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Concept analysis of patient journey disruptions: the obstacle of integrated care

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Abstract

Purpose – This article aims to clarify the concepts used to understand, analyze and improve a patient’s progress through a health service system. A patient pathway describes plans and intentions. Within it, we distinguish between the clinical pathway of decisions and interventions and the care pathway of supportive activities. As a patient pathway is implemented, it turns into a patient journey of what is done, what happens to a patient’s medical condition and what is experienced and felt. We introduce “patient journey disruption” (PJD) as a concept describing the events that need to be prevented from happening to accomplish integrated, coordinated and seamless care.

Design/methodology/approach – The method used in this paper is concept analysis. First, an expert steering group worked to refine the concept of PJDs; second, an analysis of similar concepts from related fields was done to root the concept into existing theories, and third, semi-structured interviews with professionals and patients were done to test the concept of PJDs in the home care context.

Findings – PJDs are agency-based harmful events in the execution of the care pathway that deviate the patient journey from what can be reasonably expected. PJDs are management failures, which is why they

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Paulus Torkki and Paul Lillrank have shared last authorship.
should be studied by healthcare operations management (HOM) and service science scholars with the intention to find ways to prevent them from happening.

**Research limitations/implications** – This study has limitations, including presenting conceptual ideas and preliminary results that are only indicative.

**Practical implications** – We believe that the introduction of the concept of PJDs into the literature provides a new, systematic way of approaching the different shortcomings in our healthcare production systems. Moreover, by systematically identifying different PJDs, interventions can be designed and targeted more appropriately.

**Originality/value** – Managerial challenges regarding healthcare processes have been studied but have not been well defined. The concept of PJDs is an original, well-thought-out definition.

**Keywords** Patient pathway, Patient journey, Patient journey disruption, Clinical pathway, Care pathway, Healthcare processes, Integrated care, Care coordination

**Paper type** Conceptual paper

## 1. Introduction

Patients with multi-morbidities, long-term conditions and complicated diagnostics consume up to three-quarters of the resources of health service systems, while the quality of care is not necessarily to anybody’s satisfaction (Stange, 2009; Valentijn et al., 2013). Complex patient cases are difficult to manage in complex systems with narrow specialties and multiple providers (McCarthy et al., 2016). Patient processes may break, fragment, overlap and lead to polypharmacy. It is generally acknowledged that the vision should be integrated, coordinated and seamless (Lillrank, 2012; Singer et al., 2011). Indeed, the objective of organizational design has been to optimize integration and specialization. Specialization brings competence but inevitably leads to fragmentation, which needs to be overcome by arrangements that bring together the specialized components as an integrated whole (Lawrence and Lorsch, 1967). In healthcare, various digital solutions have been proposed with varying results (David et al., 2014; Hannigan et al., 2018; Johnston et al., 2014; Mott and Bowman, 2014; Ovretveit, 2015; Strisland et al., 2016; Ward et al., 2013). While integration remains an objective, less attention has been paid to its nemesis, the problems that call for integration as a solution. Organizations can be improved through visionary designs as well as through continuous improvement through problem solving. The latter approach is grounded in operations management (OM) and adapted here. Problems need to be understood before they can be solved. Therefore, we present a conceptualization of patient journey disruptions (PJDs) as a specific type of harmful event that requires managerial solutions.

Most of the literature on healthcare errors is focused on medical errors (Grober and Bohnen, 2005; Weingart et al., 2000) and adverse events (Bates et al., 2003; Kelly et al., 2007), such as mistakes in clinical judgment, procedures and medication. However, care breaks and fragmentation are primarily not clinical but managerial issues. In healthcare processes, not all kinds of “bads” are managerially relevant, highlighting the need to distinguish between those that are and those that aren’t. PJDs are positioned in the management of patient processes. Therefore, the nature of processes needs to be explicated and defined before their problems can be assessed.

We approach these issues from the perspective of healthcare operations management (HOM) (Vissers et al., 2022). OM is concerned with control, which is the difference between what was planned and what happened. The second concern is effectiveness, from which follows the distinction between the value chain, supporting activities and waste (Hopp and Spearman, 2011). Service OM sees service production as “co-creation of value” (Vargo and Lusch, 2014), from which it follows that the patient perspective must be considered. This leads to two research questions.

**RQ1.** How should the plans, procedures, outcomes and experiences of a patient’s case be defined and described so that control, value and co-creation are duly considered?
RQ2. How should the disruptions in a patient journey be defined, described and analyzed?

The research presented here is part of a larger project PATHWAY, funded by the Norwegian Research Council, which seeks to develop tools for the management of complex patient processes. This article is organized as follows. First, we elaborate on the general concept of a patient process and make a distinction between planned patient pathways and actual patient journeys and divide the patient pathway into two components, namely the clinical and the care pathways. Second, we present the methods used. Third, we define the concept of PJD. Fourth, we empirically test the feasibility of this concept in the context of home care. Finally, we discuss the implications and future research.

2. Background

For truly integrated care (IC) and high-quality care to be delivered, it must be understood what the actual challenges are that hinder the delivery of such services. There is a plethora of literature on the “barriers” and “challenges” of IC delivery (Ling et al., 2012; Maruthappu et al., 2015; Raus et al., 2020; Threadleton et al., 2017; Tsasis et al., 2012) and what constitutes “quality” of care (Blumenthal, 1996; Campbell et al., 2000; Donabedian, 1988). Despite this, there is still a lack of conceptual clarity on what kinds of events should be prevented in the pursuit of IC and quality care. With this goal in mind, we put forward the concept of “patient journey disruption” (PJD), which frames exactly what we should be looking at in healthcare processes when aiming to implement IC and improve the quality of care. This is especially relevant in the context of chronic and multimorbid patient groups – a group that makes up roughly 20% of the patients yet consumes up to 80% of the resources. We introduce the PJD concept by building on previous work familiar from health systems science, HOM and health service research.

The fundamental building block of health service systems is the care relation (Lillrank, 2018). A person with a health issue enters a relationship with a healer or service producer, a person, team or organization that has, or claims to have, the capability to help. The care relation manifests as encounters. These can be temporal where the issue is dealt with within one encounter or step, after which the case is closed. If the case is more complicated and more encounters are required, there will be an anticipated or scheduled process with several distinct steps at another time or location or with another provider. Steps are connected with handovers – the information that helps the next step’s caregiver know what has happened and what has been planned (Manser and Foster, 2011). Based on the handover and other pertinent information, the next step starts with a setup – the cognitive and physical preparations required to perform the step. Thus, the patient process is a general term that describes a care relation between a patient and a caregiver with two or more distinct steps connected by handovers and setups (Wohlauer, 2012). A patient process can have several attributes, such as long or short, ending or continuous (chronic) and high or low intensity.

While “process” is a generic term describing any sequence of activity, “pathway” denotes a process as it is planned. While there are some differing perspectives on the definitions and exact terminology used within the context of pathways in healthcare (Kinsman et al., 2010), we adopt the following definitions: a clinical pathway denotes the planned clinical interventions and therapies that are based on a diagnosis and clinical knowledge (Campbell et al., 1998; Kinsman et al., 2010; Lawal et al., 2016; Ouwens et al., 2005; Vanhaecht et al., 2009). A care pathway describes the activities that enable and support the clinical pathway. Such activities are scheduling, communication, self-care guidelines, logistics and support (Campbell et al., 1998; Olsson et al., 2009; Schrijvers et al., 2012). The clinical and care pathways taken together constitute the patient pathway (Eklund et al., 2024;
Mould et al., 2010; Richter and Schlieter, 2019) – the service production plan for a type of patient, which is then applied and modified for individual cases. While a patient pathway is a plan, a patient journey is the totality of what is done and what actually happens to a patient’s medical condition, functioning, experience and emotions (Manchaiah et al., 2011; McCarthy et al., 2016; Oben, 2020). Patient journeys vary between individuals and may deviate from the patient pathway. They include the events, treatment outcomes, movements, communications and experiences of the patient that are related to their health issue and its treatment (Devi et al., 2020). The medical sociology literature uses the term “patient trajectory” (Allen et al., 2004; Corbin and Strauss, 1991; Strauss et al., 1963, 1985) in a somewhat similar way but does not make the distinctions between planned vs. actual and the clinical core vs all the rest that happens to a patient. There are instances of a care pathway without a clinical pathway, such as a patient with symptoms but lacking a diagnosis. In lower-income countries, there are low-cost hospitals that offer only clinical pathways, while the patient’s family is supposed to provide the care pathway (Singh and Lillrank, 2017).

A patient pathway is executed by relevant actors, including the patient. The execution is subject to variability and situational contingencies that may arise from a patient’s life situation or resource availability. Execution requires coordination of various actors, particularly when the original plan needs to be adjusted. When a patient pathway is executed, it transforms from intentions (a plan) to empirical reality and becomes a patient journey. Metaphorically speaking, “pathway” denotes a road or a path – including alternative paths and junctions – that has been laid out according to a plan or a goal to which the pathway should lead. A patient journey can exist without a patient pathway, and such is the case for any unplanned patient process and experience. Similarly, a patient pathway can exist without a patient journey if the patient journey never intersects with the patient pathway. In summary, the intersection of a patient pathway and a patient journey can be thought of as the patient journey being the empirical manifestation of a planned patient pathway. Figure 1 illustrates how both can exist in tandem with each other and further clarifies the concepts.

Patient journeys follow plans to a variable extent. All service production includes risks and uncertainties, such as variability of individuals, situations, capabilities and expectations. In healthcare, these are amplified by the imprecise nature of clinical medicine, information asymmetries and communication issues. The plannability of patient pathways varies significantly, as well as the level of detail to which plans can be made. In some areas, such as cataract and artificial joint surgery, mass vaccinations and laboratory tests, detailed and standardized processes can be made an executed. In many areas, plans can be only general guidelines that are subject to judgment and bargaining in each specific instance, resulting in routine processes (Lillrank, 2002; Lillrank and Liukko, 2004).

The patient journey has largely been discussed, highlighting the patient’s experiences to enhance service quality at service encounters (Gualandi et al., 2019, 2021; Philpot et al., 2019). Less attention has been paid to the patient journey as a continuous flow over a variety of situations punctuated by service events. The patient journey highlights “what happens to the patient, especially during transitions of care” (Beleffi et al., 2021). This is evident, especially in chronic patient journeys where the patient might be in contact with the healthcare system only once a year for a checkup, yet they live with the diagnosis and all that comes with it every day. Indeed, only the patient has an active view of what happens between the service events, and thus, the patient’s view is necessary for reconstructing a patient journey as a set of data. Patient journeys can be known by patient narratives and descriptions, systematic surveys, service provider’s stories and medical records, documenting observations and assessments made by healthcare professionals. The definitions and operationalizations for these terms adopted for this study are presented in Table 1.
Based on the above definitions, we aim to investigate the relationship between the patient pathway and the patient journey from a managerial perspective in terms of unwanted deviations from what should happen. Our aim is to define, on an abstract level, the types of events that are managerially interesting. This will help both researchers and practitioners better find and distinguish the relevant events requiring managerial intervention from the large mass of different events and deviations that can and do occur in patient processes every day yet are not problematic or otherwise relevant from a managerial perspective.

3. Methods
We conducted concept analysis based on the Wilsonian framework (Wilson, 1970), which has been further adapted (Walker and Avant, 2005) and previously used specifically in the context of healthcare to clarify, for example, concepts such as “fever” (Thompson, 2005) and “information overload” (Wang and Voss, 2022). The framework has also been previously criticized for sometimes allowing the emergence of prescriptive rather than descriptive concepts (Hupcey et al., 1996). We, however, aim to introduce a new concept to the literature. We utilized this method to thoroughly understand the complexities and implications of PJDs and their manifestation in the empirical world. The major steps of the framework followed in this paper are presented in Table 2. First, we developed the concept in an expert steering group; second, we linked the concept to OM literature, and third, we tested the conceptualization in the empirical world. These steps are detailed below, out of which Steps 3 through 8 are reported in the results of this paper.

First, the concept of PJDs was developed in an expert steering group involving the authors and outside experts who are relevant to the field from both Finland and Norway.
This group oversaw the whole development process, continuously discussed the relevancy of the analysis and engaged in debate over the definition of PJDs. This work was conducted over several online meetings and three in-person workshops in Oslo (24.-25.5.2022), (5.-7.3.2023) and (20.-23.11.2023). The results of the work done by the expert group were presented (21st April 2023) for feedback to a scientific advisory board (SAB), which included external experts from different fields of healthcare. The composition of the expert steering group and the SAB is presented in Table 3.

Second, we link the PJD concept to foundational concepts from the OM and service science literatures. This examination uncovers commonalities, differences and relationships between the concepts, familiar from other streams of literature but also differentiating the concept from other similar concepts.

Third, to test our conceptualization and demonstrate the empirical occurrence of PJDs, we conducted semi-structured interviews with home care professionals (n = 10) and patients (n = 5), following a structure of thematic questions aimed at explicable different kinds of PJDs in home care. The interview guides used in the interviews were peer-validated, and two mock interviews were conducted for both a home care patient and a home care professional. All interviews were held via an online video call or a phone call and lasted from 30 to 45 min. The interviews were recorded and further transcribed. The transcribed interviews were

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### Table 1.
Patient pathway and patient journey: definition and operationalization

<table>
<thead>
<tr>
<th></th>
<th>Clinical Pathway</th>
<th>Care Pathway</th>
<th>Patient Journey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ontology (What is it?)</strong></td>
<td>A plan for interventions for a certain diagnosis based on clinical knowledge.</td>
<td>A plan for the actions and processes to support the clinical pathway.</td>
<td>Events, encounters, and acts, states and changes in states, such as medical condition, functioning and capabilities, both cognitive and emotional experiences.</td>
</tr>
<tr>
<td><strong>Epistemology (How it known? What data?)</strong></td>
<td>Medical documents and guidelines.</td>
<td>Communicated plans and guidelines.</td>
<td>Personal and professional reports and records, clinical indicators, observations and assessments by caregivers, surveys, narratives</td>
</tr>
<tr>
<td><strong>Objective</strong></td>
<td>Whole or partial cure, save and stabilize, ease, alleviate symptoms, prevent, arrest decline.</td>
<td>The implementation of a clinical pathway considering the patient’s convenience and quality of life (QoL) in relation to resource availability.</td>
<td>A patient journey is a description of what happens and how it is experienced. It does not have an objective. Individual patients have objectives that may differ from the patient pathway.</td>
</tr>
</tbody>
</table>

Source(s): Authors’ own work
analyzed thematic analysis (Braun and Clarke, 2012). The thematic analysis was done by using ATLAS.ti 22 (version 22.2.4.0 by ATLAS.ti Scientific Software Development GmbH). Everything that was communicated was coded by first-level categorizing, which was then categorized to second levels based on larger and connecting themes. The analysis was conducted to be mutually exclusive and collectively exhaustive (MECE principal) to avoid overlapping in the analysis. The categorized themes were created by using common events and outcomes.
4. Results
4.1 Definition of patient journey disruptions (Phase 3)
A patient journey does not always proceed according to plans and expectations (Richardson et al., 2015). Some deviations have unwelcome consequences. There is a plethora of peer-reviewed research on medical errors and adverse events rooted in clinical judgment and skill (Kern et al., 2019; Richardson et al., 2015; Sabaté, 2003). In this paper, we are interested in events that are bad, harmful or unwelcome to patients and rooted in how the care pathway is planned and executed, i.e. a specific type of managerial problem. As such events appear in the patient journey, we call them PJDs. We present the definition and operationalization in Table 4.

The first defining characteristic of a PJD is that something bad or unwelcome happens to a patient or that the risk of such an event increases, leading to a near-miss situation. A deviation from the patient pathway may or may not have harmful consequences since plans are probabilistic, imperfect and fallible. There are situations where a deviation is necessary because strict compliance to plan under changed circumstances might lead with the harmful outcomes. Therefore, a deviation from plan, as such, does not yet constitute a PJD. A realization of known risks, such as the failure of a risky surgery, known side effects of a medication or the foreseen worsening of a chronic condition, is not a PJD as these are part of the clinical pathway. However, failure to communicate and consider them adequately is.

The second defining characteristic of PJD is agency; the origin of the disruption can be traced back to somebody – caregiver, administrator, patient, family or other stakeholders, doing or failing to do something. Therefore, unknown risks, unavoidable accidents and happenstances are excluded, as they are random and lack agency. While they, as such, are not yet disruptions, failure to respond to them adequately is. Agency, however, needs to be understood more broadly than individual acts. A service production system that designs patient pathways may lack some features, such as patient communication routines, which in some instances lead to a PJD, but no single individual is to blame.

<table>
<thead>
<tr>
<th>Patient Journey Disruption</th>
<th>Ontology (What is it?)</th>
<th>Epistemology (How is it known? What data?)</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>An agency-based event rooted in the execution of a care pathway with negative outcome in relation to what could be reasonably expected.</td>
<td>Personal and professional reports and records, clinical indicators, observations and assessments by caregivers, surveys, and narratives in relation to some known norm.</td>
<td>We are interested in patient journey disruptions, because they are management failures and as such, could be avoided with better management practices, leading to better treatment outcomes and ultimately create technologies for better care plan development and management.</td>
</tr>
<tr>
<td></td>
<td>A patient journey disruption has:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>An agent – someone (system or individual) does (or doesn’t do) something that results in patient journey disruption.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A reason – the action or inaction resulting in a patient journey disruption has a cause.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>An outcome – the patient journey disruption has a negative health or resource outcome.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.
Patient journey disruption: definition and operationalization

Source(s): Authors’ own work
Everything bad is not a disruption; therefore, we need to specify what kinds of bad there are. To this end, as the third defining characteristic, we postulate reasonable expectations as a benchmark. We argue that a PJD can be defined as a harmful and agency- or system-based deviation from what could reasonably be expected in a given circumstance. This means that PJDs are highly contextual.

Since everything cannot be documented in an individual patient pathway, the contextual question “what can be reasonably expected in this situation” is the key to defining a PJD. But who decides what can be reasonably expected? We propose a few sources for such decisions.

1. There are universal declarations on patients’ rights by international organizations, such as World Health Organization (WHO).
2. National laws set standards for what a patient should be able to legally reasonably expect. We do, however, recognize that in politically managed health system politicians tend to overpromise and underfund and that the law may not be specific enough.
3. In insurance-based health systems, the insurance contract sets limits to what can be expected.
4. Professional collegiums set standards of conduct documented in clinical guidelines and best practices (e.g. a documented patient pathway).

4.2 Model, borderline, related, contrary and illegitimate cases of PJDs (Phases 4 and 5)
As per the Wilsonian concept analysis framework, we constructed case examples to illuminate what does and doesn’t constitute a PJD, as presented below:

**Model case:** Patient contacts local health center with symptoms, doctor runs labs and suspects Parkinson’s and refers to a neurologist. Test results are not available at the neurologist’s office and all tests must be rerun, causing delays. This is a PJD.

**Borderline case:** Patient contacts local health center with symptoms, the doctor suspects that something is wrong, however, the health center’s policy is not to run further tests on patients presenting with these symptoms. Patient goes home and the symptoms get worse. This event occurs in both the clinical and care pathway, therefore it is borderline

**Related case:** Patient contacts local health center with symptoms, the doctor misses the signs and sends the patient home. Patients goes home and the symptoms get worse. This event occurs purely in the clinical pathway and is a medical error, therefore not a PJD

**Contrary case:** Patient contacts local health center with symptoms, doctor runs labs and suspects Parkinson’s and refers to a neurologist. Test results are available at the neurologist’s office. This is reasonable to expect.

**Illegitimate case:** Patient contacts local health center with mild symptoms expecting to receive an appointment for the following day. The health center has a policy of everyone receiving an appointment time within 2 weeks of initial contact. Thus, the expectation of a next-day appointment is not reasonable, therefore not a PJD.

4.3 Conceptual origin in operations management (Phase 6)
We believe the PJD concept is useful as it draws attention to the totality of what happens to a patient and makes a distinction between the clinical and care pathways as the origins of disruptions. It, however, needs to be positioned in relation to other concepts. In Table 5 below, we point out the origins of the concepts we draw from in our own conceptualization.
Quality control (Mitra, 2016; Ishikawa, 1985) is an integral aspect of OM that is concerned with the dichotomy between planned and actual processes (i.e. patient pathways and patient journeys). Discrepancies between these can be considered quality issues that require investigation and corrective measures. Quality problems can be traced back to two types of causes: common and special causes (i.e. system and individual agency). Whereas common causes are systemic and contribute to random variability, special causes are unique and identifiable, triggering non-random variability. In addition, quality control is closely related to lean production, which has its roots in mass manufacturing (Womack et al., 1990; Womack and Jones, 1997) and its application “lean healthcare” (Costa and Godinho Filho, 2016; Hallam and Contreras, 2018), making a distinction between the value chain, where direct value is added to the product or service and supporting activities that allow for these value-adding processes to take place (i.e. clinical and care pathways). Resources and activities that do not add value are considered “waste” such as wasteful motions, procedural and communication errors (Bharsakade et al., 2021). Processes are improved through waste reduction. However, waste can’t be defined without value, which in healthcare is a slippery concept. Errors obviously do not create value and therefore a waste. Within the care pathway, value is subjective but constrained by what can be reasonably expected. For example, is an extra five minutes of doctor’s time at the bedside value or waste? From the perspective of the clinical pathway, it is waste, while from the perspective of the care pathway it is, or may be, of significant value, and hence, it is reasonably expected. Similar theoretical approaches to management are familiar from the contingency theory (Luthans and Stewart, 1977) literature, which postulates that there is no universally best way of managing but that leaders need to adapt their decision-making to the specific circumstances at hand. A PJD can’t be anchored in specific outcomes but must be positioned to contingent reasonable expectations.

Similarly, service science (Grönroos, 1990) explores the “what” and “how” aspects of service delivery. Whereas the “what” focuses on the specific services provided, the “how” zooms in on how they are delivered (i.e. clinical and care pathways). A similar distinction can
be made between the back and front offices, where the back office supports service delivery while the front office is the part that interacts with the customer. These two are divided by the line of visibility. Service science is concerned with the co-creation of value, which considers the customers active participants in service delivery rather than just receiving the services (i.e. patient journey) (Lusch and Vargo, 2014). Service marketing has developed the concept and associated methodology for the study of “critical incidents.” These are service events that have a significant impact on how customers perceive, positively or negatively, a service delivery system (Bitner et al., 1990). Negative critical incidents may be considered a specific case of PJDs.

Process analysis (Oakland and Oakland, 2019) is the systematic examination of different types and stages of processes with the aim of understanding and improving them. In this context, standard processes are identical repetitions following one setup, while routine processes address similar but slightly differing events through decision rules and algorithms that allow bargaining (Lillrank, 2002). Problems within standard processes, assuming that the standards are appropriate, are deviations from given targets and protocols. Since many health service processes, particularly in the care pathway, are routines, a PJD can’t be simply and solely defined as a deviation (i.e. deviations vs errors). In the logistics literature, “supply chain disruption” (Tomlin, 2006) is a concept that describes adverse impacts on the smooth flow of goods and services in a supply chain, resulting in negative outcomes such as increased costs (i.e. PJD). These disruptions can be the result of a variety of situations such as labor strikes, unexpected spikes in demand or natural disasters. In this respect, a disruption is an event that disturbs the integrated, coordinated and seamless flow in a supply chain. The medical sociology perspective has it (Bury, 1982) that a health issue, particularly a degenerative chronic condition, is a disruption affecting a person’s life.

4.4 Antecedents, consequences and empirical referents (Phases 7 and 8)
We empirically tested the feasibility of the PJD concept in the context of home care services by conducting semi-structured interviews with both professionals (n = 10) and patients (n = 5). Home care involves a range of medical and personal services provided at a patient’s home to maintain or improve their health and daily living. This may include services such as nursing care, physical therapy or medical social services, as well as assistance with daily tasks like bathing, dressing and medication management. It's designed to support individuals who are aging, chronically ill, recovering from surgery or illness or disabled. Informants are presented in Table 6.

A total of 38 distinctive PJDs were identified. Out of these PJDs, five were identified by both the patients and the professionals. Many of the PJDs were individual events and specific examples, but 22 were mentioned more than once. Out of these, seven examples of the identified PJDs in home care and their causes and consequences are provided at a more detailed level in Table 7 below and four thematic categories based on the causes of disruptions are discussed further.

4.4.1 Reliable information flow. Disruptions caused by a lack of reliable information flow concern receiving up-to-date information or not knowing where to find the searched information, due to the fragmentation of various patient record systems used by care providers. It was typical that the patient, health care stations, hospital personnel or home rehabilitation team did not share the understanding or view of what was important information with the home care; this was the main reason why home care had to reach out to other care providers to complement background information concerning the patient’s treatment. The lack of understanding of what information is needed was reported in cases where the patient record systems were shared with home care. There is a possibility to
communicate through the patient record system, but it is not widely utilized, despite home care’s appreciation.

Co-operation with hospital works sometimes very well, but sometimes we don’t receive all the necessary information, and, in some cases, we don’t get information of the client returning to home care. (Professional 3)

These situations led to disruptions such as patients being treated with the wrong medication until more up-to-date information was made available and, in an extreme case, vital care not being administered at all leading to dangerous situations and an overall reduced quality of care.

4.4.2 Care coordination and responsibility. The disruptions caused by a lack of care coordination and responsibility were recognized by both patients and professionals. All professionals recognized disruptions occurring due to delays in the process of getting in contact with medical contacts. Disruptions typically occur when there is no shared understanding of who is in charge and who is responsible for what.

What we would really hope, would be that others [providers] would consider that we have a vast role in the client’s care, so we also need the information that what is decided there [health center] [...]. We don’t have any specific way to contact them, so we call the on-duty nurse who is already drowning on other work [...]. It’s one sided, they don’t contact us. (Professional 4)

Confusion around care coordination and responsibility led to disruptions such as care administration being delayed when no access to a medical professional was available and

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (years)</th>
<th>Gender (male/female/other)</th>
<th>Employment in home care (years)</th>
<th>Employment in social and healthcare sector in total</th>
<th>Title</th>
<th>Interview duration (min)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>32</td>
<td>F</td>
<td>5</td>
<td>5</td>
<td>Nurse</td>
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<td>F</td>
<td>21</td>
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<td>Area manager</td>
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<td>F</td>
<td>12</td>
<td>22</td>
<td>Supervisor</td>
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<td>32</td>
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<td>2</td>
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<td>Nurse</td>
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</tr>
<tr>
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<td>F</td>
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<td>12</td>
<td>Supervisor</td>
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<tr>
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<td>5</td>
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<td>11</td>
<td>Practical nurse</td>
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<td>10</td>
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<td>Supervisor</td>
<td>53</td>
</tr>
</tbody>
</table>

Table 6. Interview informant summary

Source(s): Authors’ own work
overlapping care being administered in the form of polypharmacy and unnecessary medication.

4.4.3 Perception of services and care. The home care professionals saw their role as important caregivers who were cooperating with the patient and their relatives, and this view was also recognized by the patient, but many of them felt that they didn’t understand the coordination of their care. There was also a significant contrast exhibited by how the professionals emphasized the importance of the service and care plan, whereas none of the

<table>
<thead>
<tr>
<th>Cause</th>
<th>Disruption</th>
<th>Type of disruption</th>
<th>Consequences</th>
<th>Example from data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-reliable information flow</td>
<td>Care is administered based on unreliable information</td>
<td>Something is done wrong</td>
<td>Reduced quality of care</td>
<td>The patient is treated with incomplete information (e.g. with wrong medication) until more precise information is received</td>
</tr>
<tr>
<td>Vital care is not administered at all</td>
<td></td>
<td>Something that should be done, is not done</td>
<td>The patient is put in danger</td>
<td>There is no information on the patient being discharged from a hospital, when they would need immediate care at home</td>
</tr>
<tr>
<td>Care coordination and responsibility</td>
<td>Care administration is delayed</td>
<td>Something that should be done, is not done in an optimal time</td>
<td>Undercare</td>
<td>Home care has no direct contact to a medical professional and often must go through third parties leading to delays</td>
</tr>
<tr>
<td>Overlapping care is administered by different actors</td>
<td>Overlapping care is administered by different actors</td>
<td>Something unnecessary is done</td>
<td>Overcare</td>
<td>Polypharmacy and unnecessary medication are administered due to different actors not being coordinated</td>
</tr>
<tr>
<td>Continuity of care</td>
<td>Care is administered differently by different actors</td>
<td>Something is done inconsistently</td>
<td>Uncertainty and lack of feeling of security increases</td>
<td>Continuously changing home care staff have differing habits of administering care leading to uncertainty in patients</td>
</tr>
<tr>
<td>Emergency care is administered without up-to-date patient information</td>
<td>Emergency care is administered without up-to-date patient information</td>
<td>Avoidable risks are taken</td>
<td>Dangerous situation</td>
<td>No knowledge of who has done what and no way to access that information in an emergency</td>
</tr>
<tr>
<td>Perception of services and care</td>
<td>Patient has no visibility to the care process</td>
<td>Information that could have been given, is not given</td>
<td>Reduced co-creation of health</td>
<td>The patient is often responsible for parts of their own care (co-creation of health) but is unaware of the big picture or the goal of the care</td>
</tr>
</tbody>
</table>

Source(s): Authors’ own work

Table 7. Patient journey disruptions in home care
patients recognized the plan’s role in the way the professionals described it, and only two patients recognized some parts of it. Moreover, some patients mentioned not knowing how their requests for care are received in home care or when to use certain services. The service and care plan were considered vital by the home care professionals, but two patients disclosed never hearing of it. Nevertheless, the patients who recognized the plan mentioned that the plan was being updated only annually or even rarely, whereas the professionals declared that the plans would be updated every six months. Two patients did not recognize the plan or its functions at all, although both were home care patients:

I have never had it [making an evaluation for services and care plan]. No, I never needed any services. (Patient 2)

Unclarities in the perception of services and care led to disruptions such as patient lacking visibility into the big picture of their care, causing reduced adherence (co-creation of health) to their own care.

4.4.4 Continuity of care. The disruptions caused by home care’s care delivery were mostly mentioned by the home care patients and concerned the inconstancy of care and not having clear communication with the home care unit. Patients also mentioned issues regarding the rapid turnover of home care personnel, which was also specified by home care professionals but from a different perspective; the professionals mentioned a lowered quality in care reporting in addition to completely missing care reports. The home care personnel also criticized the home care for not following its own protocols and instructions.

They [home care] over-treated my right arm […] and I thought it’s not going to get better […] so I stopped the treatment. […] They closed the wound with bandages, and I could not use my right arm at all, and it was sometimes completely out of use […] I didn’t feel like arguing about it. (Patient 2)

Shortcomings in the continuity of care caused disruptions such as emergency care being administered on a lack of information basis, causing dangerous situations, on one hand, and, on the other, hand care administration habits being variable, causing uncertainty in the patients.

5. Discussion
We have defined a PJD as an agency-based harmful event in the execution of the care pathway that deviates the patient journey from what can be reasonably expected. PJDs are management failures, which is why they should be studied from HOM and service science perspectives with the intention of finding ways to prevent them from happening. We expect that PJDs are mostly of interest in the cases of chronic patient processes, which tend to be lengthy and complex yet plannable. For clarity, we do not assume or endorse managing care pathways as a separate management profession, but as a task that can be performed by people who also do clinical or nursing work. As PJDs originate in the care pathway and manifest in the patient journey, they can be studied using corresponding data sources. PJDs can take many forms and may require contextual knowledge to be classified.

The types of PJDs can be approached through thematic analysis. The most typical PJDs can be assumed to be related to not knowing what to do due to poor information and neglecting to do something that should have been done due to a lack of capability or motivation. Typical PJD consequences are delays, fragmentation, discontinuity and poor adherence. Fragmentation means that a patient has two or more parallel clinical pathways that are not coordinated (Lee, 2008) and may lead to contradictions and polypharmacy in the clinical pathway and confusion in the care pathway (Maciejewski et al., 2017). Discontinuity occurs when a patient journey is terminated without a valid reason (Federman et al., 2001; Kikano et al., 2000; Nagraj et al., 2013; Petersen et al., 1994; Pitt, 2018; Rajbhandari et al., 2000).
PJDs can be negative experiences that harm adherence to care (Sabaté, 2003). Adherence means a patients’ or other stakeholders’ commitment to care, most typically to medication, but also other aspects of self-care (Daley et al., 2012; Osterberg and Blaschke, 2005).

The reasonable expectations directed at the clinical pathway and the care pathway are different. The former is constrained by technology (what can be done) and resources (what can be afforded). The latter is to some extent resource-constrained, as it might take extra time to answer patients’ concerns and fears, but is essentially subject to leadership and management manifested in organizational culture and accepted practice. In addition, reasonable expectations are subject to sense-making processes (Weick et al., 2005) by both patients and healthcare professionals. In fact, it is known that many interventions (especially those based on high patient adherence) benefit from facilitated sense-making (Jordan et al., 2009). This also means that in unclear cases where there are no documented guidelines, the question whether a PJD has occurred may be dependent on the subjective, lived experience of the participants. This is also in line with previous ideas on supply failures under two-sided information asymmetry, where perceptions play a key role in whether a failure has occurred or not (Kauppi et al., 2024). As such, any empirical identification of more difficult to identify PJDs requires an understanding of the individuals, their culture and the organization in question.

5.1 Conceptual classification
PJDs can be studied empirically from three perspectives. First, the disruption as an event (what happened) needs to be understood, for example, a wrong medication given, a delayed appointment or an encounter that leaves hard feelings. Second, the causes (and agency) can be classified into those coming from the caregiver through personal encounters, system failures or both (Vahey et al., 2004; West et al., 2018), those arising from a patient’s behavior (Sabaté, 2003), and those related to situational contingencies that are not handled appropriately (Richardson et al., 2015). Third, the consequences of disruption need to be studied to assess the loss of value.

The disruptions might be classified into categories based on the types of events (different disruptions), types of causes (e.g. communication and system failures, patient behavior and reaction to contingencies) and types of consequences (e.g. loss of time, waste of effort, faulty or incomplete care delivery, emotional distress and poor adherence) to which routine countermeasures could be developed. It might also be possible to elicit the traces a PJD leaves in patient records, which would enable quantitative research on the occurrence of PJDs. A situation where no care plan exists at all may be considered the mother of all PJDs. A patient travels in a pathless wilderness. How can one manage a process that is not at all planned?

5.2 Empirical identification
The identification of PJDs requires an interplay of qualitative and quantitative methods. While many patient pathways are limited to “box and arrow” diagrams, some provide more detailed descriptions of the standardized care for a certain diagnosis, often in textual form. These guidelines are more often targeted toward the clinical pathway and are sometimes called clinical guidelines. In some cases, a full standardized patient pathway is provided, which gives researchers and clinicians an opportunity to pick it apart and hypothesize how a perfect execution of such a patient pathway would manifest in patient registries. The construction of such comparators allows researchers to compare the ideal and planned with the real patient journeys. The objective of such research would be to identify and analyze the problems, root causes and end results to develop solutions and ultimately create technologies for better care plan development and management.
Qualitative research should be used to identify different kinds of PJDs, such as was done in the empirical inquiry of this study, while quantitative research should be used to study their impact. Patient journey mapping (Madathil et al., 2020) is one such tool for qualitatively mapping patient journeys in a structured manner. Allowing for comprehensive mapping of the care process and identifying context-specific PJDs, registry analysis (Farmer et al., 2018) and process mining (Van Der Aalst, 2016) can be great tools for studying PJDs quantitatively. They by themselves, however, do not shed light on the third definition of a PJD – was the alleged disruption reasonably expected? – which is why it is important to collect qualitative data on PJDs in the context of interest and identify how they manifest in patient registries. Only then can we, with some confidence, measure PJDs quantitatively, find the most common PJD types and identify at-risk patient groups. It is, of course, important to note that not all PJDs can be reliably identified from patient registries.

5.3 Design of interventions
After PJDs have been identified, they can be classified into managerially relevant groups. Classification by source (communications, technology, etc.) allows for proper interventions. Classifying PJDs by actors (patient, caregiver and organization) allows for interventions to be properly targeted. Finally, classifying PJDs based on outcomes (health and resources) allows prioritization of interventions based on their impact.

Our conceptualization of PJDs also gives rise to many interesting future research avenues. How do the most common PJDs affect the relevant treatment outcomes and costs? – are there significant differences in patient journeys with no disruptions when compared to those where disruptions occur? By finding answers to such research questions, we believe great advances could be made in the management of patient journeys and the construction of patient pathways to further integrate and coordinate patients’ treatment and consequently reduce costs and improve treatment outcomes.

6. Conclusions
We contribute to the stream of research relating to managerial challenges in patient process management by introducing and defining the concept of PJD. While these kinds of managerial challenges have been studied under many different names, there has been a lack of a common definition to allow for adequate comparison and context transfers. By utilizing a common definition in the study of PJDs, HOM scholars can better draw from previous studies and relate their contribution to existing knowledge. We also present initial empirical findings of what PJDs look like in the context of home care services to highlight the usefulness of the new concept.

We argue that the PJD conceptualization has the potential to improve the understanding of health service production. We believe that it provides a new, systematic way of approaching the different shortcomings in our healthcare production systems. We also provide an example of a qualitative analysis with a small sample from a narrow context to highlight how our concept would manifest in patient processes. The generalizability and transferability of these findings to new contexts remain to be seen, and future research should address new contexts as well. While we believe our conceptualization of PJDs to be coherent and useful, its actual applicability in practice and research will be defined by those conducting research on the topic in the future. Concepts are assessed not by whether they are true or false, but whether they are useful or not. The usefulness of our proposed concept is to be evaluated within this future research.
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MV: conceptualization, methodology (conceptual analysis), formal analysis (conceptual analysis), investigation (conceptual analysis), writing – original draft, review and editing and visualization. IS: methodology (interviews), formal analysis (interviews), investigation (interviews) and writing – review and editing. AB: conceptualization and writing - original draft, review and editing. PT: conceptualization and writing – review, editing and supervision. PL: conceptualization, methodology (conceptual analysis) and writing - original draft, review and editing, supervision and funding acquisition.

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