




## PAPER

# Cancer patients' expectations when undergoing extensive molecular diagnostics—A qualitative study

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## Abstract

**Objective:** Precision cancer medicine (PCM) aims at identifying tumor-driving molecular characteristics to improve therapy. Despite early successes for some cancers, the approach faces manifold challenges. Patients undergoing extensive molecular diagnostics (MD) may hope for personal benefit, although chances are small. In order to offer suitable support to this group, health-care professionals need to gain insight into patients' experience. Thus, this study sought to explore the expectations of cancer patients undergoing MD of their tumor.

**Methods:** In two German Comprehensive Cancer Centers, 30 patients with advanced-stage cancer who had exhausted conventional treatment and had consented to extensive, research-oriented MD (whole-genome sequencing n = 24, panel sequencing n = 6) participated in semi-structured interviews. Following thematic content analysis by Kuckartz, the interview transcripts were coded for expectations of MD participation and topics closely related. Moreover, patients completed questionnaires on their sociodemographic characteristics, medical history, and psychosocial distress.

**Results:** Patients reported to be expecting (a) an improvement of their treatment, (b) a contribution to research, and/or (c) additional insight to their own cancer. Further, they described to feel individually appreciated and to have a reason to maintain hope for cure or recovery by participating in MD.

**Conclusions:** Molecular diagnostics participation led patients to feel treated in a more “personalized” way, allowing them a greater sense of control in their situation of severe illness. Oncologists and psycho-oncologists need to ensure comprehensive information and empathetic support for patients undergoing extensive MD to balance their expectations and actual chances of clinical benefit.

## KEYWORDS

cancer, oncology, hope, palliative care, precision medicine, psycho-oncology, qualitative research, whole-genome sequencing

Ute Goerling and Peter Herschbach are joint senior authors.

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## 1 | BACKGROUND

Precision cancer medicine (PCM) aims to identify tumor-driving molecular characteristics in individual cancers that further inform oncologists about promising or redundant therapies. It is based on molecular diagnostics (MD), delivering complete (eg, whole-genome sequencing) or selected (eg, panel sequencing) genomic tumor information. This may add to clinical and histopathological information, thus contributing to more personalized treatment recommendations<sup>1</sup>. Witnessing successful new treatments in a few types of cancer, researchers expand the use of PCM principles to inquire about further and more effective treatment options in other malignancies<sup>2</sup>. However, PCM's development faces diverse challenges<sup>1,3-9</sup>. So far, only a small percentage of patients participating eventually receives an effective therapy and shows clinical benefit, for example, 7% of patients successfully screened in a high-throughput genomic sequencing trial<sup>10</sup>. Yet many patients hope for a treatment that truly addresses them as an individual and allows for a last-minute rescue<sup>11</sup>.

While PCM's developing stage may be reasonable considering its young age<sup>8</sup>, it poses substantial challenges to patients and caregivers as well as oncologists' communication. For example, fostering patients' informed consent is particularly difficult in PCM whose outcomes and side effects are often less defined, blurring lines between clinical and research spheres<sup>12</sup>. Lay people like most patients may find it difficult to differentiate between studies offered to them for mostly scientific purpose and studies aiming at clinical patient benefit. Thus, hopes may be high—especially since participating patients usually have exhausted conventional therapies or lack therapy standards altogether<sup>12</sup>. Exaggerated hopes in PCM, however, may distort clinical consultations<sup>4</sup> and lead patients to start therapy even with a bad prognosis<sup>11</sup>. Moreover, whole-genome sequencing may deliver secondary germline findings, providing information on hereditary disease risks, potentially impacting patients and their families in additional ways.

Thus, psycho-oncology needs to ensure support for patients and caregivers undergoing comprehensive MD. For this, insight into their expectations of and experience with MD is crucial<sup>12,13</sup>. So far, corresponding patient self-reports are mostly of quantitative nature, spanning the spectrum of MD methods. Blanchette et al<sup>14</sup> found that most patients undergoing genomic testing of their tumor or a phase 1 clinical trial did so in the hope of the results guiding their further treatment selection. Roberts et al<sup>15</sup> showed that common motivations to participate in next-generation sequencing centered on personal treatment improvements, contributing to cancer research and gaining information on hereditary aspects. Moreover, patients expected to receive written reports of sequencing findings, to discuss these with their doctors, and to learn more about applicable clinical trials, the causes of their cancer, and hereditarily relevant gene changes. Surveying patients and caregivers regarding various types of next-generation sequencing in pediatric oncology, Marron et al<sup>16,17</sup> inquired about their hope versus expectation of a benefit to themselves or future patients, finding that participants hoped for a cure more than they expected it. Qualitative studies explored patients' expectations of panel sequencing programs

after result disclosure and confirmed key expectations to be the advance of science and a hope for cure<sup>18</sup> as well as avoiding ineffective treatment<sup>19</sup>. Gray et al<sup>20</sup> asked cancer patients about their hypothetical willingness to undergo varying types of genetic testing, also finding prolongation of life or personal curiosity as potential motivations.

While previous research has outlined patient expectations of various MD approaches, an in-depth exploration of patient expectations before result disclosure is still needed. This study therefore explored patient expectations from their own narratives and further illuminated topics emerging in this context while patients were still waiting to receive MD results.

## 2 | METHODS

### 2.1 | Study procedure

This qualitative pilot study took place from November 2017 to December 2018 in the Comprehensive Cancer Centers of Berlin and Munich, Germany. Patients were eligible to participate if they underwent whole-genome sequencing (n = 24) or extensive panel sequencing (n = 6) of their tumor but had not yet received its results, were at least 18 years of age, and spoke German fluently.

Inclusion criteria of either approach required participants to be diagnosed with advanced-stage cancer, having undergone the conventional therapies, and being rather young (≤50 y) or to have a very rare cancer lacking therapy standards. Both methods yielded large amounts of molecular information then to be searched for therapy indications by MD specialists. Accordingly, they both involved a standardized consenting process about participating in a research study that could potentially render results clinically relevant to the individual. Those patients obtaining whole-genome sequencing could further opt to receive secondary germline findings pertaining to disease predispositions relevant to themselves or their relatives. In case of such findings, genetic counseling would follow.

For this psycho-oncological study, eligible patients were approached consecutively. Depending on the hospital, data collection took place before or after tumor biopsy. After written informed consent was given, participants gave information on their current level of distress via the "Questionnaire on Stress in Cancer Patients revised version" (QSC-R23)<sup>21</sup>. This includes 23 items of five subscales relating to potentially distressing experiences around cancer: psychosomatic complaints, fears, information deficits, everyday life restrictions, and social strains. For each item, individuals may check one of six possible answers (0 = "the problem does not apply to me," 5 = "the problem does apply and causes severe distress"). A sum score higher than 34 indicates an increased level of distress and potential psychosocial support needs<sup>22</sup>. Then, participants provided sociodemographic data such as their marital status and level of education as well as medical information on their current diagnosis and prior cancer treatment. Finally, a member of the study team conducted a face-to-face semi-structured interview, lasting approximately 20 minutes. The interview guide was developed with expertise from the medical and psycho-oncological field, pilot tested,

and adjusted thrice within the first five interviews. Its questions centered on the patients' perception of their knowledgeability, a visual analog scale of how informed they felt (0 = "no information," 10 = "very good information"), and their expectations and experiences surrounding MD (for interview guide see File S1). The interviews were audio-taped and transcribed verbatim, anonymizing personal information.

The study received ethical approval (Berlin: EA1/137/17, Munich: 533/17 S, 17-873) and positive data protection votes (Berlin: 473/17/ST3, Munich: verification by data protection official).

## 2.2 | Data analyses

Basic descriptive statistics were applied to the sociodemographic and medical information as well as the QSC-R23 data using IBM SPSS Statistics 25<sup>23</sup>.

The thematic content analysis following Kuckartz<sup>24</sup> offered a reliable structure to the analysis of the interview transcripts. With the application of its deductive-inductive approach, the transcripts were searched for passages referring to patients' expectations regarding MD. With the use of MAXQDA<sup>25</sup> 2018, they were coded, and codes of similar content were summarized to form subcategories. These subcategories in turn were grouped according to content, forming main categories. In a process of continuous reflection, methodological and medical experts revised this system of main and subcategories multiple times, verifying and refining the results (for final code system, see File S2).

## 3 | RESULTS

### 3.1 | Sample characteristics

The study team approached 33 patients of which three declined participation. In total, 30 patients participated (male = 16, female = 14), 15 from each hospital. The mean age was 46 years (SD = 11.2 y, range = 26-77 y), and median time from initial diagnosis was 28 months (SD = 45.5 mo, range = 0-160 mo; median = 9 mo) (for sample details, see File S3). On the QSC-R23, the participants showed a mean sum score of 32.9 (SD = 14.2), with 15 participants scoring above 34, indicating considerably heightened distress (for QSC-R23 details, see File S4).

### 3.2 | Expectations of MD participation

#### 3.2.1 | Improving treatment

Patients talked about finding additional treatment options as a key expectation when participating in MD. Many anticipated that the results derived would possibly allow their physicians to treat them more effectively. For example, a woman felt that

(...) it's a good opportunity that something can be extracted at all and that finally a look is taken at what helps AT ALL and not just any random chemo is squeezed in, hit or miss. (IP1)

For many, this expectation of a personal benefit was an important foundation for their participation:

I just hope for myself that in the end something good will come forth for me ... If I wasn't [hoping, author's note] that then I wouldn't want to participate either. Then I wouldn't need to do this to myself now, getting another puncture done. (IP2)

Some patients reflected on how prior therapies had failed to treat their cancer sufficiently. Searching for additional treatment options via genomic profiling seemed to be their last resort. A woman currently undergoing cancer treatment for several years explained:

Well the REALLY personal expectation is ... that ... something will be found that ... basically helps me. So that [the cancer] doesn't only ... stagnate but that maybe they also find something where it goes back or goes away. Right? So that not just a scarring takes place but that this tumor tissue is really ... maybe at one point ... COMPLETELY gone. (IP3)

Others expressed confidence that their current therapy would be successful and saw potential MD results as a backup plan. As one patient put it:

If the [doctors] then tell me: "Well, the chemo didn't wipe out everything" or half a year later I learn that now there is something again that ... makes you sick then ... maybe I can be happy that this study ... researched something for ME ... , also for me personally which perhaps then can be applied. (IP2)

#### 3.2.2 | Serving research

Serving research with their MD participation and, thus, future patients with similar cancers was another major expectation:

My expectation of such studies actually is that a benefit can be derived from it to potentially help other people who are in the same situation as I am and to advance in cancer research ... , so that in the future maybe it can simply be treated like a flu. (IP4)

Several patients mentioned that they liked to participate in studies like these, which they felt did not cost them much yet potentially helped others. In this sense, a patient stated that "*since I'm in medicine myself, wherever there is something new to be researched I say I'm in, no problem*" (IP5).

Especially for some who did not expect much personal benefit from the MD, contributing to scientific progress and effective therapies against cancer was an important motivation to partake:

Well, what I wanted to know I know and ... that this chance is slim of course that ... now a little magic cure for ME will be designed, of course that is very slim. But mostly one can assume to be helping research. And with the tissue extracts to maybe also be helping other people. (IP6)

### 3.2.3 | Learning more about the personal tumor

In addition, the participants voiced questions about their cancer that they hoped the profiling results might answer. For example, a woman described how the cancer had developed because her immune system was not able to fight the mutated cells. She continued to explain that *"for me it is nice to now know what that might be due to. Just because then you know it, right? Because sometimes you think you somehow did something wrong in life"* (IP7).

Another patient pondered *"why the [cancer] is so aggressive"* (IP6) and a different patient felt *"The secret will be lifted now. The secret how these metastases, how the cells work. Because that's something that has remained in the dark so far"* (IP8). Furthermore, a patient hoped to learn more about *"whether that is an innate genetic defect, where for my children, where I have to protect them or test them"* (IP9).

### 3.2.4 | Adverse expectations

Most participants declined feelings of skepticism towards MD and reported no downsides to participating. However, some had open questions regarding the processes to follow, viewed the extra time spent in hospital for the tumor biopsy as a considerable cost, or mentioned concerns about hereditarily relevant findings. One woman referred to potential concerns of data protection, putting them into perspective for herself:

For me the hope is greater to then derive a benefit, a personal benefit from it than actually the fear that anything might happen to it which is not supposed to. Basically, I still have great trust in our regulations that we have in Germany. Well, so that I think, well, I think the risk is negligible and the potential benefit for me would be greater. (IP10)

## 3.3 | Impact of MD participation

### 3.3.1 | Maintaining hope

Many patients talked about the extent to which MD participation allowed them to keep up their hope for a cure or prolongation of life. Patients' accounts differed in how strongly they expected any personal benefit from participating in MD. While some appeared confident to gain valuable insight, others were hesitant to speak of expectations at all:

My expectations I don't have. There is a remaining spark of hope that through it something comes forth

that maybe can change my treatment approach again or improve it. But that is not an expectation but rather ... we'll see. (IP10)

Even if their hope for an effective treatment was extremely small, it seemed crucial nonetheless, allowing a different outlook on things. A patient recalled how his doctor had told him that

(...) the study would be an opportunity to maybe at least have another try. To not be completely "beyond treatment." That was a nice feeling to know something is still possible. There is another arrow in the quiver. [...] Of course that is also what it's always about. That there's still a look ahead. That is of course ... , makes it much ... more bearable ... right now. (IP8)

Similarly, another patient mentioned that receiving new treatment options through this program was *"probably more the desire, well, that he found something that maybe does still work AFTER ALL. Because actually I can't warm to the 'incurable' at all"* (IP1). Along these lines, a patient described how he knew that

of course the chances are ... so slim. Of course [finding an effective treatment] is the heart's desire. Actually it is almost not possible anymore to have a full cure of the disease again at some point ... . Well, hope dies last. (IP6)

### 3.3.2 | Feeling individually appreciated

The patients also expressed to feel treated more individually because of participating in the program. As one patient put it:

And that's done only for ME. Of course I think that's great. Great, right? That someone takes the trouble or a group of people that looks at only my chunk and tries to see: where does it come from? What kind of error in the system is that? (IP7)

Moreover, some participants perceived the opportunity to participate in MD as a privilege:

In the beginning, [the doctor] told me she would request that. And it is an expensive affair and that's why not EVERY cancer patient will be able to make use of it or will be allowed to participate. Therefore, it's a bit of a little honor ... in all these difficult times. (IP2)

Another patient described how it was meaningful to him *"that [the tumor material] isn't just thrown away or burnt and then nobody cares about it anymore but rather it's looked at"* (IP11) because of his participation in the program.

While patient reports centered on the three expectations of MD, the two impacts of MD participation emerged throughout the interviews as displayed in Figure 1.

## 4 | DISCUSSION

This study illuminates cancer patients' narratives regarding their expectations and experience undergoing MD of their tumor before receiving the results, revealing expectations compatible with prior studies' findings<sup>14-20</sup>. Thus, patient expectations seem to remain rather stable throughout the MD process. In this, patients' interest to learn more about their tumor, regardless of an immediate impact on their treatment, aligns with a well-researched information need exhibited by people in general and cancer patients in particular<sup>26</sup>. According to the transactional model of stress and coping, gaining information is a vital coping mechanism in threatening situations to help reduce distress<sup>27</sup>. As most patients will experience an advanced-stage cancer as a threat and at least half of this study's participants showed heightened distress, this coping mechanism may likely have manifested in the participants, too.

A few patients hoped whereas others were concerned of potentially receiving hereditarily relevant information. This corresponds with advanced-stage cancer patients associating both benefits and harms with secondary germline findings<sup>28</sup>. Overall, however, the topic was less prominent in the interviews than were the other expectations and impacts of MD.

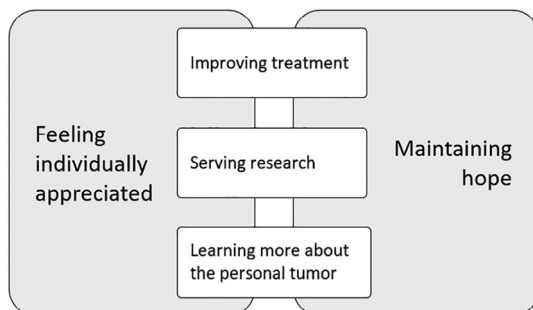
That most participants did not report negative expectations around MD seems plausible since patients with severe concerns probably would not participate in MD altogether. For those who did participate, potential strains may have felt insignificant in light of life-limiting illness. In this regard, the theory of cognitive dissonance suggests that having decided to participate in MD leads people to justify their decision from now on and, eg, reframe information that could be held against it<sup>29</sup>. Although patients report little regret of participation despite mostly unmet expectations<sup>15</sup>, participation may have caused distress and support needs nonetheless. Looking at their QSC-R23 scores, guidelines would suggest psycho-oncological support for half of this study's participants<sup>22</sup>. As the questionnaire's items mostly relate to overarching topics of having cancer, they give an impression of the participants' general psychosocial well-being rather than a

measure pertaining to distress specifically associated with MD participation. Psychological strain caused by MD would then add to the already existing distress associated with advanced-stage cancer and, therefore, should receive further attention from researchers and clinicians.

Aside from their expectations, participation in MD resulted in two emotional benefits for patients. Firstly, it led patients to maintain some degree of hope for a prolonged life or recovery. Their hope rested in the approach representing science's latest breakthrough. Del Vecchio Good et al<sup>30</sup> point out how specialized research oncology "both depends on and promotes a vision of cancer as curable" (p. 60). For patients with highly advanced cancers participating in MD, this vision may not meet reality. Although some reflected upon the unlikelihood of personal medical benefit from their participation, being offered professional support in doing so would be desirable.

While patients differed as to how strongly they anticipated a specific outcome, they generally expressed that participating made them feel special and more individually "seen." This impact already showed at the time of the interview—before patients knew any of the profiling results. Some had not even undergone tumor biopsy yet. Thus, patients may feel treated in a more "personalized" way simply by receiving MD. Perhaps, this highlights the frequent lack of time and individual attention in general cancer treatments these days<sup>13</sup>. Also, it aligns with patients and caregivers seeking health-care professionals' interest in their individual case, accuracy in treatment, and dependability, hoping to "be in good hands."<sup>31,32</sup> However, this emotional benefit may be fragile if overly based on MD breaking a case down to genetic details<sup>11</sup>.

Overall, the outlook to contribute to any of the anticipated outcomes potentially strengthened patients' sense of control. Patients with advanced-stage cancer often find themselves in situations dictated by the disease, treatments, and hospital structures. Here, potentially advancing one's or other's therapies may provide an opportunity to feel meaningful. Especially participants who held little hope for their own recovery seemed to aim at feeling effective, eg, by hoping to help future patients. Bijlsma et al<sup>33</sup> found that patients were interested in receiving unsolicited hereditary genetic information after next-generation sequencing to prepare themselves and others for the future, strengthening their sense of control, too. Similarly, health-care professionals pointed out general patient and caregiver strivings to regain a sense of control<sup>34</sup>.



**FIGURE 1** Cancer patients' expectations and the impact of participation in molecular diagnostic (MD)

### 4.1 | Study limitations and future research

This qualitative study aimed to explore a research gap rather than to quantify the frequency or intensity of single expectations. Thus, its results illustrate a variety of patient expectations rather than providing a database for extrapolation to cancer patient populations. The results stem from a comparatively well-educated and young sample, lacking perspectives of other patient groups, including those not consenting to MD. Further, patients participating from two different MD methods may limit result interpretation. Yet MD specialists rated the programs comparable in overall patient perception, and no differences

became apparent in the participants' interview responses. During data collection in the hospital, in a few cases, other patients, staff, or caregivers were in the room, and the interviewers wore white coats like doctors. However, patients' references to private topics gave the impression that they felt able to share openly regardless of these circumstances. That the questionnaires were administered before the interview and with the interviewer present did not seem to impact responses, nor whether data collection took place before or after the tumor biopsy. While some patients did and others seemed not to distinguish between hopes and expectations regarding MD, the interviews did not provide room for detailed differentiation. Future studies would deepen understanding by inquiring about details of the MD consenting process; patients' prior experience with clinical trials; and their caregivers', children's, and physicians' perspectives. Hereby, psycho-oncology would contribute further insight into psychosocial aspects surrounding the growing field of PCM, revealing support needs and implications for health-care professionals' communication.

## 4.2 | Clinical implications

Oncologists and psycho-oncologists should work together in inquiring about individual patients' hopes and expectations. In an empathetic way, patients need to receive information about how likely these are to be met. Otherwise, they may be particularly disappointed over MD outcomes that perhaps do not expand their—usually limited—therapeutic options. Facing a severe cancer diagnosis, these patients should be prepared early on that tumor-specific therapies may soon not be appropriate anymore, leading to a focus on palliative care and symptom control. Proactive support from both oncologists and psycho-oncologists may enable patients to still feel “seen” in their medical as well as personal individuality and find hope in realistic goals. This would truly constitute personalized, engaging treatment.

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## CONFLICT OF INTEREST

None to declare.

## DATA AVAILABILITY STATEMENT

The data supporting this study's findings are available from the corresponding author upon reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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