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Rijnstate

Medication@home

Expectations and experiences of cancer patients about receiving intravenous medication at home

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Abstract

Background

The amount of cancer patients is still growing and cancer became a chronic disease. This will cause more pressure on hospital capacities. To maintain providing accessible high quality healthcare, hospitals have to use their resources efficiently. In addition, hospitals want to improve their performance and deliver optimal care. This resulted in a shift from providing care at the hospital to the patient's home. Receiving medication at home could have benefits for patients, because they do not have to travel to the hospital regularly anymore. Even 33% of all cancer patients in the Netherlands would rather receive care at home than in the hospital. Rijnstate hospital made the decision to provide oncological care at home. In the future patients only visit Rijnstate hospital when the treatment cannot take place at home. From May 2021 onwards pembrolizumab (immunotherapy), and zoledronic acid (medication for osteoporosis cancer treatment) have been administered to the patients in their homes by Rijnstate. This is a very specific patient group, with a specific home-based care pathway. Not much is known about the expectations and experiences these patients have about receiving this medication at home. With this insight a contribution can be made to the medical practice of providing medication at home and the patient experience.

Methods

The study population consists of cancer patients that are treated with pembrolizumab (immunotherapy) for lung or bladder cancer, or zoledronic acid (medication for osteoporosis in cancer treatment) at Rijnstate hospital or at home between May and July 2021. Patients who did not yet receive their intravenous medication at home were interviewed individually about their expectations. Patients who already received their intravenous medication at home were interviewed about their experiences. Before starting with interviewing the ethical review committee of the UT and the Local Ethical Committee of Rijnstate hospital gave permission for this study. In all interviews the patient was introduced to receiving medication at home by discussing the care they receive at the oncological day care. Data was collected by means of telephone interviews that were guided by a semi-structured interview scheme. The themes in this scheme were based on findings of a literature search. The five themes are planning & coordination, communication: information & education, communication: interpersonal relationship, privacy & social impact and time management. The interviews were recorded with participants permission and were transcribed afterwards with the support of Amberscript. The data was analysed by thematic coding in ATLAS.ti. First open coding and after that axial coding took place. The codes were eventually classified in one of the five themes from the interview scheme with distinction between expectations and experiences. To make the results more visual, the most frequently mentioned expectations and experiences of cancer patients about receiving medication at home are presented in a patient journey map.

Results

In total 22 patients were interviewed of which 8 about their expectations and 14 about their experiences. Overall, all patients seemed satisfied with the care they receive at the oncological day care. Generally the cancer patients had positive expectations and experiences about receiving their intravenous medication at home. The most frequently mentioned positive expectation is for the theme 'communication: interpersonal; relationship' the social interaction with the nurse. For the theme 'privacy & social impact' it are staying home during the treatment and less confrontation with having a disease. For the theme 'time management' it are not having to arrange a driver or accompany to go along to the hospital and no traveling time. The most frequently mentioned

positive experiences are the same, expect for less confrontation with having a disease. The most frequently mentioned experience that could be improved is for the theme 'planning & coordination' that the announcement of the time of the appointment a day in advance is too late. For the theme 'communication: information & education' it are too little provision of information and not being clear to the patient why the care is provided at home. For the other aspects it is when the nurse is not able to puncture a vein.

Conclusions

Viewing the care from the patients perspective and thereby studying for the both the patient's expectations and experiences about receiving intravenous medication at home makes this study of added value to the literature and clinical practice. In general patients were already satisfied with the care at the oncological day care and were positive about receiving intravenous medication at home. By improving the planning and coordination of appointments, informing patients about receiving medication at home and the puncturing skills of nurses, the patient experience at home can be even better. In addition, improving the experience of the patients is a continuous process and is not finished after this study. Therefore, monitoring patients expectations and experiences is very important. A questionnaire can be set up to monitor patient expectations and patient experiences frequently to improve the patient experience further.

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Introduction

Background

The healthcare landscape is changing in the Netherlands. There are multiple reasons for this, which are technological innovations and rising healthcare expenditures [1]. Also the growing demand of healthcare is a very important one. This growing demand is a result of the longer life span of people, aging of the population and growing number of chronically ill people [2] [3]. For cancer this is also the case. The incidence of cancer in the Netherlands in 2019 was 119,240 people each year. This is twice as much as in 1990 [4]. This means that the amount of cancer patients is growing. In 2019 the 5-year prevalence of cancer in the Netherlands was 380,755 [5], which are all living cancer patients who have been diagnosed with cancer in the five previous years. This has doubled in comparison with 30 years ago [5]. A reason for that is that patients with cancer live longer, because the treatment possibilities of cancer are continuously expanding. For example, treatment indications of existing medications are expanding, which means more patients will be identified as suitable for receiving certain oncological medications [6]. This will cause more pressure on hospital capacities.

To maintain accessible high quality healthcare, hospitals have to use their resources efficiently. This resulted in a shift from providing care at the hospital to the home of the patient. Gupta Strategists stated in a report that 45% of all hospital care can be relocated to the patient's home [7]. Since a couple of years the taskforce of het Nederlandse ministerie van Volksgezondheid, Sport en Welzijn (VWS) (the Dutch ministry of Public Health, Sport and Well-being), which is called "De juiste zorg op de juiste plek" (The right care at the right place), focuses on the improvement and development of healthcare. Within this initiative there are three important pillars; preventing, replacement and relocation. Relocation means patients can receive their treatment at the GP or at home and only have to go to the hospital when it is needed [8]. The relocation of care from the hospital to the patient's home is also stated in the Dutch "Bestuurlijk akkoord medisch-specialistische zorg 2019-2022" (Administrative agreement on specialist medical care) [9]. The COVID-19 pandemic has actually even accelerated the transition to home-based cancer care [10]. Relocating care to the patient's home is in line with the upcoming focus on well-being of patients and providing patient-centred care [1]. For patients receiving their medication at home it is expected to possibly have benefits like receiving care in a familiar environment, less traveling time, less risk of infections and more personal contact with the nurse [6]. "Zorg voor innoveren" (care for innovation), a collaboration between 5 governmental organisations, also states that patients should have more input in their own treatment [11]. With giving patients the opportunity to choose for treatment at home, the patient gains more influence on his own treatment [12].

From a questionnaire of the "Nederlandse Federatie van Kankerpatiënten" (NFK) (Dutch federation of cancer patients) [13], in 2018 it appeared that at least 24% of cancer patients would rather receive care at home than in the hospital. Among patients who do not live alone this percentage is even higher. A Dutch paper from 2019 showed that even 33% of cancer patients would rather receive care at home than in the hospital [12]. The most common reason to not choose for medication at home is that the safety of it is questioned by patients [12]. A literature review from 2015 concluded that administering intravenous medication at home is safe [14] [15]. In 2019 the Dutch "Inspectie Gezondheidszorg en Jeugd" (IGJ) (Health and Youth Care inspectorate) released an assessment framework in which the safety and quality of care at home are described [16], which is a reference and guarantee of the safety and quality.

A lot of Dutch hospitals already provide different types of oncological care at home. Rijnstate hospital also made the decision to provide oncological care at home. In the future patients only visit the hospital when treatment cannot take place at home [6]. In the strategy Rijnstate states their ambition: *“providing high quality healthcare at the right place performed where it is the most effective and suits the needs of the patient”* [17]. This means close at home where possible and in the hospital when it is needed, which is in line with the right care at the right place. Rijnstate has the opinion that it is too burdensome for a patient to have to travel regularly to hospital for a longer period of time [6]. Rijnstate already provides care at home, for example oncological, neurological, cardiological, dermatological care. Within the project medication@home, Rijnstate is expanding the care which is provided at home [18]. Medication means that it concerns the administering of medication at home. For oncological care this covers multiple therapies, namely chemotherapy, immunotherapy, targeted therapy and medication as a result of side effects of therapy. These therapies are included in the medication@home project because it is non-acute plannable care, the risks of complications or side effects are minimal, the treatment is expected to be long term and helps to relieve the increasing pressure on the oncological day care. Currently, all oncological medication at home is outsourced by Rijnstate hospital to Eurocept Homecare [19], a commercial secondary home care organisation. Rijnstate wants to provide this itself because that is more efficient. Thereby it is also cheaper, but still not cheaper than on the oncological day care ward, to provide the care at home and not outsource it to Eurocept Homecare [6]. Rijnstate becomes more independent and that means simpler and more efficient communication with treating specialists. From May 2021 onwards pembrolizumab (immunotherapy), and zoledronic acid (medication for in osteoporosis cancer treatment) have been administered to the patients in their homes by Rijnstate. Patients that live beyond 25 kilometres still receive the medication from Eurocept Homecare. Therefore Rijnstate sees Eurocept Homecare as a partner. For providing care at the patient’s home Rijnstate is setting up Rijnstate service. Within Rijnstate Service the coordination, administration and provision of medication is organised [6]. In this way Rijnstate aims to organise this care most efficiently and effectively for the patient. The care pathways of the oncological medication that will be provided at home have already been set up within a project team at Rijnstate. In this team specialised nurses were involved. From their view the established pathway is of good quality care. Nurses see providing medication at home as a nice addition to their job [6]. The care pathways can be found in Appendix 1.

Knowledge-gap & rationale

In contrast to multiple studies around the world that have been conducted on providing oncological medication at home, concerning different medications and different administering types, this study focusses on expectations and experiences patients have about receiving intravenous oncological medication at home. Regarding chemotherapy at home, many studies have already been performed. These studies focused mostly on comparing providing medication at home or in the hospital, measuring patient preferences, patient satisfaction and patient experiences [20–23]. Providing oncological medication at home was well received by patients [20]. From interviewing cancer patients about their experiences with home care resulted that it is preferred over receiving care at the hospital, because the patient is in a familiar environment, has more privacy and receives more personalised care [21]. In another study 25 percent of the cancer patients preferred home care over care at the hospital [22]. Reasons to choose for receiving care at home are not having to travel to the hospital anymore and finding hospitals frightening [22]. To our knowledge only one study explored the patient experiences of receiving intravenous zoledronic acid at home. In this study patients were satisfied with receiving zoledronic acid at home, because the quality of the relationship with the nurse, no more traveling, no more waiting, being at home and less disruption of their daily routine

[24]. Only a few studies are conducted about patient experiences with receiving intravenous pembrolizumab at home [25] [26]. The experiences of patients in these studies were positive. However in none of these studies cancer patients were questioned both about their expectations before and their experiences after receiving these medications at home. There is only one Dutch study conducted last year in which cancer patients were interviewed about their preferences before [12] and experiences after receiving oncological medication at home [25]. The experiences mainly focused on why receiving medication at home is preferred over receiving medication at the hospital [25]. Patients treated with intravenous pembrolizumab were included, but also patients receiving medication subcutaneously were involved. It became clear that trust, listening and providing right information is very important to cancer patients in receiving medication at home [12].

The present study focuses on pembrolizumab against lung or bladder cancer and zoledronic acid because both medications are administered intravenously and have been provided at home by Rijnstate hospital from May 2021 onwards. The reason for this is that it is too burdensome for these patients to come to the hospital for this treatment. Especially when the administration takes place every three weeks. The patient group is very specific, with a specific home-based care pathway. In other studies often also medical results of receiving medication at home were explored, but in this study the focus is mainly on the service the hospital provides. Not much is known about the expectations about receiving this medication at home and their experiences with receiving this medication at home. In this study this was explored.

Research aim

The aim is to get insight in the expectations and experiences of cancer patients about receiving intravenous medication at home. With this insight a contribution can be made to medical practice of providing medication at home and the patient experience.

Research question

What are the expectations and experiences of cancer patients about receiving intravenous medication at home?

Sub-questions

1. What is the current experience of cancer patients at the oncological day care receiving intravenous medication?
2. What do cancer patients expect from receiving intravenous medication at home?
3. How do patients experience receiving intravenous medication at home?
4. What aspects in the care pathway of providing oncological intravenous medication at home could be improved from the patient perspective?

Theoretical framework

In this section the theories of patient expectations, patient experiences, the relationship between patient expectations, patient experiences and patient satisfaction are outlined to gather a better understanding of these concepts. Furthermore, management of patient expectations and patient journey mapping will be described and discussed in relation to this study.

Patient expectations

Patient expectations are based and explained by a variety of theories. Some of these theories, which are relevant for this study will be described. Patient expectations is a very complex term and not well studied. There is no uniform definition in the literature of the term patient expectations. Expectation itself is defined as a strong belief that something will happen or to be the case in the future [27]. Patient expectations is also defined as what patients hope will happen, so what is desired, wished or entitled for [28]. This definition includes multiple types of expectations that are described in the Theoretical framework.

Patient expectations theories

Patients have different types of expectations. In figure 1 [29] ideal, necessity, normative and predicted expectations are included, but there is a fourth type which are unformed expectations [30].

Ideal expectations (value expectations)	Aspiration, desire, want, hope, preferred outcome
Normative expectations (value expectations)	What should or ought to happen
	Entitlement (that which is owed or to which one has a right) and normative standards (that which should be)
Predicted expectations	Expected outcomes (realistic, practical or anticipated)
	The likelihood of future clinical occurrences
Unformed expectations	Not yet formed or expressed

Figure 1, Framework for understanding expectations [29].

Wherein the first three are also called value expectations [29]. Ideal expectations are desires, wants, hopes or preferred outcomes [30]. Normative expectations are about what the patient thinks should or ought to happen, also called what is the patient entitled to. These kind of expectations mostly result from what the patient is being told, led to believe or think they deserve to receive from healthcare services [30]. Predicted expectations are about what the patient believes will happen. This is the most realistic kind of expectation and is also called probability expectations because it is about the likelihood that something will happen [28]. These expectations result from personal experiences, reported experiences of other patients and other sources of knowledge such as in the media [30]. Besides the described expectations there are also unformed expectations [30]. These are expectations that are not yet formed or that the patient does not want to (verbally) express because of various reasons, like fear or not feeling comfortable. Often this is just a temporary state. Especially when something is new, like starting to receive medication at home, patients do not have expectations because they do not have the experience or any knowledge to formulate expectations. Many expectations are epiphenomenal [30], which means that expectations are being formed as the experience unfolds, so in the process of experiencing. This could also be the case in this study and will mean certain patients may not be able to properly articulate their expectations.

The expectations that are aimed to be measures in this study are ideal patient expectations because that gives more information about what patients really want and gives the opportunity to improve the care for the patient to the ideal situation.

In figure 2 [30] preconditions and influences on expectations are presented. These are not exhaustive, but are important as expectations can be different for everyone because of these personal and social influences. In addition to figure 2, a personal influence can also be level of understanding of the illness and attitude [27] [31]. Attitude is a set of emotions, beliefs and behaviours. In addition to figure 2, a social influence can also be cultural background [31]. These differences will probably also emerge in this study. Not every influence can be taken into account but age and the amount of received administrations can be kept in mind when analysing the results of this study to identify if it is related to expectations.

Personal	Social	Context
Needs	Sociodemography	
Values	Social norms	
Valencies	Group pressures	
Roles/capabilities	Task requirements	
Experience	Conditions/restrictions	
Information	Equity	
Intentions		
Attributions		
Interest		
Moods/emotions		
Perceived consequences of outcomes		

Figure 2, Personal, social and context preconditions and influences in developing and modifying expectations [30].

Besides personal and social influences there is a third set of influences. This is the context of the regarding relationship or event [30]. Healthcare is distinct from other contexts because it is commonly more emotional. Emotions may be intense and rare during the process of receiving healthcare. This emotional response can make it hard for a patient to describe the feelings and expectations they have because they are so personal and abstract. To understand the basis and causes of expectations, not only the personal frameworks matter, but also the social and service contexts. All these interact with each other and influence expectations.

Patient experience

Patient experience is much broader studied than patient expectations. By the Beryl Institute US patient experience is defined as “the sum of all interactions, shaped by an organisations culture, that influence patient perceptions across the continuum of care” [32]. The aspect of continuum of care has a link with the term patient journey which is described in the Theoretical framework. In a literature review from 2014 [33] this definition of patient experience is identified as most used by healthcare facilities globally. Another definition in this literature review made a distinction between medical and emotional interactions with the healthcare provider(s), so also the human side is taken into account. The emotional side is important in this study, because the focus is on the service of providing medication at home. It is about how the patient feels and thinks about it. In summary, patient experience is defined as the patient’s perception of the care they receive.

Relationship between patient expectations, patient experiences and patient satisfaction

There is a relationship between patient expectations and patient satisfaction. Especially predicted expectations have a positive association with patient satisfaction, because predicted expectations are more likely to match reality [29] [34] [35]. Ideal expectations do not have a positive association with patient satisfaction, because these expectations are almost always too high and therefore unrealistic [35]. Unmet expectations have a negative influence on patient satisfaction [36], but lower fulfilment scores of expectations do not preclude satisfaction [35] [37]. Important for this study is

that exploring and managing patient expectations could improve patient experiences and patient satisfaction. Besides patient expectations, patient experience is also an important determinant of patient satisfaction [38]. Some studies suggest that patient's actual experiences should be taken into account in relation to attempts to improve patient satisfaction [35]. That makes it valuable to explore patient experiences in this study. One of the most interesting findings is that patient experience is more than patients satisfaction. It is much broader and deeper than satisfaction [39]. Therefore patient satisfaction is not a primary outcome measure in this study. Exploring both expectations and experiences, could improve patient satisfaction.

Managing patient expectations

As described there is a relationship between patient expectations, patient experience and patient satisfaction. Better anticipating on or influencing patient expectations could lead to a better patient experience and a better patient satisfaction [31]. If healthcare professionals can monitor patients expectations and experiences, they can improve specific aspects in the care pathway and subsequently in the patient journey [27]. Possibly the care could be individualised to a certain extent [34]. Multiple studies indicate that when a healthcare professional is aware of the patient expectations, the healthcare professional can anticipate on and/or influence expectations [34]. It involves seeing care through the patient's eyes and thus listening to what the patient's expectations are [40]. This is in line with a patient-centred care approach, because within that approach patients are actively involved in their own medical treatment [28]. Physician-patient communication is important in managing patient expectations [31]. Throughout the literature, patients express high expectations for communication [41] and explanation of medical information [28]. Showing empathic communication may be important to increase the truthfulness of the derived expectations, because it can contribute to patient's trust in the healthcare professional [42]. The healthcare professional can ask the patient about the expectations regarding the process and outcomes of care and discuss diagnosis, prognosis and treatment plan. After discussing expectations with the patient, the healthcare professional can determine that the patient has unrealistic expectations by comparing these with the realistic expectations. If this is the case, the healthcare professional can make the patient aware of it and inform the patient about what they can expect and adjust the expectations of the patient to make the expectations as realistic as possible. This also contributes to the healthcare professional not providing unwanted services to the patient and prevent overuse of resources [43]. With the results of this study insight in patient expectations is gained. Possibly the care process can be adjusted or the patient expectations can be adjusted.

Patient journey (mapping)

This study is about the patient journey of receiving intravenous oncological medication at home. Patient journey mapping is a relatively new methodology used across the healthcare sector to improve quality of care [44]. The patient journey represents a timeline of the entire sequence of all touchpoints [45] (i.e. interactions, activities, interventions, etc.) between the patient and healthcare professional(s) within the healthcare system or all stages of a disease, such as receiving medication at home, and how the patient feels about it. [46]. This makes the patient journey map a combination of the medical (functional) and emotional journey [44] [45]. The patient journey map will be created from the patient's perspective [45] and gives therefore insight in the patient experience across the entire care journey [47] The experiences of the patient in the patient journey will most likely change along the entire journey. Insight in the patient journey enables healthcare professionals to improve the patient experience and make the care more patient-centred [48]. By visually mapping the patient journey it becomes clear where improvement in the journey is possible to better fulfil patient needs [44] and identify which steps are value adding [49]. Normally both the emotional (e.g. respect,

compassion, etc.) and functional journey (e.g. effectiveness, efficiency, etc.) are incorporated in the map [45], but for this study only the emotional, also called rational, journey is of importance. This is because the focus is on the service the hospital provides to the patient and not on the treatment results. There is no standard approach on how to map the patient journey, but a number of steps are often performed. The first step is to decide on which patient journey to map [50] [51]. In this case that are the care pathways of receiving intravenous oncological medication at home by Rijnstate hospital, see Appendix 1. The second step is to identify all actors that are involved in the journey. Actors can be doctors and nurses, but also a hospital bed or electronic patient file. Thirdly, the journey has to be divided in phases such as pre-visit, visit and post-visit. Then the actors can be placed in certain phases of the patient journey, the touchpoints. These are interactions the patient has with actors. Every touchpoint is classified by the patient in the map [50]. For example, by use of smileys or emoticons [51]. Thus a clear display of the experiences of patients is given and improvement points are identifiable [52]. The specific care pathways of pembrolizumab and zoledronic acid at home will be used to compose the patient journey map. By interviewing the patients [50] [52], the patient experience can be included in the patient journey map [48]. By interviewing patients till saturation of expectations and experiences occurs, it becomes clear what the most frequently mentioned positive and negative expectations and experiences are. In this study it is not the aim to map the patient journey, therefore only a simplified patient journey map will be constructed. In the Method section the construction of the patient journey map in this study is described. In summary, patient journey mapping gives insight in the patient's perspective on contact moments with for instance healthcare professionals, the needs of the patient and improvement points in the patient journey to optimize the patient experience [51].

Method

To answer the research question, “*What are the expectations and experiences of cancer patients in receiving intravenous medication at home by Rijnstate hospital?*”, qualitative research is conducted. Two patient groups were interviewed. In the first group cancer patients were interviewed before receiving intravenous medication at home for the first time. In the second group cancer patients were interviewed after starting with receiving intravenous medication at home. By interviewing the first group insight in the expectations of cancer patients about receiving intravenous medication at home was obtained and by interviewing the second group insight in the experiences of cancer patients about receiving intravenous medication at home was obtained. The choice for interviews is based on the principle that with interviews more in-depth information could be obtained. In this case that is desirable because it concerns thoughts, feelings and perceptions of cancer patients that are not yet noted [53]. Therefore this is an explorative-descriptive study [54].

Study population

The study population consists of cancer patients that are treated with pembrolizumab (immunotherapy) against lung or bladder cancer, or zoledronic acid (medication for osteoporosis in cancer treatment) at Rijnstate hospital. These medications have been transferred to home administration from May 2021 onwards and are administered intravenously. The three differences between the treatments with these two medications are that patients treated with pembrolizumab receive two administrations at home and then one administration at the oncological day care ward, so every third administration is at the hospital. For zoledronic acid receive all administrations at home. The second difference is that pembrolizumab for lung cancer patients is administered every three weeks, pembrolizumab for bladder cancer is administered every six weeks and zoledronic acid is administered every three months in case of metastasis or six months in case of no metastasis. The last difference is that the administering time of pembrolizumab is 30 minutes and for zoledronic acid this is 15 minutes. This could be of influence on expectations and experiences of patients, because the patient spends more time with the nurse. This is not studied because it was out of the scope of this study.

From two patient groups, patients were interviewed individually. One group (A) only received their medication on the oncological day care ward at the hospital and was interviewed to obtain information on expectations. The other group (B) has received their medication at home and was interviewed to obtain information about experiences.

Inclusion criteria

To be included in this study the participants are treated with pembrolizumab against lung or bladder cancer or zoledronic acid against osteoporosis in cancer treatment.

Group A) The patient receives one of the last or already received the last intravenous administrations of pembrolizumab or zoledronic acid for the treatment of cancer at the oncological day care ward of Rijnstate hospital and has an appointment to receive the first intravenous administrations of pembrolizumab or zoledronic acid for the treatment of cancer at home at the time of this study.

Group B) The patient received at least the first intravenous administering of pembrolizumab or zoledronic acid for the treatment of cancer at home at the time of this study.

For both groups applies that:

- The patient is able to speak and understand Dutch.

- The patient gives informed consent to participate in this research study.

Each group includes approximately 10 patients, because of the expectation that at that number of participants saturation was reached. This means that at that number no new relevant information came up when interviewing new participants about expectations and experiences about receiving their intravenous medication at home.

Informed consent

Every patient who fulfils the inclusion criteria (according to the treating nurse or specialist) was called by his/her treating (specialised) nurse to inform the patient about this study and ask if the patient is interested to be interviewed by the researcher. When the patient was interested, the patient received an information letter and informed consent form at his/her home address or e-mail address. The templates of the information letters and corresponding informed consent forms can be found in Appendix 2. For questions the patient could contact the researcher or treating (specialised) nurse by phone or e-mail. Five to seven days later the researcher called the patient to ask if the patient has decided to participate and if so, plan the interview. Every participating patient had to sign two informed consent forms, which were already signed by the researcher, and send one form back to the Oncology Department of Rijnstate hospital in a pre-stamped return envelope or by e-mail. At the start of every interview, the researcher asked the patient for permission to record the interview and also a verbal informed consent, which were recorded.

Privacy & ethics

The interviews are audio recorded. The data recording was done on an Iphone which is secured with a password and only the researcher knows this password. The audio data was transcribed within a week after the interview. Thereafter the audio recordings were deleted. The transcripts were saved on a specific secure part of the University of Twente (UT) server and on the Rijnstate server, only accessible for the researcher and supervisors from the University of Twente and Rijnstate hospital. In the audio recording or processing of the interviews no personal identifiable information of patients is mentioned. The transcribed interviews were numbered. This number was linked to the participants personal information including the patient's name, e-mail address, telephone number and amount of received treatments with the medication. This number and personal information have been saved only in Rijnstate hospital in a separate file which is besides the (specialised) nurses, only accessible for the researcher and the project manager of Rijnstate hospital. In reports or publications of this study the information of the interviews is not traceable back to a particular patient. The personal information and transcribed interviews of the patients have been saved for 2 years.

The ethical review committee of the UT and the Local Ethical Committee of Rijnstate hospital gave permission for this study.

Data collection

Each interview took approximately 30 minutes. The patients were not visiting the oncological day care ward anymore till the interview. Therefore the interviews were conducted via a video(call). Besides that, going to the participant's home for interviews was not practical, too burdensome for the patient and unsafe because of the presence of the COVID-19 pandemic. When making the appointment for the interview the participant was asked about the preference regarding the communication channel, for example calling by phone or FaceTime, Zoom, etc. In this way it was aimed to make the patient feel comfortable. The interviews were semi-structured in order to give the respondent the opportunity to tell his/her story. In all interviews the same five themes were

discussed. These are further described at the section Interview schemes. In Appendix 3 both interview schemes can be found.

Outcome measures

The two outcome measures in this study are patient expectations and patient experiences.

Patient expectations

In this study the ideal, so desired, patient expectations were measured because that gives information about what patients really wants [29] [30]. These are the ideal expectations that patients have about the service of receiving intravenous medication at home.

Patient experience

Patient experience is defined as the perception of the patient about the care received from the hospital at home [32]. The focus is on the experience patients have with receiving the service of intravenous medication at home.

Interview schemes

Structure

Both interview schemes can be found in Appendix 3. The structure of both interview schemes starts with an introduction in which the researcher asked the respondent to record a verbal informed consent. Also the aim, the structure, the duration, and a short explanation of receiving medication at home was discussed at the start of every interview. The explanation was kept short to prevent navigating the respondent too much and only give the information that is really needed to answer the questions. After the introduction, the respondent was asked about who they live with in order to get an idea of whom the respondent lives with and if that is an influence of the expectations or experiences the respondent has about receiving intravenous medication at home. Thereafter the start date of the treatment with pembrolizumab or zoledronic acid was checked by the respondent and researcher/interviewer. During every interview the researcher introduced the respondent to the subject of receiving medication at home with discussing the care they receive at the oncological day care, what they think of that care and what they expect from (group A) or how they experience receiving the care at home (group B). In this way the respondent has a frame of reference. Ideally the respondent started telling his/her story after that. If that was not the case, the researcher introduced one of the themes in the interview scheme to get the respondent tell his/her story. Therefore it were semi-structured interviews. The sequence of addressing themes was partially dependent on the respondent and how the interview unfolded. The interview was a dialogue and the themes and questions in the scheme gave direction to it [53]. It gave the respondent also the opportunity to add information which would otherwise not have been addressed. When the respondent was talking, follow-up questions were asked to let the respondent further explain or give examples. In this way the researcher was able to fully understand the respondent [53]. To close the interview, the respondent was asked if he/she had questions, remarks or additions to what was discussed during the interview. To check if the researcher understood the respondent correctly, the researcher summarised the interview. Finally the respondent was thanked by the researcher.

Themes

Five themes were set up for both interview schemes. These are planning & coordination, communication: information & education, communication: interpersonal relationship, privacy & social impact and time management. Table 1 shows the basis of which the themes were chosen and gives a description of the themes. These themes are ordered in a matching sequence with the care pathways of the treatment with pembrolizumab or zoledronic acid. In Appendix 1 the nearly similar

care pathways of medications can be found. These themes were derived from a literature search in which validated questionnaires, and qualitative and quantitative studies about patient experience were found. Research into patient expectations is not very comprehensive, especially not for this type of medications. Therefore no suitable validated questionnaires on expectations were found to be included in setting up the themes for the interview schemes [29] [35]. By measuring patient experiences, patient-centred care is an important component. The themes set up in the interview schemes correspond with the principles of the patient-centred care approach [31] [55] [56]. Apart from literature research, the themes were derived from the care pathways which can be found in Appendix 1, and experts opinions. The themes in the interview scheme are not exhaustive.

Table 1. Themes of interview schemes expectations and experiences of cancer patients receiving intravenous medication at home

Theme	Source	Description
Planning & coordination	Literature + care pathway	The expectations and experiences of the care is organised at home in terms of coordination and planning [57–61]. This includes for example, how (channel) and when (timeframe) they will be informed about appointments, if they can contact planners, etc.
Communication: information & education	Literature	The expectations and experiences of cancer patients about the provision of information by the nurse about the progress and status of the disease or the treatment and medication at home, to inform and educate the patient to the degree the patient needs and wants [57–66]. Hereby only taking into account the information you can expect from a nurse. Important is how information is provided. For example, the nurse should pay attention to avoiding the use of medical jargon [57,59,64,65,67] and be clear to the patient when explaining [58,60,61]. The nurse can possibly even facilitate autonomy and self-care by providing information.
Communication: interpersonal relationship	Literature	The expectations and experiences of cancer patients about emotional support [21,58,60,61,63,65,68,69], trust [21,57,58,69], understanding [66], help with coping, comforting [63], attention to needs and preferences [58–61,66,67], active listening [57,65,66], taking enough time, respect for patient’s values [57,58,60,61,64–66], empathy [63,67], compassion [60,70], relieving anxiety [23,58] and friendliness [21] from the nurse at home. Summarised, how the patient and the nurse’s relationship is.
Privacy & social impact	Literature	The expectations and experiences of cancer patients about the social impact of being in their home instead of the hospital. This concerns the opportunity to ask embarrassing questions because of more privacy [21,61,64], but also the presence of family or other housemates and how to cope with that [21]. Privacy can also reduce because of neighbours taking note of the visit of the nurse. The patient can also feel more autonomous [71], empowered, secure, physically comfortable [58,61] and normal at home [21]. On the other hand, having a nurse at home can cause stress.
Time management	Literature + care pathway	The expectations and experiences of patients in their time commitment when receiving care at home. They do not have to travel and they can continue other duties [23]. For example, spending more time with family and children, working more [21] and daily activities. However for some patients it possibly does not make a difference in time management.

Data analysis

The steps in the data analysis were recording the interviews, transcribing the interviews, coding the interviews and analyse the data. The audio recorded interviews were transcribed using Amberscript. The transcripts were checked for mistakes by the researcher and if needed adjusted. Thereafter thematic analysis was performed to analyse the data by the themes of the interviewschemes [72]. This in an inductive approach. The programme ATLAS.ti was used in this process. At first relevant text fragments were marked when reading the finished transcripts. These fragments were labelled with an open code. After all fragments were coded, the open coding process was reflected by looking for codes to merge within and between interview transcripts. This is called axial coding. In this way the amount of codes was reduced. Nevertheless, every code that was only mentioned once and therefore could not be merged, was included in the data analysis. Also attention was given to the relevance of the codes and if information is missing. Then the codes were ordered within the 5 themes of the interview schemes and distinction was held between expectations and experiences, and about the oncological day care or at home. After axial coding, reflection took place again.

When all data was present the findings were reported systematically by providing tables for every sub question. First a table including experiences at the oncological day care per theme was created. Then per theme a table was created including expectations and experiences about this theme. Within the tables (the themes,) codes, a description of the code and a quote was provided. The positive codes were marked as green and the negative codes were marked as red. If a positive code was mentioned by more than 50% of the patients it was included in the Results section. If a negative code was mentioned by more than 25% of the patients it was included in the Results section. The complete tables with all codes are presented in Appendix 4, in which the codes presented in the Results section are made bold. The percentages are different because negative codes were overall mentioned less than positive codes. No numbers are mentioned in the tables because in every interview all five themes were discussed but not all the same questions were asked. This is because all patients are different. Therefore mentioning numbers at every code gives no truthful information because when for example four patient are positive about something this does not mean the rest of the patients is negative about that and no there is no certainty everything is told by the patient.

To give a clear overview, the results were processed in a simplified patient journey map. This map is divided in three phases, which are before the administration, during the administration and after the administration. Within each phase relevant themes from the interview schemes were placed. Then the most mentioned positive, which are made green, and negative, which are made red, expectations and experiences are placed at the phase and theme they belong to. These are all the aspects that are in the tables in the Results section. This gave a clear display of the results in this study.

Results

In this section the findings from the interviews will be described. Firstly, an overview of the characteristics of the study population is described, then the experiences of cancer patients about receiving intravenous medication at the oncological day care of Rijnstate are described and consecutively the expectations and experiences of cancer patients about receiving intravenous medication at home by Rijnstate are described per theme from the interview scheme. To conclude a patient journey map is presented, including the most mentioned positive and negative expectations and experiences from cancer patients about receiving intravenous medication at home.

Participant characteristics

In total 22 cancer patients receiving intravenous medication by Rijnstate were interviewed by the researcher. As displayed in table 2, because of saturation, eight patients instead of 10 patients were interviewed about their expectations of receiving intravenous medication at home. Instead of 10 patients, 14 patients were interviewed about their experiences with receiving intravenous medication at home. However saturations was reached at nine patients, the remaining interviews were already planned and therefore conducted.

Table 2. Number of cancer patients interviewed about expectations and experiences of receiving treatment with pembrolizumab or zoledronic acid at home

Interview group	Medication	n
Expectations	Pembrolizumab (lung cancer)	4
	Zoledronic acid (osteoporosis)	4
	Total:	8
Experiences	Pembrolizumab (bladder cancer)	1
	Pembrolizumab (lung cancer)	3
	Zoledronic acid (osteoporosis)	10
	Total:	14

Table 3. Characteristics of interviewed patients per patient group

Patients interviewed about expectations			Patients interviewed about experiences		
		n (%)			n (%)
Age	36-45 years	2 (25)	Age	56-65 years	4 (28.5)
	46-55 years	0 (0)		66-75 years	4 (28.5)
	56-65 years	4 (50)		76 years or older	6 (43)
	66-75 years	2 (25)			
Gender	Male	1 (12.5)	Gender	Male	2 (14)
	Female	7 (87.5)		Female	12 (86)
Nr. of administrations with pembrolizumab or zoledronic acid	0-5	5 (62.5)	Nr. of administrations with pembrolizumab or zoledronic acid	0-5	8 (57)
	6-10	3 (37.5)		6-10	4 (29)
				11-15	0 (0)
				16-20	2 (14)
Living with a partner	Yes	7 (87.5)	Living with a partner	Yes	10 (71)
	No	1 (12.5)		No	4 (29)
Living with child(ren)	Yes	4 (50)	Living with child(ren)	Yes	1 (7)
	No	4 (50)		No	13 (93)

In table 3 is presented that the patient's ages range from 41 to 82 years, with a mean age of 58 years for patients in the expectations group and a mean age of 70 years for patients in the experiences group. The standard deviations are respectively 11 years and 9 years. The distribution of gender is almost similar in both groups. For the expectations group this is 12.5% males and 87.55% females. For the experiences group this is 14% males and 86% females. The number of administrations the patients already got with their medication at the hospital and/or at home ranged from two times to 18 times. Most patients who already experienced receiving their intravenous medication at home only received their intravenous medication at home once at the time of the interview. This is because most patients in this group are treated with zoledronic acid (10 out of 14) which is only administered every three months to every six months. The patients were interviewed not more than two months after their first time of receiving their medication at home, so all patients treated with zoledronic acid only received their medication at home once. Two patients received it already two times at home and one patient received it already three times at home. These were patients who are treated with pembrolizumab. The remaining patients treated with pembrolizumab received this medication only once at home. Only five patients live alone, one patient in the expectations group and four patients in the experiences group. The rest of the patients live with their partner, of which five patients also have one or two children living with them at home. In the expectations group this are four patients and in the experiences group this is one patient.

Experiences of cancer patients receiving intravenous medication at the oncological day care

Overall, every interviewed cancer patient seems satisfied with and positive about the care they receive at the oncological center in Rijnstate. In this section the oncological center as a whole is taken into account. The oncological day care is a part of the oncological center and for their treatment patients also come at other parts of the oncological center such as consulting rooms. This makes everything at the oncological center connected with each other, through the patient's eyes. Therefore in the interviews patients made no clear distinction between experiences at the whole center or just the day care. In table 4 experiences of cancer patients with receiving intravenous medication at the oncological center are presented. These are categorized by the themes from the interviewschemes. These themes are focused on receiving medication at home, because then comparisons between receiving medication at home and at the oncological day care can be made. In this case receiving medication at the oncological day care is the frame of reference. Below quotes from cancer patients about the care at the oncological center are presented. This gives an insight in the feeling cancer patients have about the care they receive there.

"I am completely satisfied with the oncology in Rijnstate. I have a very nice oncologist. The way the nurses treat me is very nice and warmly. I can't say it any other way. I am very satisfied with Rijnstate"

"It will be ensured that you have a pleasant experience there"

"They work really hard"

"The treatment in the hospital, on that ward, couldn't be better"

The most frequently mentioned positive experiences at the oncological day care are the provision of information, asking questions, the behaviour of nurses, the social interaction with the nurses, the and the service at the oncological day care. Improvement can be made in puncturing the patient's veins and waiting too long before the administration can start. Despite the fact that the patients did not like having to wait and the nurse having difficulty with puncturing veins, no cancer patient could

mention improvement points for the oncological center. The table including all experiences patients have with receiving care at the oncological day care are presented in Appendix 4A.

Table 4. Experiences of 22 cancer patients with receiving intravenous medication at the oncological center of Rijnstate hospital¹

Theme	Code	Description	Quote
Communication: information & education	Provision of information	Information about the treatment of the patient is explained clearly	<i>"Well I actually already have answers before I have a question. I noticed that with this treatment, that everything is explained so clearly by the nurses and the doctors. At least the people I've dealt with. They explain it, you get it and you know what's going to happen"</i>
	Asking questions	Patients can always ask all staff questions and knows who and how to ask questions	<i>"The nurses always answered my questions and when they did not know they said you should ask the doctor or nurse specialist"</i>
Communication: interpersonal relationship	Behaviour of nurses	Nurses are human, friendly, empathic, respectful, etc.	<i>"They are darlings. I really mean it"</i>
	Social interaction with nurses	Nurses make always time to have a (little) chat with the patient	<i>"The nurses really pay attention to you when they are working with you. Not that we have the time to really chat too long or anything, but they are interested. They ask how you are and things like that"</i>
	Service	Patients get offered coffee, tea and something to eat during the administration	<i>"I often went there in the morning and there was a nice lady who gives people coffee and tea. He gave all kinds of tasty things like a sandwich or ice cream with whipped cream. I liked that too"</i>
Time management	Waiting	Sometimes waiting for results at consulting hours or administration at the oncological day care takes too long	<i>"You always ensure that you are in the hospital early and then sometimes you even have to wait longer...For example, the last time we went to the doctor, the doctor was called away to the ICU for an emergency. That is not ideal, but that can always happen. If they know that you have to get a medicine, then I also think that they should make sure that the medicine is on the ward and that you don't have to wait another 30 minutes for the medicine to arrive"</i>

Other	Puncturing	Difficulty with puncturing a vein with the needle	<i>“That hurts and it happened again. Then you just feel that something is not right and that hurts. Then it continues to hurt and the needle has to come out again. I think that's the bad thing about it. It is not the nurse's fault. My veins are just difficult to puncture”</i>
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¹ The first column presents a theme from the interview scheme, the second column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive experiences are made green and aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Expectations of cancer patients about receiving intravenous medication at home

Of the cancer patients 90% had positive expectations about receiving their intravenous medication at home by Rijnstate hospital. They expect receiving their medication at home is similar to receiving medication at the oncological day care and is minimal as good or even better than at the oncological day care. Below quotes from cancer patients about receiving their medication at home are presented. This gives the insight that patients are in general positive about the care they expect to receive at home.

“If it is allowed, then it is only very pleasant and very nice that this is a possibility these days”

“The treatment at the hospital was fine and I didn't find it a problem to go there. At home is just ideal. You can't get it any nicer than that. And I see it as a good sign that I am allowed to get my medication at home”

“I just think it is a very sweet, great service that they come to my home”

One patient did not expect to like receiving medication at home. This patient wants to keep all medical activities out of home, because otherwise it feels like home becomes a hospital. This means that seven out of the eight interviewed cancer patients have positive expectations about receiving their medication at home. However, to be sure about their opinion all patients said they first have to really experience receiving their medication at home. Even the patient who has expects not to like it, said to be willing to try it. All patients said that if they do not like it afterwards, they want to have the choice to receive their medication at the oncological day care again.

Experiences of cancer patients with receiving intravenous medication at home

From the 14 patients that were interviewed about their experiences with receiving intravenous medication at home, 13 patients have good experiences with it. This is 90%. Below quotes from cancer patients about receiving their medication at home are presented. This gives the insight that patients are in general positive about the care they receive at home.

“I experienced it as very pleasant”

“I loved it. I found it relaxing”

“I think it's nice that they come to my home. I think that's wonderful”

“I honestly prefer treatment at home”

"I think it's ideal"

A couple of patients also mentioned that first having a couple of administrations at the oncological day care makes receiving medication at home more familiar, because the patients know the nurse from the oncological center and know roughly what the nurse is going to do. However, for a few patients it was at the beginning a little bit strange to receive their medication at home, but that feeling passed quickly. Half of the patients expected it to be similar to receiving medication at the hospital and it matched this expectation. In the quote below a patient tells about this.

"No, it doesn't really make any difference. In the hospital I was laying on a bed both times. There were very nice nurses. At home you just sit comfortably in your own chair with a cup of coffee. That is the only difference, but of course more fun"

One patient really does not want to receive her medication at home. In the next quote this patient motivates this.

"I like it better in the hospital. That also has to do with the fact that my veins are difficult to puncture. Occasionally a whole team was brought in for that. I also think that illness belongs in the hospital and as little as possible at your own place. If I was really ill and not capable of doing anything, then I might like it. The way I am now, I rather just go to the hospital"

Two other patients that have good experiences with receiving medication at home also prefer receiving their medication at the oncological day care but do not find it a problem to receive medication at home if the hospital chooses for it. One of them just feels more safe at the oncological day care and the administration of the medication was faster there because everything is already installed. The other patient sees going to the hospital as a nice alternation in daily life. In the quote below the patient motivates this.

"I didn't mind going to the hospital. I liked it, especially during the COVID-19 pandemic. Then you could come out of the house and the service there is excellent"

Besides that, there are also two patients who like the treatment at the hospital just as much as home treatment. One of these two patients is willing to go to the hospital if there is a limit, so a maximum capacity, on how many patients can receive medication at home. In the quote below the patient motivates this:

"The treatment in the hospital is perfect, but so is it at home. It's just both perfect. There are no pros or cons. My view is that if they can help someone who is less mobile with receiving medication at home, instead of me and I have to go to the hospital again, it makes no difference to me. I am still mobile and I can still move well"

Themes

In the next couple of tables the expectations and experiences of cancer patients about receiving intravenous medication at home by Rijnstate hospital are presented per theme from the interview scheme.

Planning & coordination

For planning and coordination, only experiences are presented. This is because all patients already had an appointment scheduled for receiving their medication at home for the first time and therefore experiences this. As seen in table 5 the experiences of patients about the planning of the appointments are not positive. The announcement of the time of the appointment is only a day before the actual appointment. This is expected and experienced to be too late by more than 50% (13 out of 22) of the patients. These were nearly all patients who have a job, care for children or other obligations. These patients have more occupied agendas and think it is inconvenient to know the time of their appointment only a day in advance. Patients that are almost not able to go from home, because they are for example in a bad health state, do not mind hearing the time of the appointment only a day in advance. In addition, patients said they are too tired or not feeling well after the administration of the medication that they just already plan the whole day free of any other obligations. Some patients mentioned they that they already knew the time of the appointment a week before and judge that as a reasonable period. This is remarkable, because in the procedure of Rijnstate is written that patients are only informed about the time of the appointment a day in advance. In table 5 only the most frequently mentioned experiences are included, the full table including all patient experiences about planning and coordination is presented in Appendix 4B.

Table 5. Expectations and experiences of 22 cancer patients about the theme 'planning & coordination' about receiving intravenous medication at home by Rijnstate hospital²

Experiences		
Code	Description	Quote
No timeliness of planning of time of appointment	Announcement of the time of appointment is a day in advance and that is too late	<p><i>"I would like to know sooner at what time they will be coming. Now I only hear it the day before. Now I can't actually make appointments on that day. I liked that better in the hospital. Then I already knew when I left the day care when the next appointment is. Then I could plan my day around it"</i></p> <p><i>"I find that a bit difficult, because my son plays football three times a week and then we have to eat early. I get to hear the time very late. If the appointment is in the afternoon then it will be difficult for me"</i></p>

² The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Communication: information & education

In table 6 it can be seen that from the patients that did not yet experience receiving medication at home, more than 50% (6 out of 8) of the patients revealed that on some aspects they are doubtful about what to expect when they were asked about their expectations on the different themes. In table 7 the most frequently mentioned are presented and appendix 4D all these aspects are

presented. The most mentioned aspects patients are doubtful about when receiving medication at home are the social interaction with the nurse and the nurse's skills in puncturing veins. One patients who did not yet experience receiving medication at home said it is unclear why the hospital replaced the treatment to the patient's home. This patient said that it felt like it was just announced that the medication would be provided at home from now on and there is no chance given to the patient to decide if they want it. This patients feels like it should first be discussed with and asked to the patient instead of only announcing it. In the interviews about patient's experiences another five patients mentioned that they did not know why the hospital made the decision to provide their care to home. From these five patients three patients also rather receive their medication at the oncological day care. Conflicting is that three other patients mentioned that they were told about the option for receiving medication at home at the start of their treatment with this medication. This made them already curious. In table 6 only the most frequently mentioned expectations and experiences are included, the full table including all patient expectations and experiences about information and education is presented in Appendix 4C.

Table 6. Expectations and experiences of 22 cancer patients about the theme 'communication: information & education' about receiving intravenous medication at home by Rijnstate hospital³

Experiences Code	Description	Quote
Too little provision of information	Patients do not know what to expect from certain aspect in receiving medication at home	<i>In table 7 these aspects are described</i>
Motives for replacing care to patient's home	Unclear why this treatment is replaced to the patient's home	<p><i>"I don't understand the idea behind it, but that's up to Rijnstate and not me. I don't know why Rijnstate does it. Of course I have read something in the newspaper and I found it dubious. I wonder if it is in Rijnstate's interest or in the interest of the patients. I'm still a little sceptical about that. I know the healthcare sector. I know that self-interest always comes first and thereafter the rest. That makes me doubt what the benefit is for Rijnstate and the benefit for the patient"</i></p> <p><i>"I was surprised too, because I thought at the hospital I'm there with six or seven other people at the same time. Then many more people can be treated at the same time. That also saves costs. I was surprised about that"</i></p> <p><i>"I did wonder why they do it. I have already asked the nurses here at home. Is it cheaper, do they need the space, because you need a car and all the stuff that they have to take with them. They said they don't really know either"</i></p>

³ The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive expectations and experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Table 7. Doubts 8 cancer patients have about receiving intravenous medication at home by Rijnstate hospital before the first time⁴

Theme	Code	Description	Quote
Communication: interpersonal relationship	Social interaction with nurse	Unclear what the nurse is doing during the administration and if the nurse and the patients like each other	<i>"I wondered what the nurse the whole hour is doing. Of course I don't know yet. Will she sit down to chat? Or will she do other work? No idea. You just have to wait and see if you like each other. You should have some conversation material with each other when you sit together for an hour"</i>
Other	Puncturing	Questioning what happens is the nurse is unable to puncture the patient's vein	<i>"My veins are pretty hard to puncture so I don't know how that goes. We'll see tomorrow"</i>

⁴The first column presents a theme, the second column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. The codes concerning doubts that were mentioned by more than 25% of the patients are included in this table.

Communication: interpersonal relationship

As seen in table 8 having social interaction with the nurse was expected and experienced during receiving medication at home by more than 50% (18 out of 22) of the patients. Seven patients mentioned that they have no need for extra personal attention at home and do not see it as an added value. The reason they gave is that they have enough contacts in their private life. The patients who do want more personal contact and/or attention from the nurse almost all live alone. In table 8 only the most frequently mentioned expectations and experiences are included, the full table including all patient expectations and experiences about the interpersonal relationship is presented in Appendix 4E.

Table 8. Expectations and experiences of 22 cancer patients about the theme 'communication: interpersonal relationship' about receiving intravenous medication at home by Rijnstate hospital⁵

Expectations		
Code	Description	Quote
Social interaction with nurse	Having an informal chat with the nurse	<i>"Maybe we just sit and chat with each other. Sitting in the garden when the weather is nice. We will see"</i>
Experiences		
Code	Description	Quote
Social interaction with nurse	Having an informal conversation with the nurse with a cup of coffee	<i>"These nurses who came to my house were friendly. They were not rushed and did their job quietly"</i> <i>"The nurse was just very relaxed, having a chat about all kinds of stuff. You are almost all day alone and now you have someone around you for at least an hour and a half. having a coffee and chatting"</i>

⁵The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive expectations and experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are

included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Privacy & social impact

As seen in table 9 is staying at home during the treatment and less confrontations with having a disease expected as an added value of receiving medication at home by more than 50% (respectively 7 out of 8 and 5 out of 8) of the patients. Staying at home during the treatment was also experienced as an added value of receiving medication at home by more than 50% (11 out of 14) of the patients. Most of the partners and children are content with their partner or parent receiving medication at home. In table 9 only the most frequently mentioned expectations and experiences are included, the full table including all patient expectations and experiences about privacy and social impact is presented in Appendix 4F.

Table 9. Expectations and experiences of 22 cancer patients about the theme 'privacy & social impact' about receiving intravenous medication at home by Rijnstate hospital⁶

Expectations		
Code	Description	Quote
Staying in home environment	Staying at home is comfortable and gives more rest	<i>"Especially the activity, it costs a lot of energy to go to the hospital. It is very nice that I can stay in my own routine a bit more. That it can be more relaxed, that I can close my eyes for a moment"</i>
Less confrontation with disease	At home there is less confrontation with having a disease	<i>"That I don't have to go there. I don't like the long hallway I have to go through. It is hard for me, because of my lung problem. That stays in my head, that long hallway. I often can't manage that and because of that I have to use a wheelchair. I don't like that, because it reminds me of how ill I am and makes me feel even more ill"</i>
Experiences		
Code	Description	Quote
Staying in home environment	Staying at home is comfortable and gives more rest	<i>"Home is just home. Recently, I had visitors during the administration and they just stayed. So that wasn't an issue at all"</i> <i>"I am in my own environment. The girl who did it was very nice, very calm. Totally not rushed. I thought it was ideal"</i> <i>"You feel more relaxed. In the hospital I'm not as comfortable as here. Here I have a cup of coffee with me, I sit very calm. It all went very calmly. Then I don't have to worry about it. In the hospital it is very busy, when you go in and out of the hospital. At home I don't have that. I found it relaxing"</i>

⁶ The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive expectations and experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Time management

As seen in table 10 not having to arrange a driver or accompany to the hospital anymore and no traveling time were both mentioned by more than 50% (respectively 15 out of 22 and 12 out of 22) of the patients when asked about expectations and experiences with receiving medication at home. Good to mention is three patients went to the oncological day care alone because they did not need accompany. In table 10 only the most frequently mentioned expectations and experiences are included, the full table including all patient expectations and experiences about time management is presented in Appendix 4G.

Table 10. Expectations and experiences of 22 cancer patients about the theme 'time management' about receiving intravenous medication at home by Rijnstate hospital⁷

Expectations		
Code	Description	Quote
No more arranging driver or accompany	Not having to arrange a driver or accompany to the hospital anymore	"My husband has MS, so I'm glad I don't have to ask him anymore"
No traveling time	No traveling time to the hospital, which includes parking and walking to the oncological center	"I didn't know how busy it is on the way to the hospital. Then I also didn't know how busy it is in the hospital and how long I had to wait. Those kind of things"
Experiences		
Code	Description	Quote
No more arranging driver or accompany	Not having to arrange a driver or accompany to the hospital anymore	"My son or daughter-in-law went along with me to the hospital. They were no longer allowed to come upstairs to the oncological center. They had to wait downstairs or outside. That wasn't good for them either. Now I don't have to bother them anymore"
No traveling time	No traveling time to the hospital, which includes parking and walking to the oncological center	"It's easy that I don't have to get out of the house. That always gives me a bit of trouble"

⁷ The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive expectations and experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Other

As seen in table 11 the nurse having difficulty with puncturing veins is experienced by patients when receiving medication at home. The last aspect is mentioned by more than 25% (8 out of 22) of the patients. In the hospital another nurse can take the puncturing over and try it again, but at home this is not the case and the patient has to be rescheduled for an administration at the oncological day care. Patients mentioned this worries them. In table 11 only the most frequently mentioned expectations and experiences are included, the full table including all patient expectations and experiences about other aspects is presented in Appendix 4H.

Table 11. Expectations and experiences of 22 cancer patients about other aspects then covered within the themes, about receiving intravenous medication at home by Rijnstate hospital⁸

Experiences		
Code	Description	Quote
Puncturing	Difficulty with puncturing a vein or even that the home administration had to be cancelled because nurse could not puncture a vein with the needle	<i>“Now it was no problem. It can happen. If it happens several times and I still have to go to the hospital then it will become a problem. There comes a time when I don't have a car available and then I do have a problem of course”</i>

⁸ The first column presents a code, the third column presents the description of the code and the last column presents a matching quote of an interviewed patient. Positive expectations and experiences are made green and the aspects that could be improved are made red. Only the positive codes that were mentioned by more than 50% of the patients are included in this table. Only the aspects that could be improved that were mentioned by more than 25% of the patients are included in this table.

Patient journey map

To make a more visual presentation of the expectations and experiences of the cancer patients about receiving intravenous medication at home, the most frequently mentioned expectations and experiences of cancer patients are presented in the patient journey map of figure 3. Expectations and experiences almost all correspond with each other. The positive expectations and experiences are mentioned by more than 50% of the patients and the expectations and experiences that are to be improved are mentioned by more than 25% of the patients. The positive expectations are not having to arrange a driver or accompany to go along to the hospital, no traveling time, the social interaction with the nurse, staying in the home environment during the treatment and less confrontation with having a disease. The most frequently mentioned positive experiences are the same, expect for less confrontation with having a disease. The most frequently mentioned positive experiences are the same, expect for less confrontation with having a disease. The most frequently mentioned experiences that could be improved are the announcement of the time one day in advance of the appointment, provision of too little information about what to expect from receiving medication at home, not being clear why the hospital provides the care at home and the nurse not able to puncture a vein.

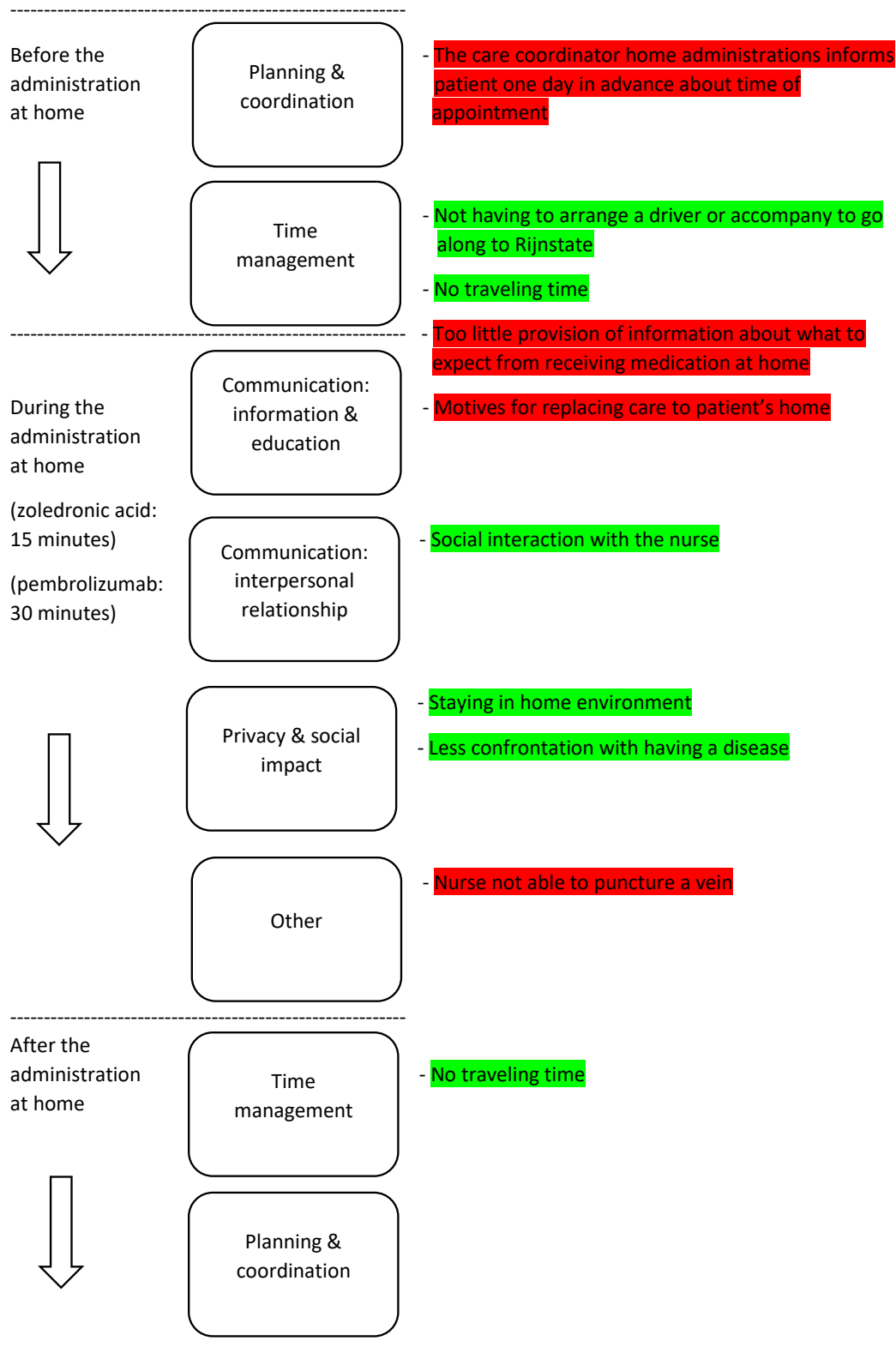


Figure 3, patient journey map including most mentioned positive and improvable expectations and experiences of cancer patients about receiving pembrolizumab or zoledronic acid⁹

⁹ The patient journey map is made up on the themes from the interview schemes in logical order of activities for the patient of receiving medication at home. The positive expectations and experiences within each theme mentioned by more than 50% of the patients are made green and the expectations and experiences that could be improved within each theme mentioned by more than 25% of the patients are made red.

Discussion

In this study semi-structured interviews were conducted with cancer patients treated with pembrolizumab for lung or bladder cancer, and patients treated with zoledronic acid for osteoporosis in cancer treatment, by Rijnstate hospital. The aim was to get insight in the expectations and experiences of these patients about receiving their medication at home. From the results it became clear that cancer patients already seem to have a good experience with receiving intravenous medication at the oncological day care the hospital. Receiving intravenous medication at home was expected and experienced as good by most (90%) interviewed patients. The most frequently mentioned positive expectation is for the theme 'communication: interpersonal; relationship' the social interaction with the nurse. For the theme 'privacy & social impact' it are staying home during the treatment and less confrontation with having a disease. For the theme 'time management' it are not having to arrange a driver or accompany to go along to the hospital and no traveling time. The most frequently mentioned positive experiences are the same, expect for less confrontation with having a disease. The most frequently mentioned experience that could be improved is for the theme 'planning & coordination' that the announcement of the time of the appointment a day in advance is too late. For the theme 'communication: information & education' it are too little provision of information and not being clear to the patient why the care is provided at home. For the other aspects it is when the nurse is not able to puncture a vein. This means that the patient experience could be improved in the planning and coordination of appointments, the provision of information and assurance that the nurse can puncture a patient's vein properly.

Interpretation of the findings and comparison with the literature

This current study shows that the experiences of cancer patients at the oncological day care are generally good. In previous studies about patient satisfaction with chemotherapy nursing care at an oncology day care center in the UK [73] and China [74] also a high patient satisfaction was reported. Both studies were based on a validated questionnaire measuring nearly the same themes as measured in this study, which were waiting time, privacy, interpersonal nursing care, nursing skills and patient information. This supports the results of this study.

Multiple previous studies about patient experiences in receiving cancer care at home found similar results as in this current study. Therefore, this supports the results of this study. A previous study about cancer care at home in Canada [21] found that patients experience more rest and relaxation at home, more privacy, less feeling of being ill and less burden on caregivers, such as family that drives along to the hospital. As expected this corresponds with the findings in this study. Another study about reasons for patients to receive cancer care at home in France [22], results as less confrontation with having a disease and not having to go to the hospital anymore, are also found in this study. In that study the same reason for not wanting to receive cancer care at home was found, which is wanting to separate home life and the place of care. Results from a study about patient experiences with receiving zoledronic acid at home state that patients satisfied with it because of the quality of the relationship with the nurse, no more traveling and/or waiting and being at home. This is similar to the results of this study. A Dutch study about patient satisfaction with providing among others immunotherapy at home, found that patients appreciated one-on-one contact with the nurse at home, the opportunity to ask questions and tell their story [75]. This is similar to the results from this study in which more contact with the nurse is seen as an added value of receiving medication at home. Also new results were found in this study. The dissatisfaction with the planning, provision of information and difficulty with puncturing veins are not found in previous studies. This could be due to the fact that this was not questioned in these studies, because the aims of the studies were

different. Furthermore, in this study a unique interview was set up and used partly based on the specific care pathway of these patients.

The preference of patients between receiving medication at the oncological day care or at home, was not a research question in this study. However, by discussing patient's expectations and experiences, the attitude towards receiving medication at home also was discussed. This led to the question what the preference of the patient was between receiving medication at the oncological day care or at home. It resulted in four out of the 22 patients mentioning that they preferred receiving their medication at the oncological day care. Two other patients out of the 22 patients mentioned they do not really have a preference. The rest of the patients preferred receiving medication at home. Beforehand it was expected that not all patients would prefer receiving medication at home. In previous studies about patient preferences, never 100% of the patients preferred receiving their medication at home [20] and had a motivation for that, such as keeping home life separated from the place of care [22]. In addition, literature shows that patients all have different personalities [30] and have therefore different preferences. In previous studies about preference most patients preferred receiving medication at home [20], the vast majority of the patients (16 out of 22) in this study also preferred receiving medication at home. This means that most patients expect and experience receiving their medication at home (to be) positive.

Patients have different personalities and backgrounds [30] and in literature it is stated that it influences their expectations and experiences. Furthermore, a component of the definition of patient experience is that it is the perception of a patient of the care they receive [32], which is personal and not for everyone the same. This could explain why two patients in this study expected and experienced receiving intravenous medication at home as unwanted and the rest of the patients were content with it or even very positive about it. This is the same with patients that mentioned have a busy life, because of e.g. their job and/or children. These patients want to know their time of appointment earlier than one day in advance and appreciate that receiving medication at home is faster. Interviewed patients who are at home at most times because they are in a bad health state, mentioned they mind less about that. Another finding was that some patients have no need for more personal attention from the nurse, because they have plenty of social contacts in their life. From the interviews resulted that patients who are lonely do have this need. This could possibly mean that being lonely, being in a bad health state and having a busy life, are personal life conditions that influence what a patient wants and therefore expects or experiences. If possible the care at home could be slightly adjusted to the patients personal life conditions of patients.

The most frequently mentioned expectations of cancer patients about receiving intravenous medication at home in this study, largely correspond to the most frequently mentioned experiences cancer patient have with receiving their intravenous medication at home in this study. This could be explained by the fact that the patients already knew what the treatment is like at the oncological day care and base their expectations for receiving medication at home on that. In the literature these are called predicted expectations [28], also called the most realistic expectations. Predicted expectations are among other things based on personal experience as here is the case. This could mean that instead of ideal expectations, predicted expectations were considered by the patients in the interviews. In the Theoretical framework is stated that ideal expectations are often not met and therefore have a negative relationship with patient satisfaction [35]. Predicted expectations on the other hand have a positive relationship with patient satisfaction because they are more likely to match reality [35]. This could be one of the reasons why patients in this study are generally positive about the care they receive at home.

From this study resulted that patients have much more experiences than expectations. This could be due to the fact that patients who did not yet receive intravenous medication at home said they do not really know what to expect precisely. These are unformed [30] expectations and mean that the patient simply does not have the knowledge to formulate these expectations. It is likely that in this case the expectations are epiphenomenal [30], which means that expectations are being shaped as the experience unfolds. For example, patients do not know beforehand that the nurse is arriving in a recognizable car, but in the unfolding of the experience this becomes clear. This means patients have no expectation about it beforehand. If the patient knew, the patient could form expectations on the aspect of a recognizable car arriving at their home. Patients know more after experiences receiving medication at home and that could explain why the experiences of patients are much more comprehensive. When patients are better informed by the hospital before receiving medication at home for the first time they possibly could have more expectations.

Remarkable is that is that when patients said during the interview that their expectations on some aspects are doubtful they tend to expect these aspect to turn out negative. For example, they question the contact with the nurse because what if they do not like each other and they question how much their administration of the medication will be delayed if the nurse is unable the puncture a vein. These are expectations in which patients assume the most negative scenario. This is in line with the theory of managing patient expectations [34] in which it is highlighted that talking with patients about their expectations can make expectations more realistic and therefore less negative. Which is in this case has not happened enough from the patient's perspective, because with at least five interviewed patients this was not discussed, and resulted in negative expectations which are not very likely to happen.

From the interviews it became clear that patients who did not understand why the care is provided at home, did also not see added value in receiving medication at home. Possibly there is a relationship between these two. It was not discussed during all interviews, but it could be that it was not explain to all patients why the hospital made the choice to replace the care to the patient's home. Possibly it could help to make clear to the patient why the hospital made this choice, so the patient can also see the added value of it.

Strengths and limitations

Strengths

The first strength is that this study was theory-based. For this study an interview scheme was set up which was based on five themes. These themes were derived from an extensive literature search about patient expectations and experiences including validated questionnaires about the experience of care in a hospital.

Another strengths of this study is that it gave patients the opportunity to express their experiences about receiving intravenous medication at the oncological day care and their expectations and experiences about receiving this medication at home. Patients mentioned that they appreciated this opportunity, and felt heard and taken seriously by The hospital. They hope that it could make the cancer care even better.

Viewing the care from the patients perspective and thereby studying for the first time both the patient's expectations and experiences about receiving intravenous medication at home makes this study of added value to existing literature. Some expectations and experiences correspond with existing literature, but also newly found expectations and experiences from this specific care pathway are of added value to existing literature. These are the announcement of the time of

appointment must be considerably in advance, more need for information about receiving medication at home before the first time and importance of the puncturing skills of the nurse.

Data saturation in this study was expected to be reached at interviewing 10 patients about expectations and 10 patients about experiences with receiving intravenous medication at home. Eventually, eight patients were interviewed about their expectations and 14 about their experiences. By interviewing eight patients about their expectations about receiving intravenous medication at home, data saturation was reached at seven patients. By interviewing 14 patients about their experiences with receiving intravenous medication at home data saturation was reached. Saturation was already reached at nine patients, but the other interviews were already planned and therefore also conducted. Moreover, it was possible that new information would come out of these interviews. It appeared that patients have fewer expectations than experiences, which could explain why data saturation was reached earlier within the group interviewed about their expectations. The fact that saturation is reached in terms of the interviews could be seen a strength of this study, since this means that the interview set-up has ensured that all the desired information has been obtained from the participants.

Limitations

The interviewed patients often said everything was perfect at the oncological day care and at home, and there were no points of improvement. When asking if the patient rated both as a ten, almost all the patients did not agree and told where improvement could be made. It could therefore not become clear if the patients were totally honest during the interviews. By asking follow-up questions, which is made possible by the semi-structured set-up, and to grade the services, it was attempted to get the most honest answers from the patient. Besides that it was also mentioned to the patients that it is essential to be honest and critical because only then the care can be improved. The fact that all participants already received at least six administrations at the oncological day care, which is a condition before a patient can get permission to receive medication at home, causes the patients to know the nurses and other staff already. This could possibly be an explanation of patients being more positive during the interviews than they really are about receiving medication at the oncological day care or at home. The patients understand for example that nurses do not have a lot of time to talk to them and that nurses not puncture wrong on purpose. If patients were interviewed without knowing the nurses, the answers could be less positive.

Eight patients who initially wanted to participate eventually withdraw. Reasons for these patients not to participate were being in a bad health state, just having received bad medical news, personal circumstances and no interest. Patients who were in a very bad health state were not able to participate and therefore the expectations and experiences of that group are not included in this study. It could be the case that patients in a bad health state have different expectations and experiences because of their circumstances. These patients could possibly make the results from this study even more positive, because for them going to the hospital is difficult and risky.

In this study two different patient groups were included, which are patients treated with pembrolizumab and patients treated with zoledronic acid. The three differences in treatment between these groups are the frequency of administration, the duration of a single administration and that patient treated with pembrolizumab receive two administrations at home and then one at the oncological day care. This means the circumstances are not the same for both groups and these differences could possibly have been of influence of expectations and experiences of patients. For example, the social interaction with the nurse is longer when the administration takes longer and has

a bigger frequency. This was out of the scope of this study and therefore not studied, but expected is that when the interaction with the nurse is longer the importance of it to the patient is greater.

Moreover, most patients only received medication at home once. During the interviews the patients mentioned that they first have to get used to it. Possibly patients who already received medication at home multiple times have different experiences because they experienced it more often.

Further research

With the results of this study a questionnaire can be set up to monitor patient expectations and patient experiences frequently. It could become clear if patient experiences alter when cancer patients receive intravenous medication at home for a longer period of time. Managers can monitor patients expectations and experiences with this questionnaire and from there improve specific aspects in the care pathway and subsequently in the patient journey to improve the patient experience and patient satisfaction [27] [35].

In this study a very specific study population was included causing these results not to be generalizable to a broader set of patients receiving other medications than included in this study because the care pathway of these patients is different. With a questionnaire also larger amounts of patients can be studied about their expectations and experiences about receiving other kinds or the same oncological intravenous medication at home. Moreover, in this study two different patient groups were included, which are patients treated with pembrolizumab and patients treated with zoledronic acid. The three differences in treatment between these two groups are already discussed. In further research it can be studied if there is a difference in expectations and experiences between cancer patients treated with pembrolizumab or zoledronic acid about receiving their medication at home.

In this study the intensity and duration of prior (cancer) treatment of cancer patients is not taken into account. Also a possible relationship between expectations and experiences with receiving medication at home and the intensity and duration of prior treatment is not studied. It could be possible that patients who already went through an intensive medical process, have a bad prognosis or are in a bad health state have a different opinion about receiving medication at home than someone who just starts with the treatment or has a better prognosis. This could be studied in further research.

Recommendations for practice

Based on the results, recommendations for practice for providing intravenous medication at the oncological day care at Rijnstate and at home are provided in this section.

Medication at the oncological day care

All patients receiving intravenous medication at Rijnstate seem very satisfied with it. This means that Rijnstate has to keep it that way and continue with this. There are two aspects about receiving intravenous medication at the oncological day care not all cancer patients are satisfied with. The first is sometimes having to wait before their administration can start. To reduce the waiting times it is recommended to investigate whether there are possibilities to improve the planning of administrations and coordination of the preparation of medication. Waiting times caused by emergencies cannot be solved. Possibly with providing intravenous medication at home, it could be less busy at the oncological day care and as a result waiting times will be shorter or even no waiting times at all anymore. The second aspect is the nurse having difficulty with puncturing a vein with the needle. To reduce the problems with puncturing veins, the hospital already took action by installing a team to help when the nurse is having difficulty puncturing a vein with the needle. Another solution is to reduce the problem could be offering a puncturing course for all the nurses who need to improve their skills.

Medication at home

The expectations and experiences of patients receiving intravenous medication at home are generally very good. Although there are some aspects where improvement is possible. The three aspects which need the most improvement to create an even better patient experience are that the announcement of the time of appointment is only a day in advance, too little provision of information before the first administration at home, not being clear to the patient why the care is provided at home and the nurse having difficulty with puncturing a vein with the needle.

Planning & coordination

Patients know the date of their appointment already weeks in advance, but they only know the time of their appointment a day in advance. A lot of patients mentioned that they would prefer knowing the time of their appointment earlier than a day in advance. The reason for this is that they have a busy life, because of their job, care for children and other obligations. Hearing the time of appointment only a day in advance is for them inconvenient, because then they cannot plan other obligations on the day of the appointment. During the interviews several patients mentioned that it would already really help to at least know the time of appointment a week in advance of the actual appointment. Then patients can plan their other obligations around it.

Information & education

In the literature it is stated that patients receiving all kinds of treatments require information about their treatment [28], this is also the case for receiving their medication at home. Patients mentioned during the interviews they are doubtful on what to expect on certain aspects because they were not informed about it. Physician-patient communication is important in managing patient expectations [31]. It could help to communicate with patients about what they think about and expect from receiving their medication at home beforehand. At first this can be discussed during consultations hours with the patient but afterwards also by nurses during the providing of medication. Also information letter could be offered specifically for receiving medication at home. In the literature is stated that showing empathic communication is important because it can increase the truthfulness of the derived expectations [42]. The healthcare professional can inform the patient about what this patient could really expect and if that raised any further questions. A couple of patients already

mentioned during the interviews that their physician asked them about their opinion about receiving medication at home beforehand. It is important to discuss this with every cancer patient. After discussing expectations with the patient, the healthcare professional can determine that the patient has unrealistic expectations by comparing these with the realistic expectations. If this is the case, the healthcare professional can make the patient aware of it and inform the patient about what they can expect and adjust the expectations of the patient to make the expectations as realistic as possible. Furthermore, patients who did not know why Rijnstate is providing their medication at home almost all did not see the added value of it. If to every patient is explained what the motives are for providing their medication at home, possibly more patients can see the added value of it.

Puncturing veins

Several patients mentioned during the interviews that their veins were difficult to puncture. It causes the patient to become uncomfortable when the nurse is having difficulty with puncturing a vein at home, because it hurts. One patient experienced the nurse not being able to puncture a vein and that patient had to go to the oncological day care the next day to get the administration, because no other nurse can take the puncturing over at home. So when a patient's veins are bad to puncture this causes uncertainty by the patient. It is recommended that if a patient wants to receive medication at home but his/her veins are difficult to puncture, this patient should only receive medication at home from a very skilled nurse. In this way the chance of the nurse having difficulty or not being able to puncture a vein and the chance that the patient's appointment has to be rescheduled at the oncological day care, becomes smaller.

Monitoring

Improving the experience of patients at the oncological day care and at home is not finished after this study but is a continuous process that needs continuous attention. This is a cycle, like the PDCA-cycle (Plan, Do, Check, Act) in which a process, in this case the care pathway of receiving medication at home, is evaluated in a repeated cycle. Therefore, monitoring patients expectations and experiences is very important. As mentioned a questionnaire can be set up to monitor patient expectations and patient experiences frequently. The frequency of monitoring the patient experience with the use of a questionnaire needs to be further determined. Managers and/or nurses can monitor patients expectations and experiences with this questionnaire and from there improve specific aspects in the care pathway and subsequently in the patient journey to improve the patient experience and patient satisfaction [27] [35] or if possible even slightly individualise the provided care based on patient preference [34].

Conclusion

This study explored the expectations and experiences of cancer patients receiving intravenous medication at home by Rijnstate hospital by conducting semi-structured interviews. Viewing the care from the patients perspective and thereby studying for the first time both the patient's expectations and experiences about receiving intravenous medication at home makes this study of added value to the literature and clinical practice. In general patients were already satisfied with the care at the oncological day care and most patients were positive about receiving intravenous medication at home on all five theory-based themes covered in the interviews. Most patients judge for the theme 'communication: interpersonal; relationship' the social interaction with the nurse as an added value of receiving medication at home. For the theme 'privacy & social impact' these are staying home during the treatment and less confrontation with having a disease. For the theme 'time management' these are not having to arrange a driver or accompany to go along to the hospital and no traveling time. The planning and coordination of appointments needs attention, because patients judge that as too late. As a solution and if possible, the patient could be informed about the time of appointment a week in advance. Also patients had questions before receiving intravenous medication at home for the first time. Not all questions can be answered but it can be explained to patients why the hospital choose to provide medication at home and answer questions about it after discussing the option for it with the patient. Furthermore, several patients have veins that are difficult to puncture. At the patient's home no other nurse can take it over when the nurse is not succeeding in puncturing a vein. To prevent that the patient has to reschedule their appointment at the oncological day care, these patients should only receive medication at home from a very skilled nurse. Improving the experience of the patients is a continuous process which is not finished after this study. Therefore, frequently monitoring patients expectations and experiences is important. A questionnaire can be set up to monitor patient expectations and patient experiences.

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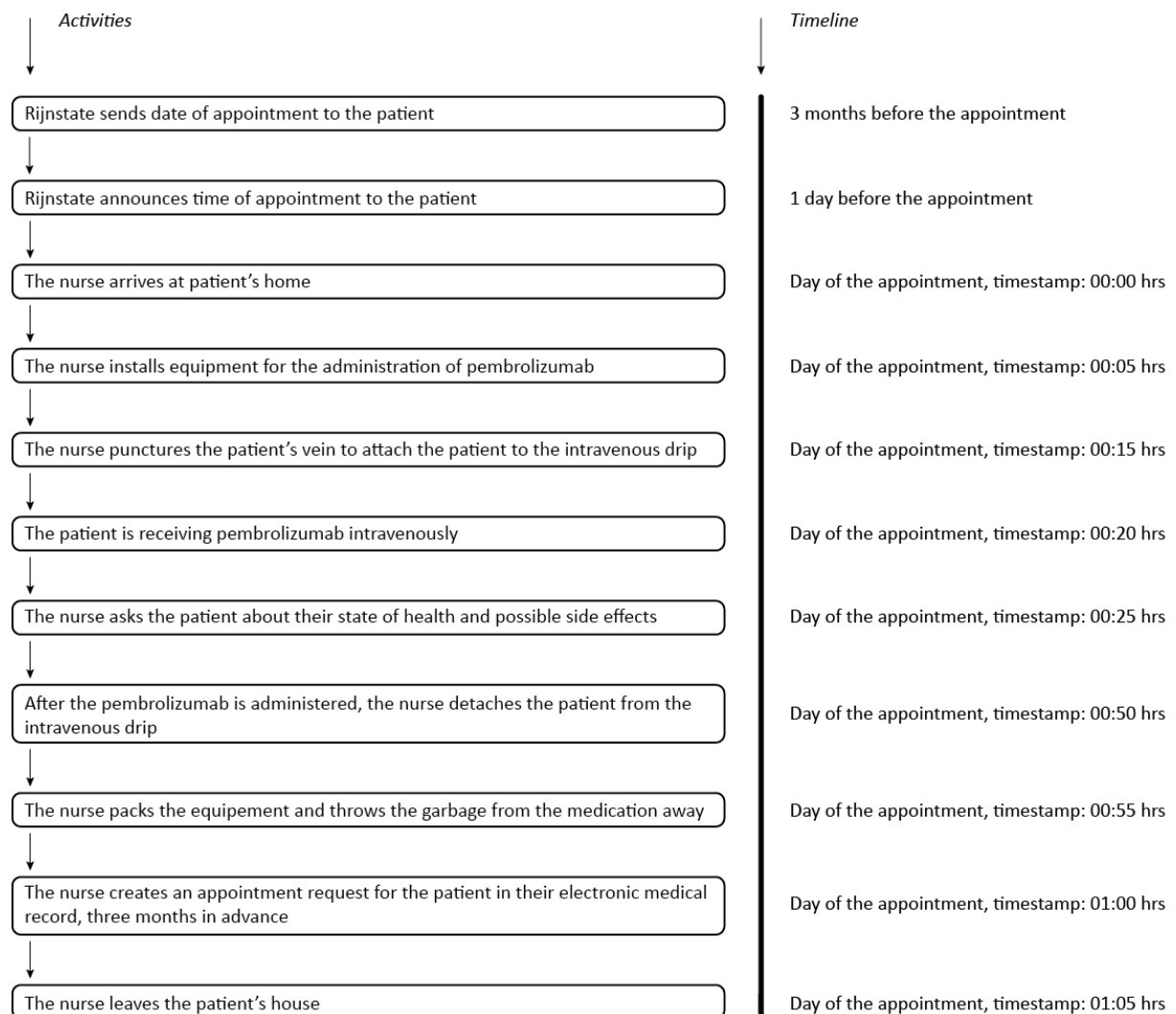
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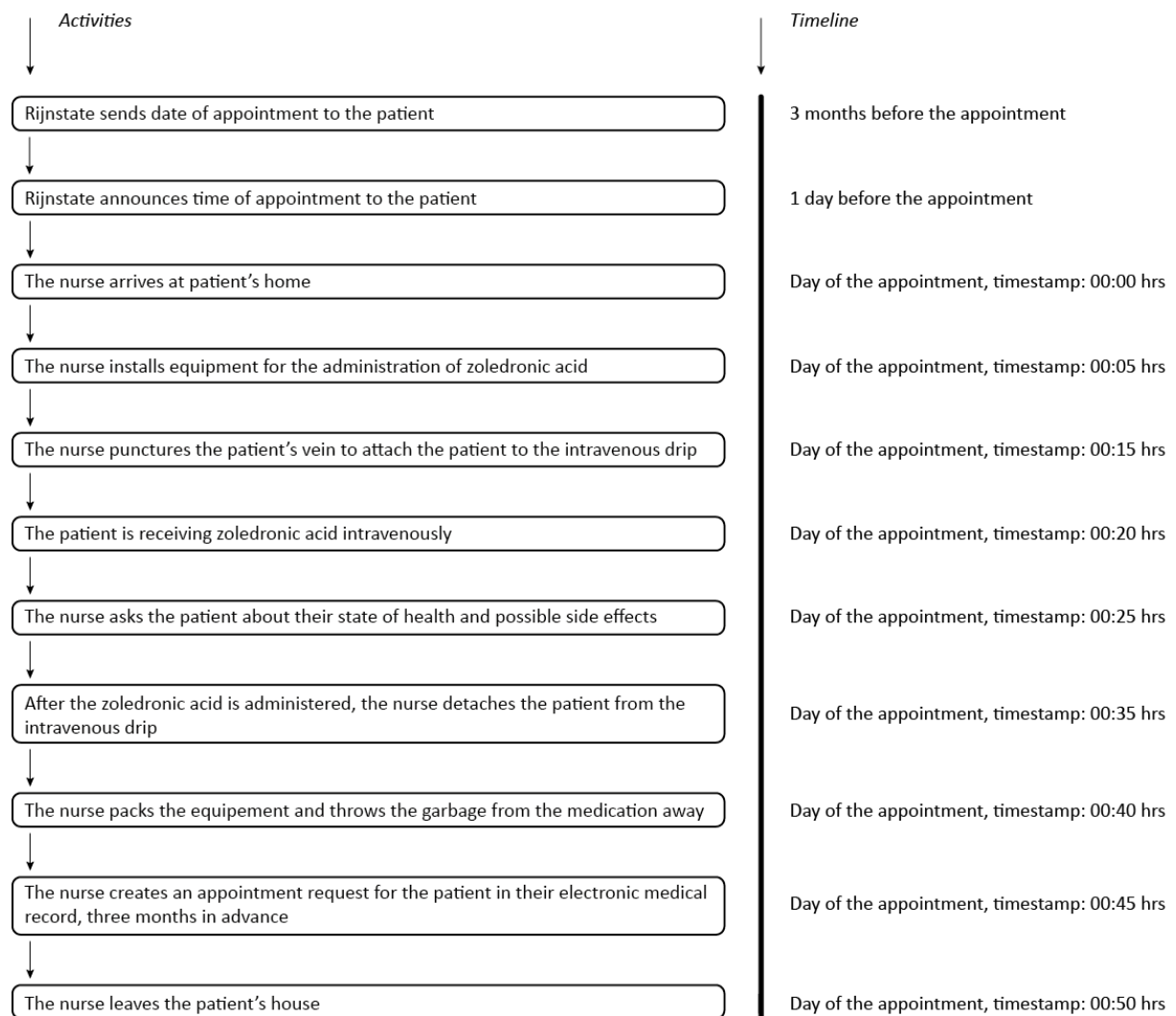
Appendix

Appendix 1: Visual care pathways pembrolizumab and zoledronic acid

Appendix 1A: Visual care pathway pembrolizumab



Appendix 1B: Visual care pathway zoledronic acid





Informatie voor deelname aan medisch-wetenschappelijk onderzoek

Verwachtingen en ervaringen van patiënten over de toediening van medicatie thuis voor de behandeling van kanker

Geachte heer/mevrouw,

U krijgt deze brief omdat u in het Rijnstate ziekenhuis wordt behandeld met het medicijn pembrolizumab voor de behandeling van kanker.

U leest in deze brief om wat voor onderzoek het gaat en wat meedoen voor u betekent. Meedoen is vrijwillig. Wilt u de informatie doorlezen en beslissen of u wilt meedoen? Als u wilt meedoen, kunt u het toestemmingsformulier aan het einde van deze brief invullen en terugsturen.

Algemene informatie

Het Rijnstate ziekenhuis heeft dit onderzoek samen met de Universiteit Twente opgezet. Prof. Dr. Carine Doggen is de lokale hoofdonderzoeker. Loes Meijerink, student Gezondheidswetenschappen, voert het onderzoek uit bij de oncologie afdeling van Rijnstate ziekenhuis. De ethische toetsingscommissie van de Universiteit Twente en de Lokale Haalbaarheidscommissie van Rijnstate ziekenhuis hebben toestemming voor dit onderzoek gegeven.

Wat is het doel van dit onderzoek?

Het doel van dit onderzoek is om inzicht te krijgen in de verwachtingen en ervaringen van u als patiënt in het thuis ontvangen van uw medicatie. Met de resultaten kan de toekomstige behandeling thuis van patiënten goed georganiseerd worden. Met uw deelname draagt u hier aan bij.

Wat houdt meedoen voor u in?

Er worden 10 deelnemers uitgenodigd voor dit onderzoek. Als u deelneemt wordt u geïnterviewd door de uitvoerend onderzoeker. Het interview duurt ongeveer 45 minuten. Het interview gaat over uw verwachtingen over het ontvangen van pembrolizumab thuis. Het interview zal plaatsvinden tijdens uw bezoek aan de dagbehandeling voor het ontvangen van pembrolizumab. Het interview zal plaatsvinden in een aparte kamer met alleen u en de onderzoeker. Als u pembrolizumab al voor de laatste keer

heeft ontvangen op de dagbehandeling of u wenst liever telefonisch geïnterviewd te worden, dan vindt het interview plaats door te (video)bellen met de uitvoerend onderzoeker. Om dit te plannen neemt de uitvoerend onderzoeker telefonisch contact met u op.

Welke gegevens worden er van u gebruikt?

Bij deelname aan dit onderzoek, zullen naast uw antwoorden uit het interview, ook het aantal behandelingen zoals u die heeft gehad met het medicijn pembrolizumab, worden opgevraagd bij uw verpleegkundig specialist Jacqueline Opdenoordt.

Gebruik en bewaren van uw gegevens

Het interview zal worden opgenomen met een audiorecorder. In de opname en de verwerking van het interview zullen geen persoonsgegevens vermeld worden. Uw interview krijgt een nummer. Dit nummer wordt gekoppeld aan uw persoonsgegevens (naam, e-mailadres, telefoonnummer en patiëntnummer) en die zullen gezamenlijk veilig worden bewaard in het ziekenhuis. Dit betekent dat uw gegevens uit het interview alleen terug te herleiden zijn naar u als persoon met behulp van dit nummer. Uw persoonsgegevens zijn alleen inzichtelijk voor de uitvoerend onderzoeker, voor de projectmanager en voor uw verpleegkundig specialist Jacqueline Opdenoordt. In rapporten en eventuele publicaties van dit onderzoek zijn de gegevens niet tot u te herleiden. Op deze wijze wordt u privacy gewaarborgd. Als u het toestemmingformulier ondertekent, geeft u toestemming voor het verzamelen, bewaren en inzien van uw gegevens. Deze zullen 2 jaar worden bewaard.

Vrijwilligheid van deelname

U kunt uw toestemming voor het gebruik van uw gegevens op ieder moment intrekken. De uitvoerend onderzoeker gebruikt wel de gegevens die al verzameld zijn. Als u dat niet wilt, kunnen uw interview gegevens worden vernietigd. Neem hiervoor contact op met de uitvoerend onderzoeker.

Wilt u meer informatie over uw rechten en privacy?

Algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u op de website van de Autoriteit Persoonsgegevens vinden. Dit is de link: www.autoriteitpersoonsgegevens.nl.

Als u vragen of klachten heeft over het gebruik of de verwerking van persoonsgegevens, of over uw rechten, kunt u contact opnemen met de Functionaris Gegevensbescherming van Rijnstate ziekenhuis: e-mail: privacy@rijnstate.nl, website: <https://www.rijnstate.nl/praktische-informatie/mijn-rechten-en-privacy>.

Heeft u nog vragen?

Vragen over het onderzoek kunt u stellen aan de uitvoerend onderzoeker of aan uw verpleegkundig specialist Jacqueline Opdenoordt.

Als u niet meer wilt of kan deelnemen is het van belang dat u contact opneemt met de uitvoerend onderzoeker. Dit kan op elk moment in het onderzoek zonder opgave van reden. Dit heeft verder ook geen invloed op uw behandeling.

Klachten kunt u bespreken met de uitvoerend onderzoeker of verpleegkundig specialist Jacqueline Opdenoordt. Wilt u dit liever niet? Dan kunt u contact opnemen met de klachtenfunctionaris van Rijnstate ziekenhuis: telefoon: 088-0057539, Postbus 955, 6700 TA Arnhem.

Hoe geeft u toestemming voor het onderzoek?

U kunt eerst rustig nadenken over dit onderzoek. Wilt u meedoen? Dan vult u beide toestemmingsformulieren in die u bij deze informatiebrief vindt. Vervolgens stuurt u een getekend formulier op in de retourenvelop naar Rijnstate ziekenhuis en het andere getekende formulier houdt u zelf. Postzegel is niet nodig. Zo hebben de uitvoerend onderzoeker en u beide een getekende versie van het toestemmingsformulier. De uitvoerend onderzoeker geeft aan uw verpleegkundig specialist Jacqueline Opdenoordt door dat u meedoet aan het onderzoek.

Contactgegevens uitvoerend onderzoeker

Telefoon: 06-13479554

E-mailadres: LMeijerink@rijnstate.nl

Dank voor uw tijd.

Met vriendelijke groet,

Prof. Dr. Carine Doggen,
Lokale hoofdonderzoeker Rijnstate ziekenhuis

Loes Meijerink,
Uitvoerend onderzoeker Rijnstate ziekenhuis & Student Gezondheidswetenschappen Universiteit
Twente

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuistoediening van medicatie voor de behandeling van kanker

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn goed beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen met het onderzoek. Of om ermee te stoppen. Ik hoef dan niet te zeggen waarom ik wil stoppen.
- Ik geef de uitvoerend onderzoeker toestemming om mijn verpleegkundig specialist Jacqueline Opdenoordt te laten weten dat ik meedoe aan dit onderzoek.
- Ik geef de uitvoerend onderzoeker toestemming om het aantal ontvangen toedieningen met pembrolizumab op te vragen bij mijn verpleegkundig specialist Jacqueline Opdenoordt.
- Ik geef de uitvoerend onderzoeker toestemming om mijn interview gegevens te verzamelen en gebruiken. De onderzoeker doet dit alleen om de onderzoeksvraag van dit onderzoek te beantwoorden.
- Ik geef de uitvoerend onderzoeker toestemming om mijn interview op te nemen door middel van een audiorecorder.
- Ik wil meedoen aan dit onderzoek.
- Graag ontvang ik aan het einde van het onderzoek een algemene samenvatting van het onderzoek:

Mijn naam is (deelnemer):

Handtekening:

Datum : __ / __ / __

Alleen door de uitvoerend onderzoeker in te vullen

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:.....

Datum: __ / __ / __

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuis-toediening van medicatie voor de behandeling van kanker

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- Ik geef de uitvoerend onderzoeker toestemming om mijn gespecialiseerd verpleegkundige oncologie Bianca Vreven te laten weten dat ik meedoe aan dit onderzoek.
- Ik geef de uitvoerend onderzoeker toestemming om het aantal ontvangen toedieningen met zoledroninezuur op te vragen bij mijn gespecialiseerd verpleegkundige oncologie Bianca Vreven.
- Ik geef de uitvoerend onderzoeker toestemming om mijn interview gegevens te verzamelen en te gebruiken. De onderzoeker doet dit alleen om de onderzoeksvraag van dit onderzoek te beantwoorden.
- Ik geef de uitvoerend onderzoeker toestemming om mijn interview op te nemen door middel van een audiorecorder.
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Datum : __ / __ / __

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Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:.....

Datum: __ / __ / __

Informatie voor deelname aan medisch-wetenschappelijk onderzoek



Verwachtingen en ervaringen van patiënten over de toediening van medicatie thuis voor de behandeling van kanker

Geachte heer/mevrouw,

U krijgt deze brief omdat u in het Rijnstate ziekenhuis wordt behandeld met het medicijn pembrolizumab voor de behandeling van kanker.

U leest in deze brief om wat voor onderzoek het gaat en wat meedoen voor u betekent. Meedoen is vrijwillig. Wilt u de informatie doorlezen en beslissen of u wilt meedoen? Als u wilt meedoen, kunt u het toestemmingsformulier aan het einde van deze brief invullen en terugsturen.

Algemene informatie

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Welke gegevens worden er van u gebruikt?

Bij deelname aan dit onderzoek, zullen naast uw antwoorden uit het interview, ook het aantal behandelingen zoals u die heeft gehad met het medicijn pembrolizumab, worden opgevraagd bij uw verpleegkundig specialist Jacqueline Opdenoordt.

Gebruik en bewaren van uw gegevens

Het interview zal worden opgenomen met een audiorecorder. In de opname en de verwerking van het interview zullen geen persoonsgegevens vermeld worden. Uw interview krijgt een nummer. Dit nummer wordt gekoppeld aan uw persoonsgegevens (naam, e-mailadres, telefoonnummer en patiëntnummer) en die zullen gezamenlijk veilig worden bewaard in het ziekenhuis. Dit betekent dat uw gegevens uit het interview alleen terug te herleiden zijn naar u als persoon met behulp van dit nummer. Uw persoonsgegevens zijn alleen inzichtelijk voor de uitvoerend onderzoeker, voor de projectmanager Rijnstate en voor uw verpleegkundig specialist Jacqueline Opdenoordt. In rapporten en eventuele publicaties van dit onderzoek zijn de gegevens niet tot u te herleiden. Op deze wijze wordt u privacy gewaarborgd. Als u het toestemmingformulier ondertekent, geeft u toestemming voor het verzamelen, bewaren en inzien van uw gegevens. Deze zullen 2 jaar worden bewaard.

Vrijwilligheid van deelname

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Contactgegevens uitvoerend onderzoeker

Telefoon: 06-13479554

E-mailadres: LMeijerink@rijnstate.nl

Dank voor uw tijd.

Met vriendelijke groet,

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Lokale hoofdonderzoeker Rijnstate ziekenhuis

Loes Meijerink,
Uitvoerend onderzoeker Rijnstate ziekenhuis & Student Gezondheidswetenschappen Universiteit
Twente

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuistoediening van medicatie voor de behandeling van kanker

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- Ik geef de uitvoerend onderzoeker toestemming om het aantal ontvangen toedieningen met pembrolizumab op te vragen bij mijn specialist(en) die mij behandelt.
- Ik geef de uitvoerend onderzoeker toestemming om mijn interview gegevens te verzamelen en te gebruiken. De onderzoeker doet dit alleen om de onderzoeksvraag van dit onderzoek te beantwoorden.
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Mijn naam is (deelnemer):

Handtekening:

Datum : __ / __ / __

Alleen door de uitvoerend onderzoeker in te vullen

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:.....

Datum: __ / __ / __

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuis-toediening van medicatie voor de behandeling van kanker

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Handtekening:.....

Datum: __ / __ / __

Informatie voor deelname aan medisch-wetenschappelijk onderzoek

Verwachtingen en ervaringen van patiënten over de toediening van medicatie thuis voor de behandeling van kanker

Geachte heer/mevrouw,

U krijgt deze brief omdat u in het Rijnstate ziekenhuis wordt behandeld met het medicijn pembrolizumab voor de behandeling van kanker.

U leest in deze brief om wat voor onderzoek het gaat en wat meedoen voor u betekent. Meedoen is vrijwillig. Wilt u de informatie doorlezen en beslissen of u wilt meedoen? Als u wilt meedoen, kunt u het toestemmingsformulier aan het einde van deze brief invullen en terugsturen.

Algemene informatie

Het Rijnstate ziekenhuis heeft dit onderzoek samen met de Universiteit Twente opgezet. Prof. Dr. Carine Doggen is de lokale hoofdonderzoeker. Loes Meijerink, student Gezondheidswetenschappen, voert het onderzoek uit bij de oncologie afdeling van Rijnstate ziekenhuis. De ethische toetsingscommissie van de Universiteit Twente en de Lokale Haalbaarheidscommissie van Rijnstate ziekenhuis hebben toestemming voor dit onderzoek gegeven.

Wat is het doel van dit onderzoek?

Het doel van dit onderzoek is om inzicht te krijgen in de verwachtingen en ervaringen van u als patiënt in het thuis ontvangen van uw medicatie. Met de resultaten kan de toekomstige behandeling thuis van patiënten goed georganiseerd worden. Met uw deelname draagt u hier aan bij.

Wat houdt meedoen voor u in?

Er worden 10 deelnemers uitgenodigd voor dit onderzoek. Als u deelneemt wordt u geïnterviewd door de uitvoerend onderzoeker. Het interview duurt ongeveer 45 minuten. Het interview gaat over uw verwachtingen over het ontvangen van pembrolizumab thuis. Het interview zal plaatsvinden door te (video)bellen met de uitvoerend onderzoeker. Om dit te plannen neemt de uitvoerend onderzoeker telefonisch contact met u op.

Welke gegevens worden er van u gebruikt?

Bij deelname aan dit onderzoek, zullen naast uw antwoorden uit het interview, ook het aantal behandelingen zoals u die heeft gehad met het medicijn pembrolizumab, worden opgevraagd bij uw verpleegkundig specialist Paulien Keizer.

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Contactgegevens uitvoerend onderzoeker

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E-mailadres: LMeijerink@rijnstate.nl

Dank voor uw tijd.

Met vriendelijke groet,

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Loes Meijerink,
Uitvoerend onderzoeker Rijnstate ziekenhuis & Student Gezondheidswetenschappen Universiteit
Twente

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuistoediening van medicatie voor de behandeling van kanker

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Handtekening:.....

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Verwachtingen en ervaringen van patiënten over de toediening van medicatie thuis voor de behandeling van kanker

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Twente

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Alleen door de uitvoerend onderzoeker in te vullen

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek.

Naam onderzoeker (of diens vertegenwoordiger):.....

Handtekening:.....

Datum: __ / __ / __

Informatie voor deelname aan medisch-wetenschappelijk onderzoek



Verwachtingen en ervaringen van patiënten over de toediening van medicatie thuis voor de behandeling van kanker

Geachte heer/mevrouw,

U krijgt deze brief omdat u in het Rijnstate ziekenhuis wordt behandeld met het medicijn zoledroninezuur voor de behandeling van kanker.

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Contactgegevens uitvoerend onderzoeker

Telefoon: 06-13479554

E-mailadres: LMeijerink@rijnstate.nl

Dank voor uw tijd.

Met vriendelijke groet,

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Twente

Toestemmingsformulier deelnemer

Verwachtingen en ervaringen van patiënten over de thuis-toediening van medicatie voor de behandeling van kanker

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Interviewschema

Verwachtingen van kankerpatiënten over het thuis toegediend krijgen van intraveneuze medicatie (pembrolizumab & zoledroninezuur)

Gegevens

Naam interviewer:

Respondent nr.:

Datum:

Plaats:

Note: de schuingedrukte tekst is alleen bedoeld ter ondersteuning van de interviewer

Inleiding

Bedankt voor het deelnemen aan dit interview.

Ik ben Loes Meijerink en student Gezondheidswetenschappen aan de Universiteit Twente. Ik doe mijn afstudeeronderzoek in Rijnstate. U bent hierover al eerder geïnformeerd door uw behandelaar en de proefpersoneninformatiebrief. Klopt het dat u toestemming heeft gegeven voor dit interview, het toestemmingsformulier heeft ondertekend en deze heeft verzonden naar Rijnstate ziekenhuis?

Geeft u toestemming om het interview op te nemen?

Het doel van dit interview is inzicht krijgen in de verwachtingen die u heeft over thuis uw medicijn voor de behandeling van kanker via een infuus toegediend te krijgen.

Het interview is opgedeeld in verschillende onderwerpen. Ik wil hierbij benoemen dat er geen goede of foute antwoorden zijn.

Het interview duurt ongeveer 45 minuten.

Toelichting: Thuis krijgt u het medicijn op dezelfde manier als in het ziekenhuis. U krijgt dus ook een infuus. Een verpleegkundige komt bij u thuis langs met alle benodigdheden om dit infuus vervolgens te geven.

Heeft u voordat we beginnen nog vragen?

Persoonlijke situatie

- Wat is uw leeftijd?
- Woont u alleen?
- Zo nee, met wie woont u?

Behandelvoortgang

- Hoe lang wordt u al behandeld met dit medicijn?

Introducerende vragen

- Hoe ervaart u de zorg op de dagbehandeling in het ziekenhuis?
- Zou u iets willen veranderen aan de zorg op de dagbehandeling in het ziekenhuis?
- Zo ja, wat zou u willen veranderen?
- Wat dacht u toen u voor het eerst hoorde dat u uw medicijn thuis kunt ontvangen?

Mogelijke antwoorden: geen zieke mensen hoeven zien in het ziekenhuis, niet meer reizen, meer individuele tijd met de verpleegkundige, meer privacy, meer autonomie, geen contact meer met lotgenoten, etc.

- Welk gevoel krijgt u bij de gedachte dat uw medicijn thuis toegediend zal worden?

Mogelijke antwoorden: stress, (on)rust, geborgenheid, comfort, etc.

- Waarom was u positief of negatief over het thuis toegediend kunnen krijgen van uw medicatie?

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Thema 1: planning & coördinatie

Voor de planning van afspraken voor de toediening van uw medicijn op de dagbehandeling in het ziekenhuis informeert uw behandelaar u tijdens spreekuren.

- Wat vindt u daarvan?
- Hoe zou u willen dat afspraken voor de toediening van uw medicijn thuis zullen worden gemaakt?
 - Kunt u dat toelichten of voorbeelden geven?
 - Door wie wenst u dat de afspraken voor de toediening van uw medicijn thuis worden gemaakt?
 - Op welke manier wenst u daarover te worden geïnformeerd?
 - Hoe lang van te voren wenst u dat een afspraak wordt gepland?
 - Wenst u dat er meerdere afspraken vooruit worden gepland?

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Thema 2: communicatie: informatie & educatie

- In hoeverre geeft de verpleegkundige informatie over uw aandoening en behandeling?
Daarbij rekening houdend met informatie die je van een verpleegkundige kan verwachten.
 - *Hoe geeft de verpleegkundige u informatie?*
Bijvoorbeeld: informatiefolder, telefonisch, spreekuur, etc.
 - *Krijgt u gelegenheid om vragen te stellen?*
Zo ja, op welke momenten?
 - *Geeft de verpleegkundige duidelijke uitleg?*

- Wat vindt u daarvan?

- Hoe zou u willen dat de verpleegkundige u informatie geeft over uw aandoening en behandeling als u thuis behandeld wordt?
 - Kunt u dat toelichten of voorbeelden geven?
 - *Hoe vaak zou u informatie willen krijgen?*
 - *Op welke manier zou u informatie willen krijgen?*
Bijvoorbeeld: informatiefolder, telefonisch, spreekuur, etc.
 - *Waarom wilt u dat?*
 - *Hoe ziet u dat voor zich?*

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Thema 3: communicatie: interpersoonlijke relatie

- Hoe verloopt het contact met de verpleegkundige op de dagbehandeling in het ziekenhuis?
 - *Neemt de verpleegkundige:*
de tijd neemt, heeft respect voor waarden, reageert op behoeftes, etc.
 - *Heeft u een prettig gesprek met de verpleegkundige?*
Zo ja, kunt u dat toelichten?
Bijvoorbeeld luisteren, empathie tonen, begrip tonen, vriendelijkheid, geruststellen, etc.

- Wat vindt u daarvan?

- Hoe zou u contact willen hebben met de verpleegkundige als u thuis behandeld wordt?
 - Kunt u dat toelichten of voorbeelden geven?
 - *Wilt u dat de verpleegkundige:*
de tijd neemt, heeft respect voor waarden, reageert op behoeftes, etc.
 - *In welke mate heeft u behoefte aan een gesprek(ken) met de verpleegkundige?*
Bijvoorbeeld angst wegnemen, vertrouwen geven, emotionele steun, op het gemak stellen, etc.
 - *Hoe wilt u dat het gesprek verloopt?*
Bijvoorbeeld luisteren, empathie tonen, begrip tonen, vriendelijkheid, etc.

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Thema 4: privacy & sociale impact

- Wat vindt u ervan dat een verpleegkundige bij u thuis komt?
- Wat vindt u ervan dat uw huisgenoten aanwezig kunnen zijn tijdens de toediening van uw medicijnen?

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Thema 5: tijdsbesteding toediening medicatie

- Hoeveel tijd bent u kwijt met de bezoeken aan de dagbehandeling in het ziekenhuis?
Dit omvat: plannen, reizen, etc.
- Waaraan besteed u deze tijd?
Dit omvat: plannen, reizen, etc.
- Wat vindt u daarvan?

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Afsluiting

Heeft u nog vragen, opmerkingen of toevoegingen op het interview?

Als ik het goed begrijp kan ik het zo samenvatten..... (De respondent kan instemmen of misverstanden rechtzetten)

Ik wil u nogmaals bedanken voor uw waardevolle bijdrage.

Appendix 3B: Interview scheme experiences

Interviewschema

Ervaringen van kankerpatiënten over het thuis toegediend krijgen van intraveneuze medicatie (pembrolizumab & zoledroninezuur)

Gegevens

Naam interviewer:

Respondent nr.:

Datum:

Plaats:

Note: de schuingedrukte tekst is alleen bedoeld ter ondersteuning van de interviewer

Inleiding

Bedankt voor het deelnemen aan dit interview.

Ik ben Loes Meijerink en student Gezondheidswetenschappen aan de Universiteit Twente. Ik doe mijn afstudeeronderzoek in Rijnstate. U bent hierover al eerder geïnformeerd door uw behandelaar en de proefpersoneninformatiebrief. Klopt het dat u toestemming heeft gegeven voor dit interview, het toestemmingsformulier heeft ondertekend en deze heeft verzonden naar Rijnstate ziekenhuis?

Geeft u toestemming om het interview op te nemen?

Het doel van dit interview is inzicht krijgen in de ervaringen die u heeft met thuis uw medicijn voor de behandeling van kanker via een infuus toegediend krijgen.

Het interview is opgedeeld in verschillende onderwerpen. Ik wil hierbij benoemen dat er geen goede of foute antwoorden zijn.

Het interview duurt ongeveer 45 minuten.

Heeft u voordat we beginnen nog vragen?

Persoonlijke situatie

- Wat is uw leeftijd?
- Woont u alleen?
- Zo nee, met wie woont u?

Behandelvoortgang

- Hoe lang wordt u al behandeld met dit medicijn?

Introducerende vragen

- Hoe ervaart u de zorg op de dagbehandeling in het ziekenhuis?
- Zou u iets willen veranderen aan de zorg op de dagbehandeling in het ziekenhuis?
- Zo ja, wat zou u willen veranderen?
- Wat dacht u toen u voor het eerst hoorde dat u uw medicijn thuis kunt ontvangen?

Mogelijke antwoorden: geen zieke mensen hoeven zien in het ziekenhuis, niet meer reizen, meer individuele tijd met de verpleegkundige, meer privacy, meer autonomie, geen contact meer met lotgenoten, etc.

- Hoe ervaart u het thuis toegediend krijgen van uw medicatie?
- Kwam het overeen met uw verwachtingen?
- Zou u iets willen veranderen aan de zorg tijdens het thuis toegediend krijgen van uw medicatie?
- Zo ja, wat zou u willen veranderen?

Wat was/waren uw eerste ervaring(en) met het thuis toegediend krijgen van uw medicatie?

Mogelijke antwoorden: geen zieke mensen hoeven zien in het ziekenhuis, niet meer reizen, meer individuele tijd met de verpleegkundige, meer privacy, meer autonomie, geen contact meer met lotgenoten, etc.

- Welk gevoel geeft het thuis toegediend krijgen van uw medicatie u?

Mogelijke antwoorden: stress, (on)rust, geborgenheid, comfort, etc.

- Waarom bent u positief of negatief over het thuis toegediend kunnen krijgen van uw medicatie?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Thema 1: planning & coördinatie

Voor de planning van afspraken voor de toediening van uw medicijn thuis, informeert de zorgcoördinator u.

- Wat vindt u daarvan?
- Zou u daar wat aan willen veranderen?
 - Kunt u dat toelichten of voorbeelden geven?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Thema 2: communicatie: informatie & educatie

- In hoeverre geeft de verpleegkundige informatie over uw aandoening en behandeling tijdens het thuis ontvangen van uw medicatie? *Daarbij rekening houdend met informatie die je van een verpleegkundige kan verwachten.*
 - *Hoe geeft de verpleegkundige u informatie?*
Bijvoorbeeld: informatiefolder, mondeling, etc.
 - *Krijgt u gelegenheid om vragen te stellen?*
Zo ja, op welke momenten?
 - *Geeft de verpleegkundige duidelijke uitleg?*
- Wat vindt u daarvan?
- Zou u daar wat aan willen veranderen?
- Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Thema 3: communicatie: interpersoonlijke relatie

- Hoe verloopt het contact met de verpleegkundige tijdens het thuis toegediend krijgen van uw medicatie?
 - *Neemt de verpleegkundige: de tijd, heeft respect voor waarden, reageert op behoeftes, etc.*
 - *Heeft u een prettig gesprek met de verpleegkundige? Zo ja, kunt u dat toelichten? Bijvoorbeeld luisteren, empathie tonen, begrip tonen, vriendelijkheid, geruststellen, etc.*
- Wat vindt u daarvan?
- Zou u daar wat aan willen veranderen?
 - Kunt u dat toelichten of voorbeelden geven?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Thema 4: privacy & sociale impact

- Hoe ervaart u het dat er een verpleegkundige bij u thuis komt?
- Wat vindt u ervan als uw huisgenoten aanwezig zijn tijdens de toediening van uw medicijnen?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Thema 5: tijdsbesteding toediening medicatie

- Hoeveel tijd bent u meer of minder kwijt aan uw behandeling nu u uw medicatie thuis toegediend krijgt?
Dit omvat: plannen, reizen, etc.
- Waaraan besteed u deze tijd?
Dit omvat: plannen, reizen, etc.
- Wat vindt u daarvan?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Afsluiting

Heeft u nog vragen, opmerkingen of toevoegingen op het interview?

Als ik het goed begrijp kan ik het zo samenvatten..... *(De respondent kan instemmen of misverstanden rechtzetten)*

Ik wil u nogmaals bedanken voor uw waardevolle bijdrage.

Appendix 4: Tables from Results

Appendix 4A: Experiences of cancer patients with receiving intravenous medication at the oncological center of Rijnstate hospital

Theme	Code	Description	Quote
Coordination & planning	Planning of appointment	Appointments are made and communicated in a timely manner	<i>"When I finished my administration I immediately receive a new appointment from the secretary"</i>
Communication: information & education	Provision of information	Information about the treatment of the patient is explained clearly	<i>"Well I actually already have answers before I have a question. I noticed that with this treatment, that everything is explained so clearly by the nurses and the doctors. At least the people I've dealt with. They explain it, you get it and you know what's going to happen"</i>
	Asking questions	Patients can always ask all staff questions and knows who and how to ask questions	<i>"The nurses always answered my questions and when they did not know they said you should ask the doctor or nurse specialist"</i>
	Intern communication	Staff communicates well with each other	<i>"I think the lines are very short, so people all have contact with each other. The communication is excellent. Everything is passed on to each other"</i>
	Answering of questions too late	Waiting too long for an answer to a question	<i>"Now we had to wait a few weeks before I got an answer. The internal communication needs to be better sometimes"</i>
Communication: interpersonal relationship	Behaviour of nurses	Nurses are human, friendly, empathic, respectful, etc.	<i>"They are darlings. I really mean it"</i>
	Social interaction with nurses	Nurses make always time to have a (little) chat with the patient	<i>"The nurses really pay attention to you when they are working with you. Not that we have the time to really chat too long or anything, but they are interested. They ask how you are and things like that"</i>
	Service	Patients get offered coffee, tea and something to eat during the administration	<i>"I often went there in the morning and there was a nice lady who gives people coffee and tea. He gave all kinds of tasty things like a sandwich or ice cream with whipped cream. I liked that too"</i>

	Informal atmosphere	The atmosphere is familiar and relaxed	<i>"You are a human being there on the ward. Sure, everyone in there has something, but you're not treated like that. Together we are also just have fun with the nurses. They are in for a joke"</i>
	Bad or no social interaction with nurse	Unfriendly unrespectful staff	<i>"Certain nurses may not have their day and then your experience will be different too. The nurses had a party at the day care ward at X. Within the corona pandemic they were partying with ten people in a room. That doesn't makes sense to me. Then the nurse tells me in an unfriendly way to walk to the back and take a chair. I don't feel too good for it, but that did not make me feel comfortable"</i>
Privacy & social impact	Mental support from other patients	Getting support out of talking to other patients	<i>"Yes, but I always liked being at the oncological day care. There are often nice people there"</i>
	Suffering of other patients	Seeing other patients suffering	<i>"Last week a physician visited a patient at the day care ward and he was talking about that patient's treatment, that he had broken legs and he couldn't take it anymore. Then I thought, it's not good when others have to listen to this. Do you understand?"</i>
Time management	No waiting	No or minimal waiting before getting the administration at the oncological day care	<i>"I did not have to wait to get my treatment. That always went smoothly"</i>
	Waiting	Sometimes waiting for results at consulting hours or administration at the oncological day care takes too long	<i>"You always ensure that you are in the hospital early and then sometimes you even have to wait longer...For example, the last time we went to the doctor, the doctor was called away to the ICU for an emergency. That is not ideal, but that can always happen. If they know that you have to get a medicine, then I also think that they should make sure that the medicine is on the ward and that you don't have to wait another 30 minutes for the medicine to arrive"</i>

Other	Safety	Hospital feels as a safe place	<i>"They know what to do and have a computer with them on which all data is stored. That gives confidence"</i>
	Puncturing	Difficulty with puncturing a vein with the needle	<i>"That hurts and it happened again. Then you just feel that something is not right and that hurts. Then it continues to hurt and the needle has to come out again. I think that's the bad thing about it. It is not the nurse's fault. My veins are just difficult to puncture"</i>

Appendix 4B: Experiences of cancer patients about the theme 'planning & coordination' about receiving intravenous medication at home by Rijnstate hospital

Experiences		
Code	Description	Quote
Timeliness of planning of appointment	Already received new appointment	<i>"I already have written proof that they are coming in August, just only without the time"</i>
Timeliness of planning of time of appointment	Already knows time of appointment a week before	<i>"When I was to receive immunotherapy at home, we were called a week in advance"</i>
Patient's preference	The hospital takes the patient's preference into account	<i>"In the morning another care organisation comes to my house to help me, so for this treatment I get planned in the afternoon by Rijnstate. I appreciate that Rijnstate my wish into account"</i>
No timeliness of planning of time of appointment	Announcement of the time of appointment is a day in advance and that is too late	<i>"I would like to know sooner at what time they will be coming. Now I only hear it the day before. Now I can't actually make appointments on that day. I liked that better in the hospital. Then I already knew when I left the day care when the next appointment is. Then I could plan my day around it"</i> <i>"I find that a bit difficult, because my son plays football three times a week and then we have to eat early. I get to hear the time very late. If the appointment is in the afternoon then it will be difficult for me"</i>
No announcement of time of appointments	No announcement of time because of fault in the system	<i>"I was not called about the time of my appointment. I had to call about that myself, because something went wrong at Rijnstate"</i>
Receiving new appointment takes long	Did not receive a new appointment yet	<i>"It is usually the case that I immediately get the appointment for the next time and now I don't have it yet after two weeks"</i>
Rescheduling of appointment	Appointment was cancelled three times in one week	<i>"They rescheduled my appointment three times in one week. That was a bit annoying and I have told them also. I am quite a busy person, so I had all</i>

		<i>kinds of appointments and I had to reschedule them every time. Eventually I said I won't do that anymore because I find it a bit annoying if I have to reschedule my appointments every time"</i>
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Appendix 4C: Expectations and experiences of cancer patients about the theme 'communication: information & education' about receiving intravenous medication at home by Rijnstate hospital

Expectations		
Code	Description	Quote
Asking questions	Better opportunity to ask questions	<i>"I always have a list with questions, so now there is even more time for that"</i>
Experiences		
Code	Description	Quote
Discuss option for receiving medication at home beforehand	The physician discussed receiving medication at home with the patient beforehand	<i>"Before I even started the therapy, I was told that this was a possibility. The first six times had to be in the hospital and then after the doctor's agreement, it could be done at home. They asked how I felt about it"</i>
Too little provision of information	Patients do not know what to expect from certain aspect in receiving medication at home	<i>In table 7 these aspects are described</i>
Motives for replacing care to patient's home	Unclear why this treatment is replaced to the patient's home	<p><i>"I don't understand the idea behind it, but that's up to Rijnstate and not me. I don't know why Rijnstate does it. Of course I have read something in the newspaper and I found it dubious. I wonder if it is in Rijnstate's interest or in the interest of the patients. I'm still a little sceptical about that. I know the healthcare sector. I know that self-interest always comes first and thereafter the rest. That makes me doubt what the benefit is for Rijnstate and the benefit for the patient"</i></p> <p><i>"I was surprised too, because I thought at the hospital I'm there with six or seven other people at the same time. Then many more people can be treated at the same time. That also saves costs. I was surprised about that"</i></p> <p><i>"I did wonder why they do it. I have already asked the nurses here at home. Is it cheaper, do they need the space, because you need a car and all the stuff that they have to take with them. They said they don't really know either"</i></p> <p><i>"I therefore wonder, what is the added value from the medical point of view of doing it at home? Do you understand what I mean?"</i></p>

Did not discuss option for receiving medication at home	Did not ask patients if they want to receive their medication at home	<i>"They could have asked patients what they think about offering that option. They could have done that"</i>
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Appendix 4D: Doubts cancer patients have about receiving intravenous medication at home by Rijnstate hospital before the first time

Theme	Code	Description	Quote
Communication: interpersonal relationship	Social interaction with nurse	Unclear what the nurse is doing during the administration and if the nurse and the patients like each other	<i>"I wondered what the nurse the whole hour is doing. Of course I don't know yet. Will she sit down to chat? Or will she do other work? No idea. You just have to wait and see if you like each other. You should have some conversation material with each other when you sit together for an hour"</i>
Other	Puncturing	Questioning what happens is the nurse is unable to puncture the patient's vein	<i>"My veins are pretty hard to puncture so I don't know how that goes. We'll see tomorrow"</i>
	Freedom of movement	Questioning possibilities of moving yourself during the administration	<i>"For example, if I have to go to the toilet, how do we do that. Do they have a IV pole? Those kind of things"</i>

Appendix 4E: Expectations and experiences of cancer patients about the theme 'communication: interpersonal relationship' about receiving intravenous medication at home by Rijnstate hospital

Expectations		
Code	Description	Quote
Social interaction with nurse	Having an informal chat with the nurse	<i>"Maybe we just sit and chat with each other. Sitting in the garden when the weather is nice. We will see"</i>
Personal attention from nurse	More personal attention from the nurse	<i>"You will have contact with someone again. Of course I am most of the time alone"</i>
Experiences		
Code	Description	Quote
Social interaction with nurse	Having an informal conversation with the nurse with a cup of coffee	<i>"These nurses who came to my house were friendly. They were not rushed and did their job quietly"</i> <i>"The nurse was just very relaxed, having a chat about all kinds of stuff. You are almost all day alone and now you have someone around you for</i>

<i>at least an hour and a half. having a coffee and chatting"</i>		
Personal attention from nurse	More personal attention from the nurse	<i>"Now I have more time to talk with the nurse. Sometimes you also have the need to talk to someone"</i>
Restless nurse	Nurse was very restless and doing everything in a hurry	<i>"The nurse was very busy. I found that less enjoyable myself. It made me nervous"</i>
No attention from nurse	Nurse was busy with laptop, which did not work properly	<i>"It normally takes about half an hour, but they were working on that laptop for a while. It didn't work properly. All attention was focused on that. I can understand that. They can't help it either, because it's all new. I thought that was a bit unfortunate, because there was no attention for me"</i>

Appendix 4F: Expectations and experiences of cancer patients about the theme 'privacy & social impact' about receiving intravenous medication at home by Rijnstate hospital

Expectations		
Code	Description	Quote
Staying in home environment	Staying at home is comfortable and gives more rest	<i>"Especially the activity, it costs a lot of energy to go to the hospital. It is very nice that I can stay in my own routine a bit more. That it can be more relaxed, that I can close my eyes for a moment"</i>
Less confrontation with disease	At home there is less confrontation with having a disease	<i>"That I don't have to go there. I don't like the long hallway I have to go through. It is hard for me, because of my lung problem. That stays in my head, that long hallway. I often can't manage that and because of that I have to use a wheelchair. I don't like that, because it reminds me of how ill I am and makes me feel even more ill"</i>
Privacy	More privacy at home, which makes it a better place to discuss private questions, matters, etc.	<i>"I can talk freely to the nurse here. Here no one needs to hear my stories"</i>
Home is no hospital	Do not want medical activities at home	<i>"I don't want my house to become a hospital"</i>
No mental support of other patients	Missing the mental support that the presence of or talking to fellow patients gives	<i>"That you are there together with other people who also receive their medication. You may not know what it all exactly is, but it does create a kind of bond when you are there. That's how I experienced it"</i>
Experiences		
Code	Description	Quote

Staying in home environment	Staying at home is comfortable and gives more rest	<p><i>“Home is just home. Recently, I had visitors during the administration and they just stayed. So that wasn't an issue at all”</i></p> <p><i>“I am in my own environment. The girl who did it was very nice, very calm. Totally not rushed. I thought it was ideal”</i></p> <p><i>“You feel more relaxed. In the hospital I’m not as comfortable as here. Here I have a cup of coffee with me, I sit very calm. It all went very calmly. Then I don't have to worry about it. In the hospital it is very busy, when you go in and out of the hospital. At home I don't have that. I found it relaxing”</i></p>
Private chat with the nurse	Home is a better place to discuss private questions, matters, etc.	<i>“At the hospital you are a little more careful with what you say. You can talk more freely at home”</i>
Less confrontation with disease	At home there is less confrontation with having a disease	<i>“In the hospital you are confronted with the facts, you have something. You don't go to the hospital for no reason. Do you understand?”</i>
Home is no hospital	Do not want medical activities at home	<i>“I think that illness belongs in the hospital and as little as possible in your own place”</i>
Occupied home	Also receiving other care at home makes it busy at home	<i>“I've had so many people at home, always from home care. For example, the cleaning lady that helps with housekeeping. Now this from Rijnstate, while I was glad I got rid of it. Now I get this at home. I don't like having all these people at home”</i>
Recognizable car	Neighbours could ask about why a Rijnstate car visited the patient	<i>“The neighbours know I have something and I was also taken away by ambulance last year. Now that car with large Rijnstate-letters is in my driveway. No neighbours asked about it yet, but I know the neighbourhood well. Then everyone immediately thinks there is something wrong with me. So I haven't heard anything yet, but I thought this might give questions from neighbours. Maybe I'm a picky one too, that I think they'll see that car from Rijnstate at my driveway. It is not a disaster”</i>
	The recognizable Rijnstate-car is convenient	<i>“It is no problem. I even think it is convenient that I can see who is coming”</i>
Being a host	Being a host is no problem	<i>“No I don't mind giving the nurse coffee or tea. We are very hospitable and it is only a small effort”</i>

Appendix 4G: Expectations and experiences of cancer patients about the theme 'time management' about receiving intravenous medication at home by Rijnstate hospital

Expectations		
Code	Description	Quote
No more arranging driver or accompany	Not having to arrange a driver or accompany to the hospital anymore	<i>"My husband has MS, so I'm glad I don't have to ask him anymore"</i>
No traveling time	No traveling time to the hospital, which includes parking and walking to the oncological center	<i>"I didn't know how busy it is on the way to the hospital. Then I also didn't know how busy it is in the hospital and how long I had to wait. Those kind of things"</i>
Faster	No waiting time for administration, so receiving medication at home is faster	<i>"You have to stay there for a while and it takes some time, so it's super cool that they can do it at home now"</i>
Experiences		
Code	Description	Quote
No more arranging driver or accompany	Not having to arrange a driver or accompany to the hospital anymore	<i>"My son or daughter-in-law went along with me to the hospital. They were no longer allowed to come upstairs to the oncological center. They had to wait downstairs or outside. That wasn't good for them either. Now I don't have to bother them anymore"</i>
No traveling time	No traveling time to the hospital, which includes parking and walking to the oncological center	<i>"It's easy that I don't have to get out of the house. That always gives me a bit of trouble"</i>
Faster	No waiting time for administration, so receiving medication at home is faster	<i>"It went much faster. That is logical because there are many other patients present in the hospital. The nurse also has to visit the other patients in between. For example when a beep goes off somewhere at a patient's chair"</i>
Longer duration	Receiving medication at home takes longer because everything needs to be set up and cleared up	<i>"It takes a little longer. In the hospital everything is ready. You just sit down and someone comes to you. Here everything has to be installed first and afterwards everything has to be cleared up. It took two hours"</i>

Appendix 4H: Expectations and experiences of cancer patients about other aspects then covered within the themes, about receiving intravenous medication at home by Rijnstate hospital

Expectations		
Code	Description	Quote
Decreased risk of getting a COVID-19 infection	The patient does not have to go to the hospital and therefore has a decreased risk of getting a COVID-19 infection	<i>"I try to limit contacts with people. Especially in this time. The infections are increasing again, so I'm glad I don't have to go to the hospital"</i>
Experiences		
Code	Description	Quote
Nurses clean up	Nurses clean everything up	<i>"They do it properly and clean up the mess"</i>
Puncturing	Difficulty with puncturing a vein or even that the home administration had to be cancelled because nurse could not puncture a vein with the needle	<i>"Now it was no problem. It can happen. If it happens several times and I still have to go to the hospital then it will become a problem. There comes a time when I don't have a car available and then I do have a problem of course"</i>