Infection prevention as a shared responsibility

Improving the patient experience during contact isolation

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Master thesis

Judith de Koning 08-11-2019

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Abstract

Healthcare-Associated Infections (HAI) can occur when microorganisms spread between hospitalized patients. To prevent highly contagious or resistant microorganisms from spreading from one patient to the other, isolation precautions such as contact isolation are applied when patients carry such a microorganism.

The first part of this theses describes how contact isolation has a negative impact on well-being on patients. The experience during contact isolation can improve by establishing an open healthcare environment and providing information during the full isolation process. Collective action theories appear to have potential to be applied to the context of infection prevention. The contribution of patients, healthcare providers and visitors to infection prevention can be stimulated by increasing community feeling, establishing connections between individuals and providing information about past actions of other individuals.

Context research has been conducted in VUmc and results on the current patient experience are gathered in a patient journey. Conclusions on the current patient experience during isolation are as following:

- 1. a shattered sense of responsibility amongst different actors
- 2. different patient persona's experience contact isolation differently
- 3. a difference in experience and behaviour of first time isolation patients and readmitted patients.

To improve the patient experience during contact isolation, the second part of this thesis focusses on creating a solution. By combining the conclusions and the literature, a design vision is formulated:

I want to increase the feeling of community amongst all actors in the contact isolation process, so that all individuals experience a sense of shared responsibility towards infection prevention in VUmc.

A first step towards the design vision is created with the guidance of the following design goal:

I want patients to develop a favourable attitude towards contact isolation during the first time into contact isolation by providing a tool that lets them experience partnership with healthcare providers and visitors in contributing to the safety of others.

Building from the patient journey and the design goal, a solution, Bundel, is proposed. It aims to increase a feeling of shared responsibility amongst the different involved actors and stimulated collaboration between individual. Bundel provides necessary and desired information to patients and visitors at fitting times.

The first time into contact isolation is slowed down by spreading the information a patient needs and wants over the isolation process. By providing all the information to patients from the start of the isolation process, they can discover the necessary information they are looking for when they are ready. In addition, visitors are increasingly involved in infection prevention, because the design makes their involvement necessary them. Bundel thereby stimulates them to personally find the necessary information.

For nurses and other healthcare providers, Bundel facilitates the transfer from a 'controller and corrector' to a 'guide and facilitator' towards patients and visitors. Therefore, responsibility that currently mainly lies with the nurse, shifts to a more equally shared responsibility amongst all actors.

Glossary

Antimicrobial resistance (AMR)

Microorganisms have the ability to stop the impact medicines such as antibiotics and antivirals. When a patient gets infected with a multidrugresistant microorganism, treatment becomes more complex and sometimes even impossible. Infections can persist and could spread to others.

Collective action

Collective action is a theory that is applied to achieve common goals when group size becomes extensive and interpersonal bonds are less strong. Collective action theory can in particular be applied to situations in which an individual's contribution to the common goal is insignificant. Limiting antimicrobial resistance is such a common goal.

Contact isolation

Also: Isolation precautions or Isolation measures

Contact isolation is one of the five isolation types applied in healthcare. Isolation measures curb the spread of microorganisms to other patients. For patients, contact isolation means that they are cared for in a single room. Healthcare providers have to wear gloves and gown when providing care to the patient.

Healthcare-associated infections (HAI)

Healthcare-associated infections are infections that patients get while receiving care for another condition.

Healthcare providers

Healthcare providers are the people that take care of patients. In this thesis, the term healthcare providers is used to describe employees of the hospital that provide direct and indirect care to patients.

Micoorganism

In this thesis, the word microorganism is mainly used to describe the bacteria and viruses for which isolation measures are applied.

Multi-resistant microorganism (MRMO)

MRMO are microorganisms that do not respond to many of the frequently used antibiotics.

Patient experience (PX)

Patient experience is how a patient feels about interaction with their received care. Patient experience is individual, personal and reflects the struggles, needs, values and wishes of patients.

Patient Journey

In journey mapping, a complicated context and its actors, relations, interactions and critical human factors concerning the process can be discovered and located. A patient journey represents the process a patient goes through while receiving care.

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Introduction

1.1 Project context

One to 15 patients in Dutch hospitals acquire a Healthcare-Associated Infection (HAI). (Prezies, 2018). HAI are associated with prolonged and extended treatment and a decrease in the quality of life (Seibert, et al., 2014; Prezies, 2017). HAI can occur when microorganisms spread between hospitalized patients. A hospital environment facilitates this transmission, as vulnerable patients are cared for closely together.

A number of patients that acquire a HAI is infected by a multidrug resistant microorganism (MRMO). Treatment of patients with these bacteria becomes more and more difficult because they are insensitive to the most common antibiotics. In the Netherlands, more and more patients carry an Extended–Spectrum Beta–Lactamase (ESBL)–bacteria (Nethmap, 2018). Antimicrobial resistance is a substantial threat to the ability to treat patients in the future.

To curb the spread of microorganism hospitals apply infection control measures. General precautions include for example frequent hand disinfection by healthcare providers. Several isolation precautions are applied when patients carry such a microorganism in order to prevent highly contagious or resistant microorganisms from spreading from one patient to the other. The applied isolation depends on the microorganisms route of transmission (WIP, 2011). The most applied form of isolation is contact isolation.

Contact Isolation (CI) means that a patient is cared for in a single bedded room. Patients are not allowed to leave their room, healthcare providers wear a gown and gloves in addition to the general precautions when they care for patients in contact isolation.

Research provides different results on the impact of CI on patients (Mehotra, 2014). Control measures have adverse effects on the well-being of carriers (Rump, et al., 2018; Abad et al., 2010). Patients that are cared for in contact isolation are more likely to have complaints during their time in the hospital. Other studies, however, mention that contact isolation does not affect patient satisfaction. Short-term isolation measures do not influence patients' levels of anxiety, depression and quality of life (Wassenberg, et al., 2010). Furthermore, the quality of care of patients has improved after moving to isolation (Chittick et al., 2016).

Moreover, patients in contact isolation do not experience adverse health effects because of the microorganism they carry. However, as soon as they receive back a positive test and diagnosis, the provided care changes and patients can experience contact isolation as unfair or stigmatizing (Lindberg, et al., 2009; Rump, et al., 2018).

Client

The hospital department of Medical Microbiology and Infection prevention (MMI) of VUmc concerns itself with all infection-related issues. The infection prevention team translates international guidelines into hospital protocols, implements them and audits their compliance. The mission of VUmc team is to support healthcare providers in providing safe care, to curb the spread of MRMO and to prevent patients from acquiring healthcare-associated infections.

In Amsterdam UMC, location VUmc, 3000 days of CI are applied on a yearly basis. The main reason for contact isolation is to provide care for patients that are a carrier of an ESBL-bacteria without it spreading to other patients.

1.2 Problem definition

Isolation precautions are crucial to apply in hospitals to curb the spread of MRMO from one patient to another. However, some patients that are cared for in contact isolation, experience isolation measures as unfair and stigmatizing (Lindberg, et al., 2009; Rump, et al., 2018) and for some patients, control measures lead to adverse effects on the well-being of these patients. By improving the patient experience, positive effects on the recovery of patients can be obtained (Mehotra, 2014).

The team infection prevention in VUmc currently has little insight into how patients experience contact isolation. It is not clear when and how patients are informed on the reason and duration of isolation, what necessary precautions have to be taken by themselves or others, and what are the conditions for termination of isolation. Furthermore, it is not clear whether they are aware of the risks for themselves, informal caregivers and others. Awareness is expected to engage patients and improve accurate application of the extra precautions by patients and their informal caregivers. It is still unclear what information patients currently receive and how this influences their comprehension and experience of the measures taken and their compliance to isolation. The team is interested in ways to improve the care path for patients in contact isolation and therefore possibly increase the experience and the effectivity of and compliance to isolation measures.

This thesis aims to research and improve the patient experience of contact isolation. The context of the research is VUmc and the design question leading this thesis is: How can the patient experience during contact isolation improve? The design question is divided into two subquestions: 1) What is the current patient experience during contact isolation? and 2) What elements lead to an improved patient experience during contact isolation?

Challenge

The first aim of this project is to create a vision and a product or service that increase the active role and contribution of the patient to the quality of isolation. Contact isolation and how it is applied in VUmc is researched and designed from a patient experience perspective.

To achieve that, this project researches and designs the patient experience from the moment of going into contact isolation (at admission or when a patient is in the hospital already) until a patient leaving isolation (at discharge from the hospital or isolation is not necessary anymore). The research focusses on the direct context of the patient, meaning the experience of the patient as well as healthcare providers and (informal) caregivers).

1.3 Project approach

This project is addressed as a research and design process. By incorporating design methodology in a research project, a complex system can be researched, analysed and improved (fig. 1). The approach of this project is divided into several phases: understand, explore, define, ideate, create and evaluate. These steps are also leading the chapters of this report. The steps have been followed in more–or–less chronological order, but going back and forth between phases happens.

Understand

For better understanding, context and existing literature on this topic is studied. This first phase specifies the different aspects of the research question, namely, contact isolation and improving the patient experience. In addition, it explains different findings from literature regarding the experience during contact isolation of patients, nurses and other involved actors.

Researching and summarizing these factors helps readers and designers to understand the context the user research is performed in (phase: explore). Moreover, the insights from the literature study serve as input for the setup and conduction of the explorative research.

Explore

In the exploration phase, research in the context has been done. This research means observing in the wards of VUmc and interviewing healthcare providers and patients. It also provides insight into the contact isolation procedure as it is in VUmc. Moreover, needs, motivations and emotions regarding the experience of patients, nurses and physicians with contact isolation, are discovered and defined. By conducting this research, it is easier to empathize with the actors and a more fitting design can be created.

Define

Through the synthesis of insights from both the understanding and exploration phase, design opportunities are defined. One design opportunity is translated into a design goal, which is supported and strengthened in the defining stage. The design goal is used to generate ideas in the phase ideate.

Ideate and Evaluate

During ideation, several creative techniques are applied in brainstorming sessions with design students, design professionals and healthcare providers. The resulting insights are clustered into concept directions. Through evaluation and validation with patients and nurses, a concept direction developed into a concept.

Create and validate

In the create phase, concept is translated into a design. The design is explained based on the design aim, interaction and the different design elements. In this phase, the design is evaluated based on the design vision and the design goal.



Figure 1: Double diamond project approach



Literature research: contact isolation and patient experience

To provide insight into how to improve the patient experience during contact isolation, this chapter describes the context of contact isolation, infection prevention and antimicrobial resistance and patient experience in general. It explains how the concepts are related and defines opportunities for improvement.

This chapter starts with insight on antimicrobial resistance as contact isolation in hospitals is applied to prevent the spread of antimicrobial resistant microorganisms and infectious diseases One of these measures and the focus of this project is contact isolation. For an understanding of the context, this chapter then explains the implications of contact isolation for hospitals, healthcare providers, patients and visitors as described in the literature.

The second part of this chapter describes the concept of patient experience. It describes the definition of patient experience and topics related and explains the experience during contact isolation of different actors based on literature. In the final part of this chapter the theory of collective action is explored in relation to contact isolation and a plan to increase the patient experience is presented.

2.1 Antimicrobial resistance

Worldwide, antimicrobial resistance is growing. Due to the overuse of antibiotics in healthcare and cattle industry, there are many bacteria which the prevailing medicines do not affect anymore (Centers for Disease Control and Prevention, 2018[1]; Centers for Disease Control and Prevention, 2018 [2]) (fig. 2). When a patient gets infected with a multidrug-resistant bacterium, treatment becomes more complex and sometimes impossible and leads to deaths (Centers for Disease Control and Prevention, 2013). Treatment of infections with these bacteria is more costly and more time-consuming and might lead to even higher drug resistance (Rump, et al 2018).

To prevent patients to get contaminated with MRMO, control measures in hospitals are in place. Basic hygiene measures are applied during the care for all patients and isolation precautions prevent the spread of MRMO's in known carriers. These extra precautions include precautions taken during patient care (personal protective equipment), disinfecting the rooms and hospital environment and caring for patients in single rooms (Rump, et al 2018).



Figure 2: Spread and prevention of antimicrobial resistance (THL 2018)

2.2 Contact isolation

2.2.1 Isolation precautions to prevent infections and transmission

In hospitals, patients often have a lower immune system, due to antibiotics, wounds and intravenous therapy. Therefore, these patients are more susceptive to contamination with bacteria and other contagious microorganisms such as influenza. Because of the lower immune system, patients also become ill from microorganisms more easily (Centers for Disease Control and Prevention, 2016). Moreover, healthcare providers care for multiple patients and patients live closely together and therefore touch similar objects, instruments or surfaces; activities that foster transmission.

There are two reasons why transmission of and thereby infection with these microorganisms should be prevented:

- 1. The microorganism is highly contagious, such as influenza and infectious diarrhoea, and have a high health impact on the patient.
- 2. The microorganism is a highly resistant bacteria, for example ESBL-bacteria and treatment of infections with this bacteria is very difficult and becomes more difficult when resistance grows. For resistant bacteria, it therefore means that when less infections occur, less antibiotics have to be used, increasing the chance of bacteria not becoming resistant to multiple types of antibiotics.

To limit the transmission of microorganisms and thereby limit healthcare associated infections and antimicrobial resistance, infection control measures are applied and infected patients are hospitalized in isolation.

In hospitals, five types of isolation are applied based on the route of transmission: 1. Contact isolation, 2. Contact-droplet isolation, 3. Aerogene isolation, 4. Strict isolation and 5. Protective isolation. Contact isolation is the most applied form of isolation and is applied for microorganisms that spread through direct contact (WIP, 2013). That means: 1) contact between a person and an object, for example the patient's bed or a doorknob, 2) contact between a person and a person, for example the patient shaking hands with the nurse or another patient and 3) contact between an object and an object, which could for example be putting down something on the table. By applying contact isolation, direct contact in any form is prevented, the transmission route of the microorganism is interrupted.

2.2.2 Implications of contact isolation

Different actors experience different consequences from contact isolation. Consequences and implications of control measures are mentioned and literature on the actor's experience with contact isolation is summarized (WIP, 2011).

Patients

The stay (in contact isolation) can vary from a day up to many weeks to months. Many patients that have to stay in contact isolation lie in the hospital for the treatment of another illness (Rump, et al., 2018).

Contact isolation, single room, means that the patient cannot leave their room. Patients are alone and cannot use the facilities outside of the room such as sports equipment, the coffee table or the fridge and are separated from other patients. Patients in contact isolation may leave the room for exams or treatments. Transportation and receiving ward then need to be informed.

Direct healthcare providers

Healthcare providers (nurses, physicians and other (supporting) staff) take care of multiple patients. Therefore, they are an important vector for of the transmission of microorganisms between patients. While providing care to all patients, healthcare providers have to apply general precautions, meaning; clean clothes every day, no jewellery and wearing your hair up. In addition, hand hygiene is applied before and after contact with patients and/or patient material.

During the care for patients in contact isolation, they have to apply extra control measures when providing care to a patient in isolation. For contact isolation, this means **wearing a gown and gloves** when going into the room and when getting in contact with the patient or patient material such as blood, urine or other bodily fluids (fig. 3 and 4).

In practice, that means that after entering the room, a healthcare provider has to disinfect her hands, put on a gown and then gloves. Before leaving the room, gloves and gown should be taken off. Hand hygiene is applied again.

Indirect healthcare providers

Indirect healthcare providers that are involved in the procedure of contact isolation are Medical Microbiology and Infection and supporting staff in the ward and the hospital, such as nutrition assistants, physiotherapist, cleaning staff and patient transport.

Medical Microbiology and Infection Prevention (MMI) is the hospital department that focusses on testing, treatment and prevention of infectious diseases. The team infection prevention advises the hospital wards on control measures such as general precautions, isolation and hand hygiene.

Other healthcare providers provide direct care to patients and therefore need to be aware of isolation measures. Supporting healthcare providers in general have similar control measures as nurses and physicians because they also apply care to multiple patients. By providing a colour coded information sheet for different types of isolation, the specific isolation measures are communicated to the involved healthcare providers.



Figure 3: Isolation measures applied by healthcare provider

Informal caregiver

Informal caregivers (e.g. partners, children, family, friends and other visitors) do not have to worry about becoming colonized or infected themselves (fig. 5). They have been in contact with the patients before and therefore might possibly be carrier already or not susceptible to the microorganism. Moreover, one of the most important conditions to get an infection is a low immune system and the use of antibiotics. Informal caregivers regularly do not have an extremely low immune system and do not use high amounts of antibiotics. However, visitors have to ensure they prevent the spread of microorganisms and should apply hand hygiene after their visit.

However, visitors have to ensure they prevent the spread of microorganisms to other patients through the shared areas in the ward or other places of the hospital. Therefore, visitors are not allowed to go in- and out of the room multiple times, but have to leave the hospital immediately after the visit. That means they cannot use shared facilities of the ward, such as the family room, kitchen or coffee table during or after visiting their loved one.

After visits they preferably do not use a bathroom in the hospital or go to the restaurant, as other patients or visitors of those patients use them too. Visitors should also apply hand hygiene after their visit.

Other patients

Other patients are the reason why isolation measures are applied. As many hospitalized patients use antibiotics and undergo treatment that break the natural barrier of the body, such as surgery and intravenous therapy, and are cared for by multiple healthcare providers, they are more susceptible to infections. In general, other patients do not notice much about contact isolation, except when a to-beisolated patient used to be with them in the room and is moved to another room.



Figure 4: Isolation measures applied by healthcare provider

Figure 5: Visitors do not have to wear a gown or gloves



2.2.3 Contact isolation in VUmc

Materials to follow protocol

In the ward, nurses, physicians, other healthcare providers and supporting staff have to follow the protocols regarding infection prevention and isolation. Healthcare providers can find the necessary information about the type of isolation a patient has at several places. When a patient is in isolation, in EPIC (the patient dossier), every healthcare provide can find the type of isolation a patient has. Moreover, an isolation card is placed next to isolation rooms. This card (fig. 6) shows the necessary measures that healthcare providers should apply when taking care of a patient in isolation.

To share information, Infection Prevention provides patient folders with explanation to the wards. However, as the context research shows (chapter 3), they are often not used by healthcare providers.



Figure 6: Isolation card - Contact isolation, single room

Isolation procedure

Patients are screened for risk factors when admitted to the hospital. The moment a patient is identified as a high risk patient, isolation precautions are applied and the patient is screened (fig. 7). High risk patients could for example be when a patient has diarrhoea, is vomiting or when he has a wound that is not healing well. When a patient has been admitted to a foreign hospital or works in the cattle industry, he is also cared for in isolation preventively. When MDRO are found in clinical cultures from an admitted patient, isolation precautions are applied also.

A known carrier of a MRMO need to test negative in several follow-up cultures to be released from isolation. For some infections (for example diarrhoea) the patient can be exempted from isolation based on the tests. The duration which a patient lies in isolation therefore also varies from patient to patient. It can vary from one or two days to weeks or even months, depending on the microorganism and recovery and discharge of the patient.



Figure 7: Isolation procedure

Isolation room

Ideally, the isolation rooms of VUmc are single rooms with a personal bathroom. When there are not enough rooms available, patients with certain microorganisms can be cared for in multi-occupancy rooms as well. When necessary, isolation rooms are single rooms that share a bathroom with another room and patients can therefore not use the toilet and shower (fig. 8).

Next to the open door of a contact isolation room, an isolation card is placed. In the hallway of the ward, there are waste bins for care materials, gowns and gloves. The new gowns and gloves are also either in the hallway or right inside the room (fig. 9). In the room, there is hand disinfectant.



Figure 8: Example of isolation room



Figure 9: Entrance of isolation room: isolation card, gowns, gloves and bins

2.3 Impact of contact isolation

Patients

Research shows that contact isolation is associated with increased anxiety and a negative impact on well-being (Abad et al., 2010). Patients experience barriers to the expression of their identity, impersonal relationships and an impact on the quality of care due to isolation. (Barrat, et al., 2010). Patients in contact isolation are more likely to have complaints related to hospitalization, communication and negative perspectives (Chittick et al., 2016).

Chittick mentions that patients report complaints regarding access to staff. Patients are unable to identify the difference between nurses, physicians and healthcare workers due to isolation gowns, which is experienced as difficult and dissatisfying (Roderick, et al., 2017). Moreover, healthcare providers are less likely to have physical contact with and are less responsive to patients in contact isolation (Kirkland & Weinstein, 1999; Lupión–Mendoze et al., 2015), while medical staff is two times less likely to enter the rooms (Malhotra et al., 2019).

Contrarily, several studies show the negative impact of contact isolation is less existensive. A study of Wassenberg et al. (2010) shows that short-term infection control does not influence patients' levels of anxiety, depression and quality of life. Furthermore, patients report their quality of care to have improved after moving to isolation (Chittick et al., 2016) and overall satisfaction with the care provided is similar to non-isolated patients (Lupión–Mendoza, et al., 2015).

The contradictory conclusions of studies are considered in a study by Rump et al. (2018), who mentions that control measures can have a large impact on patients in contact isolation, but the extent of the burden is highly dependent on the personal situation of the carrier. Therefore, rather than adhering to isolation measures as strictly as possible, it might be more beneficial to try and optimize the care for a colonized patient and his well-being in ways that do not result in unacceptable risks for other vulnerable patients.

Direct healthcare providers

Healthcare providers often experience caring for an isolated patient negatively as they mention a personal level of discomfort, physical limitation and management of workload as barriers for relationships with patients (Godsell, et al., 2013). Nurses spend more time per visit and physicians an equal amount, but it is experienced as a time burden and an increased perception of patients in isolation consuming too much time (Khan, Khakoo & Hobbs, 2006; Barker, et al., 2017). Healthcare providers, of which the largest part were nurses, mentioned feeling responsible for preventing transmission of MRSA (Seibert et al., 2014). Despite, they had difficulties using contact precautions correctly (Seibert et al., 2014). To improve their compliance to contact precautions, increased clarity of isolation protocols throughout the patients' hospital journey, enough isolation rooms, more education and involving all healthcare providers in infection prevention are mentioned.

Family

Family of patients in isolation are also upset and experience a burden by required hygiene measures (Heckel, 2017). Research with parents of children with MRSA shows that the perception of having more information on MRSA leads to less anxiety (Sengupta, et al., 2011). Knowledge gaps are about the origin and persistence and implications of being a carrier. A study with informal caregivers of patients with a positive MRSA diagnosis in a palliative unit found that family is in need of information and communication of the diagnosis and hygiene measures. Informal caregivers also wish to not be approached stigmatizing or experience disadvantages from the diagnosis of their loved one (Heckel, 2017).

2.4 Patient experience

2.4.1 Defining patient experience

Patient experience (PX) is defined based on occurrences and events happening independently and collectively across the continuum of care (Wolf & Jason, 2014). It is not only about the satisfaction of a patient with their care, it moves beyond that. Within patient experience, personalization and an individual care approach are the start to match a patients needs and preferences. Thereby healthcare providers can start to view them as partners of their care instead the one undergoing treatment.

Patient experience, as defined by the Beryl Institute (Wolf & Jason, 2014) is: "The sum of all interactions, shaped by an organization's culture that influences patient perceptions across the continuum of care". Beyond Philosophy(Wolf & Jason, 2014) explains patient experience similarly, by finding patient experience to be perceived through the conscious and subconscious mind. Therefore, one cannot simply ask about a patient's satisfaction level to determine patient experience. From these two definitions three factors can be derived:

- patient experience originates during multiple interactions over time and is about the rational as well as the emotional experience of these interactions. The time component in care is important. An experience is not based on one moment, it is the result of a sequence of interactions.
- 2. patient experience is influenced by the culture of an organization. An institute can have a large impact on the experience of patients by shaping their culture. A shared vision amongst all hospital employees leads to an overarching attitude in all interactions a patient has.
- 3. patient experience is about personal experiences and emotions that are triggered from the interactions. A patient can thus be seen as the expert of their own experiences and feelings.

In relation to contact isolation, this means that how a patient experiences contact isolation originates in the whole isolation journey. Starting when a patient is first hospitalized in contact isolation, every interaction with or realization of contact isolation adds to the PX. Moreover, it is shaped by the ideas about contact isolation that the hospital and healthcare providers have.

2.4.2 Concepts related to patient experience

Patient experience (PX) is strongly related to several concepts that are found to improve the provision of care to patients on motivational and emotional levels. Manary (2013) mentions that patient experience starts with involving patients in their care activities. Patient empowerment leads to involvement in their care process, but patients need to be engaged first to adopt the information that is shared by health care providers. In the next paragraphs, patient empowerment and patient engagement are explained.

Patient empowerment

One important part of PX is approaching a patient as an expert of his or her personal experiences (Castro, et al., 2016). By involving patients more in their care process, healthcare providers approach patients as experts. Patient empowerment entails the ability patients have and actions patients take to become more active in the decision-making process about their health and thereby improve the quality of life. It means that most patient empowerment studies are based on the idea that people have to take action to improve their quality of life by adapting their own actions. An individual responsibility, therefore, lies at the patient, although, patient empowerment also takes into account the social environment and organizations (such as healthcare systems) influencing their lives.

Patient empowerment therefore focusses on a two-way, practitioner-patient relationship (Castro, et al., 2016; Mead & Bower, 2000). Empowermentbased care and education are about enhancing autonomy and making informed decisions. Therefore, when empowering patients, they are supposed to have a more active approach regarding their care process.

By identifying patients' needs, patients taking action and patients gaining mastery over needs and issues that are identified as necessary by the patient (Castro, et al., 2016), patients gain a more active approach. Therefore, patient empowerment is perceived successful when a patient comes to terms with their threatened sense of security. To increase the sense of power and security, patients should experience control cognitively (ability to understand), decisively (ability to choose and decide) and behaviourally (ability to act). Interactions and conversations with other patients, family and friends and healthcare providers help patients to experience those senses of control by reframing their illness and developing new perspectives.

To enhance patient empowerment Castro defined the following factors: 1) dialogue is necessary: not just transference of knowledge, but a co-creation of knowledge. 2) a patient-centred approach should be applied in the whole organization. 3) Patients' competences should be enhanced, therefore we should provide enough information. 4) Active patient participation is necessary (Castro, et al., 2016) A study on patient empowerment in hand hygiene summarizes the ideas described above. They mention patient empowerment to be strongly related and increased by patient participation, patient knowledge, patients' skills and a facilitating environment (McGuckin & Govednik, 2014). That means:

- 1. Patients should be involved in their care process,
- 2. Patients have to be informed and thereby have the knowledge,
- 3. Patients need to have the skills to be involved and at last,
- 4. The healthcare system should be open and accessible for patients to become involved.

In this thesis, these factors are considered as increasing patient empowerment and therefore above standing research is summarized in these categories.

Patient involvement in care process

Patient empowerment is about an active and involved patient. If patients do not participate, they cannot function as the expert on their care process.

Informing patients and patient knowledge

Because patients find the ability to ask questions to and have fruitful discussions with healthcare providers crucial (Popescu, Neudorf & Kossey, 2016), patients need to be informed well. Initial self-management education and ongoing support are essential steps for informed participation and in the process of empowerment, and by educating patients why they should ask questions and directly asking them if they have any questions, patient involvement increases.

Patient skills

With information alone, patients are not empowered. Patients should also experience the right skills to acquire information, ask questions and become involved in their care process. Therefore, it is required that patients feel competent to do so.

Open and accessible healthcare system

Besides a feeling of competence and the provision of information, it is necessary that patients feel comfortable in being involved in their care process. Therefore, healthcare providers encourage patients and provide guidance in that discussion, because otherwise patients are not confident in doing so Therefore, communication that could activate patients to become more empowered is believed to be most successful in one-to-one conversations at the point of care (Popescu, Neudorf & Kossey, 2016), which means that to activate patients, there should be clear communication channels between patients, family and healthcare providers without fear or risk of reprisal.

Because one important aspect of patient empowerment is increasing patient knowledge and patient skills, patients need to be engaged to acquire the knowledge. Patient engagement is expected to lead to increased patient empowerment.

Patient engagement

Increased patient engagement leads to lower resource use and greater patient satisfaction and improved patient experience (Manary, et al. 2013). Research suggests that engagement can lead to increased quality of care, greater cost efficiency and improved population health (Carman, et al. 2013).

Patient engagement and antimicrobial resistance

The Canadian Patient Safety Institute studies the possible engagement of patients in antimicrobial resistance. By involving 72 Patient Advisors (individuals who have experienced care in the healthcare system and are involved in improving it), they identified factors that could increase patient involvement and engagement in this health concern (Popescu, Neudorf & Kossey, 2016). The researchers found that patients should have more knowledge about and a clear role to play in infection prevention and treatment of possible infections.

Moreover, engaging patients in infection prevention can decrease uncertainty and anxiety patients experience when dealing with infection prevention (Popescu, Neudorf & Kossey, 2016). Currently, procedures seem to be inconsistent, which leads to uncertainty and insecurity amongst patients. By providing more information about infection prevention and the patient's role, the patient's uncertainty and anxiety decreases. In addition patients are empowered to confidently self-manage their infections. Increased patient engagement regarding infection prevention also leads to increases in family involvement.

Patients should derive information at **multiple interaction points** during the patient journey in the healthcare system to engage them over their complete care process. Also, information has to be should be sent through channels that fit with the interaction point. When providing information at the right time and in the right way, it is better received, understood and acted upon.

The most effective time to communicate about antimicrobial resistance, according to Patient Assistants, is when patients and family have questions. Also, communication throughout the care process could best take place during critical transition points (e.g. admission and discharge or before a doctor visit). The patient also prefers one on one conversations with their healthcare provider.
2.5 Collective action

Antimicrobial resistance is a challenge that concerns the whole world. It requires working together at wards, hospitals, countries and worldwide. Only when many individuals invest, the effects and impact of resistance of antibiotics can be limited. It is a long-term process of which the investors, the patients that are in isolation and healthcare providers, might not necessarily see the results. A similar process can be described for isolated patients with infectious diseases, investing in the health of other patients without seeing the result of their actions.

2.5.1 Shared responsibility in antimicrobial resistance

Patients mention that antimicrobial stewardship (conserving the ability to treat patients that have infections), is a responsibility that concerns all stakeholders (Popescu, Neudorf & Kossey, 2016). Many actors (for example society in general, patients, nurses, educators, physicians and administrators) are involved in the care process and have a function in providing safe patient care (Ballard, 2013).

Despite it being a shared responsibility, as Ballard explains, nurses play a key role in the safety of healthcare. They are held accountable for following the rules and protocols, but can also increase patient safety by being competent team leaders. The impact of nurses on patient safety is significant; thus by approaching nurses as the spill of quality care, patient safety increases.

2.5.2 Collective action theory

It is the sum of all individual actions of involved actors in hospitals, such as patients, nurses or physicians that contribute to the prevention of infections. To stimulate individual actors to comply with IP measures and invest time and effort without them experiencing direct or visible results, the theory of collective action can be applied.

When individuals in a group have a common interest, by acting in a group, the likelihood of achieving common goals increases. When group size becomes more extensive and interpersonal bonds less strong, the investments of collective action sometimes seem to outweigh the goal (Wheatcroft & Price, 2017). Collective action theory aims to analyse and overcome this challenge. The collective action theory started by economist Mancur Olson (2009) and takes into account the sustainment of common goods. It dwells on collective shared responsibility amongst individuals and their motivations to invest something for 'the greater good' (Meinzen-Dick & Di Gregorio, 2004). A common good is non-exclusive but limited.

Example: The ability to treat people with antibiotics is a collective good. In general, everyone can use antibiotics (non-exclusive), but at some point, they might not work anymore (limited). On a smaller scale in the hospital, the aim to receive safe healthcare and therefore limit infections is for everyone (non-exclusive).

The influence of an individual investor in a common good is of insignificant impact on the outcome, and personal short-term investment costs are higher than individual benefits. However, when combining many different investments, the (future) benefits for the community and thus, individuals are significant.

So, individual actors have to invest time and effort to ensure the safety of current and future patients in the hospital. Physicians, nurses, patients, visitors, and supporting staff have to behave according to the protocol, even though they do not necessarily experience any advantage from it. However, their contribution alone does not lead to less healthcare-associated infections in the hospital or the prevention of antimicrobial resistance.

Multiple theories assume that the behaviour and the benefits are equal for each individual (Meinzen–Dick & Di Gregorio, 2004). In practice, the costs and benefits differ between actors. During admission patients benefit from healthcare providers applying infection prevention measures. Patients do not get infections but do not have to do much themselves. Patients with resistant bacteria or highly infectious microorganism are isolated, whereas they do not directly retrieve any benefit from that.

We can approach actions to limit the prevalence of healthcare-associated infections as a common good. and explain and influence the individual investments actors have to make using to the collective action theory.

Factors that increase collective action

There is no fixed set of guidelines to solve collective action problems. Known factors that add to the likelihood of collective action, based on the increased willingness from individuals to participate are: (Meinzen–Dick & Di Gregorio, 2004; Ostrom, 2010).

1. The number of participants involved; As the group size extends, an individual's input will become less significant and less noticeable.

2. Face-to-face communication; Communication has a strong positive effect on collective action. By communicating, preferably face-to-face, helps to grow a sense of solidarity amongst actors.

3. Links between individuals; By linking individuals in one direction (everyone connects with two other persons) instead of being part of a generalized pool, contribution to the common increases.

4. Information about past actions; When an individual has more information about previous actions of others, one is more likely to behave similarly in similar situations.

To influence these factors in the context of infection prevention and antimicrobial resistance, information about the necessity of working together and the future of antimicrobial resistance should be presented to patients in a manner that is relatable to the individual. Moreover, different individuals, such as patients, healthcare providers and informal caregivers should be linked.

2.6 Conclusion

Current literature shows that different actors can experience contact isolation in different ways. Contact isolation can have a negative impact on the patient's well-being depending on personal factors (Rump, et al., 2018). Healthcare providers experience barriers due to contact isolation and unclarity regarding protocols. Family also feel uncertain about the impact and persistence of the microorganisms. Despite the negative experiences associated with CI application is necessary to prevent transmission and HAIs. Infections and antimicrobial resistance are a threat that is existent.

Improving the attitude of patients and other involved actors towards contact isolation can be by providing information. Receiving and understanding information increases patient experience. An increase in patient understanding and knowledge should be established by providing information over a continuum of care and at multiple interaction points. Information is best received when patients and family have questions.

By providing information when patients initiate the need of information, patients feel more empowered and engagement in isolation measures increases. Patients then, become aware of the implications of being in contact isolation and understand the reason behind it. To stimulate that engagement, information should clearly communicate the patient's role and their responsibilities regarding isolation precautions. What is expected of the patient, and how can he attribute to his own health and the health of others.

Patient experience can improve by establishing an open healthcare environment. An environment in which questions from patients are welcomed and in which back-and-forth communication between healthcare providers and patients is possible. Healthcare providers should encourage patients to become involved. Patients will thereby feel confident to ask questions and provide input on their care and isolation process.

To improve patient experience during contact isolation, collective action theories have potential in the stimulation of the contribution of patients, healthcare providers and visitors to infection prevention, a community feeling should increase.

The connection between individuals should be established and information about past actions of other individuals should be provided. To achieve collective action, the healthcare network should feel like a community to all involved actors. Therefore, the necessity of working together should be communicated to the individuals. Individuals should be able to relate to the other individuals in the community. To increase the ability to relate to other individuals in the community, a personal connection between individuals should exist. Through face-to-face communication between individuals results in trust and reciprocity between individuals. Individuals are inclined to imitate behaviour. Because key individuals have a higher incentive to behave in a productive way, their past actions can be communicated to other individuals to encourage this behaviour.

Because antimicrobial resistance and infection prevention are collective action issues, applying factors from collective action theory might increase the patient experience in the specific context of contact isolation. Therefore elements from the collective action theory can be used to create an information path in which various actors provide information. It could improve the patient experience for patients in CI and subsequently contribute to compliance to the protocol. Figure 10 shows the overlap in themes exist between patient experience and collective action. Facilitating an open hospital community, establishing interpersonal connections and providing information.

Therefore a design should consider the following:

- 1. A shared vision about infection prevention and contact isolation across the hospital, so that all individuals and in particular healthcare providers are open to the involvement of patients.
- 2. The facilitation of connection between individuals within this community, without physical contact.
- 3. Clear and correct information transfer about implications and reasons behind contact isolation between those individuals.

To implement the factors that lead to improved patient experience during contact isolation, the current situation and challenges should be investigated. The in context motivations, needs and considerations regarding contact isolation of different stakeholders should be identified to create a vision, facilitate interpersonal connections and define the sort of information necessary to explain. Moreover, key moments and questions regarding contact isolation should be defined.

To gain more insight into the current experience of patients in contact isolation and on the experience of other actors involved in contact isolation, a context research is performed.



Figure 10: Model for design implications when improving both patient experience and collective action

Context research: experiencing contact isolation in VUmc



To improve the patient experience during contact isolation through the design of a product or service, the key moments, interaction moments and experience of patients have to be identified and researched. Through context research, designers can empathize with the patients, healthcare providers and other involved actors. Moreover, by researching the context of contact isolation qualitatively, designers are better able to relate with it and can thereby design products or services within this context.

This chapter provides insight into the procedure of the context research that is done in this thesis. Research was conducted with patients, nurses, physicians, infection prevention experts and other involved actors to gain understanding of the actual context of contact isolation in VUmc. The research is led by the following research questions: 1. How is contact isolation currently executed in the ward? and

2. How do different involved actors experience contact isolation?

3.1 Research aim

To be able to define the context of contact isolation in VUmc and identify opportunities to improve the experience during isolation, the following research questions with sub-questions led the study:

- 1. How is contact isolation currently executed in the ward?
 - What is the in practice, procedure regarding contact isolation?
 - Which actors are involved in the in practice procedure of contact isolation?
 - What are the actor's activities, responsibilities and interactions regarding contact isolation?
- 2. How do different involved actors experience contact isolation?
 - How do patients currently experience contact isolation?
 - What needs, values and emotions are important to patients in contact isolation?
 - How do healthcare providers currently experience contact isolation?
 - What needs, values and emotions are important to healthcare providers when taking care of patients in contact isolation?

3.2 Method

3.2.1 Method

Several qualitative research methods have been practised to answer the research questions (fig. 11). In this study, the researcher combined observations and interviews with multiple actors involved in contact isolation. The research setup can be found in appendix B.1

Interviews with infection prevention experts

This study started by performing semi-structured qualitatitive interviews with infection prevention experts, to gain a basic understanding of contact isolation and its protocols in VUmc. Three semi-structured qualitative interviews with infection prevention experts from VUmc led to answers about the current challenges of and approach to improving contact isolation. The interview questions roughly followed the themes personal background, current procedure of infection prevention and contact isolation, positive and negative aspects for different actors and the ideal future.

The interview questions can be found in appendix B.2. These interviews served, together with observation, as input for patient and healthcare provider interviews. Because the setup of the study is similar to the healthcare provider, they will further on be referred to together

Observations in the hospital

Observations were done at the vascular surgery ward and haematology ward to get familiar with the hospital context and experience the ins-and-outs of the ward. The wards haematology and vascular surgery were observed for respectively 1,5 and 4 hours. At haematology, the observer was seated in the coffee corner and looked around the ward. At vascular surgery, the observer was seated at the coffee corner, the coffee room for care providers and joined the visitation of a patient in contact isolation. The observation themes can be found in appendix B.3 .Notes were taken to capture insights. The observations provided input for the setup of the interviews with healthcare providers and patients.

Interviews with patients and healthcare providers

Semi-structured, qualitative interviews have been conducted with patients who are or were in contact isolation and healthcare providers that provide care to patients in contact isolation. The patients were hospitalized in the wards vascular surgery and haematology of VUmc and acute admission in another hospital. Interviews were also conducted with two physicians, six nurses, one employee from patient transport. The interview questions can be found in appendix B.4. The themes leading the patient interviews were: the knowledge of and information on contact isolation, the best and worst moment regarding contact isolation and the experience of that moment and the ideal future scenario of contact isolation. The interviews were audio-recorded, transcribed and through interpretations of the quotes, insights were formed.



Figure 11: Method overview

3.2.2 Participant Requirements and Recruitment

Participants have to meet several criteria. For the recruitment of both patients as well as healthcare providers, the requirements are specified below.

	Inclusion criteria		
Applying to all participants	 Participants have to be age 18 or over. Participants have to be able to communicate in Dutch 		
Applying to all patients	 Participants are currently in contact isolation or have been in contact isolation up until half a year before the interview. Participants are hospitalized in haematology, acute admission or vascular surgery in VUmc. 		
	Note: Not only patients in contact isolation, but also other types of isolation, such as strict isolation and aerogene isolation are included. At the ward there is no difference in approach between contact isolation patients and other patients in experience. Therefore the assumption has been made that the patient experience of other types of isolation are similar.		
Applying to all healthcare providers	 Participants provide care to patients in isolation Participants are nurses, physicians or supporting staff Participants are working in the wards haematology, acute admission or vascular surgery. 		

Participant requirements

	Exclusion criteria
Applying to all	• Participant is excluded when unable to give
participants	permission to participate in the interview

Participant recruitment

Patients

An involved nurse led the recruitment of patients in the designated wards. Per ward, the researcher explained a nurse the goal of the study. The informed nurse was asked to ask patients if the researcher could approach them for participating in the study. If the patient agreed to the nurse, the researcher visited them and informed the patient in detail.

The researcher explained the study and the goal of the interview to the patient, that the interview would take place at their hospital room, and that the interview would be audio recorded. When the patient chose to participate, the interview took place at a set time.

Note: The researcher recruited one patient through Facebook. The (former) patient had been admitted to another hospital and shared her story on Facebook. In a message, the researcher explained the study and the goal of the interview, that the interview could take place at a place, date and time of preference. The researcher explained that it would be audio recorded and analysed anonymously.

Healthcare providers

The researcher approached healthcare providers directly. Healthcare providers were invited to participate in person or via e-mail. If they agreed, the researcher contacted them and explained the study and the goal of the interview. The researcher explained the interview is at a location they prefer, and that the interview was preferably audio recorded. When the healthcare provider chooses to participate, date and time for the interview were set.

3.2.3 Participants

#	M/F	Ward	Type of isolation	First time isolation	Note
P1	F	Vascular Surgery	Contact isolation, single room	No	
P2	М	Vascular Surgery	Contact isolation, single room	No	
Р3	F	Acute admission	Contact isolation, multi-bed room	Yes	Admitted to another hospital
Р4	F	Haematology	Contact isolation, single room	Unknown	Wanted to have a conversation, but not be audio recorded
P5	М	Haematology	Contact isolation, multi-bed room	No	
P6	F	Haematology	Contact isolation	Yes	

Patients

Healthcare providers

#	M/F	Ward / department	Function
H1	F	Medical Microbiology and Infection prevention	Expert infection prevention
H2	F	Medical Microbiology and Infection prevention	Expert infection prevention
H3	F	Medical Microbiology and Infection prevention	Expert infection prevention
H4	F	Haematology	Haematologist
H5	F	Haematology	Nurse
H6	F	Haematology	Nurse
H7	F	Acute admission	Nurse
H8	F	Acute admission	Nurse
H9	F	Acute admission	Nurse
H10	F	Acute admission	Attending physician
H11	М	Patient transport	Patient transporter
H12	F	Haematology	Nurse

3.2.4 Research procedure

In the qualitative interviews with healthcare providers and patients, the researcher applied the following procedure. The researcher first told the participant the goal of the study, the data handling and the setup of the interview. Moreover, the preference of audio recording was explained, and when the participant agreed, a consent form was signed, then the interview started.

In practice, changes had to be made to the initial interview setup due to impracticalities because of patients lying in bed. Therefore, the initial interview setup was not entirely suitable for the interview. The participants should be comfortable both physically and mentally during the interview; thus, it became less structured and more conversation-like.

3.2.5 Analysis

To be able to translate the data from the interviews to insights, the researcher transcribed each interview. The transcripts were used to identify quotes that were notable or informative to the researcher. Based on the quotes, statement cards were created, stating: a quote and an interpretation

To analyse the data from the statement cards and find patterns, a customer journey is used. A customer journey is a method for analysing and communicating the process a user goes through over time. It maps the consecutive steps a user encounters to find more specific actions, motivations and emotions that they meet. In journey mapping, the complicated context and its actors, relations, interactions and critical human factors concerning the process can be discovered and located. By using the insights and taking the broader picture into account, one can create more fitting solutions.

When a customer journey is used to analyse and improve the healthcare system from a patient perspective, it is called a patient journey. In this report, therefore, the word patient journey is used to describe this method.

From the patient journey, themes about activities and situations arose. Based on previously defined phases (in columns) and stakeholders (in rows), all the interpretations were placed in the fitting cell of the patient journey. Within the cells, the interpretations were clustered based on similarities in interpretation and situations into themes about consequences of and considerations about (contact) isolation. Through placing different themes on the horizontal axes within a phase, series of activities and emotions could be identified. Clustering themes led to recognized links and interactions between stakeholders within a moment in a particular phase. The themes, links and interactions provide opportunities for improvement.

3.3 Constructing the Patient Journey

The patient journey is used as an analysing and communication tool for the results from the context research. To explain the results and insights that appeared from the analysis, it is important to first explain the setup of the patient journey. In paragraph 3.5 Results, the themes that originated in the patient journey are explained.

The horizontal axis of the journey map shows the procedure of contact isolation. The following phases happen during a patient's first time in isolation: 1) (prepare) admission; 2) the first time in isolation; 3) stay, in which care and visits are subphases that are reoccurring within the stage stay; 4) discharge; 5) readmission. When a patient readmits to the hospital, he follows the five phases again. During readmission, the phase first time in contact isolation is skipped. Together, these phases explain the journey every (new) patient in contact isolation goes through.

Within the phases, different actors experience several activities and consequences regarding isolation. The circles represent the factors (activities and consequences) per actor. When the activities or consequences in one vertical line, it means multiple actors are involved in that activity.

Actors

The first four rows of the patient journey visualize the actors that are involved in the contact isolation procedure. The different actors interact with each other, which is shown by the links between the corresponding activities. The order of the rows is based on the involvement level of the individual in the isolation procedure, taking the patient's activities as a starting point. The rows are: 1) Patients; 2) Nurses; 3) Family and 4) other. In the category other, the actions physicians and infection prevention experts are described.

Emotional journey

The following two rows show the emotional experiences of the patients and the nurses during the journey. An emotion line visualizes their experience and how it changes over time. The negative emotions are named based on the emotion typology (Fokkinga & Desmet n.d.) and on the positive emotional granularity cards, the positive experiences the journey are defined (Desmet, 2012).

By defining the emotional journey patients go through, we identify three different types of patients. The three different patient personas experience the procedure of contact isolation from very positive to highly negative. The patients types are described by the use of personas. Insight into the nurses' experiences is gained by visualizing the emotional journey of the

nurses as well. Nurses are the connection between the hospital and the patient and play a significant role in the procedure of contact isolation.

Insight into the nurse's experiences is gained by visualizing the emotional journey of the nurses as well. Nurses are the connection between the hospital and the patient and play a significant role in the procedure of contact isolation.

Opportunities

We can improve the patient or nurse experience during contact isolation at several moments in the patient journey. To identify the exact moments when we can improve the patient experience, we linked the opportunities to the isolation factors (activities and consequences). 3.4 Patient Journey - Current experience of first time contact isolation





3.5 Results derived from Patient Journey

In this paragraph the results from the context research are explained in themes. Because different types of patients appeared to experience the journey of contact isolation differently, the themes vary per patient persona. Therefore, these personas are explained primary to the contact isolation themes. The contact isolation themes are explained per main actor, either the patient, the healthcare provider or the informal caregiver. Themes regard implications, experiences or emotions that arise from being in isolation or caring for someone in isolation.

3.5.1 Three different patient personas

In the patient journey, three different patient experiences are identified. This means, different people experience contact isolation in different ways. One patient persona (Independent Isa, fig. 12) likes being in contact isolation, appreciates the autonomy that follows and enjoys the quietness of being alone in a room. The second persona (Compliant Chris, fig. 13) has to get used to isolation, but follows what the healthcare providers think is best for his care. The third persona (Social Suzan, fig.14) enjoys company and therefore experiences contact isolation as overwhelming.

All individual patient participants more or less fit in one of the patient persona. In figure 15, the participant spread within these personas is visualised. It shows that not every individual fits in one patient persona completely and that one patient sometimes can be a bit more like Independent Isa and another time more like Compliant Chris. The three patient personas are the extremes of patients, to identify different needs and experiences between patients.



Figure 13: Patient persona: Compliant Chris



Figure 15: Patient personas: participant spread

3.5.2 Results from a patient perspective

The results with patients as main actor are grouped based on implications, experiences and emotions. Because not all patients concern all implications, experiences and emotions, per theme it shows to which persona the theme applies.

Implications

Patients are not able to use shared facilities

It is often experienced inconvenient that patients cannot make use of the shared facilities in the ward. Not every ward has enough single rooms with a personal bathroom. Therefore, when you are in isolation, it might happen that you cannot use the toilet or shower because it is shared with other patients. A patient might then have to make use of a stool and cannot shower. Even though the nurses try to move the patient to another room and make it as comfortable as they can, it is not always possible.

Moreover, at haematology, patients cannot use the sports equipment in the ward. The sports equipment is used to strengthen and increase rehabilitation. When there is enough room, individual sports equipment is placed, but due to space limit it is not always possible. Patients find that impractical and are afraid it hinders their recovery. Also, the use of the coffee corner, fridge and family room is prohibited, which is especially an issue when patients are in a shared room, contact isolation.

Het gaat alleen maar goed als je een kamer alleen hebt. En als je op een kamer ligt, die voor twee bedoeld is, dan heb je geen eigen toilet, geen eigen douche. En dat is ingewikkeld, vooral de douche." – Patient

Rooms are very small

Often, individual rooms are very small and experienced as oppressive. Patients do not always have a lot of space to move around the bed, especially when there is also sports equipment in the room. A patient mentioned the feeling of being prisoned due to the small room size.

En dat vond ik nog wel het ergste van alles [...] Omdat het maar een heel klein hokje is. Ik kon net om mijn bed heen lopen, en dat was het zo'n beetje. – Patient

Ja, zo voelde ik dat wel, ik zeg; waar zijn de tralies? Dat is het eerste wat ik zei" – Patient







Patients have a more active attitude at readmission

As soon as patients are readmitted, they have a more active attitude. Because they are familiar with isolation measures and understand the reason, consequences and implications they start mentioning the necessity of an individual room upon arrival. Also some patients point out to care providers that they have to wear gloves when taking care of them. The (pro) active attitude, especially during admission is appreciated by nurses.

Als je patiënt het al weet, dan hoe je minder uit te leggen want dat weet ie nog van een vorige keer van zo ging het" – Nurse

Maar er wordt niet goed gelezen ofzo, ik weet het niet. Dus ik ben er heel vaak bijgebleven om te corrigeren. En dan denk ik; als je alleen bent... Ben je overgeleverd he." – Partner patient

Dus iedereen die binnenkomt, zeg ik ook; handschoenen aan. En schort zeg ik dan niet, "maar wanneer ze geen handschoenen, geef ik ze dus zelf geen hand." – Patient

Experiences

Explanation and information leads to decrease of confusion

In general, information that is given to the patients is understood quite well. However, the specifics are not always understood properly. All patients could comprehend the consequences and broad reasoning from being carrier of an infectious microorganism, but differences in protocols and differences between care institutions and explanations of different healthcare providers cause confusion.

Healthcare providers explain how the spread of the microorganism might be dangerous to other patients in the hospital and that therefore direct contact with the patient should be prevented. They also explain what the microorganism is and how often they will do tests to check if they are still carrier. Moreover, they explain that it is of no danger for their relatives. All patients were able to explain the interviewer the measures and reasons to take them, but some patients mentioned confusion about the exact behaviour of the microorganisms and if and how it is dangerous to others outside of the hospital.

A speaking example in which the 'easier' explanation becomes confusing to patients is explaining the microorganism as hospital bacteria. Patients do not understand how the microorganism is not dangerous outside of the hospital. . Questions that patients have are mainly asked to the nurse or not asked at all.

Nou ik vind dat heel verwarrend. Ze hebben het geprobeerd, nou ja ze het is een ziekenhuisbacterie [...] dus is het ziekenhuis is hij actief. Maar m'n lichaam kan toch niet zeggen; we zijn in het ziekenhuis, en nu zijn we erbuiten dus hij doet het niet meer." – Patient





Patients experience first time into isolation as overwhelming

The first time in isolation is for the patient types Compliant Chris and Social Suzan often unexpected and overwhelming. Patients are either placed in an isolation room right when they arrive at the hospital, or moved to another room when they are hospitalized already. Patients feel like it befalls them and that they are caught off-guard.

Even though the patients in haematology have had some information about isolation, for them it was still a surprise and a new experience. Patients felt that they were suddenly moved to another room.

En toen een paar dagen later door al die onderzoeken van je bloed en je urine en dat soort dingen en je ontlasting, kwam dat er dan uit. Ja en toen brak er gewoon iets." – Patient

Hoe ik het ervaarde is dat het wordt medegedeeld en meteen rddddt, naar een andere kamer. In mijn ogen hè. Dat is misschien niet zo hoor. Maar het overviel me gewoon." – Patient

Patients feel more autonomous due to single room

One of the great advantages of contact isolation is the ability to have a private room. The ability to close the door when you want to rest and not having to consider other patients when you are ill is experienced very positively. Patients are able to create their own daily rhythm without being disturbed by their roommates and feel more autonomous. Also, when patients are in a shared room, some feel like they are bothering the others.

Nurses try to compensate the situation of being alone in a room for patients by extending visiting hours and walking in at the beginning of the day to explain the schedule.

Het apart liggen vind ik prima. Al dat gekwek om me heen hoef ik niet. Lawaai hoef ik ook niet. Dus in m'n eentje, ik kan mezelf heel goed bezig houden." – Patient

Bezoek mag langer blijven, ik kan opblijven zolang ik wil, ze kunnen blijven zolang ik wil. je kan liggen wanneer je wil, je kan de deur dichttrekken wanneer je wilt" – Patient







Patients appreciate a sense of the world around them



Patients mention that they appreciate being in a room with a view and the ability to look out of the window or the door. By providing a calendar, a patient's partner creates a feeling of connection to the world outside of the hospital. Moreover, especially to patients in isolation, nurses explain what the care schedule of the day is to give a patient more grip on the day.

Kijk, zit ik niet op een mooi plekkie hier? Als ze landen, dit is nou de stijgroute vandaag, maar als het de landingsroute is dan komt er om de andere minuut een vliegtuig. Dan zie je ze zo mooi." – Patient

Emotions

Patients experience anaer



When patients were in the hospital and they had to go into isolation, they realized it was because of poor hospital hygiene that they got the bacteria which caused anger due to the negligence of the hospital.

Wanneer heb ik dat nou gekregen, ja twee jaar geleden. Ja woest, kwaad. Heel kwaad was ik. [...] Dus ik zeg; pardon?! Ik zeg; dus die heb ik aan jullie te danken dan? Had ik nog niet genoeg?" – Patient

Even after explaining that the gown, gloves and sometimes mask will be worn, the first time seeing care professionals wearing the control measures can be a shock. After the first shock that isolation can be to patients, some patients get used to the isolation measures and they resign to the situation.

For nurses, the first time someone is going into isolation is experienced poorly as well. When bringing the news a that patient has to go into isolation, nurses feel like the 'bad guy' for doing this to someone. Also for nurses, the movement of patients to another room is stressful, as they have to move other patients around as well due to lack of empty rooms. Patients feel disgusting, responsible and guilty



if they would not be careful enough. It is important to mention that the amount of information and knowledge has a limited effect, as patients who felt unclean did understand that they were of no danger to their loved ones or themselves.

Dus ik zou niet graag hebben dat ik anderen aansteek. Dat die het door mij krijgen. Dan voel ik me eigen natuurlijk wel klote." – Patient

Omdat ik me gewoon heel erg vies voelde. " - Patient

En je voelt je ook nog een soort van schuldig [...] Want ze zeggen; het is een darmbacterie die in je urineweg terecht is gekomen. Dus dan denk ik: waar is het misqeqaan qua hyqiëne ofzo. Terwijl ik juist altijd heel schoon ben." – Patient



Patients feel stigmatised

A disadvantage of being in a shared room is the stigma that comes with the isolation card. One patient mentioned finding it a violation of privacy that the information about her infection was on the door and also explained to other patients.

En nou vond ik het echt zo'n plakkaat op je voorhoofd. Zo'n stempel zeg maar. Van nou, niet daar in de buurt komen want dat kan wel eens gevaarlijk zijn." – Patient

Patients feel lonely when isolation duration increases

Especially social patients experience loneliness when hospitalization in isolation takes a longer time. They miss contact with other patients, not being able to leave the room and become bored. Nurses try to improve their situation by asking mental support to help the patients. The loneliness and frustration that might come with isolation can influence the recovery of the patients.

Lig je een week in isolatie of lig je echt een hele opname dan 4 weken in isolatie. Ik denk dat het dan ook wel meer parten gaat spelen." – Nurse

3.5.3 Results from a healthcare provider perspective

The context research showed that the nurse plays an important role in the explanation and compliance of infection prevention and contact isolation in the ward. They have the most contact with patients and therefore are often the person explaining or answering questions about contact isolation. Therefore, the main healthcare provider explained in the results is the nurse. However, other healthcare providers are discussed as well.



Nurses are greatly invested in the wellbeing of patients

Nurses put in all the effort they can to improve the stay of their patients. They try to make adjustments when a patient's wellbeing suffers from isolation measures and extend visiting hours to give the patients some benefits. In situations in which a nurse cannot change much about the situation, she feels powerless and guilty.

Nurses moreover find it unfortunate that they have less personal contact with the patients that are in contact isolation, although they intentionally go into the room more often and longer if they have time. Patients also highly appreciate the empathic attitude.

Wat ik nog wel eens doe, is dat ik dan zeg; bezoek kan wel wat langer blijven. Als de deur dicht is, ziet toch niemand het. Want dan hebben ze niet zo h et gevoel dat ze alleen zijn." – Nurse

en dan vraag ik wat ze nog nodig hebben en dan leg ik meteen een beetje de gang van zaken van de hele dag uit. Dan weten ze een beetje waar ze rekening mee kunnen houden. – Nurse

Nurse feels frustrated when others do not conform to protocol

Nurses feel highly responsible for making sure the control measures are well performed. Therefore, when others do not follow protocol, they are annoyed. Nurses understand the grounds of infection very well and want patients and their family and colleagues, mainly physicians, to act accordingly as well. However, when others do not, nurses feel like they do not listen or do not care, which is energy draining, creates frustrations and results in feeling like a police officer.

Soms vanuit de artsen die denken; oh, maar ik loop gewoon maar even naar binnen. [...] En dat het niet begrepen worden door familie of dat je het zo goed mogelijk probeert uit te leggen en dat er niks mee gedaan wordt. [...] Ja, dat is gewoon een beetje frustrerend en op een gegeven moment ben je er wel klaar mee." – Nurse

En ik heb ook geen zin om een soort politieagentje te zijn en iedereen steeds aan te spreken van hallo eh was je wel je handen of doe je wel een mondkapje voor." – Nurse

Healthcare providers experience difficulty in conforming to protocols Due to the invisibility of the results and the impracticality of the isolation measures, some healthcare providers have difficulty following the protocol. A physician mentioned that the amount of waste is against her values and that she felt that the decision for isolation measures was made behind a desk instead of practically in the ward.

The invisibility of microorganisms was mentioned by several healthcare providers. They said that the effect of infection control measures was unrecognizable, which leads to a decreased understanding of the necessity of contact isolation.

dan gaan er wel twee paar handschoenen en een muts de prullenbak en dat vind ik soms een beetje zonde van het milieu. [...] dat gaat een beetje tegen mijn eigen principes in." – Physician

Ik ben zelf niet zo ingesteld. Ik ben zelf pragmatisch ingesteld. Dus het voelt voor mij een beetje als een opgave om me er helemaal aan te verbinden" – Physician

Healthcare providers understand infection prevention and contact isolation and its implications All healthcare providers I spoke to, were able to explain contact isolation and the implications. They understand the consequences enough to perform the measures correctly. When one does not know the specific type of microorganism and how to handle it, they mention looking it up in the protocol or asking the CIP-nurse. Patient transport uses colour codes for different types of isolation, together with digital explanation of the different colours.

Healthcare providers have a preference for verbal explanation of isolation measures Nurses and physicians have a preference for explaining control measures in a conversation and do not make use of folders. Information about the reason for and implication of contact isolation is preferably explained in one clear conversation at the start of contact isolation. An exception to this is haematology, where a first explanation of the possibility of getting tested is shared with patients when they are admitted already. In their communication healthcare providers mention the reason for contact isolation to be the health and safety of other patients. When a patient does not understand the implications or does not listen to the nurse, the doctor is asked to explain.

It is unclear who is responsible for the first clear explanation. Some nurses mentioned it always being them, others said it depends on who sees the patients first and others told it depends on the reason for isolation.

[...] dan kan je nog enigszins een poging doen voor het beter uitleggen als iemand het niet begrijpt, dan wanneer je iemand een foldertje geeft met joh, lees het even door" – Nurse

3.5.4 Results from an informal caregiver perspective

Due to having only interviewed one informal caregiver, the results about visitors are mainly derived from the interviews with healthcare providers and patients.



Interviewed nurses explained that family, similar to patients, gets used to isolation measures when a patient is in contact isolation for a longer time. At first, isolation measures can be new and a shock, but later the implications become normal. Patients mentioned that informal caregivers start using hand alcohol more often. Nurses mention that many visitors keep walking in- and out of the room without applying hand hygiene.

Moreover, a clear explanation to visitors is often missing because no healthcare provider is responsible to do so and visitors have to actively ask for an explanation.

Dan had ik iemand ook in isolatie liggen, en ik heb het gezegd. En dan heb ik de zoon en dochter drie keer die kamer uit zien lopen en ik heb ze geen een keer hun handen zien wassen." – Nurse

3.6 Study limitations

When considering the results, the limitations of the study have to be taken into account. One limitation is the scope in which the interviews have been conducted. Research has only been done in 3 wards in VUmc in which many patients are in (contact) isolation. Due to more extended experience with (patients in) contact isolation, healthcare providers might not represent healthcare providers from other wards. Moreover, in total, only two physicians were interviewed and results from the two interviews varied significantly. No representative conclusions about the physician experience can be drawn. The interviewed nurses were all either CIP nurse (Contact person Infection Prevention) or highly interested and invested in infection prevention. It is unclear whether that is because all nurses find infection prevention important or because nurses that think so were more likely to participate in the research.

The results regarding informal caregivers and family of patients are mainly based on the stories of healthcare providers and patients. Only one partner of a patient was interviewed. The results might therefore not be the accurate experience.

Moreover, one patient was hospitalized in another hospital than VUmc. The insights derived from the interview agree with the other interviews, however her experiences might not be representative for the experience of patients in VUmc.

3.7 Conclusions and design implications

Based on the results of the context research, three main conclusions are identified:

- 1. Shattered sense of responsibility amongst actors,
- 2. Patients experience contact isolation differently and,
- 3. Difference in experience and behaviour between first admission and readmission.

Based on the conclusions, design opportunities are identified in the patient journey.

3.7.1 Shattered sense of responsibility amongst actors

Actors have a disparate sense of responsibility towards infection prevention. Different actors therefore act upon contact isolation differently, which leads to a contrasting experience. Nurses feel highly responsible and act as a messenger and an advocate of isolation measures. The downside of the responsibility is that nurses often feel like they have to correct patients, visitors and colleagues which they often do not feel like doing due to time pressure and not-listening receivers. They feel like police officers supervising others.

Some patients in contact isolation feel very guilty, worried and responsible for the health of other patients. They are afraid of being the source of infections to others and mention the necessity of isolation measures to healthcare providers. These patients experience contact isolation as way more negative. Contrarily, a different patient group resigns to the isolation measures they have to undergo and focus way more on their own health. This patient group does not care about control measures and if they are applied or not.

Due to invisibility of microorganisms, some physicians also do not feel responsible for improving infection prevention. By only following protocol because it is protocol, they find to have done enough. Another important party involved is medical microbiology and infection prevention, who are the educators in the system and advise on how to handle infection prevention and are therefore are and feel very responsible.

The shattered sense of responsibility is undesirable, because **control measures** are only effective to prevent infections and antimicrobial resistance when enough **people are invested** in preventing microorganisms to spread to other patients. By increasing shared responsibility, the experience of all stakeholders could improve.

3.7.2 Patients experience contact isolation differently

In the journey of (first time) contact isolation, three different patient types are identified. The largest patient group (Compliant Chris) has to get used to isolation when it's all new, but soon they got used to it, they comply and follow the healthcare providers. However, there are also two patient groups that experience contact isolation completely different. Some patients (Independent Isa) really enjoy isolation, however when this patient group has to get out of isolation, they might struggle more. Another group (Social Suzan) feels very lonely and guilty, because they are very socially oriented and therefore enjoy contact with other patients more. By acknowledging these differences, a more fitting approach can be offered to patients.

3.7.3 Difference in experience and behaviour between first admission and readmission

Patients behave differently when readmitted compared to first admission. Readmitted patients understand the control measures and are used to them already. That results in a more active attitude and patients start pointing out the necessity of control measures to healthcare providers. Therefore patients that are readmitted can be cared for differently than new patients.

However, for two patient types, Compliant Chris and Social Suzan, the first time in contact isolation is very overwhelming. It results in a very low first experience of contact isolation which predicts the further experience for patients like Social Suzan. Because of the overwhelming first admission, information is not well landed and therefore does not stick well. Focussing on improving the first time in contact isolation, might therefore lead to an improved understanding and experience.

3.7.4 Design opportunities

Based on the three conclusions, design opportunities are found and added to the patient journey. Below, they are explained in the matching category. In the patient journey the design opportunities are positioned at the point of interaction (fig. 16).

Shattered sense of responsibility amongst actors

By spreading the feeling of responsibility amongst different actors, the experience during contact isolation can improve for patients and nurses. The following design opportunities are identified in the patient journey to increase the sense of responsibility for some actors.

- Create chance for nurse to provide input on decision for isolation (Preparing) Admission
- Share with patient and nurse that they are in this together First time into contact isolation
- Make patients understand the reason of contact isolation by making it more visible First time into contact isolation
- Increase awareness of antimicrobial resistance as the reason you have to be in isolation Stay
- Show that a patient is in isolation for others, without making them feel guilty and worried Stay
- Let every actor feel responsible for their part of the protocol Stay Care
- Assign responsibility and clarify explanation for explaining isolation measures correctly to visitors Stay Visit
- Let visitors understand and feel responsible for the control measures to take – Stay – Visit
- Stimulate active role of readmitted patients Readmission

Figure 16: Design opportunities in Patient Journey


Patients experience contact isolation differently

Different patients experience contact isolation differently. The following design opportunities are based on improving the patient experience for the persona that experiences contact isolation most negatively; Social Suzan.

- Improve room size and lay-out to decrease sense of being locked in First time into contact isolation
- Give (all) patients the opportunity to connect with patients or not Stay
- Improve room size and lay-out to let patients have the space Stay
- Give patients the opportunity to get in contact with other patients in another way Stay
- Give nurses the ability to have as much and easy contact with patients in contact isolation as with other patients Stay
- Create less stigmatising isolation cards, especially in shared room isolation Stay

Clear difference between first time into isolation and readmission

The overall design opportunity based on the difference in experience between first time into isolation and readmission, is that the first time is highly overwhelming. The following design opportunities decrease the intensity of the first time into contact isolation.

- Mention isolation measures differently from other information (Preparing) Admission
- Mention and prepare patients for going into isolation in a more relaxed manner First time into contact isolation
- Let patients be in control when going into isolation for the first time First time into contact isolation
- Shorten time of getting used to isolation measures Stay
- Facilitate peace and calmness during first time in isolation Stay
- Clearly communicate the differences in protocol at other institutions before discharge – Discharge



Design brief

The context research and its concluding patient journey provide insight into the moments when the patient experience during contact isolation can improve. This chapter combines insights from literature and context research to create design directions. The project narrows down to a design vision with belonging design goal, a metaphor that helps to interpret the design goal and criteria. These factors function as the starting point for ideation and conceptualization.

4.1 Design directions

To be able to create solutions that improve the experience of the involved actors' factors, insights from literature and context research are combined into three design directions. Conclusions are about patients and other concerned actors that currently experience isolation negatively. As a start to a solution that fits with the research conclusions, design opportunities were created. By clustering the opportunities and combining them with opportunities for improving PX from literature, three design directions were formulated.

1. Shared future vision

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Patients feel like the isolation process is something they undergo passively, and nurses feel highly responsible for explaining the protocol to patients and visitors and complying to it. Healthcare providers want patients and visitors to follow isolation measures better. Both patients, visitors and some healthcare providers do not see that every actor has its contribution to infection prevention, leading to a shattered sense of responsibility. If all actors would feel like they work together; this sense could change; this is called collective action. A new strategy for educating and informing healthcare providers, patients and visitors about the shared responsibility they have, could shift the general and shared a negative attitude towards infection prevention and contact isolation towards a more shared positive future vision.

2. Interpersonal relationships between different actors Both the nurse and the patient experience contact isolation as if the healthcare provider imposes the situation on the patient. This experience, again, leads to a shattered sense of responsibility between the patient and the nurse. It decreases the patient experience. The patient feels overwhelmed and either guilty for being a burden or struggles complying to protocol. When nurses and patients feel like partners in a team, meaning that none of them is the only one responsible and both of them are doing their share, the experience will improve for both the nurse and the patient. Simulating interactions with regards to infection prevention between the nurse and the patient is one approach to form an interpersonal partner–like relationship.



3.Information and involvement



Because patients get all the information at once during their first time into contact isolation, it is overwhelming. Information is only understood when patients are in isolation for a long time or have been in isolation many times before. Nurses, however, explain the implications of contact isolation at the very first time a patient is in isolation. There is no clear structure for providing information to visitors. By providing information that is self-explanatory, engaging and relatable in a more structured manner, patients and visitors will understand information better. Patients and visitors are expected to become more involved in their isolation process.

The design directions are on different levels of practicality and ease of implementation. Creating a shared future vision is a way to increase the conception that all individuals work together against infections and antimicrobial resistance. Building a future vision probably affects a larger group than VUmc alone because antimicrobial resistance does not only involve the healthcare sector. The other two design directions; facilitating interpersonal relations and providing information are more implementable short-term. A design that aims to improve the latter two is expected to contribute to an increased shared responsibility amongst actors.

4.2 Design vision and design goal

Based on the conclusions from literature and context research and the design directions, a design vision and design goal are created. These will guide the design process.

Design vision

I want to increase the feeling of community amongst all actors in the contact isolation process, so that all individuals experience a sense of shared responsibility towards infection prevention in VUmc.

Design goal

The following design goal will be used to focus the design process and serve as a first step into reaching the design vision.

I want patients to develop a favourable attitude towards contact isolation during the first time into contact isolation by providing a tool that lets them experience partnership with healthcare providers and visitors in contributing to the safety of others.

4.2.1 Motivating the design goal

Contributing to the safety of others

Because contact isolation and infection prevention measures are in place for the protection of other patients now and in the future, the patient should know that he is contributing to that. A sense of being part of a community and providing insight into the nurse and patient together preserve the safety of others increases the favourable attitude. The design should communicate that every involved actor contributes to the protection of other patients.

Patients, healthcare providers and visitors

The design should consider the actively involved actors during isolation: the healthcare provider, patient and visitors. They all have to share responsibility during contact isolation, and therefore the actors all need to feel they are contributing to the health of others.

First time into contact isolation

Patients currently experience the first time they go into contact isolation as overwhelming and as if it befalls them. The design should, therefore, focus on changing this moment in a more involved experience to have a positive impact on the patient experience.

A favourable attitude towards contact isolation

During that first time in isolation, patients should develop a favourable attitude towards contact isolation. The design does not necessarily have to make isolation fun, but patient should experience the measures as acceptable and reasonable.

4.3 Interaction metaphor

To strengthen the design goal, an interaction metaphor is created and analysed. Through the analysis, different qualities and the characteristics of the desired interaction are defined. The qualities and characteristics are used in ideation as inspiration. During the evaluation of ideas, they guide the determination of the suitability of the ideas regarding the design goal.

Metaphor

A metaphor of interaction is used to inspire designers to learn from situations in which desired qualities of interaction already exist. By exploring the metaphor and the qualities and characteristics, typical attributes that foster the desired interaction can be identified. These factors can apply to the context one is designing for.

When approaching the design goal more abstractly, the following attributes are used to create to find a fitting metaphor:

- To contribute to someone else's benefit
- Experiencing partnership
- A favourable attitude towards taking action

Therefore, going into isolation for the first time should feel Collecting package for the neighbour you don't know (Fig. 17). Even though a resident might not particularly enjoy having the responsibility of his neighbours' package, out of courtesy, he takes the box from the mailman anyway. The resident takes care of the box and when giving it to the neighbour, receives appreciation.

METAPHORE: GOING INTO ISOLATION FOR THE FIRST TIME SHOULD FEEL LIKE COLLECTING A PACKAGE FOR A NEIGHBOUR





The interaction should therefore feel:

- Friendly
- Simple
- Committed
- Involved

To achieve that, the interaction should be

- Targeted
- Instant
- Close together

4.4 Design criteria

By combining the design goal and characteristics and qualities from the analogy, criteria for the design are defined. The design should of course be applicable in the hospital context and not go against isolation protocols. The criteria are ordered from critical to less critical. Therefore the first criterium is most important, whereas the last two criteria are extra and helpful if it they would be achieved.

Moreover, new ideas and designs are most valuable when desirability, viability and feasibility is balanced (fig. 18). Therefore, these three aspects of designs are also used as criteria for the concept directions.

The following criteria will guide the judgement of ideas and concepts. The design has to...

- ...Increase the patient feeling part of a community
- ...Stimulate partnership between the involved actors
- ...Improve the patient experience during the phase first time in isolation
- ...Involve the patient to increase their commitment
- ...Informs the patient about isolation measures
- ...Be simple and friendly



Ideation and conceptualization



At the start of this project, the design question was: How can the patient experience during contact isolation improve? Based on the research, the design question is narrowed down to the design goal: I want patients to develop a favourable attitude towards contact isolation during the first time into contact isolation by providing a tool that lets them experience partnership with healthcare providers and visitors in contributing to the safety of others. Therefore, during the phase of ideation and conceptualization, creative methods are applied to create solutions that reach the design goal. In this chapter design insights that result from creative methods are explained.

5.1 Ideation

5.1.1 Ideation activities

By applying creative techniques, ideas for improving the current patient journey and thereby patient experience are generated. In several brainstorming sessions together with design students, design professionals and infection prevention experts, ideas to increase shared responsibility and partnership amongst actors were generated (fig. 19). The setup of the sessions can be found in appendix C.1. The design activities led to insights of factors that are expected to attribute to an improved patient experience.



Figure 19: Overview brainstorming sessions

5.1.2 Ideation insights

The insights from different creation sessions are clustered and described below.

Communicating community

Visually communicate the network of individuals that contribute to infection prevention. By presenting the community to patients and other involved actors, individuals can connect to each other without physical contact. It is expected to increase the sense of partnership between patients, nurses and other involved actors.

Providing information (visually)

A highly important component of involving patients and providing information. Information should be about implications and responsibilities regarding contact isolation. By providing the information visually, information is more easily understood and remembered. Moreover, visual information triggers curiosity and involvement of patients and visitors.

Providing comfort during contact isolation

Currently, isolation is perceived as something negative that is imposed on patients. By providing a patient in contact isolation with benefits, the patient might experience isolation as something positive that is happening. Extra treats or advantages could be presented to patients and visitors.

Reframing isolation

Similar, positive aspects as not having to share a room and less strict visiting hours could be put emphasis on. Being in contact isolation could then be perceived as time for oneself.

5.2 Concept clusters

From the design goal and the design vison, the ideation methods were used to create several concept clusters. The concept clusters are developed till a basic understanding of the goal of the direction, an image and its' expected interaction moments during the patient journey.

In total, three concept clusters were formulated based on the intended effect of the concept. Each concept cluster contains two or three ideas that have similar intended effects. The three concept clusters are explained below. An elaboration of the concept clusters and ideas are described in appendix C.2.

Proposing contact isolation advantages

This concept cluster aims to improve the experience by providing advantages during the first time into isolation. In a conversation with the patient, the healthcare provider can ask how a patient things the contact isolation room and process could improve. The healthcare provider acquires an emphatic role towards the patient and is the one highlighting the positive experiences of contact isolation rather than the negative implications. This concept cluster has an indirect impact during the full isolation process but directly influences the first time into isolation (fig. 20).

Gradual information

The concept cluster Gradual information aims to remove stress during the first time into isolation by spreading information over the care process by providing an introductory video. It prepares patients for the conversation and explanation with the nurse and stimulates them to ask questions. By educating patients, they can be involved in the conversation with the nurse. It thereby facilitates two-way communication. This concept cluster mainly focusses on the first time into contact isolation (fig. 21).

Visual contribution

By visually communicating the network every individual builds upon, visual contribution aims to increase the feeling of belonging to a community amongst all actors. It presents that many patients, healthcare providers and visitors put in effort to prevent infections. The patient has an active role by visually contributing a piece to the representation when going into contact isolation. Moreover, the visual representation is placed at the ward and therefore reminds people about infection prevention and contact isolation. This concept cluster focusses on the full isolation process and beyond but is less visible to the patient when he is in the room (fig. 22).



Figure 20: Proposing contact isolation advantages



Figure 22: Visual contribution

5.2.1 Evaluation of concept clusters

The concept clusters rated based on the criteria as specified in paragraph 4. It appeared that the concept cluster Proposing contact isolation advantages does not contribute to an increased community feeling and partnership, whereas the other two do. Therefore, the other two concept clusters are evaluated with the client.

Evaluation of concept clusters with client

The concept clusters Visual Contribution and Gradual Information were presented with drawings. The drawings provided room for feedback and input, because the ideas did not seem final yet.

After explaining the concept clusters, there was a discussion about the desirability, viability and feasibility of the concept clusters to identify the strengths and limitations of the ideas from the concept clusters. The following insights resulted from the discussion. The insights functioned as input for the first concept iteration as explained in paragraph 5.3.

- 1. Make the design inclusive
 - Patients can be ill, vomiting, or have just received bad news
 - Some patients want more information, some might want less
- 2. Create ownership and link it to content, information and implications of contact isolation
 - Link the design clearly to infection prevention and its implications, while being individual and personal to patients
- 3. Track patient knowledge and questions
 - When providing information gradually healthcare providers need to be able to know how much knowledge a patient already has and gains.
 - Nurses can then provide patients with more information during the process.
- 4. Over the full care path
 - Information should be given to patients gradually, but should contain all the information necessary or different stages in the process.

5.2.2 Concept cluster evaluation and design elements

The concept cluster that has most potential is Gradual information. By providing information, the first time into isolation becomes less overwhelming and is therefore expected to directly improve the patient experience. The feeling of being part of a community is more existent in the concept cluster Visual contribution, however it stands further away from the current context. Therefore, elements of the concept cluster Visual contribution are combined with the concept cluster Gradual information.

Based on the evaluation of the concept clusters, the following necessary elements for the design have been established:

- 1. Experienced connection between involved actors
 - Between nurses and patients at the first time into isolation
 - · Between patients and visitors during visits

2. Autonomous patient because of layered information

- A patient is able to find more information whenever he wants to or needs to
- A patient is able to stop looking for more information when he wants or needs to

3. Healthcare provider in a guiding role

- The patient always receives crucial information during the first time into contact isolation
- Healthcare providers have the ability to understand what information patients already have gotten

5.3 Concept version 1

5.3.1 Description

'Het isolatiedoosje' is an information package that stimulates gradual information sharing. It guides nurses to share only the necessary information when a patient goes into isolation for the first time. The patient can find more detailed information by himself online when the patient is settled down in the isolation room (fig. 23).

5.3.2 Evaluation

Aim

The evaluation study aimed to evaluate the design based on its fit with the context and its desirability and feasibility regarding nurses. The study aims to generate input for further detailing of the design. The evaluation was taken as an opportunity to share and validate the context research results with the ward.

Method

The research results and concept version 1 were presented to nine nurses in the vascular surgery ward during their coffee break. To gather the opinions and ideas of all nurses, input-cards were used to retrieve input. The set-up of the evaluation can be found in appendix C.3.

5.3.3 Takeaways

The following insights are concluded from the evaluation and used to improve the concept.

+ The first interaction and explanation increases the feeling of partnership between the patient and nurse: Keep the first explanation of contact isolation feeling like exploring the information together.

- + Box triggers curiosity, which is appreciated. It attracts attention to the currently very invisible infection prevention for all involved actors.
- + Visuals help patients understand the information more easily: increase the number of visuals used.
- + Keep the proposal of clear explanation steps to healthcare providers so that every nurse gives the same information to the patients. It is highly appreciated that it provides guidance.

- Provide information not just digitally; giving patients a QR code and website to find more information is not applicable for most patients because they are not used to digital information.

- The effect is contact isolation, and the microorganism is less important: Provide more information about contact isolation at the first moment instead of focussing on the microorganism someone carries.

- Nurses want to keep track of the patients' understanding of information: include tracking of patients knowledge.



Figure 23: Concept version 1

Ideation and conceptualization

5.4 Concept version 2

5.4.1 Description

The second concept version is 'de isolatiebox'. It changed name to be more fitting with the context, but it in principle the same as the previous concept; patients can find information gradually. In this version, the outside of the box is used to explain the most important measures and all information is in the concept physically by using cards. The cards are grouped in 5 different themes to cover all the information necessary about the network of patients, healthcare providers and visitors and the responsibilities of the different individuals (fig 24).

5.4.2 Evaluation

Aim

The evaluation and validation study with the second concept version aimed to evaluate the concept on its interaction and fit with the context. The correctness of the information on the cards and type of information was evaluated. This study aims to generate input for further detailing of the design. The evaluation also aimed to validate the concept in relation to the design goal and design criteria.

Method

Concept version 2 was presented to and discussed with four nurses and one patient in a qualitative interview (product concept evaluation). The patient was hospitalized in strict isolation, but was able to relate to patients in contact isolation. The nurses were interviewed two-by-two to evoke a discussion about the interaction of the design. The setup of the evaluation can be found in appendix C.4.

5.4.3 Takeaways

The following insights are concluded from the evaluation and used to improve the concept.

- + Providing layers of information is a good way to take away overwhelm
- + The image and title triggers reflecting on information and explaining it to others: keep a quick overview and the more elaborate information.
- + Box and cards trigger curiosity: keep a physical object that stands in the room.
- + The knowledge and information provided is the same for every healthcare

provider. One clear guide for explaining control measures: keep written down information that everyone uses and receives.

- The design currently does not fully encourage partnership between the different actors: Increase the feeling of shared responsibility.

- The impact of infection prevention to other patients is not clear: Increase the sense of contribution to the safety of others and being in contact isolation for the greater good.

- A box might represent the feeling of being locked in a room: Increase sensitivity towards context of contact isolation.

- The box is quite large and takes up a lot of horizontal space: Increase practicality towards the context.

- Nurses do not want to give too much information because it leads to more questions: nurses should be encouraged that answering more questions does not necessarily mean a more busy schedule.

- The cards will start spreading around the room, if they are fixed somehow.



Figure 24: Concept version 2

5.5 Results and conclusions of evaluation

To conclude ideation and conceptualisation, the results of the evaluation studies are combined. Findings are explained based on the design criteria, as presented in chapter 4.4. Because of a small participant sample, conclusions only provide direction.

The patient feels part of a community

Results

The interviewed patient did not mention feeling part of a community. He did say that there is a difference in explained and applied isolation precautions between healthcare providers. Furthermore, he did not mention to feel a connection with other patients due to the design.

Nurses also did not mention that they would expect to feel related to patients or visitors. Nurses, however, did say the necessity of creating a shared responsibility. They assume that patients and visitors will take on the part of the nurses' responsibility when their knowledge and understanding increases.

Conclusion

In this version, the concept does not yet stimulate the feeling of individuals working together towards infection prevention. The design indicates shared responsibility but this is not yet experienced through the use.

Increased partnership between involved actors

Results

The patient mentioned appreciating the nurses he sees more frequently. He feels that they understand isolation precautions better. The nurses explained that the first time into isolation in this concept entails a beautiful exploration together with the patient. The nurses mentioned that during the first time into contact isolation they would give the information and come back later to discuss the information then and answer questions.

The connection between healthcare providers and visitors is appreciated because nurses often forget to inform them.

Ik zou de eerste informatie alvast geven. En dan zou ik erbij zeggen; in deze doos vindt u meer informatie, die kunt vast doornemen. En dan kom ik daar later vandaag nog even met u op terug" - Nurse

Het is wel fijn dat ook bezoek bij de informatie staat, dat is iets wat wij wel vergeten. Dus dan werkt het als een soort reminder" - Nurse

Conclusion

The patient and the nurse appreciate when the other understands the isolation measures to take. When the patient, nurse or visitor do not apply precautions correctly, a feeling of partnership decreases. Therefore, the information should be communicated to all actors and be clear for everyone involved.

Improved patient experience during the first time in isolation *Results*

The interviewed nurses mentioned that a protocol and guidance to explain the first information would be helpful. The concept appears to be something that could guide the conversation while having the same kind of interaction.

The box triggers curiosity in both concept versions. The nurses and the patient mentioned it to be a more exciting form than a regular folder.

Ik denk dat het vooral iets extra's is. Dat je eigenlijk hetzelfde doet als anders, alleen heb nu meer ondersteuning." - Nurse

Conclusion

Guiding the nurses in their explanation, slows down the provision of information during the first time into isolation. Nurses will then know what information is essential. The process will be slowed down, so information is better understood.

Moreover, physical materials provide useful guidance in the conversation. Having something to talk about is expected to increase clarity.

Involved patient to increase compliance

Results

Closely related to the increased partnership is involving the patient. Nurses expect that when they inform patients better, they will follow isolation precautions more carefully. They believe the concept does that by providing clear information. They mention that very ill patient might not retrieve knowledge from the idea, but then visitors will.

Er zullen heel veel mensen zijn die het wél gaan doen, en als zij het zelf niet doen, doet het bezoek het wel." - Nurse

Conclusion

Involving patients to increase compliance is highly related to an expanded partnership. When patients are informed and involved, they are expected to comply with isolation precautions more. It appeared that the main ingredient for

partnership is increased compliance from the other party. Only then can healthcare providers, patients and visitors trust the other in applying the right precautions.

Informs patients about isolation measures

Results

An object that contains information helps nurses to provide information. They mention that they currently do not give enough information to patients . Giving an object together with the explanation will increase the amount of information patients receive.

Het is meer dat je dit dan alvast kan geven en dat dan meer uitleg ook nog geeft. En ik denk dat mensen nu eigenlijk niet zo heel veel uitleg krijgen." - Nurse

Ik denk dat informatie nu wel tekort schiet. Iets erbij geven helpt dan wel" - Nurse

Conclusion

The guidance that the concept provides to nurses during the first explanation about isolation precautions results in one clear message. It informs all patients in the same manner. According to nurses, giving more information to patients is necessary.

Simple and friendly

Results

The patient put the box on bed between his legs. This action shows how the patient appropriates the concept. The cards made the patient reflect on his experience in isolation in a simple manner. Nurses mention that the concept is more precise and looks more beautiful than other information. They expect themselves and their colleagues to be reminded of giving it to the patient because of the looks. The box, however, relates to the feeling of being locked in in an isolation room.

Conclusion

A physical object is found to be outstanding and a good reminder to give the information to the patient. By layering information, a slower reflective interaction is provoked. The form of the concept should change to fit the context better.



Design: Bundel

This chapter describes the final design that aims to solve the design goal and functions as a first step into the design vision. This thesis seeks to answer the design question: How can the patient experience during contact isolation improve? To answer that question, Bundel is created. Bundel is an information provision tool to use during the first time a patient has to go into isolation. By providing transparent and layered information, the tool aims to increase a feeling of shared responsibility amongst involved actors. This chapter explains the use of Bundel, added value for actors and the different elements Bundel has.

6.1 Design aim/goal

Bundel (fig. 25, 26 and 27) aims to increase a feeling of shared responsibility amongst patients, healthcare providers and visitors in infection prevention. It stimulates working together between individuals and provides patients and visitors with the necessary and desired information at the right times.

The literature research (chapter 2) showed that several factors increase patient experience and collective action. Bundel encourages face-to-face, two-way communication between individuals and information that helps patients relate to others. Bundel stimulates an open attitude of healthcare providers and information is about the roles, responsibilities and actions of patients, healthcare providers and visitors.

The context research (chapter 3) explained how the first time into contact isolation is overwhelming, therefore, the first experience of contact isolation is slowed down by spreading the information a patient needs and wants over the isolation process. By providing all the information to patients from the start of the isolation process, they can discover the necessary information they are looking for when they want.

Moreover, visitors are increasingly involved in infection prevention because the design makes their involvement necessary. Bundel stimulates them to find the required information personally. Increased participation of visitors in obtaining the information is expected to be of positive influence on the compliance to infection prevention of visitors. It thereby takes away the load of the nurses.

For nurses and other healthcare providers, Bundel facilitates the transfer from a 'controller and corrector' to a 'guide and facilitator' towards patients and visitors. Therefore, the responsibility that currently lies mainly with the nurse and some patients, changes to a more equally shared responsibility amongst all actors.

Several design implications are of influence on the interaction moments, interaction and information provided. The following paragraphs explain the design with these factors as a starting point



Figure 25: Bundel: collection book



Figure 26: Bundel: collection book

Figure 27: Bundel: booklets



6.2 Interaction moments of Bundel during isolation process

Bundel is used at several moments during the care process of contact isolation. By providing interaction moments over the full isolation process, the patient experience increases because information is better obtained and understood. Moreover, patients have the opportunity to find answers to their questions when they have them. Therefore, Bundel is used at every stage of the patient journey. The nurse has a facilitating and guiding role throughout the process, but during the stay phase, the initiative to obtain information lies with the patient.



Figure 28: Interaction moments of Bundel in indended patient journey

Because of the several interaction moments patients, healthcare providers and visitors have with Bundel, it serves as an infection prevention reminder. Reminding actors is expected to lead to increased involvement and compliance from the actors. The interaction moments are visualised and explained in an indended patient journey in fig. 28. Besides, the emotional journey reflects the intended effect of the interaction moments.



6.3 Interaction scenario with Bundel

The interaction moments between Bundel, the patient, the nurse and visitors are explained in the following use scenario (fig. 29).



1. A patient is in the hospital and tests showed that the patient is a carrier. Before going into isolation, the nurse brings the patient the booklet Patiënt.



2. Supported by the booklet, the nurse gives a first explanation about the necessity and implications of contact isolation.



3. The patient then has time to skim through the booklet and read the first information.



4. As soon as the nurse has prepared the isolation room, she returns to the patient and moves him to the isolation room.



5.The nurse introduces Bundel and gives the patient the booklet Zorgverleners. The collection book already contains the booklet Algemeen.



6. In isolation, the patient can absorb the general information and information about the responsibilities of patients and healthcare providers at his own pace.



 7. When visitors arrive, they go to the service desk at the ward and receive the booklet Bezoek. The visitors go to see the patient.



8. Visitors give the information booklet to the patient, who will add it to his collection book.



9. Visitors and patients will discuss isolation precautions with the full collection book as a guide through the conversation.



10. When a patient is allowed to leave isolation, he receives the last booklet Uit isolatie from the nurse.He can take this booklet to his next destination

Figure 29: Interaction scenario

6.4 Information in Bundel

To be able to engage patients and increase collective action, provided information should be about the roles and responsibilities. In Bundel, information links to the implications of contact isolation for 1) Patients, 2) Healthcare providers, and 3) Visitors. Also, to fully cover the questions patients have, one information set about 4) General information about infection prevention, the microorganism and contact isolation is added. To close the time in isolation, Bundel also includes a set with information about 5) Leaving isolation (fig 30 and 31).

Algemene informatie

The booklet Algemene informatie (general information), provides information about contact isolation and infection prevention. It clearly explains what microorganisms are and how the transmission of bacteria and viruses is interrupted by applying contact precautions. This booklet introduces the necessity of the prevention of transmission by mentioning antimicrobial resistance and the impact on other, susceptible patients. The collection book contains this booklet from the start.



Figure 30: Booklets: Algemene informatie, Patiënt, Zorgverleners
Patiënt

The second booklet is Patiënt (Patient). It provides insight into what the implications of contact isolation for patients are. By mentioning that many patients experience contact isolation, the feeling of being part of a more substantial group increases. To increase that, patients can relate to other patients in contact isolation through patient stories.

Zorgverlener

The booklet themed Zorgverlener explains the implications of contact isolation for healthcare providers. It provides patients with pages with the responsibilities of healthcare providers and their personal stories with infection prevention.

Bezoek

One booklet; Bezoek (Visitors) is designed especially for visitors to increase their knowledge and participation. It explains how they can contribute to infection prevention. This booklet focusses on how the microorganism is not dangerous for visitors. Moreover, visitors can leave notes or messages to the patient.

Uit isolatie

The last booklet is Uit isolatie (Leaving isolation). It explains how isolation measures change when a patient leaves to another room, another care institution or home



Figure 31: Booklets: Bezoek, Uit isolatie

6.5 Design elements

Bundel consists of several design elements. An explanation of the elements and the added value of the different choices that are made are explained below.

6.5.1 Pages

The essential aspect of Bundel is the use of different pages to provide various information. The layering of knowledge on different pages slows don the information process and decreases the overwhelming first time into isolation. All information can be found in appendix D.1. To ensure the information is found back easily, every spread entails a title, an illustration and explanatory text. Pages are A6 because it is easy to read but big enough to skim through. Moreover, the booklets do not take up too much of the scarce space in a hospital room.

Space for notes and questions

The different booklets contain empty pages that encourage the patient to take notes and write down the questions they have. It stimulates the patient's initiative and increases understanding. Moreover, visitors can leave sweet messages to the patients to personalise Bundel (fig. 32).

Contribution of different actors

The nurse gives the booklets Patiënt, Zorgverlener and Uit isolatie to the patient and visitors brings him the booklet Bezoek. By clustering the information around these themes in smaller booklets, they are easy to grab when nurses are in a hurry. In addition, patients will not lose the information quickly, and the order of information is fixed. Currently, Bundel is focussed on direct healthcare providers only, but booklets make it easy to add information about the contribution of other actors such as Medical Microbiology and Infection Prevention.

Tone of voice

Bundel has a friendly and inviting tone of voice. It aims to not force patients and visitors into complying but to stimulate all actors to contribute to infection prevention. To be able to achieve that, Bundel presents contact isolation as it is, without sounding negative. The text in Bundel is encouraging: you can help other patients and us by following these precautions (fig. 33).



Figure 32: Notes and questions - spread: Algemene informatie



Figure 33: Friendly tone of voice - information booklet: Bezoek

6.5.2 Book

The information is bundled in a book because it ensures simple interaction. Skimming through a book when a patient is looking for specific information is secure. It keeps information neat and together. Furthermore, the book provides the possibility for patients to stop or keep on reading information. It facilitates autonomy because patients can find the information at their own pace when having questions about a particular theme. In addition, the collection book makes Bundel easy to store the wards.

Lastly, Bundel draws the attention of patients, healthcare providers and visitors because it stands out from regular folders. Because microorganisms are highly invisible, Bundel serves as a gentle reminder of infection prevention.

Rings

To be able to add information to Bundel and facilitate contributions from healthcare providers and visitors, circles are used to bundle the collection book. The rings can open and close to add information and provides an opportunity for the Infection Prevention Team to add information when necessary. The use scenario and fit in the context should still be evaluated.

Tabs

The cover and the tabs of Bundel provide a clear overview of the actors that contribute. Patients and other healthcare providers visually see they are all equally participating in infection prevention. The tabs ensure information to be found back easily and divide the information into themes. In addition, perforations in the tabs show that there is information to come. It triggers patients curiosity to the further information he will receive (fig. 33 and 35).

Display

To increase the visibility of infection prevention and trigger conversation about isolation precautions, the collection book can stand individually because of the thicker covers. As an indicator of contact isolation, Bundel encourages patients to ask questions and evokes interaction between the nurse and patient. Moreover, it serves as a subtle reminder of necessary isolation precautions for healthcare providers and visitor.



Figure 34: Cover shows overview of the contributing actors



6.5.3 Appearance

Visual style

Bundel is colourful and contains many illustrations of people. By using bright colours, contact isolation is assessed more positively. The imagery is chosen to be relatable to patients and visitors, without being too personal. To distinct the different actors, Bundel uses five bright colours.

Name: Bundel

The name of the design represents the aim of the design. Bundel (Bundle) encourages individuals to share responsibility and work together. Bundel is about combining strengths as an answer to the increased challenge of antimicrobial resistance. Also, the information is bundled in a book.

6.5.4 Applicable to different types of isolation

Booklets

Bundel is suitable for other types of isolation as well. By providing the booklets with the sort of isolation and a dot corresponding its colour, a distinction is made (fig. 36). The information in Bundel is currently specified for contact isolation, but can easily be adapted to match other forms of isolation.

Storage

If nurses take the wrong booklet, this has implications for the information a patient receives. By receiving information about a different type of isolation, patients might get anxious or confused because of more severe or less severe precautions. The latter should be prevented. To limit the time nurses spend looking for the correct collection book or booklet, boxes in the isolation colours are provided for the storage of the booklet. The nurse checks the isolation colour in Epic. She then takes the patient booklet from the box with the same colour (fig. 36). Right after printing the isolation card, she will also get the corresponding collection book and the second booklet from the box.



Figure 36: Appearance and applicability to different types of isolation

6.5.5 Implementation and implications

When VUmc starts to use Bundel, negative implications can be a sideeffect. We should consider several factors when implementing Bundel.

Bundel might harm the patient persona Independent Isa. Patients corresponding with this group, currently enjoy isolation and do not miss any information. To adapt Bundel to their needs personalization of the booklets could be considered.

Even though Bundel would not drastically increase the time nurses spend on explaining isolation measures, it will cost extra effort from nurses. Bundel is expected to increase compliance to control measures, which will limit the time nurses spend on correcting patients and visitors.

Bundel will cost more than a regular folder. However, it will still be relatively cheap compared to other healthcare expenses. Whether Bundel is worth increased expenses should be evaluated by verifying its effectiveness regarding emotional support and compliance. When compliance increases, Bundel can be of significant impact because less HAIs will occur.

6.6 Bundel evaluation and validation

Aim

This study of Bundel aimed to evaluate and validate the improved shape of the design. In addition, the study evaluates its appreciation of patients in contact isolation and their family.

Method

A prototype of Bundel was presented to a patient and his daughter. The patient was hospitalized in contact isolation recently (less than a week). The patient was not admitted to VUmc. As the researcher could not be present during the evaluation, the participants received a written explanation and questions. The participant wrote down the answers to the questions. The provided interview questions can be found in appendix D.2. Because only one patient from another hospital participated in this study, takeaways might not be representative of the patients of VUmc.

Takeaways

The following insights are gained from the evaluation and used to improve the concept.

+ Receiving more information is essential and highly appreciated by both the patient and his daughter.

+ information would have clarified what they were allowed to do and what they were not. The patient had learned this by experience, but that took a lot of time. By providing it at the start, anxiety would decrease sooner. More information would increase the patient experience for both patient and family.

Ja, dan hadden we veel duidelijker de grens gezien tussen wat wel en niet zou mogen. Door ervaring weet ik nu hoe het zou moeten werken, maar dat heeft een tijd gekost" - Patient

+ It is appreciated to receive separate information before moving to another room. It prepares the patient for what there is to come. Moreover, the daughter mentioned she would have liked information. The visitors' booklet could improve by including a summary of the information that they can quickly read before seeing the patient.

- The design could activate the patient more. The patient mentioned that as a patient, you are the guard of ensuring healthcare providers applying isolation precautions correctly. Currently, that is not yet communicated clearly.

- The separate booklets are easy to lose. Also, the patient mentioned that he would like to have all the information when arriving in the isolation

room. Thus, separate information before moving and independent information for visitors is appreciated. Zorgverlener and Uit isolatie can be added to the collection book at the start of isolation.

- When the patient receives the first information before moving rooms, his expectations should be managed. By already mentioning that there will be more information in the isolation room, the amount of questions will be reduced.

- Bundel could contain more in-depth information. The booklets should answer most questions patients have. One implication of contact isolation that the patient mentioned is that his treatment and tests were scheduled at the end of the day. Indicating such factors would have improved his experience.

Conclusions and recommendations



Based on the research and design performed in this thesis, conclusions can be drawn. This chapter summarizes the results and discusses how the design question: How can patient experience during contact isolation improve? is answered. Suggestions for further research and improvements for the design are explained.

7.1 Summary

Contact isolation is necessary to apply in hospitals to curb the spread of microorganisms from one patient to another. However, control measures have negative effects on the well-being of patients. Therefore, this thesis aimed to research and improve the patient experience during contact isolation.

Currently, the literature provides different insight into the experience of several actors in relation to contact isolation. It highly depends on the personal situation if contact isolation has a negative impact on the patient's well-being. Healthcare providers experience barriers due to contact isolation and unclarity regarding protocols. Family also feel uncertain about the impact and persistence of the microorganisms.

Despite the negative influence of contact isolation on the experience, application is necessary to prevent transmission and infections. Infections and antimicrobial resistance are an existent threat. Therefore, by improving the patient experience, the negative effects of contact isolation can be reduced.

There are two main reasons to reduce these negative effects. Firstly, an open healthcare system can improve patient experience (PX). An environment in which healthcare providers are open to questions from patients and in which back-and-forth communication between them is present. Secondly, to improve patient experience during contact isolation, collective action could be applied to infection prevention situations in hospitals. For every party – patients, healthcare providers and visitors – to be stimulated to contribute to infection prevention a few aspects have to be improved: a community feeling should be increased, connection between individuals should be established and information about past actions of other individuals should be provided to involved parties.

Moreover, changing the attitude of patients and other involved actors towards contact isolation can be achieved by providing more information. Receiving and understanding information increases patient experience. An increased patient understanding and knowledge could be established by providing information over a continuum of care and at multiple interaction points. Information is best received when patients and family have questions. The best way to stimulate patient engagement is for information to clearly communicate the patient's role and their responsibilities regarding isolation precautions.

By analysing both collective action and patient experience, three themes appear to overlap. The three themes are expected to improve both patient experience as well as collective action during contact isolation. It is therefore assumed that an increased collective action could lead to increased patient experience. The three themes in the framework are: 1) facilitating an open hospital community, 2) establishing interpersonal connections and 3) providing information. This thesis used these three themes to design for.

The context research of this thesis provided insight into the current situation of contact isolation in VUmc. It uncovered experiences of patients, direct healthcare providers (nurses and physicians), indirect healthcare providers and visitors during contact isolation. As the main actors of contact isolation are the patient and the nurse, the journey, experiences and emotions of these two actors are highlighted in the Patient Journey. This map shows different stages a patient goes through during their first time into contact isolation.

From context research the main conclusions about the patient experience during contact isolation are as following:

- Shattered sense of responsibility amongst actors; nurses feel highly responsible about infection prevention and following isolation protocols, whereas visitors do not feel responsible at all. Patients differ in their sense of responsibility, and so do physicians. The shattered sense of responsibility is undesirable, because control measures are only effective when enough people are contributing.
- 2. Patients experience contact isolation differently; three different patient personas exist. The largest patient group has to get used to isolation when it is all new, but once they had gotten used to it, they are OK with it and follow protocol well. Another patient group really enjoys isolation because they are in a single room, but dislikes going out of isolation again. Another group feels very lonely and guilty, because they are very socially oriented and therefore enjoy contact with other patients more.
- 3. Difference in experience and behaviour between first admission and readmission; patients behave differently when readmitted compared to first admission. Readmitted patients understand the control measures and are used to them already. That results in a more active attitude and patients start pointing out the necessity of control measures to healthcare providers. On the other hand, the first time in contact isolation is very overwhelming. Therefore, information does not stick well and it takes patients more time to get used to isolation measures.

The second part of this thesis contains the translation of research insights into a solution that aims to improve the patient experience during contact isolation. It combines insights derived from literature and context research into design directions and a design goal. A design vision and design goal were formulated to respectively direct and guide the design process.

Design vision:

"I want to increase the feeling of community amongst all actors in the contact isolation process, so that all individuals experience a sense of shared responsibility towards infection prevention"

Design goal:

"I want patients to develop a favourable attitude towards contact isolation during the first time into contact isolation by providing a tool that lets them experience partnership with healthcare providers and visitors in contributing to the safety of others."

Bundel, the design that is created as an answer to the design vision and design goal aims to increase a community feeling amongst patients, healthcare providers and visitors in infection prevention. It stimulates collaboration between individuals and provides patients and visitors with the necessary and desired information at the right times.

For nurses and other healthcare providers, the design facilitates the transfer from a 'controller and corrector' to a 'guide and facilitator' towards patients and visitors. Therefore, responsibility that currently lies mainly at the nurse and some patients, changes to a more equally shared responsibility amongst all actors.

Bundel exists of several elements. Five different booklets can be collected in one folder. Three of the booklets are about the implication of contact isolation on patients, healthcare providers and visitors. Additionally, one booklet about general information about infection prevention, antimicrobial resistance and contact isolation and one booklet about leaving isolation are included. Through themes, tabs and imagery, information can be easily found back when a patient has questions for their healthcare provider.

7.2 Discussion

To answer the first research question: What is the current experience of different actors during contact isolation, literature and context research on contact isolation have been performed. From both literature and design research, it appeared that different patients experience contact isolation differently. Patients experience isolation positively when they are more individually oriented and negatively when patients are very social. The experience during contact isolation is also dependent on the duration of isolation and whether or not a patient focuses more on their treatment. A negative first time in isolation appears to lead to confusion about information, a feeling of being dangerous and a negative attitude towards contact isolation in a later stage of the isolation process. Literature research mentions information provision to be improving the patient experience and the design research supports this, as many patients mentioned wishing more information as well. Providing the information gradually is expected to decrease the overwhelm, but unfortunately this has not yet been validated.

Because patients are not the only involved actors in the isolation process, the experience of healthcare providers and visitors has also been studied. Literature research mentions that for healthcare providers, nurses specifically, contact isolation has negative practical implications such as an experienced higher workload. Contact isolation however, is also of influence on the emotional experience of nurses. As the context research showed, shattered sense of responsibility leads to frustration, because healthcare providers want to provide good quality care to all their patients.

The research has only been performed with participants from VUmc. The feeling of shattered responsibility amongst nurses is not found in the literature used in this thesis. It is uncertain whether the feeling of shattered responsibility also applies to involved actors from other healthcare institutions.

The second research question: What elements can improve the patient experience during contact isolation, is answered in literature and context research. Increasing shared responsibility amongst actors is expected to be one way to improve the patient experience. From validation studies with healthcare providers, a shattered sense of responsibility appeared to be a recognized issue related to infection prevention. However, will patient experience improve by increasing shared responsibility and collective action? Because patient experience has elements in common with collective action theory, we can expect that when these elements increase, both patient experience as well as contribution to infection prevention increases. This however could not be validated in this thesis due to research restrictions and time limit. Additionally, currently no link between patient experience and collective action theory is found. Collective action theory could be researched more broadly by studying increased collective action and its influence on (user) experience in other sectors than healthcare.

Bundel is a first step to reach the design vision proposed in this thesis. It is still uncertain whether or not Bundel will result in an increased feeling of shared responsibility. The collaboration between patients, healthcare providers and visitors could not be tested because of a small participant sample and research restrictions. In the evaluation and validation studies performed, patients and healthcare providers had difficulty imagining how the working together would work. It therefore is assumed that shared responsibility is not yet enough incorporated in Bundel and therefore questionable whether it will be a first step towards the design vision. In paragraph 7.4, recommendations for improving Bundel are presented.

7.3 Conclusions based on project aims and goals

The project started with the following goal: This thesis aims to create a vision and a product or service that increase the active role and contribution of the patient to the quality of isolation and thereby improve the patient experience during contact isolation.

The design vision that this thesis presents is expected to lead to an increased involvement of patients in the isolation process and infection prevention in hospital. By increasing the feeling of shared responsibility, collective action is aimed for. Because patients, healthcare providers and visitors all understand that they contribute to a higher goal, their attitude towards infection prevention increases. A willingness to follow protocol amongst healthcare providers, patients and visitors is expected to increase. Moreover, I believe that, by feeling part of a community the feeling that contact isolation is imposed on patients decreases. The patient experience during contact isolation is expected to improve when striving to reach the feeling of community amongst actors in the contact isolation process.

The final design is designed to be a first step towards the design vision and based on the design goal. The main aim the design has to fulfil in order to be the first means to reach the design vision is A tool that lets patients experience partnership with healthcare providers and visitors in contributing to the safety of others. Because the design stimulates interaction between patients and healthcare providers and visitors at multiple points during the isolation process, it is expected to establish a partnership between individuals. Firstly, healthcare providers and visitors have to contribute to the information a patient receives about contact isolation. Therefore, they become actively involved and a conversation about isolation precautions is evoked. Secondly, at repeating interaction moments during the isolation process, such as care provision and visits, the design gently reminds individuals of the to be taken precautions.

The other part of the design goal is to let patients develop a favourable attitude towards contact isolation during the first time into contact isolation. The design aims to reach that by diffusing information over the isolation process and give patients the ability to find information when they have questions. By spreading information, instead of concentrating all information at the first time into isolation, the first time into contact isolation is less overwhelming for patients. Because information is layered, it is better understood, leading to a more favourable attitude towards contact isolation.

To conclude, I believe increasing a sense of shared responsibility supports in dealing with antimicrobial resistance and the prevention of infections in hospitals. Because antimicrobial resistance is a threat that concerns the whole world, increasing shared responsibility and applying collective action theories could be extended beyond hospitals, the healthcare industry or even countries. We should start to view antimicrobial resistance as something that concerns every individual in the world to a greater or lesser degree and therefore every individual should feel like being part of a community that works together.

7.4 Recommendations for future research and design

7.4.1 Bundel

To further develop Bundel into a design that is implementable in VUmc, some research and development still have to be performed. In the explained version, the provision of information is assessed as successfully contributing to the patient experience during contact isolation. Unfortunately, the design does not adequately stimulate shared responsibility and collective action yet. Research and design recommendations mainly focus on increasing the community feeling and the applicability in the hospital context.

When implementing Bundel in the form of a booklet as it is right now, it is essential to research what information should be provided to cover all the necessary information. The information should include the questions that patients have during and after the isolation process. Moreover, the information should stimulate collective action. To develop the new information, iterative research through design process should be applied; developing text and information and test with patients whether it is understood and covers their questions.

To be able to improve Bundel so that it fits with the context, the interaction of the design should be tested more thoroughly. It can improve by defining how the design would match with the experience of different patients types and an increased partnership between the involved actors. Costs and benefits of the design should be analysed and considered. The effect of Bundel on the compliance of patients, healthcare providers and visitors should, therefore, be assessed. When Bundel leads to increased compliance, and thus, fewer infections, the benefits for VUmc will be more significant than the costs. A minimum viable product that only contains the layered information could be a solution that is easier and less costly to implement.

Besides, clear overall protocols need to be in place and communicated in Bundel. Only then confusion about infection prevention and isolation precautions amongst patients, healthcare providers and visitors can be eliminated, and patient experience will improve.

Soon, when patients are more digitally skilled, a digital version of Bundel could be created. By providing the information on a (mobile friendly) website, anyone can find information anywhere. The education materials can be kept, and patients can still see all the information when they are at home.

In addition, by linking an account of a patient to epic, it becomes possible to track knowledge of a patient and his family. The data about the knowledge of patients can support nurses and other healthcare providers in providing care to patients. Moreover, the Infection Prevention team can gain insight into what questions patients have. They can create better fitting materials.

7.4.2 Patient experience during contact isolation

This thesis provides insight into the patient experience during contact isolation based on literature and context research. More extensive insights on how to improve the experience during contact isolation could be gained by analysing qualitative data derived context research based on the theory of patient experience. The following questions that arose from this thesis could thereby be answered.

Will actively involving patients in contact isolation and infection prevention lead to improved patient experience? The existing literature on improving patient experience is mainly about treatment options and decisions. The patient, however, cannot make whether or not he want to be treated in isolation.

This thesis combines insights from two theories: patient experience and collective action. This link is made because preventing infections and antimicrobial resistance seems to be a collective action issue. We currently assume that an increased shared responsibility leads to improved patient experience.

To improve patient experience during contact isolation, we could start considering different patient personas by providing them with care and information in various manners. The knowledge that patients have different attitudes towards (contact) isolation could be used as a basis to create more dynamic protocols that fit with that specific patient.

Because patients experience contact isolation differently, this could be similar for visitors and healthcare providers. Researching how they individually experience isolation precautions, could also provide insight into how to approach involved parties besides patients.

There is a difference in attitude towards contact isolation between first admission and readmission, that could be considered more. At readmission, patients know a lot about infection prevention and contact isolation. By using the patient's knowledge, they will feel less stigmatised and patronised. Healthcare providers could explain the measures as applied in VUmc but should consider the existent understanding of the patient more.

7.4.3 Infection prevention as a shared responsibility

Approaching infection prevention as a shared responsibility should be communicated to and felt in all layers of the hospital organisation. From management to the Infection Prevention team to the healthcare providers in the wards. When all people think this to be shared investment, compliance will increase.

To be able to deal with antimicrobial resistance on a hospital, national or even global level, the sense of shared responsibility should be increased. To be able to reach that on a broader scale than VUmc, several changes should be made. First of all, the tone of voice when talking about infection prevention should change. Contact isolation is often associated with something negative, but it should not be perceived negatively. Being a carrier of a microorganism is not necessarily scary or dangerous. By changing the wordings, this could be communicated more easily.



Personal reflection

This past half a year has been an enjoyable experience. I have learned a lot about doing research and design in a for me new sector, namely healthcare. During the project, refined my skills and developed new ones. It provided me with new insights into my way of working and the value I as a designer can bring.

I started this project with enthusiasm and excitement to learn about contact isolation. In the first weeks of this project, I experienced the difficulty of during research in healthcare. Writing a research protocol in full detail improved my research setup significantly. I was used to writing a more or less structured setup for interviews and then go. But in this project, approval of the medical ethical committee was needed. I now value a wellthought-through research setup more. You need to take into account the person you are interviewing as much as if you would do with a user when creating a design.

The use of a patient journey as an analysis document was new for me. It was nice to be forced to transcribe all the interviews and take the time to analyse all the collected data thoroughly. I enjoyed completing the analysis in one large document and then discovering patterns and finding opportunities for improvement very much. I never expected that a patient journey could provide such significant insight to healthcare providers.

The healthcare sector is full of enthusiastic people that have a heart for improving the lives of people. It has been wonderful to see how driven healthcare providers are. Many of them were very open to helping me with my project. Unfortunately, I underestimated the time healthcare providers have. I would have liked to incorporate co-creation in my design process even more, but their schedules would not allow for a few hour sessions. I applied several methods to stimulate the creativity of healthcare providers in a short amount of time. It was interesting to see how, after asking the right questions, some of them appeared to be very creative. That experience inspires me to stimulate more non-designers to be creative.

During the second phase of my graduation project, I struggled more. I feel like creating a design is not my strong suit and therefore ideating, conceptualisation and detailing was difficult.

Moreover, this project provided me with a lot of insight into my way of approaching and performing projects. Doing an individual project always has been a struggle for me, but this project taught me to keep continuing. Even when it was difficult and not so fun anymore; there was always light at the end of the tunnel, and I knew it would get better. I learned that I could ask for help when I struggle or when I need input to continue and realised so many people are willing to help me.

I love how my graduation project made me realise the value of designers in social sectors such as healthcare. The value I can bring because of my skills as a designer, but also because of my skill set is proven to be useful in all kinds of projects!



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