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Yours sincerely, doctor X

An ethical reflection on employing patient-directed discharge letters in hospital care

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Summary

Patient-directed discharge letters (PDL) are letters sent to patients after hospital care. They are adjusted to patient needs in terms of language use and letter content. Their use is increasingly recommended and used in hospital care. Empirical research indicates their potential for improving care, HCP-patient relationships, and patient self-management. Yet, the ethical dimension of using has not been explored before. This thesis explores whether it is morally justified to use PDL, and if so, under what conditions. It employs the Normative Empirical Reflective Equilibrium as a method for moral reasoning. In this model, morally relevant facts, moral intuitions, ethical principles and background theories relevant for the use of PDL are considered. The analysis highlighted that negligent employment of PDL can risk reinforcing epistemic injustices or increasing health disparities. To avoid this, the use of PDL is justified under certain conditions. Based on these conditions, this ethical reflection concludes with a practical recommendation for just employment of PDL in hospital care, and an example PDL that meets these conditions.

Key words: patient-directed discharge letter, discharge communication, person-centred care, epistemic injustice, health literacy

Abbreviations

GP	General practitioner
HCP	Healthcare professional
NE-RE	Normative Empirical Reflective Equilibrium
NL	The Netherlands; Dutch
PCC	Person-centred care
PDL	Patient-directed discharge letters
RE	Reflective equilibrium
UK	United Kingdom
SES	Socio-economic status
WHO	World Health Organization

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Introduction

"After ten minutes, my mother and I walked out of the hospital, and my mother said: "Alzheimer's disease? No, that's not about me. What did she say again?" [1]

Falling ill can be an overwhelming and life-changing experience. It is the fundamental purpose of healthcare to support patients[2] in reshaping life under new conditions. Unfortunately, the introductory quote exemplifies that this does not always occur successfully. Patients submerge in an abundance of information: 40-80% of medical information discussed in clinical encounters is forgotten immediately.[3] In line with broader societal trends, patients are increasingly asked and expected to self-govern in the domain of health and disease; a landscape that is becoming more and more complex in itself.[4] Moreover, as diagnoses, medication regimens, and treatment plans often change in the course of hospital care, good information transferal is crucial in the complex and error-prone process of care transitions from secondary to primary care settings.[5] Research has shown that inadequate discharge planning can have serious consequences, such as adverse events, readmissions, and death.[6] Despite this awareness, discharge communication shows shortcomings and research has only been partially effective at improving this.[7] Consider this against the background of an ageing population with a climbing incidence of multimorbidity and chronic illnesses in western societies, in combination with an urge for shorter hospital stays and longer home-based follow-up of care.[8] The need for adequate discharge processes that involving patients and supporting to (re)gain control over their life after being struck by illness is evident.

In response to growing appeals to self-management, initiatives facilitating patient participation and patient empowerment emerge. They are embedded within broader tendency towards

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[1] This quote was taken from a patient interview conducted as part of a qualitative study on the value of patient-directed discharge letters (Maats 2021).

[2] I am aware that using the term "patient" is contested for – among other things - disempowering and passivizing connotations, and that alternatives exist (e.g. health consumer, client, care recipient) (Christmas and Sweeney 2016). I nonetheless adhere to the terminology throughout this thesis for purposes of clarity and to be consistent with biomedical and bioethical literature. Moreover, it is argued that the term "patient" best describes the situation of increased dependency when falling ill, and that patients prefer to be called this way. See Petit-Steeghs (2019, 18).

[3] Khaleel et al. (2020); Liu and Kuang (2016); Van der Meulen et al. (2008); Kessels (2003).

[4] Haker, Hosper, Van Loenen (2019); FNO (2021).

[5] Weetman et al. (2019a); Buurman et al. (2016); Hesselink et al. (2012); Shepperd et al. (2010).

[6] Buurman et al. (2016); Hesselink et al. (2012).

[7] Weetman et al. (2020); IGZJ (2015); Buurman et al. (2016).

[8] Weetman et al. (2019b); Harris et al. (2018); Buurman et al. (2016); Hesselink et al. (2012).

person-centred care (PCC) approaches in western healthcare.[9] It is increasingly acknowledged that recognizing ‘the person behind the patient’ is not only desirable for purposes of efficiency or patient wellbeing. More fundamentally, it is considered a basic patient right in a fair and equitable healthcare system.[10] An intervention that can potentially smoothen discharge procedures in a person-centred manner is the use of patient-directed discharge letters (PDL).

Medical discharge letters are historically used for purposes of interprofessional communication and documentation. Recently, there is rising interest in sending discharge letters to patients too.[11] Several terms are used for indicating this practice (e.g. patient letter, copy, summary, personalised letter); all refer to patients receiving some form of written information about received hospital care. Throughout this thesis, I adhere to the following definitions:

- **Traditional discharge letter**: a letter or written summary following inpatient or outpatient hospital care, in medical terminology, sent between healthcare professionals (HCPs) for the purpose of interprofessional communication or medical documentation.
- **Copy letter**: a traditional discharge letter with the patient copied in.
- **Patient-directed discharge letter:** a letter or written summary following inpatient or outpatient hospital care that is provided to patients and adjusted to their needs in terms of language use and letter content.

It is indicated that PDL can improve care, HCP-patient relationships, and patients’ self-management.[12] These insights have led to the establishment of professional guidelines recommending the use of PDL in the Netherlands (NL) and the United Kingdom (UK).[13]

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[9] Petit-Steeghs (2019).

[10] Jotkowitz and Porath (2007).

[11] Weetman et al. (2020, 2019a, 2019b); Harris et al. (2018); Buurman et al. (2016).

[12] Lindhardt et al. (2020); Weetman et al. (2020a, 2020b, 2019a, 2019b); Buurman et al. (2016); Lin et al. (2014).

[13] The Academy of Medical Royal Colleges (2018); Van Seben et al. (2017).

Thesis

Despite its recommended use in practice, academic literature on ethical aspects of using PDL is scarce. Although much of the empirical literature implicitly considers ethical issues related[14], there is - to the best of my knowledge - no academic literature that explicitly reflects on the morality of using PDL. It is plausible that ethical evaluation is obscured for the apparent positive effects of using PDL – it is indeed convincingly argued that they enhance quality of care and patient wellbeing, and that patients show a general preference for receiving them.[15] Upon common-sense consideration of these insights, their use is justified rather unproblematically. Moreover, disputes about whether the positives outweigh the negatives are for the most part empirical in nature. Granting that, I will hold that using PDL is at least *prima facie* morally justified. Closer consideration does however raise morally relevant questions. First, there is a risk of increasing health disparities if PDL are only accessible by, useful to, or effective for certain patient groups. Second, there are epistemic concerns: it is argued that interventions aimed at patient participation carry a risk of reinforcing existing power hierarchies, rather than truly empowering patients.[16] Translating this to PDL reflects the worry that they merely learn patients to 'think and talk' like doctors, rather than supporting them to share their own experiences in decision-making practices. If so, the use of PDL may have a disciplinary instead of empowering effect.

These worries indicate that, although the empirical evidence regarding PDL is promising, this is not to say that the practice should not be open to scrutiny at all. With the ethical side of the medal unexplored, it cannot satisfactorily be determined whether or how the use of PDL is morally justified apart from in the prima facie case. This thesis contributes to overcoming this knowledge gap by exploring the ethical dimensions of PDL. This analysis will be guided by the following question:

Is it morally justified to use patient-directed discharge letters, and if so, under what conditions?

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[14] E.g. referring to "weigh[ing] the benefits (…) against the drawbacks" (Weetman et al. 2019a, 7), or considerations of how patient autonomy is affected (Weetman et al. 2019a).

[15] Maats (2021); Weetman et al. (2020 adult; 2019); Buurman et al. (2016).

[16] Thomas et al. (2020); Kidd and Carel (2018); Carel and Kidd (2014).

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To answer this question, I will address the following sub-questions:

- To what extent does employing PDL pose a risk of reinforcing epistemic injustices in healthcare and how can this risk be minimalized?
- To what extent does employing PDL pose a risk of increasing health disparities and how can this risk be minimalized?

Methodology

This thesis is part of an inter- and multidisciplinary evaluation of using PDL in hospital care. Interdisciplinarity is integrative to me as an academic student. Being in the final stages of both the Medicine and Applied Ethics Master's programmes allows me to combine practical experiences as a medical intern with theoretical background gained from studying (bio)ethics. This dual role facilitated a multidisciplinary examination of the question of how PDL are best employed in practice. As part of a medical research internship at the University Medical Center Utrecht, I conducted a qualitative interview study on the value of PDL. The empirical insights gained in this study contribute to biomedical literature. Furthermore, they inform the normative analysis laid out in this thesis.[17] Additional to the empirical literature on PDL, which speaks to biomedical, psychological, sociological, and nursing debates, I draw on multiple sources in this thesis. I employ concepts from epistemology and political philosophy in addition to common approaches in bioethics and considerations of the fundaments of health and illness rooted in the philosophy of medicine. Furthermore, as this thesis is the final exercise of the *Applied* Ethics Master's, its ultimate purpose is to use academic insights for developing a practically useful recommendation for using PDL. Taking these various perspectives enriches the ethical analysis, yet it also calls for a rigorous method to structure the reasoning process. I find the Normative Empirical Reflective Equilibrium (NE-RE) as developed by Van Delden and van Thiel (1998) to provide this method.

The RE as a method for moral reasoning

The NE-RE is based on political philosopher John Rawls' Reflective Equilibrium (RE) that he employed for evaluating principles of justice. The evaluation in his RE consists in comparing the formulated principles to *considered judgments*. Such considered moral judgments are a person's initial beliefs arising from a basic human sense of justice.[18] Candidate principles of justice must cohere with considered moral judgments in the RE. Acceptable coherence is reached if they are consistent and mutually supporting or explaining.[19] If they are not, the agent performing the reflective exercise ought to adjust the elements until coherence is reached.[20] A key characteristic of the RE is its dynamic nature; going back and forth between different types

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[17] A full description of this study and the results can be found in the appendix.

[18] Rawls (1999, 42; as cited from De Maagt 2017).

[19] Daniels (2016).

[20] Daniels (1979).

of beliefs[21], testing and adjusting them until coherence is reached. None of the elements is fixed, and, if needed, new beliefs can be added to the matrix to reach coherence. This continuous process of revision contrasts foundationalist approaches to ethics, which claim that some subsets of moral beliefs are so self-evident that they are directly justified. (source)

Rawls' RE was advanced and adjusted by several authors, and its applicability extends far beyond formulating principles of justice in political philosophy. It is employed in practical ethics for both structuring the reasoning process to arrive at moral judgments, as well as justifying them based on coherence between the different elements of the RE.[22] Due to the weight attributed to considered moral judgments, the RE is prey to critiques of subjectivism. In response, suggestions are made to increase its accountability. Daniels (1979) proposed to widen the RE by incorporating background theories as well. Its normative force was further strengthened by Van Delden and Van Thiel (1998), who suggested to add empirical elements and incorporate moral intuitions of agents other than the agent performing the deliberative exercise.

The NE-RE, its elements, and justifying its use in this project

The use of empirical data in bioethics is extensively debated.[23] An important worry is that using insights with descriptive nature for drawing normative conclusions falsely implies that *is* coincides with *ought* – a problem known as the is-ought gap, or Hume's law.[24] In response, it is argued that Hume's law need not imply that we must reject the use of empirical research in ethics altogether. Rather, it should be considered how empirical data can be used validly in moral deliberation and decision-making. Van Thiel (2009) suggests that empirical research can be relevant to bioethics in three ways: 1) it can provide factual information about states of affairs, 2) it can obtain information in light of a normative research question, 3) it can gather moral intuitions of groups of persons.[25] The use of the "factual information" terminology gives rise to other concerns. Within the biomedical paradigm, it is common to distinguish 'objective' evidence from subjective experiences. Moreover, the objective is generally *prioritized* over the subjective, as illustrated by the strong reliance on evidence-based medicine in western

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[21] As cited from Van Thiel, the beliefs are different in level of "generality and reflection". (2009, 5)

[22] Daniels (2016)

[23] Molewijk and Frith (2009); Miller and Wendler (2006); Sugarman (2004); Alvarez (2001).

[24] Van Thiel (2009).

[25] Van Thiel (2009, 6-8)

medicine.[26] Yet, from perspectives of the philosophy of science, the mere use of the term *facts* is contested. Although I will adhere to the terminology as proposed by Van Delden and Van Thiel (1998), using the heading 'morally relevant facts' for addressing empirically gathered information serving as input for the NE-RE, I do not hold that such things as objective truths exist. In contrast, I argue for a higher appraisal of subjective experiences in healthcare throughout this thesis. Moreover, as much of the empirical literature on PDL consists of qualitative studies, the empirically gathered information partly reflects subjective experiences too, highlighting the arbitrariness of the objective/subjective distinction. Experiences with and opinions about PDL are interdependent, overlapping, and mutually reinforcing in practice. Nonetheless, I choose this terminology because it captures the descriptive nature of the methods used for gathering the information addressed. Although the distinction between facts and intuitions remains artificial, it is my aspiration that adhering to it will help structuring the reasoning process of the NE-RE.

To increase the reliability of the reasoning process, Van Delden and Van Thiel propose to include moral intuitions of agents other than "the thinker".[27] It is long contested what role moral intuitions have in ethical reasoning. There is the Kantian view of morality on the one hand, considering agents to be purely rational beings arriving at moral judgements through deliberate reasoning from free will. This free will, that is at the basis of human reason, is independent from external influences. In this view, there is no place for emotions, social forces, or intuitions, in moral deliberation.[28] On the other hand, there are insights from moral psychology suggesting that human moral agency is highly affected by emotionally charged, automatic moral intuitions. Haidt (2001), for instance, argues that we are motivated to rationalize our intuitions rather than critically assessing them. This has invited critiques on the reliability of human moral judgment altogether. If our thinking about moral issues is based on unconscious 'gut reactions', which we are likely to defend as advocates rather than to assess them like judges, why is there such a thing as moral reasoning at all? I take a stance somewhere in the middle between Kant and Haidt, for four reasons. First, Paxton, Ungar and Greene (2012) argue that, even though the validity of moral reasoning is often overestimated, it is not completely powerless either. They show that if people have good arguments and enough time to reflect on them, they can weaken or abolish unjustified moral intuitions. Second, it is possible to identify common-sense moral

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[26] Michaels (2020).

[27] Van Thiel (2009, 63).

[28] Johnson (2016).

principles (i.e. do no harm, respect the freedom of others) about which consensus generally exists. It suggests that there are at least some moral intuitions that reflect a generally shared understanding about what is morally justified or not. Beauchamp and Childress substantiate this, grounding their four-principle approach to bioethics on the concept of *common morality:* "norms about right and wrong human conduct that are so widely shared that they form a stable social compact." (2012, 3-4) Third, if much of our moral conduct is based on intuitive reactions, explicating such intuitions is the first step towards analysing their fundamental ground – regardless of whether they are justified or not. Rejecting moral intuitions altogether would be like throwing the baby out with the bathwater. Instead, being aware of internal and external influences enables us to critically challenge our initial moral intuitions in order to arrive at moral conclusions. Fourth, acknowledging the fallibility of moral intuitions is one of the core elements of the (NE-)RE. It is for this reason that Van Delden and Van Thiel propose to include initial beliefs of other agents too, increasing the diversity of moral 'gut reactions' represented in the NE-RE and thereby enriching the reasoning process. This gives rise to the question: whose moral intuitions should be collected and included in the RE in the first place? Most ethicists hold the view that theory and practice should, and do, "mutually influence each other in the process of searching for reliable moral judgment and theories."[29] Based on accounts of moral wisdom and its achievement through formative experiences and learning from practice, Van Thiel argues that "moral wisdom is in part dependent on – and can vary with – experience."[30] Therefore, she suggests including moral intuitions in the NE-RE in the form of moral wisdom expert-knowledge from people moving in a certain moral practice. It is important to note here that these expert intuitions, nor any other element in the NE-RE, do not have priority over other elements in the reasoning process.

The resulting NE-RE thus allows for integration of multiple morally relevant sources: empirical facts about the practice under evaluation, moral wisdom, ethical principles, and background theories.[31] As the vast body of literature on PDL consists of empirical studies investigating their effects in practice, using the NE-RE allows for integrating these insights with theoretical considerations. This empirical literature is relevant to the normative question guiding this thesis mainly in the first sense formulated by Van Thiel (2009): it provides facts about states of affairs regarding PDL. Some studies, however, gathered stakeholder perspectives on the use of PDL,

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[29] Van Thiel (2009, 62).
[30] Van Thiel (2009, 63).
[31] Van Thiel (2009).

including my own qualitative interview study. These provide insight into moral wisdom of those involved in the practice of using PDL (e.g. patients, family, HCPs). It is precisely for this reason that the NE-RE is appealing for my purpose of performing an interdisciplinary analysis of the multidimensional practice of using PDL. It enables collecting, structuring, evaluating, and balancing morally relevant insights from different angles and on different levels of abstraction, to ultimately reach moral judgment on whether and under what conditions it is justified to use PDL.

This approach is not uncontested (nor is any other approach to moral reasoning in bioethics for that matter). The debate on methodology in this field is as lively as it is long-standing.[32] Providing a thorough justification for taking this path requires delving into this debate, which falls outside the scope of this thesis. I defend using the NE-RE - admittedly, rather concisely[33] - by pointing out that it is exactly the purpose of overcoming this problem of method and justification that the NE-RE serves as an advancement of Rawls' RE. Moreover, the quality of both the elements of the NE-RE as well as the reasoning process itself are increased in multiple ways as compared to the RE: Rawls already includes only *considered* judgments - not just any ad hoc thought about morality, but initial moral judgments that are formed under certain conditions making them *considered*. The NE-RE takes this further by including not just any moral intuition, but *moral wisdom* of experienced agents. In this thesis, several stakeholder perspectives are added to the matrix, representing a diversity of views that stem from practical experience with discharge procedures and PDL. Furthermore, they are substantiated with morally relevant facts from empirical research. Subsequently, they are examined from the perspectives of different ethical principles and in light of broader background theories. It is granted that the morally relevant facts and moral intuitions taken as starting points are undeniably value-laden, and the reasoning process itself is affected by personal characteristics of the agent employing the NE-RE – in this case, me. Yet, as Van Thiel points out, the reliability of the outcome of moral deliberations depends on the quality of the arguments provided when reasoning towards coherence, rather than the objectivity of the elements at the start. [34]

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[32] See, for instance, Beauchamp and Childress (2012, 390-424).

[33] For a more elaborate discussion of the justification and reliability of the (NE-)RE, I refer to Van Thiel (2009, 67-82) and Beauchamp and Childress (2012, 390-424).

[34] Van Thiel (2009, 71-73).

Scope

This thesis focuses on PDL following adult hospital care in the Netherlands. I only consider adult patients as communication with people under 18 years involves distinctive considerations, such as matters of competence and parental responsibility. Exploring the ethical dimensions of sending PDL to persons under the age of 18 years deserves a separate analysis from the one performed in this thesis. Furthermore, this thesis applies to all patients discharged from hospital care, regardless of the nature of this care. Patients deserve to be properly informed about every clinical encounter, however ‘minor’ or ‘short-term’ the health issue may be. Every diagnosis, treatment, or medical test can sweep people off their feet regardless of its nature. Categorizations in terms of chronic versus acute illnesses, inpatient versus outpatient care, or based on specific disciplines would disregard this and therefore feel arbitrary. All care is rooted in the same fundament of western medicine, with the same values and ideologies underlying clinical encounters. I take that the normative dimension of using PDL is not affected by practical varieties to the extent that it requires a separate ethical analysis. Finally, much of the empirical literature on PDL employs the terminology “patient-directed discharge letters” to represent both inpatient and outpatient discharge letters, providing a pragmatic argument for considering them conjointly in this thesis too. Therefore, while acknowledging that undeniable differences between clinical encounters exist, I will consider hospital care at broad. Finally, I presume that PCC is morally desirable throughout this thesis, but given its fundamental role in this analysis I further elaborate on its theoretical framework and justification in section 2.2.1.

Outline

After this introductory section presenting the main purpose, research question, and methodology of this thesis, Chapter 1 addresses morally relevant facts and moral intuitions drawn from the empirical literature on PDL. In Chapter 2, I confront these insights with ethical principles and background theories. In Chapter 3, I work towards finding coherence among these elements to provide an ethical account of using PDL. I conclude with a recommendation for their employment in practice.

Chapter 1: Insights from empirical literature

In this chapter, I address empirical literature on PDL and health literacy. The information presented is morally relevant in four regards. First, it provides insight in the positive and negative effects of PDL, both of which are relevant to this moral inquiry as it provides grounds for balancing benefits and burdens. Second, employment of PDL is justified in the literature on different grounds. Elucidating these justificatory pathways taken to defend the use of PDL helps identify morally relevant considerations other than consequentialist arguments focusing on benefits and burdens. Third, as one of the moral concerns raised about PDL is their risk of increasing health disparities due to limited accessibility, I address empirical insights about the concept of health literacy – i.e. the skills needed to be capable of managing your own health and care – in section 1.1.2. Fourth, some empirical studies provide insight into stakeholder preferences regarding the use of PDL. This information is relevant in the first regard just described, but it also provides insight into moral intuitions of experienced agents. I address these insights separately, in section 1.2.

1.1. Morally relevant facts

1.1.1. Empirical research into PDL

For two decades, it was recognized that copy letters could promote patient wellbeing[35], and recent studies into the effects of PDL support this.[36] Positive and negative effects are described, see Table 1. They are shown to positively affect patient outcomes, outcomes related to patient relatives and family involvement, HCP communication and work satisfaction, HCP-patient relationships, and organisational aspects of care. Nonetheless, PDL are only limitedly used in practice, and do not meet quality requirements.[37] The main barrier for using PDL is the fear of adverse effects (mainly negative patient outcomes and higher workload) among HCPs. Especially in case of bad news or sensitive topics, HCPs have reservations.[38] However, actual adverse effects occur only minimally.[39] Furthermore, patients do not object against confrontation with sensitive topics as long as it is relevant to the clinical encounter.[40] Moreover,

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[35] Harris et al. (2018); Baxter et al. (2008); Roberts and Partridge (2006); Nielsen et al. (1994).

[36] Maats (2021); Lindhart et al. (2020); Weetman et al. (2019a, 2019b); Buurman et al. (2016); Lin et al. (2014).

[37] Weetman et al. (2019a).

[38] Maats (2021), Weetman et al. (2019).

[39] Weetman et al. (2019a).

[40] Weetman et al. (2019a).

using PDL shows benefits particularly in bad news settings. It helps patients recall information, provides a sense of control, helps them process the news and feel comforted, and clarifies what to expect from the future.[41]

Table 1. Positive and negative effects of using PDL

Positive effects[42]

On patients:
- Increased understanding.
- Higher satisfaction.
- Reduced anxiety.
- Increased autonomy.
- Reinforcement of self-management abilities.
- Better preparation for discharge (mentally, practically).
- Improved treatment compliance.
- Improved decision-making capacities.
- More involvement in decision-making.
- Feeling seen and acknowledged.

On patient relatives or family:
- Increased understanding.
- Adequate transferral of care management.
- Better preparation for patient discharge (mentally, practically).

On HCP-patient relationships:
- More open relationships.
- Better communication.
- Strengthening mutual trust.

On HCPs and colleagues:
- Higher work satisfaction.
- Better communication with primary care settings, clearer task divisions.

On organisational aspects of care:
- Increased quality of medical records and discharge letters.
- Less unnecessary or avoidable re-admissions.
- More efficient organisation of outpatient consultations.

Negative effects[43]

Arousal of negative patient emotions, or increased patient harm, due to:
- Unwanted confrontation with sensitive topics.
- Overburdening with medical information they cannot process or comprehend.
- Letter inaccuracies.
- Unexpected receival of PDL.
- Feeling undermined when addressed with in plain language.
- Confidentiality breaches.
- Poor accessibility (e.g. due to language barriers or low literacy)

On HCPs and/or organisational aspects of care:
- Higher workload.
- Confusion among other HCPs when expecting traditional discharge letter.
- Misalignment of GPs' and patients' informational needs.

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[41] Damian and Tattersall (1991).

[42] Maats (2021); Lindhart et al. (2020); Weetman et al. (2019a, 2019b); Buurman et al. (2016); Lin et al. (2014).

[43] Maats (2021); Weetman et al. (2020b, 2019a, 2019b); Harris et al. (2018); Boaden and Harris (2005).

Additional to anticipating adverse effects, other barriers for the limited use of PDL were described. See Table 2 for facilitators and barriers for implementation.

Table 2. Facilitators and barriers for implementation of PDL

Facilitators	**Barriers**[44]
• Positive effects as described in Table 1. • Recommended use in UK and NL guidelines.[45] • General patient and HCP preference for working with them.[46]	• Anticipation of adverse effects (negative patient outcomes, higher workload, resource consumption). • Practical obstacles (limited time available, differences between types of consultation and medical departments) • Conservatist views and hierarchical structures among HCPs. • Lack of internationally consistent policy.

Patients and HCPs working with PDL are generally in favour of their use.[47] Their preferences regarding letter content differ; patients wish to receive future-oriented, practical advice, whereas traditional letters are past-oriented for documentational purposes.[48] It was found that letter content, combined with the way in which they are employed, letter content, and the setting in which they are embedded strongly affect the potential for facilitating patient participation. For instance, higher levels of patient involvement were observed when PDL were used to structure discharge conversations, with HCP and patient going through the letter together, as compared to cases in which PDL were drawn up and sent to patients after consultation.[49]

Moral considerations related to using PDL are addressed to some extent in the literature, yet often implicitly or shallowly (its absence is, indeed, what inspired this thesis). Generally, three arguments for (recommending) the use of PDL are provided. First, their potential for increasing quality of care is considered to outweigh the risk of adverse effects. Negative outcomes reported are more often anticipated than actually happening, or they are a result of suboptimal

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[44] Maats (2021); Weetman et al. (2020b, 2019a); Buurman et al. (2016).

[45] UK Department of Health (2003); Ministerie van VWS (2017).

[46] Maats (2021); Weetman et al. (2020a)

[47] Maats (2021); Weetman et al. (2020a, 2020b, 2019 review)

[48] Maats (2021).

[49] Maats (2021).

employment.[50] Second, involving patients in care, starting with adequately informing them about their health status and corresponding options, increases legitimacy and accountability of medical decision-making.[51] Third, as patients are subjects of medical care, properly informing them is considered a patient right, and so, the right thing to do.[52] It fits within a broader context of PCC; an ideology that is increasingly adopted in western healthcare services – I further elaborate on this approach in section 2.2.1.

1.1.2. Health literacy

As the landscape of healthcare is becoming increasingly complex, adequate levels of responsibility, independence, and participation are required of patients to navigate it.[53] Not everyone is equally capable of taking on this active role: despite high rankings in European lists of healthcare quality, health inequalities in the Netherlands are growing.[54] People with lower socio-economic status (SES) have a shorter life span of six years, dealing with health issues 15 years earlier.[55] It is acknowledged that health is determined for the greatest part by factors that fall outside the individual sphere: SES, living- and working conditions, and social context greatly affect individuals' health.[56] Social differences in these domains lead to health disparities that are ethically indefensible. They are caused by factors that individuals cannot control, and are constituted and reinforced through broader and complex social injustices.[57] Therefore, an interest emerged in identifying factors that affect individuals' ability to achieve good health.

A growing body of empirical studies suggests that *health literacy* plays a key role here. Differences in health literacy levels contribute to growing health disparities.[58] Many competing conceptualizations of health literacy exist, but most definitions share "a focus on individual skills to obtain, process and understand health information and services necessary to make appropriate health decisions."[59] Health literacy involves three types of skills: functional (e.g. reading and writing), communicative (e.g. understanding written information, abstraction,

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[50] Weetman et al. (2019a); Harris et al. (2018).

[51] Petit-Steeghs (2019); Gordon (2005).

[52] Weetman et al. (2019a); Van den Bovenkamp and Trappenburg (2009).

[53] Rademakers (2014); WRR (2017); FNO (2020).

[54] Poll (2021); Bussemakers (2020).

[55] Poll (2021).

[56] Dahlgren and Whitehead (1991).

[57] Bussemakers et al. (2020); FNO (2020); Wetenschappelijke Raad voor het Regeringsbeleid (2017).

[58] Rademakers (2014); Haker (2019); Bussemakers et al. (2020); Wetenschappelijke Raad voor het Regeringsbeleid (2018).

[59] Sørensen et al. (2012, 3).

reflection), and critical skills (e.g. applying information, prioritizing, organizing).[60] It is demonstrated that health literacy is directly related to poor health outcomes: it leads to significantly higher risks of severe medication errors and chronic diseases, and reduced life expectancies. Consequently, people with limited health literacy use nearly double the amount of medication and consume more healthcare, whilst also experiencing less quality of received care.[61] Health literacy is found to be a stronger predictor of health status than age, income, profession, educational degree, or cultural background.[62] Therefore, the WHO considers health literacy a central determinant in health inequalities.[63]

It was repeatedly shown that about 30% of the Dutch population has inadequate health literacy.[64] Scientific councils acknowledge that Dutch governmental policies have failed to diminish health disparities in the past decade.[65] It appears that most strategies have only reached or been effective to people with adequate health literacy. Herewith, many interventions aimed at improving health contributed to increasing rather than decreasing health disparities. It is now acknowledged that more comprehensive, multidimensional approaches are necessary for overcoming this gap.[66] As PDL can increase patient understanding and self-management – which are capacities required for adequate health literacy - it is hypothesized that they can increase health literacy.[67] The causal link between PDL and health literacy is however not extensively studied.[68] Moreover, virtually all research into PDL focuses on non-diverse patient groups, excluding people with limited health literacy from study participation.[69]

1.2. Moral intuitions

Having derived morally relevant facts from the empirical literature, I now turn to identifying moral intuitions. It starts with deciding whose moral intuitions to include in the first place. Based on Van Thiel's argument for the relevance of moral wisdom, I use empirical studies

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[60] Nutbeam (1998, 2000).
[61] Heijmans, Brabers and Rademakers (2018); Bostock and Steptoe (2012); Berkman et al. (2011); Paasche-Orlow et al. (2005); Volandes and Paasche-Orlow (2007).
[62] Ad Hoc Committee AMA (1999).
[63] WHO (2013).
[64] Heijmans, Brabers and Rademakers (2018); Sorensen et al. (2020, 2012).
[65] Bussemakers et al. (2020); Wetenschappelijke Raad voor het Regeringsbeleid (2018); FNO (2020).
[66] Bussemakers et al. (2020); Wetenschappelijke Raad voor het Regeringsbeleid (2018); FNO (2020).
[67] Maats (2021).
[68] Maats (2021).
[69] Weetman et al. (2020a, 2019a); Harris et al. (2018); Buurman et al. (2016).

exploring stakeholder opinions about PDL for gathering moral intuitions for the NE-RE.[70] As the people who participated in these studies have experience with discharge communication[71], their moral intuitions about what discharge communication should or should not entail is based on expert-knowledge. I consider their opinions to form moral wisdom about the practice that is under evaluation.[72]

Stakeholders (i.e. patients, patient relatives, hospital workers, general practitioners (GP), experts in the field of (health) literacy) in all studies considered show a general preference for using copy letters or PDL. Reasons mentioned cohere with empirically established benefits:

- Potential to inform, involve, and empower patients.
- Potential to improve health literacy.
- Respecting the right to medical information and patient autonomy.
- Improving HCP-patient relationships.
- Supporting PCC.
- Increased HCP work satisfaction.
- Increased efficiency of consultation hours.
- Increasing involvement of family and relatives, increasing their abilities for care management in home settings.

People with limited health literacy similarly supported the use of PDL. Using an accessible letter format as the default, including short sentences, plain language, blank lines, pictograms, and so on, would support interpretation and increase their autonomy.[73] Moreover, they indicated that, even when being unable to (fully) read or comprehend the letters themselves, receiving them would still enhance their ability to become informed and expand their options to act. They are usually dependent on family or relatives for interpreting health information and receiving a PDL would facilitate this similarly to helping patients to interpret health information.[74]

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[70] Maats (2021); Weetman et al. (2020a, 2020b, 2019 review); Harris et al. (2018); Fenton et al. (2017); Lin et a. (2014); Baxter et al. (2008); Singh, Budeda and Housden (2007); O'Driscol et al. (2003).

[71] In my study, for instance, having experience with discharge procedures was one of the inclusion criteria. (Maats 2021)

[72] The information displayed here partly overlaps with what is discussed under moral intuitions. As I draw moral intuitions from qualitative interview studies, which also form the vast body of empirical literature on PDL, this overlap is inherent in this approach. I choose to arrange it this way to respect the basic structure of the NE-RE, and in an attempt to distinguish stakeholder experiences about what PDL actually *do* in practice, from their opinions on how they *should* be employed. Nonetheless, I admit the ambiguity in this distinction.

[73] Maats (2021).

[74] Maats (2021).

Some stakeholders indicate that PDL can transfer responsibilities for self-management from HCPs to patients, which was interpreted as a good thing by some and as problematic by others.[75] It was considered problematic when patients are unwilling or uncapable of taking on this responsibility. In one study, patients favoured receiving a copy letter over a "personalised" letter (62% versus 14%), the latter being experienced negatively more often by participants.[76] Reasons for this described were transparency[77], pragmatism[78], and proportionality[79]. Some patients do not see the need of receiving either copy letters or PDL. For this reason, the importance of providing patients a choice on receiving PDL was emphasized.[80]

Although all stakeholders were generally in favour of using PDL, there was broad consensus that they should meet certain conditions to be successful and prevent harms[81], including:

- Do not sent unannounced or when unwanted.
- Combine letter with verbal information.
- Verify patient details before sending.
- Avoid using value judgments.
- Formulate potentially confrontational information carefully.
- Letter content must be clear, accessible, and relevant.

It was generally supported that PDL must be accessible to all patients for their use to be morally justified. Different ideas were shared on how to deal with this. The moral importance of making an accessible format the default was stressed by some participants, yet others pointed out difficulties in accounting for patient diversity and clinical encounters when employing a universal format. Some participants expressed the concern of undermining or offending people with adequate health literacy when using PDL in plain language as the default. Yet, securing accessibility by using a limited health literacy format as default was generally preferred over accounting for diversity on four grounds: first, HCPs are not (always) capable of recognizing patients with limited (health) literacy. Second, making it the default constitutes a form of

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[75] Maats (2021).
[76] Weetman et al. (2020a, 6).
[77] i.e. having access as a patient to the information that is shared between HCPs.
[78] i.e. both patient and HCP drawing on the same letter simplifies communication.
[79] i.e. personalised letters were considered "going too far" or copy letters considered "fine" too.
[80] Weetman et al. (2020a); Fenton et al. (2017); Baxter et al. (2008); Singh, Budeda and Housden (2007); O'Driscol et al. (2003).
[81] Maats (2021); Weetman et al. (2019a).

acknowledging the existence of patients with limited (health) literacy and respects their right to information. Third, the limited health literacy-format is still accessible, and probably also appreciated, by people with adequate health literacy, which does not hold for the vice versa situation. Finally, the burden of feeling undermined when patients with adequate health literacy receive a letter in plain language was considered relatively minor in comparison to the decreased accessibility of health information for people with limited health literacy.

Chapter 2: Confronting the empirical with the ethical

After drawing morally relevant facts and moral intuitions from the empirical literature, let us now turn to considering the normative dimension of this practice more explicitly. First, I consider the intuitions and facts from the perspectives of four biomedical ethical principles. Second, I bring two ethical frameworks into the NE-RE that serve as background theory. I address the implications of considering the use of PDL within these frameworks of principles and background theory.

2.1. Moral principles

As with moral intuitions, bringing ethical principles into the matrix requires reflection on what principles to select in the first place. A common approach to ethical issues in biomedicine is Beauchamp and Childress' (2012) theoretical framework of bioethical principles. It consists of the principles of respecting autonomy, beneficence, nonmaleficence, and justice. Their role in bioethics is to serve as "mid-level" mediators between high-level ethical theory and practice-based moral intuitions.[82] As approach to ethical issues in medical practice is widely known and employed, the four principles form a natural starting point for our ethical deliberation using the NE-RE. One could arguably take alternative principles as a starting point. While acknowledging this, I justify starting with these principles simply because it is the most influential and commonly used moral framework for ethical reflection in medical practice. As reflected by the moral intuitions, people involved in the field of healthcare have become habituated to interpreting moral issues in terms of benefits and burdens, self-governance, and fairness – aligning with the principles of beneficence, nonmaleficence, respect for autonomy and justice. Furthermore, a framework of these four principles covers the most aspects of using PDL: their use is defended by appeals to consequentialist arguments and increased patient autonomy, and moral concerns about health disparities be interpreted from the perspective of justice. Finally, if the analysis nevertheless highlights areas that remain underexplored from these four perspectives taken, we are at liberty to add principles to the matrix – its dynamic nature is one of the key advantages of the NE-RE.

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[82] Holm (2002).

2.1.1. Respect for autonomy

The principle of respecting autonomy is strongly embedded in Western medical practice. Its importance is emphasized, and its practice formally required, by health policy, legislation, professional codes of conduct, and hospital mission statements. In healthcare, autonomy is often considered a patient right: the right to act freely. Yet, autonomy can be understood as more than a right. Feinberg (1986) provided a conceptualization of autonomy in four understandings: it can be interpreted as a *right* to autonomy, as the *capacity* to act autonomously, as an *actual condition* (i.e. possessing and exercising several virtues related to self-government), and as a *character ideal* (i.e. a combination of virtues that represents the ideal authentic individual). Virtues that are related to self-government the autonomous character ideal include, for instance, self-possession, individuality, self-determination, self-rule, authenticity, independence, integrity, self-discipline, self-trust, initiative, self-responsibility.

The principle of respecting autonomy thus requires of HCPs to treat patients as autonomous agents: as authentic individuals who have the right and capacity for self-governance based on their personal values, beliefs, or desires. They should facilitate meeting the actual condition of autonomy by supporting patients' capacity to act autonomously, for instance by providing information on treatment options to accommodate patients in figuring out what the best course of action is according to their *own* preferences. Respecting autonomy thus extends beyond the mere absence of interference with autonomous patient decisions - a negative duty. It also involves the positive duty to support patients in exercising autonomy. As rightly formulated by Beauchamp and Childress: "Such respect for autonomy involves respectful *action*, not merely a respectful *attitude.*"[83]

Morally relevant facts and moral intuitions reflect that using PDL aligns with the right to autonomy that follows from having the capacity to act autonomously. Providing PDL respects patients' right to self-governance and expands their capacity to act through being adequately informed about their options and more involved in decision-making. As reflected by the insights on health literacy, not all patients possess similar capacities for acting autonomously. Hence, they need different levels of support for reaching the actual condition of autonomy. To respect all patients' right to autonomy, HCPs must acknowledge this and account for patient diversity. If PDL misalign with patients' informational needs, for instance due to being composed in

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[83] Beauchamp and Childress (2012, 107)

medical-technical language or containing information that is less relevant to patients, they may fail in expanding patients' capacity for autonomous action, which is why they are unable to reach the actual condition of autonomy. In these instances, the right to autonomy is not satisfied. Hence, additional to the mere supply of PDL, respecting autonomy demands of HCPs to adjust letter content to patients' informational needs.

Note that having the right to autonomy does not imply that patients *must* always act autonomously: they have a similar right to refrain from acting autonomously. It is plausible that some patients prefer for their HCPs to make treatment decisions instead of having to decide this themselves. This is relevant to using PDL, as the empirical literature pointed out that not all patients are willing to receive them. Respecting this will not violate patients' capacity for nor right to autonomous action – indeed, choosing to refrain from autonomous action is an autonomous act in itself and, as long as the option to act autonomously is available to them, the right to autonomy is respected. Yet, refusing to receive a PDL does constrain patient autonomy in the sense of an actual condition and a character ideal: if patients refuse to receive PDL, they may be less informed, involved, or empowered to the extent that they are not able to meet the actual condition of acting autonomously. Moreover, choosing not to receive PDL is incoherent with acting as an ideally authentic and autonomous individual; it is incompatible with virtues as self-responsibility, independence, and initiative. There are, of course, situations in which patients do not need PDL to meet the actual condition of autonomy: when being hospitalized for an asthma exacerbation for the tenth time, receiving a PDL may not contribute that much to a patient's self-management abilities. Nonetheless, given the low recall rates of medical information clinical encounters, I take the instances in which the PDL adds absolutely nothing to patients' self-governance abilities to be a minority. Yet, granting the possibility, let us hold that patients *can* be constrained in their autonomy as an actual condition and character ideal when they refuse to receive a PDL, but that it need not always be the case. This does not imply that patients are not allowed to refuse PDL; it just highlights how patient refusal of PDL can still be in coherence with respecting autonomy as a right and a capacity, but that it is not likely that autonomy in the sense of an actual condition or character ideal are realised in such cases. When patients choose to employ their capacity for autonomous action by using PDL to get informed and involved, they also contribute to reaching the actual condition of autonomy, which makes patients more autonomous in the sense of a character ideal.

Such interpretations of autonomy are not uncontested. Scholars from communitarian, feminist, and identity politics traditions suggest that current interpretations of autonomy are aimed at an ideal of substantive independence, self-sufficiency, and individualism – which indeed align with the virtues of self-governance described earlier.[84] It is typical for Western societies that value liberty and individualism to emphasize people's ability and right to act independently. However, as those authors note, people do not function completely isolated, nor are they fully self-sufficient. Instead, humans are interconnected to and dependent on other human beings. Such concepts of interdependence and social connectedness are obscured by conceptions of autonomy that focus on individuality and self-governance. The conception of autonomy as a character ideal offers a solution here. In recognition of human's interconnectedness and the vast impact of social influences, Feinberg explicitly leaves room for community membership in his picture of the virtuous, authentic individual "whose self-determination is as complete as is consistent with the requirement that he is, of course, a member of a community."[85]

This conception of the socially situated autonomous individual is relevant to using PDL, as patients are especially dependent on others for autonomous action in medical contexts. They need HCPs to lend them access to tests and treatments, they need support from family and friends in dealing with altered life conditions, they need practical support of others in the case of physical inabilities, and so on. Their decision-making in medical contexts is often affected by their social situation. The decision to treat a hip fracture conservatively – i.e. longer recovery with pain killers and rest – or surgically – i.e. with risks of narcosis but shorter period of invalidation and revalidation – can depend heavily on one's living conditions, work situation, or partner. Care and health management do not stop when leaving a hospital – it is transferred to primary care settings, which consists for a great part of patients' social network of family, friends, and neighbours who act alongside GPs and homecare organizations. The empirical literature reflects that PDL can increase patient autonomy by involving their caretakers in discharge procedures, and they can increase autonomy of these caretakers themselves by expanding their options for managing care for patients in home settings. When writing PDL, it is important that HCPs acknowledge this and employ PDL so that they are helpful for transferring care to home settings (e.g. including information that is relevant to caretakers' ability to take care).

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[84] Christman (2004).

[85] Feinberg (1986, 45; as cited from Schermer 2002, 3).

Beneficence

Attending to the welfare of patients is both the foundation and goal of medicine.[86] The principle of beneficence puts HCPs under the moral obligation to prioritize actions that are beneficial to patients' wellbeing. For justified use of PDL, they should be beneficial to patients' wellbeing. This prompts questions about how we ought to understand patient wellbeing, for which many conceptualizations exist.[87] Without exploring these conceptualizations, as it falls outside the scope of this thesis, I propose to use a capabilities-based understanding of patient wellbeing. The capability approach is a broad framework for conceptualizing wellbeing based on individual capabilities to live a good life.[88] In this framework, wellbeing consists in the freedom to live a life that is valuable to themselves. This freedom is conceptualized in terms of capabilities*:* instead of focussing on what people feel, or have, or whether their desires are fulfilled, wellbeing is understood as having the capability to do whatever and be whoever one prefers. It requires having the opportunity to act according to one's personal values or life goals. This account is useful to this analysis for three reasons. First, the empirical literature and moral intuitions reflect that an important argument for using PDL is that it expands patients' options to act and self-manage. This focus on self-determination is captured in the capability approach. Second, being based on individual interpretations of a good life, it can account for patient diversity and counters paternalistic tendencies that lure when HCPs make treatment decisions based on their interpretations of what is best for patients. Third, as being capable to act requires removing obstacles - of any nature - for acting, it captures all dimensions of life. Economic, social, cultural, institutional, or societal hindrances to acting freely are taken into consideration on a capabilities-based account of wellbeing. As the empirical literature highlighted, health is related to many aspects of life that go beyond individual sphere, which is accounted for in this approach.

On this account, PDL can contribute to patients' wellbeing as they expand their capability set and provides the opportunity to shape health according to their individual values. Increased understanding of their condition and corresponding options provides patients the opportunity to act, or refrain from acting, based on this information. It is up to patients to handle this opportunity according to their own desire. Moreover, PDL are found to yield benefits for the

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[86] Beauchamp and Childress (2012, 202).

[87] For instance, theories that describe wellbeing in terms of meeting criteria of an objective list (e.g. good health, food security, love), or theories in which wellbeing is described by the extent to which subjective desires are fulfilled. See Bester (2020).

[88] Robeyns (2005).

people writing them, as HCPs described higher work satisfaction, more efficiency, and more person-centred work attitude because of using PDL. It seems that using PDL is coherent with the principle of beneficence. Yet, the capability approach allows for diverse and individual interpretations of wellbeing. This prevents me from drawing general conclusions about the beneficence of PDL for *all* patients. An opt-out system could be a solution here, so that all patients are offered PDL but the option to refuse remains open to them.

Nonmaleficence

The principle of nonmaleficence tells us to "abstain from causing harm to others".[89] It is often considered to go hand in hand with the principle of beneficence. Yet, important differences would get lost if they are conflated into one principle. The principle of nonmaleficence is a negative one - do not inflict harm – and beneficence a positive one – prevent harm, provide benefit. Some argue that the negative duty to do no harm is more stringent than positive duties to help others, but Beauchamp and Childress show that this is not universally true: "If in a particular case a health care provider inflicts a very minor injury – swelling from a needlestick, say- but simultaneously provides a major benefit such as lifesaving intervention, then we consider the obligation of beneficence to take priority over the obligation of nonmaleficence."[90] It shows that inflicting harm is sometimes justified, in light of the net benefit produced. Hence, understanding the concepts of beneficence and nonmaleficence in the ways described, the corresponding principles put HCPs under the moral obligation to provide net medical benefits to patients (beneficence) with minimal harm (nonmaleficence). Such acts of balancing benefits and burdens are part of common practice in healthcare. Every treatment decision is preceded by an analysis of whether (risk of) harms are proportionate to its expected benefits. Empirical insights are important here for predicting the risk of harm and the likeliness of benefits to occur.

For interpreting PDL from perspectives of the principle of nonmaleficence, we should thus establish what harms or risks are related to their use. The empirical literature provides a clear overview of the possible harms involved. They mainly involve concerns about adverse effects, such as arousing negative patient emotions, violating confidentiality, or higher workload for HCPs. Some harms are related to suboptimal employment of PDL and are preventable, for instance by announcing the use of PDL and attaching the GP letter for purposes of transparency.

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[89] Beauchamp and Childress (2012, 150).

[90] Beauchamp and Childress (2012, 151).

More interesting still, moral intuitions (of both HCPs and patients) reflect a general preference for using PDL, regardless of these anticipated adverse effects. Apparently, in daily practice, the risks or harms involved are considered proportionate to the benefit produced by those who work with them. This is supported by the empirical findings showing that adverse effects occur only minimally. Hence, based on the morally relevant facts and moral intuitions, we can establish that using PDL seems to produce net benefit. However, it is important to consider the possibility of new harms to occur when employing PDL more structurally than they are now. Negative effects related to HCP workload, resource consumption and implementation barriers can potentially lead to increased patient harms, for instance when HCPs have less time for consultation due to writing PDL. Also, new, unanticipated harms could occur. Whether this is truly the case and whether this changes the net benefit to the extent that it tips the scale towards PDL being more harmful then beneficent, can only be established through trial and error and repeating studies on larger scale. Yet, it is an unlikely scenario given that the empirical literature also consists of pilot studies, testing the structural implementation of PDL on multiple hospital wards.[91] Nonetheless granting the possibility of increased harms when implementing a hospital-wide policy of using PDL, let us hold that implementation must be accompanied by continuous evaluation of possible adverse effects or harms occurring to minimally satisfy the principle of nonmaleficence. As results of empirical inform risk/benefit assessments, it is important that the effects of PDL are monitored concurrently to its implementation. If necessary, changes to either letter format, way of employment or implementation policies can be made to reduce patient harms and increase the net benefit produced.

Justice

Justice can be interpreted as “fair, equitable, and appropriate treatment”.[92] It is intimately linked to the concept of equality, yet, just treatment entails more than equal treatment. Rather, ever since Aristotle, moral reflection on principles of justice is guided by the concept of equity - to treat equals equally, and unequals unequally.[93] Accordingly, justice in healthcare, in its most basic understanding, consists of universal access to appropriate healthcare and fair distribution of scarce resources.[94] From this perspective, limited health literacy is highly relevant to using PDL, as it forms an obstacle to equal access to care. To avoid social injustices through

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[91] Buurman et al. (2016).
[92] Beauchamp and Childress (2012, 250)
[93] Gillon (1994).
[94] Daniels (2001).

sustaining or increasing health disparities, the usefulness and accessibility of PDL for people with limited health literacy must be considered.

People with limited health literacy themselves indicated a preference for receiving PDL, and other stakeholders underscored the importance of using an accessible format as the default. In theory, a conflict of principles arises here. Employing a limited health literacy friendly-format implies writing letters in plain language, using as few and simple words as possible.[95] Consequently, important information may get lost as it is impossible to grasp detailed test results, diagnoses or treatment considerations in such formats. Although accessible, they risk being less informative, which diminishes their beneficence. Moreover, it was pointed out that people with adequate health literacy can feel undermined by receiving letters for people with limited health literacy, increasing the risk of adverse effects. Overall, the net benefit produced may be affected by this to the extent that using PDL is no longer in line with principles of beneficence and nonmaleficence. The empirical literature does not raise much suspicion of this happening in practice, but it must be noted that people with limited health literacy were excluded from participation in most studies. Moreover, the piloted PDL were not adjusted to patients' health literacy. A possible solution could be to individualize PDL for every patient, yet this is likely to become too demanding to be practically possible for HCPs without inflicting new harms, for instance due to unfair distributions of their time. Given this, combined with the foreseen difficulties of recognizing people with limited health literacy in the first place, employing a universally accessible format seems to be a better option for three reasons. First, the fear of adverse effects is only an anticipated one, which has not been confirmed in practice. It provides another argument for concurrent monitoring its effects when implementing PDL. Second, receiving a less informative PDL is still more beneficent than receiving no letter at all. Third, even if people are harmed by feeling offended, I find it reasonable to consider this a relatively minor harm that is outweighed by promoting justice for social groups that are already marginalized in the domain of health and healthcare – a considered judgment that is supported by the moral intuitions of others, as is reflected by the defended use of an accessible format of as the default regardless of the potential to undermine people with adequate health literacy in the literature.

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[95] See Maats (2021) for full description of the criteria that PDL should meet to be accessible for people with limited health literacy.

Furthermore, setting a default does not mean that individual adjustments are never possible or permissible. If HCPs know that patients show a preference for including specific details and adequate health literacy to process such information, it is of course to their freedom to include them.

I introduced the concept of epistemic injustice in the introduction of this thesis. It is a distinctive form of injustice, and concerns about its appearance in healthcare are voiced by academic scholars. Given its distinct and theoretical nature, I will dedicate a separate discussion to it in 2.2.2.

2.2. Background theory

In this section, I incorporate background theory in the NE-RE to further enrich the reasoning process. As this thesis is grounded on the general assumption that PCC is morally desirable, I first consider the fundaments of this conceptual framework to healthcare more closely and use it to develop a set of principles that should provide guidance for recommendations on justified use of PDL. Then, I turn to the framework of epistemic injustice to examine the roots of existing power-knowledge structures in healthcare and its implications for PDL.

2.2.1. Person-centred care

PCC is a conceptual model grounded on the notion of recognizing the *person behind the patient*; considering patients to be individual, authentic humans who actively participate in decision-making so that care aligns with their personal values and life goals.[96] Philosophical support for this movement runs along similar lines as the consequentialist, quality-of-decision-making, and deontological arguments offered for using PDL. I am aware that this approach to healthcare delivery is not uncontested and that rival ideologies exist.[97] It is however not the aim of this thesis to justify PCC approaches in general; this would deserve a lengthier and more in-depth critical analysis than I can offer here.[98] Nonetheless, scholars have noticed a strong tendency towards supporting PCC approaches as an alternative to disease-centred models in healthcare.[99] PCC approaches are advocated for their essential role in effective medical treatment and

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[96] Ekman et al. (2011); Castro et al. (2016).

[97] See, for instance, Arnold, Kerridge and Lipworth (2020); and Dewing (2004).

[98] I refer to the WHO (2016); De Boer (2013); Richards et al. (2013); Bleker and Crowley et al. (2000); and Coulter (1999) for such analyses.

[99] Petit-Steeghs (2019); Castro et al. (2016); Ekman et al. (2011).

empowering effects on patients. This is acknowledged by Dutch hospital boards and governmental bodies, as well as international health organizations, as is shown by the wide adoption and proclamation of person-centredness as a key element and goal for healthcare in the 21st century.[100] This ideological approach to healthcare delivery affects what conduct in healthcare is understood as morally desirable. Therefore, I wish to elaborate on the conceptual model of PCC. Explicating the concepts and norms that are at its core, clarifies what is fundamentally required of PDL, or any other intervention, to fit within a context of PCC.

The conceptual model of person-centred care

PCC takes the individual preferences and needs of patients as the central focus of healthcare services and emphasises the need for responsiveness to a diversity of patient needs.[101] It represents a fundamental shift in understanding health and illness: in order to improve health and healthcare, expertise must be sought outside as much as inside the medical sphere, including the views and knowledge of patients and their relatives in medical care and decision-making contexts.[102] Although the terminology of person-centredness is dominant in health care policy documents, mission statements and academic research, a universally accepted definition is absent. Therefore, it is understood in various ways and applied diffusely in practice. This was also noted by Castro et al. (2016), who performed a concept analysis to establish that person-centredness is intimately linked to concepts of patient empowerment and patient participation. They developed a conceptual model of PCC which understands patient participation as a *strategy* to facilitate PCC, which in turn leads to patient empowerment (see Figure 1). They argue that patient empowerment transcends patient participation and patient-centredness "as a meta-paradigm that connects more concrete paradigms. Patient-centredness is an antecedent of empowerment while patient participation is often mentioned as a condition for patient-centered care and patient empowerment." (2016, 1931). Moreover, they hold that patient-centeredness is located on micro-level only in health care institutions, "related to the caretaker perspective". (2016, 1930)

Castro et al. consider person-centredness to have three attributes: 1) a holistic approach of health and disease that includes biophysical, psychological, and social perspectives of patient

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[100] Kaljouw and Wijma (2020); UMC Utrecht Connecting Worlds (2020); Castro et al. (2016); WHO (2016); Ekman et al. (2011); Wolfe (2001).

[101] Petit-Steeghs (2019); Entwistle et al. (2012).

[102] Richards et al. (2013).

experiences, 2) treating the person as a unique person which involves HCP characteristics such as sensitivity, empathy, and treating with dignity, and 3) sustainable and genuine patient-caregiver partnerships that built on open communication, mutual trust, and shared knowledge. Fundamentally, in their view, PCC is about balancing power between HCPs and patients.

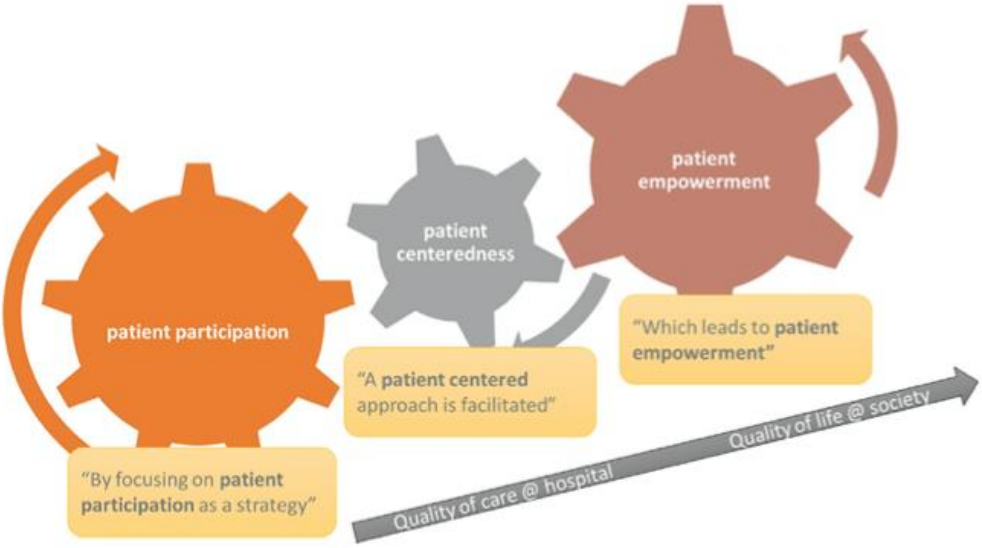

Figure 1. Process model for concepts of patient empowerment, patient participation and patient centeredness in healthcare, as developed by Castro et al. (2016).

Their conceptualization of patient empowerment as the outcome of PCC is contested by others. McCormack et al. (2015), for instance, define person-centredness as: "An approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development." (2015, 193) On this view, patient empowerment *facilitates* person-centred care approaches to practice, rather than vice versa. This account is supported by Petit-Steeghs (2019), who understands patient empowerment to be a prerequisite for enabling patient involvement, and, in turn, PCC. She defines PCC as "a partnership to ensure that health-related decisions include patients' preferences and needs" (2019, 16). She advances the concept of "knowledge co-creation"[103] as an important facilitator for PCC. This knowledge co-creation

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[103] Petit-Steeghs (2019, 11).

requires empowerment of both participants in medical decision-making: patients ánd HCPs (see Figure 2). Although Castro et al. refer to HCP characteristics such as sensitivity and empathy, Petit-Steeghs's account clarifies what this requires in practice: PCC should not only facilitate making knowledge explicit to patients ("knowledge articulation") but also focus on empowering HCPs so that they can promote PCC. She argues that in knowledge co-creation processes, the path towards patient-centredness is not linear, but "a complex, iterative communicative process in which understandings are developed, shared and deepened" (2019, 22). It progresses beyond the mere combination of experiential and professional knowledge, requiring integration of the input from empowered patients and empowered HCPs. Her account emphasizes the dynamic nature and mutual beneficence of HCP-patient interactions. This conceptualization is attractive, in my view, as it accurately depicts HCPs and patients as *equal* participants striving for a shared goal of achieving good health. They have equal status in medical decision-making, rather than 'inviting' patients to participate in practices that are dominated by HCP views or biomedical knowledge.

Consisting of three phases: knowledge articulation (i.e. making knowledge explicit to patients), knowledge integration (i.e. "a complex iterative communicative process in which understandings are developed, shared and deepened" (2019, 22), and knowledge embedment (i.e. sustainable implementation of outcomes of knowledge co-creation in health care services);

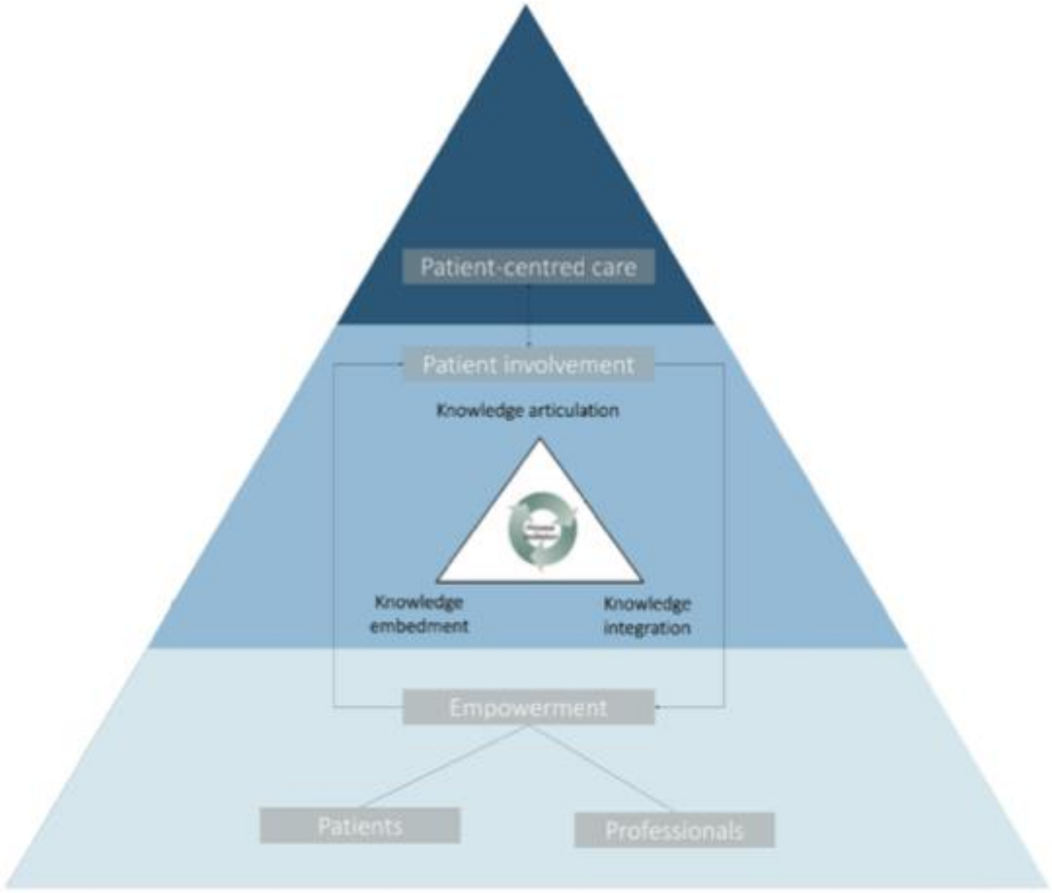

Figure 2. Conceptual framework for patient-centred care through patient involvement and empowerment through knowledge co-creation processes, as developed by Petit-Steeghs (2019).

Finally, although Castro et al. (2016) consider PCC to be situated on micro level only – i.e. individual HCP-patient encounters – I will hold that the conceptual framework of PCC is applicable to all levels of healthcare. Petit-Steeghs (2019) emphasis on the importance of HCP-empowerment and knowledge embedment already indicates that PCC approaches transcend the individual sphere of clinical encounters. Educational programmes directed at training reflective skills, as well as institutional policies aimed at supporting PCC work methods are examples of HCP empowerment that take place at meso level. Moreover, as put forward by McCormack et al., realizing PCC “requires a sustained commitment from organisations to the ongoing facilitation of developments, a commitment both in clinical teams and across organizations.” (2011, 1) They identify workplace and learning culture to be important contextual factors affecting the development of PCC. Underscoring PCC also requires fundamental shifts on macro level, including the collaboration of not only patients and HCPs, but also hospital boards, policy makers, and so on.

Principles of person-centred care

Given the variety of definitions and interpretations of what PCC entails, I propose to capture its fundamental meaning in three principles that can provide guidance when thinking about embedding PDL in a PCC context. Combining insights from the authors just discussed, I take the following three principles the basic structure of a framework for PCC:

1) **Respect for persons.** Patients are treated as unique and autonomous individuals with personal values and life goals, which ought to be explored and respected in clinical encounters. Such explorations call for a holistic approach to health and illness.
2) **Partnership**. Partnerships in healthcare are rooted in equality and aimed at the co-creation of knowledge which transcends beyond mere combination of professional and experiential knowledge. Communication is open and dialogical, based on mutual respect and empathy, and dynamic.
3) **Culture of empowerment**; Both patients and HCPs are empowered to facilitate PCC. Patients are empowered individually through enhancement of competencies for self-determination as well as through active participation in the shaping of health services. HCPs are trained to develop reflective skills necessary for open communication. Healthcare institutions are organized to sustainably embed a culture of empowerment.

For PDL to align with PCC, they should be employed in such a way that they promote respect for persons, partnerships, and cultures of empowerment. This entails that PDL cannot merely reflect HCP’s interpretation or summary of clinical encounters. Rather, PDL should depict a holistic understanding of illness, incorporating patient experiences and values. Moreover, including patients’ experiential knowledge in PDL can promote partnerships as it facilitates HCP-patient dialogues. Ideally, PDL are employed to support processes of knowledge co-creation, integrating professional and experiential knowledge. As suggested in the empirical literature, PDL have more potential for patient participation if used to structure discharge conversations as compared to sending them afterwards. In this way, PDL facilitate open dialogues and sharing of knowledge. Finally, considering the use of PDL in this PCC framework highlights the importance of embedding them in a culture that empowers both patients and HCPs and that ensures sustainable partnerships between them.

2.2.2. Epistemic Injustice

Epistemic injustice is a significant yet often unnoticed form of injustice. It is worthy of closer consideration because it affects epistemic relations between HCPs and patients. It is for that reason that the last section of this chapter delves deeper into the concept and its implications for HCP-patient interactions. I first address the concept at broad and its occurrence in healthcare, after which I consider its relevance for using PDL.

The concept of epistemic injustice

Epistemic injustice is “a wrong done to someone specifically in their capacity as a knower”[104], and it is argued that patients are prone to suffering epistemic injustices due to epistemic asymmetries between them and HCPs.[105] The nature of this moral wrongdoing is distinctively epistemic: it consists in underestimating someone’s capacity to share knowledge. Miranda Fricker, who introduced the influential framework of epistemic injustice, distinguishes two forms: testimonial and hermeneutical injustice. In instances of testimonial injustices, speakers suffer from unjust devaluation of their credibility – they are not *believed*. In cases of hermeneutical injustice, speakers are excluded from epistemic practices due to the absence of shared interpretative tools – their social experiences are “obscured from collective understanding owing to a structural identity prejudice in the collective hermeneutical resource.*”* (2007, 155) This lack of shared language makes it problematic to give meaning to certain experiences, which can occur to the extent that persons who suffer from hermeneutical injustice cannot even make sense of those experiences themselves. Illustrative examples highlighting the importance of the collectivist sharing of understandings, are the #MeToo and Black Lives Matter movements. Although women or Black people individually experienced being intimidated or discriminated against for a long time, and were perhaps able to share these experiences within their social groups, it was only after uniting their voices that the silence was broken and other social groups started to *understand* the harms inflicted on women and Black people. Societal debates on the topics created not only awareness about its existence, a new, shared language to express experiences was created too. Nowadays, little more is needed than referring to ‘a #metoo situation’ to explain experiences of sexual intimidation. Moreover, people struggling to make themselves understandable due to a lack of shared resources are also

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[104] Fricker (2007, 1).

[105] Kidd and Carel (2018).

prone to be deemed less credible: hermeneutical injustices are apt for reinforcing testimonial injustices.

Note that one could be rightly recognized to have limited epistemic agency in a certain context; the reason that patients visit doctors is because they seek their medical advice, acknowledging that HCPs have epistemic authority in providing such advice. The ethical wrong, according to Fricker, consists of making such value judgments about epistemic agency based on *identity prejudice:* negative stereotypes linked to a speaker's social identity. If we do not believe others because they are female, black, poor, ill or based on other features of their social identity that wrongly affect our credibility assessment, this stereotyping becomes ethically problematic. The beliefs we hold about how social identity relates to trustworthiness are formed at the collective level of societies. Therefore, epistemic injustice is the operationalization of social powers based on unjust conceptions of social identity – what Fricker calls "identity power" (2007, 15). Identity power corresponds to broader networks of social hierarchies, knowledge-power structures, and institutionalized beliefs of what knowledge or whose beliefs are meaningful or not. For this reason, epistemic injustice is inherently related to social injustices in broad.[106]

On this note, we can sketch a more nuanced view of the epistemic relation between patients and HCPs; we just established that patients seeking medical advice legitimizes HCP's epistemic authority for providing this advice. Yet, clinical encounters consist of more than providing medical advice. Patients share their complaints, HCPs interpret this and suggest diagnostic tests, develop a differential diagnosis based on the results, and provide treatment options. Ideally, coherent with principles of PCC, HCPs acknowledge that patient input is relevant to all steps in this process and actively cooperate with patients in reaching treatment decisions. As such, the decision to take treatment A or treatment B is not one that is made by HCPs with epistemic authority. Rather, it is a dynamic process in which patient and HCP are partners with equal epistemic status, both contributing their valuable knowledge to the decision-making practice

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[106] This is supported by other scholars, such as Benjamin Sherman: "epistemic injustice reinforces and amplifies broader social injustices." (2016, 230) Kate Schmidt depicts the interaction of social identity and epistemic injustices as a metaphorical birdcage, referring to conceptualizations of Marilyn Frye: "made up of a number of intersecting barriers. Examining any one wire in the cage (a single wrong) is not enough to see the overall picture of oppression (Frye, 2000)." (2019, 16) Subsequently, she proposes an "intersectional approach" to epistemic injustice, which focuses on "the forces of oppression as they are actually experienced by individuals; this necessarily includes untangling the ways that subtypes of epistemic injustice are experienced in overlapping non-separable ways." (2019, 113).

and cooperatively working towards the shared goal of reaching a treatment decision that is in line with patients' personal values or goals.

Epistemic injustice in clinical encounters, then, occurs when HCPs do not belief, value, or understand patients' epistemic contributions to clinical encounters *because* they are patients. If HCPs do so, two problematic consequences arise. First, it obstructs the opportunity to obtain knowledge.[107] This is epistemologically problematic in the pursuit of truths, but more relevant to clinical encounters is the practical consequence of obscuring valuable information from medical decision-making practices, which can obstruct reaching the shared goal (e.g. of successful diagnosis, or treatment, or symptom relief). Second, it is an ethical wrong more fundamentally: Fricker points to the intrinsic value of being recognized as an epistemic agent. Our rational capacity is what "lends humanity its distinctive value". (2007, 44) Hence, when a person is excluded from participation in epistemic practices, she is essentially wronged in a capacity that makes her human. Not recognizing the fundamental human value of epistemic agency, Fricker continues, is a form of "epistemic objectification": degrading a speaker from an active participant in epistemic practices to, at best, a passive source of information; "from subject to object." (2007, 133). The ontological violation of human rationality is however not the only dimension of harm. This primary wrong is followed by secondary setback: speakers may lose confidence in their own beliefs, which can become self-fulfilling prophecies when persons who are epistemically wronged persistently lose confidence in their intellectual capacities. If they refrain from sharing their experiences or beliefs because they *themselves* feel unable to offer meaningful input in the conversation, the epistemic injustice occurs at a stage where it prevents them from trying to contribute to epistemic practices in the first place. If patients' testimonies are repeatedly disregarded in medical decision-making, they will eventually refrain from sharing their experiences at all.

Testimonial injustices can be incidental, or agent-specific: HCPs can incidentally make wrong credibility assessments, and some HCPs may have internalized negative stereotypes about patient credibility whereas others have not. Hermeneutical injustices occur only in structural, non-agential forms; they do not follow from individual wrongdoings. Given its origin in collective lack of shared understandings, they are part of a broader patterns of structural prejudices. This is where epistemic injustices conjunct with broader social injustices: collective

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[107] Sherman (2016).

prejudices often cause or reinforce hermeneutical marginalization of already disadvantaged groups. This also holds for structural testimonial injustices that are based on collectively held beliefs about the credibility of certain social groups. As Fricker points out: "At root, both kinds of systematic epistemic injustice stem from structural inequalities of power." (2007, 156)

Institutionalized power structures

These insights on structural inequalities of power find their origins in the work of Michel Foucault. On his account, power is intimately related to knowledge. Marc Roberts (2005) provides a helpful examination of his work. Foucault described a historical tendency in Western cultures to develop new ways of observing human behaviour in various settings (e.g. in prisons, schools, hospitals), after which he "suggests that the knowledge of the human sciences is employed to refine and intensify the exercise of power."[108] In other words, the emergence of new disciplines (e.g. criminology, pedagogy, psychiatry) enables scientists to describe human conduct, which inevitably causes categorization and distinction between what is 'normal' and what not. According to Foucault, this constitutes refined ways of exercising disciplinary power through social relations – its nature being quite accurately captured by the term 'disciplines'. Ultimately, people are tied to their social identity to the extent that it controls their behaviour. If people adopt a certain social identity – e.g. that of a prisoner, a student, a patient – they will become subject to an internalized form of social control: they perceive of *themselves* as being dependent on others. Accordingly, they adapt their behaviour to what is socially expected from them. On this note, it is possible that patients can internalize identity prejudices and act accordingly – if there is an institutionalized social perception of patients as passive objects in clinical encounters rather than agents with full epistemic status, it is likely that patients perceive of themselves as being epistemically inferior to HCPs. As Fricker pointed out, this can be self-reinforcing. Moreover, such self-understandings legitimize institutional forms of power exercise; think of laws, policies and guidelines for correction and punishment which are widespread in western societies (e.g. isolated confinement of prisoners who misbehave, detainment for students who act up, compulsory hospitalization of psychiatric patients).

I consider this institutionalization of knowledge-power relations relevant to the ethical analysis of PDL.[109] Upon a Foucauldian understanding, exercises of identity power can be

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[108] Roberts (2005, 35).

[109] It is of course possible to focus on agential or incidental forms of epistemic injustices too, or the role of individual agents in the exercises of power based on knowledge-hierarchies. I choose not to, for two reasons.

institutionalized and legitimized through structural reinforcements of power-knowledge hierarchies. It is interesting to consider the potential of structural employment of PDL for rebalancing such hierarchies. More still, to defend the justified use of PDL, we must ascertain that they do, at the very least, not reinforce structural exercises of identity power. To do so, we must first get a clearer image of what identity power in the context of healthcare entails.

Pathocentric epistemic injustice

Ian Kidd and Havi Carel argue that healthcare services and institutions display structural exercises of identity power, which they call "pathocentric epistemic injustice".[110] They are the result of prejudicial stereotypes that lead to negative attitudes towards patients and illness at broad. Such stereotypes include the conception of ill persons as "cognitively impaired, overwrought, unable to 'think straight', existentially unstable, anxious, and so on", which causes HCPs to devalue their credibility (testimonial injustice) and exclude them from practices in healthcare where social understandings are shaped (hermeneutical injustice).[111] Testimonial injustices occur mainly at the level of individual clinical encounters, disregarding patient testimonies because they are irrational or otherwise unreliable. Epistemic exclusion based on hermeneutical injustices also occurs outside consulting rooms; as they are founded on social norms and societal understandings, it transcends the borders of biomedicine and clinical practice. When patients are not invited to participate in hospital boards, advisory bodies, research committees, educational programs, and so on, they are excluded from the places where social meanings are constructed.[112] Consequently, patient experiences cannot find their way to societal discussions about the meaning of illness, nor challenge the norms that carry epistemic authority. Kidd and Carel argue that this exclusion is based on a general perception that patients' lack of medical training renders them incapable of epistemic participation. All instances in which patients are disabled to express themselves in their own words because of collective understandings, or the absence of it, of what it is to be a patient, they are denied hermeneutical agency.[113] Moreover, as such places where social meanings are constructed constitute the development of social norms, hermeneutical exclusion from these practices leads to further

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First, my examination of PDL is motivated by the intention to implement it as a structural intervention. In this light, it is not that relevant whether individual HCPs exercise power or inflict epistemic injustices incidentally. Rather, it is useful to determine whether PDL can help to counter epistemic injustices structurally. Second, I simply lack space to address all forms in which epistemic injustices present at length. It is worthwhile to dedicate further inquiry to how PDL affect agential or incidental forms of epistemic injustice in the future.

[110] Carel and Kidd (2018, 211).

[111] Kidd and Carel (2017, 338).

[112] Kidd and Carel (2019, 2018).

[113] Kidd and Carel (2019, 4-5).

reinforcement of existing norms rather than introducing new, alternative understandings of social experiences. Think of, for instance, marginalization of elderly or patients with psychiatric disorders in societal debates; disregarding their epistemic agency based on a collectively shared interpretation of their credibility being deprived due to being old or mentally ill, prevents them from sharing their social experience. If this occurs structurally, collective interpretations of how valuable contributions of elderly or mentally ill patients are to societal debates are not likely to change. Kidd and Carel argue that pathocentric epistemic injustices are reinforced through institutionalized, professional norms in western medicine. A strong focus on 'objective', quantifiable information renders subjective patient experiences epistemically inferior.[114] Such prioritization of biomedical understandings of health and illness are deeply rooted in a western tendency to have "naturalistic conceptions of health"; understanding illness as biophysical cell dysfunctions that affect processes of survival and reproduction.[115] On this account, non-biomedical experiences are considered not, or less, meaningful in the conception of health and illness. It is this traditional, deeply embedded societal view on health that forms the core of pathocentric epistemic injustice.

Ultimately so, overcoming pathocentric epistemic injustices requires revision of these fundamental conceptions that are at the core of daily medical practice. It is illusory to think that using PDL can overturn this societally anchored naturalistic conceptions of health and illness. Yet, they are not powerless in counteracting epistemic injustices either. I will address to ways in which PDL could contribute to granting patients a higher epistemic status in clinical encounters: the virtue of epistemic justice, and epistemic participation.

The virtue of epistemic justice

Fricker developed the notion of *epistemic justice*, an anti-prejudicial virtue that we "can, and should, aim for in practice" to counteract epistemic injustices (2007, 98-99). She distinguishes the virtue of testimonial justice from the virtue of hermeneutical justice, both of which require a "reflexive critical awareness" on the hearer's side: virtuous hearers should adopt a sensitivity to how their and the speaker's social situatedness affect the epistemic practice in which both are involved. (2007, 91) Testimonial justice, then, consists in hearers' awareness of how social identities (of speakers, but also their own identity) may affect their credibility judgments.

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[114] Carel and Kidd (2017, 340-342).

[115] Kidd and Carel (2018, 227).

Fricker construes the virtue of hermeneutical justice as “an alertness or sensitivity to the possibility that the difficulty one's interlocutor is having as she tries to render something communicatively intelligible is due not to its being a nonsense or her being a fool, but rather to some sort of gap in collective hermeneutical resources. The point is to realize that the speaker is struggling with an objective difficulty and not a subjective failing.” (2007, 169) Such sensitivity thus requires more than assessing the likeliness that what a speaker is saying is true. Rather, possessing the virtue of hermeneutical justice entails allowing the possibility for multiple interpretations of phenomena to exists, none of them possessing authority for appealing to ‘the’ truth. Combining the virtues of testimonial and hermeneutical justice, then, makes virtuous hearers to judge speaker credibility based on assessment of both testimonial and hermeneutical contexts, which are linked to social identities of both the hearer and the speaker, and correct for them when initial judgments are flawed.

The relevant question for this inquiry is: can PDL promote that HCPs adopt virtues of epistemic justice? The idea that this virtue consists in acknowledging that multiple interpretations of phenomena exist and that all have equal status in epistemic practices coheres with principles of PCC. I have argued that PDL can promote PCC if they promote respecting patients as persons, promoting partnerships and are embedded in cultures of empowerment. Hence, if PDL can promote PCC, it seems that they can also promote the virtue of epistemic justice in this sense. Yet, human capability to make conscious assessments of how social identities affect epistemic practice is contested. Benjamin Sherman doubts whether humans are intellectually able to make such assessments in the first place, let alone that we can adjust for them when prejudicially flawed. Drawing on insights from psychological literature about cognitive dissonances and confirmation biases, he considers it more likely that human beings irrationally valorise flawed credibility judgments, rather than objectively correct for them. Moreover, such a virtue of epistemic justice exists, Sherman argues that striving for it is not helpful in counteracting epistemic injustices. Pointing towards psychological literature again, he highlights how studies have shown ironic effects of trying to be anti-prejudicial – moral self-licensing or rebound effects[116] make it a rather ineffective exercise. “While it would be good to become someone who is habitually and characteristically dis-posed to be just, aiming to achieve this virtue makes us, I think, less likely to actually achieve it” (2016, 231).

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[116] According to Brown et al. (2011), moral credentialing is “the act of affirming one’s egalitarian or pro-social values and virtues might subsequently facilitate prejudiced or self-serving behavior”. (2011, 1).

PDL and virtuous listening

I will hold that the virtue of epistemic justice is nevertheless a valuable concept for determining whether and how using PDL is justified within a framework of epistemic injustice; perhaps by counteracting, but at least not reinforcing, epistemic injustices. I provide two reasons.

First, I grant Sherman's claims that it may not be possible for agents *themselves* to change what they "happen to believe at the moment" (2016, 238), and that it is unlikely that people are "habitually and characteristically disposed to be good" (2016, 231). Yet, it is nonetheless possible:

A) for *others* to help agents to become more virtuous;
B) for agents to become more virtuous in *certain settings*.

There are good arguments to support both A) and B). I already addressed Paxton, Ungar and Greene's (2012) defence of the possibility to alter moral intuitions, indicating that we can alter our beliefs when being made aware of their unjust grounds by others. Insights on implicit biases and how we deal with them support this.[117] Although it is unlikely that we can counter implicit biases in ourselves, even upon conscious reflection, there are promising results of adopting approaches to tackle implicit biases by making people aware of them. [118] Similarly, granting that HCPs are not likely to adjust prejudiced credibility judgments upon self-reflection, it is nonetheless possible that they are able of doing so when being made aware of them by others, for instance by training skills of sensitivity for epistemic context just like implicit bias trainings for HCPs exist. I take the existence of such trainings to also support for B): implicit biases are widespread in the general population, and it is a rather utopian image to hold that we can counter them so that persons never exhibit implicit bias at any point in any person's life anymore. Yet, this does not withhold us from attempting to tackle implicit biases in certain contexts, for instance in professional contexts such as clinical encounters. Without claiming that HCPs should be virtuous listeners in all social encounters in their lives, hospitals can require HCPs to develop epistemic sensitivity in the specific context of clinical encounters with patients. In that sense, training HCPs to learn skills of virtuous listening does not differ that much from training other professional competencies, say, communicative or academic skills, both of which are core components of medical curricula.

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[117] Implicit biases are "associations outside conscious awareness that lead to a negative evaluation of a person on the basis of irrelevant characteristics such as race or gender." (FitzGerald and Hurst, 2017, 1)

[118] Zestcott, Blair and Stone (2016).

Second, as with other virtues, being unable to reach the state of a fully virtuous listener does not mean it is not worth striving for at all. If the virtue of epistemic justice helps HCPs to become *more* epistemically sensitive in clinical encounters with patients, without ever fully possessing the cognitive ability to correct for flawed credibility judgments, it is still an improvement in comparison to not trying to be virtuous at all. Hence, the virtue of epistemic justice is something worth striving for in the pursuit of countering pathocentric epistemic injustices, even when HCPs can never reach the state of fully virtuous listeners. Fricker herself states that it should not be handled as an algorithm for action-guidance, but rather as a "clear guiding ideal" (2007, 91-92)

Authentic shared decision-making

That HCPs are able to develop skills of sensitive listening is supported by Aliki Thomas et al. (2020), who propose to incorporate ways for promoting "critical reflexivity required to address issues of epistemic injustice" in medical education (2020, 409) They provide arguments for how "authentic shared decision-making" can help counteract both testimonial and hermeneutical injustices in healthcare. They adhere to similar claims as Kidd and Carel have made about biomedical knowledge being epistemically prioritized over other types of knowledge, pointing towards its legitimization through medical education by elevating biomedical knowledge to "gold standard status" (2020, 413) and dismissing "the stories of patients, family members, and even health care professionals (…) as inconsequential." (2020, 411) Due to its reinforcements through education, they propose pedagogical ways to overcome this, specifically looking at the humanities for providing valuable input for creating shared hermeneutics. To overcome the dismissal of patient experiences as illegitimate, they suggest revising the content and teaching methods of medical curricula. On their account, medical education should move towards a more proportionate focus on biomedical and non-biomedical forms of knowledge, promote open dialogue and critical reflection, and including patients as educational partners. Exposure to their perspectives early in medical education to create awareness that patients are equal members in medical decision-making practices and that their knowledge is vital to them. Ultimately, these educational reforms should support future clinicians' development of critical reflexivity, helping them challenge their own assumptions and provide insight in "the factors that shape and reinforce oppressive systems in practice" (2020, 414).

I see a role for using PDL here. If PDL successfully reflect patient narratives and proportionately focus on both non-biomedical and biomedical knowledge forms, they can contribute to legitimizing patient experiences as valuable epistemic contributions. Moreover, PDL itself can form a shared hermeneutic in itself: they literally consist of a shared interpretation of the clinical encounter – if principles of PCC are respected – which is accessible by both participants in the epistemic practice. As through including patient experiences in educational methods, PDL can constitute daily exposure to patient stories. Furthermore, if PDL are employed to structure discharge conversations, they can promote open dialogues between HCP and patients, contributing to authentic shared decision-making.

Epistemic participation

Kate Schmidt (2019) proposed another way to promote epistemic justice in healthcare: the notion of *epistemic participation.* She argues that epistemic injustices are fundamentally about participation in social activities of inquiry. Epistemic justice, so understood, is not about being believed; rather, it is about being recognized as a potential participant in epistemic practices. This notion of epistemic participation shifts the focus from the capacity to know or testify to the agent’s capacity for participation. As acts of social inquiry involve multiple agents, epistemic justice requires cooperation of these agents in pursuit of their shared epistemic goals. For successful cooperation, agents must recognize each other’s epistemic capacities for contributing to this shared inquiry. This requires adopting a certain attitude towards epistemic partners with whom one cooperates. Schmidt argues that this attitude is best conceptualized in terms of the *virtue of inclusion*. Rather than individual virtues of epistemic justice, she proposes to cultivate the group-based virtue of inclusion to counteract epistemic injustices. She considers it a collective virtue as it is “predicated upon a social collection of individuals, rather than on a single person.” (2019, 90) This virtue of inclusion requires that social practices are implemented in inclusive environments, and that inclusivity is not occurring merely incidental, but as a consequence of collectively shared norms and core group-features. According to Schmidt, ideal inclusive environments should “promote growth and well being of each individual – what I call epistemic flourishing. This approach emphasizes maximizing the abilities of each individual to act as an epistemic agent” (2019, 87) through structural strategies that cultivate inclusivity. Schmidt proposes three strategies for doing so. 1) Work to change group norms; including a diversity of epistemic norms promotes anti-prejudicial social behaviour, countering “harmful norms” with “newer healthier norms”. (2019, 97) 2) Adjust group components; making groups more sensitive for inclusion by changing both structural features, for instance by making epistemic practices structurally more accessible, as well as individual dispositions that can promote inclusion (e.g. trying to be accepting towards others' beliefs, avoiding shaming, and being open to feedback). 3) Social feedback mechanisms; to address behaviour that violates group norms of inclusion, promoting "self-conscious realizations in others and ourselves." (2019, 98)

The notion of epistemic participation coheres with the principle of embedment within cultures of empowerment. It highlights that promoting epistemic justice should be sustained through structural institutionalization of the fundamental principles that underlie both PCC and epistemic justice. The virtue of inclusion clarifies what this requires: inclusive institutions which represent a diversity of group norms and promote anti-prejudicial behaviour. Individuals working in such environments have a sensitivity for important features of inclusion and promote reinforcement of inclusivity through social feedback and self-reflection. Again, PDL as a single intervention will not be capable of such institutional reform. Yet, if employed so that they align with PCC, they fit neatly within an inclusive environment as just sketched. They promote inclusion of other-than-HCP views, stimulate developing anti-prejudicial sensitivity in the ways described in relation to the virtue of epistemic justice, and they can form daily reminders for HCP to see the potential for cooperation with patients. More fundamentally, when being employed structurally or hospital-wide, their use advertises a group norm of inclusivity – hospitals using PDL proclaim that they fundamentally care about the flourishing of patients.

Chapter 3: Just employment of patient-directed discharge letters

The ethical analysis highlighted areas where moral compromises could occur when employing PDL in hospital care. Although the risk of moral problems exits, this does not yield reasons for considering the use of PDL unjustified. Rather, it informed the development of several conditions for justified use of PDL throughout this thesis. To secure that using PDL is in coherence with the elements of the NE-RE, their employment in practice should meet these conditions. These conditions inform a concrete recommendation on just employment of PDL. Before proceeding to that, I address the moral compromises that can arise when using PDL and formulate corresponding conditions for just employment of PDL.

The capacity to act

Insights on health literacy and patient diversity reflected that not all patients possess similar capacities for shaping care and self-management of health. As I conceptualize patient wellbeing in terms of the opportunity to act according to one's individual interpretation of a good life, the capacity to act is relevant to both principles of respecting autonomy and beneficence. To be in coherence with all these elements, it is important that PDL are adjusted to individual patient needs. The principle of respect for persons provides guidance on how to do so. For PDL to align with individual patient needs, they should centre around patient values and life goals, recognizing their authenticity and self-determining agency. Rather than reinforcing HCP views on health and illness, PDL should revolve around what patients wish to obtain within clinical encounters and medical decision-making. Including a section in PDL that explicitly considers why patients seek medical advice and what their goal is in the clinical encounter, can contribute to doing so.

Universal accessibility

Insights on health literacy and justice highlighted that PDL must not contribute to increasing health disparities. To do so, they must be accessible and useful to all patients, not only patients that have adequate health literacy. I argued that this is best realized when using a limited health literacy format as the default, even though this seems to be incoherent with principles of beneficence and nonmaleficence. Moral intuitions of other thinkers provided support for considering this disbalance in the NE-RE justified in light of the net benefit produced and social justice promoted by using PDL in plain language as the default.

The option to refuse

Addressing different understandings of autonomy highlighted an ambiguity in respecting the principle of autonomy. On the one hand, patients have the right to refuse receiving PDL based on their capacity to autonomously decide to do so. Yet, if patients do not receive PDL, the actual condition of autonomy and autonomy as a character ideal are constrained. The principle of beneficence provides guidance here. To avoid paternalistic tendencies, the option to refuse receiving PDL should be available to patients. Patients themselves are the only ones who can decide what actions best suit their interpretation of a good life. It justifies their right to refrain from acting autonomously in the sense of meeting the actual condition of autonomy or acting as an ideally authentic individual. Therefore, the option for patients to refuse receiving PDL must be warranted.

Acknowledging social situatedness

Considerations of patients' dependence on their social network highlight the importance of acknowledging their social situatedness. PDL can warrant this when their content do not only meet individual patient needs, but also reflect that patients need support of their environment when going home after discharge. This can be realized by including a section in PDL that highlight patients' social situation and what is needed for successful transfer of care from hospital to primary care settings.

Mode of employment and timing

The principle of nonmaleficence showed that adverse effects of PDL are mostly anticipated or due to suboptimal employment of PDL. To avoid causing negative effects, several conditions for optimal employment were mentioned, including announcing that patients receive a PDL, combining the distribution of the PDL with verbal information, verifying patient details before sending it, avoid the use of value judgments, careful formulation of sensitive information, increasing transparency by attaching the traditional letter that is sent to GPs to it, and including clear, accessible, and relevant content. Taking these suggestions into account, the preferred mode of employing PDL is to go through the letter with patients and family together during a discharge conversation, rather than sending it afterwards. In this way, the PDL can promote open dialogue between patient and HCP during this conversation. Also, employing it this way constitutes a moment for clarifying misunderstandings or different interpretations. The PDL serves as a shared hermeneutical resource here, providing a document that is accessible to both participants in the clinical encounters. In this way, using PDL also contributes to promoting epistemic justice. To allow patients and their family or relatives to prepare for this discharge conversation, it should be announced that the conversation will take place.

Concurrent implementation and evaluation

Another possible adverse effect that was highlighted when considering the principle of nonmaleficence, is the possibility of new, unanticipated harms to arise when employing PDL structurally in hospital care. Implementation barriers reflect foreseen practical issues of increased HCP workload and difficulties in fair distribution of resources available to HCPs. Moreover, empirical input is necessary for making adequate risk/benefit assessments related to using PDL. Therefore, the implementation of PDL should be accompanied by continuous monitoring to inform evaluations of their effects in practice.

Recognizing patients' epistemic status

In a strive against epistemic injustice, structural ways to recognize and secure patients' epistemic status in clinical practice should be promoted. Accordingly, PDL are morally justified within a framework of epistemic injustice if they promote equal epistemic status of HCPs and patients and facilitate incorporating experiential knowledge in decision-making, and at the very least not reinforce the prioritizing of biomedical understandings of health. To do so, it is of crucial importance that PDL do not merely reflect biomedical interpretations of health or HCP views on medical encounters but revolve around patients' individual values and holistic approaches to illness experiences (cohering with the PCC principle of respecting persons). If and only if they are employed in this manner, they can contribute to promoting partnerships in healthcare and, hence, not reinforce epistemic injustices. Practically, this entails that PDL are structured rigorously different than traditional discharge letters. Rather than revolving around medical history, diagnoses, test results, and treatment advice, they should centre around patient experiences and reflect the process of knowledge co-creation that preceded or conjoined the discharge process. Using PDL under the conditions that they promote PCC and holistic understandings of illness, they can promote developing virtues of epistemic justice by training HCPs to consider patient narratives as legitimate and valuable input in clinical encounters. Using PDL to facilitate cooperation between patients and HCPs forms a way of promoting epistemic participation.

Embedment in the right environment

When using PDL in an environment that has no sensitivity to the influence of social identities on epistemic practices nor is motivated to look for cooperation and inclusivity, it is not likely that they will sustainably promote PCC and epistemic justice. I have addressed possible directions for promoting the development of critical reflexivity, sensitive listening, anti-prejudicial behaviour among HCPs, through education and institutionalization of group norms aimed at empowerment and inclusivity. If PDL are embedded within an environment that is not or only minimally aimed at inclusivity and empowerment, I take that their use is still justified if they meet the other conditions formulated. As such, they will not reinforce epistemic injustices or create other moral compromises. Yet, embedment in a less-than-optimal environment decrease PDL’s ability to reach their full potential for enabling partnerships and authentic shared decision-making clinical encounters. Therefore, they are best embedded within a culture of empowerment and inclusivity, in which principles of PCC and epistemic justice are core features of medical education, professional norms, daily practice, and social interactions. Although using PDL as a single intervention will not be capable of realizing a culture of empowerment, their use can nevertheless contribute to institutionalization of what is at the core of promoting PCC and epistemic justice. Through using PDL, healthcare institutions such as hospitals reflect a fundamental understanding of HCP-patient interactions as equal partnerships rather than epistemic hierarchies. By adopting PCC-supporting and epistemic-justice promoting interventions such as PDL, healthcare institutions show a virtue of inclusivity, valuing a diversity of norms, experiences, and perspectives. Ultimately, it sends the message that hospitals value and respect what is at the core of healthcare: patients.

Yours sincerely, doctor X

Conclusion and recommendation

This thesis aims to answer the question: *Is it morally justified to use patient-directed discharge letters, and if so, under what conditions?* I formulated two sub-questions that guided the ethical analysis, providing direction as to where moral compromises with using PDL might occur:

- To what extent does employing PDL pose a risk of reinforcing epistemic injustices in healthcare and how can this risk be minimalized?
- To what extent does employing PDL pose a risk of increasing health disparities and how can this risk be minimalized?

In order to answer these questions, I employed the NE-RE for gathering morally relevant insights from different sources. I described empirical insights about using PDL and health literacy and deduced moral intuitions from qualitative studies on PDL. I confronted these intuitions with the four biomedical ethical principles and interpreted them against the background of conceptual frameworks of PCC and epistemic injustice.

Both sub-questions can be answered in similar vein: yes, using PDL poses a risk of reinforcing epistemic injustices and increasing health disparities. They can reinforce epistemic injustice to the extent that they can sustain traditional power-hierarchies and exercises of identity power. Moreover, PDL can indeed increase health disparities if they are only accessible for or useful to people with adequate health literacy. Nevertheless, this does not lead to the conclusion that using PDL is morally unjustified. Instead, PDL show potential for improving patient wellbeing and autonomy through expanding patients' capacity to act. Adverse effects and risk of harms are minor or preventable. PDL can promote social justice by making health information accessible to people with limited health literacy. Furthermore, PDL can contribute to promoting epistemic justice in healthcare by supporting the development of virtue of epistemic justice, epistemic participation, and inclusive environments. Finally, the use of PDL is coherent with principles of PCC: they can promote respecting patients as persons, partnerships between HCPs and patients, and HCP and patient empowerment.

Hence, the use of PDL is morally justified if they are not employed negligently, but under certain conditions. The last section of this thesis provides a concrete recommendation for practice that consists of these conditions, accompanied by suggested PDL format that meets these conditions.

Recommendation

For just employment of PDL, they should meet the following conditions:

- I) They reflect patients' reason for attending to hospital care and their goal in the clinical encounter.
- II) They reflect patients' social situation and what is needed for successful transfer to primary care settings.
- III) The information included is clear and relevant to patients' individual situation.
- IV) They are used in a universally accessible format, which includes:
  - a. Short sentences and words;
  - b. Avoidance of medical jargon and acronyms;
  - c. Blank lines;
  - d. Pictograms;
  - e. An invitation to call in case of questions.
- V) The traditional discharge letter is attached to the PDL.
- VI) They are employed in the form of an opt-out system; allowing patients to refuse receiving PDL.
- VII) Their distribution is accompanied or followed by a discharge conversation, in which PDL are used to create an open dialogue with patients and family or relatives.
- VIII) Their implementation is accompanied by continuous monitoring and evaluation of their effects in practice.

Furthermore, PDL are ideally embedded within a culture of empowerment and inclusivity. This is not a necessary condition for their justified use, yet it contributes to their ability to reach full potential.

A suggested format for a PDL that satisfies the above-mentioned conditions about letter content or format, is included on the next page. It is merely an initial suggestion; future research could be devoted to further developing the format. Including patient representatives in the development of PDL formats and ideas on modes of employment is of the utmost importance. This thesis has highlighted other avenues for further exploration too, such as the interplay between the concepts of epistemic injustice and person-centred care, how to promote and sustain epistemic justice in healthcare, and the role of medical education in promoting just and accessible healthcare.

Yours sincerely, doctor X

Example of a patient-directed discharge letter

Date: …

Dear ….

You receive this letter because you were hospitalized / visited the hospital.
It is a summary of what we discussed.
We hope it helps you understand what happened and what to do when you get home.
The letter that we sent to your GP is attached to this one.

You came to the hospital because….[119]
This affects your life in the following way…. [120]
Your goal during hospitalization / of this consultation was….[121]
so that you can …. [122]
You shared the following information about yourself and your social situation: …[123]

Medical findings
Important test findings were …
We discussed that your symptoms are the result of …. *(diagnosis including brief explanation)*
We agreed to treat this as follows: … *(medication/conservatively/physiotherapy/...)*
Our considerations for this treatment decision were: …

What to expect from the future
Symptoms that may occur:
You receive: …. *(treatment)* to support this.

Recommendations
We discussed what you need for further recovery at home, namely… (*home care, family support/...)*
You can: *(take medication/exercise/...)* to support recovery/relief pain/….
Follow-up appointments are: ….
Please contact us if you experience…. *(alarming symptoms)*

Contact
If you have any questions, do not hesitate to contact us: (*phone number)*
You can also speak to your GP.

It was a pleasure to meet you. I wish you the best.

Yours sincerely,
Doctor X

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[119] *e.g. you experience shortness of breath/pain in your knee/are worried about.../you cannot sleep/....)*

[120] *(e.g. you cannot work, you are in pain, you feel anxious/stressed, ...)*

[121] *(e.g. recovery, pain control, reassurance, stress relief ...)*

[122] *(e.g. get back to work, get better, live without pain, sleep well, take care of partner, ...)*

[123] *(e.g. social situation, living condition, mental wellbeing, religious/spiritual/existential circumstances, ...)*

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