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Full Length Article

"Who am I to say that I'm not going to take it": patient perspectives on decisions about antithrombotic therapy in the context of advanced cancer

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ABSTRACT

Introduction: The decision to reconsider antithrombotic therapy (ATT) in cancer patients nearing the end of life is complex given the increasing risk of haemorrhage and thrombosis. A decision support tool (DST) is being developed to facilitate this process. Understanding patients' experiences, values, and perspectives are an essential component, yet remain largely unexplored.
Aim: To explore these patients' experiences, values and perspectives regarding ATT use.
Methods: Qualitative study using semi-structured interviews with patients with advanced cancer receiving ATT, across Denmark, France, Spain, and the United Kingdom. Data were analysed using Framework Analysis.
Results: Sixty patients and 13 relatives participated. Three major themes were generated:

1. ATT is important and lifelong: Deprescription was perceived as counterintuitive; continuation was preferred, providing a sense of security.
2. Varying perspectives regarding roles and responsibilities in ATT decision-making: Patients' views regarding their role varied. When a good relationship existed with their clinician, patients trusted them to lead on the decision. Relatives played a key supportive role.
3. Challenges in navigating ATT management in the context of advanced cancer and multiple comorbidities: Decisions relating to ATT were rarely made in isolation. Patients prioritised cancer management and described difficulties navigating multiple health concerns.

Conclusion: Patients found decision-making around ATT near the end of life multifaceted, occurring amid a myriad of competing priorities. While patients reported a reticence to discontinuing, ultimately many deferred

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such decisions to a clinician, whose role was highly valued. These findings support a need for a DST, to support informed and shared choices in ATT decisions.

1. Introduction

Advance care planning for patients with terminal and life limiting illness has become the standard of care across many European countries and includes deprescribing of medicines that are no longer beneficial. Deprescribing near the end of life may reduce untoward side effects and toxicities arising from altered pharmacokinetics and pharmacodynamics in the agonal process [1]. This is especially important for antithrombotic therapies (ATT), comprising anticoagulants and antiplatelet agents, whose balance of benefit versus harm changes over time [2–4].

Cancer accounts for over one quarter (25.8 %) of deaths in Europe, with many of these patients receiving ATT [4,5]. In particular, approximately 5–15 % of patients with cancer are anticoagulated for venous thromboembolism (VTE) or to prevent stroke from atrial fibrillation or mechanical heart valves [4,6]. A further 25–35 % receives antiplatelet agents for the prevention of arterial disease, including ischaemic heart and peripheral arterial diseases [4,6].

The decision whether to continue ATT in patients with advanced cancer near the end of life is particularly challenging, and unclear due to the paucity of evidence. While guidelines contain strong recommendations for the initiation of ATT, they offer little direction to those requiring long term ATT with regard to management near the end of life [7–10]. Additionally, the data used to inform these guidelines excluded patients of poor prognosis (<3–6 months), despite ATT prescribing increasing by 60–80 % in the last year of life for patients with cancer, particularly among older persons [4,6,11]. In three quarters of these latter patients, ATT commenced in the last year of life will continue until death [6,12]. An increasing body of observational and epidemiological data suggests most cancer patients receiving ATT will continue them until the end of life [13–15]. Some studies report this has resulted in increased bleeding complications and reduced quality of life [16–18].

The factors which influence the decision to continue or discontinue ATT at the end of life are unknown. It is unclear whether this reflects the perspectives of clinicians or patients, and before any guidance can be offered it is important to identify any potential barriers to rationalising ATT within the context of advance care planning. This study is a subcomponent of a programme of research funded by the European Union (EU) called SERENITY, which aims to design, create and evaluate a digital decision support tool (DST) to support cancer patients and clinicians making decisions about continuing or stopping ATT towards the end of life [19]. This qualitative study aimed to explore experiences, values and perspectives of patients with advanced cancer regarding ATT management and identify factors that might influence these decisions.

Alongside this qualitative study, other studies within the SERENITY programme, including a realist review [20], flash mob study [14] and epidemiological data [13,15], will jointly inform the subsequent development, and implementation of the DST, which will later be evaluated in a randomised controlled trial. Interviews with clinicians were undertaken also, and will be reported elsewhere.

2. Methods

2.1. Study design

A qualitative study based on semi-structured interviews with patients with advanced cancer (and relatives if present) receiving ATT was conducted across four European countries: Denmark, France, Spain and the United Kingdom (UK). The study is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) guidelines [21].

2.2. Setting and recruitment strategy

Patients were recruited across four hospitals, two tertiary care hospitals/centres and two palliative specialised care units (SPCUs) between April 2023 and March 2024. Patients were identified and approached by their clinician based on prespecified inclusion criteria (Table 1), including adult patients with advanced cancer receiving ATT, comprising anticoagulant or antiplatelet agents. Patients could be taking an anticoagulant or antiplatelet, at any dose, for any of the following indications: atrial fibrillation/stroke prevention, ischaemic heart disease, mechanical heart valve, peripheral vascular disease, deep vein thrombosis or pulmonary embolus. Advanced cancer was defined as metastatic or locally advanced cancer which was considered incurable and no longer responsive to systemic anticancer therapies. Patient relatives, when acceptable to the patient, were also invited to take part. Relatives were defined as the person(s) who looks after and/or supports the patient and were identified by the patient.

If the patient confirmed participation, the researcher contacted the patient, answered any questions they had relating to the study and participation, and arranged a date, time, and mode of interview of their choice (face-to-face - at the hospital or patients' home, or via telephone). Patients were purposively sampled, and recruitment processes aimed to seek variation in ATT indication, cancer diagnoses and sociodemographic characteristics. Due to heterogeneity between participating countries and ATT indication, diversity in patients' experiences were expected. Therefore, we anticipated a minimum of 60 patients to be recruited across the four countries [22].

2.3. Data collection

Semi-structured interviews with patients alone or as a patient-relative dyad were conducted. Participants received both oral and written information about the study and provided informed consent prior to interview. Participation was voluntary, and participants were assured of their right to withdraw from the study at any time without providing a reason, with no effect on their medical care.

All research teams collaborated on the development of the English interview guide (Supplementary File 1), containing questions and prompts related to the research aims and informed by a realist review conducted within the SERENITY project. The realist review aimed to

Table 1
Inclusion criteria.

Patients	Relatives
• Adult (aged 18 years or above) • Diagnosed with advanced cancer* • Receiving anticoagulant or antiplatelet agents for one of the following: atrial fibrillation/stroke prevention, ischaemic heart disease, mechanical heart valve, peripheral vascular disease, deep vein thrombosis or pulmonary embolus • Life expectancy of less than one year according to the healthcare professional • Capacity to give informed consent • Capacity to undertake a 30–60 minute interview in the first language of recruiting country	• Adult (aged 18 years or above) • Capacity to give informed consent • Capacity to undertake a 30–60 minute interview in the first language of their respective country

* Advanced cancer was defined as metastatic or locally advanced cancer which was considered incurable and no longer responsive to systemic anticancer therapies.

further the understanding of the existing evidence in deprescribing in palliative care and shared decision-making, and develop theories to support the development of a shared decision support tool, the overarching aim of SERENITY [19]. The realist review [20] also informed the qualitative interview guide, and the development of analytical frameworks, outlined in the data analysis section below. The interview guide was then translated into their native language as relevant. Demographic information on participants was collected alongside interviews.

Each research team were responsible for local data collection and contributed to the analysis (UK – EB, ME, KL, SS, SN; Denmark – AAH, MS, HE; Spain – CF, VA, NC; France – IM, HH, NSM, support from medical students). All researchers who undertook data collection were female, either researchers and/or clinicians with experience conducting qualitative research. Interviewers made their role and the research topic clear to the participant prior to the interview commencing. The variety of interviewers and study settings was noted, and the research team had monthly meetings to enhance a common approach to the data collection.

Interviews were audio recorded and transcribed verbatim by a member of the research team at each respective site (DK, FR SP) or transcribed by a trusted agency (UK), in the respective native language. All research teams had an additional researcher check the transcript for accuracy. Brief interview summaries of each full interview transcript, detailing key elements of each interview, were written in English by the respective research teams to aid initial analyses across all countries.

2.4. Data analysis

Data were analysed using Framework Analysis, a qualitative method using both inductive and deductive approaches enabling the retrieval of data that converge towards a theoretical framework, while also allowing for additional themes to emerge [23]. NVivo (12 or 14) and Microsoft Excel were used to manage the data.

The Framework Analysis followed the five interconnected steps below. The collaborative analysis approach across the four countries is also shown in Fig. 1.

1. **Familiarisation** of initial interview transcripts were undertaken by research teams in each country to facilitate discussions on emerging findings. Interview transcripts remained in native language throughout the analysis process. To support analysis, interview summaries were developed in English and shared to support the generation and testing of the initial thematic framework, comprising a set of codes categorised to organise and manage the data. These codes were developed jointly by the research teams, using initial interview transcripts. Findings from a realist review [20] undertaken as part of the SERENITY programme also informed the development of the thematic framework.
2. Development of the **thematic framework** involved multiple iterations as subsequent interviews were transcribed, summarised and tested against the thematic framework. A 'final' version of the thematic framework was generated, incorporating categories within experiences of ATT and views on involvement in decision making, shared decision making and the proposed DST.
3. The final version of the framework was used to code/**index** all interview transcripts by each respective research team, using the thematic framework.
4. The codes were then **charted** into a framework matrix, a spreadsheet where the categories and codes from the thematic framework were summarised per participant. Each research team completed their own framework matrix in their respective native language. A condensed version of the framework matrix was translated into English to support analysis and reporting.
5. The research teams **mapped and interpreted** the findings using the framework matrices from each research team. This was undertaken through detailed and regular discussions, including an initial 5-day face-to-face analysis meeting. Each research team had their respective framework matrix in their native language, as well as the condensed English version. Joint discussions following a face-to-face meeting were held online to discuss and further establish the final themes and sub-themes. Analytical memos with prompts were used to capture and facilitate discussions during the initial analysis, and for subsequent refining of the final themes and sub-themes.

2.5. Ethical considerations

Individual ethical approvals were sought in each country. Data collection and storage were handled by each respective research team. No personal, identifiable data was shared between research teams.

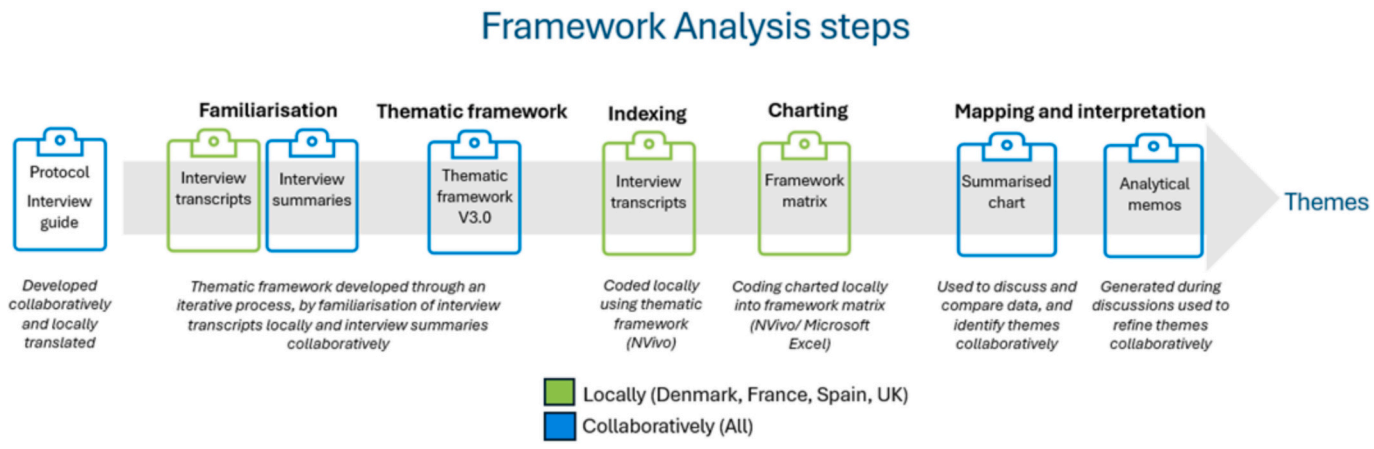

Fig. 1. Data analysis process.
Fig. legend: Description of qualitative data analysis process. These data were analysed using Framework Analysis, following the five interconnected steps outlined above: 1. Familiarisation; 2. Thematic framework; 3. Indexing; 4. Charting; 5. Mapping and interpretation [ref]. The protocol was developed collaboratively in English, followed by translation in each respective country as required. Interview transcripts were summarised briefly, and these summaries were translated into English to support collaborative analysis processes throughout the first two stages (familiarisation and development of thematic framework). Once the thematic framework was developed and finalised, each research team coded their interview transcripts (indexing) using the thematic framework, followed by charting the coded transcripts, which constituted the 'framework matrix'. This matrix was summarised and translated, and used collaboratively as the basis to map and interpret these data via group discussions. These discussions and key findings were mapped using analytical memos, and later collated and discussed further, leading to the generation of the final themes and sub-themes.

- Denmark – the study was conducted in compliance with the General Data Protection Regulation and is part of North Denmark Region's record of processing activities (File No. F2022-157);
- France - Favourable ethical opinion obtained from the French Research Ethics Committee Ile de France I on April 28, 2023 (REC reference 23.00815.000198);
- Spain - The study protocol was approved by the Ethical Committee for Clinical Research of the Hospital Clinic Barcelona with the Code number (2023-0336 ER-01);
- UK – favourable ethical opinion from the London – South East Research Ethics Committee (REC); February 24th 2023 (IRAS: 323195, REC reference 23/PR/0115).

2.6. Patient and public involvement

A patient and public involvement (PPI) task group was established to support meaningful PPI across all SERENITY programme studies [24]. The aim of involving the public was to help ensure the qualitative study was appropriately conducted, was of high quality, and reflected the needs of the studied population. Two public contributors, one from the UK and one from Denmark, contributed to the design of the study; activities included protocol development, and interview guide development. An additional contributor recruited in the UK took part in a pilot interview. The contributors reviewed and provided feedback on the thematic framework, and the generation of themes and sub-themes from these data, and the lead public contributor has co-authored this paper (KS). PPI contributions were planned and tracked using the Public Involvement in Research Impact Toolkit (PIRIT) [25,26], which incorporates the UK National Standards for Public Involvement. An overview of involvement, engagement and impact can be found in Supplementary File 2.

3. Results

Sixty patients were interviewed, with 13 patients accompanied by a relative. Interviews lasted between 6 and 72 min (median = 36 min) and were conducted at the patients' home ($n = 23$, 38 %), hospital ($n = 32$, 53 %) or via telephone ($n = 5$, 9 %). Of the patients interviewed, 32 (53 %) were Female, ages ranged between 48 and 97, and the most common cancer type was lung cancer (20, 33 %), followed by breast (10, 17 %) and colorectal (9, 15 %). Cancer associated thrombosis was the most common reason for ATT (26, 44 %), followed by ischaemic heart disease (11, 18 %) and atrial fibrillation (6, 10 %). Detailed patient demographics are presented in Table 2. Of the 13 relatives, 12 (92 %) were spouses. Framework Analysis led to the generation of the following three themes (Fig. 2).

1. ATT is important and lifelong.
2. Varying perspectives regarding roles and responsibilities in ATT decision making.
3. Challenges in navigating ATT management in the context of advanced cancer and multiple comorbidities.

Participant identifiers for quotes in the subsequent sections are arranged as follows: country (DK – Denmark, FR – France, SP – Spain, UK – United Kingdom); participant type (P – patient; C – relative), followed by a number. Additional quotes can be found in Supplementary File 3.

3.1. Theme 1: ATT is important and lifelong

3.1.1. ATT continuation perceived as fundamental and assumed

Patients expressed varied individual preferences and perspectives regarding ATT, with many indicating a preference to continue treatment. Patients described they understood or had been informed that their ATT would be lifelong. Those receiving ATT before their cancer diagnosis described ATT as part of their normal routine, a habit

Table 2
Participant demographics.

	All	DK	FR	SP	UK
	n (%)	n (%)	n (%)	n (%)	n (%)
Patients	60	14	16	16	14
Sex					
Female	32 (53)	4 (29)	12 (75)	7 (44)	9 (64)
Male	28 (47)	10 (71)	4 (25)	9 (56)	5 (36)
Age, years					
45–54	6 (10)	0 (0)	2 (13)	2 (13)	2 (14)
55–64	9 (15)	1 (7)	4 (25)	1 (6)	3 (21)
65–74	23 (38)	5 (36)	5 (31)	8 (50)	5 (36)
75–84	18 (30)	7 (50)	5 (31)	3 (19)	3 (22)
85+	4 (7)	1 (7)	0 (0)	2 (13)	1 (7)
Type of cancer					
Lung	20 (33)	9 (64)	5 (31)	5 (31)	1 (7)
Breast	10 (17)	0 (0)	5 (31)	3 (19)	2 (14)
Colorectal	9 (15)	0 (0)	3 (19)	4 (25)	2 (14)
Gastrointestinal (inc. upper) (GI)	7 (12)	1 (7)	0 (0)	0 (0)	6 (43)
Genitourinary	6 (10)	1 (7)	1 (6)	2 (13)	2 (14)
Other	6 (10)	3 (22)	1 (6)	1 (6)	1 (7)
Head and neck	2 (3)	0 (0)	1 (6)	1 (6)	0 (0)
Reason for ATT medication					
Cancer-associated thrombosis	26 (44)	2 (14)	6 (38)	8 (50)	10 (72)
Atrial fibrillation	6 (10)	1 (7)	2 (13)	2 (13)	1 (7)
Ischaemic heart disease	11 (18)	6 (44)	3 (19)	1 (6)	1 (7)
Stroke (+/− Atrial fibrillation)	3 (5)	2 (14)	0 (0)	1 (6)	0 (0)
Heart valve	2 (3)	1 (7)	1 (6)	0 (0)	0 (0)
Multiple ATT indications	12 (20)	2 (14)	4 (25)	4 (25)	2 (14)
Current ATT treatment					
Direct oral anticoagulants (DOAC)	24 (40)	6 (43)	6 (38)	3 (19)	9 (64)
Low molecular weight heparin (LMWH)	17 (28)	1 (7)	4 (25)	8 (50)	4 (29)
Antiplatelets	16 (27)	7 (50)	4 (25)	4 (25)	1 (7)
Vitamin K antagonist (VKA)	1 (2)	0 (0)	1 (6)	0 (0)	0 (0)
Dual antiplatelet therapy	2 (3)	0 (0)	1 (6)	1 (6)	0 (0)
Time on ATT					
<1 year	20 (33)	1 (7)	5 (31)	5 (31)	9 (64)
1–5 years	20 (33)	3 (22)	6 (38)	8 (50)	3 (22)
>5 years	20 (33)	10 (71)	5 (31)	3 (19)	2 (14)

Type of cancer:

- *Gastrointestinal – oesophageal, cholangiocarcinoma, pancreatic, liver, small bowel*
- *Genitourinary – gynaecological, prostate, renal*
- *Other – unknown origin, melanoma, lymphoma, carcinoma unknown primary, mesothelioma*
- *ENT – ENT, tonsil*

Reason for ATT medication:

- *Multiple ATT indications - stroke and cancer associated thrombosis (CAT); stent/atrial fibrillation (AF); stroke and ischaemic heart disease (IHD); CAT and IHD; AF and IHD; IHD, AF and CAT; heart valve and AF*

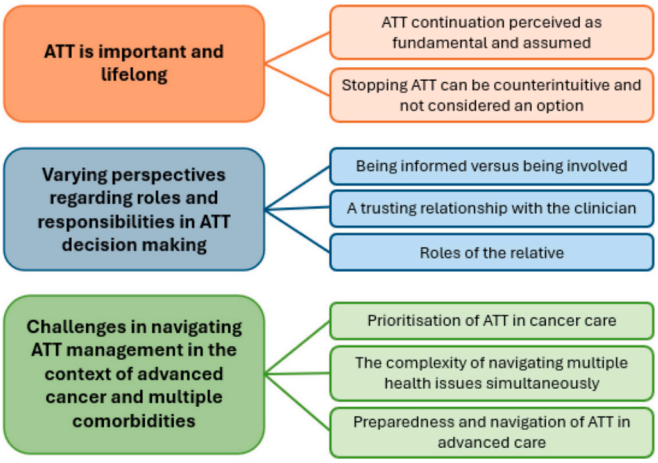

Fig. 2. Themes and sub-themes.
Fig. legend: Final themes and associated sub-themes generated from Framework Analysis.

integrated into their lives. For many, ATT provided patients with a sense of security, and while some patients were open to exploring options, they were reluctant to discontinue ATT altogether.

> *"The security that heparin gives me… It gives me a lot of security, above all… knowing that I am protected from a possible... thrombosis."*
> *[SPP2 – cancer associated thrombosis (CAT)]*

Notably, this sense of importance towards their ATT was widespread among patients for various indications and settings, regardless of their level of knowledge and understanding of ATT.

> *"I knew it was serious, the medication… I'm just glad to be alive. So, I just take it."*
> *[UKP9 – atrial fibrillation (AF)]*

Among patients knowledgeable about their ATT, many expressed greater concern for the underlying reason for its use (e.g. clot, stroke), over that of bleeding or discomfort of injections.

> *"When I remember the thrombosis, the bleeding is nothing… The injections become a bit painful because of the haematomas, but… it's not much, if anything at all [compared to thrombosis]."*
> *[FRP9 – CAT]*

Thus, patients' perception of ATT as fundamental and assumed to be lifelong could be so strong, it could outweigh the associated side effects related to ATT.

3.1.2. Stopping ATT can be counterintuitive and not considered an option

Patients expressed a fundamental view that it is counterintuitive and contradictory that medication could be risky and harmful, and if risk of a major health concern was prevalent or could be prevented, medication should not be stopped. Patients held on to the initial treatment decisions made by their clinician, reasoning that continuation of ATT remained justified.

> *"There must be a reason I'm taking it. That I was prescribed it back then."*
> *[DKP3 – ischaemic heart disease]*

As such, they felt no decision needed to be made about their ATT. Notably, some patients described the only reason they would stop was if they were 'cured'.

> *"If I'm given the drug, it's because I need it. If I'm cured and don't need it anymore, I don't mind stopping it."*
> *[FRP4 – CAT]*

This sense that continuing ATT was the only option was so strong that some patients even disregarded their clinicians' recommendation to stop it, adjusting their usual trust in their clinicians' opinion and subsequently questioning this suggestion.

> *"My[senior doctor] had decided that I shouldn't be on Apixaban. Well, I would have to be on some sort of blood thinner."*
> *[UKP22 – multiple ATT indications]*

Some patients described they had never thought it was necessary, or felt able to question their ATT treatment. This contrasted with other medications patients perceived there was more room for personal choice.

> *"Who am I to say that I'm not going to take it [oral anticoagulant]. That's a position you're in, really, because if you don't take it, and you have a stroke… You know, the onus is back on me… I don't see how you can say no, but other tablets I can refuse, because of side effects or certain anti-sickness tablets."*
> *[UKP32 – AF]*

Thus, patients did not feel stopping ATT was an option in many situations, particularly in comparison to other medications.

3.2. Theme 2: Varying perspectives regarding roles and responsibilities in ATT decision making

3.2.1. Being informed versus being involved

Patients' preferences on their role in ATT decisions ranged from deferring entirely to clinicians, to the view the decision was theirs alone. This variability often depended on their understanding of ATT and perceptions of involvement in care decisions. Many equated being informed with being involved, which shaped their satisfaction with care. Patients who felt inadequately informed saw it as a shortfall in care, while those who felt well-informed reported greater satisfaction with the decision-making process.

> *"When we're involved, the patient feels important. Being taken into consideration contributes to our own healing."*
> *[FRP9 – CAT]*

Patients' knowledge base varied significantly, with some reporting being unaware they were receiving ATT or why. These patients described it as difficult to actively engage in ATT decisions, and for some, a perception that they were unable to provide an opinion, or that their perspective held less value over that of the clinician.

> *"But my opinion shouldn't matter in this. They can't rely on my opinion. I can't contribute one; I'm eager for them to tell me what's best for me."*
> *[SPP10 – multiple ATT indications]*

In contrast, those with a stronger understanding of their ATT appeared more proactive in their perceived role in ATT management.

> *"I would make that decision myself, if I thought the treatment overshadowed the costs. If the treatment exceeded the quality of life, I would just stop."*
> *[DKP2 – mechanical heart valve]*

While some patients reported wanting to be more informed and involved in ATT decisions, others were concerned that asking questions would place the responsibility for decision making on them.

> *"I don't dare ask the doctor my questions, because I'm afraid he'll think I'm in charge."*
> *[FRP6 – CAT]*

Therefore, reasoning and influences on patients preferred involvement in ATT decisions were multifaceted, with some perceptions posing a potential barrier to engaging in these decisions.

3.2.2. A trusting relationship with the clinician

Patients described a strong sense of trust in their clinician, and how they preferred for them to initiate and lead on ATT decisions. This stance was evident regardless of patients' varied preferences for involvement and their desired level of information about their ATT. However, in conjunction with this, there also appeared to be a reluctance to question the clinicians' judgement among some patients.

> *"I trust all the doctors, what I've seen all along is that they've got my best intentions at heart. I would never criticise them."*
>
> *[UKP31 – CAT]*

While trust was valued, having an established relationship with their clinician who knew them well was equally important. This combination of specialised professional knowledge and personalized care was essential in building trust in ATT decisions.

> *"Not just anyone can come and say that to me [ATT discontinuation]. It has to be someone who knows me, one of the doctors I already talk to in there [oncology department]."*
>
> *[DKP14 – ischaemic heart disease]*

In particular, with cancer as a significant health concern, some patients reported they valued the opinions of their oncologist more highly than others in ATT decisions. This was evident across countries.

> *"I don't know if I should reduce the duration? Reduce the dose? Postpone chemo and continue Innohep (Tinzaparin)? I need an oncologist's opinion on what's most important."*
>
> *[FRP12 – multiple ATT indications]*

Thus, both clinician expertise and an established, trusting relationship with the clinician, were key components for patients in ATT decision-making, of which the oncologist was commonly the key clinician who fit these criteria.

3.2.3. Roles of the relative

Relatives played various roles in ATT decisions. Family members and close friends were found to be a significant support to patients across the countries, from administering ATT, interacting with healthcare professionals, and helping retain key information about ATT. Commonly, the spouse was the primary caregiver, adopting a primary role. At times, both patient and spouse referred to themselves as a single unit throughout the medical journey.

> *"During this whole process, we have both been involved all the time."*
>
> *[DKP5 – CAT]*

In cases where the spouse did not fulfil this role, other family members such as children or siblings, provided assistance and companionship to patients. In contrast, some patients described instances whereby the clinician discussed and informed the relative without the patient, a practice not always aligned with patients' preferences. Others reported instances of male spouses stepping back from the supportive role, potentially highlighting the influence of traditional gender roles in caregiving responsibilities.

> *"My husband had an allergy to doctors, I think he accompanied me to the doctor only once, then he stopped... that was something that made me angry, because I accompanied him to everything... my son comes with me, but sometimes they talk and I don't get it… 'yes, yes, don't worry, I'll explain it to you.' And of course, when he says that, I'm left in the dark... he doesn't explain it, or he explains it in his own way."*
>
> *[SPP1 – CAT]*

Although not typical, when relatives solely took over ATT management, this left some patients uninformed, limiting their opportunity to be involved in decisions. For the majority however, relatives played a significant and positive supportive role in ATT management and decisions.

3.3. Theme 3: Challenges in navigating ATT management in the context of advanced cancer and multiple comorbidities

3.3.1. Prioritisation of ATT in cancer care

Patients interviewed had advanced cancer and various comorbidities, shaping their perception of ATT decisions. In particular, prioritisation was central to ATT management, and patients described ATT as an important medication, tending to prioritise its' continuation to avoid possible thrombosis or stroke.

> *"If you've got a clot on your lung, or, if you've had a heart attack or a stroke, the side effects are a minor consideration, when you're in a major health trauma like that."*
>
> *[UKP7 – relative of CAT patient]*

However, patients generally considered ATT secondary to cancer and its treatment, often framing ATT decisions through the lens of its impact on their cancer care. Patients described tolerating all medications they considered to be under the umbrella of cancer care, which included ATT. This appeared particularly evident among patients with cancer associated thrombosis.

> *"All the medications they give me to fight cancer are all susceptible to causing these kinds of damage... you have to dare to take risks, and if it makes you feel really bad, then fine, but at least we've done everything we could, right?"*
>
> *[SPP7 – CAT]*

For patients with pre-existing conditions requiring ATT, some described a sense of ownership over their ATT, having managed it effectively over time. However, facing cancer often disrupted this sense of control as cancer and its treatments took priority.

> *"I have been on Warfarin for 20 years… I could manage it and knew exactly what to do... But in the end, when I got sick [cancer] and all that, I couldn't manage it at all."*
>
> *[DKP2 – mechanical heart valve]*

While ATT was recognised as an important medication, patients' concerns regarding their cancer overwhelmed other health concerns and medications.

3.3.2. The complexity of navigating multiple health issues simultaneously

Patients described the considerable burden of navigating multiple health issues simultaneously, with ATT being one of many. Throughout their journey, patients described seeing multiple specialists, particularly if they had been on ATT long before their cancer diagnosis. This often led to a fragmented care experience, with the roles of different clinicians and treatments blurring, making it difficult to keep track of their care and understand the purpose of each medication.

> *"Everything gets blurred after a while… there's so many meetings, about my health. And different people, you know, I see, I've seen about four or five [clinicians – different specialties]."*
>
> *[UKP9 – AF]*

Patients disclosed specific challenges of navigating multi-disease, including the difficulty of distinguishing side effects of different medications and the overwhelming volume of information they received. Other medications often caused more concern, leaving patients with little mental space to focus on their ATT.

> *"With my cancer illness, since I started getting sick in a traumatic and sudden way with three different issues… I practically didn't grasp that the specific treatment with anticoagulants was specifically for the clot I had. I thought it was just part of the whole process involving the three conditions I had."*
>
> *[SPP3 – CAT]*

Thus, ATT was just one of many concerns for patients, and often not

prioritised over that of other medications and treatments. As such, this affected patients' ability to focus on ATT specifically, and subsequently engage in decisions about their ATT.

3.3.3. Preparedness and navigation of ATT in advanced care

Patients expressed facing a great deal of uncertainty about their cancer prognosis, and notably, were in varied stages of processing their advanced disease stage.

> *"I think that mentally I am already thinking to myself that a day will come, I don't know when, in two days, three days, four days... a month."*
> *[SPP1 – CAT]*

During this time, some patients described a sense of isolation and abandonment in relation to their care, particularly around their experience of discharge from oncology, and referral to palliative care services.

> *"Nothing has been optimal since I became a terminal patient. I really feel like I've been left alone with everything."*
> *[DKP11 – CAT]*

Patients highlighted the value of being prepared for these decisions, which they thought would help address uncertainties and ease concerns around stopping ATT. However, patients also described needing time to process and understand their situation.

> *"I was just not very well, because I wasn't really taking notice, but looking back on it now, I understand it, now I've come in the second time, they're doing things, and I understand what's going on a lot better… I'm also happy to say is that right? Take me off a tablet every now and again."*
> *[UKP33 – ischaemic heart disease]*

Alongside this, some patients expressed concern over receiving the information they need to be prepared for this decision, due to the wider connotations of their advanced disease.

> *"We might also be afraid, in many cases, of making fools of ourselves by asking the wrong questions. And we might also be afraid of getting the wrong answers, ones that don't quite align with what we want to hear."*
> *[DKP1 – AF]*

Thus, patients found themselves unprepared for a possible shift in ATT management goals, underpinned by the delicate balance between being prepared, and acceptance of their advanced disease stage.

4. Discussion

The cancer journey brings with it many decisions that need to be made by patients regarding their care, often within the context of ongoing uncertainty and disconnect in continuity between different services. The management of arterial and venous disease is rarely prioritised in advanced cancer and is usually viewed as just one of many complications. Although patients had variable levels of knowledge, expectations and experiences of ATT, the majority understood ATT as a fundamental part of their care and assumed ATT to be life-long. Stopping ATT was rarely considered a management choice. Patients also expressed a wide range of preferences regarding their involvement in ATT decision-making but would entrust their clinician to lead on this, so long as they were known to them.

Patients' knowledge, experiences and expectations of their ATT strongly influenced preferences and values which guided their decision-making. The reason for initiating ATT appeared to take primacy over the potential hazards of the medicine. For some, this was driven by fear of recurrence of the thrombotic event; for others, it was the knowledge and understanding of the rationale for ATT continuation, and the sense of security it provided. For those who did not remember the reason for receiving ATT, some still described a sense of importance towards their ATT and that it should not be stopped. While some patients described experience of bleeding and/or bruising, and acknowledged their risk of bleeding, it was generally an accepted side effect. It appeared bleeding risk was less tangible for patients when compared with their experience of a clot or stroke. This can be evidenced particularly by patients' strong sense of importance of continuing ATT even when they had forgotten the reason for it, and also in the fear described by some patients regarding having another clot or stroke. Patients with no reported preference and/or ambivalence towards their ATT instead solely trusted their clinician to advise them.

Our findings echo previous research which has identified wide variance and gaps in patient knowledge regarding anticoagulants [27–30]. When such knowledge gaps were sustained, it left patients poorly equipped for ATT-related decisions. We also found that ATT knowledge can have paradoxical effects, and could act as a facilitator or a barrier for engaging in decisions. For example, a lack of knowledge was distressing for some patients who felt they had been poorly informed, while for others, this reduced distress and allowed them to defer to the clinicians' expertise. This was most prevalent across patients interviewed in France and in keeping with previous research highlighting lack of distress from CAT, and a preference towards a "guidance cooperation" patient-doctor relationship model [29,31]. Identical studies previously conducted in the UK and Spain reported the "mutual participation" model to be more prevalent, along with greater distress related to CAT [28,30], in line with findings from this study. The "mutual participation" model also appeared to be more favoured in Denmark.

While patients considered ATT to be an important medication, this view was considered in the context of how it impacted their cancer and its treatment. This supports previous research suggesting that, for patients, cancer and its treatment takes primacy over their other treatments (including ATT) [27,32]. This inevitably impacted ATT-related decisions, since patients struggled to process multiple pieces of information regarding more than one health related challenge. Consequently, when facing several end of life or advanced disease-related decisions, particularly when they were not ready to confront them, decisions regarding ATT were viewed as low priority and of negligible significance.

Our findings showed that most patients preferred ATT decisions to be led by their clinician, particularly one with whom they had an established and trusting relationship, a component essential to ensure patients remain engaged in the shared decision-making process [33]. However, this process is challenged by the fragmented continuity of ATT management, especially when patients are referred to clinicians not well known to them. Studies have shown that in clinical practice, shared decision-making occurs as multiple, staged decisions, and with different clinicians, and that long-term conditions are particularly sensitive to this distributed decision-making process [34,35]. This is particularly relevant to ATT in advanced cancer where the patient journey may be convoluted, especially where ATT has been commenced prior to a cancer diagnosis. This highlights the need to revisit preferences and choices throughout the patient journey.

While the clinicians' role in ATT decision-making was clear, patients' preferences and perspectives on their own role in the process varied, as per previous literature [36]. For many, being informed of the decision was a minimum expectation, although the terms "being informed" and "being involved" were used interchangeably. For some, being informed constituted sufficient involvement, while others preferred to be more actively involved, with the final decision being their responsibility alone. In contrast, others did not wish to be involved or even informed of the decision. Some did not feel this was a role they could take on, possibly due to their lack of knowledge of ATT. It might also reflect passive involvement by deferring to the clinician as a coping strategy when faced with multiple decisions [37,38]. This seems a plausible explanation, since patients face many difficult conversations and decisions around this time, and ATT might be one medication decision they feel they can defer to the clinician. Therefore, a careful balance is needed

between understanding the reasoning behind deferring to clinicians' decision and ensuring patients understand they can contribute to the ATT decision should they want to.

The supportive role of relatives in decision-making was observed across all participating countries, yet slightly more pronounced in Spain. This supports previous evidence of distress among relatives of CAT patients in Spain and their need to be more involved [30]. Therefore, understanding the individual dynamics of a patient and relative unit and socio-cultural variation of the relatives' role is essential to capture when understanding influences surrounding ATT decisions.

While previous evidence suggests the differing experiences of symptomatic and incidental CAT strongly informed their perspectives [39], our findings showed that ultimately, preferences on ATT primarily leaned towards continuation among both groups. Reasons for this are unclear but it may be that specific elements of the patients' experience may have greater influence than merely the differences in experience with symptomatic or asymptomatic CAT. Our population was in more advanced stages of cancer and end of life management than those previously described in the literature. In addition, many of the studies were conducted when low molecular weight heparins (LMWH) were the standard treatment of CAT where patients had additional motivation to stop anticoagulation to avoid ongoing injections. However, due to the focus of this study, it is difficult to discern definitive reasons for this difference. Additionally, while there were differences in patients' perspectives across ATT indications, to be expected due to the diversity of the population interviewed, the variances across patients' preferences, experiences and knowledge, were common findings evident among patients interviewed.

Ultimately, our findings highlighted continuation of ATT was generally preferred. While existing evidence shows patients do express a willingness to reduce medications near end of life [40], our findings suggest ATT is not such a medication. Our findings are consistent with other studies that observed ATT to be a long-established routine in many patients' lives, which provided a sense of safety and security, and was to be taken for life [28–30]. These elements in particular influenced patients to view ATT cessation as counterintuitive since it was an important and essential medication. This finding is an essential consideration in the development of the decision support tool (DST), as patients with fixed perspectives regarding their ATT tend to be weighted towards continuation, and this reasoning can be made up of many factors, not all of which informed-based. A DST can help to provide patients with a balanced view on the decision to be made relating to their ATT, ensuring patients are equipped with knowledge, support and guidance to be involved in ATT decisions should they wish to.

Another important consideration was that despite patients' varied understanding, knowledge and preferences towards involvement in ATT decision making, clinicians judgement and role in leading and initiating ATT decisions is very highly valued. However, for some, this perspective to defer solely to the clinicians' judgement identified that, among some patients, there are gaps in knowledge and understanding, which if addressed, may empower patients to feel this is a decision they can be involved in. A DST can help inform, and provide patients with the knowledge that they have the option to be involved in ATT decisions should they wish to, and supporting a decision that is shared between them and their clinician, while also providing a clear distinction between many other medications and decisions they may be faced with around this time (Table 3). These findings have contributed to the ongoing development of a DST, which will be evaluated in a randomised controlled trial [19].

4.1. Strengths and limitations

A key strength was the large and varied sample of patients interviewed, across diverse cultural contexts. This provided a broader understanding of the research topic, enhancing transferability, and potential application to a wide range of settings. However, applicability of our findings to other contexts should be conducted cautiously and contingent on the population profile and similarities with our sample. Thirteen relatives were interviewed, which, while the important role played by relatives was captured, there may be some perspectives missed due to the low numbers of relatives recruited, and relatives not being the focus of the interviews. Future exploration of relatives/caregivers perspectives may provide insights and more nuances that could not be fully explored here. Public contributors involved in this study were a strength, with their relevant experience both in this context, and in being involved in larger, complex studies. However, we were unable to recruit public contributors in France and Spain. The inclusion criteria encompassed patients estimated to be within the last year of life, therefore for some a decision about their ATT in the context of end of life was a hypothetical question and this could have impacted their reported preferences, thus a limitation of the study. Another strength of this study is the multidisciplinary expertise of our research teams and the strong background in qualitative methodologies. Interviews were analysed in their native language, a strength in that the meaning intended by participants was captured in the data analysis process, and not lost in translated transcripts, increasing the trustworthiness of the findings [41,42]. Translation following data analysis was conducted in the form of a condensed framework matrix, undertaken by the respective research teams. However, it is important to note the impact the variance in interviewers may have had on data analysis (and collection). To help mitigate this, a comprehensive protocol and interview guide were standardized across the research teams, including regular meetings to discuss varied stages of data collection and analysis. Framework analysis proved to be appropriate for this large dataset across multiple geographical locations.

5. Conclusion

The management of ATT at the end of life is complex but strongly influenced by patients' views that it is an important medicine which is intended for life. While patients acknowledge the importance of ATT, issues around the management of their cancer will usually take primacy. Ultimately the decision whether to continue or cease ATT is a personalized one which is taken within the context of patients' values and preferences and based on previous experience and that of their treating physician. Our findings support the potential benefit of a DST for this purpose.

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Table 3
Key considerations for the decision support tool (DST).

Decision support tool should:
• Be Flexible to account for differences in patient preferences about depth of knowledge about and involvement in ATT decision-making
• Be accessible outside of the clinical setting so that patients have time to prepare for decision making conversations about ATT that often take place within a broader context of managing multiple conditions
• Complement clinicians' involvement and be clear and sensitive to patients' advanced disease and multiple health concerns
• Provide information about the risks of ATT while also facilitating respect of patients' decisions, acknowledging that patients' perspective on wellbeing may extend beyond the management of physical side-effects of ATT

CRediT authorship contribution statement

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Declaration of competing interest

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