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Towards a theory of (de-)stigmatizing: A practice view on the adoption of stigmatized practices in organizations based on the case of pediatric palliative care in a hospital

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Abstract

Although studies suggest that organizations take up stigmatized practices from their environment, research on the intra-organizational adoption of these practices is rare. This is a major shortcoming because stigma, as a negative social evaluation, is ubiquitous and erodes social acceptance, which is a key determinant of practice adoption. Consequently, stigma attributed to practices is a potentially critical source of adoption failure. However, since adoption studies have not yet systematically integrated stigma into their analyses, our understanding of how stigmatized practices are constructed within organizational settings and with what impact on adoption is still largely underdeveloped. In seeking to address this shortcoming, I draw on a practice perspective to theorize stigmatized practices as continuously constructed through people's everyday actions – that is, through (de-)stigmatizing.

I elaborate on the (de-)stigmatizing perspective by conducting an embedded case study of the adoption of pediatric palliative care in a hospital. Pediatric palliative care aims to improve the quality of life for children with life-limiting illnesses and their families yet is stigmatized as 'giving up the fight for a cure' and being limited to 'end-of-life care'. From my empirical analysis, I theorize different stigmatizing and destigmatizing dynamics, their triggers, impact on adoption, and interrelations. My findings advance research by offering a revised view of the adoption of (stigmatized) practices in organizations and a more integrative view of the social construction of stigma. It also provides practical insights into the adoption of palliative care in hospitals, a practice that the World Health Organization deems essential to healthcare systems.

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List of Abbreviations

Abbreviation	Meaning
EOL	End-of-life
ICU	Intensive Care Unit
MMA	Mixed Martial Arts
PPC	Pediatric Palliative Care
PTT	Primary treatment team
WHO	World Health Organization

A note on the anonymization of the empirical data

To uphold the ethical integrity of this research and to protect the identities of the organization and all individuals involved, comprehensive anonymization procedures were applied. These measures were guided by established ethical standards, including the Academy of Management (AOM) Code of Ethics (2023) and the American Sociological Association (ASA) Code of Ethics (2018). The anonymization process focused on two levels: the organization and the individuals in the clinical cases.

Organizational anonymity _ This study is based on an in-depth case study conducted at a hospital, referred to throughout the thesis by the pseudonym Horizon. To preserve the organizations anonymity, all identifying information – including geographic references, national or regional identifiers, and the hospital’s mission statement – has been removed. Furthermore, the timeline of pediatric palliative care (PPC) implementation has been generalized. Instead of citing specific years, I refer to temporal markers such as “several years into implementation” to avoid linking events to institutional records or historical developments.

Individual anonymity _ The case study includes clinical cases of children eligible for PPC. Each child was assigned a pseudonym using a randomly selected female first name, regardless of actual gender. Age is indicated using broad categories (e.g., newborn, infant), and survival time is described in non-specific terms (e.g., “alive at the time of research”) to enhance confidentiality. To further protect anonymity, medical details have been minimized in the narratives. Diagnoses are presented in general terms, such as “life-limiting illness” or “congenital malformation”. In a related vein, any references to the specific medical specialties (e.g., oncology, cardiology) have been avoided. Instead, I refer to the medical professionals involved as primary treating physicians or nurses. Additionally, family contexts – such as religious or cultural backgrounds – were limited to avoid the inclusion of potentially identifying information.

1 INTRODUCTION

1.1 Motivation for the study

1.1.1 Neglect of stigma in practice adoption research

Organizations adopt new practices based on their expected performance and social benefits (Naumovska, Gaba, et al., 2021; Sturdy, 2004). Studies of practice adoption have traditionally focused on practices that came to be widely accepted and taken for granted in a field (Ansari et al., 2010; Gondo & Amis, 2013). However, not all practices that organizations adopt enjoy positive social evaluations (Jung & Mun, 2017; Sanders & Tuschke, 2007) and some may even be stigmatized (Chuang et al., 2011; Reinmoeller & Ansari, 2016) and are therefore perceived as possessing undesirable characteristics (Goffman, 1963). A timely and important example of a beneficial but stigmatized practice, which I also investigate in this study, is pediatric palliative care (PPC). Although the practice aims to improve the quality of life for children with life-limiting illnesses and their families (WHO, 2023), the term ‘palliative care’ is often associated with ‘giving up the fight for a cure’, ‘end-of-life care’, and ultimately ‘death’ (Cherny, 2009; Shen & Wellman, 2019; Zimmermann et al., 2016).

To date, three bodies of research offer insights into the adoption of practices in organizations, yet adoption studies of stigmatized practices remain scarce. First, much research has focused on the decisions made by organizations – typically their managers (Klein & Sorra, 1996) – to take up practices from their external environment (e.g. Kennedy & Fiss, 2009; Tolbert & Zucker, 1983; Westphal et al., 1997). These organizational-level adoption studies view stigmatized practices as a subset of practices that are institutionally “contested” (Chuang et al., 2011). This view indicates that stigmatized practices are relatively rarely introduced into organizations due to the strong resistance they face from social audiences in the organization’s environment

(Sanders & Tuschke, 2007). These audiences perceive the practices as possessing elements that violate social norms (Naumovska, Gaba, et al., 2021), rendering them highly illegitimate and therefore entirely inappropriate and unacceptable (Suddaby et al., 2017). For example, Chuang et al. (2011) hinted at same-sex partner health benefits as a contested practice that faced stigma from anti-gay activists and religious groups because they perceived the practice to violate traditional family norms.

Second, extant research offers insights into the intra-organizational adoption of practices, focusing either on their initial implementation (e.g. Canato et al., 2013; Jacqueminet & Durand, 2020; Klein & Sorra, 1996) or on their change as established routines (e.g. Bucher & Langley, 2016; Dittrich et al., 2016; Feldman, 2000). These streams of research describe practice adoption as a contested social process but have yet to explore the stigmatization of practices as a possible source of this contestation.

The implementation of practices is a contested social process as it involves time-consuming shifts in skills, roles, power relationships, and existing routines (Barley, 1986, 1990; Edmondson et al., 2001; Raman & Bharadwaj, 2012). In addition, the characteristics of a practice are usually not initially aligned with the characteristics of the organizational setting, so that organizations must adapt the practice (Ansari et al., 2010). In particular, practices that violate social norms within an organizational setting, and are therefore seen as a “poor cultural fit”, may not be adopted without significant adaptations (Canato et al., 2013). These adaptations can involve discursive or substantive modifications to the desired or espoused practice (Ansari et al., 2014; Canato et al., 2013; Jarzabkowski et al., 2016). While such adaptations may facilitate greater acceptance among organizational members during implementation, they can present a significant dilemma for organizations: the risk of diluting or compromising critical features of the practice in the process (Ansari et al., 2014; Canato et al., 2013).

Research on change of practices as routines has revealed that changing established practices in organizations is a significant practical challenge (Feldman & Pentland, 2003) and a theoretical puzzle (Bucher & Langley, 2016), as their espoused features and actual performances are interdependent and mutually reinforcing (Bucher & Langley, 2016; Howard-Grenville, 2005). Reorienting these recursive dynamics may be particularly difficult when a new practice has a poor cultural fit and thus lacks support (Bertels et al., 2016). Organizations can address the challenge of reorienting established practices by providing occasions for collective experimentation and reflection (Bucher & Langley, 2016; Edmondson et al., 2001; Rerup & Feldman, 2011). However, while these efforts can explain the initiation of routine change, less is known about whether and how the reorientation process continues in daily practice.

Given the many difficult changes that can come with the intra-organizational adoption of a practice, it is not unusual for organizations to encounter problems and fail to achieve a practice's expected performance and social benefits (Ferlie et al., 2005; Zbaracki, 1998). In particular, the adoption of stigmatized practices seems to be prone to adoption failure as actors tend to resist practices that are inconsistent with their norms and values (Canato et al., 2013; Jacqueminet, 2020). However, since neither organizational- nor intra-organizational adoption studies have yet systematically integrated the concept of stigma into their analyses, our understanding of how practices become stigmatized and how this impacts their adoption remains underdeveloped. This gap is significant because research on stigma suggests that this social construction may be a particularly critical source of adoption failure.

1.1.2 Stigma as a potential source of adoption failure

Stigma has been frequently conceptualized as a social evaluation (Pescosolido & Martin, 2015; Pollock et al., 2019) that, like other social evaluations, has a cognitive, affective and behavioral component (Dovidio et al., 2003). Based on this

conceptualization, stigma attributed to practices in organizations may be more widespread than adoption research suggests. Cognitively, people assign a stigma when they perceive certain attributes to violate their normative expectations (Goffman, 1963) rather than social norms. While social norms are broadly accepted rules of conduct within a society or social group (Gibbs, 1965), normative expectations are the specific beliefs about how someone or something should be in a given context, based on those social norms (Goffman, 1963). Since normative expectations are context-specific (Dovidio et al., 2003), even practices that seem innocuous or beneficial could become stigmatized (Kreiner et al., 2006). That is, they can become associated with undesirable characteristics and as a result discredited as a whole (Pollock et al., 2019). In fact, scholars have referred to stigma as “ubiquitous” (Dovidio et al., 2003, p. 7).

Second, stigma is likely to pose significant challenges for the adoption of practices in organizations because the social evaluation involves negative affective responses, such as fear, anger, and dislike, and discriminatory behaviors, including avoidance, violence, and refusal, directed at the stigmatized target or its proponents (Dovidio et al., 2003; Goffman, 1963). Crucially, the adoption of a stigmatized practice may erode the social acceptance of an organization as a whole (Devers et al., 2009; Hudson, 2008). However, this spillover effect depends critically on whether an organization makes a stigmatized practice the core or merely part of its activities (Kreiner et al., 2006). Third, stigma is challenging to overcome because as a moral evaluation it is driven by unconscious processes that are resistant to rational evidence and change (Pollock et al., 2019). Additionally, negative evaluations tend to exert a stronger and more enduring impact and are more resistant to disconfirmation than positive perceptions, which further contributes to the persistence of stigma (Ashforth, 2019).

The example of palliative care points to the context-specific nature of stigma and its possibly negative impact on practice adoption. Although palliative care can be

provided in various settings (WHO, 2016), the stigma associated with the practice is predominantly perceived as a problem in hospitals (Bandieri et al., 2023; Cherny, 2009; Shen & Wellman, 2019). The social norm in hospitals is to provide curative treatment, and patients, based on this norm, expect to be cured. Palliative care violates this normative expectation because, although it does not exclude curative measures, its primary focus is on treating life-limiting illness. This violation may be particularly pronounced in the context of children as they are generally associated with innocence and expected to have a long future ahead of them. As a result, preparing for their end-of-life can seem “inherently unnatural [to] many parents and physicians, who struggle to accept that nothing more can be done for a child” (Wiener et al., 2013, p. 3).

While palliative care is ideally initiated upon diagnosis and provided concordantly with curative treatments (Murray et al., 2017), referrals to palliative care services tend to be made in the late stages of disease, if they are made at all (Hausner et al., 2020). Such late referrals limit the potential benefits of palliative care (Murray et al., 2017) and can thus be considered adoption failures (Klein & Sorra, 1996). As one important reason for late referral, clinical studies point to the stigma attributed to palliative care by patients and their caregivers (e.g. Bandieri et al., 2023; Cherny, 2009; Salins et al., 2020; Shen & Wellman, 2019). Specifically, the stigma surrounding palliative care – perceived as giving up and solely focusing on EOL care – can trigger fear and shock in patients, leading them to resist using the practice (Zimmermann et al., 2016).

1.1.3 Limited insights into managing stigma in organizations

Since stigma is a potentially critical cause of adoption failure, the question arises as to how it can be overcome or at least mitigated. Stigma research has predominantly focused on practices as a stigmatizing attribute of organizations (Pollock et al., 2019). Consequently, while these studies have identified various stigma management strategies (Zhang et al., 2020), these findings may not be transferrable to managing

the stigmatization of practices within organizations, especially those that are generally seen as legitimate and socially accepted, such as hospitals (Paetzold et al., 2008).

Organizations may experience either “core” or “event” stigma from the practices they employ (Hudson, 2008). Core stigma results when organizations are inextricably linked to a stigmatized practice, such as men’s bathhouses (Hudson & Okhuysen, 2009), Mixed Martial Arts (MMA) organizations (Helms & Patterson, 2014), and abortion clinics (Augustine & Piazza, 2022). In contrast, event stigma arises from practices that are perceived as discrete, anomalous, or episodic transgressions such as bankruptcy (Sutton & Callahan, 1987) and fraud (Frandsen & Morsing, 2021). For organizations, the consequences of stigma can, for example, involve economic and regulatory sanctions (Helms & Patterson, 2014; Hudson & Okhuysen, 2009), stakeholder disengagement (Vergne, 2012), internal tensions related organizational identity (Tracey & Phillips, 2016), and discrimination against an organization’s members (Frandsen & Morsing, 2021). Thus, ultimately, stigma represents a threat to an organization’s performance and survival (Carberry & King, 2012; Hudson, 2008).

Because event stigma is linked to a specific stigmatizing practice, an organization can eliminate the stigma by discontinuing or “decoupling” the practice (Elsbach & Sutton, 1992), thereby “redrawing its boundaries to exclude the offending part(s)” (Devers et al., 2009, p. 158). Since for core-stigmatized organizations the stigmatizing practice is an integral part of their activities, decoupling is hardly possible for them. Instead, core-stigmatized organizations may employ shielding and concealing strategies, such as picking isolated locations or disguising their activities (Hudson & Okhuysen, 2009; Wolfe & Blithe, 2015). Moreover, they may adapt the stigmatizing practice (Helms & Patterson, 2014), engage in co-optation, whereby they draw attention to the value their stigma to take advantage of it (Campana et al., 2022), and reframe the stigma in a more positive light (Tracey & Phillips, 2016).

While various stigma management strategies employed by organizations can mitigate, and some even remove (Hampel & Tracey, 2017), organizational stigma, these strategies may be less effective in the context of practice adoption within organizational settings untainted by stigma, such as hospitals adopting palliative care. First, decoupling is essentially equivalent to adoption failure. Second, shielding and concealing may prevent organizational members from engaging in the practice. Third, as mentioned earlier, practice adaptation can lead to the loss of a practice's core features. Lastly, not all stigmas can be co-opted or reframed in a more positive light, such as the stigma surrounding palliative care as giving up, EOL care, and death.

Similarly, research on stigma management within organizations holds little insights for the adoption of stigmatized practices because for the most part it sought to understand the determinants and effects of disclosure decisions by individuals with concealable stigmas, such as being homosexual (e.g., Jones & King, 2014; Ragins, 2008). Additionally, scholars have largely overlooked the iterative and continuous process actors perform to manage the effects of stigma collectively with other actors (Aranda et al., 2022). Given that stigma is socially constructed (Link & Phelan, 2001), this oversight limits our understanding of when efforts to manage stigma reduce, perpetuate, or even worsen the perceptions and responses of critical audiences.

Research on palliative care has suggested renaming the practice “supportive care” to manage its stigma because the term's more positive connotation can facilitate earlier referrals (Dai et al., 2017; Dalal et al., 2011). However, while this renaming might initially mitigate stigma, the ambiguity of the new term (Cramp & Bennett, 2013) could lead to similar associations with EOL care and fear, ultimately undermining the intended benefit of the name change (Zambrano et al., 2020). Therefore, rather than concealing the association of palliative care with death and dying, other studies advocate for actively changing perceptions of palliative care, for example, through

educational efforts (Zimmermann et al., 2016). Yet, more elaborated insights into how such a change in perceptions can occur, are still rare, particularly given that stigma limits the desired, “espoused” performance (Rerup & Feldman, 2011, p. 577) of palliative care in hospitals as a practice that improves quality of life.

1.2 Outline of the study

1.2.1 Research question on adopting stigmatized practices

Overall, research on practice adoption and stigma indicates that the adoption of stigmatized practices in organizations requires more concerted research attention. First, adoption studies suggest that stigmatized practices are introduced into organizations, albeit potentially relatively rarely, because at least some social audiences perceive them as violating social norms and therefore contest them. Moreover, adoption research indicates that the adoption of stigmatized practices within organizational settings is prone to failure, as organizational members tend to resist practices that are at odds with established norms and therefore a poor cultural fit.

Second, research on stigma adds to our understanding by suggesting that the stigmatization of practices within organizations may be a more prevalent than adoption studies suggest. This is because stigma arises from the violation of context-specific normative expectations, rather than social norms in general, and from this perspective, even seemingly innocuous or beneficial practices may carry the potential for stigma. This prevalence is problematic since stigma erodes social acceptance, which is a key determinant of practice adoption. Stigma can elicit strong negative affective and behavioral responses in people and is difficult to overcome. Thus, stigma research points to the stigmatization of practices as a possibly critical source of adoption failure.

Although both research on practice adoption and stigma imply that practices can be stigmatized and that stigma could be a source of adoption failure, none of these streams of research has yet thoroughly explored how practices can be stigmatized and

how this shapes their adoption in organizations. Accordingly, our understanding of the adoption of stigmatized practices is still at a particularly nascent state. This includes a lack of understanding of how stigma can be managed in organizational settings, as studies have focused more on the responses of rather than within organizations to stigma. Scholars have also overlooked the iterative and continuous processes actors engage in to manage stigma collectively with other actors.

In sum, the adoption of stigmatized practices in organizations needs to become a subject of more concerted research efforts. This observation leads me to formulate the following fundamental research question: *How are stigmatized practices constructed within organizational settings and with what impact on adoption?* To address this question, I draw on a practice perspective (Feldman & Orlikowski, 2011), as it takes practices seriously (Reckwitz, 2002) and, with relationality as a core principle (Jarzabkowski & Bednarek, 2018), is suitable to fruitfully advance existing theorizing of actors' collective efforts to manage stigma. I first develop a conceptual view of the adoption of stigmatized practices and then expand this view on the grounds of an empirical study. In the following, I explain the approach of my study in more detail.

1.2.2 Conceptual development of a (de-)stigmatizing view

To develop a practice perspective on the adoption of stigmatized practices in organizations, I first present a detailed review of existing research on practice adoption and stigma in Chapter 2. Based on this review, I emphasize the need for a deeper understanding of the adoption of stigmatized practices in organizations and argue that a practice perspective can meaningfully enhance both adoption and stigma research. I then draw on commonly recognized practice-theoretical principles (e.g. Feldman & Orlikowski, 2011; Lê & Bednarek, 2017) to move beyond extant understandings of stigma in general and stigmatized practices in particular.

A practice perspective advances current understandings of stigma and responses to stigma by not treating them as independently given phenomena, but as mutually constituted through people's practices (Feldman & Orlikowski, 2011; Orlikowski, 2002), which are organized constellations of actions (Schatzki, 2002). To account for the performative nature of practices (Nicolini & Monteiro, 2017), I refer to these actions as "stigmatizing" when they enact stigma and "destigmatizing" when they counteract the discreditation. The relational view of a practice perspective implies that stigmatizing and destigmatizing are not separate but innately entwined, even mutually constitutive flows of action (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017). A practice perspective therefore directs us to examine the construction and adoption of stigmatized practices within organizational settings as (de-)stigmatizing.

Critically, I see the view of (de-)stigmatizing as complementing and not substituting for extant conceptualizations of stigma. I argue that it can highlight some aspects that may be overlooked when privileging stigma as an outcome of social construction processes at the expense of (de-)stigmatizing as its everyday enactment.

1.2.3 Empirical elaboration of a (de-)stigmatizing view

To elaborate on the conceptual perspective of (de-)stigmatizing, I conducted a single in-depth case study of a pediatric palliative care (PPC) service at a hospital, incorporating seven clinical cases of children who qualified for the service as embedded units of analysis (Yin, 2009). In [Chapter 3](#), I lay out the field study's design, including the research context and my methods of data collection and analysis.

The case of PPC is not only theoretically revelatory, given the stigma associated with the practice, but also of practical importance. Due to the evidenced benefits of palliative care, the World Health Organization (WHO) declared the practice "an ethical responsibility of health systems" (WHA, 2014, p. 2), emphasizing the need for its widespread adoption by hospitals. Notably, palliative care, for both adults and children,

improves the quality of life of patients with life-limiting illnesses and that of their families by alleviating their physical, psychosocial, and spiritual suffering (WHO, 2020). Thus, gaining a better understanding of how this practice can be successfully adopted in hospitals is crucial. The case of PPC that I explored offers this understanding because, rather than renaming the practice, the PPC team at the hospital focused on changing families' and healthcare professionals' perceptions of it.

My empirical study is designed to reconstruct the specific clinical cases in order to trace the adoption process of PPC. This case-focused approach allows for an in-depth exploration of how PPC is introduced and integrated into everyday clinical practice. Given the sensitive nature of the context, the main data source for information about the clinical cases came from interviews. I interviewed members of the interdisciplinary PPC team, as well as healthcare professionals who acted as gatekeepers to the PPC service by making referral decisions. These interviews were complemented by a year of observations of the PPC team's weekly meetings, and numerous documents.

Using an iterative approach to data analysis (Locke et al., 2008), I identified various stigmatizing and destigmatizing dynamics, their triggers, and impact on adoption. I present these findings in Chapter 4 through detailed narratives of four clinical cases. I found that stigmatizing involves actors separating themselves from a practice in ways that suppress its espoused enactment, leading to a discrediting meaning of the practice. In contrast, destigmatizing involves actors aligning themselves with other focal audiences of the practice in ways that cultivate its espoused enactment and thereby valorize it. While stigmatizing dynamics are triggered by people's inadequate understandings of a practice, whether in "general" or "practical" terms (Schatzki, 2002, p. 79), destigmatizing dynamics unfold when these understandings are wise (Goffman, 1963, p. 19). Ultimately, stigmatizing dynamics undermine people's ability to

understand, accept, and engage in a practice as it is espoused within the organization, while destigmatizing dynamics empower them to adopt it.

I drew my findings together in a conceptual model that theorizes practice adoption as a process of (de-)stigmatizing. I discuss this model, the theoretical contributions of my findings, the study's limitations and implications for future research in Chapter 5. My study's theoretical contributions are that it leads us to reconsider the adoption of practices in organizations and that it advances a more integrated view of stigma.

First, my theorizing reveals that stigmatized practices are not merely a subset of undesirable practices that may or may not be introduced into organizations; rather, they are the result of ongoing, mundane activities within organizations. Second, my findings address the dilemma of practice adaptations in implementation research: while these adaptations can increase acceptance among focal audiences, they can also result in the loss of the practice's core features. My findings suggest that, rather than adapting a practice, aligning its enactment with focal audiences to empower them in adopting the practice may be a more fertile approach. This approach also contributes to solving the puzzle of recursiveness in research on routine change. Third, my findings prompt a shift away from the assumption that people are inherently knowledgeable actors, as postulated by practice research, and towards a greater focus on how they become knowledgeable and on the consequences of their inadequate understandings.

Fourth, my theorizing contributes to a more integrative view of stigma as a social construction by advancing a relational view in which stigma and associated responses are seen interdependent and mutually constitutive. Fifth, the findings reveal how the everyday activities of constructing and responding to stigma are consequential for and constitutive of broader processes of stigmatization and destigmatization. Sixth, my findings are a step towards overcoming the pronounced divide between social actors

in stigma research by showing that actors can take on different roles through their actions at a given moment and over time.

Finally, Chapter 6 summarizes my findings by offering actionable insights for the adoption of PPC in hospitals, and it concludes that the view of (de-)stigmatizing makes the adoption of stigmatized practices in organizations less perplexing.

2 POSITIONING

To begin my inquiry, I first argue that the adoption of stigmatized practices within organizations constitutes a significant yet underexplored research puzzle, one that can be effectively addressed through a practice perspective. I develop this argument in two parts. First, I examine existing research on practice adoption. This review reveals that while prior studies recognize the possibility of stigmatized practices being introduced into organizations, they have largely overlooked how such practices are integrated into an organization's ongoing activities. If anything, they suggest the organizational integration of stigmatized practices is prone to failure, as these practices lack the social acceptance essential for successful adoption. However, because adoption studies have not systematically incorporated the concept of stigma into their analyses, they provide limited insight into how practices become stigmatized and how this influences their adoption. To address this gap, I turn to existing understandings of stigma.

In the second part of my positioning section, I argue that stigma is a potentially critical source of adoption failure, as it not only undermines social acceptance but is also pervasive. This ubiquity means that even seemingly innocuous practices may become stigmatized, suggesting that stigmatized practices are likely more common than adoption studies have traditionally acknowledged. While existing stigma research highlights the significance of this issue, it provides little insight into addressing the puzzle of adopting stigmatized practices. To date, stigma research has primarily focused on practices as a stigmatizing attribute of organizations and on the management of stigma *of* organizations, rather than exploring stigma management *within* them. I therefore conclude the review by introducing a practice perspective that encourages the study of stigma within organizations as (de-)stigmatizing. As I will argue, this perspective can meaningfully advance both research on practice adoption and stigma, as it takes practices seriously and supports the relational nature of stigma.

2.1 Adoption of practices in organizations

The (non-)adoption of practices in organizations has long been a central concern in organizational literature (Gondo & Amis, 2013; Lewis & Seibold, 1993; Sturdy, 2004). Three streams of research provide insights into this core issue. The first stream examines the introduction of new practices into organizations (e.g. Fiss & Zajac, 2004; Westphal et al., 1997). The second stream explores the implementation of practices within organizations after their initial introduction (e.g. Ansari et al., 2010; Jacqueminet & Durand, 2020). Finally, the third stream of research focuses on the change of practices as organizational routines (e.g. Bertels et al., 2016; Bucher & Langley, 2016). In the next three chapters, I review each of these streams of research to ground my inquiry and to surface challenges associated with the adoption of practices in organizations, especially when they are stigmatized. I conclude this review by arguing that the adoption of stigmatized practices in organizations is still largely a puzzle.

2.1.1 Introduction of contested, stigmatized practices

Organizational practice adoption is a process that begins with a decision – typically made by senior managers – to introduce a new practice into an organization (Klein & Sorra, 1996). Ideally, organizations introduce practices that align with broader societal beliefs and norms (Kennedy & Fiss, 2009; Tolbert & Zucker, 1983; Westphal et al., 1997). Such practices are seen as legitimate, i.e. proper, appropriate, and desirable (Suchman, 1995), and are thus widely supported (DiMaggio & Powell, 1983).

However, not every practice receives broad-based social acceptance and support. Research on contested practices highlights that organizations operate at the intersection of multiple social audiences, each with differing moral values, ideologies, and belief systems (Chuang et al., 2011; Jung & Mun, 2017; Sanders & Tuschke, 2007). Due to these differences in “moral convictions” among social audiences (Pollock

et al., 2019, p. 449), practices and adopting organizations may be simultaneously viewed positively by some audiences and negatively by others (Hudson, 2008).

In particular, contested practices “face stiff opposition” from “at least some powerful actors” in the organizations’ environment (Sanders & Tuschke, 2007, p. 34). This opposition arises because these actors perceive the practices as embodying “strongly counternormative elements” (Naumovska, Zajac, et al., 2021, p. 410), rendering them improper, inappropriate, or undesirable in their view (Suddaby et al., 2017). In extreme cases, critical audiences may evaluate norm-deviant practices as so illegitimate that they stigmatize them (Elsbach & Sutton, 1992; Hudson, 2008).

Stigmatized practices are thus a specific type of contested practice, characterized by intense negative moral judgment and strong opposition from social audiences, as they view them as undesirably deviant from prevailing norms (Chuang et al., 2011). Newly created practices or those adopted from other fields are “particularly vulnerable to contestation and stigmatization” (Chuang et al., 2011, p. 191) since they often transgress social norms (Lawrence, 2017; Rao et al., 2003). For example, Chuang et al. (2011) hinted at same-sex partner health benefits as an emergent practice that was socially contested and stigmatized by antigay activists and religious associations for challenging traditional family norms. Similarly, Reinmoeller and Ansari (2016) pointed to competitive intelligence as an innovative information-gathering practice, widely contested and stigmatized by the public for defying ethical and legal standards.

While direct research on the introduction of stigmatized practices into organizations has remained rare, scholars have increasingly examined the organizational uptake of contested practices in general (Jung & Mun, 2017; Naumovska, Gaba, et al., 2021). Organizations that adopt contested practices run the risk of falling into disrepute themselves (Chuang et al., 2011; Sanders & Tuschke, 2007). Still, previous research has shown that the introduction of contested practices into organizations is not unusual

and has described how such contested adoptions occur (e.g. Briscoe & Murphy, 2012; Fiss et al., 2012; Jung & Mun, 2017; Sanders & Tuschke, 2007).

Organizations may adopt socially contested practices not only for their potential performance benefits (Sturdy, 2004) but also in pursuit of social objectives (Jung & Mun, 2017). For example, organizations may give in to pressures from social movements or other interest groups to introduce a certain contested practice in order to secure their support or avoid conflict with them (Briscoe & Safford, 2008; Fiss & Zajac, 2004). Moreover, organizations may want to establish themselves as “exemplary users” of a practice that “could possibly disrupt the social order” and to thereby either improve or preserve their social position in a field (Compagni et al., 2015, p. 268). Such early adoption is often facilitated by managers who have experiences with similar contested practices (Kraatz & Moore, 2002; Sanders & Tuschke, 2007).

In sum, while organizations generally strive to introduce practices that have garnered broad social acceptance, such acceptance is not always assured. Social audiences can hold differing moral convictions causing practices to misalign with their advocated norms and ultimately leading them to contest – and potentially stigmatize – these norm-deviant practices. Despite the risk of reputational damage, organizations may still introduce socially contested practices to leverage their potential benefits. The realization of these benefits, however, hinges on the organization’s implementation efforts and its capacity to change established routines, as I detail in the next chapters.

2.1.2 Practice implementation and adaptation

Once a practice has been introduced into an organization, it needs to be integrated into its ongoing operations or daily activities (Klein & Sorra, 1996). This implementation process is seldom straightforward, even for practices that are widely seen as legitimate (Gondo & Amis, 2013), as practices are “rarely blueprints that can simply be plugged into a context in unproblematic ways” (Jarzabkowski et al., 2016, p. 253). In fact, new

practices typically possess certain characteristics that do not initially align or ‘fit’ with those of the adopting organizations (Ansari et al., 2010; Gondo & Amis, 2013).

Scholars have identified three types of misfit that affect implementation processes: technical, cultural, and political (Ansari et al., 2014; Ansari et al., 2010). First, a technical misfit arises when *focal audiences* in an organization, such as employees, lack skills and technologies to perform a practice (Ansari et al., 2010). Second, a cultural misfit occurs when a practice’s characteristics are misaligned with the norms and values of these audiences (Canato et al., 2013; Klein & Sorra, 1996). Third, a political misfit manifests when a practice conflicts with the interests, power structures, and agendas of focal audiences (Carlile, 2004; Eisenhardt & Zbaracki, 1992).

Addressing technical, cultural, and political misfits is essential for organizations to increase the acceptance of a practice among focal audiences (Ansari et al., 2010; Sillince et al., 2001). Acceptance is a key determinant of both the introduction and implementation of practices in organizations (Gondo & Amis, 2013; Kostova & Roth, 2002) because of its “action-generating properties” (Kostova & Roth, 2002, p. 217). When focal audiences lack acceptance for a practice, it can result in their widespread reluctance to engage in it (Ferlie et al., 2005; Raman & Bharadwaj, 2012), ultimately stalling or hindering implementation efforts (Canato et al., 2013).

Overcoming technical, cultural, and political misfits during implementation usually requires change in both the organization (organizational change) and the practice (practice adaptation) (Ansari et al., 2014; Leonard-Barton, 1988). First, necessary organizational change may entail time-consuming shifts in roles, power relationships, skills, and collaborative routines (Barley, 1990; Edmondson et al., 2001; Raman & Bharadwaj, 2012). Second, practice adaptations may involve discursive or substantive modifications (Ansari et al., 2014; Canato et al., 2013) to the *espoused practice* (Jarzabkowski et al., 2016) which “embodies the abstract idea” of a practice (Feldman

& Pentland, 2003, p. 95). More specifically, substantive adaptations to the espoused practice may include, altering or removing rules, principles and concepts that prescribe how a practice is to be performed (Ansari et al., 2014; Ansari et al., 2010).

Crucially, practice adaptations can pose a dilemma for organizations. On the one hand, they can make a practice more meaningful or suitable within an organizational setting, thereby increasing its acceptance among focal audiences (Ansari et al., 2010). On the other hand, such adaptations can lead to the loss of a practice's "core essence" (Ansari et al., 2014, p. 1317). For example, if organizations were to implement same-sex partner health benefits (Chuang et al., 2011) less fully than health benefits provided to heterosexual partners, in an attempt to appease critical audiences, it would undermine the practice's original value of promoting equality and inclusivity.

Organizations may address the practice adaptation dilemma by ordering or even forcing audiences to implement the practice (Canato et al., 2013; Nutt, 1986). Through this "coerced implementation", interpretations of the practice by focal audiences may evolve as they gradually experience its impact on organizational activities (Canato et al., 2013). Ideally, focal audiences will internalize the value of a practice and, as a result, become committed to it (Gondo & Amis, 2013; Kostova & Roth, 2002).

However, a coerced implementation has its limits in fostering genuine acceptance of a practice. First, it is less feasible in professional organizations, such as hospitals, where professionals like physicians have significant autonomy over their work (Anteby et al., 2016; Ferlie et al., 2005). Second, while coercive pressure may bring about changes in focal audiences' interpretation of a practice, these audiences are less accommodating if they perceive the characteristics of a practice as conflicting with their core moral convictions (Canato et al., 2013). Third, coercion and contestation cannot coexist indefinitely; eventually the tension must be resolved through adaptation, decoupling or abandonment of the practice (Ansari et al., 2010; Canato et al., 2013).

Both decoupling and abandonment are forms of implementation failure (Klein & Sorra, 1996). Decoupling occurs when a practice is introduced into an organization but is not integrated into its ongoing activities and enacted by focal audiences (Hengst et al., 2020). Abandonment involves a practice being completely discontinued or discarded due to a lack of alignment or support (Burns & Wholey, 1993). Given the significant changes that implementing a new practice may require, it is not surprising that organizations frequently encounter challenges in the process, leading them to decouple from or abandon the practice altogether, thereby failing to realize its anticipated benefits (Ferlie et al., 2005; Zbaracki, 1998).

To conclude, there seems to exist a disconnect between research on the introduction of practices into organizations and implementation studies. Although the latter recognizes that new practices can be contested due to a lack of fit with the norms and values of focal audiences, they have not yet considered the possibility that norm-deviant practices may be stigmatized. As a result, implementation studies offer limited insights into whether and how stigmatized practices can be successfully integrated into an organization's activities, despite facing an extreme negative evaluation and a heightened opposition from audiences. This neglect seems critical, in particular since stigmatized practices can drive societal change. As indicated, same-sex partner health benefits, for example, promote the equal treatment of lesbian and gay employees.

I now turn to research examining the change of practices as routines. While this body of work has also not yet specifically addressed stigmatized practices, it offers valuable insights into practice adoption by providing a more dynamic, micro-level perspective compared to studies on the introduction and implementation of practices.

2.1.3 Change of practices as organizational routines

Practices do not exist in isolation but rather in “configurations” (Nicolini & Monteiro, 2017, p. 111), meaning they are always interconnected with other practices (Shove et

al., 2012). Due to this inherent interdependence of practices, implementing a new practice in an organization requires its integration with existing organizational practices (Edmondson et al., 2001). These existing practices are referred to as “routines” when they represent “repetitive, recognizable patterns of interdependent actions carried out by multiple actors” (Feldman & Pentland, 2003, p. 95). Practices in the form of routines have garnered considerable research attention because they are seen as integral to the functioning of organizations (Parmigiani & Howard-Grenville, 2011).

While earlier perspectives characterized routines as rigid sequences (e.g., Gersick & Hackman, 1990; Nelson & Winter, 1982), more recent research describes them as dynamic *performances* (Feldman et al., 2016): ongoing flows of action that are flexible and continuously evolving rather than mere repetitions. Research from the dynamic routines perspective suggests that the integration of new practices often involves undesirable performance deviations (Raman & Bharadwaj, 2012), which arise from the recursive dynamics inherent in the established practices (Bucher & Langley, 2016).

Performance deviations occur when focal audiences do not enact a practice as it is espoused within the organization (Feldman & Pentland, 2003; Howard-Grenville, 2005; Raman & Bharadwaj, 2012). These deviations may be desirable or undesirable (Orlikowski, 2000). Desirable performance deviations involve flexible adaptations – improvisations and workarounds – that safeguard or enhance the espoused practice (Bertels et al., 2016). In contrast, undesirable performance deviations encompass actions and inactions that undermine the espoused practice (Raman & Bharadwaj, 2012), thereby preventing the realization of its anticipated benefits.

New practices are particularly susceptible to undesirable performance deviations, as focal audiences, both individually and collectively, have yet to reorient their existing routines to accommodate the new practice (Canato et al., 2013; Edmondson et al., 2001). Reorienting routines requires adjusting the mutually reinforcing espoused

aspects and actual performances that define them (Feldman & Pentland, 2003). In this recursive relationship, espoused rules, principles, and concepts guide how routines are performed, while performances, in turn, reinforce the espoused aspects (Feldman et al., 2016). This interdependence makes reorienting routines a practical challenge and theoretical puzzle (Bucher & Langley, 2016). These issues are especially evident when a new practice that has to be integrated into existing routines is not accepted, as it deviates from the norm and is thus a poor cultural fit (Bertels et al., 2016).

Still, studies of routine change offer insights into how espoused aspects and actual performances of routines can be reoriented to accommodate a new practice (e.g., D’Adderio, 2014; Edmondson et al., 2001). These studies show that when actors (e.g., managers) change espoused aspects of routines, merely announcing these changes is insufficient to prompt corresponding shifts in actual performances. Instead, actors need to disrupt ongoing routine performances (Jarzabkowski et al., 2012) by placing focal audiences in settings outside their everyday activities (Bucher & Langley, 2016). Such an approach allows them to reflect on their work, discuss the changes, and begin internalizing them (Bucher & Langley, 2016; D’Adderio, 2014; Edmondson et al., 2001). This initial routine change can then be fostered through vicarious learning (Bresman, 2013) and experimentation (Rerup & Feldman, 2011) in everyday practice.

While the existing studies offer insights into how actors can “seed” routine change (Bucher & Langley, 2016, p. 609), our understanding of how these changes are sustained and solidified in daily practice is still limited. Notably, current approaches fall short of explaining how recurring undesirable performance deviations can be reoriented to align more closely with the espoused practice. This gap leaves us with an incomplete picture of how practices evolve from “weak” to “strong” routines (Bapuji et al., 2012) – that is, from being infrequently and inconsistently enacted to becoming well-coordinated, repetitive, and recognizable patterns of action.

2.1.4 Adoption of stigmatized practices as a puzzle

Collectively, existing research describes the adoption of practices in organizations as a contested social process. The espoused characteristics of new practices rarely, if ever, initially align with the characteristics of the adopting organizations, leading to a limited acceptance of the practice among employees and other focal audiences. When audiences perceive a practice as deviating undesirably from social norms, they may not simply contest the practice, but stigmatize it – that is, strongly devalue and fiercely oppose it. Nonetheless, stigmatized practices may be introduced into organizations for their anticipated benefits, as the case of same-sex partner health benefits indicates.

However, whether stigmatized practices can then be integrated into an organization's activities is still a puzzle, as neither studies on practice implementation nor studies on routine change have yet even acknowledged that practices can be stigmatized. As a result, we lack insight into whether stigmatized practices can be adapted without losing their essential characteristics, or whether existing routines can be reoriented to include a new, yet stigmatized practice. Current studies, if anything, suggest that stigmatization can contribute to adoption failure by excluding practices from social acceptance, which is a critical determinant of practice adoption. Thus, more attention should be paid to the stigmatization of practices in adoption processes.

The neglect of stigma in adoption research is surprising given that it has already become an important concept for examining problematic issues affecting the lives of and within organizations (Jones & King, 2014; Pollock et al., 2019; Zhang et al., 2021). I address this neglect, continuing with a review of stigma research in the next chapter.

2.2 Construction and countering of stigma

Inquiries into stigma originated with Goffman's analysis (1963) of stigma as both an individual and social construct, and have since expanded to include other *targets*, such as occupations (e.g., Ashforth & Kreiner, 1999) and organizations (e.g. Hudson,

2008). Research on stigma across various targets has traditionally focused on stigma as a sociocognitive perception or evaluation outcome (Major & O'Brien, 2005; Pollock et al., 2019). In contrast, more recent studies examine stigma not as an outcome, but as a dynamic process of social construction, thus shifting the focus toward stigmatization (Link & Phelan, 2001; Pescosolido & Martin, 2015; Zhang et al., 2021).

First, studies from a social evaluation perspective have identified various types, characteristics, and consequences of stigma, as well as responses aimed at mitigating it (Dovidio et al., 2003; Pescosolido & Martin, 2015; Zhang et al., 2021). Second, process-oriented studies offer insights into the emergence (e.g. Wang et al., 2021), transfer (e.g. Kvåle & Murdoch, 2021), maintenance (e.g. Dong et al., 2023), or removal of stigma (e.g. Siltaoja et al., 2020). Below, I provide a review of stigma research from the social evaluation and process-oriented perspectives. I then argue that research from these perspectives has important limitations and introduce a practice perspective, aiming to advance both the study of practice adoption and stigma.

2.2.1 Social evaluation perspective

In his classic monograph, Goffman (1963) defined stigma as an attribute that deeply discredits a person by linking the person to a set of undesirable characteristics. For example, a person who has a “physical deformity” may be viewed not only as “physically unattractive but also generally ‘bad’, lacking in intelligence, morality, and/or social skills” (Paetzold et al., 2008, p. 187). Crucially, Goffman established stigma as a social evaluation (Dovidio et al., 2003). As such, it is a social construct: it is “less about ‘true’ or ‘objective’ attributes” (Devers & Mishina, 2019, p. 17), and more about those perceived and subjectively assigned to a target by others (Pollock et al., 2019).

Types and consequences of stigma. As a social evaluation, stigma has been extensively explored through efforts to categorize its types and identify its consequences (e.g., Ashforth & Kreiner, 1999; Goffman, 1963; Hudson, 2008).

Goffman (1963) hinted at four types of stigma based on common *stigmatizing attributes*. Individuals may be attributed a physical stigma due to physical deformities (e.g., scars); a moral stigma due to character blemishes (e.g., addictions); a social stigma based on an association with a stigmatized person (e.g., an addict); or a categorial stigma tied to a group membership based on race, gender, or religion. Goffman (1963) emphasized that, once attributed to people, stigmas serve as a justification for excluding, attacking, or otherwise discriminating against them.

Similar to individuals, occupations have been attributed physical, moral, and social stigmas. Specifically, occupations are attributed a stigma if their work involves dirt, death, or danger (physical stigma); dubious, intrusive, or aggressive methods (moral stigma); and/or associations with stigmatized people or subservient relationships (social stigma) (Ashforth & Kreiner, 1999; Hughes, 1958). Members of occupations stigmatized on these three dimensions are referred to as “dirty workers” because they “are seen to personify” the work and are therefore “stigmatized in the same way as the work they perform” (Mavin & Grandy, 2013, p. 232). For example, garbage collectors are seen as “scum” (Hamilton et al., 2019, p. 894), slaughter house workers as “killers” (Baran et al., 2016, p. 365), and exotic dancers as “bad girls” (Mavin & Grandy, 2013, p. 232). Due to this devaluation, members of stigmatized occupations, much like people who are stigmatized based on personal characteristics, are vulnerable to various types of discrimination (Shepherd et al., 2022; Toubiana & Ruebottom, 2022).

Research on organizational stigma has suggested that organizations experience either “event” or “core” stigma (Hudson, 2008). Event stigma arises from “discrete, anomalous, episodic events” (Hudson, 2008, p. 253), such as bankruptcy (Sutton & Callahan, 1987), product recalls (Zavyalova et al., 2012), and financial fraud (Frandsen & Morsing, 2021). In contrast, core stigma results not from specific misconduct, but rather from the practices an organization engages in routinely because they are at the

heart of its business, as in the case of arms dealer (Vergne, 2012), mixed martial arts (MMA) organizations (Helms & Patterson, 2014), and abortion clinics (Piazza & Augustine, 2022). As Hudson (2008) notes, core stigma in an organization is due to the nature of “who it is, what it does, and whom its serves” (p. 253). For organizations, both event and core stigma can lead to social and economic sanctions (Devers et al., 2009), making it difficult for them to attract customers, hire employees, secure financing, and other necessary resources (Frandsen & Morsing, 2021; Hudson & Okhuysen, 2009; Tracey & Phillips, 2016). Ultimately, then, stigma can pose a threat to organizational performance and viability (Carberry & King, 2012).

Characteristics of stigma. Although stigma can have a particularly negative impact on its targets, whether and how stigma is actually “enacted” or “made real” (Pescosolido & Martin, 2015, p. 91), depends not only on its type but also on its perceived characteristics (Jones et al., 1984; Ragins, 2008; Zhang et al., 2021). As Ragins (2008) explains, “stigmas involve a range of characteristics that evoke different reactions in different social settings” (p. 206). Extant research points to four defining characteristics of stigma that influence people’s perceptions of and responses to the negative social evaluation, including concealability, centrality, controllability, and peril (Crocker et al., 1998; Jones et al., 1984; Kreiner et al., 2022; Zhang et al., 2021).

Concealability refers to the extent to which a stigmatizing attribute is visible or rather hidden or disguised (Dovidio et al., 2003; Ragins, 2008). Concealability matters because for an attribute to elicit a response at all, it must first be perceived by others (Goffman, 1963; Ragins, 2008). Centrality relates to the relative proximity of a stigmatizing attribute to a target’s identity (Kreiner et al., 2006; Zhang et al., 2021). Regardless of the type of target, the more central or core the source of a stigma is to it, the greater the resultant stigmatizing (Kreiner et al., 2006). For example, while the coroner is attributed a physical stigma for dealing with cadavers on a regular basis,

this is not the case for a general physician who does so only occasionally (Zhang et al., 2021). Controllability involves the extent to which a target is seen as responsible for having or maintaining a stigmatizing attribute (Ragins, 2008). Attributes that are perceived as controllable (e.g., HIV infection) are viewed as more blameworthy than those that are not (e.g., congenital deformity) and are therefore evaluated and sanctioned more negatively (Devers et al., 2009; Ragins, 2008; Zhang et al., 2021).

One of the key characteristics shaping people's responses to stigma is the extent to which they perceive it as a peril or threat (Jones et al., 1984; Link & Phelan, 2014; Mishina & Devers, 2012; Stangor & Crandall, 2003; Yang et al., 2007; Zhang et al., 2021). People may perceive stigma as threat to a material or concrete good, such as health and safety ("tangible threat") and/or to the social, political, or spiritual order ("symbolic threat") (Crandall & Moriarty, 1995; Yang et al., 2013, p. 57). The more stigma takes on the character of a danger for people, threatening to diminish or destroy what they value most (Yang et al., 2007), the more it tends to evoke strong negative emotions (e.g., disgust, fear, and anger) and behavioral responses in them (Link et al., 2004; Lyons et al., 2017; Stone et al., 1992).

Since stigma is socially constructed, the threat it poses to people is not necessarily 'real' but is based on their perceptions and judgements (Pollock et al., 2019). So, for instance, although MMA is perceived as physically extremely harmful, there is no evidence that it is actually more dangerous than other combat sports (Helms & Patterson, 2014). Indeed, given the socially constructed nature of stigma, even "seemingly innocuous" actors and practices may be attributed a stigma and perceived as a threat (Kreiner et al., 2006, p. 620). Veiling, for example, is widely perceived as a symbolic threat in Western societies because the practice is associated with "the problems of Islam" and, in particular, is seen as a sign of Muslim women's submission to "patriarchal authority" and their "lack of agency" (Sandikci & Ger, 2010, p. 18).

However, stigma can vary greatly depending on the cultural context (Dovidio et al., 2003), as in the case of veiling. “In countries such as Turkey, Egypt, and Malaysia”, veiling is seen by many not as a threat but as an “ordinary” and “fashionable” clothing practice (Sandikci & Ger, 2010, p. 19). Culture exists at many different levels – e.g., group, organizational, field, societal – and each of these cultural contexts might affect how stigma is constructed, perceived, and responded to (Kreiner et al., 2022). The context-specific nature of stigma implies that targets of stigma “are not necessarily recognized as such by [everyone] or at all times, yet they bear an enduring mark that signals a socially recognized difference” that can evoke negative responses from people who perceive it (Link et al., 2004; Vergne, 2012, p. 1029).

Responses aimed at mitigating stigma. In addition to examining the types, characteristics, and consequences of stigma, research from a social evaluation perspective has extensively investigated the responses of its targets (Pollock et al., 2019; Zhang et al., 2021). Although some studies have suggested that targets of stigma can leverage the negative social evaluation (e.g., Helms & Patterson, 2014), or that it even has “built-in benefits” (Kassinis et al., 2022, p. 2155), most research has concluded that targets perceive stigma as a burden that they seek to mitigate and, if possible, remove forever (Kreiner et al., 2022; Zhang et al., 2021). In particular, the literature describes a variety of responses of targets that aim to mitigate the enactment of stigma by influencing the visibility and centrality of stigmatizing attributes (Goffman, 1963; Kreiner et al., 2022; Zhang et al., 2021). Common responses that influence these stigma characteristics include concealment, dilution, and shielding.

Concealment involves targets of stigma hiding or disguising their discrediting attributes to “pass” as normal (Goffman, 1963, p. 73; Hudson, 2008; Kreiner et al., 2022). For example, gay men may dodge questions about their personal lives in the workplace (King et al., 2017), sex workers may lie to relatives about their occupation

(Kong, 2006), and organizations, such as men's bathhouses, may use discreet facades to prevent casual recognition (Hudson & Okhuysen, 2009). Concealment can help actors avoid negative responses from others in the first place, but it has its limitations. Not all stigmatizing attributes can be permanently hidden (e.g., addiction) or hidden at all (e.g., skin color). Moreover, when people learn about concealment attempts of targets, they may lose trust in them and respond negatively not only to the stigma itself but also to the perceived misconduct (Sutton & Callahan, 1987).

Accordingly, intertwined with the response of concealment is the question of whether targets should reveal their stigmatizing attribute. Existing research suggests that a primary predictor of whether targets conceal or reveal a stigmatizing attribute is the extent to which they anticipate that others will accept it (Hudson & Okhuysen, 2009; Jones & King, 2014). To make more informed disclosure decisions, stigmatized individuals often rely on "signaling", especially in ambiguous situations (Clair et al., 2005; Jones & King, 2014). Individuals who engage in signaling, send messages, drop hints, give clues, or provide other implicit messages about their stigma "as an interim step to see if it seems safe to reveal more" (Clair et al., 2005, p. 83). Although signaling can minimize the risks associated with revealing a stigmatizing attribute (Clair et al., 2005), it is cognitively taxing for individuals because they constantly need to monitor their environment to interpret potential responses to their signals (Jones & King, 2014).

Targets whose stigma is known to others, either through disclosure or overt visibility, may dilute the discrediting attribute "to keep [it] from looming large" (Goffman, 1963, p. 102; Zhang et al., 2021). Dilution can occur in multiple ways, including adapting the stigmatizing attribute and compensating for it by mastery of other, more recognized areas of activity (Zhang et al., 2021). For example, MMA organizations have changed the rules of MMA to reduce the health risks associated with the combat sport (Helms & Patterson, 2014) and tobacco companies have diversified into the less

controversial food industry (Vergne, 2012). Dilution may allow targets of stigma to gain social acceptance and thus avoid social sanctions (Zhang et al., 2021), but like concealment, it has limitations. The adaptation of a discrediting attribute may not always be possible (e.g., blindness), or adaptation efforts may result in the loss of core attributes of a target if they are too extensive (e.g., abandonment of cages in MMA). Similarly, some stigmatizing attributes (e.g., murder) can hardly be compensated.

Another common response aimed at mitigating stigma, shielding, involves targets surrounding themselves with similar others to form “distinctive in-groups” that provide “social buffers” or a “bulwark” against the stigmatization by outsiders (Ashforth et al., 2007, p. 158). Crucially, stigmatizing outsiders can be actors who bear the stigma themselves (Kreiner et al., 2022; Toubiana & Ruebottom, 2022), such as hospital security guards who discredit those colleagues who resist euphemizing their work (Johnston & Hodge, 2014). The in-group, in turn, may consist not only of targets of stigma, but also of non-stigmatized others with whom they are affiliated, as in the case of men’s bathhouses and their suppliers (Hudson & Okhuysen, 2009).

In contrast to concealing and dilution, the shielding response is more conflictual because targets of stigma manifest their deviation from prescribed norms and expectations rather than attempting to resonate with them. Therefore, although shielding can reduce the exposure of targets to stigmatizing responses and enable support (Zhang et al., 2021), it may also exacerbate their social exclusion and sanctioning (Moon, 2012). While the extent of conflict arising from concealment, dilution, and shielding may vary, all these responses seek to mitigate the harmful effects of stigma without challenging or changing the negative evaluation itself.

Overall, research from a stigma-as-evaluation perspective is extensive and helps to address the puzzle of the adoption of stigmatized practices in organizations to some extent. First, studies of stigma characteristics offer insights into when stigma attributed

to a practice may spill over to an adopting organization. As mentioned, a critical role in shaping the perceptions and enactment of stigma plays the centrality of a stigmatizing attribute to a target's identity or activities. Thus, the occurrence of a spillover effect depends on whether an organization makes a stigmatized practice core to its activities or only a part of them. For example, general hospitals that perform abortions are typically not stigmatized, unlike abortion clinics (Augustine & Piazza, 2022). Moreover, an organization's risk of becoming a target of stigma depends on whether it can conceal the adoption a stigmatized practice (Briscoe & Murphy, 2012).

Second, insights into the consequences of stigma corroborate the idea that stigma attributed to a practice can make its adoption more challenging and prone to failure, as the evaluation can trigger various discriminatory behaviors. However, studies from evaluation perspective have also shown that stigma can be mitigated, suggesting that stigmatized practices may be successfully adopted after all. The extent to which the identified stigma-mitigation responses can be applied to promote the adoption of stigmatized practices has yet to be explored. Research in this area has primarily treated practices as stigmatizing attributes, with a focus on organizations that are inextricably linked to a stigmatizing practice (e.g., MMA organizations). Thus, the identified stigma-mitigation responses may not apply in contexts where organizations make stigmatized practices only a part, rather than the core, of their activities.

More generally, the stigma-as-evaluation perspective is limited, as it offers little insights into the social construction of stigma. In the next section, I explore research that focuses on analyzing how stigma is socially constructed.

2.2.2 Process-oriented perspective

While stigma as an outcome has been explored extensively, the processes of its social construction have received less attention (Pescosolido & Martin, 2015; Zhang et al., 2021). First, these processes include the emergence, transfer, and maintenance

of stigma, which collectively are processes of stigmatization (Dong et al., 2023; Zhang et al., 2021). Stigma emergence marks the initial stage of stigmatization, where certain targets come to be seen as undesirably deviant and are discredited (e.g., Wang et al., 2021). Stigma transfer is the process by which stigma spreads from one target to others (e.g., Kulik et al., 2008) and stigma maintenance leads to the persistence of stigma over time (e.g., Dong et al., 2023). Additionally, the social construction of stigma includes its reduction and potential removal, commonly referred to as processes of destigmatization (e.g., Hampel & Tracey, 2017). Below, I first discuss the processes of stigmatization, followed by those of destigmatization. I then present research pointing to the importance of examining stigmatization and destigmatization as interconnected rather than separate processes, thus shifting the focus to (de-)stigmatization.

Stigmatization. Initial insights into the emergence of stigma were provided by Goffman (1963), who argued that stigma arises during fleeting social interactions, particularly between strangers. He observed that societies establish norms defining acceptable attributes for their members, which, when internalized, shape individuals' "normative expectations" – implicit demands about how others should be and behave in specific situations (Goffman, 1963, p. 2). Stigma arises when an individual perceives an attribute in another person that violates these expectations, leading to the ascription of negative characteristics and the devaluation of that person as a whole (Goffman, 1963). Because normative expectations are situationally bound, an attribute perceived as neutral or even positive in one context may be stigmatizing in another (Paetzold et al., 2008). As Goffman (1963, p. 127) noted, "for every little failing there is a social occasion when it will loom large", highlighting that any attribute – and, by extension, any person – can potentially be stigmatized.

Building on Goffman's (1963) account, scholars in psychology and sociology have examined stigmatization processes targeting individuals and social groups in different

settings (Pescosolido & Martin, 2015). This research suggests that stigma emerges through the two-stage process of (1) labeling undesirable deviations from the norm and (2) associating them with negative stereotypes, which are rigid and over-generalized beliefs and expectations (Becker & Arnold, 1986; Biernat & Dovidio, 2003; Link & Phelan, 2001; Stangor & Crandall, 2003). Through socialization processes, these views on what constitutes a stigma are shared among members of a social collective, fostering common beliefs about the undesirability of particular attributes and shaping emotional and behavioral responses to them (Becker & Arnold, 1986; Major & O'Brien, 2005). This shared “perceived stigma” (Pescosolido & Martin, 2015, p. 94) as well as personal characteristics (e.g., educational background) and situational cues (e.g., visibility of an attribute) influence whether people attribute a stigma to another person in social encounters (Crocker et al., 1998; Major & O'Brien, 2005). Furthermore, social-psychological research emphasizes that stigmatization depends on power. It requires power to create and spread views of moral deviance and to enact them in the form of discriminatory consequences (Link & Phelan, 2001; Link et al., 2004).

Organizational scholars have suggested that occupations, organizations and their respective members, similar to individuals and social groups, can become stigmatized through individual and collective processes of labeling and stereotyping (e.g. Devers et al., 2009; Wang et al., 2021; Wiesenfeld et al., 2008). This line of research highlights that stigmatizing behaviors are driven by the aim of audiences to identify violations of societal norms and restore adherence to those norms in order to ultimately eliminate the perceived stigma threat (Devers et al., 2009; Wang et al., 2021). Stigmatization then operates as a form of social discipline or control (Devers et al., 2009). This was the case, for example, with men’s bathhouses that were closed by authorities (Hudson & Okhuysen, 2009) or MMA organizations whose events were banned by them (Helms & Patterson, 2014). In each case, the behavior of authorities was motivated by their

belief that these organizations should not exist because their core practices pose a hazard to people's well-being (Hampel & Tracey, 2019).

In addition to studies on the emergence of stigma, there is also research that offers insights into stigmatization as the social construction of stigma through transfer and maintenance processes (e.g. Dong et al., 2023; Kulik et al., 2008; Mikolon et al., 2021). First, stigma is seen as “contagious” (Dong et al., 2023, p. 1057). It has been found to transfer to individuals (Goffman, 1963), occupations (Wiesenfeld et al., 2008), and organizations (Vergne, 2012) who are associated with targets of stigmatization through cognitive assimilation processes (Kulik et al., 2008) and shaming attempts (Kvåle & Murdoch, 2021). Second, stigma is seen as “persistent” (Link & Phelan, 2001, p. 379). This persistence does not happen automatically, but through ongoing stigmatization processes that maintain the stigma (Zhang et al., 2021). While numerous studies have implicitly uncovered factors that may contribute to stigma maintenance (e.g. Mikolon et al., 2021), few have addressed the actual mechanisms underlying its perpetuation (Zhang et al., 2021). In one of these few studies, Dong et al. (2023) found that stigma is reinforced by reverberation and fueled by denial and dodging practices.

Destigmatization. Beyond its emergence, transfer, and maintenance, the social construction of stigma also involves its reduction and potential removal (Hampel & Tracey, 2017). In these destigmatization processes, targets of stigmatization ideally “shift from a stigmatized state to one without discrediting social evaluations” (Coslor et al., 2020, p. 301). This shift is driven by particular responses from targets of stigmatization, most notably cooptation and reframing (Zhang et al., 2021).

Cooptation involves targets of stigmatization drawing attention to the value and distinctiveness of their stigma to take advantage of it (Zhang et al., 2021). For example, MMA organizations used the stigma of extreme violence attributed to MMA to recruit new members and to create controversy with critical stakeholders, which provided an

opportunity to “proactively educate” them about “misconceptions associated with the practice” (Helms & Patterson, 2014, p. 1475). RuPaul’s Drag Race not simply displayed but “spectacularized” the stigma of drag queens, constructing a “new reality” around the stigma that led to its “normalization” (Campana et al., 2022, p. 1979).

Specifically, through the exaggerated, recurring portrayal of drag queens as social deviants and the showcasing of their own emotional struggles, drag queen reality was depicted as “familiar” and “relatable”, and became acceptable to the public (Campana et al., 2022, p. 1979). However, cooptation is not without risk, since it also bears the potential to generate tensions that reinforce social disapproval and hostility (Campana et al., 2022; Helms & Patterson, 2014). As such, destigmatization through cooptation may be “fragile” and “temporary”, especially when stigma is perceived as a serious threat by stigmatizing audiences (Campana et al., 2022, p. 1972).

Since stigma is largely constructed and conveyed through language, reframing it in a more positive light is another a key response that can facilitate destigmatization. (Ashforth & Kreiner, 1999; Lyons et al., 2017; Zhang et al., 2021). For instance, insurance companies shifted the meaning of life insurances from an immoral gambling with the life of the insured to securing the financial survival of their families (Quinn, 2008; Zelizer, 1978). Bullinger et al. (2022) found that refugee job-placement organizations tried to redefine the moral worthiness of refugees as a low-skilled, potentially dangerous social group by visualizing them as “hardworking professionals”, “role models”, and “stylish and creative young people” (p. 16).

Similarly, Keystone, a social enterprise stigmatized for supporting migrants, emphasized that “migration is good for the economy” and “essential for public services” rather than a threat (Tracey & Phillips, 2016, p. 746). Thus, the organizations sought to remove stigma attributed to refugees and migrants by showing how these social groups provide positive value to society, albeit with little success, as their stigma

persists. In fact, Bullinger et al. (2022) concluded that the reframing practices of “professionalizing”, “domesticizing”, and “stylizing” can also “communicate negative meanings” (p. 15) and may therefore actually reinforce the stigmatization of refugees.

Countering stigmatization is generally difficult because the constructed “negative perceptions tend to have a stronger and more enduring impact and are more resistant to disconfirmation than positive perceptions” (Ashforth, 2019, p. 24). Still, some studies have shown that a sustained removal of stigma may be possible (e.g., Hampel & Tracey, 2017; Johnson et al., 2022; Siltaoja et al., 2020). These studies suggest that removing stigma within organizations and broader social contexts is a longer-term process that requires a range of responses by different social audiences at the ‘right’ time. As Lashley and Pollock (2020b) wrote about stigma removal of medical cannabis companies, “the ordering of activities [...] is important: certain actions must be separated in time and will be unsuccessful until they are connected to other actions that have already taken place” (p. 36).

In particular, reframing as an isolated response may be unsuccessful since meaning making requires power (Link & Phelan, 2001), which targets of stigmatization are less able to employ than stigmatizing audiences due to their devaluation (Lyons et al., 2017). To balance the power asymmetry, targets of stigmatization may seek the help of “sympathetic others” – non-stigmatized actors who “share their worldview” and are willing to “advocate for it” (Kreiner et al., 2022, p. 110). Sympathetic others may facilitate destigmatization in society at large (Hampel & Tracey, 2017; Siltaoja et al., 2020) and within organizations (Ashforth et al., 2007; Johnson et al., 2022).

At the societal level, Siltaoja et al. (2020) show that in Finland in the 1970/80s, journalists helped organic farms reframe organic farming from a “threat to national competitiveness and food security” (p. 12) to a “profitable and beneficial [practice] that served everyone’s interests” (p. 16). Regarding stigma removal within organizational

settings, occupational stigma studies have pointed to the role of managers (Ashforth et al., 2007) and job coaches (Johnson et al., 2022). Managers of stigmatized occupations have been found to counter negative perceptions of the public and clients by emphasizing the value of the occupation, negating specific issues, using humor, and acting contrary to occupational stereotypes (Ashforth et al., 2007). Job coaches build relationships between stigmatized and non-stigmatized members of organizations (Johnson et al., 2022). This “bridgework” includes the re-shaping of stigmatized employees as valuable workers, bypassing their inflexible, devalued traits by drawing on flexible attributes of the organization, and diffusing compassion on all sides to ensure that perceptions of value will last (Johnson et al., 2022).

Despite all efforts to remove stigma, the destigmatization process might sometimes remain incomplete. There are targets of stigmatization that may become normal in the eyes of some, perhaps many, but hardly all members of a society, as they violate deeply held social norms, such as gay people (Chuang et al., 2011), sex workers (Toubiana & Ruebottom, 2022), and abortion clinics (Augustine & Piazza, 2022). For these targets of stigmatization, destigmatization seems to be an ongoing process.

(De-)stigmatization. In exploring the social construction of stigma, studies have primarily taken a “unidirectional approach” (Mikolon et al., 2016, p. 639). They have focused on either stigmatization or destigmatization processes, rather than on how these processes are interrelated and evolve over time (Zhang et al., 2021). Stigma is constructed “in the nexus of social interactions” among diverse audiences (Aranda et al., 2022, p. 2). As a result, responses of targets of stigmatization and, where involved, sympathetic others influence the responses of stigmatizing audiences, and vice versa (Kreiner et al., 2022). This relational nature of stigma makes its creation, transfer, maintenance, and reduction an iterative and dynamic process, with actors frequently shifting between different responses (Goffman, 1963; Jensen & Sandström, 2015).

Consequently, because theories based on a unidirectional approach overlook the dynamics of (de-)stigmatization, they may be incomplete and even inaccurate.

One important dynamic, which has long been overlooked but has recently garnered attention, is the potential for responses aimed at reducing stigma to inadvertently lead to (re-)stigmatization. For example, Mikolon et al. (2021) show that sales personnel's attempts to reduce the occupational stigma attributed to them inadvertently reinforced it. Similarly, Toubiana and Ruebottom (2022) demonstrate that sex workers, through their efforts to destigmatize their occupation, simultaneously contributed to its stigmatization. This suggests that stigmatization and destigmatization "may not be distinct processes, as the literature has often implied" (Toubiana & Ruebottom, 2022, p. 28). However, it remains unclear when responses contribute to destigmatization or, conversely, to (re-)stigmatization (Mikolon et al., 2021; Ruebottom & Toubiana, 2021).

In particular, (de-)stigmatization dynamics within organizational settings have remained underexplored. Most intra-organizational stigma studies have sought to understand the determinants and effects of disclosure decisions made by individuals with concealable stigmas (e.g., Clair et al., 2005; Jones & King, 2014; Ragins, 2008). However, some rare studies have approached the destigmatization of individuals as a relational process (e.g., Johnson et al., 2022; Lyons et al., 2017). For example, Lyons et al. (2017) theorized how stigmatized individuals can change the meaning of stigma at the group level through ongoing negotiations with their co-workers. Their conceptual study indicates that valuable insights into (de-)stigmatization dynamics can be gained from a detailed study of people's everyday micro-responses to stigma.

A focus on ongoing micro-responses to stigma aligns with Goffman's (1963) often neglected argument (Frandsen & Morsing, 2021) that stigma is constructed in mundane social interactions. As Goffman (1963) noted, in social encounters, stigmatized individuals must repeatedly decide whether to reveal or conceal their

stigmatizing attribute – that is, whether “to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where” (p. 42). Each small response can thereby have significant consequences, placing the stigmatized in a “constant tension between [...] containment and havoc” (Jensen & Sandström, 2015, p. 129). In navigating this tension, stigmatized individuals can only partly rely on “past experience, since new contingencies always arise, making former concealing devices [or other responses] inadequate” (Goffman, 1963, p. 110). The question, then, is what they rely on. One possibility is signaling, which may help choosing between multiple, potentially contradictory responses (Jones & King, 2014). Still, we lack insights into how targets of stigmatization navigate everyday tensions.

Overall, the social construction of stigma within organizational settings remains largely underexplored. Consequently, research from a stigma-as-process perspective contributes little to our understanding of the adoption of stigmatized practices in organizations, beyond reinforcing the need to address this puzzle. In particular, Goffman’s (1963) original proposition that stigma is context-specific – arising from the violation of normative expectations rather than norms – undermines the need to better integrate the social construct into adoption research. This is because it suggests that stigmatized practices may be a more prevalent issue than previously recognized.

In the next chapter, I introduce a practice perspective (e.g., Feldman & Orlikowski, 2011) as a way forward to address the puzzle of the adoption of stigmatized practices in organizations *and* to advance a more relational understanding of the social construction of stigma. A practice perspective is well-suited to extend both research on practice adoption and stigma, as it not only takes practices seriously (Reckwitz, 2002), but is also “profoundly relational” (Jarzabkowski & Bednarek, 2018, p. 799).

2.2.3 Introducing a practice perspective

A practice perspective builds on practice theory, which has gained prominence in organization studies as part of a broader “practice turn” in the social sciences (Feldman & Orlikowski, 2011; Nicolini, 2013). While practice theory encompasses diverse theoretical approaches (Sandberg & Tsoukas, 2015), it is unified by shared principles (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017; Nicolini, 2013). First, it asserts the *primacy of practice*, proposing that all social phenomena are socially constructed through practice (Lê & Bednarek, 2017; Nicolini & Monteiro, 2017). Second, practice theory submits to the *centrality of action* in practices, arguing that they emerge, persist, and evolve through people’s everyday actions (Feldman & Orlikowski, 2011; Schatzki, 2012). Third, practice theory emphasizes the interrelation of phenomena, which is shaped through processes of *mutual constitution* (Feldman & Orlikowski, 2011).

Based on these principles, I propose that a practice perspective on the adoption of stigmatized practices in organizations – and on stigma more broadly – requires shifting our focus to (de-)stigmatizing. While I outline each principle and its implications individually below, it is important to recognize that these principles are inherently interconnected (Sandberg & Tsoukas, 2015). Thus, they collectively shape a particular practice perspective on stigma. In particular, relationality is a foundational principle, as it underscores the interdependence of all elements and actions within a practice-theoretical approach (Lê & Bednarek, 2017). In what follows, I first elaborate on the shift to (de-)stigmatizing and subsequently articulate my research question.

(De-)stigmatizing. First, practice theorists emphasize the ontological primacy of practice (e.g., Heidegger, 1962; Schatzki, 2002). They argue that practices, rather than individuals or societies, constitute the foundation of all social phenomena (Schatzki, 2002). This means these phenomena emerge, persist, and evolve through practices (Feldman & Orlikowski, 2011; Sandberg & Tsoukas, 2015). Consequently, practice

theory directs us to examine practices as the basic unit of analysis (Nicolini & Monteiro, 2017) for understanding how social phenomena, such as stigma, are constructed. From this perspective, stigma is not an external attribute assigned to a target (e.g., actor or practice) requiring a response. Instead, *stigma and its associated responses are embedded within and inseparable from the practices that produce them*. Thus, the primacy of practice principle highlights the need to examine the practices through which stigma is constructed and navigated within a specific social context.

Moreover, practice theory submits to the centrality of action in practices. This is reflected in its definition of practices as evolving organized activities (Lê & Bednarek, 2017; Nicolini & Monteiro, 2017; Schatzki, 2002). As such, practices are “sets of doings and sayings” (Schatzki, 2002, p. 77), or “flows of action” (Jarzabkowski et al., 2019, p. 854), which continuously evolve as they are enacted over time (Sandberg & Tsoukas, 2015). Rather than viewing practices as static or fixed entities, practice theory stresses their dynamic nature (Feldman & Orlikowski, 2011; Nicolini & Monteiro, 2017), focusing on “practices in action” (Jarzabkowski et al., 2016, p. 251). In this view, the ongoing and everyday enactment of practices – practicing – becomes central to understanding how practices evolve and give rise to social phenomena (Feldman & Orlikowski, 2011; Gherardi & Laasch, 2022; Nicolini, 2011).

Together, the principles of the primacy of practice and the centrality of action within practices suggest that *stigma and responses to stigma are constructed through the act of practicing*. I refer to this practicing as stigmatizing when it manifests stigma and as destigmatizing when it counters the discreditation. Specifically, stigmatizing may involve actions that create, reinforce, or perpetuate stigma, whereas destigmatizing may encompass those that reduce, remove, or prevent it (Aranda et al., 2022; Goffman, 1963; Pollock et al., 2019; Zhang et al., 2020). The shift from describing the social construction of stigma as ‘stigmatization and destigmatization’ to framing it as

'stigmatizing and destigmatizing' reflects practice theory's focus on dynamic, ongoing activity rather than abstract processes (Feldman & Worline, 2016; Whittington, 2003).

While practice theory foregrounds practices, it recognizes individuals as their "carriers" (Reckwitz, 2002, p. 256), who enact them based on their "general" and "practical" understandings (Schatzki, 2002, p. 77). General understandings encompass people's collective notions of what constitute appropriate or meaningful actions within a particular practice (Sandberg & Tsoukas, 2015; Schatzki, 2002). Practical understandings, in contrast, refer to the skills, know-how, and competencies that individuals draw upon to perform a practice in a specific social context (Schatzki, 2002; Smets et al., 2015). Practice theory generally assumes individuals to be "knowledgeable" (Orlikowski, 2000, p. 421) and able to adapt their practicing to new, context-specific circumstances (Jarzabkowski et al., 2016; Whittington, 2006).

Crucially, practices are seen as socially rather than individually constituted (Sandberg & Dall'Alba, 2009; Schatzki, 2009). They emerge through the interrelated actions of multiple individuals, who may or may not be aware of one another's actions (Jarzabkowski & Bednarek, 2018; Lê & Bednarek, 2017). Building on this understanding, *I specifically define stigmatizing and destigmatizing as the ongoing flows of actions and interactions through which individuals construct and reconstruct stigma in a certain setting*. This definition highlights the social construction of stigma as "something that people do" (Jarzabkowski & Bednarek, 2018, p. 799).

Lastly, practice theory is rooted in the principle of "the relationality of mutual constitution" (Feldman & Orlikowski, 2011, p. 1242), which asserts that phenomena are fundamentally shaped through their relationships with one another (Michel, 2014). This principle leads practice theory to reject dualism – the view of phenomena as independently given and irreducible – and instead embrace duality, emphasizing their interdependence (Feldman & Orlikowski, 2011). For example, mind and body or action

and cognition, traditionally seen as opposites, are reinterpreted in practice theory as interconnected and mutually shaping (Nicolini, 2017; Reckwitz, 2002). In particular, relationality emphasizes the importance of connections between phenomena, while mutual constitution stresses their reciprocal nature: each phenomenon simultaneously shapes and is shaped by the other (Feldman & Worline, 2016; Michel, 2014).

Foregrounding the relationality principle within *practice theory* *compels us to conceptualize stigmatizing and destigmatizing not as distinct or separate flows of action but as inherently intertwined and mutually constitutive performances*, through which individuals continuously construct and reconstruct stigma (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017). These interconnected performances can only be fully understood in relation to one another, with each simultaneously shaping and being shaped by the other (Lê & Bednarek, 2017). Consequently, a practice perspective invites us to examine stigma in general – and stigmatized practices specifically – within organizational contexts as (de-)stigmatizing.

Importantly, the term (de-)stigmatizing is not meant to imply that stigmatizing and destigmatizing performances occur in a balanced or evenly alternating manner. Instead, their prominence is shaped by context-specific dynamics, such as power relations, capacities for action, and prevailing interests and norms (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017; Michel, 2014). These factors can lead one type of performance – stigmatizing or destigmatizing – to dominate over the other.

Exploring local (de-)stigmatizing dynamics is crucial because, although these dynamics are experienced and enacted at the micro-level, their consequences can extend beyond specific organizational settings, creating broader impacts (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017). Drawing on the principle of relationality, practice theorists argue that “any practice is embedded in a web of practices” (Feldman & Worline, 2016, p. 308), linking the “here-and-now of the situated practicing and the

elsewhere-and-then of other practices” (Nicolini, 2009, p. 1392). Attending to this interconnectedness enables research from a practice perspective to shed light on both the localized constructions and reconstructions of stigmatized practices and the broader patterns that emerge, such as how stigma evolves and unfolds through interactions across time and space (Lê & Bednarek, 2017; Nicolini, 2009).

Research question. In sum, the three core principles of practice theory – primacy of practice, centrality of action, and mutual constitution – call for studying the social construction of stigma as (de-)stigmatizing, which involves a focus on the dynamic, interconnected flow of actions in which individuals create, maintain, reduce, remove or prevent stigma. In essence, this perspective leads to a focus on the *doing and undoing* of stigma, which can complement research on both practice adoption and stigma.

First, a (de-)stigmatizing perspective deepens the understanding of stigmatized practices in adoption research by acknowledging the foundational, dynamic, and relational nature of practices. While existing adoption studies depict stigma as an unfavorable attribute assigned to *certain* practices, a practice perspective suggests that stigma is made relevant (or irrelevant) through the ways people enact a practice in their everyday actions. By focusing on how practices become stigmatized (or not) through their *mundane* enactment, a practice perspective suggests that stigmatized practices may be more prevalent than previously acknowledged in adoption studies.

Second, a (de-)stigmatizing perspective can advance research on stigma by offering a more relational and integrated view of its social construction. Unlike existing studies that focus on either specific audiences attributing stigma or particular targets countering it, a practice perspective suggests that neither stigmatizing audiences nor stigmatized targets exist independently of or prior to their enactment of stigma. Instead, both emerge dynamically and interdependently in practice. As the roles of actors are shaped through their doing and undoing of stigma, these roles may possibly evolve as

actors' practicing changes. By recognizing the mutual constitution of audiences, targets, and practices, a practice perspective can ultimately provide a more nuanced understanding of stigma's dynamic and socially embedded nature.

To conclude, while research on practice adoption points to the introduction of stigmatized practices into organizations, it has yet to address how these practices become integrated and routine. This gap is significant, as stigma triggers strong negative responses in people that can hinder adoption, even when practices – like same-sex partner health benefits – may offer important benefits. Although stigma research suggests that stigma can be mitigated or removed, it provides limited insight into how these processes unfold within organizations. There exists thus a critical gap in understanding the adoption of stigmatized practices in organizations. A practice perspective, which implies that stigmatized practices are constructed through their enactment, offers a valuable lens to address this issue. I therefore build on a practice perspective and ask: *“How are stigmatized practices constructed within organizational settings and with what impact on adoption?”*. To address this question, I conducted an interpretive embedded case study of a pediatric palliative care service at a hospital, as described in the following methods chapter.

3 Methods

In conducting this study, I aimed for “methodological fit” – or “internal consistency” – among its components, including prior work, the research question and the research design (Edmondson & McManus, 2007, p. 1155). A good starting point for achieving such fit is considering the state of prior theory, which can range from mature to nascent (Edmondson & McManus, 2007; Eisenhardt, 1989). As argued in the positioning chapter, theory on the adoption of stigmatized practices is still in its early stages, as little research exists on this phenomenon. Based on this gap, I formulated an open-ended research question that explores “how” stigmatized practices are constructed within organizational settings and their impact on adoption.

If “little is known, rich, detailed and evocative data are needed to shed light on the phenomenon” (Edmondson & McManus, 2007, p. 1162). Qualitative research is well-suited to provide such data, making it particularly effective for addressing novel questions of ‘how’, which seek tentative or provisional explanations (Lee, 1999; Miles et al., 2014; Sandberg, 2005). Qualitative research, in general, encompasses a range of approaches that rely on non-numerical data and various analytical techniques, without focusing on counting or measuring (Bansal et al., 2018; Creswell, 2018; Lê & Schmid, 2019). To explore the construction and adoption of stigmatized practices from a practice perspective, I conducted an interpretative qualitative embedded case study of the PPC service at Horizon, a mid-sized nonprofit teaching hospital in a Central European country. To ensure confidentiality, the hospital’s name has been changed and identifying details obscured (Beane & Orlikowski, 2015). This includes the timing of the PPC service implementation and the years in which data were collected. As an indication, the implementation of the PPC service at Horizon spanned about fifteen years – a typical duration for clinical innovations to reach general usage (Bauer & Kirchner, 2020). I collected my data during the latter half of this implementation phase.

In the methods chapter, I begin by elaborating on the case study design and research setting, explaining why the PPC service at Horizon qualifies as a revelatory case. Specifically, I examine the stigma associated with palliative care and outline the espoused practice of PPC at Horizon. Following this, I provide a detailed account of my methods for data sampling, collection, and analysis, offering a comprehensive overview of my research approach.

3.1 Case study design and setting

I chose an interpretative qualitative research approach, as it aligns with the practice perspective's commitment to the social construction of reality (Berger & Luckmann, 1967). The goal of interpretive research is to examine how individuals, through their actions and interactions, continuously construct a shared reality that is seen as both objectively factual and subjectively meaningful, rather than attempting to uncover a pre-existing world assumed to be out there (Prasad & Prasad, 2002; Walsham, 2006).

A practice perspective, with its particular emphasis on everyday actions (Feldman & Orlikowski, 2011; Lê & Bednarek, 2017), requires deep immersion in the field, involving close engagement with the carriers of a practice (Kaplan & Orlikowski, 2013). Therefore, as is common in practice-based interpretative research (Lê & Schmid, 2019), I examined a specific practice (PPC) within a single organization (Horizon). A single case design allows for a detailed exploration of "a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident" (Yin, 2009, p. 18). This design is effective for addressing "how" questions (Yin, 2009) and for generating new theoretical insights (Gioia et al., 2013; Siggelkow, 2007). It can thereby support the development of a theory of (de-)stigmatizing, shedding light on the dynamics of stigmatizing and destigmatizing practices and the intricate connections between these performances.

To obtain further granularity of (de-)stigmatizing performances and achieve variation for analytical comparisons (Bechky, 2011; Kaplan & Orlikowski, 2013), I employed an embedded case design (Yin, 2009). This design centers on a primary case while incorporating multiple sub-units of analysis, enabling a comprehensive and nuanced exploration of complex phenomena within their real-life context (Stake, 1995; Yin, 2009). I operationalized this design by reconstructing seven purposefully sampled clinical cases that qualified for PPC at Horizon. By examining these clinical cases as embedded units of analysis, I was able to compare and contrast the practicing of PPC across different focal audiences, including the PPC team and healthcare professionals from various departments at Horizon. While interpretative research does not aim for generalizability (Prasad & Prasad, 2002), examining diverse sub-units can enhance the transferability of findings to other settings (Howard-Grenville et al., 2021).

In sum, an interpretative embedded single case design is effective for addressing the question of how stigmatized practices are constructed and with what impact on adoption because it facilitates nuanced insights into the “subtleties, complexities and contextual nature” of (de-)stigmatizing dynamics (Pescosolido & Martin, 2015, p. 105). Crucially, conducting a single in-depth case study requires a research site offering high potential for new, revelatory insights into the phenomenon of interest (Gioia et al., 2013). PPC at Horizon is such as a revelatory case for two reasons. First, the term ‘palliative care’ carries a stigma that is widely regarded as a significant barrier to the practice’s adoption by patients and their caregivers (Cherny, 2009; Zimmermann et al., 2016). Second, rather than opting to rebrand the practice by changing its name – a solution commonly proposed in clinical studies (e.g., Dai et al., 2017; Dalal et al., 2011) – the PPC team at Horizon countered the palliative care stigma through their day-to-day enactment of PPC, offering a unique lens into how it can be addressed in practice.

In the following chapters, I first present the stigma associated with palliative care, drawing on insights from the existing health science literature. I then describe how this stigma specifically manifests in the context of my case study at Horizon. Next, I outline the espoused practice of PPC at Horizon, explaining its goals and guiding principles. Lastly, after having set the stage with an understanding of the overarching research context, I detail my approach to sampling clinical cases, along with the methods of data collection and analysis, showing how these elements are interconnected.

3.1.1 Stigma associated with palliative care

Due to the evidenced benefits of palliative care, the World Health Organization (WHO) declared the practice “an ethical responsibility of health systems” (WHA, 2014, p. 2), emphasizing the need for its widespread adoption by hospitals. Palliative care improves the quality of life for patients with life-limiting illnesses and their families by alleviating their physical, psychosocial, and spiritual suffering (WHO, 2020). Ideally, palliative care is initiated upon diagnosis and provided in parallel with curative treatments (Mack & Wolfe, 2006; Murray et al., 2017). Early initiation gives healthcare professionals the most time to enhance the quality of life for patients and their families, thereby maximizing the effectiveness of the practice (Hannon et al., 2017).

Despite compelling evidence of the effectiveness of an early initiation of palliative care, referrals tend to be made in the late stages of disease, if they are made at all (Hausner et al., 2020). Late referrals limit the potential benefits of palliative care (Murray et al., 2017) and can, therefore, be viewed as adoption failures (Klein & Sorra, 1996). Health science research (e.g., Shen & Wellman, 2019) and my data on the PPC service at Horizon suggest that stigma associated with palliative care among focal audiences, including patients and their caregivers, is one explanation for these delays.

Health science perspective on palliative care stigma. According health science research, the adoption of palliative care is hindered by two types of stigma: “anticipated

stigma” and “endorsed stigma” (Pescosolido & Martin, 2015, p. 92). First, there is an *anticipated stigma*, particularly among physicians, who expect most patients and families to associate palliative care with negative outcomes, such as “giving up”, “end-of-life [EOL] care”, and “death” (Cherny, 2009; De Clercq et al., 2019; Hui et al., 2015). As a result, physicians may perceive the early initiation of palliative care as “daunting” (Salins et al., 2020, p. 13), fearing adverse reactions from patients and families, and are therefore hesitant to initiate the practice (Cherny, 2009; Shen & Wellman, 2019).

Studies have shown that patients and their families may indeed endorse negative views about palliative care, perceiving it as an inferior treatment option, and may thus reject it (Bandieri et al., 2023; Shen & Wellman, 2019; Zimmermann et al., 2016). It is assumed that this *endorsed stigma* of palliative care has emerged for three reasons. First, palliative care developed as a specialty practice in the 1970s from the EOL care of oncology patients in hospices (Clark, 2007). Second, although palliative care is not limited to EOL care, it involves dying and death (Cherny, 2009), which is a taboo subject in contemporary Western culture (Zimmermann & Rodin, 2004). The death of children is particularly taboo, being deemed ‘too sad’ to talk about (Kübler-Ross, 1983). Third, Western society practices preventative and curative medicine. As palliative care accepts that all life ends in death, it may implicitly be seen as contradictory to the core goal of modern medicine to prevent, treat, and cure disease (Morrison & Meier, 2004).

To mitigate stigma surrounding palliative care, several studies suggest renaming the practice to ‘supportive care’, as this term carries a more positive connotation and may therefore facilitate earlier referrals (e.g. Dai et al., 2017; Dalal et al., 2011; Fadul et al., 2009). Conversely, other research advocates retaining the term ‘palliative care’ while actively working to reduce stigma through widespread education of healthcare professionals and the public, coupled with continuous efforts in everyday clinical practice to promote its adoption (e.g. Bandieri et al., 2023; Salins et al., 2020;

Zimmermann et al., 2016). For example, healthcare professionals – particularly physicians – should be made aware of how their communication about palliative care shapes focal audiences' perceptions of the practice and influences decisions on whether to seek this care (Zimmermann et al., 2016). Despite these recommendations, health science research provides limited insights into how palliative care adoption can be effectively promoted among focal audiences in daily clinical practice. In contrast, the case of PPC at Horizon provides valuable insights into addressing this challenge.

Manifestation of palliative care stigma at Horizon. Healthcare professionals at Horizon also experienced an anticipated stigma, as described in extant health science research. In particular, physicians believed that the term palliative care inevitably evokes negative associations in people's minds, such as 'end-of-life care', 'giving up', and 'death'. These associations led to fears that families would respond negatively when presented with the PPC service. Specifically, physicians anticipated that families would experience profound despair and reject PPC. This anticipated stigma made the initiation of palliative care a challenging endeavor for the healthcare professionals, despite their desire to support patients and families effectively. Table 1 depicts the anticipated palliative care stigma at Horizon using the tripartite view of social evaluations – their cognitive, affective, and behavioral aspects (Dovidio et al., 2003).

In addition to anticipated stigma, the PPC team at Horizon also faced endorsed stigma. Negative attitudes about palliative care were openly expressed among healthcare professionals and families. They perceived the practice as a last-resort intervention rather than a proactive approach aimed at improving quality of life. The stigmas surrounding palliative care initially emerged in focus group interviews I facilitated during a formative evaluation, which sought to identify the barriers and enablers of implementing PPC at Horizon. While the evaluation highlighted many

implementation challenges well-documented in the literature, the perception of palliative care as stigmatized emerged as an intriguing new condition.

The stigmas surrounding palliative care proved persistent. A follow-up evaluation on the PPC service's implementation progress a few years later revealed that most initial challenges were addressed, resulting in greater acceptance of PPC among treatment teams. In focus group interviews, many healthcare professionals now regarded the PPC service as “established” in the hospital. However, the anticipated stigma of palliative care continued to pose a significant challenge to its timely initiation by physicians. Despite this, the PPC team rejected calls from healthcare professionals to rename the practice for two reasons. First, it believed that clarifying the true purpose of palliative care could dispel any negative connotations. Second, the PPC team felt that terms like ‘supportive care’ diminished PPC's significance by not fully acknowledging the reality of death and the comprehensive scope of the practice.

Table 1: Anticipated palliative care stigma by health professionals at Horizon

Evaluative dimension	Anticipated stigma of palliative care	Illustrative quotes
Cognitive	Families tend to associate the term palliative care with EOL care, giving up, and death	<p>“Families equate PPC with end-of-life care. For them, it means that we have given up the fight against the disease and will do nothing more than administer pain killers.” (Senior physician, 1st evaluation)</p> <p>“The name 'Palliative Care' is not particularly helpful. It is still understood by families and society as end-of-life care, which adds an extra hurdle when presenting the service.” (Nurse manager, follow-up evaluation)</p>
Affective	The term palliative care can trigger feelings of hopelessness, fear, and utter despair in families	<p>“I have a patient from Serbia who is in a catastrophic state of health. Still, I have not yet involved the PPC team because this would destroy the girl. This would deprive her and her grandparents of any hope for the situation to improve.” (Chief physician, 1st evaluation)</p> <p>“I think that when parents hear Palliative Care, their first reaction is fear, as they worry that it means their child is about to die.” (Nurse, follow-up evaluation)</p>
Behavioral	Families are likely to oppose and reject the PPC offer	<p>“When we introduce PPC to parents, we are likely to encounter massive resistance.” (Nurse, 1st evaluation)</p> <p>“My sense is that people have negative associations with Palliative Care, equating it with ending treatment and assisted dying. As a result, parents are likely to reject it.” (Senior physician, follow-up evaluation)</p>

Based on focus group data collected at Horizon for a formative evaluation of the PPC service, with a follow-up evaluation conducted three years after the initial one.

Collectively, insights from existing health science studies and the initial focus group data suggest that PPC at Horizon is a particularly revealing case. They indicate that not only endorsed stigma, where negative attitudes are openly expressed, but also anticipated stigma, where stigma is expected, can pose significant barriers to practice adoption. This adds to the complexity of stigma dynamics, suggesting that adoption issues may stem not only from direct rejection but also from anticipated resistance.

In the next chapter, I outline the espoused practice of PPC at Horizon, offering insights into how palliative care is envisioned and ideally enacted within the hospital. Examining the espoused practice is crucial, as it establishes the foundational objectives and principles that can serve as a benchmark for assessing whether PPC becomes constructed or dismantled as a stigmatized practice. Additionally, analyzing the espoused practice helps to clarify why PPC at Horizon is a particularly illuminating case for understanding stigma dynamics. It also provides a rationale for why an embedded case design is an effective approach to address the research question.

3.1.2 Espoused practice of palliative care at Horizon Hospital

The espoused practice of PPC defines the abstract approach (Jarzabkowski et al., 2016) to how PPC should be carried out within the hospital. It was developed by the PPC team, drawing on international best practices and their own research into specific PPC needs of patients and their caregivers. The PPC team formalized its approach into a concept that received hospital management's approval, with regular reviews ensuring its continued relevance. A significant review by an independent professional organization later reaffirmed the high-quality standard of PPC at Horizon. While these reviews have led to minor adaptations, the core objectives and guiding principles of the espoused PPC practice have remained unchanged.

Espoused objectives and principles of PPC. At Horizon, PPC was espoused as a complementary auxiliary practice to acute care, the hospital's core practice. Acute

care focuses on treating diseases and injuries with the aim of achieving a cure. However, despite advances in modern medicine, curing certain conditions remains unattainable. PPC was designed to complement acute care in cases where a child's illness is, or has become, life-limiting. Common causes of such conditions at Horizon included cancer, heart failures, neurological and genetic disorders, metabolic diseases, and severe disabilities resulting from traumatic brain injuries.

Life-limiting illnesses often impose a heavy symptom burden on children and present considerable challenges for families caring for their seriously ill child. The primary aim of PPC at Horizon was to alleviate the suffering and difficulties associated with life-limiting diseases, thereby enhancing the quality of life for both the affected children and their families. PPC also sought to prolong life when possible and to provide peaceful EOL care when necessary. To provide comprehensive relief, PPC was grounded at Horizon in principles that were the opposite of those of acute care. Unlike acute care, PPC embraced an approach to care that is (a) progressive rather than fast-paced, (b) holistic rather than narrowly focused, (c) inclusive rather than paternalistic, and (d) relational rather than bureaucratic (see Table 2).

Table 2: Espoused practice of acute care and PPC at Horizon

Practice dimension	Features of acute care	Features of PPC
Aim or objectives	<i>Cure</i> : Healing diseases, providing recovery from injuries, and prolonging life	<i>Relief</i> : Improving quality of life and dying when a disease is or has become life-limiting
Tempo or pace	<i>Fast-paced</i> : Immediate treatment and care	<i>Progressive</i> : Gradual introduction and support
Focus of attention	<i>Narrow, specialist</i> : Treatment of particular diseases or organs	<i>Holistic, generalist</i> : Focus on the 'whole person' in treatment
Interactional order	<i>Paternalistic</i> : Physicians rather than patients determine the course of the treatment	<i>Inclusive</i> : Involvement of patients and their relatives in the provision of care
Organizational form	<i>Bureaucratic</i> : Separate clinics with high degrees of autonomy	<i>Relational</i> : Counseling team working across clinics

Based on interviews, observations, and documents collected at Horizon.

First, PPC differed from acute care in terms of the pace at which it should be practiced. Acute care at Horizon was fast. It consisted of the immediate treatment of

injuries and illnesses to ensure the best possible chances of recovery. The pace of work was particularly high in the emergency department and intensive care unit (ICU), where children are admitted in a life-threatening condition. In contrast, PPC was ideally practiced progressively, with a gradual introduction and extension of support. The indication for PPC, a life-limiting diagnosis, often triggers a crisis in the lives of the children and their families (Himelstein, 2006). A gradual introduction of PPC gave them time to process the diagnosis and overcome the initial crisis situation. A slow start also allowed PPC providers to first familiarize themselves with a family's support needs.

Second, PPC deviated from acute care in that it had a holistic rather than a narrow treatment focus. To achieve cure, acute care relied on narrow specialization. Physicians and nurses were trained as experts for specific organs (e.g., heart, lungs), ailments (e.g., allergies), or diseases (e.g., epilepsy, eating disorders) and expected to focus on their narrow specialty in daily practice. Thanks to their specialized training and experience the health professionals were able to diagnose, treat, and care even for patients with complex illnesses. PPC, on the other hand, was not disease-centered, but considered the 'whole person' when caring for patients. With its holistic view, the practice could help patients as well as their families to better manage not only physical, but also psychosocial, and spiritual challenges associated with life-limiting illnesses.

Third, unlike acute care, PPC aimed to build inclusive relationships with patients and families rather than paternalistic ones. In a paternalistic model, healthcare professionals make most treatment decisions based on what they believe is in the patient's best interest, often arguing that patients and families are too vulnerable and overwhelmed to navigate medical details and risks (Cohen, 1985; Murgic et al., 2015). In contrast, PPC viewed children and parents as autonomous agents, recognizing that they best understand what enhances *their* quality of life. PPC, therefore, actively

involved them as co-producers of their own well-being, ensuring their voices and experiences were central to care decisions.

Lastly, PPC was organized in a relational and not, like acute care, in a bureaucratic organizational form. Bureaucracies are “designed to segment participants into areas of functional specialization” (Gittell & Douglass, 2012, p. 712). While this structure supported acute care’s narrow, specialist approach, it hindered the holistic perspective central to PPC. For this reason, PPC was not established as a standalone specialist clinic but as an interprofessional counseling team working across clinics, both inpatient and outpatient. The team included physicians, nurses, psychologists, and a social worker, enabling it to address the various needs of ill children and their families. Over time, the PPC team expanded its relational structure by building a network of affiliates, such as liaison nurses on the wards, outpatient pediatricians, and mobile care services, to provide more holistic and coordinated support.

Espoused initiation of PPC. To access and serve patients, the PPC team relied on referrals from attending physicians. At Horizon, physicians in various hospital clinics held considerable autonomy in their work and authority over patients, often referring to them as “their” patients. This hierarchical structure meant that PPC team members could not directly approach patients or their families. They could only become involved when formally called into cases by attending physicians, who were required to follow a prescribed procedure. These physicians had to assess specific hospital criteria for initiating PPC (see Table 3), which, in line with the holistic focus of PPC, considered not only the disease trajectory but also the child’s overall condition and family situation.

When a clinical case met the PPC indication criteria, physicians were required to obtain the consent of the child and/or their parents, who acted as proxy decision-makers, before involving the PPC team. Grounded in the principle of inclusive relationships, PPC was offered as a voluntary service from the hospital to families.

Importantly, families were not expected to decide immediately whether to accept the offer. Reflecting the progressive approach of PPC, physicians were encouraged to present the offer and give families time to consider their decision. If families chose to proceed, the physicians were expected to facilitate contact with a PPC physician. The PPC physician would then reach out to the families to build a relationship and involve other team members as needed to address the families' specific care needs.

Table 3: Horizon's criteria for initiating PPC in clinical practice

Dimension	Indication criteria
Disease burden	<ul style="list-style-type: none"> • Serious malformations diagnosed prenatally or at birth that are expected to result in either rapid death of the child after birth or a complex course • Symptoms that affect the frequency of hospital visits or the child's daily life (e.g., decreased food intake and activity, worsened breathing)
Therapy status	<ul style="list-style-type: none"> • Poor response to therapies • Start of an experimental or life-prolonging therapy
Life expectancy	<ul style="list-style-type: none"> • Medical events from which the child does not seem to recover • Shortened life expectancy, or 'Yes-answer' to the 'surprise question': would you be surprised if this patient died within the next 6-12 months?
Family situation	<ul style="list-style-type: none"> • Desire for PPC on the part of the patient or parents • Difficult psychosocial situation of the family (e.g., parents become unable to work, siblings do worse at school)

Based on Horizon's PPC concept and interviews with PPC physicians.

Given how PPC was espoused at Horizon, it has provided a valuable opportunity to explore how stigmatized practices are constructed and adopted in response to varying circumstances. Since PPC needed to be continually re-adopted as new children and families were admitted to the hospital – each with a unique social background and disease trajectory – a 'one-size-fits-all' approach of practicing PPC was unsuitable. Furthermore, PPC involved multiple healthcare professionals across various hospital departments, each tasked with supporting the practice, making it ideal for examining the relational construction of stigmatized practices. Finally, because PPC was already integrated into the hospital's daily operations rather than being in an early implementation phase, it allowed for a practice-oriented investigation into how stigma merges, is sustained, or countered through mundane actions and interactions.

Given the complex nature of PPC, an embedded design that analyzes multiple clinical cases promised to be particularly useful to unlock the revelatory potential of the case. Specifically, studying multiple clinical cases allows for capturing differences in patients' disease trajectories and in the specialists' practices within the hospital. This design, therefore, facilitated a more nuanced understanding of how PPC is enacted in practice. In the next chapter, I elaborate on the sampling of the clinical cases, along with my approach to data collection and analysis, as all three aspects are intertwined.

3.2 Data collection and analysis

In my approach data collection and analysis, I adhered to established standards for quality (e.g., Flick, 2004) and to ethical principles in qualitative research (e.g., Hopf, 2004). While existing studies propose various “means for good qualitative research” (Pratt et al., 2020, p. 10), there is considerable overlap in their practical recommendations (Cloutier & Ravasi, 2021). In line with these guidelines, I employed the following strategies: (1) prolonged immersion in the research field, (2) purposeful sampling of clinical cases and informants, (3) triangulation of multiple data sources, including interviews, observations, and documents, (4) constant comparison of data, (5) thick description analysis, and (6) meticulous data organization (Creswell, 2018; Lincoln & Guba, 1985; Miles et al., 2014; Pratt et al., 2020; Tracy, 2010). Using these strategies strengthens the “trustworthiness” of my findings, “inspiring confidence that they can be relied upon and used” (Sigismund Huff, 2009, p. 345).

Alongside the standards for promoting research quality, adherence to fundamental ethical principles was integral to my research. Among these principles, the “avoidance of harm” and “informed consent” formed the cornerstone of my ethical approach (Hopf, 2004, p. 334), ensuring the protection and dignity of participants throughout the study (Creswell, 2018; Miles et al., 2014). In line with the principle of avoiding harm, I

prioritized participants' well-being by implementing measures to minimize risks of emotional, psychological, or reputational damage (Hopf, 2004; Miles et al., 2014). As the broadest ethical consideration (Hopf, 2004), this principle guided every stage of my research process and served as the foundation for specific ethical practices.

First, I clarified whether my study required approval from the responsible ethics committee (Creswell, 2018). As a research facility with many clinical trials running, Horizon has extensive experience with ethical considerations. An internal ethics consultation confirmed that ethics committee approval was not necessary. Second, I carefully selected informants, paying close attention to the sensitivities of their roles and circumstances (Dickson-Swift et al., 2007). I deliberated on the inclusion of patients and their families by weighing potential risks against the benefits of their participation (Miles et al., 2014). Ultimately, I decided against their inclusion to prevent potential emotional distress and harm. Instead, I relied on healthcare professionals as the primary informants for my study. To protect all individuals directly or indirectly involved in my study, I anonymized identifiable details, safeguarding their confidentiality and minimizing a risk of reputational harm (Saunders et al., 2015).

A core component of avoiding harm is the principle of informed consent (Miles et al., 2014). It involves transparently communicating to study participants the research objectives and methods, empowering them to make voluntary and well-informed decision about their involvement (Hopf, 2004). Respecting participants' autonomy in this way not only upheld their rights but also fostered trust, encouraging more open and meaningful interactions during data collection (Miles et al., 2014). However, I also recognized that providing detailed information about the study posed a potential risk of bias, as participants might consciously or unconsciously alter their behavior based on their understanding of the research (O'Reilly, 2012). To address this, I carefully balanced the need for transparency with the potential impact on data integrity (Tracy,

2010). This involved sharing sufficient information for informed decision-making while minimizing the likelihood of introducing bias into the study. I next elaborate on my approach to data collection and analysis, showing how I applied strategies to improve research quality while adhering to the ethical principles of qualitative research.

3.2.1 Qualitative data collection

Ideally, I could have “shadowed” (McDonald, 2005) the PPC team and treatment teams in their daily practice to explore the construction and adoption of PPC at Horizon as a stigmatized practice. Shadowing as the main method of data collection would have been ideal from a practice view, as it allows for the observation of the real-time accomplishment of practices as people’s everyday actions (McDonald, 2005; Nicolini, 2009). However, due to the sensitivity of the context, I did not pursue this approach.

The research context was very sensitive, as children represent a particularly vulnerable population (Miles et al., 2014). In addition, the families were in a very stressful situation due to the serious or even fatal illness of their children (Hudson et al., 2010), and my presence as an external observer could have put them under additional strain (Dickson-Swift et al., 2007). The presence of an external observer could have been perceived by the families as an intrusion into their privacy and thus put a strain on the intimate and delicate relationship between them and the medical professionals (DeCamp et al., 2022). This in turn could have changed the behavior of both parties. Furthermore, families and health professionals might have altered their behavior just because they know they are being observed. This “Hawthorne effect” (O'Reilly, 2012, p. 93) can lead to data that does not reflect typical (inter-)actions in PPC and ultimately compromise the quality of the findings. Overall, the research setting limited the possibility of carrying out unobtrusive, ethically responsible observations, especially without a professional background in healthcare.

Thus, instead of shadowing, I conducted in-depth interviews that focused on the initiation and uptake of PPC in seven selected clinical cases. Conscious to avoid bias from a single data source (Eisenhardt & Graebner, 2007), I triangulated the clinical case interviews with other interviews, observations of PPC team meetings and teachings, as well as documents. Table 4 provides an overview of my data sources.

Sampling of clinical cases and informants. My main method of data collection consisted of interviewing members of the PPC team and treatment teams about the initiation and uptake of PPC in selected clinical cases. I relied on a PPC physician to purposefully sample the cases, as external researchers are not granted access to the hospital's patients records for confidentiality reasons. Besides, the support of the PPC physician was very valuable because she was most familiar with all the cases of the PPC team and therefore also best able to judge which cases met the sampling criteria.

Specifically, I asked the PPC physician to select recent cases with contrasting adoption outcomes from the main treatment teams at Horizon, where the key informants were still working at the hospital. First, the recency of the cases was an important sampling criterion to minimize retrospective bias (Huber & Power, 1985). In recent cases, informants' memories are 'fresher', reducing the risk of inaccuracies in the information provided during interviews. Second, cases were selected based on contrasting adoption outcomes, including some that ended in the successful adoption of PPC by the families (i.e., good cases) and others where adoption was limited or even failed altogether (i.e., bad cases). Such polar sampling renders emergent constructs and their interrelationships more salient (Eisenhardt, 1989). Third, clinical cases from both similar and different treatment teams at Horizon were selected to provide a balanced view and control for variability, ensuring meaningful comparisons.

Table 4: Data sources and use in analysis

Source of data	Details on the data	Use in analysis
Interviews (52)		
Clinical cases	<ul style="list-style-type: none"> • <i>Collection period:</i> 1 year • <i>Number of clinical cases:</i> 7 • <i>Number of interviews:</i> 32 <ul style="list-style-type: none"> - 22 interviews with treatment team members - 10 interviews with PPC team members • <i>Number of informants:</i> 30 <ul style="list-style-type: none"> - 22 treatment team members: physicians (13), nurses (7), social worker (2) - 8 PPC team members: physicians (2), nurses (3), psychologists (2), social worker (1) 	Examining the construction and adoption of PPC as a stigmatized practice, including de-/stigmatizing triggers, dynamics, and their impact on adoption
Non-case related	<ul style="list-style-type: none"> • <i>Collection period:</i> 1 year • <i>Number of interviews and informants:</i> 12 <ul style="list-style-type: none"> - 4 hospital management members: CEO, medical director, nursing director, deputy head nursing - 8 PPC team members: physicians (5), psychologist (1), scientist (1), secretary (1) 	Determining the implementation status of PPC at Horizon and exploring the practicing of PPC
Focus groups	<ul style="list-style-type: none"> • <i>Collection period:</i> 3 months (first round); 3 months (follow-up round after three years) • <i>Number of interviews:</i> 8 • <i>Division of groups:</i> Based on disciplines <ul style="list-style-type: none"> - PPC team - ICU, neonatology - Oncology, SCT, cardiology - Neurology, rehabilitation, metabolism • <i>Number of informants:</i> 59 <ul style="list-style-type: none"> - 13 PPC team members - 46 treatment team members 	Building trust with informants, becoming familiar with the context, and becoming aware that PPC is seen as a stigmatized practice
Observations (62)		
PPC team meetings	<ul style="list-style-type: none"> • <i>Collection period:</i> 1 year • <i>Interval:</i> Once per week • <i>Number of meetings:</i> 52 (82 hours) 	Exploring the practicing of PPC
PPC team teachings	<ul style="list-style-type: none"> • <i>Collection period:</i> 1 year • <i>Interval:</i> Selected dates • <i>Number of teachings:</i> 10 (18 hours) 	Understanding the espoused practice of PPC
Documents (169)		
Horizon	<ul style="list-style-type: none"> • PPC concept, including first version (5) • PPC team teaching presentations (20) • PPC team annual reports (6) • Horizon annual reports (15) 	Understanding the espoused practice of PPC and gathering evidence on the stigma of palliative care
Other	<ul style="list-style-type: none"> • Newspaper articles about PPC at Horizon (6) • Policy documents on palliative care (32) • Scientific publications on palliative care (86) 	

Fourth, we selected the clinical cases based on the availability of members of the PPC team and treatment teams who had extensive knowledge of the cases. The availability of these key informants was crucial to obtaining rich insights into the

practicing and adoption of PPC. Focus group interviews conducted during the formative evaluations of the PPC service had revealed differing perspectives on PPC among healthcare professionals at Horizon, particularly between physicians and nurses. Consequently, cases were also sampled with a focus on ensuring the availability of diverse professionals as key informants. Crucially, although parents also would have been valuable informants, we chose not to conduct interviews with them for ethical reasons. The loss of a child is one of the most difficult and tragic life events a person can endure (Munson & Leuthner, 2007; October et al., 2018). Engaging individuals in discussions about such a traumatic experience without adequate professional training risks retraumatizing them (Mailloux, 2014).

The clinical cases were sampled in two rounds, with four cases in each round. The second round began after most interviews for the initial cases were completed. To further enrich the data and ensure a more comprehensive understanding of the practice and adoption of PPC, I asked the PPC physician to select an additional four cases. Expanding the sample aimed to capture a broader range of experiences, perspectives, and variations in practice, thus enhancing the trustworthiness of the findings (Eisenhardt, 1989; Nelson, 2017). In the second round, we applied the same sampling criteria as in the first round, as these criteria had proven effective in identifying insightful cases. While we originally included eight cases in the sample, one 'bad' case was lost due to the withdrawal of key informants. More specifically, one informant was unwilling to be interviewed and another suddenly quit the hospital and was subsequently unavailable for an interview. Although the loss of the fourth bad case was unfortunate, the remaining three bad cases and a total of seven cases still provided rich insights for theory development.

Table 5 presents the seven selected clinical cases. Each case is assigned a pseudonym using a female first name for the affected child, irrespective of actual

gender, to ensure anonymity. In accordance with Horizon's PPC indication criteria, all cases qualify for PPC due to a high disease burden, poor therapeutic outlook, limited life expectancy, and complex family circumstances. Specific medical diagnoses are not disclosed to maintain confidentiality. All PPC interventions were initiated between 2015 and 2020. In three cases (Lily, Maria, and Anya), PPC involvement was initiated by intensive care physicians. In the remaining four cases (Eve, Ava, May, and Ella), referrals were made by the respective *primary treatment team*, defined as the medical specialty primarily responsible for the child's ongoing care (e.g., cardiology, neurology, oncology, pulmonology). The cases are ordered by the extent of PPC adoption, ranging from non-adoption, to limited adoption, and finally to extended adoption.

Interviews about clinical cases. To prepare for the interviews, I obtained basic case information from the PPC physician who had selected them. This included details about the child (e.g., first name, diagnosis, date of birth, and death, if applicable), the treatment teams (e.g., specialty, role, key informants), the PPC team (e.g., period of involvement, key informants), and a brief explanation of why the case was considered positive or negative from a PPC perspective. When recruiting PPC and treatment team members, I broadly described the study as focusing on the adoption of PPC at Horizon. I did not disclose its specific focus on PPC as a stigmatized practice to ensure authentic and unbiased responses (O'Reilly, 2012). Over one year, I conducted 32 clinical case interviews with 30 healthcare professionals. Table 6 summarizes the informants by treatment team affiliation (primary treatment team [PTT], ICU, or PPC), professional role (physician, nurse, psychologist, or social worker), and their informant codes, based on these criteria. All participants signed a consent form detailing data use and anonymization measures. Around half opted for video calls over in-person interviews. While I worried this might limit rapport or openness, the concern proved unfounded – informants were comfortable with the format, and interview quality remained high.

Table 5: Description of the clinical cases

Clinical case	Lily	Anya	Eve	Maria	Ava	May	Ella
PPC indication							
Disease burden	High: Life-limiting malformation diagnosed prenatally	High: Life-limiting disease; frequent hospital stays	High: Life-threatening disease; continuous hospitalization	High: Life-limiting malformation diagnosed prenatally	High: Life-limiting disease diagnosed at birth	High: Life-limiting disease diagnosed at birth	High: Life-limiting malformation; frequent hospital stays
Therapy status	Life-prolonging therapy	Life-prolonging therapy	Poor response to therapies	Life-prolonging therapy	No real therapy options	No real therapy options	Life-prolonging therapy
Life expectancy	Uncertain survival	Limited	Uncertain survival	Uncertain survival	Few months	Few months	Limited
Family situation	Highly distressed parents	One parent already deceased	Highly distressed parents	Strongly religious parents	Normally distressed parents	Parents reject life-prolonging measures	Single parent without family support
PPC initiation							
Child's life stage	Newborn	Adolescent	Toddler	Newborn	Infant	Newborn	Young child
Referral team	Intensive Care Unit	Intensive Care Unit	Primary treatment team	Intensive Care Unit	Primary treatment team	Primary treatment team	Primary treatment team
Child's condition	Dying	Critical condition	Dying	Critical condition	Continuous deterioration	Continuous deterioration	Critical condition
Survival time	< 2 weeks	Still alive at time of study	< 2 weeks	Still alive at time of study	< 12 months	< 12 months	Still alive at time of study
PPC adoption							
PPC provided	None	Psychological counseling; life support	End-of-life care at home	Transition to home and support with home care	Assistance with care at home, end-of-life care	Assistance with care at home, end-of-life care	Assistance with care at home; psychological counseling
Extent of adoption	None	Limited	Limited	Extended	Extended	Extended	Extended

All interviews followed a similar structure, consisting of three parts. I began each interview with background questions about the informants' roles at Horizon, their understanding of PPC, and their perceptions of its implementation within the hospital. Second, I asked informants to recount the clinical case. Once they had shared their narrative, I followed up with more targeted questions concerning the initiation of PPC, the support provided to families by the PPC team, the families' responses, and the nature of collaboration between the PPC team and the primary treatment teams. Third, I invited informants to compare the selected case with other cases in which PPC had been indicated, with the aim of understanding whether the case was considered typical or atypical based on their experience. These comparisons provided insight into how the selected case aligned with or diverged from other PPC cases the informants had encountered. Throughout the interviews, I took notes and recorded my reflections afterward. The interviews lasted 45-90 minutes, with an average duration of 60 minutes. Each interview was recorded and transcribed verbatim using MaxQDA.

Other types of interviews. While the clinical case interviews were my primary data source, I also used other types of interviews to supplement and contextualize my analysis. First, these interviews included the eight focus groups, which I helped conduct as part of formative evaluations of the PPC service. With one exception, all focus group interviews were recorded and transcribed. We structured the focus groups using the Consolidated Framework for Intervention Research (Damschroder et al., 2009), which outlines five implementation categories: practice characteristics, delivery processes, and characteristics of focal adopters, the inner setting and the outer setting. These interviews were instrumental for me in building rapport with informants, understanding the context, assessing the implementation progress, and gaining insights into the perceptions of PPC as a stigmatized practice.

Table 6: Healthcare professionals interviewed about clinical cases

Clinical case	Treatment team	Health professional	Informant code
Lily Newborn with a life-limiting malformation	PTT ICU PPC	Physician Nurse Physician	PTT physician 1 ICU nurse PPC physician 1
Maria Newborn with a life-limiting malformation	PTT PTT PTT PTT ICU PPT	Physician Nurse Nurse Social worker Physician Physician	PTT physician 2 PTT nurse 1 PTT nurse 2 PTT social worker 1 ICU physician PPC physician 1
Anyia Adolescent with a life-limiting disease	PTT PTT PTT PPC PPC	Physician Nurse Nurse Physician Social worker	PTT physician 3 PTT nurse 3 PTT nurse 4 PPC physician 1 PPC social worker
Eve Toddler with a life-threatening disease	PTT PTT PTT PTT PPC PPC	Physician Physician Nurse Social worker Physician Nurse	PTT physician 4 PPT physician 5 PTT nurse 5 PTT social worker 2 PPC physician 1 PPC nurse 1
Ava Newborn with a life-limiting disease	PTT PTT PPC PPC	Physician Physician Physician Psychologist	PTT physician 6 PTT physician 7 PPC physician 2 PPC psychologist 1
May Newborn with a life-limiting disease	PTT PTT PTT PPC PPC	Physician Physician Nurse Physician Nurse	PTT physician 8 PTT physician 9 PTT nurse 6 PPC physician 2 PPC nurse 2
Ella Young child with a life-limiting malformation	PTT PTT PPC PPC PPC	Physician Physician Physician Nurse Psychologist	PTT physician 7 PTT physician 10 PPC physician 1 PPC nurse 1 PPC psychologist 2

PTT = Primary treatment team; ICU = Intensive Care Unit.

Second, in addition to the clinical case interviews, I conducted twelve non-case-related interviews with Horizon's management team and PPC team members, all of which were recorded and transcribed verbatim. Interviews with the management team provided further insight into the implementation of PPC at the hospital. I also conducted semi-structured interviews with two distinct groups of PPC team members: those

primarily involved in the implementation of PPC, and those not interviewed for the clinical case studies, including assistant physicians, a PPC research scientist, and the PPC team's secretary. These interviews yielded varying degrees of insight into the development of PPC nationwide, the implementation of PPC at Horizon, and the discrepancies between the espoused and actual practices of PPC within the hospital.

Observations and documents. Finally, observations of PPC team meetings and teachings, along with various documents, were essential for my analysis. Over the course of a year, I observed and documented weekly meetings in which the PPC team discussed new and ongoing cases, gaining valuable insights into their daily practices and decision-making processes. Additionally, by attending several PPC team-led teachings for hospital staff and medical students, I deepened my understanding of the espoused practices of PPC at Horizon. I also collected relevant documents regarding the PPC service and the broader landscape of palliative care within the country.

In summary, I was unable to directly observe the PPC and treatment teams in daily clinical practice. As a result, my understanding of PPC in practice relies primarily on interview data about clinical cases. This is a clear limitation, as ethnographic data would have offered more grounded insights into how PPC is constructed and adopted. However, as Orlikowski (2002) notes, interview-based accounts can still provide valuable entry points into understudied phenomena from a practice perspective. This is grounded in the view, following "Giddens (1984; Giddens & Pierson, 1998), that people are knowledgeable and reflexive – they often understand and can articulate their actions better than researchers assume" (Orlikowski, 2002, p. 255). Likewise, Gioia et al. (2013) emphasize that organizational actors are "knowledgeable agents" who can explain their thoughts, intentions, and actions (p. 17). In line with this, I found that the medical staff at Horizon were skilled at recalling patient details and reflecting thoughtfully on case progress during interviews.

3.2.2 Iterative process of data analysis

My data analysis followed an iterative approach, as is common practice-based interpretive research (e.g. Jarzabkowski et al., 2019; Nicolini & Korica, 2021). I thus moved between my data and emerging theoretical arguments (Locke et al., 2008; Mantere & Ketokivi, 2013). I took three analytical steps to develop theory from data: (1) constructing a detailed story of a key clinical case (Geertz, 1973); (2) conducting a systematic analysis within and across clinical cases (Eisenhardt, 1989), using tables as analytical devices (Cloutier & Ravasi, 2021); (3) and developing a process model (Langley, 1999). Table 7 summarizes my analytical approach and outcomes.

Step 1: Detailed chronological description of a key clinical case. My first analytical step was to write a detailed chronological account of Maria's case (Langley, 1999) using a thick description mode of analysis (Geertz, 1973). I selected Maria's case for its revelatory nature – it initially appeared destined for a failed adoption of PPC but ultimately became a success, with both the parents and PTT team embracing the practice. Through this description, I identified nine critical moments in the PPC adoption process, each marking a turning point where PPC either advanced, regressed, or failed. For each moment, I coded the actions of healthcare professionals as either stigmatizing or destigmatizing based on whether they discredited or promoted PPC relative to its espoused practice at Horizon. Actions refer to specific steps or deeds taken by individuals (Lê & Bednarek, 2017). Stigmatizing actions included, for example, not involving the PPC team, bypassing PTT physicians in the decision to initiate PPC, and excluding the PPC physician from a parent meeting. Destigmatizing actions included, for instance, introducing the PPC team as home care experts, giving parents the choice of using PPC, and actively listening to them. Each critical moment began with an incident overview and concluded with an interim adoption outcome, such as Maria's parents agreeing to meet with a PPC physician.

Table 7: Analytical approach and outcomes

Step of analysis	Analytical move	Results of analysis														
Step 1: Detailed chronological description of a key clinical case (Geertz, 1973)	Crafted a rich chronological narrative of Maria's case, as the case seemed particularly insightful	<ul style="list-style-type: none">• Identified critical moments of PPC adoption• Revealed outcomes of PPC adoption• Captured various stigmatizing and destigmatizing actions														
Step 2a: Systematic analysis <i>within</i> clinical cases using tables as analytical devices (Cloutier & Ravasi, 2021; Eisenhardt, 1989)	Maria's case: Categorized stigmatizing and destigmatizing actions into broader activities	<ul style="list-style-type: none">• Stigmatizing: Categorized delaying and excluding as separation activities• Destigmatizing: Categorized entraining, advocating, and allying as alignment activities														
	Other cases: Examined stigmatizing and destigmatizing actions	<ul style="list-style-type: none">• Extended list of critical moments• Extended list of stigmatizing and destigmatizing actions														
Step 2b: Systematic analysis <i>across</i> clinical cases using tables as analytical devices (Cloutier & Ravasi, 2021; Eisenhardt, 1989)	Refined categories of stigmatizing and destigmatizing activities	<ul style="list-style-type: none">• Added verbal distancing to the category of separation activities• Added interactional distancing to the category of alignment activities														
	Examined why and how separation activities stigmatize	<ul style="list-style-type: none">• Identified stigmatizing dynamics:<table><tr><th>Separation activities</th><th>Suppression of e. practice</th><th>Discreditation of e. practice</th></tr><tr><td>Delaying</td><td>⇒ Rushing</td><td>⇒ Dramatizing</td></tr><tr><td>Distancing</td><td>⇒ Downplaying</td><td>⇒ Trivializing</td></tr><tr><td>Excluding</td><td>⇒ Blocking</td><td>⇒ Marginalizing</td></tr></table>	Separation activities	Suppression of e. practice	Discreditation of e. practice	Delaying	⇒ Rushing	⇒ Dramatizing	Distancing	⇒ Downplaying	⇒ Trivializing	Excluding	⇒ Blocking	⇒ Marginalizing		
	Separation activities	Suppression of e. practice	Discreditation of e. practice													
	Delaying	⇒ Rushing	⇒ Dramatizing													
Distancing	⇒ Downplaying	⇒ Trivializing														
Excluding	⇒ Blocking	⇒ Marginalizing														
Examined why and how alignment activities destigmatize	<ul style="list-style-type: none">• Identified destigmatizing dynamics:<table><tr><th>Alignment activities</th><th>Cultivation of e. practice</th><th>Valorization of e. practice</th></tr><tr><td>Entraining</td><td>⇒ Anchoring</td><td>⇒ Normalizing</td></tr><tr><td>Advocating</td><td>⇒ Demystifying</td><td>⇒ Legitimizing</td></tr><tr><td>Allying</td><td>⇒ Actualizing</td><td>⇒ Authenticating</td></tr><tr><td>Distancing</td><td>⇒ Delineating</td><td>⇒ Protecting</td></tr></table>	Alignment activities	Cultivation of e. practice	Valorization of e. practice	Entraining	⇒ Anchoring	⇒ Normalizing	Advocating	⇒ Demystifying	⇒ Legitimizing	Allying	⇒ Actualizing	⇒ Authenticating	Distancing	⇒ Delineating	⇒ Protecting
Alignment activities	Cultivation of e. practice	Valorization of e. practice														
Entraining	⇒ Anchoring	⇒ Normalizing														
Advocating	⇒ Demystifying	⇒ Legitimizing														
Allying	⇒ Actualizing	⇒ Authenticating														
Distancing	⇒ Delineating	⇒ Protecting														
Categorized de-/stigmatizing dynamics based on “dimension of practicing” of separation and alignment activities (Nicolini, 2011, p. 612)	<ul style="list-style-type: none">• Distinction between temporal, verbal, and interactional de-/stigmatizing<table><tr><th>Practicing dimension</th><th>Separation activities</th><th>Alignment activities</th></tr><tr><td>Temporal:</td><td>Delaying</td><td>Entraining</td></tr><tr><td>Verbal:</td><td>Distancing</td><td>Advocating</td></tr><tr><td>Interactional:</td><td>Excluding</td><td>Allying</td></tr><tr><td>Interactional:</td><td>-</td><td>Distancing</td></tr></table>	Practicing dimension	Separation activities	Alignment activities	Temporal:	Delaying	Entraining	Verbal:	Distancing	Advocating	Interactional:	Excluding	Allying	Interactional:	-	Distancing
Practicing dimension	Separation activities	Alignment activities														
Temporal:	Delaying	Entraining														
Verbal:	Distancing	Advocating														
Interactional:	Excluding	Allying														
Interactional:	-	Distancing														
Step 3: Development of a process model (Cloutier & Langley, 2020; Langley, 1999)	Examined triggers of stigmatizing and destigmatizing dynamics	<ul style="list-style-type: none">• Identified inadequate understandings of the espoused practice as triggers of stigmatizing dynamics• Identified wise understandings of the espoused practice as triggers of destigmatizing dynamics														
	Examined the impact of stigmatizing and destigmatizing dynamics on adoption	<ul style="list-style-type: none">• Identified that stigmatizing dynamics disempower focal audiences to adopt the espoused practice• Identified that destigmatizing dynamics empower focal audiences to adopt the espoused practice														
	Connected abstracted theoretical dynamics	<ul style="list-style-type: none">• Developed a model of practice adoption as a process of (de-)stigmatizing and two theoretical summaries														

The rich case description of Maria served as a valuable first analytical step. The detailed timeline of events contextualized the actions of those involved, shedding light on why and how certain adoption outcomes occurred. This chronological approach also facilitated the initial identification of patterns and trends, revealing recurring themes that might not have been apparent from isolated snapshots of data. Notably, it allowed me to see that some actions could simultaneously be both destigmatizing and stigmatizing. For example, the PPC team members' decision to wait for treating physicians to involve them in a case, rather than initiating involvement themselves, was destigmatizing in that it aligned with the hospital norm of granting decision-making authority to physicians. However, this approach also contributed to the stigmatizing of PPC, as it allowed physicians to delay the team's involvement in cases.

Step 2: Systematic analysis within and across clinical cases. Having completed Maria's rich chronological case story, I grouped the stigmatizing and destigmatizing actions that I identified in her case into broader sets of actions, or activities (Jarzabkowski et al., 2007). Specifically, I grouped the actions and labeled them according to their empirical characteristics, using labels from the literature where applicable (Hengst et al., 2020). First, I identified two stigmatizing activities: *delaying* espoused actions of PPC and *excluding* focal audiences. I categorized these activities as *separation* activities, as they both involve individuals detaching themselves from the practice of PPC. Specifically, delaying involves avoiding engagement with the practice, while excluding involves keeping other focal audiences of the practice at a distance.

Second, I identified three destigmatizing activities: *entraining* to focal audiences, *advocating* for the adoption of PPC, and *allying* with focal audiences. I categorized these activities as *alignment* activities, as each involves efforts to harmonize the practice of PPC with the practices and goals of focal audiences. Entraining involves synchronizing the tempo and timing of actions with focal audiences as "zeitgebers"

(Ancona & Chong, 1996; Granqvist & Gustafsson, 2016). Advocating refers to reframing PPC to align the practice with the values and interests of focal audiences (Dutton & Ashford, 1993; Maguire et al., 2004), while allying entails providing actual support that resonates with these values and interests (Hampel & Tracey, 2017).

Following recommendations for theory building from multiple cases (e.g. Eisenhardt, 1989; Eisenhardt, 2021), I expanded my analysis beyond Maria's case to include the other six clinical cases. I started with a within-case analysis for each case, using tables as analytical devices (Miles et al., 2014) to help organize and interpret the data (Cloutier & Ravasi, 2021). For each case, I created two tables: one for stigmatizing actions and another for destigmatizing actions, sorted by critical moments. I then developed two additional tables per critical moment to compare stigmatizing and destigmatizing actions across cases. This cross-case analysis revealed patterns and variations in the actions and activities across the clinical cases.

Based on the within-case and cross-case analyses, I solidified and refined the emerging constructs from Maria's case. Notably, I expanded the categories by adding *verbal distancing* to the separation activities and *interactional distancing* to the alignment activities. Distancing activities were particularly prevalent in Lily's case. Verbal distancing involves actors demarcating themselves from a practice through their manner of (not) speaking about it. Interactional distancing involves actors physically distancing themselves from other carriers of a practice to prevent further misalignment or conflict. This form of distancing can help actors to navigate their involvement with a practice in alignment with their own goals and the expectations of their context. Thus, up to this point, my analyses revealed three stigmatizing activities (i.e., delaying, verbal distancing, excluding) and four destigmatizing activities (i.e., entraining, advocating, allying, and physical distancing). Moreover, I categorized the stigmatizing activities as separation activities and the destigmatizing activities as alignment activities.

I continued the cross-case analysis by exploring *why* and *how* separation and alignment activities stigmatized or destigmatized PPC. To deepen this analysis, I also incorporated data from non-case-related interviews with PPC team members. As an initial analytical move, I created a table for the separation activity 'delaying', recording associated actions along with particularly revealing quotes. I then analyzed how these actions stigmatized PPC, discovering that they *dramatized* the practice, making it appear more threatening than its espoused practice at Horizon.

Subsequently, I investigated why delaying dramatized PPC and found that it led to the shortening or omission of espoused actions due to time constraints, resulting in a *rushed* enactment of the practice. A notable example was when physicians postponed involving the PPC team until just days before a child's death. This left the PPC team with insufficient time to improve a family's quality of life and forced them to rush into EOL care, which is a far more dramatic and threatening intervention.

Similarly, I analyzed why and how verbal distancing and excluding stigmatized PPC. I found that verbal distancing led healthcare professionals to *downplay* PPC's benefits, constructing it as less meaningful or important than it truly was, thereby *trivializing* the practice. Physicians also stigmatized PPC by excluding the PPC team from the treatment process, which *blocked* their espoused practicing of PPC and pushed it into an ineffective position – *marginalizing* the practice (Hein & Ansari, 2022). Taken together, I recognized that rushing, downplaying, and blocking all *suppressed* (Hehenberger et al., 2019) PPC's espoused enactment, while dramatizing, trivializing, and marginalizing *discredited* the espoused practice.

After analyzing the separation activities, I turned to the alignment activities to explore why and how they destigmatized PPC. I found that alignment activities helped cultivate and valorize the espoused practice. First, entraining cultivated PPC by *anchoring* it in both its own norms and those of acute care. This valorized PPC by

normalizing the practice for focal audiences (Ashforth & Kreiner, 2002), as it became embedded in the expected or routine dynamics of their everyday (inter-)actions. Second, advocating cultivated PPC by providing clarity and understanding of the practice's espoused features. This *demystifying* made the practice seem more proper and desirable, thereby *legitimizing* it (Suchman, 1995). Third, allying with focal audiences cultivated the espoused practice of PPC by *actualizing* its intended enactment. This valorized the practice by *authenticating* or proving its benefits. Fourth, interactional distancing cultivated PPC by *delineating* the boundaries of the practice, thereby *protecting* it from further discreditation.

Finally, I recognized that the separation and alignment activities operated at distinct "dimensions of practicing" (Nicolini, 2011, p. 612). First, delaying and entraining are activities that influence the tempo and timing of a practice's enactment. I categorized the stigma construction related to these activities as *temporal stigmatizing* and *temporal destigmatizing*, highlighting how timing and rhythm shape a practice's meaning. Second, verbal distancing and advocating are activities that construct a practice through what is said and left unsaid about it, as well as the manner in which it is communicated (e.g., with hesitation or in passing). Accordingly, I termed the stigma construction through these activities as *verbal stigmatizing* and *verbal destigmatizing*. Third, excluding, allying, and physical distancing are activities that shape the interactional order within the practice. I subsumed the dynamics triggered by excluding as *interactional stigmatizing*, while those of allying and physical distancing as *interactional destigmatizing*.

The full data structure of my analyses is detailed in the tables provided in Appendix A (stigmatizing dynamics) and Appendix B (destigmatizing dynamics). Appendix A outlines the various separation activities and actions and how they suppress and discredit the espoused practice of PPC, presenting particularly revealing quotes.

Similarly, Appendix B outlines the alignment activities and actions, demonstrating how they cultivate and valorize PPC, also supported by illustrative quotes. Table 8 below summarizes the stigmatizing and destigmatizing dynamics by clinical case.

Table 8: Stigmatizing and destigmatizing dynamics by clinical case

De-/stigmatizing dynamics	Lily	Eve	Anya	Maria	Ava	Ella	May
Stigmatizing							
<i>Temporal</i> : Delaying → Rushing → Dramatizing	X	X	X	X	-	X	-
<i>Verbal</i> : Distancing → Downplaying → Trivializing	X	X	-	-	X	-	-
<i>Interactional</i> : Excluding → Blocking → Marginalizing	-	-	X	X	X	X	-
Destigmatizing							
<i>Temporal</i> : Entraining → Anchoring → Normalizing	X	X	X	X	X	X	X
<i>Verbal</i> : Advocating → Demystifying → Legitimizing	-	-	X	X	-	X	X
<i>Interactional</i> : Allying → Actualizing → Authenticating	X	X	X	X	X	X	X
<i>Interactional</i> : Distancing → Delineating → Protecting	X	-	-	X	-	-	-
Extent of adoption	None	Limit.	Limit.	Ext.	Ext.	Ext.	Ext.

The “X” indicates that evidence of the stigmatizing or destigmatizing dynamic was found, while a hyphen (-) indicates that the dynamic was not present in the data. Ext. means extended and limit. means limited.

Step 3: Development of a process model. In the final step, I developed a model that theorizes practice adoption as a process of (de-)stigmatizing. In constructing this model, I first focused on identifying the factors that informed the stigmatizing and destigmatizing of PPC by health professionals. To achieve this, I paid particular attention to parts of the interviews where they described their understanding of the practice and the rationale behind their actions.

I observed that health professionals, particularly physicians, engaged in stigmatizing when they had *inadequate understandings* of PPC, including distorted “general” understandings and/or a lack of “practical” understandings (Schatzki, 2002, p. 79). Distorted general understandings involved negative associations with and attitudes toward PPC, while the lack of practical understandings involved missing know-how to perform specific espoused actions of the practice. Such inadequate understandings could place PPC in conflict with physicians’ professional values. In

response to this tension, physicians engaged in pronounced separation activities, including significantly delaying the initiation of PPC, vehemently verbally distancing themselves from the practice, and/or completely excluding the PPC team.

In a related vein, I found that healthcare professionals destigmatized PPC when they had “*wise*” *understandings* of PPC (Goffman, 1963, p. 19), including undistorted “general” understandings and/or competent “practical” understandings of the practice. Focal audiences’ general understandings of PPC were undistorted when they had internalized the practice’s goals and features as they were espoused in the hospital. Competent practical understandings of PPC contained actors’ know-how to select and judiciously enact the practice according to situation-specific demands.

Moreover, I examined the stigmatizing and destigmatizing dynamics by creating tables that integrated the activities and their interim and overall impact on the adoption of PPC. This approach allowed me to systematically collect, sort, and organize the data, facilitating a comprehensive assessment of how stigmatizing and destigmatizing dynamics influenced the adoption of PPC in each clinical case. I found that they had opposite effects on the ability of families and physicians to adopt PPC. Stigmatizing limited their ability to understand, accept, and perform PPC and thus *disempowered* them to adopt the practice fully or at all. As a result, physicians retained their inadequate understandings of PPC. In contrast, destigmatizing promoted the understandings, acceptance, and use of PPC by families and physicians, *empowering* them to adopt the practice more fully. In this way, physicians developed wiser understandings of PPC that informed them to destigmatize rather than stigmatize PPC.

Lastly, I incorporated my constructs into an empirical model, which I then abstracted into a conceptual model. During this stage, I also wrote narratives for three other cases – Lily, Eve, and Anya – that provided particularly revelatory insights. Writing these narratives not only helped me refine my theoretical constructs and clarify

their interrelationships but also revealed that the construction of PPC was a highly dynamic and ongoing process. The members of the treatment teams and the PPC team continuously constructed and reconstructed PPC as a stigmatized practice through their (in)actions. Consequently, stigmatizing and destigmatizing activities were interrelated, with stigmatizing dynamics limiting opportunities for destigmatizing, while destigmatizing efforts counteracted or reinforced stigmatizing dynamics.

Crucially, although I presented my analysis as a relatively straightforward three-step process for the sake of clarity, it was, in fact, highly iterative. I continually cycled among the analytical moves, case data, emergent theory and literature to further refine my constructs and their interrelationships (Eisenhardt, 1989; Klag & Langley, 2013). In this process, I created numerous tables, many of which I discarded because the data was insufficient, or they failed to yield meaningful insights. I rewrote and refined the case of Maria and the other three cases multiple times, continuously adapting my models as my theoretical ideas evolved and I made a “conceptual leap” (Klag & Langley, 2013). I cycled through and refined my findings until I perceived that I had arrived at a coherent theoretical contribution (Martin & Eisenhardt, 2010). In the next chapter, I present my findings through four detailed clinical cases, selected for their revelatory nature.

4 FINDINGS

To show the dynamic construction of PPC as a stigmatized practice, I recount the case stories of Lily, Eve, Anya, and Maria. I selected these four clinical cases for their revelatory nature. Together, they provide a comprehensive account of the stigmatizing and destigmatizing dynamics, their triggers, adoption impact and interrelations.

As I recount the revelatory cases, I first give some *background* information on the children's medical history, including the indication for PPC. I then delve deep into critical moments that significantly shaped the care relationship between the PPC team and a child, its parents, and the treatment team. At each of these critical moments, the provision of the service either progressed, deteriorated, or failed. For each critical moment, I provide (1) an *incident* description giving an overview of the situation; (2) illuminate the *stigmatizing* dynamics and their triggers; and/or the *destigmatizing* dynamics; and (3) depict the *outcome* of the stigmatizing and destigmatizing practice work. At the end of each case, I discuss to what extent this work empowered or disempowered the adoption of PPC by families and physicians.

I present the four cases in order of their adoption outcomes, from the least to the most extensive adoption. I begin with Lily's case, where the parents refused care from the PPC team, followed by the cases of Eve and Anya, each resulting in a limited adoption of PPC. In the fourth case, Maria, the adoption of PPC was most extensive, containing particularly many critical moments. Initially, Maria's case was destined to end in a limited or even failed adoption of PPC, much like the other cases. However, it took a pivotal turn and became a "key case" for the PPC team, as it "opened the door to the cardiology department" for the team (PPC physician 1). Due to the series of critical moments and key interventions that unfolded, the Maria case ultimately ended with a successful adoption of PPC. Consequently, the Maria case is notably longer and more complex than the cases of Lily, Eve, and Anya.

4.1 Lily: (De-)stigmatizing PPC as announcing impending death

4.1.1 Case background: Newborn with a life-limiting malformation

Lily was a newborn who met all the criteria established by the hospital for initiating PPC including (1) a high disease burden (2) a poor response to therapies, (3) a shortened life-expectancy, and (4) a difficult family situation. First, Lily was born with a complex, life-threatening malformation, so she had to be transferred to the ICU immediately after birth. The malformation could not be cured, but the hospital's specialists hoped to be able to correct it at least to some extent in order to prolong Lily's life. To this end, they subjected her to "all kinds of therapies" (ICU nurse). During treatment, Lily "seemed to be suffering" but the specialists had "no easy solutions to many of her problems" (PTT physician 1). Lily's condition finally improved to the extent that she could be transferred to the neonatal ward. However, she then "got stuck" there (PTT physician 1). After months of treatment, the specialists reached a point where they were unable to offer any further treatment options.

In addition to her critical condition, Lily qualified for PPC due to her difficult family situation. Her parents were in conflict with their families and therefore on their own. Moreover, Lily's parents "deeply mistrusted" the treatment team (ICU nurse). They "questioned therapies", "accused people of giving wrong medication", and "kept watch at their daughter's bedside" (PTT physician 1). Moreover, their mistrust caused them to constantly behave in a "passive-aggressive manner towards the medical staff" (ICU nurse). Lily's parents' mistrust in the treatment team was very likely rooted in their formative experiences with the corrupt healthcare system in their home country:

"They grew up in [country], the parents, and the healthcare system there is corrupt. If you don't pay, you don't get good treatment. [The healthcare professionals] will really just let you die – you don't matter to them if you don't pay well. [Lily's parents] are not the only ones; I think people in [country] are simply traumatized by the healthcare system there. Everyone from there has some kind of negative experience with a relative. I'm from [country] too. That's why Lily's parents opened up to me." (ICU nurse)

4.1.2 Critical moment 1: An intensivist called in a PPC physician

Incident. In the neonatal ward, Lily's condition was stable for a while, but then suddenly deteriorated so much that she had to be transferred back to the ICU, where the treatment team called in a PPC physician. Lily was a few months old at the time.

Temporal stigmatizing. Lily was treated by many specialists, but her primary treatment team was responsible for initiating PPC. According to the hospital's indication criteria for PPC, the PPC team should ideally have been involved shortly after Lily's birth. However, the physicians in her primary treatment team had a *distorted general understanding* of PPC and as a result *delayed* involving the PPC team for months. The physicians regarded "palliative situations" as those in which "nothing more can be offered" (PTT physician 2). Thus, as long as they saw any treatment option, they commonly did not consider calling in the PPC team, as a nurse noted:

"From the doctors' side, it's always a sticking point. It's always a topic of discussion: 'Do we need this? Why should we do this now? We still have this or that treatment ahead of us.' PPC is basically seen as: 'We're backed into a corner. We have no options left. Let's call in Palliative Care and make the end a little nicer.' To put it bluntly." (ICU nurse)

The PTT physician's distorted understanding of PPC put the practice at odds with their core professional value of curing disease. The physicians had a strong curative focus: "We always want to heal, always want to make everything better" (PTT physician 1). It was therefore not easy for them to accept when they ran out of treatment options. Moreover, the physicians "believed in miracles for far too long", as one of them admitted (PTT physician 1). So, when the physicians involved the PPC team in a case, the child was usually in the ICU and already close to death, as a nurse reflected:

"I've never experienced in my three years here that the Palliative Care team was involved when a child was simply very sick and had been in the ward for a long time. Instead, it had to first be admitted to the ICU. That might sound dumb, but it had to get to the point where the child was in the ICU and almost dying, and THEN the team would be involved. Not for ALL children... I mean, not all children who deteriorate in the ICU have the team involved, but only those where it's completely hopeless. I mean, really, really hopeless. I find it sad, honestly, that it almost has to get to that point where you think: Oh God, the child is about to die, and then we bring the team in." (PTT nurse 1, interview Maria)

In Lily's case, the physicians also delayed involving the PPC physician until the child's death was imminent. At that point, Lily's survival depended entirely on a heart-lung machine, with no remaining treatment options to improve her condition. This delay resulted in a *rushed* introduction of PPC, leaving the parents no opportunity to process or engage with the need for the practice. As PPC physician 1 described it, PPC was "poured over them like a bucket of water", underscoring how abrupt and overwhelming the process had been. Moreover, given Lily's critical state, the PPC team had no time to focus on enhancing the family's quality of life. Instead, their efforts were limited to managing the immediate crisis. As a PPC physician explained:

"When we talk about quality of life, I need time to actually create quality of life. I can't achieve that right before death. At that point, we can't talk about improving quality of life anymore. We can talk about quality of dying and a good death, but not about quality of life." (PPC physician 1, non-case interview)

The rushed and constrained introduction of PPC *dramatized* the practice as EOL care, overshadowing its espoused purpose of improving quality of life for those with life-limiting illnesses. As EOL care, PPC becomes directly associated with death, making the practice more threatening than its intended focus on holistic well-being.

Temporal destigmatizing. When the intensivists called the PPC physician, they asked her to come quickly due to Lily's critical condition. The PPC physician *entrained* to the treating physicians as the zeitgeber for the initiation of PPC by hurrying to the ICU. In doing so, she *anchored* PPC in the acute care norm of immediate treatment. This helped *normalized* PPC, as it seamlessly integrated the practice into Lily's treatment process and everyday clinical practice. As a PTT physician noted, "Our daily work is very fast.", and he expected the PPC team to keep up with that pace:

"I believe it's important to be quick. When [PPC] is needed, it's needed quickly. Basically immediately. I think it's good if it can be organized in a streamlined and spontaneous way. [...] I believe it's part of it to be available in a short amount of time. Unpredictable. It helps to be there when the team or the parents feel that they're ready, and not a week later or something. It can't be an emergency service because there are too few people for that, and that's not what it is. But I mean, the low-threshold, fast, and spontaneous aspect has to be there in the beginning. Otherwise, it doesn't work." (PTT physician 1)

While entraining normalized PPC by aligning it with the acute care norm of immediate action, it simultaneously perpetuated the practice's dramatization as EOL care. The PPC team did not want PPC to be understood and adopted solely as EOL care. However, the PPC physician unintentionally reinforced this limited understanding of the practice when she rushed to the ICU immediately after the physicians called her in. By acting quickly in response to the critical situation, the PPC physician further entrenched the meaning that PPC was only relevant at the end of life. In this instance, entraining thus played a dual role: while it normalized PPC within the fast-paced dynamics of acute care, it also restigmatized the practice as an emergency EOL intervention rather than a progressive holistic support that improves quality of life.

Outcome. The treatment team greatly appreciated that the PPC physician tried to support them in Lily's case. Its members found it valuable that she was available so quickly: "We called her, and she came. That was really good" (PTT physician 1).

4.1.3 Critical moment 2: A PPC physician met Lily's mother for the first time

Incident. In the ICU, the PPC physician was met by an intensivist who took her to Lily's bedside to introduce her to the child and her parents. However, only the mother was present. So, the PPC physician had to introduce herself to the father another time.

Verbal stigmatizing. The intensivist had the *distorted general understanding* of PPC that its initiation is a "declaration of surrender" (PPC Physician 1). That is, for the intensivist, starting PPC was tantamount to admitting defeat and giving up the fight for a child's life, which brought the practice into conflict with her core professional value of curing disease. In response to this tension, the intensivist *verbally distanced* herself from PPC when introducing the practice to Lily's parents in ways that *downplayed* its value, which ultimately undermined its importance and usefulness, thus *trivializing* it.

First, the intensivist verbally distanced herself from PPC by dropping the practice on Lily's parents without prior notice. The physician did not inform them about the PPC

offer beforehand but only casually introduced it during the PPC physician's visit. Such an abrupt introduction downplays the espoused purpose of PPC by disguising the practice's broader scope and ultimately trivializing it as just another acute care therapy.

As the PPC physician notes:

"I just experienced this again, where I think: THAT is where the problem begins – when we are introduced in a way that completely catches parents off guard. Like, just quickly: 'Oh, by the way, I just brought the palliative care physician with me. I'd like to introduce her to you as well.' That is a NO-GO! I could say: 'Today, the inflammation markers were too high. We took blood cultures. We found a rare germ there. I've already brought the infectious disease specialists along.' That follows a completely different logic. But since palliative care doesn't operate in an acute mode like intensive care, you can't handle it like that!" (PPC physician 1, non-case interview)

In particular, for parents like Lily's, who "fight day and night at their child's bedside for months" and are "suspicious of the whole system", PPC is a "BIG issue" (PPC physician 1). Therefore, they "cannot hear the word 'palliative' for the first time in the presence of the person who represents this area" (PPC physician 1).

Second, the intensivist verbally distanced herself from PPC by hesitating when introducing it to Lily's parents. This hesitation downplayed the practice's espoused value, ultimately trivializing it as an inferior substitute for acute care, making it seem like an undesirable option. As the PPC physician remarks: "It was OBVIOUS that [the intensivist] was EXTREMELY uncomfortable offering PPC to Lily's mother. It seemed as if she didn't want to do it but was forced to" (PPC physician 1).

Third, the intensivist's verbal distancing involved trying to appease Lily's parents that she was still fighting for their daughter's life, despite the PPC team's involvement. This framing downplayed PPC by implying that it was not part of the efforts to save Lily's life, trivializing it as an inferior, even useless, practice. As a PPC physician states:

"I experienced this a few times with this intensivist, where she would always say: 'Here's the palliative care team, but just so you don't misunderstand, we're still doing a lot.' And I stood next to her, and I wanted to sink into the ground because I thought: 'Well, in reverse, that means palliative care does nothing and is essentially trying to sell them, in quotation marks, that their child has to die. But we are obligated to involve such a team. But, as you can see, I'm still fighting for your child's life.' So, completely contradictory, with double messages that no one can understand, especially not someone who is emotionally burdened." (PPC physician 1)

Interactional destigmatizing. After the intensivist's introduction, the PPC physician spoke directly with Lily's mother. During the conversation, the PPC physician realized that Lily's parents were "EXTREMELY stressed" (PPC physician 1), and that her sudden, unprepared visit only added to the strain on the mother, as the term "palliative" frightened her (PPC physician 1). The PPC physician was not surprised by the mother's fear, as the practice had been presented to her in an "extremely unfavorable" manner (PPC physician 1). To alleviate the mother's anxiety, the PPC physician kept the conversation brief and then *distanced* herself by stepping away from the bedside. In doing so, the PPC physician *delineated* PPC as an unobtrusive, voluntary support service, thus *protecting* the practice and herself from further discrediting by the mother, who was known to easily become aggressive under stress.

Outcome. When saying goodbye, Lily's mother told the PPC physician that she did not want her to "just drop by" again, but that she would "get in touch" with her (PPC physician 1). However, the mother never contacted the PPC physician.

4.1.4 Critical moment 3: The PPC physician attended a parent meeting

Incident. The next time the PPC physician met Lily's parents was at a joint meeting with the entire treatment team, which took place three days before Lily's death. At this meeting, the PPC physician met Lily's father for the first time.

Verbal stigmatizing. The members of Lily's treatment team *lacked a practical understanding* that the stigma attributed to PPC is not given but constructed. They assumed that parents generally associate PPC with a "lack of treatment options" (PTT physician 1) and "death" (ICU nurse) and did not realize that they were constructing these negative associations through their actions, particularly their delay in involving the PPC team. The physicians and nurses were highly concerned that Lily's parents would stigmatize PPC, as this could have further deteriorated their relationship with them. With their deep mistrust and aggression, Lily's parents were already "making

everyone feel so uncomfortable”, which both “the nurses and the physicians couldn’t deal with very well” (PTT physician 1). The medical staff felt that Lily’s parents did not believe them, no matter what they said, as one nurse recalled:

“It was REALLY bad. There was a lot of distrust, no matter what you said. You could have provided proof in black and white, and they wouldn’t have believed it. I mean, you could have stood on your head, and they still wouldn’t have believed it. Not even from me, although I had a good rapport with them. They didn’t believe me either. They often told me, ‘You have to say that, as you work for them.’” (ICU nurse)

In response to the tensions with Lily’s parents, the treating physicians continued to *verbally distance* themselves from PPC during the meeting in ways that downplayed the practice’s purpose and ultimately trivialized it. The distancing actions included not mentioning the name of the PPC team, failing to introduce the practice to Lily’s parents themselves, and only allowing the PPC physician to speak last, after other physicians had either started leaving or had already left. These actions *downplayed* PPC by failing to provide it with the attention and importance it deserved, ultimately *trivializing* it as an afterthought, secondary to acute care. As the PPC physician reflects:

“We were sitting in a big room, and [the intensivist] said to the parents: ‘Here is the surgery team, and this is the nursing staff, whom you know well, and these are the physicians who have been taking care of you for a long time, and this is someone from, I don’t know, and then there is another department.’ And I thought: Great! Exactly the same thing. Then it was a really long conversation, and at some point, it was like: ‘[PPC Physician’s name], do you want to say something about what you could offer?’... The conversation had neither a beginning nor an end. There was no time frame. People started leaving as soon as I finally got a chance to speak or had already left earlier. The parents had been told that the meeting would last one hour. It took two hours. All that happened was this: ‘You already know everyone, and this is someone from another department.’ I was not given the floor at the beginning, where I was meeting the father for the first time in a conversation. I had seen the mother once. I never saw the father. I thought to myself, they should have let me say a few words at the beginning about why I am here, or the leading physician should have said: ‘We’ve INVITED [PPC Physician’s name] INTENTIONALLY because this is a field she is very familiar with.’ At least something to lay the groundwork, not just at the end, ‘Now I’d like to let [PPC Physician’s name] have a word at the end.’” (PPC physician 1)

Interactional destigmatizing. When the PPC physician was finally given the floor in the meeting, Lily’s parents were already “completely enraged” (PPC physician 1). Nevertheless, the PPC physician *allied* with the attending physicians and tried to help them convey to Lily’s parents that their daughter’s life was beyond saving. The PPC

physician's attempt to mitigate between the two parties consisted of her first communicating to the parents that the treatment team had done its best to prolong Lily's life. Secondly, the PPC physician sensitively explained to Lily's parents that it was time to stop treatments that were no longer helping, and that by agreeing to this, they were not abandoning Lily but expressing their love for her:

"I said to Lily's parents: 'Look, you can see that the team working with Lily and with you has put in an INCREDIBLE amount of effort. They've tried EVERYTHING. The LAST machines and so on have been brought in, but they just can't help. So now, it's about this: How can you say goodbye to your beloved daughter? How can you honor your daughter's love by agreeing to stop treatments that no longer help.'" (PPC physician 1)

By allying with Lily's treatment team, the PPC physician *actualized* the espoused benefits of PPC, *authenticating* PPC as a practice that can contribute valuable "soft skills" to "difficult conversations" (PPC physician 1). When advocating for PPC in the hospital, the PPC physician highlighted to her colleagues that she "could provide something different from what they could offer when discussing resuscitation status or changes in treatment goals with parents" (PPC physician 1). In Lily's case, the PPC physician demonstrated this capability, as members of Lily's treatment team praised her for the way she approached the child's parents. They acknowledged that she had done "a very good job" and "had formulated everything so well" (PPC physician 1). Despite the PPC physician's best efforts to ease Lily's parents' distress, the father remained so agitated that he told the PPC physician to "shut up" (PPC physician 1). As a result, she was ultimately unable to explain the support she could offer the family.

While the PPC physician allied with the treatment team and thereby authenticated PPC, she also continued to trivialize the practice. Ultimately, PPC was *trivialized* to such an extent that Lily's parents did not even consider the practice as EOL care, but only as an announcement of impending death. The parents were under the impression that the PPC physician had only been called to inform them that the treatment team had given up and that Lily would therefore die, as they told a nurse after the meeting:

I was at the bedside with her, with the child, I was taking care of her. The parents then told me: 'Do they think we're stupid? We already know what this means! She is going to die, and they want to discuss how she will die.' They completely emptied their anger at the bedside with Lily. [...] They were totally enraged. They were REALLY angry that we had even considered this, because in their view, we had given up on their daughter, and now [the PPC physician] was coming to talk about death and how she would die. That was the mother's statement as well. And the mother also told me afterwards that if she sees her again, she doesn't know what she will do. She will totally lose it." (ICU nurse)

Outcome. Lily's parents were still beside themselves long after the meeting when they had returned to their daughter's bedside. In their anger, they told a nurse that they do not want the PPC team to support them.

4.1.5 Critical moment 4: The PPC physician visited Lily again at her bedside

Incident. After the parent meeting, Lily's condition suddenly took an acute turn for the worse and in all the excitement, the ICU nurse forgot to inform the PPC physician that Lily's parents refused her support. Unaware of the parent's refusal, the PPC physician visited Lily again in the ICU the day after the parent meeting.

Interactional destigmatizing. When Lily's parents saw the PPC physician they "completely freaked out" (ICU nurse). They shouted at the PPC physician that they didn't want her there "at the bedside or at another meeting" (PPC physician 1). The PPC physician thereupon *distanced* herself from the parents. She accepted their refusal of PPC and withdrew from Lily's case. Immediately after the visit, the PPC physician wrote a circular email to the members of the treatment team, informing them that the parents did not want her support and that she would therefore no longer meet with them. By withdrawing from the case, the PPC physician *delineated* the boundary of PPC as a voluntary offer, thereby *protecting* the practice from further discreditation. Over the years, the PPC physician has learned that when PPC is forced upon people, it can become a harmful practice:

Interviewer: "How has your approach to motivating parents to seek palliative support changed over the years?"

PPC physician 1: "I have become much gentler. I don't want to convert anyone. I don't want to make anyone's life harder than it already is. I often say that. And if families don't

want it, then I don't push it. I've learned that there's NO point in forcing some concept onto someone. It doesn't work at all. It's traumatic. It makes their life harder. Or even to say: It's extremely nice when children are able to be openly informed about their illness and can also talk about their dying. But if parents absolutely don't want that, and you try everything to explain why it would be important, then I don't go behind the parents back and do something because that's their story, not mine." (Non-case interview)

Although the PPC physician withdrew from Lily's case, the treatment team continued inviting her to meetings. She *distanced* herself further, reinforcing the *delineation* of PPC as a voluntary offer and thereby *protecting* the practice from a continued improper adoption. The PPC physician refused all invitations from the treatment team, telling its members: "I'm sorry, but I told you that the parents don't want my support. I certainly won't come to a meeting when the parents don't want me to. That makes no sense" (PPC physician 1). In the end, the PPC physician did not even send the family a "letter of condolence", as she felt that this would "make things worse" (PPC physician 1).

Outcome. By distancing herself from Lily's case, the PPC physician empowered Lily's parents to gain some control over a situation that was otherwise beyond their control. It also honored their judgment in making the right decisions for their child. Lily eventually died two days after the PPC physician withdrew from her case.

4.1.6 Overall outcome: Failed adoption of PPC

In the end, the unfolding stigmatizing and destigmatizing dynamics *disempowered* Lily's parents to adopt PPC. The constructed meaning of PPC as an announcement of impending death, which is as dramatic as it is trivial, made it impossible for them to accept the practice. The parents' rejection of PPC in turn prevented the PPC team to help them cope with Lily's passing. Without anyone to support them in the grieving process, Lily's parents remained "angry and full of reproaches" towards the treatment team long after their daughter's death (PTT physician 1).

However, Lily's case could have developed differently if PPC had been initiated earlier. If the PTT physicians had done this shortly after Lily's birth by advocating PPC

to Lily's parents as a standard support service for seriously ill children, the chances of them accepting PPC might have been greater, as the PPC physician suspected:

"With a diagnosis that is actually known from birth... It would have been good to include palliative care as PART of the overall team much earlier. Just as there are psychologists, hygiene specialists, and nutrition counselors. It should be established as a fixed part and communicated as: 'In such difficult situations, the psychologist involved, not because you are mentally ill, but because this is an exceptional situation. Similarly, also the PPC physician brings continuity, advises us, and can sometimes offer a stronger outside perspective.' This wouldn't necessarily have meant that these parents would have accepted me, but the chance might have been a little greater." (PPC physician 1)

Ultimately, the (de-)stigmatizing dynamics reinforced the healthcare professionals' inadequate understanding of PPC. While some members of the treatment team acknowledged it was a "difficult situation" for the PPC physician, there was "little self-reflection on their part about what they could have done differently" (PPC physician 1).

One PTT physician even felt that their approach of initiating PPC was basically ideal:

Interviewer: "Is there anything, from your perspective, that could have been done differently in Lily's case to gain the parents' acceptance for the palliative care service?"

PTT physician 1: "I don't know. I think it was optimal. I think they just came when they were called. Then they made contact, and then... You probably can't do it any better. I wouldn't know how. Maybe, if they had come during a calmer phase, not only when the decision was made that nothing could be done anymore. That might have helped. But otherwise, I think it went pretty well."

In contrast, the PPC physician found that Lily's case was "very sad and far from ideal" (PPC physician 1). She reflected on many things that both the treatment team and she herself could have handled better. In particular, the PPC physician aims to ally more closely with the treating physicians in future cases by advising them on how best to present the PPC offer to parents:

Interviewer: "Is there anything you would do differently in hindsight?"

PPC physician 1: "I should have asked: How did you introduce me? Did you already talk to the parents about this? How did you talk about it? How was it received? If you want this to be successful, I suggest that you do this and that. The conversation certainly shouldn't take place at the bedside. Maybe it should involve both parents and so on..."

To summarize, in Lily's case, PPC was temporally, verbally, and interactionally (de-)stigmatized as a practice that consisted in the announcement of impending death. This construction of PPC disempowered Lily's parents from accepting the practice,

leading them to reject it. It also reinforced the treating physicians' inadequate understandings of PPC. In contrast, while PPC was similarly stigmatized in Eve's case, its adoption was slightly more successful, as I will illustrate.

4.2 Eve: (De-)stigmatizing PPC as end-of-life care

4.2.1 Case background: Toddler with a life-threatening disease

Eve was a few months old when she was diagnosed with a life-threatening disease. After initially successful therapy, she suffered a relapse in infancy and had to undergo further treatment. This treatment consisted of further intensive therapy, a subsequent transplant and finally an experimental therapy. In the course of treatment, Eve increasingly qualified for PPC due to a poor response to the therapies. The PTT physicians failed to significantly improve Eve's condition, which reduced the chances of success of the transplant. The PTT physicians carried out the transplant anyway, but as expected it was unsuccessful. Eve suffered a second relapse, for which the PTT physicians had no further treatment options apart from experimental therapy. The start of an experimental therapy was a key indication for PPC at Horizon, as the chance of success of such a treatment is usually poor. In Eve's case, it was "particularly poor", because with "a second relapse, [like the one Eve suffered from], there is basically nothing more to be gained" (PPC physician 1).

4.2.2 Critical moment 1: The PTT team called in a PPC physician

Incident. After a few months, Eve's experimental therapy remained unsuccessful. As a result, the PTT team decided to end the treatment and call in a PPC physician. Eve was a toddler at the time.

Temporal stigmatizing. Eve's primary treating physicians *lacked practical understandings* of PPC and therefore *delayed* involving the PPC team. According to the hospital's PPC indication criteria, the PTT physicians could have involved the PPC

team towards the end of the first therapy. However, they failed to do so because they lacked the practical understanding that PPC should be practiced in a reciprocal rather than a paternalistic relationship with families. Instead of giving Eve's parents the choice of whether they wanted to use the PPC offer, the PTT physicians withheld it from them. The physicians believed that Eve's parents were so focused on their daughter's survival that they would not have accepted early PPC:

Interviewer: "Could the PPC team have been involved earlier in Eve's case?"

PTT physician 4: "That wouldn't have been possible. The parents simply wouldn't have accepted it. Maybe a few days earlier, but otherwise, I don't think it would have been possible. The parents were too focused on the idea that the child must live and recover. They wouldn't have accepted it earlier."

Next, the PTT physicians could have initiated PPC from the start of the transplant given its "relatively poor" chance of success (PTT physician 4). However, they generally felt low self-efficacy in offering PPC to parents during ongoing treatment. The physicians feared that they would not be able to prevent parents from associating PPC with a failure of curative measures and thus losing trust in the treatment team. For the physicians, such a loss of trust could jeopardize the achievement of their core professional value, the healing of illnesses, as they were dependent on the parents as proxy decision-makers for their children in the treatment process. The PTT physicians were therefore reluctant to initiate PPC during Eve's transplant and experimental therapy, even though the therapies' chances of success were not the best:

Interviewer: "Could the PPC team have been involved earlier in Eve's case?"

PTT physician 5: "Well, mmh... [...] The situation was already such from the beginning that the disease was not improving, and if you see that as the reason to say, there's always the possibility that she... [...] The best scenario is, of course, when the disease improves and then you proceed with the transplant. You can say: 'Okay, the transplant has fewer chances of success because the disease is not gone.' So, before going into the transplant, the Palliative Care team could have been introduced there. Mmh... We do tend to hesitate... Hesitate because we fear we might upset the parents and suggest that there's no chance. Many parents perceive it that way when Palliative Care is introduced. They associate it with: 'It's hopeless. Now the Palliative Care team is here.' It's quite a difficult situation because you don't want to lose the parents' trust when you tell them: 'Of course, we're doing the transplant. We believe it's a possibility for healing, BUT we've also thought about Palliative Care.' It's not easy to put that into words. I mean,

to convincingly explain to the parents that you're still doing everything to try and heal the illness. For most parents, that's hard to separate."

By delaying the involvement of the PPC physician in Eve's case until the end of the experimental therapy, the PTT physicians – similar to the physicians in Lily's case – *rushed* and constrained the introduction of PPC, leading to a *dramatizing* of the practice as EOL care because by that time Eve's death was already imminent. In Eve's case, the EOL phase was particularly dramatic. Due to the "rapid progression of the [disease]", she needed blood transfusions "every few days" (PTT physician 5). She also "suffered from pain that became increasingly difficult to treat" (PTT physician 5). Eve eventually "could no longer walk and was bleeding everywhere" (PPC physician 1). Overall, she was "in a catastrophically poor condition" (PPC physician 1).

Temporal destigmatizing. The members of the PPC team *entrained* with the PTT physicians, using them as the zeitgeber for initiating PPC by waiting and then hurrying. Initially, the PPC team held back, waiting until the physicians called them in. A nurse on the PPC team had been involved in Eve's case since the initial diagnosis. She knew that the transplant had little chance of success and believed the PPC team should have been involved earlier as a backup plan:

"Eve was a toddler. These are always high-risk situations, and we knew that the prognosis was NOT good. Therefore, it would have been GOOD if we had developed some sort of plan with the family earlier: hope that Plan A works, but also be prepared for Plan B." (PPC nurse 1)

However, the PPC nurse did not push for early involvement, nor did she take the initiative to involve the PPC team on her own. Similarly, other members of the PPC team never intervened autonomously; they always waited for the treating physicians to call them in. As a PPC physician emphasized: "I am not going to any family of my own accord. I would NEVER do that." (PPC physician 1)

When the PTT physicians finally called in a PPC physician, she promptly made herself available to support Eve's case. By entraining with the physicians in these ways

– waiting for the physicians to act first and then hurrying once called – the PPC team’s involvement became *anchored* in acute care norms, where attending physicians take the lead and treatment is immediate. This helped *normalize* PPC by seamlessly integrating it into acute care practice. However, similar to Lily’s case, the PPC physician’s response also reinforced the stigmatization of PPC as EOL care.

Outcome. The PTT physicians appreciated the PPC physician’s willingness to support them with Eve’s case. The PPC physician was concerned that organizing EOL care at such short notice would place a great strain on her team’s resources.

4.2.3 Critical moment 2: A PPC physician met Eve’s father for the first time

Incident. The PPC physician went to the ward to introduce herself to Eve’s parents. However, she only met Eve’s father there. The mother was absent.

Verbal stigmatizing. The PTT physicians should have informed the parents about their daughter’s critical condition and the resulting need for PPC. However, the physicians *verbally distanced* themselves from PPC by asking the PPC physician to contact Eve’s parents directly. This avoidance behavior was not only due to a lack of practical understanding of how to present PPC to parents, but also reflected a *distorted general understanding* of the practice. PTT physicians perceived the need for PPC – the recognition of a disease’s incurability – as a personal failure. Consequently, they felt uncomfortable referring families to the PPC team, as a PPC physician suggested:

Interviewer: “How do you experience the willingness of the [PTT team] to use PPC?”

PPC physician 1: “It’s difficult. For them, palliative care is something to avoid. Well, that’s a very negative way of putting it, but... when I think about the situation with Eve, the desperate ‘Oh, actually, it’s so uncomfortable for me to refer the child to you.’ [...] This has to do with their mentality as physicians. For some of them, it’s the greatest failure if they can’t cure a child, and with that, palliative care is essentially a ‘No Go’.”

By delegating the introduction of PPC to the PPC physician, the PTT physicians withheld their support for the practice, *downplaying* its value. As a result, PPC was *trivialized* as an external add-on or an afterthought. This lack of proper introduction

and support reduced PPC's importance and credibility, making it seem secondary to the treatment process. The following quote illustrates this:

Interviewer: "Why do you prefer to meet parents for the first time together with the attending physicians?"

PPC physician 1: "Because, unless a specialist says, 'Hey, this mother mentioned in the consultation that she heard about you and would like to make contact with you or someone from your team', I see that as a clear mandate. But when the specialists themselves says, 'I think it would be good for the palliative team to get involved here' and then sends us in, I find it difficult because they're not even there to say, 'Look, this is [name PPC physician]. She is the head of the palliative team, which does this and that.' It feels like an additional reinforcement, rather than just fading away and saying, 'Can you talk to her?'."

Interactional destigmatizing. Although the PPC physician found it "extremely unfortunate" to meet Eve's parents alone (PPC physician 1), she *allied* with the PTT physicians and followed their request. By doing so, she presented PPC as an easily accessible, low-threshold option, *actualizing* its espoused benefits. This approach made PPC seem like a flexible addition to the care plan, one that could be introduced without disrupting ongoing treatment. It helped portray PPC as approachable and adaptable to the situation, thereby *authenticating* it as a supportive practice in the context of a child's critical condition.

However, by allying herself with the PTT physicians in this way, the PPC physician also condoned their verbal distancing and thus perpetuated the *trivializing* of the practice. Indeed, without an PTT physician introducing the PPC physician to him, Eve's father was slow to understand the importance or seriousness of her appearance: "It took him a while to categorize me and understand things like care plan, resuscitation status and and and... Palliative, what is that anyway?" (PPC physician 1).

In his confusion, the father responded to the PPC physician, "in the first moment with openness and then in the second moment with impressive hostility and aggressiveness" (PPC physician 1). The PPC physician assumed that the father's change of heart came about because the conversation with her and then with his wife

made him realize for the first time that his child was dying. Until the PPC physician's visit, the family had fought tirelessly for Eve's recovery:

Interviewer: "What was the reason for the shift from openness to hostility in Eve's father?"

PPC physician 1: "I think it has to do with the fact that he felt I was the one telling him that his daughter was dying. He then discussed this with his wife, and in that conversation, either through his wife's reaction or by sharing what I had said, he truly understood for the first time what I had actually communicated. And that really turned him around. This also means that he probably hadn't really heard it before, because everyone had been saying that they are in fight mode. We were fighting for her life. We keep going. There's definitely something more that can be done. We must not give up."

Outcome. Eve's parents were devastated after the PPC physician's first visit. The parents had fought for their daughter's life for so long, and now they were told that the fight was over, and their daughter was going to die.

4.2.4 Critical moment 3: The PPC physician attended a parent meeting

Incident. After the PPC physician's initial contact with Eve's father, they met again the next day at a joint meeting with the PTT physicians. The meeting took place in a small room separate from the ward where Eve was treated.

Verbal stigmatizing. At the meeting, the PTT physicians continued to verbally distance themselves from the need for PPC by *hesitating* to discuss Eve's critical condition, which inevitably *downplayed* the need for PPC and thus *trivialized* its importance. This hesitance was invoked by a *lack of practical understanding* of how to inform parents of their child's impending death. After a failed transplant, a child was usually transferred back to another department, which took over the case until the child dies. In the transplant department, children only died if there was a complication during transplantation, which, as far as a PPC nurse recalled, had only been the case for "two or three patients in the last ten years" (PPC nurse 1). For comparison: "In [the other department], maybe five patients die every year, and then there are also all those who die at home" (PPC nurse 1). The physicians thus lacked experience in providing EOL care, including telling parents that their child is going to die.

Interactional destigmatizing. Because the attending physicians struggled to talk about Eve's critical condition, the PPC physician assisted them in informing Eve's father about his daughter's need for EOL care and how it could be organized. By *allying* with the attending physicians in this way, the PPC physician *actualized* and thereby *authenticated* PPC as offering valuable soft skills for difficult conversations, as was the case with Lily. However, this also placed the PPC physician back in the uncomfortable position of discussing a child's impending death, thus perpetuating the trivializing of PPC. At the end of the meeting, the PPC physician felt that she had become the "angel of death" to Eve's father, who had only come to tell them that "it's over now" (PPC physician 1). This role of the angel of death was as dramatic as it was trivial, reflecting how the nature of PPC became paradoxical through this interaction.

Outcome. The meeting was brief and largely unproductive. While Eve's father agreed that his daughter should be cared for at home by the PPC team, he was too agitated to discuss the details of care organization or address other critical issues, including Eve's resuscitation status. The PPC physician's account of the meeting further describes its course and outcome:

"The meeting was incredibly SHORT and, in my opinion, NEVER properly prepared: 'We're having this conversation now because your daughter is in such bad condition. And we want to discuss this and that.' But actually, no one wanted to talk about it, and everyone was surprised by how intense the family's reactions were. So, everyone actually hesitated to address how dramatic the situation was. We couldn't discuss the resuscitation status. [...] The family was so shocked. I wrote down here [in the case file]: 'The family is reacting very shocked, but also angry. We can't discuss the next steps. They wish for care at home.' And four days later, the child was dead." (PPC physician 1)

4.2.5 Critical moment 4: Eve was released from the hospital to die at home

Incident. The day after the meeting with Eve's father, Eve was discharged from the hospital so that she could die at home. The PPC physician and a nurse from her team supported the parents with EOL care.

Interactional destigmatizing. After Eve's parents agreed that Eve should die at home, the PPC physician quickly *allied* with them. Together with a nurse from her team,

she rapidly organized Eve's outpatient care, including various therapies and a specialized nursing service. The PPC physician and nurse also made home visits, even though the family lived farther away. These actions helped *actualize* PPC as a practice that directly addresses the family's immediate needs. By facilitating Eve's care at home, the PPC team turned PPC into a tangible, integrated service, offering the family some final, precious moments of quality life. For example, Eve's father was able to finish a princess castle for his daughter, highlighting PPC's role in creating "important moments to remember" (PPC physician 1).

Through this support, the PPC team *authenticated* PPC as a vital and adaptable practice that responds to families' needs in critical situations. However, this also placed the PPC physician in the challenging position of addressing Eve's impending death, thereby perpetuating the stigma of PPC being linked to death. When the family expressed their fear at the possibility of Eve dying at home, the physician's role felt particularly intense. "It was unimaginable for the family to lose this child" (PPC nurse 1). In their deep despair, they even warned the PPC physician that they may resort to violence if their daughter died:

"Until the last moment, it was like this: 'This cannot happen. If our daughter dies here, we cannot guarantee anything. We cannot guarantee that we won't become violent.' I wasn't sure what was going to happen." (PPC physician 1)

Three days after Eve's discharge from the hospital, the toddler had an acute crisis that prompted the PPC physician to make an emergency visit to the family. Together with an emergency doctor, the PPC physician was initially able to stabilize Eve. However, on her way back, the PPC physician received a call informing her that Eve had passed away. She immediately returned to the family to confirm the child's death and offer further support. In the end, "Eve died so quickly that no one could keep up" (PPC nurse 1), especially not emotionally:

“I think everyone was emotionally overwhelmed. There was no time to process everything. It developed at such a rapid pace. From the first conversation until Eve passed away, not even a week went by.” (PPC nurse 1)

Outcome. Despite earlier threats, Eve’s parents did not become violent towards the PPC physician after their daughter’s death. In fact, their attitude towards the physician shifted completely. As the family gathered to mourn, following their cultural traditions, the PPC physician “felt like part of the family” (PPC physician 1). It was “incredible” for the PPC physician, as there was “total peace”, and Eve’s parents even told her: “It’s nice that you are here” (PPC physician 1).

4.2.6 Overall outcome: Limited adoption of PPC

Ultimately, the unfolding of the stigmatizing and destigmatizing dynamics led to a *weak empowerment* of Eve’s parents to adopt PPC. Unlike in Lily’s case, the PPC team was at least able to support the parents in their daughter’s EOL care. This eventually led to *wiser general understandings* of PPC among the treating physicians. They perceived the PPC team as “very supportive”, “flexible”, “pleasant to work with” and developed a “great appreciation” for its work (PTT physician 4). The physicians developed this positive understanding through the experience of the added value that the PPC team provided not only for the family but also for them in the EOL phase. One PTT physician particularly appreciated how the PPC team made her work easier:

“In Eve’s case, I clearly noticed the added value in not having to organize the home care, pain management, transfusions, and nursing service. I also didn’t have to deal with the concrete problems, such as when the child, for example, bleeds or has a fever at home. I wasn’t called as the attending physician, but all of that was taken over by Palliative Care. And that can be very time-consuming, especially in such a final phase. The establishment of the treatment plan, which is crucial in a palliative care setting, where all the key contacts are defined, what to do in case of complications, bleeding, fever, pain, and what concrete steps to take – this was all handled by Palliative Care. I was able to practically hand over the patient’s care.” (PTT physician 5)

While Eve’s attending physicians had developed more positive general understandings of PPC, they continued to lack practical understandings of how to present the practice to families. One PTT physician noted: “It is still a challenge for me

to tell families that we are considering PPC. That is the most difficult moment. After that, PPC is usually a support, but introducing it is difficult" (PTT physician 4). Similarly, another PTT physician "still had difficulty to choose a time to initiate PPC and to phrase it in a way that would keep parents from thinking: 'Now they've given up on our child and now it's all over'" (PTT physician 5). As this inadequate practical understanding of PPC persisted among the physicians, they continued to stigmatize the practice.

For the PPC physician, supporting the treatment team and Eve's parents to better cope with Eve's impending death came at the expense of her own personal resources. Organizing Eve's EOL care was a "huge effort" for the PPC physician (PPC physician 1). In fact, after Eve died, the physician felt like she had run a "marathon": she was "totally exhausted the next day" (PPC physician 1). For the PPC physician, Eve was therefore a "bad story, which could have been VERY different if everything had been planned and prepared a little earlier" (PPC physician 1). That would have "saved her a lot of energy" (PPC physician 1) or perhaps even given her some:

"I don't want to say that Palliative Care evokes feelings of happiness, but when care is successfully provided and a child can pass away relatively peacefully, creating a calm situation because everything is well-prepared, it can certainly bring a sense of peace within oneself. However, if that's not the case and you feel like you're in battle mode with a perspective different from the family's, it's incredibly draining." (PPC physician 1)

The course of Eve's case made the PPC physician wonder whether she should withhold her help in similar cases in the future: "I ask myself, in a case like this, wouldn't it be better to say, 'Hey, a child in this condition, you organize it yourself. I am not doing it.'" (PPC physician 1). However, such an approach would be at the expense of the families. In addition, the physicians are "usually very grateful" for the support of the PPC team in EOL situations (PPC physician 1). Rejecting the physicians' requests for help would negate this gratitude. It could even lead to tensions with them, as it would violate the hospital's norm that healthcare professionals should support each other whenever possible for the benefits of the patients.

To summarize, in Eve's case, PPC was temporally, verbally, and interactionally (de-)stigmatized as EOL care. This construction empowered Eve's parents to reluctantly accept the PPC offer and contributed, to some extent, to advancing the attending physicians' understanding of PPC. In the following section, I will illustrate the (de-)stigmatizing of PPC in Anya's case, which provides further evidence of why and how attending physicians stigmatized PPC.

4.3 Anya: (De-)stigmatizing PPC as an accompaniment into death

4.3.1 Case background: Adolescent with a life-limiting disease

Anya was an adolescent with a congenital life-limiting condition. She and her family moved to the country when she was a teenager and subsequently received care from specialists at Horizon, where she met all the indication criteria for PPC. Specifically, Anya (1) suffered from a high disease burden, (2) responded poorly to therapies, (3) had a shortened life-expectancy and (4) was subject to many social triggers of distress.

Firstly, due to inadequate medical care in her home country, Anya was in such a critical state of health at the time of her relocation that immediate hospitalization was necessary. During her hospital stay, the PTT physicians managed to improve Anya's condition to the extent that she "felt much better" (PTT physician 3). However, her condition was still "poor" (PTT physician 3). Unfortunately, Anya did not initially qualify for a transplant, which significantly reduced her life expectancy. In fact, she was "in a situation where it could have ended at any time" (PTT physician 3). After the hospitalization, the physicians continued to treat Anya in the outpatient clinic, although she had to be admitted to the hospital from time to time to stabilize her condition.

Anya seemed to be coping well with her serious illness: "She was always positive. She was always smiling. She always said, 'I'm fine.', even when she was EXTREMELY unwell" (PTT physician 3) and despite significant social stressors, such as the unexpected death of a parent. Although Anya's family was highly supportive, she

nonetheless had to assume a great deal of personal responsibility: “She made the decisions. A lot was left to her, which was simply too much for a child of her age with a life-limiting illness” (PPC physician 1). Anya was also “lonely” (PPC physician 1) because her illness made social interactions difficult. “Anya wasn’t very mobile” and therefore limited in her opportunities to meet friends (PPC physician 1).

4.3.2 Critical moment 1: A PTT physician called in a PPC physician

Incident. Several years into her treatment, Anya was admitted to the ICU during an acute health crisis that left both her and the intensive care physicians fearing for her life. In response, a physician from her primary treatment team requested the involvement of a PPC physician.

Temporal stigmatizing. According to the hospital’s PPC indication criteria, the primary treatment team physicians could have involved the PPC team when they first assumed Anya’s care following her relocation to the country. However, the physicians *delayed* initiating PPC until this critical incident. The medical tests eventually revealed that “Anya’s physical condition wasn’t that bad”, but that she “just had a panic attack” (PTT physician 3). Nevertheless, a PTT physician involved the PPC team because “it was the first time that Anya mentioned that she was struggling with this issue”, her death, and they hoped that with the help of the PPC team they could address it.

The PTT physicians delayed initiating PPC due to inadequate understandings of the practice. First, the physicians had a *distorted general understanding* of PPC. They assessed the need to involve the PPC team in cases based on their own perceived need for support and not based on the indication criteria set by the hospital. The PTT physicians called in the PPC team when issues arose that they could not address during their general consultations, including thoughts about dying, organizing complex therapies, and EOL care:

PTT physician 3: "I am familiar with palliative care here at the hospital and understand that it doesn't simply mean bringing them in when there's nothing more that can be done. Instead, they essentially accompany children and their families who are severely affected by an illness where medicine might not allow for long-term survival. They don't only provide support in the last days of life but potentially over years, addressing aspects we can't cover in general consultations."

Interviewer: "What kind of aspects?"

PTT physician 3: "For example, thoughts about dying. How to deal with them. Support with such thoughts or fears. What is still possible. Also, overseeing the complex therapies that some patients undergo and organizing pain therapies. And maybe some preparation for the time that might come, when the end is near. In that situation, primarily supporting the family and organizing a setting that aligns with the child's or the parents' wishes."

With Anya, the PTT physicians saw no need to involve the PPC team until she had her panic attack that revealed her fear of dying. Until then, Anya had never mentioned that she was worried about her death. Moreover, the organization of her therapy was not too complex for the PTT physicians and EOL care was not yet an issue for them, as they were still in the "stabilization phase" (PTT physician 3). Therefore, before Anya had her attack, the physicians had always considered it "too early" to call in the PPC team (PTT physician 3). This view was reinforced by the curative focus of the physicians and the fact that the involvement of the PPC team made them feel like they had given up and failed:

Interviewer: "Why is it that the PPC team is often involved so late?"

PTT physician 3: "Because we're doctors, and we always feel like we can somehow manage it ourselves. It's not really in our nature. It's sometimes also the feeling that... It's like giving up. That's a bit... And maybe even: I didn't succeed. It's that feeling too."

Another barrier for the PTT physicians to involve the PPC team in cases was their *lack of practical understanding* of how to present the PPC offer to patients and parents. The physicians feared that the term PPC would trigger feelings of giving up also in the families if these associated the practice with EOL care. Like the physicians in the previous two cases, those in Anya's assumed that people generally associated PPC with the end of curative measures. This anticipated stigmatizing made it difficult for the physicians in their daily practice to introduce patients to the PPC team:

“When you say the word [Palliative Care], everyone understands it as end-of-life therapy. When nothing else works, that’s when the palliative care doctors step in. That’s the common perception. [...] It’s somewhat an issue with the name. It’s just something we use. To go into palliation means you’re no longer pursuing active therapy to cure the illness but are instead focusing solely on measures to alleviate pain, accepting that the patient may die in the process. That’s what is commonly understood by the word palliative. When a patient is ‘palliative’, it means no more is being done – no more active therapy for the illness or life-prolonging measures. No more antibiotics. Those kinds of things. And the common thought is that the palliative care team takes on this role, managing these measures. It’s as if you’re giving up on the patient and handing them over. And that’s what makes it so challenging in practice. When I want to involve the palliative care team with a patient, the difficult part is explaining it to them in a way that doesn’t make them feel like we’re giving up on them. And that’s why the term Palliative Care might be a bit of a problematic name.” (PTT physician 3)

The anticipated stigmatizing of PPC was a barrier for the PTT physicians to involve the PPC team, as it conflicted with their efforts to maintain a positive relationship with a patient and its parents, as in Anya’s case. Although the physicians spoke openly with Anya and her parents about her critical condition, their focus was on enabling the girl to live as normal a life as possible despite her serious illness:

“For me, it was an emotional moment to tell the family that I would involve the Palliative Care team. It was not an easy moment in the relationship with this girl and her parents. Because it’s... It’s simply the topic of dying. When you involve this team, the topic of dying is immediately present. Although I had always said that it is a difficult situation, we had always tried to focus on the positive. We tried very hard to help her continue with her apprenticeship. She was determined to work. We worked a lot with the school so she could attend it. We did everything we could to support her so she could do what she wanted as much as possible.” (PTT physician 3)

By delaying the initiation of PPC until what was perceived by Anya and the treatment team as a life-threatening respiratory distress attack, the PTT physicians created a need to introduce PPC abruptly. This sudden involvement framed PPC as a crisis intervention rather than a gradual, supportive practice. The *rushed* introduction *dramatized* PPC as exclusively tied to EOL care, intensifying its association with death.

Anya was very aware of the seriousness of her illness, but she also had a strong will to live, as reflected in her attitude: “I live, and I fight, and death is not an issue for me” (PPC social worker). For her, the dramatic timing of PPC’s introduction clashed with her focus on fighting and living. This made PPC feel invasive, as she perceived

the presence of the PPC physician as a signal that she needed to discuss dying, something she actively resisted. As the PPC physician explained:

"[Anya] repeatedly said: 'I know that I have a serious illness that I could die from, but I don't want to die. I want to live.' Because of this, she sometimes had a very ambivalent relationship with us, as she thought – she even explicitly said this once – 'She thought that when I come, she would have to talk about dying with me.'" (PPC physician 1).

Temporal destigmatizing. As in the previous two cases, the PPC team also *entrained* in Anya's case to the treating physicians as the *zeitgeber* for the initiation of PPC. Firstly, although members of the PPC team were aware of Anya's critical condition early on, they waited and did not intervene on their own initiative. Secondly, the PPC physician made herself available immediately after being called by the PTT physicians and visited Anya in the ICU. Entraining anchored PPC within the acute care norms, where attending physicians take the lead and treatment is immediate. This helped normalize PPC for the attending physicians, making it a seamless part of the treatment process. However, it also contributed to the restigmatizing of PPC as EOL care. Given the timing of the intervention – immediately following an incident that Anya perceived as life-threatening – it seems almost inevitable that she would feel compelled to discuss her death with the PPC physician.

Outcome. Despite her fear of having to speak to the PPC physician about her death, Anya agreed to be supported by the PPC team. The PTT physicians appreciated that the PPC physician was available so quickly to help them with Anya's case.

4.3.3 Critical moment 2: The PPC team supported Anya in her daily life

Incident. After the treating physicians had stabilized Anya's condition, they discharged her from the hospital. They then continued to treat her in the outpatient clinic. Moreover, the PPC team began to support Anya.

Interactional destigmatizing. After Anya agreed to PPC, the team actively *allied* with her by building a relationship of trust and support, focusing on her well-being

beyond medical interventions. This alliance was critical in *actualizing* the practice of PPC, which was not just about managing EOL care but improving quality of life. The PPC physician introduced Anya to the team's psychologist, who provided "emotional support" (PPC social worker), helping her cope with her illness and strengthening her sense of self. As the PPC social worker noted, the psychologist was able to "calm" and "strengthen" Anya after her panic attack. Additionally, the team facilitated practical support, such as "taking Anya shopping to nurture her teenage spirit and arranging transport services to ease her commute to school" (PPC physician 1).

Through these actions, the PPC team *authenticated* PPC as a practice that genuinely improves quality of life and is not just about preparing for death. As the PPC physician explained, "Of course, this is not something that would normally be considered highly specialized medicine, but for Anya it was valuable and precious". Indeed, Anya "appreciated it a lot" (PPC social worker). The team's support allowed Anya to experience her teenage years as normally as possible, reinforcing PPC's role in enhancing life quality despite illness, as the PPC physician explained:

PPC physician: "With Anya, we focused a lot on aspects that promote life orientation and quality of life."

Interviewer: "What did this quality-of-life entail?"

PPC physician: "It was about her living a life that corresponds to her age. She's a pretty girl, but you can immediately see that she's very ill. It was about giving her the opportunity to feel accepted as a normal, young girl and to carry out her age-appropriate tasks without constantly feeling: 'I'm sick. I'm sick. I'm sick.' Instead, she has many healthy aspects, even sweet ones, that she can live out. She shouldn't be so exhausted when going to school that she gets nothing out of it. Rather, she should arrive at school like others, who experience the school day as fun."

Verbal destigmatizing. While the PPC team supported Anya, the PPC physician also actively *advocated* for her role to Anya. After the panic attack, Anya feared that the PPC physician's involvement meant she would have to talk about her death. To address this, the PPC physician made a conscious effort to communicate that her role was not about discussing death, but rather supporting Anya's life:

“[Anya] was often alone in the hospital. Whenever she was there, I tried to visit her, mainly to ease the fears she had expressed earlier, saying, ‘I’m not coming to talk to you about death.’ I told her, ‘I’m a normal person, and I’m not here to talk about death. I’m here to ask how you’re doing, what goals you have, and what we can do together, like looking at photos from your birthday or the dress you bought.’ I also kept reassuring her, ‘I’m the boss of [name of PPC psychologist], and I’ll make sure she helps you do things that are completely separate from what you’re afraid of.’” (PPC physician 1)

Through these conversations, the PPC physician explicitly advocated for her role by distancing herself from death-related topics and emphasizing that she was there to support Anya’s life. This advocacy aimed to show Anya that the PPC team was not solely focused on EOL care but could assist with everyday issues and goals, allowing Anya to focus on living rather than dying.

Despite these efforts, the PPC physician struggled to *demystify* her role in Anya’s eyes. Although the physician clarified that her presence was not about death, Anya did not develop a full sense of comfort with the physician. As the PPC physician noted, Anya became more “okay” with meeting her, but the relationship remained distant, with no “warm connection” developing. This suggests that the physician’s advocacy efforts were not entirely successful in dispelling Anya’s misconceptions about the role of PPC.

As a result, the PPC physician could not fully *legitimize* her role or make it seem more appropriate and desirable. While she focused on practical matters and everyday support – such as helping Anya with her goals and life tasks – these efforts did not fully valorize the role of PPC for Anya. The contrast with Anya’s relationship with other members of the PPC team – particularly the psychologist, with whom Anya developed a “very close” relationship (PPC social worker) – highlighted the physician’s difficulty in legitimizing her own role. The more personal, supportive relationship with the psychologist helped authenticate the team’s work, but the PPC physician’s approach failed to valorize herself as a prime carrier of PPC in Anya’s eyes.

Outcome. Despite the PPC physician’s best efforts, Anya remained reluctant to interact with her. The PPC physician therefore stayed in the background and had

“relatively little contact” with the girl (PPC physician 1). In the end, the psychologist became Anya’s main attachment figure in the PPC team.

4.3.4 Critical moment 3: Anya was transitioned to another hospital

Incident. One month before Anya’s eighteenth birthday, the primary treatment team at Horizon began preparing her transition to another hospital that could provide more age-appropriate specialized care. At that time, the PPC team had been supporting Anya for over a year.

Interactional stigmatizing. The transition was “very hurried as the [PTT physicians at Horizon] feared that Anya could suffer a critical incident shortly after her birthday and then be admitted to the other hospital where no one knew her” (PTT nurse 4). Due to the urgency, the PTT physicians involved only a small group of people in the process, excluding the PPC team. This exclusion effectively blocked the espoused practice of PPC, which involves a collaborative, interdisciplinary approach to ensure holistic care that aligns with the patient’s evolving needs. By not involving the PPC team, the PTT physicians failed to facilitate necessary collaboration, preventing the integration of palliative care into Anya’s transition. The PPC physician was informed about the transition only after it had already begun, reducing her role to a reactive one:

PPC physician 1: “It wasn’t really a collaboration. With other children, you transition them by having a joint session with the continuing care providers. Here, I found out about it more or less by accident and then took care of our part. But there was never a larger collaboration.”

Interviewer: “What exactly was your role in the transition?”

PPC physician 1: “I just told the palliative care department at the other hospital that when Anya gets hospitalized and is doing poorly, and she still can’t be transplanted, it is important for palliative aspects to be integrated.”

The lack of PPC involvement hindered the enactment of the espoused practice, which should have been integrated throughout Anya’s care, ensuring continuity and addressing both her medical and emotional needs. Instead, the hurried and fragmented transition left the PPC team sidelined, unable to contribute meaningfully.

The exclusion of the PPC team – by *blocking* the effective enactment of PPC – *marginalized* it, relegating PPC to a secondary, passive role in Anya's care.

Outcome. After Anya's transition from Horizon to the other hospital was completed, the PPC team was no longer involved in Anya's case. Unfortunately, not long after the other hospital took over Anya's care, she "collapsed" and "needed an emergency transplant" (PTT physician 3). The transplant became possible as a new antibiotic had since been approved that could fight Anya's germs in her affected organ. Anya survived the transplant, but she could still die from the germs if they got out of control:

"Since the transplant, she has had to take antibiotics constantly. The germ remains in her body and if it flares up despite immunosuppression, there is nothing we can do. It will always be a dangerous situation." (PTT physician 3)

4.3.5 Overall outcome: Limited adoption of PPC

Although the PPC team was able to improve Anya's quality of life, the unfolding of the stigmatizing and destigmatizing dynamics only *weakly empowered* the girl to adopt PPC. The circumstances under which the PPC physician was involved in Anya's case deeply anchored PPC for the girl as a practice that will accompany her to death. This association made it difficult for Anya to accept PPC, or the PPC physician as the main carrier of the practice, because it conflicted with her great will to live.

Ultimately, the PPC team's efforts have not really advanced the PTT physicians' understanding of PPC, as they did not notice much of the practice's enactment. There was "never any real collaboration" between the PTT physicians and the PPC physician (PPC physician 1). The specialists sometimes spoke to each other "quickly in the hallway" about her case (PPC physician 1), but otherwise did not coordinate their actions. As a result, the PTT physicians "didn't know much" about how the PPC team was supporting Anya (PTT physician 3). The physicians only noticed that the PPC team was able to avoid the stigmatizing of PPC by Anya and her family because they

did not seem to feel abandoned. Moreover, the PTT physicians perceived the PPC team's involvement as a relief not only for Anya, but also for the nurses on the ward:

Interviewer: "You said that the PPC team accompanied Anya in a "subtle, beautiful way". [PTT physician 3: Yes.] Can you please elaborate on that?"

PTT physician 3: "They managed to introduce it in a way that the patient didn't feel like she was being given up on, or that nothing more could or would be done. Instead, it was essentially, 'This is part of it because I'm so ill.' And they were really able to talk about the fears and the situation well. I think that really relieved her. [...] The relief was also important for the clinic and the nursing staff on the ward. They were always so shocked when Anya came back and how badly she was doing. I think for the ward, the thought that the PPC team was involved was very valuable."

Ultimately, however, the PTT physicians were still unaware of the need to involve the PPC team early, for example at a time when a child's condition was critical but stable. The physicians were also still afraid that families might not accept the PPC offer due to the stigma associated with the term 'palliative'. If anything, Anya's case has made the PTT physicians aware that they may need to become more open to an earlier involvement of the PPC team. In order to achieve this openness, they believed that they had to repeatedly experience the added value associated with it:

PTT physician 3: "There are families where I've been concerned about how they will handle it. Will they be able to accept it? I think when we're dealing with something like a lung transplant, it's relatively straightforward because you can say, 'Look, this is a transplant, and it carries an incredibly high risk of something going wrong.' You have to discuss this beforehand. That's relatively easy. But when a patient is in a stable condition, where you know there is a risk, but everything is stable, you end up thinking: 'Why should I involve the PPC team if there's no immediate issue?' I'm probably still a bit restrictive in those cases and could probably become more open."

Interviewer: "What would help you become more open?"

PTT physician 3: "Gaining more experience that earlier involvement makes life easier."

Indeed, authenticating the added value of PPC seemed to be crucial for the PPC team to overcome the separation of attending physicians from the practice. Over the years, the PPC physician had many conversations in which she tried to explain to her colleagues what PPC is (not) and does (not). However, she found that advocating the benefits of PPC to the primary treating physicians was far less effective than allying with them and demonstrating these benefits, even if it was long-term process:

Interviewer: “How have you tried to achieve earlier involvement so far? Which measures would you say have been successful, and which less so?”

PPC physician 1: “We've tried a lot. I've repeatedly tried to engage in conversations with the heads of the departments to explain things. Often, this is just lip service: ‘Yes, yes, I know it's important, but...’. I found this less successful than when individuals experience firsthand what kind of added value we can bring to families. And that takes a lot of time. But once that fear is reduced, it becomes much easier, and it's much more natural to say: ‘The PPC team is part of this setting. Period’.”

In Anya's case, the PPC physician struggled to ally with the PTT physicians as it was “almost like a competitive situation [with them] that just felt stupid” (PPC physician 1). In her view, “[they] don't have to compete with each other just because they belong to different disciplines” (PPC physician 1). After Anya's case, the PPC physician had decided to work more closely with the treating physicians by “communicating the rules of the game earlier, including the fact that there must be joint meetings to avoid everyone working in parallel” (PPC physician 1).

To summarize, in Anya's case, PPC was temporally, verbally, and interactionally (de-)stigmatized as an accompaniment to death, which hindered the full adoption of the practice. Despite the PPC team's support over nearly a year, Anya ultimately could not accept the PPC physician. The PTT physicians also struggled with adopting PPC, as Anya's case did not advance their understanding of the practice. In contrast, the adoption of PPC in the next case, Maria, was more successful, although it also started with a significant delay in the PPC team's involvement by the attending physicians.

4.4 Maria: (De-)stigmatizing PPC as improving quality of life

4.4.1 Case background: Newborn with a life-limiting malformation

Maria was a newborn who met the criteria set by the hospital for starting PPC in terms of her disease burden, response to therapies, life-expectancy, and family situation. First, Maria was prenatally diagnosed with a complex, life-limiting malformation. Consequently, she was already in the care of her primary treatment team during pregnancy. Maria's poor malformation was confirmed after her birth and

medical examinations also revealed “a whole range of other diagnoses” (PTT nurse 1). In addition to the malformation, Maria was diagnosed with intellectual and digestive dysfunctions that increased her care dependency. In particular, Maria was “low on oxygen saturations and therefore needed ventilatory support the whole time” (PTT physician 2). She also had “pale attacks and vomited a lot” (PTT nurse 1).

The PTT physicians were unable to cure Maria’s malformation, but they hoped to be able to at least improve her condition and prolong her life through various interventions. For many of these interventions, it was uncertain whether they would be successful: “We had to take some actions where we didn’t always know, ‘How do we move forward?’” (PTT physician 2). The interventions did not initially improve Maria’s condition as she was suffering from “all kinds of complications” (PTT nurse 1). Indeed, the specialists were faced with “problems on so many levels” that they were unsure whether Maria would survive: “The situation was always tense, and we did not know: Will she make it?” (PTT physician 2).

Despite Maria’s multiple disabilities, her parents “loved her more than anything” (PTT nurse 1). Nevertheless, dealing with the parents was not always easy for the treatment team because they belonged to a religious community that prohibits certain medical interventions and makes death taboo.

4.4.2 Critical moment 1: Maria was transferred to the ICU after surgery

Incident. After another surgery, Maria was transferred to the ICU in a life-threatening condition. Her state of health remained critical for weeks afterwards. It was highly uncertain whether Maria would survive.

Temporal stigmatizing. According to the hospital’s PPC indication criteria, the PTT physicians could have involved the PPC team in Maria’s case as early as her prenatal diagnosis with a complex, life-limiting malformation. However, the physicians *delayed* initiating PPC. As seen in Lily’s case, the PTT physicians had a *distorted*

understanding of PPC, perceiving it primarily as EOL care. This misconception led them to involve the PPC team only when they believed no further treatment options were available. In Maria's case, the doctors never felt they had reached this point:

"We never had to tell [the parents], 'You know, we have no options left. We have to let [Maria] go now.' That never happened in that way. Fortunately." (PTT physician 2)

Thus, the PTT physicians did not involve the PPC team, even though Maria was in a life-threatening condition in the ICU for weeks. By delaying the initiation of PPC day after day, the physicians were on the verge of dramatizing PPC as EOL care.

Temporal destigmatizing. Members of the PPC team regularly visited the ICU, as many of the children under their care were treated there. Because of these visits, they were aware of Maria's case. However, as in previous instances, the PPC team did not directly approach Maria's parents to offer support. Instead, it waited for the PTT physicians to initiate their involvement. By *entraining* to the physicians as the *zeitgeber* – the authority determining the timing of PPC initiation – the PPC team *anchored* PPC in the norm that the treating physicians should lead each case.

This approach ensured that PPC was introduced at a time when the physicians were ready to accept it. As PPC physician 1 explained, "[PPC] has a lot to do with readiness, not only on the part of the affected families, especially the parents, but also on the part of the professionals, especially the physicians." By entraining their actions to the physicians' readiness, the PPC team effectively *normalized* PPC, embedding it into the standard workflow of the ICU in a way that felt non-disruptive. This unobtrusive integration helped reduce potential resistance from physicians by presenting PPC as a collaborative and aligned part of the care process.

However, this alignment through entraining also enabled physicians to perpetuate the stigmatizing of PPC as solely EOL care. By deferring to the physicians' timing, the PPC team relinquished control over when and how the practice was initiated in each case. Consequently, the initiation of PPC often coincided with the point at which

physicians believed no further treatment options were available. This pattern reinforced the perception of PPC as exclusively EOL care among physicians, creating a vicious cycle in which PPC was consistently reconstructed as stigmatized in each new case.

Outcome. Maria's parents were prevented from deciding for themselves whether they wanted to use the PPC service. This in turn hindered the PPC team to support them and the treatment team.

4.4.3 Critical moment 2: An intensivist presented PPC to Maria's parents

Incident. Maria had been in the ICU for several weeks without the PTT physicians initiating PPC when an intensivist finally did. The intensivist presented the PPC offer to Maria's parents to obtain their consent to call in the PPC team.

Temporal, verbal, and interactional destigmatizing. Unlike the PTT physicians, the intensivist had wise understandings of PPC. First, the intensivist had an *undistorted general understanding* of PPC. She understood PPC as it was espoused by the PPC team: as a practice that improves the quality of life of children with life-limiting illness and their families. For the intensivist, PPC was particularly about responding best possible to the families' wishes and offering them ongoing support:

"Palliative Care is primarily about fulfilling or making the wishes of the sick child and their family come true as much as possible. It is about providing support, ensuring that there's always someone available to call." (Intensivist)

Knowing the benefits of PPC, the intensivist was upset that Maria's PTT physicians kept delaying the involvement of the PPC team in cases:

"I think it's a shame... I mainly see these children, and I think it's a shame that the [PTT physicians] don't involve the palliative care team earlier. There are so many children there with life-limiting conditions who definitely won't reach adulthood. I think the PPC team could be involved, especially because the [PTT physicians] don't like talking about death. I believe this could help prepare the families a bit better." (Intensivist)

In Maria's case, the delay in involving the PPC team was of particular concern to the intensivist, as it was uncertain whether Maria would survive and, if so, whether and how her parents would care for her. Given the PPC team's expertise in supporting

parents in caring for their critically ill child, it was imperative for the intensivist to finally involve the PPC team in Maria's case:

"We didn't even know if she would survive. And even if she does, we didn't know: 'Can she go home, or do the parents even want to take her home?'. These are the kinds of questions the PPC team handles exceptionally well, as they know what is possible and what isn't. [...] That's why I felt the PPC team HAD to be involved. It couldn't continue without them." (Intensivist)

The intensivist's general understanding of PPC was shaped by her collaboration with the PPC team in previous cases. The physician had already called in the PPC team several times before, which also gave her *competent practical understandings* of how best to present the PPC offer to parents. An important part of this understanding was not to be afraid of parents' responses to the offer, because "although some parents may reject PPC, there are also many who appreciate the support" (Intensivist). Her wise understandings of PPC enabled the intensivist to temporally, verbally, and interactionally destigmatize the practice when she introduced it to Maria's parents.

Firstly, the intensivist temporally destigmatized PPC by *entraining* the PPC team's involvement into Maria's care during a routine weekly review meeting, aligning it with ongoing treatment discussions. This timing constructed PPC as a natural extension of the treatment plan, not an abrupt intervention. As PPC physician 1 noted, "There are situations when children have just overcome a critical phase, and we are called in, which can be irritating for parents who then ask, 'What is the message here?'". In contrast, Maria's timing was crucial, as she remained in a precarious condition.

By harmoniously entraining PPC into the treatment process, the intensivist *anchored* it within the existing care norms, integrating it seamlessly into the holistic approach to managing complex conditions. This alignment helped *normalize* PPC, positioning it as a standard, complementary aspect of care rather than exclusively EOL care. As PPC physician 1 stated, "Maria was still in such a critical situation where it was completely open what was coming next", reinforcing PPC's relevance in the

ongoing treatment process. However, as PPC physician 1 cautioned, finding the right time to introduce PPC can be “extremely tricky: it may be that you are too early or, conversely, too late.”

Secondly, the intensivist interactionally destigmatized PPC by *distancing* Maria’s parents from their daughter when discussing the potential involvement of the PPC team. The physician purposefully chose to hold the meeting away from the bedside to avoid the emotional distractions that being in close proximity to Maria would create. As she explained: “I always tried to organize such meetings away from the child, as the parents are otherwise too distracted.” By doing so, the intensivist created a space where the parents could think and discuss the situation more abstractly, minimizing the emotional burden of confronting the potential for death in front of their child.

The interactional distancing *delineated* PPC from the emotionally charged ICU environment. By conducting the discussion outside of the bedside, the physician constructed the practice as something separate from the urgent, life-saving care being given to Maria. This ultimately helped *protect* the PPC practice from a potential stigmatizing. Had the meeting occurred at the bedside, where Maria’s parents were more likely to experience emotional breakdowns, the PPC team could also have been negatively perceived by other parents in the ICU, as a PPC physician 1 suggested:

Interviewer: “Where should the conversations take place better, if not at the bedside?”

PPC physician 1: “In a meeting room.”

Interviewer: “Do you have special meeting rooms for this?”

PPC physician 1: “There are some really bad rooms. Many rooms are NOT good at all. They are just dark chambers where, in the ICU, mothers are actually pumping breast milk, or there’s a worktable for someone else. So, it’s anything but ideal. But I still think that getting out of this cocoon with the child, and not having a situation in front of the child where you cry, maybe even break down, or who knows what happens, especially with other parents around... that’s not possible! It’s really difficult!” (Interview Lily)

Thirdly, the intensivist verbally destigmatized PPC by actively *advocating* for its added value to Maria’s parents. This advocacy began with addressing Maria’s limited

life expectancy, framing it as a “finite situation” without explicitly referencing death. This phrasing tactfully acknowledged the reality of Maria’s condition while respecting the parents’ religious beliefs and avoiding the stigma associated with discussing death. By doing so, the intensivist positioned PPC as a natural and necessary part of the care process. The intensivist further highlighted the PPC team’s expertise, portraying them as a trusted resource to help the family navigate the challenges ahead:

“I told them that they are someone who is always available for questions, if there are any problems. For example, someone who knows about home care. They help in the moments when things get difficult, or decisions need to be made. With them, there is someone there whom you know well and have a good relationship with.” (Intensivist)

This depiction reassured the parents of PPC’s practical and emotional benefits, cultivating a sense of trust in the team. The physician also emphasized that PPC was a voluntary offer, allowing the parents to explore the team’s support without feeling pressured: “They can get to know the PPC team and then decide on their own to what extent they take advantage of its offerings” (Intensivist). By presenting PPC in this manner, the intensivist alleviated fears of judgment or coercion, framing it instead as a collaborative and supportive partnership. Importantly, how the intensivist communicated this advocacy was as crucial as what she said. Her authentic belief in PPC’s value was conveyed through her conviction and confidence:

“If it doesn't come from within you, from within yourself, if it's not authentic, if you don't feel like ‘THIS is the right next step, we absolutely HAVE to do this, and we probably should have done it last week, but I thought today is a good moment’, then as the messenger, you’ve lost, and I have lost anyway. [...] So, as the messenger, you just have to be 100% behind it. If you’re just taking it on as a task and checking it off because it’s been on your agenda for weeks, it’s going to go wrong, because you’ll convey that with every fiber of your being. You can’t prevent that.” (PPC physician 1)

These advocacy efforts *demystified* PPC by clarifying its purpose as a form of specialized, non-intrusive support rather than an indicator of failure or an exclusive focus on EOL care. By promoting a desirable understanding of PPC as a valuable and complementary service, the intensivist *legitimized* its role in Maria’s care. Her framing reinforced PPC’s appropriateness and necessity, making it seem not only acceptable

but also beneficial for the family's journey. This legitimization, grounded in both what was said and how it was communicated, constructed PPC as an integral and trustworthy component of holistic care.

Outcome. The intensivist's destigmatizing efforts enabled Maria's parents to consider and be open to PPC rather than being affronted by it. At the end of the meeting, the parents agreed to meet with a PPC physician.

4.4.4 Critical moment 3: A PPC physician met Maria's parents for the first time

Incident. The PPC physician went to Maria's bedside in the ICU to introduce herself to the parents. However, she only encountered Maria's mother there. Therefore, the PPC physician introduced herself to Maria's father another time.

Temporal destigmatizing. The mother appeared tense as she "nervously cradled" Maria in her arms (PPC physician 1). The PPC physician was therefore at risk of being sent away by her. To mitigate this risk, she carefully *entrained* to Maria's mother by behaving like a guest. This approach reflected the physician's awareness that she did not have the "lead" in this case and was merely "joining it" (PPC physician 1). As she put it, "I initially behaved like a guest, in order to eventually become a member and be accepted, both in the family and in the treatment team" (PPC physician 1).

The role of the guest provided a delicate yet effective approach for *anchoring* PPC within the family's social and emotional environment. By asking Maria's mother for permission to enter the room, the PPC physician aligned her actions with familiar, non-threatening social norms, contrasting sharply with her previous role as a PTT physician. As she noted, in her previous role, she had a "mandate that allowed her to enter a room at any convenient or inconvenient time" (PPC physician 1). This deliberate act of deference anchored the PPC practice in a context of respect and relationality, rather than authority or intrusion, making it easier for the mother to accept.

When Maria's mother initially could not hear the PPC physician because "her hearing aids were switched off" (PPC physician 1), this incident "somewhat threw [the physician] off." However, the PPC physician reinterpreted the moment as a "bridge," recognizing that it symbolized the mother's vulnerability and her need to shield herself from constant observation. In the hospital, parents like Maria's are under scrutiny 24 hours a day. This relentless surveillance, as described by a social worker, is particularly challenging for inexperienced parents of critically ill children:

"In the hospital, you are under observation 24 hours a day. You have a whole host of nurses and physicians who see everything and write it down right away. That's very difficult to cope with, especially for such young parents with their first child, as was the case with Maria's. They still had to find their feet and didn't know what to expect with such an ill child." (Social worker 1)

The PPC physician's presence risked adding to this burden of observation. However, by continuing to act as a guest – "friendly," "polite," and "cautious" (PPC physician 1) – she distinguished herself from the authoritative or evaluative roles that other caregivers might occupy. This positioning anchored PPC in a framework of trust and partnership, aligning it with Maria's mother's need for supportive rather than judgmental interactions.

Through careful entrainment, the PPC physician facilitated Maria's mother's gradual openness. By listening attentively and allowing conversations to unfold naturally, the physician encouraged the mother to share personal matters, such as "about her family and her husband's family" (PPC physician 1). The PPC physician further *normalized* her presence by ensuring that her visit was "relatively short" (PPC physician 1), avoiding any sense of intrusion. When leaving, she provided her business card and reassured Maria's mother that she could reach out to her at any time.

In sum, by entraining to Maria's mother in a slow, careful, respectful way, the PPC physician anchored PPC in a socially familiar role, fostering trust and reducing resistance. Guests are often associated with family and friends, figures welcomed into

the home with openness. Similarly, by acting like a guest, the PPC physician promoted trust and approachability, which normalized PPC as a non-threatening, supportive part of the care process. This normalization was further reinforced by the PPC physician's willingness to signal her own insecurity:

"I'm not an exceptionally confident or incredibly self-assured person. I always approach people very cautiously, form an impression, and take that with me, and I also notice: 'Yes. This makes me feel insecure.' Even though that might sound negative or weak at first, I believe it's something very valuable to shape the next encounter in a way that the other person feels understood. If I don't act like: 'Yes, the first meeting was completely clear, and now we'll do it this way and that way.' But instead, if there's something questioning, something careful, TENTATIVE about it." (PPC physician 1)

After the meeting with Maria's mother, the PPC physician introduced herself to Maria's father another time. Maria's parents were rarely able to visit their daughter at the same time due to their work and commitments to their religious community.

Outcome: The PPC physician managed to establish contact with both of Maria's parents. They both agreed to meet the PPC physician again.

4.4.5 Critical moment 4: The PPT physicians learned about the PPC initiation

Incident. The intensivist informed the PTT physicians about the PPC initiation, only after she had already called in the PPC physician. The decision to involve PPC was not discussed with the PTT physicians in advance, despite them leading on the case.

Interactional stigmatizing. By *excluding* the PTT physicians from the decision to initiate PPC, the intensivist effectively *blocked* their potential support for the practice. This *marginalized* PPC by preventing the alignment and consensus of the entire care team, which is essential for presenting a unified approach to the parents. As a result, the practice lacked the collective endorsement needed to gain traction within the caregiving team. Ultimately, this created a latent conflict, undermining PPC's foundation as a collaborative, team-based approach to care. As an ICU nurse explained, the lack of coordination could create significant tension that parents would

perceive, disrupting the overall caregiving environment. For this reason, the ICU nurses would never independently involve the PPC team, as one explained:

“We could approach the Palliative Care team independently, without the doctors somehow being involved... But it’s not advisable, because the team should stand united behind it. There shouldn’t be any discrepancies within the team, because you feel that at the bedside. The parents feel it. The children feel it. And we don’t want that. That’s why, we could do it, but we don’t.” (ICU nurse, interview Lily)

In contrast to the ICU nurse, the intensivist *lacked a practical understanding* of the potential consequences of her uncoordinated actions. She bypassed the PTT physicians and informed them about the involvement of the PPC team only after the fact, without considering how the physicians might respond. As she explained:

“Maria had been on the intensive care unit for so long that we decided that this [i.e., PPC] had to happen. We just informed the [PTT physicians] that we had done it. There wasn’t much discussion; we just said, ‘We’ve done it, and that’s how it is now’.” (Intensivist)

Indeed, the intensivist’s uncoordinated approach created noticeable tension, as it brought PPC into conflict with the PTT physicians’ normative expectations, understandings, and professional goals. First, the intensivist’s actions violated the PTT physicians’ expectation that they should have been the ones to decide whether to involve the PPC team. Although Maria was in the ICU, she was still their patient. The intensivists were “not the treating physicians,” but merely “service providers,” as the ICU was “an intermediary ward” (Intensivist). Accordingly, in this context, the PTT physicians expected that the decision-making authority for the treatment process would rest with them. As PPC physician 1 explained, the PTT physicians voiced their dissatisfaction, stating: “Why was PPC involved? This should have been done by us.”

The involvement of PPC also contradicted the PTT physicians’ distorted general understanding of the practice, specifically their belief that PPC was only appropriate when all treatment options had been exhausted. In their view, Maria did not meet this criterion, and therefore, they questioned the necessity of involving the PPC team.

Moreover, the PTT physicians perceived the initiation of PPC as a threat to the trust they had established with Maria's parents. Due to their inadequate understanding of PPC, the physicians feared that Maria's parents would associate it with a lack of further treatment options. Such an association had the potential to erode the trust that Maria's parents had placed in the PTT physicians, which was especially concerning given that the parents were the key decision-makers in Maria's treatment. Prior to the involvement of PPC, Maria's parents had shown unwavering trust in the physicians, even allowing them to perform medical interventions that contradicted their religious beliefs. The parents had explicitly stated their trust in the PTT physicians, saying: "If you see another chance for therapy, we would like to take it. We want to make everything possible for our child" (PTT physician 2).

The perceived moral conflicts prevented the PTT physicians from accepting the PPC team's involvement. When they found out about the PPC team's engagement, they were "irritated," which not only "led to noticeable tensions between the ICU and the [PTT physicians]" (PPC physician 1) but also had a direct impact on the PPC team. The PTT physicians made it difficult for the PPC team to integrate with the treatment team, as highlighted by a social worker:

"It was not easy for the PPC team to get involved by the [PTT physicians]. That is, to get information from the ward or about meetings or to be involved in the planning of Maria's discharge from the hospital. In fact, it was a struggle for the team." (Social worker 1)

By *excluding* the PPC team from the decision-making process, the PTT physicians *blocked* the team's ability to fully practice PPC, thereby *marginalizing* the practice. The exclusion prevented the PPC team from enacting the support it aimed to provide, effectively hindering its potential contribution to the overall care process. As a PPC physician explained, without a collaborative approach and clear understanding among the team, the PPC practice cannot fulfill its intended purpose:

“When PPC is not understood and not wanted, it cannot achieve what it aims for, namely, to relieve families, to take away their fears and also to encourage them to try another therapy that may improve the prognosis.” (PPC physician 1)

Outcome. Maria’s parents noticed the tension among the caregivers, leading them to perceive that the involvement of the PPC team was not widely supported. This perception caused them to approach the PPC team more cautiously.

4.4.6 Critical moment 5: The PPC team set out to overcome its exclusion

Incident. The PPC team set out to overcome the initial tensions and to build a collaborative working relationship with the PTT physicians and the other caregivers.

Temporal destigmatizing. To overcome the exclusion, the PPC physician entrained with the primary treatment team, gradually aligning her approach with their established practices. She first approached a social worker from the primary treatment team, who had been involved in Maria’s care from the beginning. With the social worker’s guidance, the PPC physician gained insights into how to navigate the team’s dynamics and establish rapport with the PTT physicians. The social worker advised her on how to best approach the treatment team, including when to take initiative and how to engage with parents in a way that complemented the team’s ongoing efforts:

“I often had with [the PPC physician] ... How shall I call it? Well, some tactical assessments about how she should proceed with the treatment team as I know the people well. I gave her advice about whether it makes sense to proactively... Who should she approach and who rather not? Should she invite herself or arrange meetings with the parents on her own?” (Social worker 1)

By engaging with the PTT physicians and nursing team in a manner that respected their existing workflows, the PPC physician gradually *anchored* PPC in the core norm of acute care, where decision-making authority rests with the primary attending physicians. In alignment with this norm, the PPC physician regularly participated in rounds and attended parent meetings alongside the PTT physicians. In doing so, she demonstrated how PPC could complement the acute care model by offering additional support to families without disrupting the established care processes. Through these

efforts, PPC transitioned from a peripheral practice to an integral part of the care process. As the treatment team became more accustomed to the PPC physician's presence and contributions, the practice was increasingly *normalized* as an essential service. Eventually, the PTT physicians invited the PPC physician to attend their meetings, formally integrating her into their decision-making process.

Interactional destigmatizing. The PPC team *allied* with the PTT physicians by offering expertise and collaborating in decision-making, which *actualized* the espoused practice of PPC. In meetings, the PPC physician advised the PTT physicians on how to handle difficult situations, such as what to tell Maria's parents and which treatment options remained viable. As one PTT physician recalled:

"We discussed in this very bad phase: 'What do we tell the parents? Where do we stand? Which options still exist, which don't? We had time and again exchanged our expertise. But that wasn't just me. The senior physicians, assistant physicians, and nurses, they all discussed and prepared things jointly with the PPC team.'" (PTT physician 2)

Further, the PPC physician guided the PTT physicians in specific care tasks, such as when she helped a ward team during an EOL situation. She asked, "What do you need?" (PTT nurse 1) and then "helped the ward physician fill out the death certificate and told her what else she needed to do in this situation" (PTT nurse 1). The situation was exceptional for the ward physician because, while "there are many seriously ill children on the ward, when their condition becomes acutely life-threatening, they are usually transferred to the ICU" (PTT nurse 1). The ward team is therefore "hardly trained and experienced in dealing with dying children" (PTT nurse 1). In helping the ward team, the PPC physician actualized PPC by demonstrating its practical role in supporting not only families but also caregivers.

Through her actions, the PPC physicians *authenticated* PPC as a valuable "extra layer of care" (PPC physician 1). When educating other care providers about PPC, the PPC team always emphasized that it is not imposing itself on cases, as it aims at collaboration and not competition: "[We] explain: What is palliative? What do we do.

Why do we do it? We are not in competition, we do it together” (PPC physician 1). The PPC team demonstrated its collaborative approach in Maria’s case by trying to build a working relationship with the PTT physicians. Besides, instead of replacing Maria’s previous caregivers, “a well-established team consisting of a nursing expert, psychologist, and social worker” (Social worker 1), the PPC team strengthened their forces when it could have covered all three professions itself.

Outcome. The routine exchange between PPC physician and PTT physicians ensured that the latter never felt left out again, laying the grounds for continued collaboration. This also reassured other care providers and Maria’s parents.

4.4.7 Critical moment 6: Maria’s parents considered withdrawing from PPC

Incident. After Maria’s parents had already agreed to PPC, the mother suddenly told the PPC physician that she wishes to withdraw her consent. The mother was concerned that Maria will not get a surgery she is hoping for when the family continues to use palliative care. The request took the PPC physician completely by surprise.

Verbal destigmatizing. The PPC physician *advocated* for PPC by addressing Maria’s mother’s concerns and correcting misunderstandings to prevent her from withdrawing consent. She emphasized that acute care and palliative care are not mutually exclusive, reassuring the mother that she was “always striving to find ways for the child” (PPC physician 1) and that their goal was to “make everything possible” for Maria (PPC physician 1). Through these actions, the physician *demystified* PPC by explaining that it is not a “one-way ticket” (PPC physician 1). She reassured Maria’s mother that if the child improved, PPC would be discontinued, emphasizing its flexibility. Furthermore, the physician clarified that PPC doesn’t make the prognosis but instead supports the family as the situation evolves: “We support a child and its family as much as possible” (PPC physician 1). By advocating for PPC and thereby demystifying its role, the PPC physician *legitimized* the practice. She positioned it as

a responsive, complementary resource that could adapt to Maria's fluctuating condition, making it a valuable support option in uncertain times for Maria's parents.

Outcome. The PPC physician was able to correct the mother's misconception about PPC and to convince the parents to continue using the offer. This, in turn, prevented the PTT physicians from gaining another negative impression of PPC.

4.4.8 Critical moment 7: Maria's parents reached out to the PPC physician

Incident. The treatment team repeatably reminded Maria's parents about the fact that their daughter might die, which upset the parents. Eventually, they reached out to the PPC physician to voice their concerns.

Interactional destigmatizing. After the conversation with Maria's parents, the PPC physician *allied* with them by conveying their distress to the treatment team. Members of the team felt Maria's parents had a "skewed understanding" of her condition, believing that "once Maria left the ICU, she would be well and recover completely" (Intensivist), a view misaligned with medical realities. In response, the caregivers repeatedly told the parents that Maria might die: "We often had to bring the parents in and say, 'You know, she might die now'" (PTT physician 2).

This persistent effort to correct Maria's parents' perceived misunderstanding stemmed from the team's fear of being accused later of withholding information: "There is often the accusation from parents: 'Nobody told us how seriously ill our child is'" (PPC physician 1). However, the caregivers *lacked the practical understanding* that Maria's parents' hopeful demeanor was a coping mechanism common among families of critically ill children. Parents tend to "hide all negative messages and say: 'It will be fine. We notice what great will to live our child has'" (PPC physician 1). This may convey the impression that parents don't fully understand the seriousness of the situation, as a PPC physician explained:

Interviewer: "Why do professionals keep reminding parents that their child may die?"

PPC physician 1: "Because they don't realize that parents, who don't constantly talk about it or show no signs of worry and sadness at the bedside, might not have heard it. They may not be aware that this can be a strategy of the parents to say: 'Okay, I know that. But I won't feel any better if it's always mirrored back to me. I need to focus on my child. I want to be happy. I want to be positive, even if there isn't much reason to be positive.' And when professionals feel like it hasn't been understood, they feel the need to say it again and again without realizing that the response to such a statement doesn't always have to be parents bursting into tears and saying, 'I know that. I'm aware of it.' Sometimes, it's simply accepted without comment. I mean, it's difficult to deal with that."

It can be very distressing for parents to hear repeatedly from a treatment team that their child could die, not only because it undermines their coping mechanism, but also because they may feel discriminated against. Parents may get the impression that their child does not receive the best possible treatment like every other child because of their personal background. Specifically, Maria's parents could have assumed that they would be discriminated against because of their religious affiliation that is a target of stigmatization in Western culture. Of course, children in the hospital were not treated differently because of their family background, but parents could easily feel this way, as the PPC physician knew:

"When professionals say, 'We are worried that your child might die', you sometimes get the feeling that there are parents who feel offended by this. As if their child isn't being given the same chance as another child. As if it has something to do with them as individuals, as people, which it absolutely doesn't. A statement like that would never be made because they might be Portuguese, or Yugoslavian, or anything else. That's not the case. But I think it quickly gets into the parents' minds that they need to fight for something they don't actually need to fight for because it's not even up for debate. The idea that a certain ethnicity, religion, or any other background could lead to a child being denied any therapies is nonsense." (PPC physician 1)

The PPC physician worked with Maria's caregivers to help them understand that the parents' behavior reflected a coping mechanism and that they did comprehend the seriousness of the situation. This effort *actualized* the espoused practice of PPC by demonstrating its core value: supporting families' unique needs and ensuring their perspectives are respected in care decisions. As the PPC physician put it: "There is a lot of individuality, and I think it is important that one language is spoken [by everyone] and not that the next person comes along and says: 'Do you know that your child may die?'" (PPC physician 1).

By aligning with Maria's parents and addressing their concerns, the PPC physician *authenticated* PPC as a valuable practice that balances medical realities with socio-psychological support. This approach not only improved the parents' experience but also proved to the PTT physicians that PPC could enhance the overall care relationship rather than create conflict. The PTT physicians acknowledged this mediating role:

"Sometimes it's helpful to have someone who is, so to speak, an outsider. We've often known each other for a very long time, the families and us as caregivers, and then it can be really beneficial to have someone involved who isn't a [member of the primary treatment team]. Someone who can look at things a bit more objectively, without as much emotional involvement, and simply assess the situation as it actually is. Someone who, with medical expertise, can consider: Where is support needed now? What does this family specifically need at this moment?". (PTT physician 2)

Outcome. Thanks to the support of the PPC physician, Maria's treatment team was able to respond better to her parents' needs, avoid unnecessary friction with them and thus improve the overall care relationship.

4.4.9 Critical moment 8: Maria was moved from the ICU to the general ward

Incident. Maria's health improved and she was transferred from the ICU to the general ward, where her in-hospital care continued. Her parents were keen to take her home and the PPC team helped them organize the transition into home care.

Interactional destigmatizing. After Maria's transition, the PPC physician immediately allied with the parents to organize their daughter's home care for the period after she was discharged from the hospital: "I very quickly tried to focus on the time after the hospital. That was a success factor, I think" (PPC physician 1). Organizing Maria's home care revolved around creating a care plan, a key element of PPC practice. Such a plan is intended to provide parents with the structure and peace of mind needed to care for their child at home. As one social worker explained: "In the hospital, there is always someone they can ask. It is then a big step to go home and be on your own" (Social worker 1). With the care plan, parents have a compendium providing them with "all important information about their child's therapies and care

providers” (PTT nurse 2). As Maria was a complex case, many different aspects had to be clarified and recorded in her care plan:

“One had to come up with an entire plan. Whom should the parents call if Maria’s condition deteriorates? When should they call for help? What will be done then? How should they react in emergency situations? All this had to be defined. Also, where is the limit? In other words, when do you still take what measures?” (PTT nurse 1)

The creation of Maria’s care plan was particularly complex because her parents wanted to move abroad with their daughter immediately after her discharge from the hospital. To make all the necessary arrangements, the PPC team *allied* with the PTT physicians and nurses by actively involving them into creation of the care plan. “Most of the care plan, the largest part, had to be filled in by the physicians” but also the nurses were “given defined tasks regarding what they had add from the nursing side” (PTT nurse 1). In assigning tasks to nurses, the PPC physician relied on the PTT physicians as conduits, as one nurse recalled:

“During the ward rounds, the physicians sometimes said: ‘[The PPC physician] would be happy if you could add this and that to the care plan’. Like such specific assignments. It doesn’t necessarily have to go through the physicians. I think it happened in this case as the physicians had to write much more into the care plan. Probably they had a meeting with the PPC team, and it asked them: ‘Could you please forward this to the nurses?’. We have one to two rounds everyday with our physicians and our communication is much closer.” (PTT nurse 1)

To facilitate the collaborative creation of the care plan, the PPC team set up a folder on the hospital’s drive that contained “a document that anyone could edit without any problems” (PTT nurse 1). However, not without having first discussed any changes to the plan with the other members of the treatment team, i.e., “each detail or each address you write in the plan has to be agreed upon” (PTT nurse 1). The PPC team coordinated the co-creation of Maria’s care plan by seeking low-threshold exchanges with all caregivers. “You could always ask them questions” (PTT nurse 1); conversely, the PPC team also addressed people directly if they had any questions:

“[The PPC physician] has her office two doors down from mine and just comes by when she has questions, and then we chat. I think it’s great when it can be so simple and low threshold. Since the parents wanted to move abroad, the question was: What about the home care service? What about the oxygen? And logopedics? I also had a close

exchange with the nursing expert from the PPC team. We discussed: Who does what? Who contacts whom?" (Social worker 1).

By allying closely with Maria's parents and their caregivers to create Maria's care plan, the PPC team *actualized* the espoused practice of PPC, translating its principles into actionable support. The PPC physician promised Maria's parents that she would support them in any way she could, and she delivered on that promise. When the PPC team planned Maria's home care, it "gave a high priority to the needs of Maria's parents" (PTT nurse 1) and was thanks to its holistic perspective able to "point out issues that would otherwise have been forgotten or ignored" (Social worker 1). In fact, the PPC was able to "cover everything, including medical, nursing, psychiatric and social issues" (Social worker 1). Its holistic view differentiated the PPC team from Maria's treatment team, as a PPC physician suggested:

"[We] tried to consider further aspects, which are relevant when caring for a child with a complex disease than the individual specialist who draws on all of his or her expertise to address the heart or feeding issue. [We] looked at the family from a holistic perspective and at Maria as part of her family. [We] thought, for example, about the mother who is expecting a second child: How does it work? How does it work living abroad with such a seriously ill child? Close to the border, but still it was an issue. What do we do in an emergency?" (PPC physician 1).

The PPC team's active involvement and unwavering reliability further *authenticated* PPC as a practice that provides comprehensive, family-centered care. By consistently following up on agreements and ensuring that no detail was overlooked, the PPC team demonstrated its commitment to the families it served. This reliability was noted by other caregivers, who contrasted it with the often-disjointed communication typical of hospital wards, as a social worker noted:

"Often, it's like this: you agree on something and then, because of the way medical responsibilities are structured on the wards, someone else might be in charge two days later, and many things just fizzle out. The PPC team is very reliable, which I think is very good. It follows up if it doesn't hear from you. I find that very positive." (Social worker 1)

Outcome. The PPC team's efforts culminated in a detailed care plan that was agreed with the parents and treatment team. This created the possibility that Maria might be discharged into home care if her condition improved sufficiently.

4.4.10 Critical moment 9: Maria was discharged from the hospital

Incident. Maria was discharged from the hospital several months after her birth. The family moved abroad, where it came partly under the care of another hospital. Still, the PPC team continued to be accessible to Maria and her parents.

Temporal destigmatizing. The PPC team *entrained* closely to Maria's parents before her discharge from the hospital, demonstrating responsiveness to the family's immediate needs and rhythms. Members of the team made themselves available even on short notice, responding promptly whenever the parents sought their presence:

"Before Maria's discharge from the hospital, the mother asked frequently: 'Is [the PPC physician] coming by today?'. When the mother asked for someone from the PPC team, you had to call that person who then made herself available quickly". (PTT nurse 1)

After Maria's discharge, the PPC team maintained this temporal flexibility and accessibility. The PPC physician was "always reachable" for Maria's parents, "even under her private number" (PTT nurse 1). Additionally, the PPC physician proactively organized a "home visit right after Maria left the hospital when she recovered surprisingly quickly and well after all" (PPC physician 1).

By entraining its actions to the family's temporal realities, the PPC team *anchored* the practice of PPC in its espoused norms of continuity, responsiveness, and needs-based care. This alignment demonstrated the PPC team's commitment to meeting the family's evolving needs, reinforcing these core principles as intrinsic to PPC. Through these repeated acts of accessibility and adaptability, the PPC team *normalized* PPC as an integrated and ongoing care practice, rather than one solely associated with EOL scenarios. Initially, the PPC physician sought to transfer Maria's palliative care to a hospital closer to the family's home to simplify care coordination. However, realizing that such a shift would compromise the quality of care, she decided to continue overseeing Maria's palliative care herself:

"I was the one who tried to collaborate from the palliative side with the other hospital. However, I recognized at some point it doesn't work. [...] I had the feeling that it would

get too complicated. Therefore, I decided that I keep the PPC aspects and [Maria] is only cared for by the other hospital for cardiological issues.” (PPC physician 1)

This decision further underscores temporal destigmatizing by highlighting the PPC team’s adaptability to ensure continuity and responsiveness, even when logistical challenges arose. By consistently aligning its actions with its espoused norms, the PPC team reinforced the perception of PPC as a reliable and valuable form of care, thereby contributing to its normalizing.

Interactional destigmatizing. Even one year after Maria was released from the hospital, the PPC team maintained its relationship with Maria’s family, exemplifying how the practice of PPC extended beyond episodic care. This ongoing engagement allowed the PPC physician to remain informed about Maria’s condition and provide support during critical moments. For example, when Maria was hospitalized for another surgery, the PPC physician once again supported the family, reinforcing their trust in the team’s enduring care:

“I know one or two cases, also long-term cases like Maria, who continue to be our patients from time to time even today. In those cases, as well, [the PPC physician] or one of her colleagues would stop by the department to check in with the child: ‘How are you doing?’. She also uses such a hospital stay for that purpose.” (PTT nurse 2)

By consistently *allying* with Maria’s parents through their most challenging times, the PPC team built a strong relational foundation. This alliance involved active listening, tailored support, and a readiness to intervene when needed, emphasizing the PPC team’s commitment to providing holistic care to the family. In doing so, the PPC team *actualized* the espoused value of PPC as a practice rooted in continuity, psychosocial support, and responsiveness.

Through these sustained efforts, the PPC team *authenticated* the espoused practice of PPC, demonstrating that it was not merely theoretical but an integral and reliable component of care. This ongoing relational engagement highlighted PPC’s broader scope – supporting not just EOL situations but enhancing the overall quality

of life for the child and family. As the only constant caregiver throughout Maria's journey, the PPC team provided a sense of stability that was deeply valued by the family. This was noted by a PTT physician:

"The only constant in the end was the palliative care team. That was surely something very important for the family, that they had a sense of continuity. I think that's also an important aspect of this palliative care situation – that you offer them consistency. From inpatient to outpatient care, they essentially have the same points of contact throughout. This gives parents the feeling: 'They know how things were for us back then. They know how things are for us now. They can assess us well.' It was quite demanding, but it worked well." (PTT physician 2)

Outcome. The parents appreciated the support of the PPC team and felt well prepared for the discharge, which went off without a hitch. Maria's care at home worked well and the specialists at the hospital remained informed about Maria's development.

4.4.11 Overall outcome: Extended adoption of PPC

Like the previous cases, Maria's case began with a delay in the initiation of PPC by the PTT physicians. Unlike in the previous cases, however, the destigmatizing of PPC then became dominant and *empowered* Maria's parents and the PTT physicians to adopt PPC. The turning point marked the efforts by the intensivist, as it ended the PTT physicians delay in starting PPC. The intensivist's destigmatizing efforts enabled Maria's parents to make an informed decision about whether to adopt the PPC offer. This in turn enabled the PPC team to ally with the parents, PTT physicians, and other caregivers and to thereby authenticate the value of PPC. In this way, the PPC team both integrated and differentiated itself so that it became successfully embedded in Maria's treatment team. In other cases, too, the PPC team had seamlessly embedded itself, which made it akin to a puzzle piece, as a social worker suggested:

"They are like an additional piece of the puzzle. For me, it's very fluid what the Palliative Care Team takes on and what it doesn't. I think that really depends on the case, on the situation, which I find very good. So, you can't clearly say: 'They do this. They don't do that.' That's why it's like a puzzle piece. They fit in and really look at: 'What is needed? What can we offer?'. And for me, they are especially a very valuable support and addition for the family when it comes to the outpatient setting at home." (Social worker 1)

Unlike the PTT physicians, the intensivist had relatively wise general and practical understandings of PPC that enabled to initiate the practice in a destigmatizing way. The intensivist gained these understandings through her previous experience of involving the PPC team in cases and subsequent experience of the added value it can provide. Similarly, the PTT physicians gained *wiser understandings* of PPC through their positive experiences with the PPC team in Maria's case. In particular, the case promoted their general understanding of PPC to the extent that it basically matched the understanding advocated by the PPC team. That is, the PTT physicians "no longer saw PPC as EOL care, but as support for their patients in medically challenging situations and with complex family circumstances" (PTT physician 2). The physicians have come to appreciate that the PPC team, with its holistic approach, can support these complex patients and families in a variety of ways:

"It's GOOD that there is someone who sees things a little bit detached from the narrow disease issue and simply looks at the family, the child, and the environment, but still with this medical expertise. I think that's a completely different approach than what a social worker might be able to offer. Although I don't want to claim that it's social work. It has so many components. So, it's a very strong psychosocial support and, of course, also organizational assistance, and she [i.e., the PPC physician] simply has solutions. She knows how to solve certain things in the [Country] system. She knows where to start and can give the families good advice on how to deal with the situation. She's someone who talks to them. Listens. Counsels. So, it's really diverse." (PTT physician 2)

The wiser general understanding of PPC informed the PTT physicians to involve the PPC team earlier into cases. After Maria's case, they have involved the PPC team in "several other cases", in part even "VERY early" (PPC physician 1). However, the PTT physicians still needed to improve their practical understandings of how best to present PPC to parents. They still felt that the PPC offer causes anxiety in parents because they associated it with the exhaustion of curative measures and the imminent death of their child. This anticipated stigmatizing of PPC by parents continued to make it difficult for the PTT physicians to introduce the practice to them:

"For the general population, meaning the parents, 'palliative' is often associated with the idea that the child is doomed to die and that the only thing left to do is accompany them

until they pass, making that journey as comfortable as possible. I think that's what many people imagine. That makes it so difficult when you bring up involving the team, as parents then feel: 'Okay, now they've given up. Now the therapy is over. There's nothing more to be done. Now it's only about making the farewell as comfortable as possible.' This is what many parents perceive as an alarm bell, because they can't differentiate it." (PTT physician 2)

For the PPC physician, Maria's case advanced her practical understanding of PPC. From the incident with the PTT physicians, she has learned to entrain to all the treating physicians of a child early on to ensure that none of them feels bypassed. Specifically, when a child is referred to her now, she asks: "To what extent have the other physicians caring for the child been informed and involved in the decision to call us in?" (PPC physician 1). After tensions with the PTT physicians had eased, Maria's case was considered by the PPC physician to have "gone really well" (PPC physician 1). She did not feel that "anyone had felt bypassed or uninformed again" (PPC physician 1).

In summary, in Maria's case, PPC temporally, verbally, and interactionally destigmatized and adopted as a practice that improves quality of life. Maria's parents not only accepted the PPC physician, but even developed a "close relationship of trust" with her (PPC physician 1). The parents regularly contacted the PPC physician and then not only reported on Maria's developmental progress, but also asked the physician how she was doing. The PTT physicians had also built-up trust in the PPC team. They found that the PPC physician became a "confidant" for Maria's parents (PTT physician 2) who holistically supported them without disrupting their relationship with the parents. Based on their wiser understanding of PPC, the PTT physicians involved the PPC team more effectively into cases. Indeed, Maria was a "key case" for the PPC team, as she "opened the door to [this department] for it" (PPC physician 1). In the next chapter, the discussion, I synthesize my findings from all cases into an empirical and more abstract theoretical model depicting the construction and adoption of stigmatized practices as a process of (de-)stigmatizing. Moreover, I present theoretical summaries of the stigmatizing and destigmatizing dynamics.

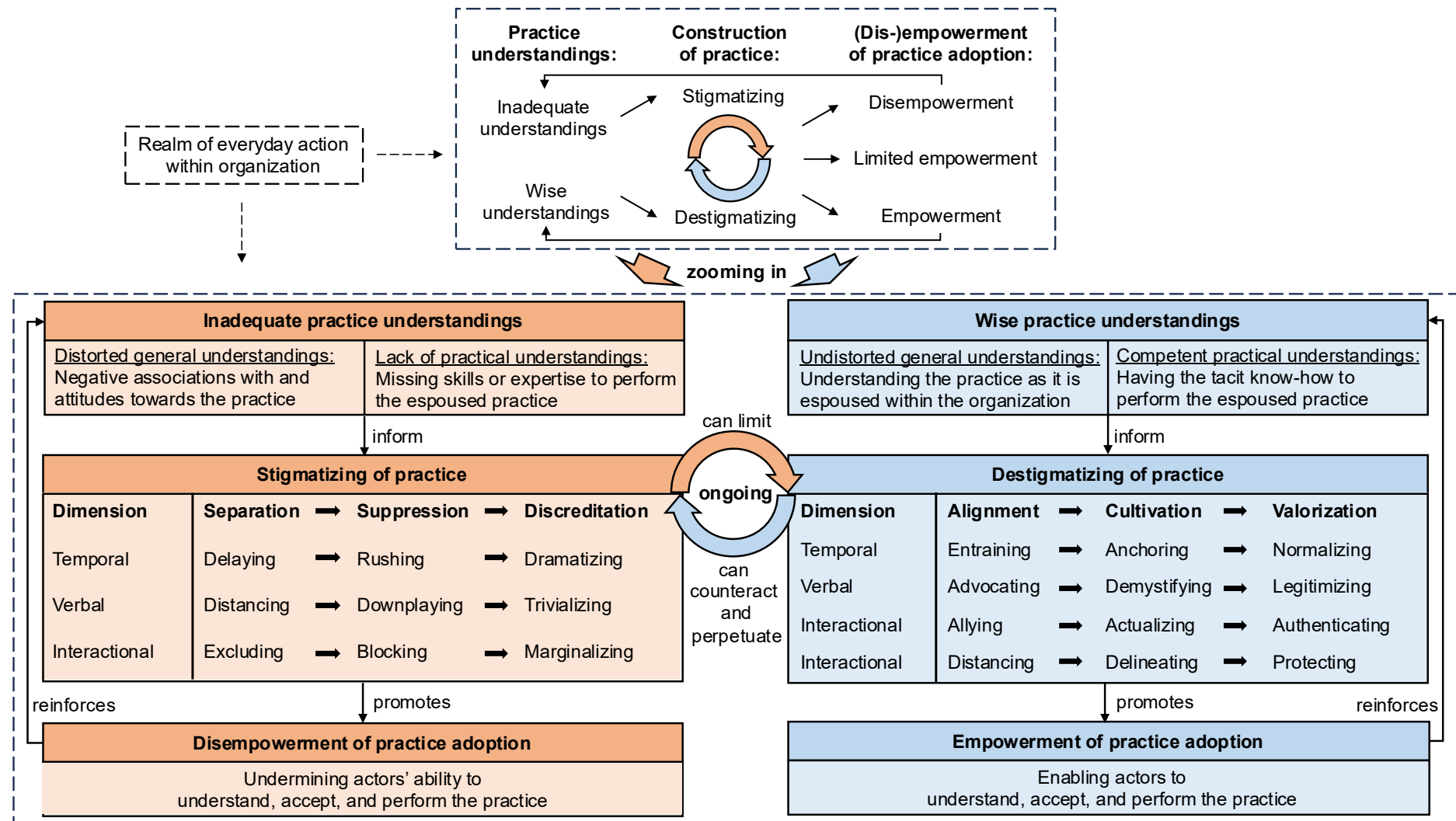
5 DISCUSSION

I first developed an empirical model, which I subsequently abstracted into a conceptual model to guide further inquiry. The development of both models was informed by the empirical data I gathered and the theoretical insights from existing literature. The empirical model represents a data-driven understanding of the practice adoption process, grounded in specific observations and findings from my research. It theorizes practice adoption as an ongoing, dynamic process of (de-)stigmatizing within organizational settings. Building on this, the conceptual model provides a higher-level, theoretical framework that integrates the findings from the empirical model with broader concepts and theories, offering a more abstract perspective on the process. I begin my discussion by providing a detailed description of the empirical model. I then explain the conceptual model. Finally, I discuss how my findings address the gaps in practice adoption and stigma research identified in the positioning section. Lastly, I outline the limitations of my study and suggest directions for future research.

5.1 Theorizing practice adoption as a process of (de-)stigmatizing

This study set out to explore how stigmatized practices are constructed within organizational settings and with what impact on adoption, using a practice perspective. From this lens, stigmatized practices are continuously constructed through actors' everyday actions, which can either enact stigma (stigmatizing) or counteract it (destigmatizing). Through the PPC case study at Horizon, I examine these dynamics and their impact on adoption, integrating the findings into an empirical model (see Figure 1). I first explain the stigmatizing dynamics, followed by the destigmatizing dynamics, both based on the empirical model. I then discuss their interrelation and present my conceptual model.

Figure 1: Empirical model of practice adoption as a process of (de-)stigmatizing



5.1.1 Stigmatizing dynamics, triggers, and adoption impact

Stigmatizing dynamics are informed by *inadequate understandings* of a practice in “general” and/or “practical” terms on the part of actors (Schatzki, 2002, p. 79). *Distorted general understandings* contain actors’ negative associations and attitudes towards a practice. These understandings can cause actors to perceive it as inappropriate to enact a practice in a given context despite the practice’s espoused benefits. Actors have a *lack of practical understandings* of a practice when they do not have the know-how to perform the espoused actions of a practice that are pertinent to a particular situation. As a result, they are unable to “go on” (Giddens, 1984, p. 43).

Stigmatizing dynamics can unfold when inadequate practice understandings trigger actors to separate themselves from a practice. These *separation* activities can involve delaying, verbal distancing, and excluding. With the first two activities actors separate themselves from a practice by avoiding becoming carriers of the practice, and with the third activity they keep other carriers of the practice at a distance. Separation as an avoidance behavior (Putnam et al., 2016) can be particularly pronounced when actors’ inadequate understandings of a practice put it at odds with their core values. In response to this tension, actors may significantly delay the initiation of the practice, verbally distance themselves vehemently from it, and/or completely exclude other practice carriers, such as experts, from ongoing activities.

Separation activities can stigmatize a practice by suppressing and thereby discrediting it. *Suppression* involves that the practice is prevented from unfolding as it is espoused within the organization, while *discreditation* involves that the espoused meaning or value of a practice is undermined or reduced. With each of the separation activities – delaying, distancing, and excluding – a practice is suppressed and discredited in different ways. According to the practicing dimension at which the separation activities are performed, I referred to the stigmatizing dynamics as

temporal, verbal, and interactional stigmatizing. If a practice is temporally, verbally, and/or interactionally stigmatized, this can very much impair the ability of actors to understand, accept, and engage in a practice and thus *disempower* them to adopt it.

A closer look at the *stigmatizing dynamics* reveals how separation activities suppress, discredit, and disempower (see Table 9). Firstly, *temporal stigmatizing* consists in actors delaying the initiation of a practice, thereby reducing the time available for its espoused enactment. The compressed timeline can create pressure to rush the practice by omitting or shortening espoused activities. This suppression of the practice can create a sense of urgency that discredits it as threatening or otherwise dramatic. A more dramatic meaning can ultimately disempower actors to adopt a practice by triggering repugnant emotions (e.g., disgust, fear or anger) in them. Such negative emotional responses are seen as a core dimension of the manifestation of stigma (Dovidio et al., 2003; Link et al., 2004; Pollock et al., 2019).

Secondly, *verbal stigmatizing* can occur when actors distance themselves from a practice by what they (do not) say about it and how they say it. By verbally distancing themselves, actors signal a lack of endorsement for the practice. This can be done by presenting it only casually to focal audiences, hesitating to introduce it, anonymizing the practice by omitting its name, reassuring audiences that it won't harm them, or delegating the responsibility of introducing it to others. These verbal distancing actions all downplay the practice's value and significance, potentially making it seem less important or trivial. When actors are prevented from recognizing the importance of a practice and are disempowered to understand its potential benefits, they may question the need to adopt it and ultimately refrain from doing so.

Table 9: Summary of stigmatizing dynamics

Dimension	Separation from the espoused practice	Suppression of the espoused practice	Discreditation of the espoused practice	Disempowerment of focal audiences to adopt the espoused practice
1. Temporal	<u>Delaying:</u> Temporizing or postponing the initiation of the practice	<u>Rushing:</u> Shortening or omitting activities due to a lack of time	<u>Dramatizing:</u> Making the practice (appear) more serious or threatening	<u>Creating tensions:</u> Actors likely respond with anger, fear, or disgust to the practice, making them reluctant to adopt it
2. Verbal	<u>Distancing:</u> Demarcating from the initiation of the practice using verbal cues	<u>Downplaying:</u> Diminishing the espoused value of the practice	<u>Trivializing:</u> Making the practice seem less important or complex than it is	<u>Limiting understanding:</u> Actors are prevented from understanding the practice's value, impairing their motivation to adopt it
3. Interactional	<u>Excluding:</u> Failing to include focal audiences into ongoing activities	<u>Blocking:</u> Impeding the enactment of the practice	<u>Marginalizing:</u> Relegating the practice to a peripheral, ineffective position	<u>Limiting experience:</u> Actors are prevented from experiencing and ideally internalizing the added value of the practice

Focal audiences = Actors who are supposed to adopt or support the adoption of a practice

Thirdly, *interactional stigmatizing* involves actors excluding other carriers of the practice, such as practice experts, from ongoing activities, for example, through opposing, bypassing, ghosting, or subordinating them. Exclusion activities can block the espoused enactment of the practice, especially if the exclusion restricts the access of practice experts to information and focal audiences. As the enactment of the practice is blocked, it is relegated to an ineffective, marginal position. As a result, focal audiences are prevented from experiencing the espoused value of the practice and may thus be disempowered from becoming committed to engage in it.

Ultimately, the disempowerment of actors to adopt a practice through stigmatizing dynamics can reinforce their inadequate understandings of the practice. As a result, stigmatizing can lead to a vicious circle in which a practice is recurrently (re-)stigmatized. However, actors may also destigmatize a practice, which I explain next.

5.1.2 Destigmatizing dynamics, triggers, and adoption impact

Actors can destigmatize a practice when they have *wise understandings* of it, including undistorted general and competent practical understandings. Actors with *undistorted general understandings* have internalized the purpose and features of a practice, as they are espoused within the organization. *Competent practical understandings* contain actors' know-how to select and judiciously perform a practice according to situation-specific demands. Destigmatizing is achieved through *alignment* activities that lead to the *cultivation* and thereby *valorization* of a practice. Like the stigmatizing dynamics, the destigmatizing dynamics can be categorized as temporal, verbal, and interactional. Destigmatizing dynamics foster focal audiences' understanding, acceptance and use of a practice and thus *empower* them to adopt it. A closer look at the *destigmatizing dynamics* reveals what activities wise actors undertake to align with focal audiences and how these alignment activities cultivate, valorize and empower (see Table 10).

Table 10: Summary of destigmatizing dynamics

Dimension	Alignment with focal audiences	Cultivation of the espoused practice	Valorization of the espoused practice	Empowerment of focal audiences to adopt the espoused practice
1. Temporal	<u>Entraining:</u> Synchronizing timing and pace of practicing with readiness and goals of focal audiences	<u>Anchoring:</u> Rooting the practice in its own norms and those of the organization's core practice	<u>Normalizing:</u> Embedding the practice in expected or familiar social dynamics of focal audiences	<u>Avoiding tension:</u> Prevents actors from perceiving the practice as disruptive or problematic, which enables them to openly engage with it
2. Verbal	<u>Advocating:</u> Explaining to focal audiences the espoused norms and goals of the practice	<u>Demystifying:</u> Providing clarity and understanding of the practice's espoused features	<u>Legitimizing:</u> Promoting desirable and eliminating undesirable practice understandings among focal audiences	<u>Informed decision:</u> Provides actors with an understanding of the practice that allows them to make a better-informed decision about whether to adopt it
3. Interactional	<u>Allying:</u> Joining forces with focal audiences to enact the practice	<u>Actualizing:</u> Supporting the realization of the espoused features of the practice	<u>Authenticating:</u> Demonstrating the espoused value of the practice	<u>Internalizing value:</u> Enables actors to experience the added value of the practice and thereby to become committed to it
4. Interactional	<u>Distancing:</u> Separating from focal audiences or shielding them from core practice	<u>Delineating:</u> Establishing, enforcing or maintaining the practice's boundaries	<u>Protecting:</u> Preventing a (continued) discreditation of the practice	<u>Containing misconceptions:</u> Prevents actors' misconceptions about practice from being confirmed and/or new ones from emerging

Focal audiences = Actors who are supposed to adopt or support the adoption of a practice

First, *temporal destigmatizing* is invoked when actors entrain to focal audiences. This involves that they align their pace and timing of enacting a practice with the readiness and goals of those actors who are supposed to adopt the practice or support its adoption. Actors can entrain to focal audiences by accommodating to their readiness, probing their needs, engaging with them, and enduring their actions. Entraining to focal adopters can cultivate a practice by anchoring it in its own norms and those of the organization's core practice. In this way, a practice is embedded in expected or familiar social dynamics of focal audiences, which normalizes the practice for them. The valorization of a practice as normal prevents focal audiences from perceiving it as problematic, disruptive, or otherwise undesirably deviant. This avoidance of tensions can ultimately empower them to be open to engage in the practice. Aligning with focal audiences through entraining to them thus provides the ground for further destigmatizing activities.

Second, *verbal destigmatizing* can unfold when actors advocate for the espoused purpose and features of a practice to focal audiences. Ideally, actors explain these characteristics in a way that makes them clear and easy to understand. Such advocacy efforts may involve affirming what the practice is and what it does, while repudiating what it is not and does not do. This demystification can foster positive understandings of the practice and eliminate negative misconceptions among focal audiences, helping the practice appear legitimate. The valorization of a practice as legitimate empowers focal audiences to make more informed decisions about whether to engage it.

Third, *interactional destigmatizing* can unfold differently depending on whether actors ally with or distance themselves from focal audiences. Allying involves actors joining forces with focal audiences to enact the practice together. This may include assisting and nurturing focal audiences, brokering relationships on their behalf, or coordinating actions between them. These actions help bring the practice's espoused

enactment to life and ultimately demonstrate or prove that the practice can offer real, valuable benefits. As focal audiences experience the practice's authentic value, they are empowered to "internalize" this value (Kostova & Roth, 2002, p. 217), which in turn fosters greater commitment to adopting the practice.

However, actors may also distance themselves from focal audiences. This may occur when focal audiences reject the use of a practice or seek to adopt the practice in ways that are misaligned with its espoused features. Moreover, distancing may consist in actors shielding focal audiences from the organization's core practice in a "reflective space" that helps them reorient towards the practice (Bucher & Langley, 2016, p. 600). All these distancing activities delineate a practice's boundaries, which can protect the practice from (further) discreditation. The valorization of the practice as a protected practice prevents focal audiences from seeing their misconceptions about the practice confirmed and/or from developing new ones. This may empower them to adopt the practice better next time.

If a practice is temporally, verbally, and/or interactionally destigmatized, this can foster wiser understandings among focal audiences that inform them to destigmatize a practice themselves. Destigmatizing can then unfold in a virtuous cycle in which the practice is recurrently (re-)destigmatized. Whether and how actors are able to align their enactments of a practice with focal audiences to promote the practice's adoption depends on the previous enactments of the practice by other actors and focal audiences' responses to this enactment, as I explain below.

5.1.3 Interrelation of stigmatizing and destigmatizing dynamics

Stigmatizing and destigmatizing are not separate but interrelated dynamics. Stigmatizing can limit the scope of action for destigmatizing, while destigmatizing can counteract and perpetuate stigmatizing. Ideally, actors can counteract stigmatizing by overcoming it. First, advocacy activities can enable actors to overcome temporal,

verbal, and interactional stigmatizing dynamics. Specifically, actors can advocate to end the delay in the initiation of a practice, to recognize and not trivialize the importance of the practice, and to become included in ongoing activities. Moreover, actors may overcome interactional stigmatizing by entraining to focal audiences, as this can normalize their presence for them. If actors succeed in overcoming initial temporal, verbal, and/or interactional stigmatizing, this provides them with the opportunity to ally with focal audiences and empower them to not only accept the practice but to become committed to it. In this way, among all alignment activities, allying can contribute the most to promoting wise understandings among focal audiences.

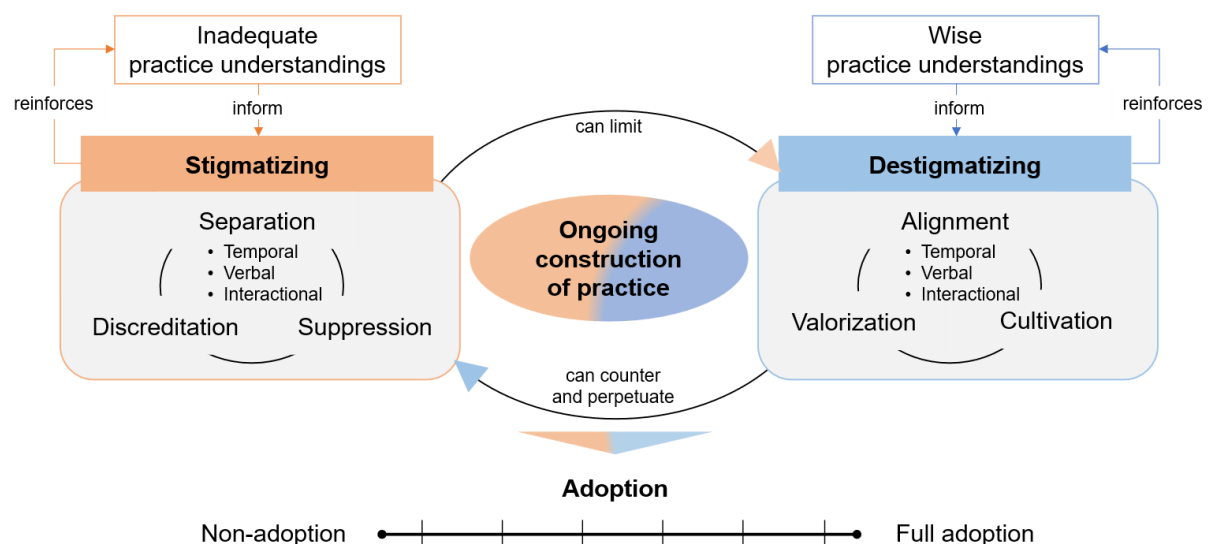
However, actors may not be able to overcome stigmatizing if it limits their scope of action to align with focal audiences. Exclusion can be particularly limiting as actors may not realize that they are being excluded or realize it too late to take countermeasures, such as advocating for their inclusion. Furthermore, delaying the introduction of a practice can dramatize it to such an extent that its discreditation due to lack of time becomes irreversible. In this situation, entrainment and alliance activities can simultaneously valorize the practice and perpetuate its stigmatizing. Alternatively, interactional distancing can end the stigmatizing by interrupting it, but it risks creating new tensions with focal audiences by withholding support. Thus, delaying may present actors with the dilemma of how best to align with focal audiences.

Theoretically, stigmatizing dynamics can dissipate once all focal audiences have experienced the destigmatizing dynamics and gained wise understandings of a practice that inform them to enact a practice in a destigmatizing way themselves. In practice, however, it can be difficult to completely overcome stigmatizing dynamics for different reasons. First, it may be difficult if the circle of focal audiences extends beyond an organization's employees to its customers or other stakeholders and is therefore very large. Second, distorted general understandings of focal audiences can be

persistent as negative associations and attitudes are resistant to disconfirmation and thus to change (Ashforth, 2019; Pollock et al., 2019). Accordingly, focal audiences may have to repeatedly experience destigmatizing dynamics until their general understandings of a practice are completely undistorted. Likewise, it may take focal audiences numerous destigmatizing experiences to develop competent practical understandings, in particular if a practice is relatively complex and subject to opposite norms than the organization's core practice. For these various reasons, stigmatizing can persist in practice without ever fully resolving. Therefore, my model suggests that the stigmatizing and destigmatizing of a practice are both *ongoing* dynamics.

Building on the empirical model, which maps the specific stigmatizing and destigmatizing dynamics observed in the case of PPC at Horizon, I developed a conceptual model to abstract these insights beyond the case context. The conceptual model identifies key mechanisms and relationships underlying the construction of stigmatized practices and their influence on adoption (see Figure 2).

Figure 2: Conceptual model of practice adoption as a process of (de-)stigmatizing



My conceptual model offers a theoretical framework to guide future research on practice adoption and stigma in similarly complex or sensitive organizational settings. In the following section, I elaborate on the contributions of my study in greater detail.

5.2 Theoretical contributions, limitations, and future research

My findings make significant contributions to scholarship on practice adoption and stigma. First, they prompt a re-evaluation of how (stigmatized) practices are adopted within organizational settings. Second, they advance a more integrative perspective on the social construction of stigma. In the following section, I first discuss the contributions of my study to the field of practice adoption, followed by its implications for stigma research. I conclude the discussion by reflecting on the limitations of my study and suggesting future research avenues it opens up.

5.2.1 Reconsidering the adoption of (stigmatized) practices

By exploring how stigmatized practices are constructed within organizational settings and with what impact on adoption, this study is one of the first to address the intra-organizational adoption of stigmatized practices. Although some studies have recognized that organizations take up stigmatized practice from their environment (e.g. Chuang et al., 2011; Reinmoeller & Ansari, 2016), little, if any, research has examined their uptake at the frontline (Stice-Lusvardi et al., 2024). The reason for this is, perhaps, a tendency in organization studies to conceptualize stigma as a condition worse than illegitimacy, the opposite of legitimacy (Suddaby et al., 2017), and the predominant treatment of practices as entities in conventional adoption research (Naumovska, Gaba, et al., 2021). Together, these views suggest that stigmatized practices are relatively rarely introduced into organizations as they “embody” features (Ansari et al., 2010, p. 80) that violate societal norms and are therefore seen as highly undesirable and inappropriate (Chuang et al., 2011). As a result, scholars may have not further considered the intra-organizational adoption of stigmatized practices.

In contrast, this study follows calls not to “equate stigma with legitimacy”, but to keep stigma research “separate from – and untainted by – legitimacy” (Helms et al., 2019, p. 5). Moreover, by mobilizing a practice perspective, it allows us to see that

stigmatized practices are not negatively evaluated entities that may or may not be introduced into organizations, but rather constructed within them through people's everyday actions. More specifically, from a practice view practices "do not exist out there" (Orlikowski, 2002, p. 252) with certain fixed or given properties, such as having a stigma or not. Rather, a practice is continuously under construction within the moment-by-moment activities of the actors engaged in it and stigma is constituted and reconstituted through this practicing (Feldman & Orlikowski, 2011; Jarzabkowski et al., 2018). As noted, I refer to practicing as stigmatizing when it enacts stigma and destigmatizing when it counteracts the discreditation.

If stigmatized practices are seen as being dynamically constructed through people's everyday actions, it can be assumed that they occur more frequently in organizations than scholars have previously recognized. This implication reinforces the need to uncover stigmatizing and destigmatizing dynamics, their triggers, impact on adoption and interrelationships. Thus, a key contribution of this study is that it takes a first step towards unravelling these dynamics by outlining a model that theorizes practice adoption as a process of (de-)stigmatizing. This theorizing is important not only because it unpacks stigmatizing as a critical source of adoption failure, but also because it addresses the dilemma of practice adaptation in implementation studies and the puzzle of recursiveness in practice-based work, as I elaborate below.

Alleviating the dilemma of practice adaptation. Implementation studies have pointed to the dilemma that practices need to be deliberately adapted in order to be adopted, but may lose their "core essence" in the process (Ansari et al., 2014, p. 1317). To address this dilemma, scholars have begun to explore how organizations attempt to "actively manage" practice adaptations by focal audiences during implementation through formal measures such as "defining mandatory 'core' and discretionary 'peripheral' aspects of a practice" (Ansari et al., 2014, p. 1331). However, such formal

measures have limits, especially with professionals, as they enjoy a high degree of autonomy in their work and authority over their clients (Anteby et al., 2016). Moreover, extant research indicates that “purposeful adaptations” (Gondo & Amis, 2013, p. 229) are inevitable when a practice is a poor fit with an organization’s culture (Canato et al., 2013). My findings help further address the dilemma of practice adaptation, including in the challenging context of poor fit adoptions within professional organizations.

Implementation studies would see the case of PPC at Horizon as an example of “low cultural fit” (Ansari et al., 2010; Bertels et al., 2016; Canato et al., 2013), as the practice is characterized by features that are directly opposite to those of the hospital’s core practice. Specifically, these studies would assume that physicians and families, as focal audiences of PPC, refrain from engaging in the practice because its focus on treating life-limiting illnesses is at odds with their core value of achieving healing. To overcome this cultural misfit of PPC, according to existing implementation research, the hospital would need to “drop or modify” espoused features of the practice that are “incompatible with the core values” of its focal audiences (Canato et al., 2013, p. 1747).

Indeed, the PPC team was initially under much pressure to adapt the features of its practice that deviated from the hospital’s core practice. In particular, physicians wanted the PPC team to change its name to “Supportive Care Team” to avoid associations with death and dying. However, the PPC team did not give in to this demand because it felt that such a name change would not do justice to its activities. Similarly, the PPC team resisted other requests for adaptations that they believed would undermine the core of its service. In previous cases of low cultural fit, organizations eventually had to give in and adapt core, ill-fitting features of the new practice (e.g. Canato et al., 2013). In contrast, the PPC team at Horizon managed to avoid substantial adaptations of its espoused practice of PPC and my analysis offers an understanding how.

My analysis allows us to see that the deviation of PPC's espoused features from prevailing norms and values at Horizon was not a problem per se, but rather physicians' inadequate understandings of the practice and the way they performed it because of these understandings. Specifically, it was due to distorted general and a lack of practical understandings of PPC that treating physicians perceived the practice as conflicting with their professional values and stigmatized it in such a way (e.g. as the announcement of immanent death) that it also came into conflict with the values of the affected families. Thus, from this perspective, the dilemma of practice adaptation can be addressed by improving focal adopters' understandings of a practice.

Extant implementation studies mainly point to deliberate efforts, including discursive sensegiving (e.g. Gondo & Amis, 2013), forced engagement (e.g. Canato et al., 2013), and skill transfer (e.g. Compagni et al., 2015), to change focal audiences' understandings of a practice. However, each of these measures is inevitably limited, as learning a practice requires continuous participation in the practice (Gherardi & Nicolini, 2002; Orlikowski, 2002), especially if it is relatively complex (Attewell, 1992). The PPC team promoted such participation in PPC through ongoing efforts to align their enactment of the practice with the needs and interests of focal audiences. This alignment approach is much more subtle than the deliberate change efforts described in prior adoption research. Specifically, rather than 'forcing' or 'telling' physicians and families to behave in a particular way, the PPC team got them to engage in PPC of their own volition. Its practice alignment activities thus represent a kind of "soft power" rather than "hard power" approach to practice adoption (Lashley & Pollock, 2020a).

Specifically, I identified four alignment activities: entraining, advocating, allying, and physical distancing. By engaging in these activities, the PPC team was able to cultivate PPC's espoused features and thereby valorize the practice. Ultimately, these destigmatizing dynamics could promote the ability of families to adopt PPC and also

physicians' understandings of the practice, albeit only incrementally. As noted in the previous chapter, focal audiences' inadequate understandings can be persistent, and stigmatizing dynamics limit destigmatizing dynamics. Nonetheless, over the six years I collected the data, the PPC team faced less and less pressure to adapt their practice.

My theorizing of practice adoption as a process (de-)stigmatizing thus addresses the dilemma of practice adaptation by offering two important, interrelated insights. First, it enables us to see that the misfit between a practice and its focal audiences is not inherent to the practice but may result from focal adopters' inadequate understandings of it. Second, it shows how continuous efforts to align the enactment of a practice with the beliefs and interests of focal audiences can enhance their practice understandings and thus limit the need for substantial adaptation of the practice. Collectively, these insights suggest that adoption studies may need to revisit their conceptualizations of the role of and need for practice adaptations in implementation processes. Specifically, my findings indicate that adaptations of practices may not be as inevitable and essential to make them “meaningful and suitable within specific organizational contexts” (Ansari et al., 2010, p. 68) as emphasized in prior implementation research.

Instead of practice adaptations, this study shows – consistent with a more dynamic practice ontology – how the meaning and added value of practices critically depend on focal audiences' understandings of them and how they perform them based on these understandings. Since improving focal audiences' practice understandings may be far from easy and therefore take time, organizational managers should be careful not to rush adaptations of new practices, especially their core features. Crucially, this study's observations do not deny the need for deliberate adaptations of practices to promote their adoption (Jarzabkowski et al., 2016). Rather, they suggest that greater attention should be given to the inadequate understandings of a practice among focal audiences, as these may serve as triggers for adaptation pressures. Adoption could

then be more effectively promoted by adapting the focal audiences' understandings of the practice, rather than focusing solely on altering its espoused features.

Reducing the puzzle of recursiveness. From a practice lens, the espoused and actual performance of a practice are “interdependent and mutually reinforcing”, making their reorientation a major “challenge” in practical terms and a “puzzle” in theoretical terms (Bucher & Langley, 2016, p. 595). A few practice-based studies have theorized that interruptions in practice performances can “block” their recursive dynamics (Jarzabkowski et al., 2019, p. 876), allowing actors to temporarily detach from them and “reflect” on new ways of acting (e.g. Bucher & Langley, 2016; Edmondson et al., 2001; Obstfeld, 2012). Studies have also shown that experimentation can “seed” change in practices (e.g. Bucher & Langley, 2016, p. 609; Rerup & Feldman, 2011). My model of practice adoption as a process of (de-)stigmatizing offers insights into the “performative struggles” (D’Adderio & Pollock, 2014) that can follow the seeding phase.

First, focal audiences may struggle to perform the newly espoused practice and thereby recurrently stigmatize it. While practice studies generally assume that people – as “carriers” of practices (Reckwitz, 2002, p. 250) – are “purposive, knowledgeable, adaptive, and inventive agents” (Orlikowski, 2000, p. 423), this study shows that their knowledgeability in the process of adopting a new practice may initially be limited. Specifically, focal audiences can have distorted general and a lack of practical understandings of the new practice and as a result separate themselves from the practice in ways that suppress and thereby discredit it. This stigmatizing can disempower focal audiences from performing the practice, which in turn can reinforce inadequate practice understandings among these actors, as my findings suggest. Ultimately, these recursive dynamics can lead to a practice becoming a “weak routine”, which Bapuji et al. (2012) refers to as an action pattern that is performed only

infrequently and inconsistently and, I would add, is prone to disruptions or “breakdowns in the flow of practice” (Lok & De Rond, 2013, p. 188).

Previous research found that breakdowns enable actors to reflect upon and experiment with alternative ways of acting (e.g. Jarzabkowski et al., 2019; Lok & De Rond, 2013). My findings offer the more nuanced understanding that such adaptative activities can be hindered by focal audiences’ inadequate understandings of a practice. For example, in the case of Lily, the parents rejected PPC, which led to a “total breakdown” (Lok & De Rond, 2013, p. 188) of the practice, as the PPC team had to withdraw from the case as a result. However, the physicians were unable to recognize that their late involvement of the PPC team in the case contributed to this escalation. Likewise, in the other cases, the physicians were relatively limited in their ability to reflect on how they could have better involved the PPC team. In contrast, the PPC physicians and other members of their team were not only able to reflect on the failures of the treatment teams but were also very aware of what they could have done better.

Both in conventional implementation studies and in practice-oriented work, there seems to be a certain inattention to the fact that professionals, such as physicians, can also be limited in their practice understandings and that this limitation can critically inform their actions. Contributing to this neglect is possibly that professional occupations are defined by their high expertise (Anteby et al., 2016), and that extensive bodies of literature have emphasized that their actions are driven either by motives of power and self-interest (e.g. Currie et al., 2012; Kellogg, 2012; Raman & Bharadwaj, 2012) or commitment to their professional values (e.g. Kyratsis et al., 2017; Wright et al., 2021; Wright et al., 2017). Thus, by showing that perceptions of limited expertise can affect professionals’ adoption behavior, this study answers calls to “capture the broader set of motivations besides self-interest that guide professional action” (Muzio et al., 2013, p. 703). Moreover, my findings suggests that professionals may need more

guidance in adopting new practices than previous studies – with their view of professionals as knowledgeable, autonomous actors – would have us believe (e.g. Greenwood et al., 2019; Koljonen & Chan, 2023; Raman & Bharadwaj, 2012).

While extant practice-based work highlights the need for interruptions to initiate the reorientation of recursive dynamics in practices, my findings point to continuity in practicing as an important driver for reinforcing this initial reorientation. PPC team members were not only very consistent in their sayings and doings – i.e. they ‘walked the talk’ – but also in their efforts to align their enactment of PPC with the treatment teams and families. Each of their alignment activity cultivated the unfolding of PPC in a different way, thereby reorienting focal audiences, as far as preceding stigmatizing activities allowed, toward the practice’s espoused features. This differs from approaches previously identified in the literature in which actors merely compensated for performative deviations from the espoused practice (e.g. Bertels et al., 2016).

Practice scholars assume that sense and meaning of a practice are acquired through participating in it (e.g. Nicolini, 2009), and my findings show that it can be very arduous to foster this learning process in focal audiences if they stigmatize a practice as it disempowers adoption. Stigmatizing can significantly limit the possibilities of wise practice carriers to align with focal audiences and reorient them towards the espoused meaning and benefits of a practice, as it happened to the PPC team in the cases of Lily and Eve. As a result, promoting wiser understandings of a practice among focal audiences may be an incremental process and thus also the shift of a practice from a weak to a “strong” routine (Bapuji et al., 2012), i.e. a recurring action pattern that is relatively consistent with the espoused practice. Since I did not conduct a longitudinal study, I am unable to offer further insights into the unfolding of this shift. However, my findings suggest that (de-)stigmatizing dynamics may play a crucial role in the

emergence of routines, a theme that remains underexplored in the literature (Bapuji et al., 2012; Feldman et al., 2016).

In summary, my findings and theorizing of practice adoption as a process of (de-)stigmatizing encourage us to reconsider the adoption of practices in organizations in three ways. First, they allow us to see that stigmatized practices are not a subset of undesirable practices but mundane discrediting social constructions in organizations. Second, they indicate that deliberate practice adaptations are less important to make practices meaningful than previously indicated. Third, my findings encourage us to assume less that people are knowledgeable actors and to focus more on how they become knowledgeable and the consequences of their inadequate understandings.

5.2.2 Advancing a more integrative view of stigma

Practice theory has been used to reinterpret many social phenomena (Corradi et al., 2010), but stigma is not yet one of them. Scholars have conceptualized stigma primarily as a socio-cognitive evaluation (Major & O'Brien, 2005; Pollock et al., 2019) and increasingly as a collective process of social construction (i.e., stigmatization) or deconstruction (i.e., destigmatization) (Zhang et al., 2021). Research based on these two stigma concepts has provided valuable insights but is limited in three important ways. First, it is divided into social actors as targets of stigma(tization) – including individuals, occupations, and organizations – with limited linkages between these strands of research (Zhang et al., 2021). Second, it neglects the relational nature of stigma, as studies have explored either the social construction of or responses to stigma but rarely how these two are interrelated (Aranda et al., 2022). Third, prior research has underexplored the everyday actions through which stigma is constructed and responded to within organizational settings (Frandsen & Morsing, 2021; Lyons et al., 2017). This study addresses these three limitations that prevent a more comprehensive understanding of stigma by developing a practice view of the construct.

Advancing a relational view on stigma. First, this study advances a relational view on stigma by demonstrating that the construction of stigma and the associated responses are not separate but mutually constitutive phenomena. While others have shown that stigmas are socially constructed (e.g. Devers et al., 2009; Wang et al., 2021; Wiesenfeld et al., 2008), my work goes beyond these studies by showing that this construction also critically underpins the process of responding to stigma. Specifically, it shows that actors can have a certain ‘response repertoire’, but what response they ultimately enact and how depends on the previous construction of stigma. For example, whether and how the PPC team was able to advocate the benefits of PPC depended critically on the timing of its involvement in a case. If this involvement occurred only at the end of life, the team could no longer offer PPC as a practice that improves quality of life, but only as one that improves the quality of dying.

Thus, the construction of and responses to stigma can only be understood in conjunction and must therefore be examined together. Although scholars increasingly acknowledge that the two phenomena are entwined (e.g. Frandsen & Morsing, 2021; Toubiana & Ruebottom, 2022), the dominant focus of the literature to date has been on “stigma-management strategies [as] the different means of responding to, managing, and coping with stigma” (Zhang et al., 2021, p. 193). This is perhaps unsurprising as stigma is considered to have detrimental consequences for social actors at all levels of analysis (Pescosolido & Martin, 2015; Zhang et al., 2021). Accordingly, there has been much interest to understand how actors counteract the social construction (Aranda et al., 2022). Conceptualizing stigma from a practice view and using rich case data has enabled me to illuminate both the construction and deconstruction of stigma and uncover processual relationships between them.

Specifically, such a processual association includes that responses to stigma can simultaneously counteract and perpetuate the social construction. In particular, I have

identified entraining and allying as two responses that can have this double effect. While these two responses can reorient views towards acceptance, they can also maintain the construction of stigma as they are “resonant” rather than “oppositional” responses (Lyons et al., 2017, p. 623). My findings suggest that whether such resonant responses not only counteract but also perpetuate stigma depends on the specific time and situation in which they are enacted by particular actors. In contrast to entraining and allying, interactional distancing is a more oppositional response. Such a response challenges ongoing stigmatizing and can thus prevent it from being maintained but can also trigger new tensions. Together, these findings corroborate and extend burgeoning views (e.g. Mikolon et al., 2021; Ruebottom & Toubiana, 2021) that conceptualizing stigma-management strategies as mere mitigation or coping responses neglects their role in the social construction of stigma. Overall, then, a more relational approach to stigma is important because it can reveal unanticipated nuances and complexities.

Revealing micro-activities of constructing and responding to stigma and their consequentiality. While extant stigma research has pointed to practices as stigmatizing attributes of social actors (Aranda et al., 2022), this study takes one step further and theorizes stigma and responses to stigma as socially constructed through practice and thus as interrelated dynamics of stigmatizing and destigmatizing. More specifically, my findings show that both stigma and responses to stigma are constructed in-the-moment, as part of everyday actions and are therefore much more micro and dynamic than prior work suggests (Pollock et al., 2019; Zhang et al., 2021).

Both stigmatizing and destigmatizing dynamics may involve many small doings and sayings, each of which can be highly consequential (see tables in Appendix A and B). Crucially, my findings show that the consequentiality of these micro-activities arises not only from their content, i.e. what is said and done, but also their “timing” and “tempo” at which they are enacted (Nicolini, 2011, p. 610). In particular, with delaying

and entraining, I identified activities that capture the temporal dimensions of stigma construction and deconstruction respectively. In doing so, I have answered calls to illuminate the temporal aspects of (de-)stigmatization (e.g. Wiesenfeld et al., 2008), a theme that has rarely been explored to date (Dong et al., 2023).

My practice-level conceptualization further suggests that actors construct stigma in the moment without necessarily considering the consequences of their actions. That is, they do not intend to stigmatize and may not even be aware that they are doing it because they have inadequate practice understandings. This finding is interesting because it points to a somewhat paradoxical dynamic between power and lack of empowerment as a driver of stigmatizing behavior. While extant research suggests that actors need some form of formal power or authority to stigmatize (e.g. Link & Phelan, 2001; Lyons et al., 2017), my findings indicate that it may be a sense of powerlessness that triggers their stigmatizing. Actors who feel powerless may engage in stigmatizing as a way to assert control or cope with their *perceived* lack of influence. For example, physicians used their formal power as case managers to delay the involvement of the PPC team in cases as they perceived a lack of control or self-efficacy to present PPC to parents in a way that makes them accept the practice.

My findings therefore suggest that actors need to be empowered in order to end their stigmatizing behavior. To date, research has mainly explored how stigmatized actors can develop a sense of mastery and self-efficacy to deal with their devalued social identities (e.g. Hein & Ansari, 2022; Leybold & Nadegger, 2023; Ruebottom & Toubiana, 2021). In contrast, direct research on the empowerment of stigmatizers is still scarce. Some initial insights on this issue are provided by studies on the destigmatization of organizations. In line with my findings, these studies suggest that advocacy activities (Helms & Patterson, 2014) and allying with stigmatizers (Hampel & Tracey, 2017) can help stigmatizing actors improve their inadequate practice

understandings. In addition, my study shows how entraining and distancing can empower actors in ways that facilitate advocacy and allying activities.

Scholars have used a variety of terms to capture destigmatization processes, such as removing (Zhang et al., 2021), reducing (Lashley & Pollock, 2020b), or overcoming stigma (Garcia-Lorenzo et al., 2022), indicating difficulties in assessing whether complete destigmatization has taken place or is even possible (Aranda et al., 2022). By adopting a practice view, this study points to destigmatizing as an ongoing, effortful accomplishment. From this perspective, stigma cannot be removed so that it is gone forever. Instead, the absence of stigma is the outcome of people's everyday actions. Curiously, in their recent comprehensive review of stigma research, Zhang et al. (2021) acknowledge that the persistence of stigma is the result of "purposeful and inadvertent actions and inaction" (p. 209), but continue to treat destigmatization as a potentially finite process that, as such, may not require further action.

In contrast, my study suggests that destigmatization is an ongoing process that is maintained through micro-activities that counter the construction of stigma moment-by-moment in a continuous fashion. Hence, responses to stigma, such as allying with stigmatizers, are not "stable once attained; rather, such responses need to be continuously worked at" (Jarzabkowski & Lê, 2017, p. 457). Moreover, by showing that stigmatizing dynamics can limit destigmatizing dynamics and thus the empowerment of actors, my study expands our understanding of how stigmatization processes are maintained. In particular, I have shown that temporal stigmatizing is problematic as it limits the time available for countermeasures. In doing so, my study answers calls to illuminate the "actual mechanisms" underlying stigma maintenance (Zhang et al., 2021, p. 309). Overall, my findings suggest that the construction of and response to stigma is a much more dynamic process than extant research indicates.

Moving beyond the social actor divide. Advancing a practice-oriented and thus more relational and dynamic view on stigma is important because it allows us to move beyond the pronounced but problematic divide between social actors that is prevalent in stigma research, not only in relation to stigmatized actors, but also in relation to their audiences. Stigma research is characterized by the approach of assigning a certain role to actors a priori and then examining the actions that these actors carry out in this role. In particular, scholars have distinguished between four types of roles actors can take: They can be “the stigmatized”, “the stigmatizers”, “wise” supporters of the stigmatized, or the “targets” of stigma transfer (Goffman, 1963; Kreiner et al., 2022). However, my findings challenge the idea that actors can be clearly categorized according to these types of roles in (de-)stigmatization processes, for three reasons.

First, my findings show that actors can take on more than one role at a time based on their actions. The conventional view in stigma research would be to focus on PPC professionals as members of a stigmatized occupation as their work is associated with death and dying (Ashforth & Kreiner, 1999). However, instead of attributing stigma to the PPC team a priori, I examined from a relational, micro-activity-oriented practice view how stigma was constructed. This revealed that the PPC team as a carrier of PPC was not only stigmatized, but also contributed to the stigmatizing of PPC as EOL care by entraining to and allying with physicians who involved it in cases just days before a child’s death. Similarly, the intensivist in the case of Maria can be seen as both a wise supporter and a stigmatizer of PPC. While the intensivist presented PPC to Maria’s parents in a destigmatizing way, she stigmatized the practice to the PTT physicians by bypassing them in the decision to involve the PPC team.

Second, my findings blur the distinction between the roles that actors can assume as the findings show the roles are continuously “in their making” (Sele et al., 2024, p. 534). This means that the roles of actors, based on their actions, can evolve over time,

or even within a single moment – for example, from stigmatizers to supporters. This was the case with Maria’s mother, for instance, when she approached the PPC physician to withdraw her consent to use the PPC service, but then maintained it after the physician convinced her to do so. In addition, over the course of Maria’s case, the PTT physicians increasingly evolved from stigmatizers to wiser supporters of PPC and the PPC team. Thus, while some scholars have previously recognized that actors can be stigmatized and stigmatizers (Toubiana & Ruebottom, 2022), my findings extend this initial insight by illuminating that actors’ roles are constructed in-the-moment on an ongoing basis and can therefore be much more fluid than previously indicated.

Third, a practice perspective allows us to see that actors can hardly be categorized as ‘targets of stigma transfer’, as stigma is “inseparable from its constituting practice” and therefore “cannot be transferred” or simply spill over (Orlikowski, 2002, p. 271). Practices are generated through people’s actions; accordingly, also the emergence of stigma (or the lack thereof) hinges on what people say and do. For example, PPC is attributed the stigma of ‘giving up the fight to cure’, and physicians at Horizon feared that if they introduced the practice to parents, they would inevitably associate them with this stigma, thus making them targets of stigma transfer. However, the PPC stigma actually only emerged through the physicians’ actions and inactions, particularly their delay in involving the PPC team until the EOL phase. In contrast, the intensivist in Maria’s case was able to introduce PPC as a practice that is complementary and not in conflict with curative measures and was therefore not stigmatized.

By seeing stigma as situationally constituted in practice, and thus as stigmatizing, it may be more suitable to think about the problem of stigma transfer as a “stretching out and expansion” of stigmatizing (Nicolini, 2007). Such an expansion occurred most clearly in Maria’s case when the intensivist bypassed the PTT physicians in the decision to involve the PPC team. This bypassing violated the PTT physicians’

normative expectations that, as Maria's case managers, it should have been their decision to involve the PPC team. As a result, the physicians were upset with the intensivists and excluded the PPC team. All these tensions between the physicians were observed by Maria's parents, who then distanced themselves from the PPC team.

The initial stigmatizing of the intensivist thus stretched out to other actors and over time, as the exclusion of the PPC team lasted for quite a while. This idea of an expansion of stigmatizing suggests that, if we want to overcome the social actor divide in stigma research "across, within, and between levels of analysis" (Zhang et al., 2021, p. 193), we need to explore the "serial constructions" of and responses to stigma (Jarzabkowski & Lê, 2017, p. 457) among various actors over time and across spaces (Nicolini, 2007; Seidl & Whittington, 2014).

Despite the already pronounced divide between social actors in stigma research, Aranda et al. (2022) have argued that the distinction between the actors needs to be expanded even further. The authors suggest that there are "overt and covert" stigmatizing and supportive audiences and "active and passive" stigmatized actors (pp. 21-24). Aranda et al. (2022) consider it "essential" to further differentiate between targets of stigma and their audiences and to examine the relationships between all these actors to "more realistically understand the origins, reactions and consequences of stigma" (p. 25). However, a practice lens allows us to see that these additional distinctions between overt/covert and active/passive actors are problematic. First, as mentioned above, actors can take on different roles at a time based on their actions and these roles can evolve over time. For example, actors can simultaneously and/or over time perform actions that support stigmatized actors both overtly and covertly. Second, "at the micro-level, all responses are in their own way 'active' responses" (Jarzabkowski & Lê, 2017, p. 457). Thus, while it is important for a better understanding

of stigma to examine the interconnections between different actors, this examination should be carried out openly without assigning fixed roles to these actors in advance.

In summary, my findings and theorizing of the construction of and responses to stigma as a process of (de-)stigmatizing contribute to a more integrative view of stigma as a social construction in three important ways. First, they advance a relational view in which stigma and associated responses are seen interdependent and mutually constitutive. Second, they reveal how the everyday activities of constructing and responding to stigma are consequential for and constitutive of broader processes of stigmatization and destigmatization. Third, my findings are a step towards overcoming the divide between social actors in stigma research by showing that actors can take on different roles through their activities at a given moment and over time. Below, I discuss the limitations of my study and point to opportunities for future research.

5.2.3 Limitations and future research directions

My findings are based on a single revealing case but, with caution to the limitations of the study, may be used to make sense of practice adoption and stigma dynamics more broadly. Specifically, the study is limited in two main ways. First, it was conducted as a single case study in a specific context, which inevitably has idiosyncratic features that may not be found in other contexts (Langley & Abdallah, 2011). Second, the study was methodologically limited in its ability to capture the actual accomplishment of practices as evolving everyday activities, as it was based on retrospective rather than real-time data and made limited use of longitudinal data (Nicolini, 2009). These two limitations of the study, together with its contributions, open up opportunities for future research. In particular, they call for an expansion of research on (de-)stigmatizing dynamics to broader contexts with a stronger practice-oriented view.

Extending research on (de-)stigmatizing dynamics to broader contexts. First, scholars might examine the applicability of my findings and fruitfully extend them by

focusing on organizational contexts with different sets of actors and practices. While I conducted my study in a hospital, others might choose less professionalized organizations where managers have more power, and members have less autonomy over their work. Such organizations would be an interesting contrasting case setting given the role that power and empowerment, and the lack thereof, appear to play in (de-)stigmatizing processes. In my study, I did not further investigate the actions of managers, as they did not feature prominently in the adoption process. Managers at Horizon decided on the implementation of PPC in the hospital but were subsequently not involved in the day-to-day decisions to call in the PPC team in the clinical cases. Future research could examine the stigmatizing and destigmatizing activities of managers to determine how they differ from practice experts such as the PPC team.

Furthermore, it might be interesting to examine the (de-)stigmatizing activities of actors at lower hierarchical levels individually and as a critical mass within organizations. As these actors have lower formal power, it can be expected that they engage in more subtle, less conspicuous stigmatizing activities than delaying actions and excluding other focal audiences. The question then arises what these activities might be. It would also be interesting to focus on (de-)stigmatizing activities that include actors outside organizational boundaries, such as the media, affiliated organizations, professional associations, and regulatory bodies. All these organizations also played a role in the adoption of PPC at Horizon, although not in the specific clinical cases that I examined. For example, one member of the PPC team regularly gave interviews to the media to promote PPC as a practice that can improve the quality of life of children suffering from a life-limiting illness and their families. However, these interviews were not welcomed by all medical staff at Horizon, which possibly influenced their decision to (not) involve the PPC team in cases. It is also conceivable that such advocacy activities lead to external stakeholders stigmatizing an organization, as they first draw

attention to the adoption event that might otherwise have gone unnoticed. On the other hand, it is also possible that external stakeholders, such as professional associations, contribute to intra-organizational destigmatizing activities, for example, through accreditation measures that verify compliance with practice standards. Thus, there exists ample opportunities to explore the stretching out of stigmatizing and destigmatizing dynamics across organizational boundaries.

Additional research could not only focus on different sets of actors but also on different types of practices. First, I encourage future research to explore the (de-)stigmatizing of practices that, other than PPC, are not commonly attributed a stigma. In my study, physicians' anticipated stigmatizing of PPC by parents greatly influenced physicians' enactment of the practice by triggering them to stigmatize it themselves. It would therefore be interesting to explore what drives stigmatizing dynamics in the absence of such a widely perceived stigma. Furthermore, a perceived stigma might emerge through the (de-)stigmatizing dynamics in the course of the study, which would expand our still limited understanding of how collective perceptions that a stigma is attributed to an actor, or a practice, develop in the first place (Wang et al., 2021).

Second, unlike PPC at Horizon, which was designed as a downstream ancillary practice to the hospital's main practice of acute care, future research could focus on practices that are more core or integral to an organization's operations. Previous research suggests that such a difference in practice design could be "theoretically relevant", as it "affects the nature of connections among actors" (Turner & Rindova, 2012, p. 44). Similarly, previous research has found that interferences in adoption initiatives can lead to emotional responses of focal audiences that undermine adoption outcomes (Kanitz et al., 2022). Since emotional responses are critical in the construction of stigma and alignment activities probably more difficult when organizations adopt more than one new, relatively complex practice at a time, it may

be informative for future studies to examine (de-)stigmatizing dynamics in cases of simultaneous practice change initiatives.

Exploring (de-)stigmatizing dynamics from a stronger practice-oriented view.

Scholars could also extend my findings by examining (de-)stigmatizing dynamics from a more practice-oriented view using real-time longitudinal data. While I had to rely on post-hoc accounts in my study, focusing on (de-)stigmatizing as a flow of everyday actions actually demands a real-time, in situ investigation (Nicolini, 2017). In contrast to post-hoc accounts, a situational approach to studying practices allows for a more comprehensive exploration of the various dimensions of practicing (Nicolini, 2011; Nicolini & Monteiro, 2017). Based on this approach, future research could thus possibly identify new stigmatizing and destigmatizing activities and relationships between them.

For example, future research from a situational practice perspective could explore in more detail the doing and undoing of stigma by focusing on social and material aspects such as the use of artefacts, body movements, and social interactions (Nicolini & Korica, 2021). All of these aspects are still largely missing from stigma research. Furthermore, it might be illuminating to examine (de-)stigmatizing dynamics more thoroughly in terms of what is said and how it is said by focusing on the use of figurative language, such as metaphors. I found indications in my data that through the use of figurative language the PPC team was able to establish “high-quality connections” (HQCs) with children and parents, which are “short dyadic interactions” that are “generative and life giving” (Livne-Tarandach & Jazaieri, 2021, p. 1130). Furthermore, it appeared that PPC team members fostered their connection to families through the way they used their voice. When the PPC physician explained in our interviews how she introduces PPC and herself to the families her voice became very soft and compassionate. In this way, she was able to create an incredible sense of calm from one second to the next. Although my study lacks the observational data necessary to

verify and deepen these initial insights, I hope that they will motivate other scholars to explore the development of HQCs through verbal destigmatizing and beyond.

Finally, longer periods of data collection, especially observations, would enable research into changes in (de-)stigmatizing dynamics and the resulting effects. In particular, it would be interesting to know whether certain stigmatizing and destigmatizing activities become more or less prominent over time or whether actors begin to engage in new activities at some point based on their experiences. As already mentioned, a longitudinal approach could also shed more light on the role of (de-)stigmatizing dynamics in the shift of practices from weak to strong routines or the lack of such a shift. In summary, there seems to be much value in future research on (de-)stigmatizing dynamics in broader contexts with a stronger practice-oriented view.

In the next chapter, I will conclude my study by outlining its practical implications and summarizing how it shifts our understanding of stigma in general and the adoption of stigmatized practices in particular.

6 CONCLUSION

In this chapter, I conclude my study by first outlining the practical implications of my research, in alignment with calls for conducting “practical and responsible research” (Hideg et al., 2020). By focusing on the adoption of stigmatized practices, particularly in the context of pediatric palliative care, I highlight the tangible implications for hospitals aiming to integrate this essential service into their clinical practices. In doing so, I address how my findings can guide hospitals in overcoming the barriers posed by stigma and enhancing the adoption of palliative care in healthcare settings.

Specifically, my study presents three interrelated practical implications. First, the stigma associated with palliative care is not an inherent or static condition, but a socially constructed phenomenon shaped by how the practice is enacted. Second, healthcare professionals need a combination of sound general knowledge and practical expertise in palliative care to perform the practice in ways that reduce, or ideally prevent, stigma. Third, for healthcare professionals to acquire these informed understandings of palliative care, it is crucial that they personally experience and appreciate its benefits, which can be facilitated by aligning the practice of palliative care with their own clinical practices.

In the second part of the conclusion, I turn to the theoretical contributions of my research. I argue that my study shifts our understanding of stigmatized practices from isolated phenomena to dynamic, ongoing flows of action within organizational life, offering new insights into how stigma is constructed and how it impacts the adoption of practices.

6.1 Practical insights for the adoption of palliative care

6.1.1 Social construction of the palliative care stigma in clinical practice

In addition to its theoretical contributions, my study offers practical insights for the adoption of PPC in hospitals. The stigma associated with the term “palliative care” – often linked to ideas of giving up, EOL care, and death – has been identified as a significant barrier to physician referrals and the utilization of the practice by patients and their caregivers (Cherny, 2009; Shen & Wellman, 2019; Zimmermann et al., 2016). Some clinical studies have suggested renaming palliative care to “supportive care” to convey a more positive connotation (e.g., Dai et al., 2017; Dalal et al., 2011; Fadul et al., 2009). Conversely, others advocate for changing the perceptions of the public and healthcare professionals regarding palliative care, though they provide only broad suggestions, such as educational initiatives, without detailing specific strategies to achieve this shift (e.g., Zimmermann et al., 2016).

My study advances current understandings of the palliative care stigma and how it can be overcome in two important ways. First, it demonstrates that the stigma is not a given, but socially constructed through the actions of health professionals, especially those of physicians, in everyday clinical practice. Second, based on this fundamental understanding, my study shows how the adoption of palliative care by health professionals, patients, and their caregivers can be promoted. Below, I summarize my findings in a way that offers more actionable insights for practitioners, starting with the construction of the stigma surrounding palliative care.

Clinical studies of palliative care (Salins et al., 2020), along with the results of my research, suggest that initiating palliative care is a challenging endeavor for physicians. They anticipate that patients and their families will stigmatize the practice and therefore reject its use. As a result of this anticipated stigmatization, physicians *delay* making referrals to palliative care services. My study shows that this delay is what creates the

stigma of palliative care as EOL care in the first place, and that this construction bears the potential for a vicious cycle, where the resulting stigma further discourages timely referrals, reinforcing the perception that palliative care is solely for EOL situations.

More specifically, by postponing referrals, physicians inadvertently shape the perception that palliative care is only appropriate when all other treatment options have failed, thereby creating the association between palliative care and EOL scenarios. This construction of palliative care as EOL care dramatizes the practice, prompting negative responses from patients and their families. In turn, these negative responses reinforce physicians' beliefs that palliative care is problematic, further complicating its integration into patient care. The initial delay in referrals thus contributes to a vicious cycle where the stigma is both constructed and perpetuated, as physicians anticipate and then encounter resistance, making them even more hesitant to initiate palliative care in the future. This dynamic ultimately makes it increasingly difficult to shift perceptions and integrate palliative care earlier in the treatment process, where it could be performed as intended – as a practice that enhances quality of life.

Additionally, my study reveals how physicians construct palliative care as a practice with limited benefits by *verbally distancing* themselves from it when presenting it to patients and families. Specifically, physicians may distance themselves and thereby trivialize palliative care by hesitating, dropping, or delegating the introduction of the practice, anonymizing it, or appeasing patients and families. When physicians hesitate to introduce palliative care, they convey reluctance and signal that they do not fully support it. Casual introduction – i.e., simply dropping PPC on patients and their families – diminishes the practice's importance by presenting it as a mere formality rather than a critical component of care.

Avoiding the term “palliative care” and using vague or euphemistic language obscures its true nature and benefits of the practice, leading to misunderstandings

about its purpose and value as a serious, necessary form of care. Moreover, appeasing patients that curative treatments will continue despite palliative care frames the practice as secondary, rather than integral, to comprehensive care. Similarly, delegating its introduction to palliative care specialists suggests it is less relevant to the primary care team, reinforcing the perception of palliative care as a subordinate rather than essential aspect of the treatment process. All five verbal distancing activities can contribute to a diminished perception of palliative care, making it seem less crucial, which can hinder its early adoption by patients and their families.

Finally, my study demonstrates how physicians construct palliative care as an inferior practice by *excluding* palliative care professionals from the treatment process by opposing, bypassing, ghosting, and subordinating them. Specifically, the exclusion of palliative care professionals undermines the intended value of palliative care by blocking their ability to effectively perform the practice, thereby marginalizing it. First, when physicians oppose palliative care professionals – such as by rejecting their help – they prevent these professionals from enhancing patient care. Similarly, bypassing palliative care professionals in treatment decisions limits their ability to support patients and families effectively. Third, ghosting palliative care professionals – failing to communicate or engage with them – further isolates them and obstructs their involvement. Lastly, subordinating palliative care professionals pushes palliative care to the periphery of the treatment process by undermining their expertise and diminishing their involvement in treatment decisions. This subordination can manifest as treating palliative care specialists' input as secondary or less significant compared to other treatment modalities. Collectively, these four exclusion activities can reinforce the perception of palliative care as secondary, less integral to patient care.

In summary, my study shows that patients' and their families' understanding of palliative care depends on when physicians introduce the practice, how they present it

and how they involve its specialists in the treatment process. The data structure of the stigmatizing dynamics, detailed in Appendix A, offers an overview of the various actions and activities that contribute to the construction of the palliative care stigma. These findings have important implications for research on the stigma. Future studies should not only assess patients' and families' perceptions of palliative care but also explore how these perceptions are influenced by physicians' actions. Since the timing of introduction, the nature of communication, and the involvement of palliative care specialists critically shape the palliative care stigma, these factors should be carefully considered to understand how the stigma emerges and affects the practice's adoption.

6.1.2 Advancing general and practical understandings of palliative care

To overcome the stigma surrounding palliative care and promote its adoption, my study emphasizes the need to enhance both the general and practical understandings of palliative care among health professionals, particularly physicians, as these understandings inform their enactment of the practice. First, advancing general understandings involves not only conveying the espoused features of palliative care to health professionals but also sensitizing them to the fact that the stigma associated with palliative care is largely constructed through their own enactment of the practice.

Second, advancing practical understandings requires boosting the perceived self-efficacy of health professionals in introducing palliative care to patients and their families. The health professionals must become both competent and confident in effectively communicating the features of palliative care, as well as in addressing any concerns or misconceptions that patients and families might have. By enhancing their perceived self-efficacy, health professionals are more likely to engage in thoughtful and effective discussions about palliative care, making it easier for them to integrate this essential practice into the overall treatment in good time before the EOL phase.

To advance both the general and practical understanding of palliative care among healthcare professionals, as demonstrated by the case of PPC at Horizon, it is essential not only to provide comprehensive training but also to create opportunities for them to personally experience and appreciate its benefits. Training should be designed to deepen health professionals' knowledge of palliative care, including its goals, benefits, and indication criteria. This training should also include practical skills for effectively communicating the espoused purpose and advantages of palliative care to patients and their families and addressing potential misconceptions.

However, training alone is rarely sufficient for the successful adoption of palliative care by health professionals. As my analysis suggests, they must also experience firsthand the positive impact that palliative care can have, not only on patients' quality of life, but also in making their own work easier. When health professionals personally experience the benefits of palliative care – such as alleviating suffering, enhancing patient and family satisfaction, and improving the overall care experience – they are more likely to internalize its value. This personal recognition can shift their attitudes toward palliative care from seeing it as a secondary or stigmatized offer to understanding it as a vital and proactive component of patient care. As a result, health professionals will be more motivated and better equipped to advocate for and integrate palliative care into their own practice, thus overcoming existing barriers and contributing to the broader acceptance and adoption of palliative care.

Thus, a crucial question is how health professionals can come to experience and appreciate the value of palliative care in practice. My study has identified that palliative care specialists can play a pivotal role in fostering this understanding through four alignment activities: entraining to and allying with health professionals, patients, and their families, advocating for the practice, and, when necessary, distancing themselves from focal audiences. First, *entraining* involves palliative care specialists aligning the

pace and timing of their practicing with the readiness and goals of health professionals, patients, and their families. This alignment helps to harmonize palliative care with the established norms and routines of acute care settings, making the practice more familiar and acceptable to the focal audiences. My study identified four entraining activities that facilitate this process: accommodating, probing, engaging, and enduring.

Accommodating involves palliative care specialists adapting their approach to fit the expectations and readiness of attending physicians and other health professionals. By aligning their timing and procedures with their acute care practice, they ensure that palliative care becomes an integrated part of the existing workflow rather than a disruptive addition. Probing entails palliative care specialists exploring and understanding the needs and preferences of patients and families. This activity allows them to tailor their interventions to better fit the specific concerns of those in need of palliative care, ensuring that it aligns with their immediate goals and expectations.

Engaging involves actively establishing and maintaining contact with patients and their families, building rapport and ensuring their continued support. By consistently interacting with patients and their families, palliative care specialists establish a continuous presence and show their commitment to addressing the patients' evolving needs. This proactive engagement helps to integrate palliative care into the daily experience of patients and families, making it a more familiar and supportive aspect of their care. Enduring involves maintaining a consistent presence and continued support despite potential challenges or resistance. By persistently offering palliative care services and demonstrating their value over time, specialists help to solidify the practice's role within the broader treatment plan.

Together, the four entraining activities can help to embed palliative care within the existing norms and routines of acute care settings, making it a familiar and integrated component of patient care. This normalization reduces the perception of palliative care

as disruptive or problematic, thereby enhancing its acceptance among health professionals, patients, and families and integration in the treatment process.

Second, *advocating* for palliative care can play a crucial role in legitimizing the practice by clearly defining and clarifying its value to both patients and health professionals. Two advocacy activities are affirming and repudiating understandings of palliative care. Affirming involves explaining what palliative care is and highlighting its core benefits and goals. By articulating the positive aspects of palliative care, such as its focus on improving quality of life and providing comprehensive support, physicians and palliative care specialists help establish its value and relevance in patient care. This positive reinforcement helps to build a clearer understanding of palliative care's role and can promote acceptance among patients and their caregivers.

Repudiating, on the other hand, involves clarifying what palliative care is not. This action addresses and dispels common misconceptions and myths that might undermine the practice. Explicitly distinguishing palliative care from concepts like EOL care or giving up on treatment, corrects misunderstandings and reduces the stigma associated with palliative care. This helps to counteract negative perceptions and reinforces the practice's legitimacy as an integral part of comprehensive patient care. Together, these two actions of affirming and repudiating work to legitimize palliative care by providing a clear, accurate portrayal of its purpose and benefits while simultaneously dispelling misconceptions. This dual approach can not only enhance understanding but also foster greater acceptance and integration of palliative care.

Third, *allying* with focal audiences authenticates the benefits of palliative care by demonstrating its value through collaborative engagement. Palliative care specialists can achieve this by assisting health professionals, nurturing patients and families, as well as brokering relationships, and coordinating actions between all parties involved. Assisting other health professionals involves providing support and guidance to

colleagues to ensure they understand and can effectively incorporate palliative care into their practice. By offering practical help, palliative care specialists demonstrate their role as collaborators rather than outsiders, thereby reinforcing the credibility and value of palliative care within the broader healthcare team.

Nurturing patients and families involves actively supporting and addressing their needs and concerns throughout the care process. By building strong, trusting relationships with patients and families, palliative care specialists highlight the benefits of their approach and show that it is centered around compassionate and individualized care. This nurturing reinforces the authenticity of palliative care by showcasing its commitment to enhancing patients' quality of life. Brokering relationships involves facilitating connections between health professionals, patients, and families. By serving as intermediaries, palliative care specialists help to bridge gaps in communication and ensure that palliative care is effectively integrated into the patient's overall treatment plan. This activity underscores the practice's importance and reinforces its desirability by ensuring that all parties involved work together cohesively.

Coordinating actions entails organizing and aligning the efforts of health professionals, patients, and families to ensure that palliative care is delivered smoothly and effectively. By managing these interactions and ensuring that all parties are working towards common goals, palliative care specialists can validate the practice's role in the care continuum and demonstrate its practical relevance. Through these allying activities, palliative care specialists help to authenticate the practice by embedding it into the existing healthcare framework, showing its value through collaborative efforts, and reinforcing its legitimacy within the patient care process.

Finally, it may sometimes be necessary for palliative care specialists to *physically distance* themselves from certain situations to protect the integrity of palliative care and prevent the practice from being discredited. Distancing may involve opposing an

improper use of palliative care and withdrawing when the support is not desired. Opposing involves rejecting requests from other physicians if those requests suggest an improper use of palliative care. This selective involvement helps preserve the practice's intended purpose and ensures it is utilized appropriately, thereby reinforcing its value and preventing it from being perceived as a secondary or catch-all solution.

Withdrawing occurs when palliative care specialists step back when patients or families do not wish to receive their support. By respecting these preferences and exiting gracefully, specialists demonstrate their commitment to patient autonomy and the respectful application of palliative care. This approach emphasizes that palliative care should align with the needs and desires of patients and families, rather than being imposed. Through these two distancing activities, palliative care specialists safeguard the practice from potential discreditation and maintain its credibility. They ensure that palliative care remains authentic and effective by applying it in ways that uphold its core values and respect patient choices.

Ideally, through engaging in alignment activities, health professionals can gain more profound general and practical understandings of palliative care, which in turn enables them to initiate the practice more effectively. To achieve this, health professionals can adopt strategies similar to those used by palliative care specialists. First, entraining for them involves aligning the pace and timing of palliative care with the readiness and goals of patients and families to integrate it smoothly into the existing treatment process. Second, distancing means introducing palliative care in a separate space away from the child's bedside to maintain a focused and private discussion with parents. Third, advocating involves that they clearly define and communicate what palliative care is (not) to clarify its espoused features and address misconceptions. Fourth, allying involves building supportive relationships with patients, families, and palliative care specialists to ensure effective collaboration and coordination.

In summary, my analysis of the PPC case at Horizon demonstrates that altering perceptions of palliative care and successfully integrating it into patients' treatment processes is a challenging and lengthy endeavor, but it is achievable. Successfully promoting the adoption of palliative care in everyday clinical practice requires a multifaceted approach, involving a variety of actions and activities. My data structure in Appendix B provides an overview of these actions and activities that can contribute to the destigmatizing of palliative care.

Overall, it seems crucial that healthcare professionals maintain both flexibility and consistency in their approach to practicing palliative care because these seemingly opposing qualities together ensure that care is both adaptable to individual needs and reliable in quality. Flexibility allows the professionals to tailor their approach to the unique circumstances of each patient and family. Every patient's situation is different, and a rigid, one-size-fits-all approach may fail to address specific needs, cultural contexts, or personal preferences. By being flexible, health professionals can adjust their methods to best support the patient's medical condition, psychological state, and family dynamics, thereby providing care that is more personalized and effective.

Consistency, on the other hand, is essential for building trust and establishing a standard of care. When specialists are consistent in their core principles – such as prioritizing patient comfort, respecting autonomy, and providing clear communication – patients and families can rely on the care they receive. This balance of flexibility and consistency allows specialists to provide personalized care while adhering to the values that define effective palliative care, ultimately facilitating its deeper integration into everyday clinical practice and ensuring it is respected and trusted by all involved.

In the next and final chapter, I conclude that a view of (de-)stigmatizing makes the adoption of stigmatized practices less puzzling. I start by recapitulating the unresolved puzzles in extant research and then explain how the new view addresses them.

6.2 Stigmatized practices: From isolated to mundane phenomena

6.2.1 Adoption of stigmatized practices as isolated events

My study was motivated by the observation that while previous research suggests organizations take up stigmatized practices from their environment, it offers limited insights into whether and how these practices are adopted within organizations. I argued that this inattention may be partly due to the conceptualization of stigmatized practices in adoption research as a subset of contested practices (e.g. Chuang et al., 2011). In this view, stigmatized practices violate social norms (Naumovska, Gaba, et al., 2021), are thus perceived as highly illegitimate or inappropriate (Suddaby et al., 2017), and face strong opposition that can extend to the adopting organizations as a whole (Sanders & Tuschke, 2007). This view implies that stigmatized practices are rarely or only exceptionally introduced into organizations. Accordingly, scholars may have overlooked or not fully considered the adoption of stigmatized practices by and in organizations, potentially limiting the development of research interest in this area.

Similarly, research suggests that the successful intra-organizational adoption of stigmatized practices is an exceptional occurrence or, indeed, a conundrum. While studies on intra-organizational practice adoption have not yet taken into account that practices can be stigmatized, they have focused on norm-deviant practices and have shown that their adoption is a major challenge as organizational members tend to resist them (e.g. Bertels et al., 2016; Canato et al., 2013). Stigma research further contributes to this understanding by highlighting that stigma, as a negative social evaluation (Pollock et al., 2019), elicits discrediting associations, strong negative affective reactions, and discriminatory behaviors (Dovidio et al., 2003). Consequently, stigma excludes its target from social acceptance (Goffman, 1963). Given that acceptance is a key determinant of practice adoption in organizations (Gondo & Amis, 2013), stigma associated with a practice seems almost inevitably to be a source of adoption failure.

6.2.2 (De-)stigmatizing as a mundane practicing

While adoption studies imply that stigmatized practices in organizations are a relatively rare or isolated occurrence, I argued that stigma research hints at the fact that they may be more common than adoption scholars previously recognized. Unlike adoption studies, stigma research postulates that stigma arises not from the transgression of broad social norms but from the violation of specific, context-dependent normative expectations (Goffman, 1963). In this view, stigma is a pervasive social construct (Dovidio et al., 2003), implying that even practices which seem innocuous or beneficial can potentially become stigmatized (Kreiner et al., 2006).

The pervasive nature of stigma, combined with its power to undermine social acceptance, makes it a potentially critical yet overlooked source of adoption failure within organizations. By theorizing practice adoption as a process of (de-)stigmatizing, my study advances this understanding in two important ways. First, it takes a step further by revealing that stigmatized practices are not merely common occurrences, but indeed mundane construction within organizations. Second, it offers a more constructive perspective by demonstrating that the adoption of stigmatized practices is not necessarily doomed to fail. Rather than viewing stigma as an inevitable negative condition, the view of (de-)stigmatizing shows that stigma arises through everyday actions. Therefore, it can be addressed by influencing these actions and ultimately by improving peoples' understandings that inform them.

The development of (de-)stigmatizing as a more constructive view on stigma is a significant overall contribution of my study, especially given that stigma is widely recognized as a problematic issue in societies (Pescosolido & Martin, 2015). By shifting perspectives, my study demonstrates that “the way we see the problem is the problem” (Stephen Covey). This advanced view uncovers novel approaches to address stigma and to enhance the adoption of vital practices like palliative care.

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Appendix A: Data structure stigmatizing dynamics

Table A 1: Temporal stigmatizing of PPC by attending physicians

<u>Separation</u> from the espoused practice: <u>Delaying the</u> initiation of PPC	<u>Suppression</u> of the espoused practice: <u>Rushing the</u> enactment of PPC	<u>Discreditation</u> of the espoused practice: <u>Dramatizing</u> PPC as a threat	Illustrative quotes
<p><u>Temporizing:</u> Physicians initiate PPC only on the last day before the holidays</p>	Ambushing parents with PPC; giving them no time to orient to the offer	Constructing PPC as a crisis or emergency measure	“There are people who have known for weeks that they want to register the child and then do it on the last day before the holidays, which is EXTREMELY unfortunate because it sends a message to the parents: ‘I’ll just quickly do this now because the holidays are coming, and something could happen during that time.’ That’s a hidden message, and it’s extremely unfavorable.” (PPC physician 1, non-case interview)
<p><u>Postponing:</u> Physicians only initiate PPC when the resuscitation status needs to be discussed</p>	PPC physicians don’t have time to build a relationship with parents first	Constructing PPC as a therapy that ends life-saving measures	“Often, discussions about resuscitation are the first conversations you have to have in palliative care. That’s a difficult starting point because it doesn’t help you build a relationship or trust. Instead, you get associated with taking away a potential means of help from the patient, and by extension, the parents, which is challenging.” (PPC physician 1, interview Ella)
Physicians initiate PPC only a few days before the death of a child	Leaving the PPC team no time to improve quality of life	Constructing PPC as EOL care	“When we talk about quality of life, I need time to actually create quality of life. I can’t achieve that right before death. At that point, we can’t talk about improving quality of life anymore. We can talk about quality of dying and a good death, but not about quality of life.” (PPC physician 1, non-case interview)

Table A 2: Verbal stigmatizing of PPC by attending physicians

<u>Separation</u> from the espoused practice: <u>Verbal distancing</u> from PPC	<u>Suppression</u> of the espoused practice: <u>Downplaying</u> PPC's added value	<u>Discreditation</u> of the espoused practice: <u>Trivializing PPC</u> as less important	Illustrative quotes
<u>Hesitating:</u> Physicians introduce PPC to parents reluctantly	Tarnishing the added value of PPC	Constructing PPC as an inferior substitute for acute care	"There was a tense atmosphere because the primary referring physicians struggled to involve the palliative care team... to offer that. It was difficult for them to... That was one of the hurdles often described in palliative care, that the specialists grappled with the fact that they couldn't offer the family anything better and now had to bring us in because the prospect of a cure was so minimal." (PPC physician 2, interview Ava)
<u>Dropping:</u> Physicians casually introduce PPC to parents	Disguising the scope of PPC	Constructing PPC as a simple acute care therapy	"I just experienced this again, where I think: THAT is where the problem begins – when we are introduced in a way that completely catches parents off guard. Like, just quickly: 'Oh, by the way, I just brought the palliative care physician with me. I'd like to introduce her to you as well.' That is a NO-GO! I could say: 'Today, the inflammation markers were too high. We took blood cultures. We found a rare germ there. I've already brought the infectious disease specialists along.' That follows a completely different logic. But since palliative care doesn't operate in an acute mode like intensive care, you can't handle it like that!" (PPC physician 1, non-case interview)
<u>Anonymizing:</u> Physicians omit to mention the name of the PPC team	Stripping away the identity of PPC	Constructing PPC as a generic support offer	Interviewer: "How do other doctors introduce you to the parents?" PPC physician 2: "It's different. Not infrequently, it's like: 'There is also another team that is here to support you and look after you. They are especially there for the transition to the outpatient setting and take on coordinating tasks.' So, I am rarely introduced as the senior physician in Palliative Care." (Interview May) Interviewer: "Why is it important to you that it's called Palliative Care?" PPC physician 1: "Because any other term would dilute it and might even be a euphemism. Palliative Care expresses that we are dealing with a life-limiting illness, and that death is a part of our care and our concept. This is not the

<u>Separation</u> from the espoused practice: <u>Verbal distancing</u> from PPC	<u>Suppression</u> of the espoused practice: <u>Downplaying</u> PPC's added value	<u>Discreditation</u> of the espoused practice: <u>Trivializing</u> PPC as less important	Illustrative quotes
<p><u>Appeasing:</u> Physicians emphasize that they continue to fight for a child's life despite the PPC team's involvement</p>	<p>Delineating PPC as a practice that is not part of the efforts to save the child</p>	<p>Constructing PPC as an inferior, even useless practice</p>	<p>case with Supportive Care. In Supportive Care, we don't talk about dying and death, and I think that needs to be transparent." (Non-case interview)</p> <p>"I experienced this a few times with this intensivist, where she would always say: 'Here's the palliative care team, but just so you don't misunderstand, we're still doing a lot.' And I stood next to her, and I wanted to sink into the ground because I thought: 'Well, in reverse, that means palliative care does nothing and is essentially trying to sell them, in quotation marks, that their child has to die. But we are obligated to involve such a team. But, as you can see, I'm still fighting for your child's life.' So, completely contradictory, with double messages that no one can understand, especially not someone who is emotionally burdened." (PPC physician 1, interview Lily)</p>
<p><u>Delegating:</u> Physicians leave the introduction of PPC to the PPC team</p>	<p>Withholding support for PPC</p>	<p>Constructing PPC as an external add-on or an afterthought</p>	<p>Interviewer: "Why do you prefer to meet parents for the first time together with the attending physicians?" PPC physician 1: "Because, unless a specialist says, 'Hey, this mother mentioned in the consultation that she heard about you and would like to make contact with you or someone from your team', I see that as a clear mandate. But when the specialists themselves says, 'I think it would be good for the palliative team to get involved here' and then sends us in, I find it difficult because they're not even there to say, 'Look, this is [name PPC physician]. She is the head of the palliative team, which does this and that.' It feels like an additional reinforcement, rather than just fading away and saying, 'Can you talk to her?'". (Interview Eve)</p>

Table A 3: Interactional stigmatizing of PPC by attending physicians

<u>Separation</u> from the espoused practice: <u>Excluding</u> the PPC team	<u>Suppressing</u> of the espoused practice: <u>Blocking the</u> enactment of PPC	<u>Discreditation</u> of the espoused practice: <u>Marginalizing</u> PPC as ineffective	Illustrative quotes
<u>Opposing:</u> Physicians reject help from the PPC team	Preventing the PPC team to enact PPC	Relegating PPC to an incapacitated position	Interviewer: “How were you treated differently as a [PTT physician] compared to a palliative care physician?” PPC physician 1: “There was a sense of rejection, like: ‘What do you want here? We can do this ourselves.’ It made me feel questioned. In my role as a [PTT physician], my professional support was always highly appreciated, with clear instructions like: ‘Now we do this, and then that.’ When I took on the role of a palliative care physician, which often involved communication and soft skills, it was much harder to say: ‘I might bring something else to the table when I lead the conversation about the resuscitation status or a change in treatment goals, rather than if you were doing it.’” (Non-case interview)
<u>Bypassing:</u> Physicians fail to involve the PPC team in treatment decisions	Preventing the PPC team to enact PPC	Relegating PPC to an incapacitated position	<p>“What happened repeatedly was that we, as the palliative care team, felt bypassed because decisions were made or tests were initiated that we knew nothing about or that we would have liked to discuss first, as we had the impression that they could have been spared for the child.” (PPC physician 2, interview Ava)</p> <p>“The [PTT physicians] carried out therapies without consulting with us. They thought: ‘This requires a cough assist.’ It’s a device that helps someone who can’t cough on their own. All these additional measures were EXTREMELY unsettling for this mother. I would have preferred, as requested, that they would say: ‘What are we doing? With what goal? At what pace? And how do we set this up.’” (PPC physician 1, interview Ella)</p>

<u>Separation</u> from the espoused practice: <u>Excluding</u> the PPC team	<u>Suppressing</u> of the espoused practice: <u>Blocking the</u> enactment of PPC	<u>Discreditation</u> of the espoused practice: <u>Marginalizing</u> PPC as ineffective	Illustrative quotes
<u>Subordinating:</u> Physicians shift admin work to the PPC team	Undermining the expertise of PPC physicians	Relegating PPC to a peripheral position	Interviewer: “Do you experience differences in collaboration with the specialized departments?” PPC physician 1: “Yes. In the use of it. Sometimes even in the misuse. There are people who feel like, ‘The child is also under Palliative Care, so they can take care of the IV certificate, the prescriptions, and everything else.’ I get a bit degraded to being a secretary.” (Non-case interview)
<u>Ghosting:</u> Physicians no longer involve the PPC team after it has supported them	Preventing the PPC team from enacting PPC	Relegating PPC to an incapacitated position	

Appendix B: Data structure destigmatizing dynamics

Table B 1: Temporal destigmatizing of PPC by the PPC team

<u>Alignment with focal audiences:</u> <u>Entraining to focal audiences</u>	<u>Cultivation of the espoused practice:</u> <u>Anchoring PPC in prevailing norms</u>	<u>Valorization of the espoused practice:</u> <u>Normalizing PPC as familiar</u>	Illustrative quotes
<p><u>Accommodating:</u> The PPC team <i>awaits</i> attending physicians' consent to engage PPC physicians are readily <i>accessible</i> to the attending physicians</p>	<p>Complying with the acute care norm that the physicians have the lead</p> <p>Complying with the acute care norm of immediate treatment</p>	<p>Integrating PPC seamlessly into everyday clinical practice</p> <p>Integrating PPC seamlessly into everyday clinical practice</p>	<p>"I would never go to any family on my own initiative. I would never do that. [...] I definitely don't want to step on anyone's toes, because that would EXTREMELY disrupt our acceptance if we barged in." (PPC physician 1, interview Maria)</p> <p>"I've always had the idea: I don't want to create an official registration ceremony, but rather for us to be approached even on the stairs. That is, low threshold, without a big explanation of why someone now wants this consultation. So, when someone thinks of palliative care, they should be able to say, 'Hey, I have a child. Can we talk about this quickly?'" (PPC physician 1, non-case interview)</p> <p>"There's no fixed communication structure. I can say in the hallway, 'I'll refer this patient now to you.' I'm grateful that when I get the sense that a patient needs palliative care, I can call [one of the PPC physicians] and say, 'I'd like to introduce you to this child.'" (PTT physician 7, interview Ella)</p> <p>"In another case, I thought that if [the PPC physician] hadn't arrived within fifteen minutes, the window of opportunity would have been missed. It was a patient who needed surgery on her head because of an abscess that could have been life-threatening. The child was also very sick with heart issues. The neurosurgeons were there. The decision had to be made with the mother whether it was possible to avoid the surgery. [The PPC physician] arrived very quickly. She made an excellent connection in no time. The decision had to be made right then. It wouldn't have been possible to make it later. The surgery had to be arranged." (PTT physician 1, interview Lily)</p>
<p>PPC physicians <i>rush</i> to assist attending physicians</p>	<p>Complying with the acute care norm of immediate treatment</p>	<p>Integrating PPC seamlessly into everyday clinical practice</p>	

<u>Alignment</u> with focal audiences: <u>Entraining</u> to focal audiences	<u>Cultivation</u> of the espoused practice: <u>Anchoring</u> PPC in prevailing norms	<u>Valorization</u> of the espoused practice: <u>Normalizing</u> PPC as familiar	Illustrative quotes
PPC physicians <i>accompany</i> the attending physicians on initial visits to parents at their child's bedside	Complying with the acute care norm that the physicians have the lead	Integrating PPC seamlessly into physicians' everyday practice	Interviewer: "Why did you go with the other doctors to visit the parents at the beginning?" PPC physician 2: "Well, I think from the role we have as consultants for inpatient patients, they very clearly also see themselves as the leaders... as case managers for the family. Also, depending on the specialist, they want to be aware firsthand of what we are discussing and step in if things aren't going in the right direction. That's how it seemed to me. And it was important to me that they didn't feel like I was doing something that wasn't in line with their intentions. I believe it comes from that mindset." (Interview May)
<u>Probing:</u> PPC physicians <i>ask</i> parents for permission to visit them at their child's bedside	Complying with the PPC norm of respect for parental authority	Establishing a connection with the parents	"Before I go to the bedside, I ask: 'May I come to you after the conversation? I also want to get to know your child.' This is often a good first contact, showing that it's completely natural for me to want to meet the child. Through the shared time at the bedside, you can start a low-threshold conversation." (PPC physician 2; interview May)
PPC physicians repeatedly <i>offer</i> their help to parents	Complying with the PPC norm of a gradual introduction	Establishing a connection with the parents	Interviewer: "You mentioned that you need to keep engaging with these families. How do you manage to stay involved without being intrusive?" PPC physician 1: "That's difficult. I experience this a lot in the inpatient setting here. It's that passing by, where I often feel the mother would rather not see me, but I still do it. I try to keep it short if I sense it's not a good time. But I still rely on the principle: 'Constant drops wear down the stone.' And maybe there will come a moment when they say: 'Now we'd like to have you,'" (non-case interview)
The PPC team <i>listens</i> to the attending physicians and families	Complying with the PPC norm of a gradual introduction	Establishing a connection with the parents	"Often, in the initial conversations, we take a rather passive role in the sense of briefly introducing what we do, and then listening." (PPC physician 2, interview May) "Sometimes, what's needed from the professionals is not much, just an ear to listen. It helps me tremendously when I get to know the concepts and spiritual thoughts of a family. When they share this with me, I find it

<u>Alignment</u> with focal audiences: <u>Entraining</u> to focal audiences	<u>Cultivation</u> of the espoused practice: <u>Anchoring</u> PPC in prevailing norms	<u>Valorization</u> of the espoused practice: <u>Normalizing</u> PPC as familiar	Illustrative quotes
PPC physician try to <i>sense</i> what information parents need about PPC	Complying with the PPC norm of a gradual support	Presenting PPC as an unobtrusive, possible future support option	enriching. I also believe that by doing this, we can improve the care for the child and the family.” (PPC physician 2, interview Ava) “I broadly present our offer to the parents, showing them all the possible aspects, so they can see or hear what options are generally available. I then mention that this doesn’t have to be something for now, but it could be a topic at some point in the future, and that they can try it out to see if it suits them or not. I try not to overwhelm them, but instead, I try to sense how much information they want, or if it’s something we leave for now and revisit at a later time, or if I sense that they would like to know more. I also always give them our brochures, telling them they can read them in peace. And depending on the family, I also give them the booklet ‘Caring Decisions’. These are all things that need an introduction, and I wouldn’t give them to every family.” (PPC physician 2, interview Ava)
The PPC team <i>enquire</i> about parents’ needs and wishes	Complying with the PPC norm of a gradual support	Presenting PPC as a responsive, needs-based support integrated into the family’s care	“Then [after getting to know the parents], it’s actually not clear what exactly will happen, but it’s about: What do people need from us? What are their needs and wishes? For example, the social worker would never think of saying after two months: ‘By the way, here are the Muslim burial options’, but that is something that would be asked about, and we always check in again like, ‘How is this and that going at home? Do you need anything?’” (PPC physician 1, interview Ella)
<u>Engaging:</u> PPC physicians regularly <i>stop by</i> at a child’s bedside	Complying with the norm that PPC is a relational service	Integrating PPC seamlessly into the treatment process	“The [PPC physician] came regularly to the ward. I don’t think it was always just her; she has a whole team. I just saw her occasionally. She would quickly come into the wardroom and ask, ‘How is Maria? I’ll quickly go to her, if that’s okay.’” (PTT nurse 1, interview Maria)
PPC physicians regularly <i>visit</i> at home	Complying with the norm that PPC is a relational service	Providing PPC support in a familiar, comfortable setting	“I visited the family at home more and more often. These home visits resulted in very good conversations with the parents. I remember home visits where the father was able to talk openly about what death and dying had done to him. The helplessness, the feeling of not having done enough. Those were

<u>Alignment</u> with focal audiences: <u>Entraining</u> to focal audiences	<u>Cultivation</u> of the espoused practice: <u>Anchoring</u> PPC in prevailing norms	<u>Valorization</u> of the espoused practice: <u>Normalizing</u> PPC as familiar	Illustrative quotes
PPC physicians regularly <i>call or</i> <i>write</i> parents	Complying with the norm that PPC is a relational service	Integrating PPC seamlessly into the families' everyday life	good moments. It was important that I was able to have these conversations with them at home, in an environment where they felt comfortable." (PPC physician 2, interview Ava) "I made many phone calls, especially with the mother, who wanted to talk to me early on about what comes after. She wanted to talk concretely about dying and death. She wanted to know what would happen practically. She needed that." (PPC physician 2, interview Ava) "The family wanted to be at home by themselves without external professionals, so they declined home visits. However, what the parents really appreciated were phone calls with me at any time of the day or night. That worked well. We could discuss everything very well over the phone." (PPC physician 2, interview May) "I am mainly involved with the [parent] by email, by phone, and when she was hospitalized. Which she often was." (PPC physician 1, interview Ella) "At times, [the outpatient nursing service] was closer to the family than I was. They had more resources to be on-site and to be there for a long time. I found a way to make use of their presence. I started by having them call me when they were there, so I could get an impression of the family." (PPC physician 2, interview Ava)
PPC physicians <i>contact</i> other caregivers to obtain information	Complying with the norm that PPC is a relational service	Integrating PPC seamlessly into the child's everyday care	
<u>Enduring:</u> PPC physicians <i>hold back</i> with therapeutic measures until parents give their consent	Complying with the PPC norm of parental authority	Integrating PPC unobtrusively into the treatment process	Interviewer: "What do you mean you had to endure a lot?" PPC physician 2: "It was a restless child with many long crying episodes. It took some time before we could introduce morphine. At times, it also took a while in terms of dosage, until we had the parents to the point where they said, 'Yes, okay. We need this now. We can see that the child is benefiting from it.' These were processes that I would have liked to be faster, but I also had to endure that the parents needed to come to the point on their own where they could accept it. And that they could see that it works, that it is important, and that it is not a drug or, in that sense, a problem that it is an opioid that could lead

<u>Alignment</u> with focal audiences: <u>Entraining</u> to focal audiences	<u>Cultivation</u> of the espoused practice: <u>Anchoring</u> PPC in prevailing norms	<u>Valorization</u> of the espoused practice: <u>Normalizing</u> PPC as familiar	Illustrative quotes
PPC physicians are constantly on <i>standby</i> in the terminal phase	Complying with the acute care norm of immediate treatment	Integrating PPC seamlessly into the child's everyday care	to addiction. When you have pain, you need to treat it with an appropriate painkiller, and morphine is a well-known medication." (interview Ava) "That was also something to endure. Not knowing: Is she going to die now, or how much longer will she live? I always made sure to have my emergency kit with me, so that I would be independent, day and night, and able to go to the family if needed. It wasn't always equally exhausting. The effort increased over time because the dying process stretched on for a long time." (PPC physician 2, interview Ava)
The PPC team <i>accepts</i> if parents reject support	Complying with the PPC norm of parental authority	Integrating PPC unobtrusively into a child's care	"I would have liked to have an exchange with the daycare. But if the parents tell me that it's not necessary, then my hands are tied. I have to respect that." (PPC physician 2, interview May)

Table B 2: Verbal destigmatizing of PPC by the PPC team

<u>Alignment with focal audiences</u> <u>Advocating</u> PPC to focal audiences	<u>Cultivation of the espoused practice:</u> <u>Demystifying</u> PPC's features	<u>Valorization of the espoused practice:</u> <u>Legitimizing</u> PPC as desirable	Illustrative quotes
<u>Affirming:</u> PPC physicians explain what PPC is and does	Providing clarity and understanding of the practice	Promoting desirable understandings of PPC	<p>Interviewer: "You said that when you explain Palliative Care to parents properly, the term loses its threatening nature. How do you explain it?" PPC physician 1: "For example, yesterday I told the family that for me, it's about accompanying them with an additional perspective. A look into the future. What will it look like when they go home? At that point, intensive care will no longer play a role. The current setting will no longer be there. I also try to explain that outside the core team, we are trying to build a relationship and trust to provide long-term support and be an anchor when things get difficult." (Non-case interview)</p> <p>"At the beginning, it's always about building a relationship and trust, and that takes time. Parents sometimes have trouble understanding that. Yesterday, I also told parents: 'You know, I just come by and sit with you to get to know you and for you to get to know me. So, I can see how you interact with your child. That helps me to offer support in situations where there are difficult, complex questions.'" (PPC physician 1, non-case interview)</p>
<u>Repudiating:</u> PPC physicians explain what PPC is not and does not	Providing clarity and understanding of the practice	Preventing or correcting undesirable understandings of PPC	<p>PPC physician 1: "The mother had concerns about what the role of PPC actually means." Interviewer: "When there are such concerns, how do you try to resolve them?" PPC physician 1: "I try to repeatedly emphasize that we are always striving to find paths for the child and that Palliative Care is not a one-way street. That if the child is doing so well that they no longer need Palliative Care, we are very quick to step out again. That we are not the ones making the prognosis, but that the prognosis evolves, and we try to help the child and the family as best as possible and support any therapy that benefits the child." (Interview Maria)</p>

Table B 3: Interactional destigmatizing of PPC by the PPC team

<u>Alignment with focal audiences</u> <u>Allying with focal audiences</u>	<u>Cultivation of the espoused practice:</u> <u>Actualizing PPC's espoused benefits</u>	<u>Valorization of the espoused practice:</u> <u>Authenticating PPC as beneficiary</u>	Illustrative quotes
<p><u>Assisting:</u></p> <p>PPC physicians <i>advise</i> the treatment team on medical issues</p> <p>PPC physicians <i>take over</i> difficult conversations with parents</p> <p>PPC physicians <i>relieve</i> treatment teams from writing meeting minutes and shares these with them</p> <p>The PPC team <i>informs</i> treatment teams about care decisions</p>	<p>Supporting other physicians with specialized expertise</p> <p>Supporting other physicians with communication skills</p> <p>Saving treatment teams time and keeping them informed</p> <p>Filling information gaps of the treatment teams</p>	<p>Demonstrating that PPC can provide relief</p> <p>Demonstrating that PPC enhances patient-centered decision-making</p> <p>Demonstrating the collaborative nature of PPC</p> <p>Proving that PPC can make the work of the treatment teams more effective</p>	<p>“With [May], administering medication was initially very difficult. There were many discussions with the PPC team, during which they provided various tips on how to administer the medication. In the end, she received a feeding tube. This provided relief for the parents.” (PTT physician 8, interview May)</p> <p>Interviewer: “What role do you play in resuscitation discussions?”</p> <p>PPC physician 1: “I often take on the explanations because many [doctors] find it EXTREMELY awkward to talk about this topic at all. It’s briefly touched upon and then quickly dropped because it’s so difficult and EMBARRASSING, so I often take over.” (Non-case interview)</p> <p>“We can act as a kind of bait by taking on tasks from teams that are already at their limit, which allows us to showcase our capabilities a bit. Sometimes I do it this way: I create a meeting protocol and then tell them about it. Then they’re happy, because drafting a protocol is not a very rewarding task. By doing that, I make us more visible. I also write reports on home visits and send them out to say, ‘Hey, this is what we did’, or ‘These were the results.’ I think this helps others to refocus.” (PPC physician 1, non-case interview)</p> <p>“If a child is at home to die and the parents can’t cope, and then the child comes in with the ambulance, we often don’t know anymore: What has been agreed? What’s allowed? What should be done? What shouldn’t be done? That’s when it’s SUPER helpful for us if the PPC team is involved, because then we call them and get all this information.” (Intensivist, interview Maria)</p> <p>PPC physician 1: “When you say ‘resuscitation’, there’s something soulful in the term. The <i>anima</i>. It promises something incredibly good, gentle, and delicate. But how BRUTAL it actually is – that’s something very few people realize. They think it’s some kind of magic spell and then the person is back. They don’t understand that you’re essentially pounding on the chest, and</p>
<p><u>Nurturing:</u></p> <p>The PPC team <i>informs</i> parents about issues relating to their</p>	<p>Supporting parents to stay informed and involved in their child's care</p>	<p>Demonstrating that PPC enhances patient-centered decision-making</p>	

<u>Alignment with focal audiences</u> <u>Allying with focal audiences</u>	<u>Cultivation of the espoused practice:</u> <u>Actualizing PPC's espoused benefits</u>	<u>Valorization of the espoused practice:</u> <u>Authenticating PPC as beneficiary</u>	Illustrative quotes
child's treatment, care, and death			that for the people doing it, it's quite a physical workout. Very FEW people grasp that, and you have to tell them that it HURTS and that we don't fully know what a person might perceive during it. We can even break ribs in the process." Interviewer: "Do you explain it to parents as openly as you're explaining it to me?" PPC physician 1: "Yes!". (Interview Ella)
PPC physicians <i>alert</i> parents to problems and challenges they need to address	Supporting parents to stay informed and involved in their child's care	Demonstrating that PPC enhances patient-centered decision-making	"Of course, I'm not just the kind, supportive person walking alongside, watching everything and nodding in agreement. I'm also the one who says, 'I see a problem there, and you need to address it. I'd appreciate it if we could discuss this together.' Often, these are issues like resuscitation status, parents needing more support, such as night-time [nursing care] or care for a sibling." (PPC physician 1, non-case interview)
The PPC team provides parents with <i>emotional care</i> (e.g. empathy, understanding)	Supporting parents with a more holistic focus	Demonstrating that PPC can provide relief to parents	"It is my hope that the conversations I've had can help [the parent] feel taken more seriously. I reflected back to [the parent] that I think she has already endured an incredible amount of suffering and that she is, in fact, very strong for what she has gone through. Essentially, within the context of her behavior – behavior that is often perceived as inadequate from the outside due to her very strong reactions – I made sure she heard that, actually, she is very strong. This taps into a resource of hers. There are certainly shifts in perception. When one doesn't feel to be taken seriously, one can feel weak and powerless. Hearing that she is doing an incredible amount exceptionally well and that, if she weren't as strong as she is, it might have led to even worse situations – that is reassuring for a [parent] to hear." (PPC psychologist 2, interview Ella)
The PPC team <i>counsels</i> parents on social issues related to the life-limiting disease	Supporting parents with a more holistic focus	Demonstrating that PPC can provide relief to parents	"I look at what the family needs to maintain their daily life. Do they have a sibling? Is there a need there? What is the work situation for both parents? Is there a need for education on how the parents should proceed? This is usually the case. Sometimes, it's also the case that they are relieved when I directly contact the employer to clarify, one-on-one, what the options are. Then, there's the topic of finances – additional costs that a sick child generates. How are the parents doing in this regard? Are there financial

<u>Alignment</u> with focal audiences <u>Allying</u> with focal audiences	<u>Cultivation</u> of the espoused practice: <u>Actualizing</u> PPC's espoused benefits	<u>Valorization</u> of the espoused practice: <u>Authenticating</u> PPC as beneficiary	Illustrative quotes
The PPC team <i>trains</i> parents in caring for their seriously ill child	Enabling parents to be involved in their child's care	Demonstrating that PPC can help improve families' quality of life	shortages? Do we need to potentially balance this out through a foundation request? Indeed, relief is a big topic – both during hospitalization and also after discharge.” (PPC social worker, interview Anya) “I started with nursing interventions, for example, bathing a ventilated child. Of course, that causes oxygen saturation drops. So, the boy was unstable 24 hours a day at that time. [...] Or I looked at the transfer with the mother—the transfer from the bed to the stroller onto the mat. I didn't take over a physical therapy job, but I focused on the handling with her and discussed the topic of safety. Through the family, I started realizing that I often work with families on the topic of safety. Specifically, safety in handling: What do they need to feel safe when caring for their critically ill child? And with the knowledge that the child could die at any time. So, I started with bathing and ended up discussing car transportation with the family. It was a very, very long process.” (PPC nurse 2, interview May)
<u>Brokering:</u> The PPC team mediates in conflicts between parents and the treatment team	Supporting parents and caregivers to interact more effectively	Demonstrating the collaborative and supportive nature of PPC within the medical team	“I remember a father whose child had leukemia. He had threatened the attending physician, saying he would kill him if he didn't cure his child. At the time, I tried to approach the man and said, 'I heard in the report that you made this threat. It really upset the team. Are you aware of that?' I also asked, 'Did you say that out of your great pain because you don't know what else to do? Or should we be concerned? Do we need to take protective measures?' [...] In the end, the father hugged the same doctor he had threatened after the child's death and thanked him for accompanying them. This is how things can change.” (PPC psychologist 2, interview Ella)
The PPC team <i>transfers</i> information between the caregivers and	Supporting parents and caregivers to interact more effectively	Demonstrating the collaborative and supportive nature of PPC within the medical team	“[One parent] had started sending emails to each of us individually. At some point, I said, 'Hey, this isn't working.' It's an incredible waste of resources. Then I said, 'Let's sit down and discuss how we can handle this. We can tell the [parent] to send the emails to me, and I'll forward them.' Or she can call me, and I'll try to consolidate and distribute the information accordingly. I

<u>Alignment</u> with focal audiences <u>Allying</u> with focal audiences	<u>Cultivation</u> of the espoused practice: <u>Actualizing</u> PPC's espoused benefits	<u>Valorization</u> of the espoused practice: <u>Authenticating</u> PPC as beneficiary	Illustrative quotes
parents as a conduit			believe that worked and provided relief on the neurology side.” (PPC physician 1, interview Ella) “The [parent] calls me, has a problem, and I register it as an emergency. I prepare it in advance, so the [parent] doesn't have to explain herself in her stress. I'm also in contact with the school, who really appreciated that.” (PPC physician 1, interview Ella)
PPC physicians <i>refer</i> parents to additional support offers	Supporting parents with a more holistic focus	Demonstrating that PPC can provide relief to parents	“I respect what families, and their individual members, want to share and what they wish to keep to themselves. At the same time, I want to open doors so they know that if they have a need to talk about certain topics, they can, whether with me or other professionals. I spoke with the father about the possibility of talking to other fathers in similar situations. He took advantage of that.” (PPC physician 2, interview Ava)
<u>Coordinating:</u> PPC physicians <i>agrees</i> treatment decisions with the treatment teams	Supporting treatment teams work more effectively	Demonstrating that PPC enhances patient-centered decision-making	“The palliative care team never said on its own, ‘Now we will give morphine.’ It was always discussed interdisciplinarily or with me to check if it was compatible with the other medications.” (PTT physician 8, interview May) “When we heard that the parents didn't want to feed May with a feeding tube, we felt that we needed to broaden the support for both us and the parents. So, we organized an ethical discussion. The parents were a bit surprised at first, but afterwards, the father said that they appreciated it. It made them feel taken seriously when so many different people were involved in addressing their daughter's symptoms.” (PPC physician 2, interview May)
The PPC team <i>organizes</i> the creation of a care plan	Supporting parents to stay informed and involved in their child's care	Demonstrating that PPC enhances patient-centered decision-making	“[The PPC team] creates a care plan in consultation with us. An important part that documents everything. It includes the resuscitation status, and the various people involved in a case. What will be done at different points, such as in the case of seizures, pain, fever, nausea. This plan is provided to the parents and the [home care service]. It is also stored in our system. Most people can then refer to it. It is continuously updated when something changes. This plan is discussed with the parents and approved by them.” (PTT physician 8, interview May)

<u>Alignment</u> with focal audiences <u>Allying</u> with focal audiences	<u>Cultivation</u> of the espoused practice: <u>Actualizing</u> PPC's espoused benefits	<u>Valorization</u> of the espoused practice: <u>Authenticating</u> PPC as beneficiary	Illustrative quotes
The PPC team <i>coalesces</i> in the outpatient setting the specialists as a case manager	Supporting treatment teams to work more effectively	Demonstrating the collaborative and supportive nature of PPC within the medical team	"[The PPC physician] takes on the role of a case manager, at least in the outpatient setting. In the inpatient setting, we remain responsible, because the patient is primarily in our setting. But in the outpatient setting, she can take on that role. I find that very attractive, especially for patients who have problems on various levels and lack a person coordinating things. [...] This is what palliative care offers. They bring everything together again. All the specialties are somewhat consolidated without claiming to take over, for example, cardiological care. But they still manage to bring it all together in some way." (PTT physician 2, interview Maria)

Table B 4: Interactional destigmatizing of PPC by the PPC team

<u>Alignment</u> with focal audiences: <u>Distancing from</u> focal audiences	<u>Cultivation</u> of the espoused practice: <u>Delineating</u> PPC's boundaries	<u>Valorization</u> of the espoused practice: <u>Protecting</u> PPC from devaluation	Illustrative quotes
<u>Opposing:</u> PPC physicians refuse requests for assistance from other physicians if they seek improper use of PPC	Enforcing what is not within the scope of PPC	Defending against a misuse of PPC	<p>Interviewer: "Are there aspects you don't address in the initial conversation?"</p> <p>PPC physician 1: "For example, I really don't like discussing resuscitation issues in the first conversation, and I really don't like it when the request is, 'Can you please have a resuscitation discussion with them?' I think that's unacceptable. I can't walk into a family I don't know, a child I don't know, and say, 'I'm here to talk to you about what to do if your child is unresponsive.' That's just a NO GO! I also see it as an abuse of colleagues. I then say, 'I can pre-discuss this conversation with you, and you can lead it. I can also be present and assist, but I will not lead such a conversation if I'm meeting the family for the first time. Forget it. Can you please inform the child about their life-limiting condition? Mmh, I'm not doing that.'"</p> <p>Interviewer: "Why is that a no-go for you?" PPC physician 1: "Because it's not a trust-building measure. I don't know the parents. I don't know where they stand. If it were the case that the parents really wanted to discuss assisted dying with me, then there's a motivation on their side to get information about a difficult topic. I'm totally open to doing that. But because a treatment team thinks it needs to be discussed and I have no idea where the parents stand, I have to say: 'No, I'm DEFINITELY not doing that.' [...]</p> <p>And you've heard a bit of that in the meetings too: 'Can you now make a transition' from a patient I've never seen? I say, 'No, I'm not doing that.' [...]</p> <p>I also don't go to a child who has passed away at home, where we weren't involved, and declare the death. I say, 'No, I'm not doing that. You can handle it yourself or talk to the pediatrician about it.'" (Non-case interview)</p>

<u>Alignment</u> with focal audiences: <u>Distancing</u> from focal audiences	<u>Cultivation</u> of the espoused practice: <u>Delineating</u> PPC's boundaries	<u>Valorization</u> of the espoused practice: <u>Protecting</u> PPC from devaluation	Illustrative quotes
<u>Withdrawing:</u> PPC physicians accept when parents don't want their support and leave	Enforcing the norm of parental autonomy	Preventing that PPC becomes a burden for families	Interviewer: "How has your approach to encouraging parents to seek palliative care changed over the years?" PPC physician 1: "I've become much gentler. I don't want to convert anyone. I don't want to make anyone's life harder than it already is. I often say that. And if families don't want it, I don't push it. I've learned that there's no point in imposing any concept on someone. It's not promising success. It's traumatizing. It makes their lives harder. Or even saying: It's extremely nice when children are able to be very openly informed about their illness and talk about their death. But if parents absolutely don't want that and you try everything to explain to them why it would be important, don't go behind the parents' back and do something because it's their story, not mine." (Non-case interview)

Table B 5: Destigmatizing of PPC by ‘wise’ attending physicians

<u>Aligning:</u> Connecting acute care with PPC	<u>Cultivating:</u> Promoting PPC as it is espoused	<u>Valorizing:</u> Elevating the merit or value of PPC	Illustrative quotes
<u>Entraining:</u> Physicians initiate PPC with increasing complexity of the disease course	<u>Anchoring:</u> Applying the hospital's criteria for initiating PPC	<u>Normalizing:</u> Integrating PPC seamlessly into the treatment process	Interviewer: “What is the ideal time to initiate palliative care?” PPC physician 1: “That’s a good question. It’s not always the same because it has an individual aspect. But when the course of the illness becomes so complex that you realize: This isn’t easy to solve, and it’s going to be a long journey with many side issues, even on a psychosocial level. There are follow-up problems, for example, with siblings or parents who can no longer work or are falling behind in school, then I think it requires a more complex approach than just saying, ‘I’ll fix this on an organ level.’ [...] In a child where more than two organ systems are affected, you can’t think in terms of just one organ system, but you have to think in the overall context. That would be the point where you have to say: ‘Now, you need to think about this.’” (Non-case interview)
Physicians give parents time to think about the PPC offer and are available to answer any questions they may have about it	Complying with the PPC norm of a gradual introduction	Habituating parents to PPC	“[In PPC] there’s no quick fix. You have to take your time. It requires several attempts. When a child becomes dependent on ventilation, you might look at it in the morning and by the afternoon say, ‘We need to intubate in the next two hours.’ But that’s not the case with palliative care. You can announce it. You can say, ‘Remember, I talked about this two days ago... last week. Have you thought about it? How did it feel for you? Do you have any questions?’ It’s about preparing them, not just dumping a bucket of water over them.” (PPC physician 1, interview Lily)
Physicians let parents decide whether they want to use PPC	Complying with the PPC norm of parental authority	Preventing parents from perceiving PPC as a threat	“The parents were given time to decide if they really wanted it at that moment. In the hospital, initial contact was made without any obligations from the parents. So, the parents didn’t have to commit to wanting [PPC].” (PTT physician 8, interview May)

<u>Aligning:</u> Connecting acute care with PPC	<u>Cultivating:</u> Promoting PPC as it is espoused	<u>Valorizing:</u> Elevating the merit or value of PPC	Illustrative quotes
<u>Distancing:</u> Physicians introduce PPC to parents in a room away from their child's bedside	<u>Delineating:</u> Shielding parents from their child as an emotional stimulus	<u>Protecting:</u> Mitigating the risk that parents will stigmatize PPC	<p>Interviewer: "How should the conversations take place, if not at the bedside?" PPC physician 1: "In a meeting room." Interviewer: "Do you have special meeting rooms for that?" PPC physician 1: "There are some really bad rooms. Many rooms are NOT good at all. They're just dark chambers where mothers on the ICU are pumping breast milk or there's a worktable for someone. It's anything but ideal. But I still think it's important to get out of that cocoon with the child and not have a situation in front of the child – even if the child is sedated, intubated, or whatever – where you're crying, maybe even breaking down, or whatever happens, with other parents around... That's not possible! It's very difficult!" (interview Lily)</p> <p>"Parents are constantly told: 'I have [Name of PPC doctor] here, just so you don't misunderstand, but Palliative Care is also part of it.' These are such difficult phrases to say delicately, to make it really clear: 'We made a difficult decision with [experimental therapy] that is not state-of-the-art or textbook, but we are taking a very special approach. It's experimental, so we are trying to integrate as many support structures into this system as possible, which can help it go well, or if it doesn't, ensure that you have a safety net.' You can also announce us in this way". (PPC physician 1, interview Anya)</p> <p>"I called the senior PPC physician and told her that I'd like to discuss a child with her, assuming that she would be involved sooner or later. I invited her to the next large interdisciplinary meeting. I wanted her to be there as an important participant, connecting directly with the neurologists and ventilation specialists. I also already knew when the next parent meeting would take place and wanted her to be there. So, it was about bringing her on board, aligning the medical expertise, ensuring she was up to date, and then preparing the parent conversation." (PTT physician 8, interview May)</p>
<u>Advocating:</u> Physicians explain to parents sensitively what PPC is and does	<u>Demystifying:</u> Providing clarity and understanding of the practice	<u>Legitimizing:</u> Promoting the espoused understanding of PPC	
<u>Allying:</u> Physicians inform the PPC team about a case and invite it to joint meetings	<u>Actualizing:</u> Using formal authority to integrate PPC into the treatment	<u>Authenticating:</u> Demonstrating commitment to PPC as a valuable support offer	