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Challenges in self-management of persons living with advanced cancer: An exploratory, in-depth interview study

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Abstract

Objective: To obtain insight in self-management challenges of persons with advanced cancer and factors that influence their self-management.

Methods: Exploratory study among persons with advanced cancer. We conducted in-depth interviews and performed an inductive thematic analysis, using open, axial and selective coding.

Results: We interviewed 33 persons with advanced cancer. Four self-management challenges were identified: (1) Dealing with physical and psychological symptoms and problems. (2) Navigating the illness trajectory, including management of clinical appointments and treatment regimens, end-of-life planning life and 'maintaining normality'. (3) Managing relations with healthcare professionals, including contributing experiential knowledge to medical decision-making. (4) Navigating changes in the social environment. Some participants responded proactively to these challenges, for example, by actively searching for information to obtain an extensive understanding of their illness and (re)scheduling medical appointments for a better fit in their agenda. Self-management strategies seemed to be influenced by patients' personality, life history, moment in the illness trajectory and the social environment.

Conclusion: Self-management challenges of persons with advanced cancer are based largely outside the professional care setting. Self-management strategies in response to these challenges are typically aimed at maintaining a normal life. Self-management support should be tailored to patients' needs and part of trustful partnerships with patients and relatives.

KEYWORDS
care paths, oncology, palliative care, qualitative research, self-care, self-management

1 | INTRODUCTION

Patients with advanced cancer experience physical, emotional and psychosocial symptoms and concerns due to their disease, treatments and prognosis (Greer et al., 2020), impairing their quality of life (Higginson & Costantini, 2008). Although usually many healthcare providers are involved in their medical care, most of the time, patients, together with their relatives, need to manage a huge

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part of their care and lives themselves. This can be highly complex. Self-management in this context has been defined as 'the strategies used by persons with the aim of managing the physical, psychosocial and existential consequences of living with a progressive, life-threatening disease and its treatment' (Rietjens et al., 2018).

Three reviews have summarised quantitative and qualitative studies addressing self-management strategies and self-management support of patients with advanced cancer (Budhwani et al., 2019; Johnston et al., 2009; van Dongen et al., 2020). The first is a systematic review of 18 studies conducted by Johnston et al. (2009), addressing self-care and end-of-life care in advanced cancer (Johnston et al., 2009). A decade later, Budhwani et al. (2019) conducted a scoping review on self-management, self-management support needs and interventions for patients with advanced cancer, including 55 studies (Budhwani et al., 2019). The most recent one, conducted by van Dongen et al., 2020, is a systematic review including 31 studies describing self-management strategies and attitudes of patients with advanced cancer (van Dongen et al., 2020). These reviews show that patients with advanced cancer engage in multiple self-management behaviours in many domains such as medicine and pharmacology, lifestyle, mental health, social support, knowledge and information, navigation and coordination and medical decision-making (Budhwani et al., 2019; Johnston et al., 2009; van Dongen et al., 2020). Furthermore, patients with advanced cancer have a wide variety of self-management support needs relating to the management of physical symptoms and its complex treatment regimens and dealing with psychosocial issues and uncertainty (Budhwani et al., 2019).

Most studies on self-management behaviours of patients with advanced cancer describe particular aspects of what people do, rather than their lived experience and day-to-day challenges in self-management. This makes it difficult to ascertain how self-management needs of patients with advanced cancer can best be supported. In addition, in-depth insight into *why* persons self-manage their illness as they do is relevant, as this could help to elucidate which patient groups experience difficulties in self-management or need support. The van Dongen review concludes that more in-depth exploration of such factors is needed. In this review, only six quantitative studies provide some explorative, partially conflicting evidence suggesting that age, level of physical functioning and education might be associated with certain self-management behaviours (van Dongen et al., 2020).

To gain in-depth insight in patients' day-to-day self-management challenges and factors influencing their self-management, qualitative research is particularly suitable as it primarily focuses on understanding and interpretations, rather than quantification of patients' beliefs, emotions, behaviours and interactions in daily life (Green & Thorogood, 2018). Therefore, in this qualitative study, we aim to (1) explore the challenges that persons with advanced cancer are confronted with in self-management of their illness and their strategies to deal with these challenges and (2) examine the possible factors influencing self-management.

BOX 1 Interview guide used in conducting the interviews

1. Can you tell me something about yourself and your situation?
2. What consequences does the illness have on your life?
3. What helps you to deal with the consequences you described?
4. Which of the consequences bothers you most?
5. What could help you to better manage your illness and its consequences?

2 | METHODS

2.1 | Study design

As little was known about this topic, we conducted an exploratory study with in-depth interviews among persons living with advanced cancer, to produce an in-depth understanding of the challenges of they experience in self-managing their illness.

2.2 | Study sample

Participants were eligible when they were 18 years or older, were diagnosed with advanced cancer (any type) and were able to provide written consent. Advanced cancer was defined as cancer that can no longer be cured (Kim et al., 2016). We recruited participants purposively to include a diverse group with people from different cultures and educational levels. Oncologists, general practitioners and nurses from one academic hospital, one general hospital and two hospice care facilities asked eligible participants whether they were interested in participating in the study. Calls for participation were circulated via websites of a patient organisation, the main research and social media platforms. We contacted potential participants by phone and sent them extra information by postal mail. They signed informed consent to participate prior to the interview. We conducted interviews at a location of the participant's choice (mostly at their homes). Participants who needed to travel received reimbursement for their travel expenses. Interviews were conducted until no new information arose from the interviews. The research ethics committee of the main institution granted approval of the study.

2.3 | Data collection

We developed an interview guide prior to starting the interviews, partly based on our systematic review on self-management experiences of patients with advanced cancer (Box 1) (van Dongen et al., 2020). Interviews were conducted between September 2018 and July 2019. The interviewers took field notes. One interview was conducted and analysed in Turkish by a Turkish speaking member of the research team. After the interviews, participants completed a questionnaire on demographic characteristics (e.g., type of cancer, year of diagnosis and current treatment). Interviews were audiotaped and transcribed.

2.4 | Data analysis

We performed an inductive thematic analysis, using open, axial and selective coding (Strauss & Corbin, 1990), supported by NVivo 12 pro. HN (anthropologist) and RS (psychologist) read five of the transcripts and identified initial themes (open coding), which were discussed with members of the research team, with backgrounds in nursing, psychology, oncology, social sciences, epidemiology and health sciences; some team members have clinical experience and patient experience as well. The open codes were organised into an initial coding tree, by going back and forth through the themes and the transcripts, using the constant comparative method (axial coding). The initial coding tree was tested by HN and RS on another five transcripts; the codes were discussed with the larger team, and the coding tree was adjusted accordingly. Subsequently, all transcripts were coded with the final coding tree by HN and RS. Members of the research team (HN, RS, SD, NL, MA, LK, EW, CR, AH and JR) met several times to refine the initial themes and subthemes, by discussing the coded transcripts, themes and subthemes, and each theme in relation to the other themes. After 33 interviews, thematic saturation, which was defined as little or no changes made to the codes, was reached in all covered research areas (Green & Thorogood, 2018), and the findings were organised according to the main themes (selective coding).

Qualitative rigour of the study was enhanced by stimulating confirmability and reflexivity in regular meetings of the research team, discussing interviewers' and researchers' potential biases regarding the study topic. In addition, the interviewers kept a diary that stimulated them to reflect on the content as well as their own emotions during the interviews. Analytical rigour was enhanced by dual coding and exploration of divergent views during the analyses. Credibility was further enhanced through investigator triangulation, where a broad team of researchers was involved in the coding and interpretation of the data.

TABLE 1 Characteristics of patients enrolled

	Patients ($n = 33$) *n* (%)
Gender	
Male	16 (49%)
Female	17 (52%)
Age	
18–40 years	1 (3%)
41–60 years	9 (27%)
61–80 years	21 (64%)
>80 years	2 (6%)
Nationality	
Dutch[a]	32 (97%)
Other	1 (3%)
Education	
Less than high school	2 (6%)
High school graduate	14 (42%)
Some college	6 (18%)
College graduate	5 (15%)
University	6 (18%)
Living situation	
At home	30 (91%)
Healthcare institution	2 (6%)
Other	1 (3%)
Marital status	
Married/living together	25 (76%)
Not married	5 (15%)
Divorced	2 (6%)
Widowed	1 (3%)
Children	23 (70%)
Of which living at home	6 (18%)
Religious (yes)	12 (36%)
Type of cancer	
Colon	7 (21%)
Lung	3 (9%)
Breast	13 (39%)
Prostate	3 (9%)
Other[b]	7 (21%)

[a] One patient had a Moroccan background, and one patient had a Surinam background.

[b] Other cancer types were liver, peritoneal, penile, cervix, oesophagus, melanoma and ovary.

3 | RESULTS

We interviewed 33 participants. Interviews lasted an average of 50 minutes (SD 14 minutes). Seventeen (52%) participants were female (Table 1). The age of participants ranged from 33 to 85 years. Thirty-two participants (97%) had the Dutch nationality, of whom one had a Moroccan background and one a Surinam background. One participant had the Turkish nationality. Most participants resided at home (91%) together with a partner (76%). Most participants had a high school degree or higher (93%). Eighteen participants were recruited in the general hospital, 11 in the academic hospital, two in the hospice, one through social media and one through the website of a patient association.

The results are described in two parts. In part I, we describe four self-management challenges of persons living with advanced cancer and their self-management strategies. In part II, we describe the factors influencing self-management.

3.1 | Part I—Self-management challenges

3.1.1 | Dealing with physical and psychological symptoms and problems

Participants indicated that living with advanced cancer posed extensive physical and psychological challenges to which they responded with a variety of behaviours. Many actively engaged in maintaining a healthy lifestyle, such as staying physically active and maintaining a healthy diet. It gave them the feeling to be 'in charge' of their health. Participants often mentioned to manage physical and psychological discomfort by walking.

> If I want to take a break from it all, I put on my good boots […] and I will go out into the polder […] fantastic right? Into the forest. Alone. I think that is the best psychiatrist there is. P012, male, 73, prostate cancer

Besides, several psychological strategies were identified as well. Some sought help from a psychologist to support them with the emotional burden of their illness, while others did not. Sometimes, they used cognitive strategies, such as trying to ignore, nuance or actively deal with negative thoughts. Others described behavioural strategies, for instance, seeking distraction by practicing hobbies or writing down different scenarios about how their illness might progress.

> Usually, I use my notebook to come up with a couple of scenarios, ranging from bad to less bad, and then I can read that back. That is my way of managing everything, to get it out of my head […] It is about all the things that come to mind, doom scenarios, but also hope I cherish. P034, male, 58, lung cancer

3.1.2 | Navigating the illness trajectory

Participants explained they were not always able to continue their usual activities the way they were used to. They sometimes had to plan ahead: distribute their activities over the day, find substitute activities and define moments of rest, for instance, by cooking for multiple days or clustering household activities. Most of them reported wanting to live 'as normally as possible', and their medical management sometimes threatened this goal. Many participants valued a daytime routine, to try and live their lives as normally as possible, for instance, by continuing their hobbies and usual activities.

> I want to live as if everything is just right […] I want to be normal […]. Your life continues and you want to live a normal life. P007, female, 33, breast cancer

Many participants found that the medical system was sometimes difficult to navigate through. Some had difficulties planning their medical care. They needed to check and adhere to often difficult medication schemes, and this largely dictated their agendas. Many participants indicated they had to take charge of their clinical appointments, as these were not always well coordinated or did not fit in their personal agenda.

> It is complicated, […] You have an appointment here, another appointment there, another appointment, and another one, you will be in the hospital 100.000 times. P015, female, 68, cervical cancer

Planning for the end of life was mentioned by several interviewees as being important. This ranged from talking with their loved ones about their approaching death and participating in advance care planning conversations with a healthcare professional, to arranging practical matters, such as finances, mortgages and buying a grave.

3.1.3 | Managing relations with healthcare professionals

Many participants explained that they increasingly needed to collaborate with a variety of healthcare professionals, which was often challenging. Besides, they sometimes struggled with finding information about the disease or treatment. Many indicated wanting to have a good and reciprocal relationship with their healthcare professionals and tried to consciously invest in this. Such a relationship provided a trustworthy environment for the discussion of preferences for medical care and treatment. Several participants stressed the importance of contributing their own experiential knowledge to the decision-making. Some noticed that not all healthcare professionals were fully aware of the impact of their illness and their treatment on their daily life and that they had to actively bring this up.

> I know a lot about it; therefore, I can challenge the doctor. If he says something, I will tell him 'that is not how it works' […] I am no doctor, do not have that expertise […], but I am an expert by experience. I do not know everything, but I do know what the medication is doing with my body. P021, female, 63, breast cancer

Most interviewees reported that they were satisfied about the collaboration with their healthcare professionals and the care they received. Yet some others indicated they had to deal with conflicts with a healthcare professional, for instance, due to different opinions about treatment.

Participants used their healthcare professional as their main source of information. For some, this was sufficient. Others were proactive and keen on finding the best possible information and treatments themselves and used the internet to find more information although many pointed to possible incorrect information on the internet or a focus on negative consequences of their illness. Some interviewees indicated they wanted more information about their illness or (alternative) treatments:

> I think that [information about the illness] is highly interesting […]. Scientifically, I have a very broad interest [in my illness] despite the fact that this affects me. P003, male, 65, prostate cancer

3.1.4 | Managing the social environment and social support

Many participants described challenges in dealing with the changes in their social environment as a result of their illness. Some reported, for instance, that they had less energy for maintaining their friendships. Some others described that they were sometimes approached differently by others, received unwanted advice or intrusive or inappropriate comments (e.g., 'Hey, are you still here?'). As a result, they had to relate differently to their social environment.

The social environment was often leveraged as a source of support. This sometimes served a practical goal (e.g., helping with household activities and going to clinical appointments) and often a psychological goal. Many interviewees mentioned that talking with friends gave them some relief. Patients did not only receive support but sometimes also searched for ways to provide support to fellow patients. This could include participation in a peer support group, volunteering in a patient association or being active on social media. Patients were often grateful if they were able to help someone else.

> When I speak to a fellow patient and I am able to give some advice or support, that gives me a lot of satisfaction. P019, female, 58, lung cancer

However, not everyone was interested in peer support groups. Some interviewees indicated that talking about their illness would probably only made them feel down.

3.2 | Part II—Why do persons living with advanced cancer self-manage the way they do?

When asked, participants were often unaware of *why* they dealt with their illness the way they did. They described their self-management strategies as being 'normal' to them. However, from the analysis, four factors emerged that affect self-management: personality, life history, the moment in the illness trajectory and the social environment.

3.2.1 | Personality

Some participants explained that the way they dealt with their illness was rooted in their personality. Often heard phrases were 'That is just how I am' and 'I have always dealt with things this way'.

> I do not know; it is just who I am. And everybody says I am managing so well and I am so strong. Well, it is not something I have to work for, I think it is just in my nature. P006, male, 57, peritoneal cancer

Many interviewees described themselves as being assertive. They described that this helped them to protect their boundaries, to stay in charge of their own health and to discuss concerns and disagreements with healthcare professionals. Other important personality characteristics, according to participants, were to stay realistic, put things in perspective, be flexible and have a practical mindset without getting carried away by emotions. Also, a positive outlook was important for many.

> I am more conscious about it [about being positive]. I was not necessarily negative […], I always danced through life actually. […] But now I think it [positivity] is actually a survival strategy. I think if you can be positive and are not always grumbling, you can get very far. P017, female, 58, breast cancer

However, some interviewees indicated that their personality affected their self-management in a more negative way. One of them, for instance, described that she always tends to say 'yes' when people ask her for help, which makes her cross her boundaries often, leaving her fatigued and saddened that she cannot do the things she used to do.

3.2.2 | Life history

Self-management strategies were also associated with life experiences, such as previous experiences with cancer in the family or among friends. Some were strengthened by having witnessed these previous experiences, because people may have survived cancer or were able to cope with the illness in a positive way. Other interviewees described more negative experiences. They articulated how they saw others managing illness poorly and stated that they wanted to do better themselves. Some of the interviewees were healthcare professionals themselves. They described that their professional experiences had helped them in managing their own disease. Some mentioned that they were sometimes approached as a healthcare professional, while they preferred to be approached as a patient.

> I am a general practitioner by training, [..] so I am very stubborn in wanting to do things myself […] A negative

> side is that I have easy access to the medical literature, which means that you sometimes realise things are not as positive as you initially thought […] Another negative side is in the contact with medical specialist, because they will often say 'you understand this, right?'. P014, male, 59, colon cancer

3.2.3 | Moment in the illness trajectory

Participants often described similar patterns of responding to their illness throughout the illness trajectory. Shortly after the diagnosis of advanced cancer, many arranged practical matters to seek a feeling of control. Examples are arranging their finances and drafting an advance care directive. However, as the illness progresses, patients seemed to focus more on the integration of their illness into a normal, daily life.

> You really have a life before and after your diagnosis, that is really true […]. In the beginning you are changing everything. The moment you hear it, you will drop everything, then slowly you will rebuild everything. P011, female, 50, breast cancer

3.2.4 | Social environment

Apart from being a source of support itself, participants described that the social environment (such as family, friends and colleagues) also affected *how* they self-managed their disease and its consequences. For some, their social environment was a motivation to try to manage their illness as actively as possible. Some said their family and friends were worth living for or motivated them to engage in certain self-management behaviours:

> There are enough people in our lives, friends, who are worth living for, they are sweet and kind and nice. P001, male, 69, lung cancer

Some participants described that the practical social support they received sometimes meant that they had to do less themselves, which was considered positive by some:

> It is actually very relaxed, because you do not have to do anything anymore, because nobody is expecting it from you. So it does have something very easy, everybody is very eager to help and support you, because they feel sorry for you. P011, female, 50, breast cancer

4 | DISCUSSION

Our study reveals the full width of the 'work' that persons with advanced cancer are faced with, in the medical, psychosocial, existential and daily living domains. We found that particularly challenging aspects of living with advanced cancer are having to deal with physical and psychological symptoms and problems, navigating the illness trajectory, managing relationships with healthcare professionals and managing the social environment and social support. Comparable domains are found for chronic disease patients, but within each domain, self-management strategies seem to be more divergent and ambivalent, and therefore potentially more challenging, for patients with advanced cancer (van Dongen et al., 2020). Patients' self-management strategies were diverse and appeared to be influenced by their personality, their life history, the moment in the illness trajectory and their social environment. Our study shows that persons living with advanced cancer deal with the consequences of their illness in various, personal and often creative ways. Their self-management strategies seemed to be rooted in their personality and previous life experiences: patients indicated to always have dealt with challenges in a certain way, learned this along the way or recognised the need to deal with the consequences of their illness in response to personal experiences. A subgroup of patients adopted proactive and articulate self-management behaviours: They actively searched for information to obtain an extensive understanding of their illness, orientated on the best possible treatments and (re)scheduled their medical appointments for a better fit in their personal agenda. This group has previously been referred to as 'e-patients': patients who are 'equipped, enabled, empowered and engaged in their health and health care decisions' (deBronkart, 2013). It may not always be easy for clinicians to relate to e-patients, as their behaviour may challenge them to adopt less traditional roles in clinician–patient partnerships (Kaba & Sooriakumaran, 2007; van Dongen et al., 2022). For instance, research has shown that many healthcare professionals underestimate the benefits and overestimate the risks of online health resources for patients and that many patients are hesitant to share internet-based information with their healthcare professional (Eysenbach, 2003). This lack of openness could harm patient–professional communication and their relationship.

A recurrent finding in our study is that self-management strategies are typically aimed at maintaining normality. Many participants explained that they tried to continue the hobbies and usual activities they engaged in before they became ill. However, as the illness progresses, many seemed to focus more on the integration of their illness into a normal, daily life. Interestingly, the desire for maintaining normality seems to be contrary to the common notion that people want to draft and complete a bucket list, to 'get the most out of their remaining live', and plan, for example, on accomplishing personal goals (Periyakoil et al., 2018). For several participants, living a normal life was threatened by the medical management of their disease which sometimes largely dictated their agenda. For instance, scheduling and attending hospital visits and taking the right medicines at the right time sometimes impaired their normal and usual daily living activities. This is also apparent in other studies (Daveson et al., 2014; May, 2006; Walsh et al., 2011). Corbin and Strauss (1985) postulated that chronic illness involves medical work, daily life work and biographical work. Being overwhelmed by the medical work might mean that there is less time and energy to be spent on daily life work and biographical work, including family gatherings, placing the illness in ones' biographical context and meaning making of ones' situation. May et al. (2009) called for *minimally disruptive medicine* as a response to the work that is delegated to patients and families. Critically, this involves respecting patients for what they do, as well as for who they are. In their Burden of Treatment Theory, they suggest that by redesigning healthcare services so that they are better coordinated, more patient-centred and acknowledging patient complexity, patients could be better equipped to handle their health problems (May et al., 2014).

This study has some limitations. First, it might be possible that participants with a special interest in the topic, with particular negative or positive experiences towards the care they received, or who were still functioning relatively well, were overrepresented, thereby giving a somewhat biased picture. This overrepresentation also holds for persons who were married or living together and persons with breast cancer. Furthermore, although we purposively included a relatively large group of participants from a variety of backgrounds, it was difficult to recruit persons from varying cultural backgrounds. This should be considered in future research. Lastly, our open inclusion criterion of advanced cancer (cancer that can no longer be cured) may have resulted in a relatively heterogeneous sample of patients, as it is known that the life expectancy of patients with advanced cancer varies, potentially impacting experienced challenges in self-management. Although thematic saturation was reached in all covered research areas, the generalisability of the themes should be considered with caution.

4.1 | Implications for clinical practice

Our study shows that self-management of persons with advanced cancer largely takes place beyond the classical professional care setting. The consequence is that the experience of illness and the changes it brings to patients' lives often remain unacknowledged by healthcare professionals, while patients' self-management nevertheless affects the care and treatment within the medical setting (Carel, 2012). Healthcare professionals need to relate and respond to the large diversity of self-management strategies they encounter, for instance, when patients engage in alternative treatments. Moreover, they have the opportunity to support patients in their self-management. Our study provides several insights that they can leverage. First of all, the initiation of open conversations with patients and their relatives is crucial to broach their experiential knowledge of their illness and to identify what consequences of the disease and its treatment patients are faced with, how proactive they are and what self-management support needs they have. Healthcare professionals could adjust their own style of guidance accordingly. Second, discussing to what extent patients attach importance to ‘maintaining normality’ is important, including exploring what normality means, and how medical care and treatment could be provided in such a way that it is minimally disruptive to patients' lives (May et al., 2009). Here, timing is crucial: Right after the diagnosis of advanced cancer, many persons tend to focus on emotional and practical matters, but as illness progresses, they focus more on the integration of their illness into a normal, daily life. Third, we recommend that healthcare professionals (for instance, a nurse or nurse practitioner; van Hooft et al., 2015) map, together with the patient, patients' self-management palette. What self-management behaviours does a person use commonly, now and in the past? Could he or she leverage these successfully in other domains? What is the role of the family in supporting the patient's self-management? And can a patient, within certain domains, develop new self-management behaviours?

Our findings also suggest that peers could support patient self-management, individually, through social media, or through peer support self-management groups. In our study, not all, but some participants were interested in giving or receiving peer support. As clinical services are unlikely to meet all the needs of patients with advanced cancer, some of their needs could potentially also be met outside formal healthcare systems, especially those needs where peers could contribute by sharing their experiential knowledge and creative self-management strategies (Walshe & Roberts, 2018). While peer support is gaining increasing momentum, it is largely neglected—or even raises resistance—in formal healthcare systems (Walshe & Roberts, 2018). Its potential, challenges and potential integration with healthcare systems deserve further study.

5 | CONCLUSION

Self-management challenges of persons living with advanced cancer situate largely beyond the medical domain. Patients respond to these challenges by personal and often creative self-management behaviours. These are typically aimed at maintaining a normal life. Self-management support should be tailored to patients' specific problems, needs and personal history. It should be aimed at consolidating effective self-management behaviours, and it should be embedded in trustful partnerships with patients and relatives. Self-management of persons living with advanced cancer will become increasingly important, partly due to novel treatments that increasingly turn advanced cancer into a chronic condition (Levit et al., 2013; Swain et al., 2015), and partly because clinical services may not be able meet all the needs of those with advanced cancer. Therefore, future studies should focus on innovative methods that support patients in dealing with their illness and that leverage their experiential knowledge of their illness.

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CONFLICT OF INTEREST

None declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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