with low probabilities of being cured.

Conclusions: The study raised important issues regarding patients' understanding of precision medicine and challenges concerning how to involve patients in medical decision-making. Although technical advances were viewed positively, the role of the physician as an expert and person-of-trust cannot be replaced.

Practice implications: Regardless of patients' preferences for involvement in decision-making, information plays a crucial role for patients' perceived involvement in their care. The concepts related to precision medicine are complex and will imply challenges to patient education.

1. Introduction

Acute myeloid leukemia (AML) is a blood cancer that results in bone marrow failure. The median age of diagnosis is around ~70 years [1]. Despite recent advances, the 5-year patient survival reaches 30%, dropping to 5–10% in elderly patients [2]. Treatment approaches include combination chemotherapy, use of hypomethylating agents,

possible targeted therapies, novel immunological treatment approaches and/or allogeneic hematopoietic stem cell transplantation [3]. Many therapies used to treat AML involves the risk of life-threatening toxicities and severe chronic side effects that can substantially impact patients' quality of life (QOL) [4].

Despite recent advances in the treatment of AML, between 40% and 50% of younger patients, and the majority of elderly patients do not

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respond to induction therapy or relapse and in time become resistant to treatment [5]. Clinical outcomes and therapy response of patients with AML differ widely with patient age and inter-individual molecular and genetic heterogeneity, which are all prognostic factors [6]. Initial treatment decisions therefore involve an assessment of 'fitness' for induction chemotherapy [7] as well as the role of genetics in response and resistance evaluation to new agents [8].

There exists various definitions of precision medicine, but often the concept include the use of individual features, computational power and algorithms to predict and optimize individual disease risk and treatment response [9]. Precision medicine involves various technologies, such as next generation sequencing (NGS), molecular profiling, adaptive trials and targeted treatments. The concept of precision medicine is sometimes used synonymously with stratified medicine and personalized medicine [10]. However, while precision medicine builds on sub-classification of disease to enable tailoring of treatment to individual response, personalized medicine also emphasizes patient participation and preferences [11]. Precision medicine incorporates patient data into clinical therapy treatment using an experimental approach where therapy and research is combined. Instead of large randomized clinical trials, the number of research subjects in precision medicine trials can be very few. Precision medicine therefore have scientific uncertainties [12]. Patient might also require participating in research projects and sharing their data to benefit from precision medicine.

Shared decision-making (SDM) is a strategy weighing patients' values and preferences together with clinical findings [13]. SDM is especially appropriate in uncertain and preference sensitive situations. These are situations where multiple options exist and the scientific evidence are not clearly in favor for one the options, or the patient perceive the risk-benefit trade-offs different from the health care professionals [14]. In these situations, physicians should explore patients' preferences [15]. It requires that information is shared and that decisions are informed. Therefore, SDM needs to build on a good doctor-patient relationship.

Patient involvement in decision making for cancer treatment has been shown to improve additional patient reported outcomes, including QOL and satisfaction. Even if studies have shown that the majority of patients preferred shared decision-making [16], not all patients want to have an active role.[17] Furthermore, stakeholders have expressed concerns that patient-doctor communication may become more complicated with precision oncology, due to the patients' unwillingness or ability to participate in the decision-making process [18].

MEET-AML (Metabolic vulnerabilities for personalized therapeutic approaches in acute myeloid leukemia) is a European research project. The overall aim is to develop a model of personalized medicine that integrates the disease phenotype, therapeutic opportunities and preferences of AML patients that can be used for their disease management. The aim for this study was to explore patients' with AML perceptions about decision-making and precision medicine, so that their preferences and values can be incorporated into the precision medicine advances made in MEET-AML, and thereby make it personalized.

2. Methods

The study was a qualitative, semi-structured interview study.

2.1. Setting and participants

Patients with AML were recruited via Helsinki University Hospital (Finland), IRST IRCCS (Italy), and Charité Universitätsmedizin Berlin (Germany). All three hematological centers offer specialized cancer care and have a large catchment area. Finland and Italy have public funded health care, free of charge to residents. Germany is funded by a statutory contribution system that ensures free healthcare for all via health insurance funds.

Patients were informed about the study and gave their written

consent before interviews started. The study was approved by ethical committees in the respective countries (Helsinki University Hospital EC, number HUS/3405/2020, Charité institutional ethics committee, number EA1/279/20, IRST, Comitato Etico della Romagna, Prot. 8001/2020). Participation was voluntary and patients could withdraw at any time without any consequence on their treatment or care.

The participants varied in age, sex, and time since diagnosis (Table 1). The disease state of the patients varied: all in remission in Helsinki, at different stages in Berlin (initial treatment or relapse), one at disease onset (before treatment), two refractory patients and one at disease relapse in Italy.

A semi-structured interview guide was developed by the research group and a patient representative from the Acute Leukemia Advocates Network (ALAN), based on previous research (Supplement file A). It included questions about the patient's perspective on treatment, treatment decisions, precision medicine and data sharing. After the first interview, the interview-guide was revised by removing a question that was perceived as repetitive. Patients were initially asked about their pre-existing perception about precision medicine. Thereafter, a common description about the concept was read to the patients. The interview also included a ranking exercise [19]. The patients were given a list with aspects of cancer treatments; physical side effects, psychological side effects, treatment effectiveness, administration routes and susceptibility to infections (Supplement B). The patients were asked to rank the aspects in order of importance. Patients were then asked to motivate their choices. This was done to explore their reasoning and motives behind their preferences for cancer treatment and to inform selection of attributes for a choice based survey in an upcoming study.

The interviews were conducted from February 2021 through January 2022. A hematologist (Helsinki), and two psycho-oncologists (Charité and IRST), conducted the interviews, either at the clinic or by phone due to COVID-19 restrictions. The hematologist had treated the patients, while the psychologists had never met the patients before the interview. The interviews lasted between 17 and 59 min (mean 34 min). No incentives were given. The interviews were audio taped. A professional translator transcribed the interviews verbatim and translated the transcripts into English. The English transcriptions were analyzed using thematic content analysis [20]. The first interview was coded by ÅG and UK independently. After reading the transcribed interviews, open coding was applied, which entails making a summary statement (a code) of what has been said. The coding was compared, and deviations were discussed. The remaining transcripts were analyzed by ÅG. Any hesitations about meaning and interpretation were discussed with the person conducting the interview. All the codes were then listed and duplicates crossed out. Similar and overlapping codes were then grouped together into categories which were discussed and labelled by the group. Data collection continued until saturation of data was achieved, meaning that no new themes or information emerged during the interviews [21].

3. Results

The analysis resulted in three categories with additional sub-categories (Fig. 1).

Table 1
Description of participants N = 16.

	N (%)	Mean (std)
Age (years)		57.8(18.4), range: 24–79
Women	6 (38)	
Men	10 (63)	
Country		
Finland	7 (44)	
Italy	4 (25)	
Germany	5 (31)	
Time since diagnosed with AML (months)		19.7 (15.6), range: 2–48

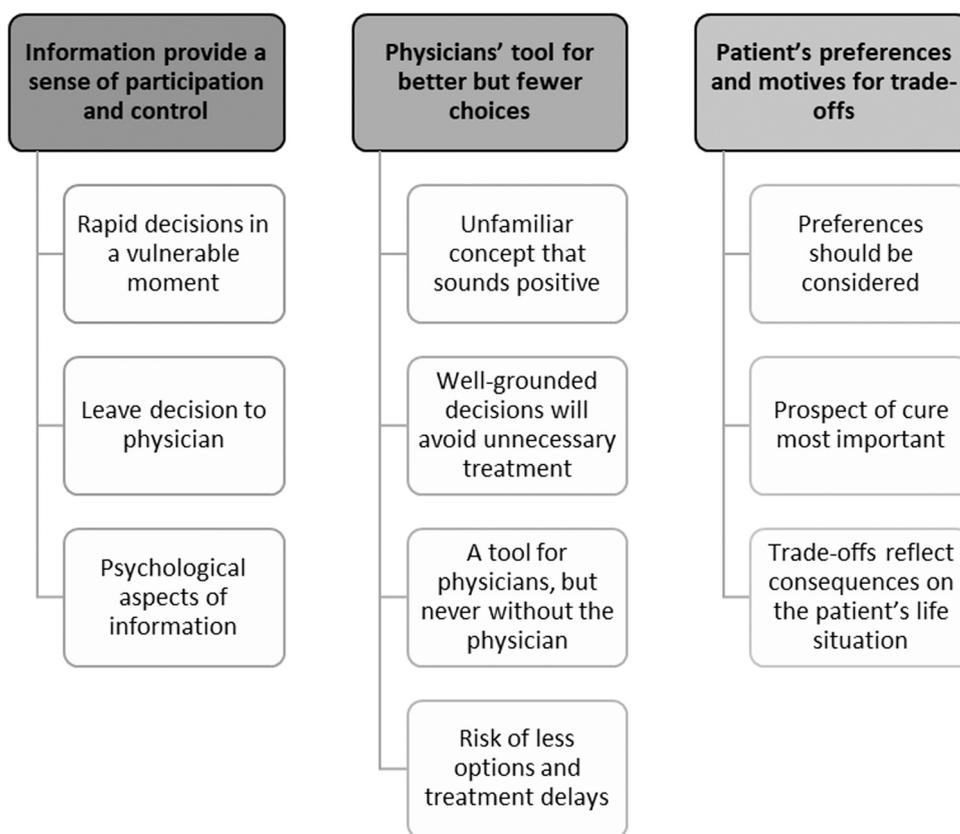


Fig. 1. Categories and sub-categories.

3.1. Information provide a sense of participation and control

3.1.1. Rapid decisions in a vulnerable moment

Many patients experienced that treatment was initiated immediately after receiving their AML diagnosis, when they were in shock from receiving a life-threatening diagnosis and feeling loss of control over their life. They said that this put them in a vulnerable mental state, in which it is difficult to make any decisions at all.

P12. : I actually only went to the hospital because my mother was worried [...] When I arrived at the hospital, they said they can't let me out of the hospital anymore, because otherwise I'll die. [...] that was just very surreal for me, so when I was here on the ward and the first night I was also completely overwhelmed and then of course completely stressed out. And the next day the treatment started basically.

3.1.2. Leave decision to physician

Most participants thought it was difficult to have an opinion about treatment decisions, since they lack the medical knowledge needed for it. Patients perceived high trust in their physicians to choose the best treatment for them. Several patients emphasized that not every situation allows for options and had no experience of being presented with any option, rather that treatments were recommended to them. One patient expressed that he does not wish to be involved in the treatment decision.

P4. : Well, there were not any questions about the treatment decisions. I had complete confidence in the professionals.

3.1.3. Psychological aspects of information

Information was requested and valued by the patients, although not mainly for the purpose of decision-making. Instead, it was needed for mental preparation, to know what to expect from the treatment and why things were done, as a way to cope, and to increase perceived control over the situation.

P1. : That's something I'd like to know, but it would not necessarily affect my decision, since it's a matter of life and death after all.

Some patients said that they first made treatment decisions intuitively and read the patient information at a later stage. Some patients avoided information about treatments, since it could make them loose hope. However, one patient said that this tendency composed a contradiction, since the patient, at the same time, wanted to know "the raw truth of what is going on." Another reason for avoiding information was when the patients did not perceive there to be an actual choice to decline treatment if they want to recover.

P9. : For psychological reasons, I do not want to be too informed about this, so my wife and sister, who's involved in health care, take care of it a lot. [...] The word leukemia is a word that scares me a lot.

3.2. Physicians' tool for better but fewer choices

3.2.1. Unfamiliar concept that sounds useful

Precision medicine was an unfamiliar concept to almost all patients. After the interviewer described the concept, most thought it made sense and were hopeful about its usefulness.

P14. : I would fundamentally support anything that, as you have described, serves to address the patient's individual situation or clinical picture and then concentrate a therapy or treatment on that, always with the intention of achieving the best treatment result.

Many expressed a high level of trust of future algorithms used in precision medicine, and some related that trust to their general high trust in health care professionals.

P6. : I don't have any competence in that. But I do have trust.

3.2.2. Well-grounded decisions will avoid unnecessary treatment

Patients perceived the fact that there is “real knowledge” in the background as a way to ensure that decisions are correct for the individual patient. They also hoped that precision medicine would help avoid ineffective treatments and thereby spare the patient of unnecessary side-effects.

P13. : *OK, on the basis of the particular markers, that might be particularly useful for skipping treatments that will have no effect anyway, and maybe could spare the patient a little something.*

3.2.3. A tool for physicians, but never without the physician

The patients perceived precision medicine as a tool for physicians that will support and justify their decisions.

P10. : *I believe that they can definitely be of great help for the doctors who then have to make choices, allowing them to make them based on a comparative situation, and taking many elements into account, which only an analysis of this kind can offer.*

However, the patients thought it was crucial that physicians do not rely too much on the algorithm. They expressed that computers, unlike physicians, do not see the human side of the patient while the physicians can consider aspects not entered in the algorithm. They thought physicians therefore should be able to decide against the algorithm, based on benefits for the patient’s life situation. The gut feeling of the attending physician is something they stated to be very important and their decision on what is right for the patient is most crucial to consider.

P10. : *The cons are that it should not be accepted without question by the doctor, but always be related to the person, to the individual clinical case that he is managing, without passively adopting the indications that may come from these studies, but always comparing them and translating them to match the clinical condition of the patient he is treating.*

Furthermore, the human side of the physician was strongly emphasized, in terms of the doctor who treats you, being able to ask questions, and, that the physician shows empathy for the patient. Therefore, it was perceived that an algorithm could never re-place the physician.

P11. : *Only a computer without a human brain, no. I would still also like to be advised a little bit and, yes, this advisory function should not replace that, and trusting the doctor who treats you.*

3.2.4. The risk of reduced options and treatment delays

The patients anticipated the risk of being offered less treatment options in case the algorithm would not find them eligible for the treatments. This could create a tension between the physician and the patient in cases where the patient wants the treatment. Another concern was that precision medicine may take too much time, and it is critical to initiate treatment fast.

P12. : *OK, you don't fit into the algorithm, so we won't treat you. That's rubbish too. [...] That might even be a disadvantage. That if you don't fit into the algorithm, that you can't be treated with the specific treatment.*

3.3. Patients preferences and motives for trade-offs

3.3.1. Preferences should be considered

The patients thought that patients’ views on how to balance effectiveness with other aspects of treatment should be considered. Some suggested that preferences should be incorporated in the algorithm, while others thought that patients’ preferences should be considered through a more meaningful consultation.

P9. : *Maybe, doing more meaningful interviews at the beginning of therapy. Sometimes it's taken pretty much for granted that there's this problem, and this is the right treatment.*

3.3.2. Prospect of cure most important

Due to the severity of AML, being “a life and death matter,” patients considered effectiveness of the treatment the most important aspect of treatment, and that all other factors are secondary to it. That could mean accepting low probabilities and trying experimental treatment, when standard treatment does not have the decisive effect, therefore also accepting higher risks and uncertainty. The possibility to intervene was perceived reassuring since it brought hope of being cured.

P1. : *It's really difficult, when you're told that the probability of this working is really low, but you still. You still go through with it.*

3.3.3. Trade-offs reflect consequences on the patient's life situation

The additional aspects of treatment were subordinated efficacy. The reasoning behind the importance of these, to a large extent related to previous experiences, and the importance of being able to continue their life and being self-sufficient. A young mother preferred receiving a less heavy outpatient treatment for a longer time, rather than an inpatient treatment for a shorter time, since it enabled her to spend time with her child during treatment. Another younger patient empathized the advantage of being an outpatient and being able to participate in everyday life, something that is limited when being diagnosed with AML.

P13. : *At that moment you part with everything because you don't go to work anymore, you don't see your friends anymore, your life is completely gone. [...] Positive aspects of a treatment is the availability of the patient, so when I am undergoing treatment, how much can I participate in public life.*

Even though side effects were unwanted by the patients, temporary side-effects were perceived inevitable if they want to be cured. However, they considered severe, chronic side effects less acceptable since they may influence the QOL the rest of their life.

P1. : *I know people who have undergone the same type of AML treatment as me, but who live with really severe, chronic side effects and need to rethink all their plans and they may have needed go into early retirement and are no longer able to do anything and. who also are not happy with their lives even though they are alive. [...] So, if it's like, you'll still be alive in 10 years but can't walk and so on, then you have to think about where you draw the line.*

4. Discussion

The patients with AML participating in this study described that they are in a vulnerable state, both physically and mentally, when treatment decisions are taken. Patients also expressed that their lack of medical knowledge makes it difficult to have an opinion about the treatment choice. Our findings reflect the results from a recent study in the UK [22]. They found that most patients wanted to be informed about and given the opportunity to discuss treatment benefits and risks with their clinician. However, most patients felt ill equipped to make decisions on their own behalf, and therefore wanted their physician to make a recommendation. Preferences for clinician recommendations were based on the patients’ respect for the hematologists’ clinical knowledge and expertise, trust in their professional judgement, and faith that they would act in the best interests of the patient [22]. Likewise, the patients in our study expressed a high degree of trust in their physician and their ability to make the right decisions for them. The type of vulnerability described by patients with AML has been shown to increase patients’ trust in the physician [23].

Perceived lack of knowledge and not having the strength to process information may constitute an obstacle for SDM [24]. However, one should acknowledge that not all the treatment decisions per definition are preference sensitive; there might only be one treatment available or the scientific evidence clearly favors one of the treatment options. Furthermore, SDM, is not always about making the patient choose, but to involve them in the discussion. Entwistle et al. [25] state present a conceptual framework model of patient involvement in treatment

decision-making. It acknowledges that patients can be involved not only based on what they say and do to influence a decision, but also based on what they think and feel about their contributions to decision-making and their relationships with their clinicians. The patients in our study stated that they want to be informed about available treatments and the benefits and risks involved, even if it does not influence their decisions. Being informed about what, why, and when things are being done to them, was said to create involvement and a sense of control and ease, and gave the patients a possibility to prepare mentally. In contrast, patients also expressed that information about serious side-effects can be overwhelming and bring them down mentally while they in some cases did not have an actual choice to decline the treatment if they wanted to stay alive.

The patients in our study expressed that, since AML is a “life and death matter,” they are willing to accept high risks and low probabilities of being cured. On one side, the patient’s will to accept these risks should be respected, since it is the patient’s life that is at stake. On the other hand, this raises ethical considerations since it is doubtful whether the patients are sufficiently informed and comprehend the risks they say that they are willing to accept.

Regarding patients’ perceptions and attitudes towards precision medicine, most patients were unfamiliar with the concept. Although the patients stated that they would trust an algorithm, the trust for the physician is stronger. The human side of a physician and the doctor-patient relationship was also something that the patients empathize. Therefore, the physician should have the overall responsibility and can never be replaced by an algorithm, a finding previous studies also reported [26,27].

Although the possibility to avoid unnecessary treatments was considered positive, the possibility of having reduced treatment options was considered a downside. A study from the UK, found that patients may be disappointed when results from molecular testing of the tumor reveals that the patient is not eligible for the targeted therapies [28]. Patients perceived the ability to intervene as reassuring, and something that keeps their hope of being cured, and makes them accept high risks and very low probabilities of being cured. The patients’ trade-offs between benefit and risk may therefore collide with physicians and algorithms. Weighing in patients’ trade-offs in precision medicine is therefore fundamental for achieving personalized care.

4.1. Practice implications

With the implementation of precision medicine comes the increase of uncertainty, and thus more preference sensitive decisions. Meanwhile, AML, put individuals’ in a vulnerable situation, where the patients are inclined to leave treatment decisions to their physicians. Regardless of patients’ preferences for involvement in decision-making, information plays a crucial role for patients’ perceived involvement in their care. The concepts related to precision medicine are complex and will imply challenges to patient education.

4.2. Study limitation

The interviews were conducted in the patients’ native language and then translated to English by a professional translator. It is therefore possible that nuances in the language were lost in translation. However, the translations were checked within the research group and uncertainties discussed. In Finland, the interviewer had been the patients’ treating physician. This could have implications for the interview, since it is possible that the patients felt hesitance to express negative emotions and experiences. However, it may also make the patient feel comfortable talking to a person that they know and trust. Furthermore, the results from the Finnish interviews did not differ compared with the Italian and German, with regard to expressing criticism or negative feelings. Study staff with no prior relationship recruited the German patients, whilst hematologists recruited the patients in Italy and Finland. Therefore,

there was a risk that the patients felt a pressure to participate. However, it was underlined that participation was voluntary and the refusal would not affect to their treatment. Some patients did refuse participation.

In qualitative research, the aim is to gather a variety of perceptions, which is why you often strive to recruit a heterogeneous sample [29]. The participants in this study varied in age, sex, nationality and time since AML diagnosis. This increases the possibility to gather different views and is a major strength of this study. Data was collected in Europe, and values and perception may differ in other parts of the world. In countries that lack publicly funded healthcare, it is possible that issues around the cost of care would emerge in patient interviews. Future studies may incorporate additional demographic data such as race, gender identity, socio-economic status and education level as these may reflect health disparities and influence perceptions of treatment. A thorough description of the participants and the setting is important to enable the reader to evaluate the transferability of the results. At the same time, we wanted to protect the identity of the patients, and therefore, kept the description restricted.

5. Conclusions

The study raised important issues regarding patients understanding of precision medicine and challenges concerning how to involve patients in medical decision-making. Although technical advances were viewed positively, the role of the physician as an expert and person-of-trust cannot be replaced.

Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

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CRediT authorship contribution statement

Grauman Åsa: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Software, Writing – original draft, Writing – review & editing. **De Padova Silvia:** Conceptualization, Data curation, Supervision, Writing – review & editing. **Meggiolaro Elena:** Data curation, Project administration, Writing – review & editing. **Martinelli Giovanni:** Conceptualization, Data curation, Funding acquisition, Supervision, Writing – review & editing. **Marconi Giovanni:** Writing – review & editing, Data curation, Investigation, Supervision. **Aakko Sofia:** Methodology, Project administration, Writing – review & editing. **Kihlbom Ulrik:** Conceptualization, Formal analysis, Funding acquisition, Supervision, Writing – review & editing. **Nier Samantha:** Conceptualization, Methodology, Writing–review & editing. **Zingaretti Chiara:** Data curation, Investigation, Writing–review & editing, Project administration. **Lang Katharina:** Methodology, Project administration, Writing – review & editing. **Heckman Caroline A.:** Conceptualization, Funding acquisition, Supervision, Writing – review & editing. **Bullinger Lars:** Conceptualization, Data curation, Funding acquisition, Supervision, Writing – review & editing. **Haller Karl:** Data curation, Formal analysis, Writing – review

& editing. **Simonetti Giorgia:** Project administration, Writing – review & editing, Conceptualization, Funding acquisition, Investigation. **Kontro Mika:** Conceptualization, Data curation, Funding acquisition, Methodology, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no competing interests.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.107883](https://doi.org/10.1016/j.pec.2023.107883).

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