KATHOLIEKE UNVERSITEIT LEUVEN
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“IT’S A MATTER OF ATTUNEMENT”

Exploring couple communication in times of child loss and child cancer

— An Hooghe

Promotor: Prof. Dr. Peter Rober
Co-Promotoren: Prof. Dr. Robert Neimeyer
Prof. Dr. Paul Rosenblatt

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“IT’S A MATTER OF ATTUNEMENT”:

EXPLORING COUPLE COMMUNICATION IN TIMES OF CHILD LOSS AND CHILD CANCER

An HOOGHE

Promotor:	Prof. Dr. Peter Rober
Co-promotor::	Prof. Dr. Robert Neimeyer
	Prof. Dr. Paul Rosenblatt
Chair:	Prof. Dr. Paul Enzlin
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De verwondering aan het begin van dit project…

“Ik beheerste wat in onze cultuur moet beheerst worden: rauwe emoties zijn niet mooi om naar te kijken, expressieve pijn is storend voor de medemens, de mensen met het meeste verdriet deden het meeste hun best elkaar en de andere gezinsgenoten te ontzien. Wij zwegen voornamelijk over het onzegbare….Het is een van de meest hardnekkige paradoxen waar ik in mijn overdenkingen op blijf botsen: het cliché dat “woorden tekortschieten” klopt naar mijn gevoel helemaal, maar anderzijds zijn er (in onze cultuur toch) vooràl die woorden die ervoor moeten zorgen dat je niet van iedereen los raakt..”.

Getuigenis van een moeder tien jaar na het overlijden van haar zoon
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***

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***

Mijn interesse in het therapeutisch werken met koppels en gezinnen die geconfronteerd worden met rouw, ziekte en verlies wordt al jaren lang door vele collega's mee gedragen. Ik heb werkelijk het grote geluk van al een lange tijd te mogen samen werken met boeiende collega's die met mij meedenken en mij vaak stimuleren om verder te werken aan een project waarvoor ik hun waardering kan horen en voelen. In de beginjaren waren Anke Bonnewyn, Dorine Broekaert, Heidi Peeters en Loes Peeters mijn gesprekspartners binnen mijn zoektochten in de gerontopsychiatrie. Nadien, met de volledige overstap naar Context, kwamen er talrijke collega's bij die op de een of andere manier een invloed hadden op mijn denken over rouw en verlies. Dit zijn in de eerste plaats mijn collega opleiders van de Relatie & Gezinstherapie opleiding en Rouwopleiding, waaronder Peter Rober, Lieven Migerode, Barbara Lavrysen, Geertje Walravens, Katrien Lagrou, Karine Van Tricht, Paul Enzlin, Luc Van de Ven, Walter Rombouts, Dirk De Wachter, Peter Adriaenssens, Elke Van Roie, Yves Spysschaert, Lucia Dehaene, Imke Baetens, Uschi Vandenbroeck, Eveline Goethals en Birgit Vanderhaeghen.
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***

Anders Nabij. Een project ernaast…

De voorbije twee jaren ontstond er nog een project naast mijn doctoraat. *Anders Nabij*, een boek dat ik samen schreef met vijf ouders, in stille kracht rouwend om hun kinderen.
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***

Zo nu en dan heb je een herberg nodig op de tocht…

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***

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NEDERLANDSE SAMENVATTING

***"Het is een kwestie van afstemming"**:* Een exploratie van koppelcommunicatie bij kinderkanker en het verlies van een kind

Wanneer men geconfronteerd wordt met iets dat zo ingrijpend is als een kankerdiagnose of het overlijden van een eigen kind, wordt er algemeen vanuit gegaan dat het goed is om de emotionele impact hiervan te delen door erover te spreken met de partner, omdat het helpend en noodzakelijk wordt geacht om hier als individu en als koppel mee om te gaan. Ongetwijfeld kan het spreken met elkaar hierover een manier zijn om emotioneel met elkaar te verbinden en elkaar te steunen in moeilijke tijden. Echter, koppelcommunicatie in de context van kinderkanker of het verlies van een kind door overlijden is vaak een grote uitdaging voor vele koppels. Daarenboven is het huidige onderzoek verre van eenduidig over het veronderstelde heilzame effect van het spreken of delen van pijnlijke emoties.

Het algemene doel van dit doctoraatsonderzoek was het beter begrijpen van koppelcommunicatie, spreken en niet spreken, in de context van kinderkanker en het verlies van een kind. Daartoe onderzochten we de *ervaringen* van rouwende ouders en ouders wiens kind behandeld werd voor kanker, en de betekenissen die zij gaven aan het 'niet spreken' met elkaar over hun emoties, of het zwijgen in elkaars nabijheid. Daarnaast onderzochten we ook de ervaringen en opvattingen van hulpverleners werkend op een afdeling kinderoncologie.

We gebruikten hiervoor een kwalitatief onderzoeksopzet. In kwalitatief onderzoek vertrekt men gewoonlijk niet van een specifieke hypothese die men empirisch onderzoekt. Veeleer wordt datgene wat men onderzoekt systematisch geëxploreerd, wat resulteert in een rijke beschrijving die gegrond is in de data. Deze beschrijvingen kunnen dan leiden tot fundamentele reflecties over conceptuele kwesties.

We deden vijf studies, gepresenteerd in de vijf hoofdstukken. Hoofdstuk 1, 2 en 4 gaan over de exploratie van koppelcommunicatie bij rouwende ouders. Hoofdstuk 3 en 5 gaan over onderzoek in de context van kinderkanker, inclusief de opvattingen van hulpverleners op kinderoncologie (Hoofdstuk 5).

We begonnen met een exploratieve pilootstudie (Hoofdstuk 1) met een rouwende moeder en haar partner. Gebaseerd op een diepte-interview, een boek dat ze schreef, en een getuigenis die ze gaf op een lezing, deden we een thematische analyse. Nadien deden we een narratieve analyse waar we ons richtten op de evolutie binnen dit koppel betreffende hun delen en niet delen van rouwervaringen sinds het overlijden. De basislijn in hun verhaal ging over de nood aan stilte en afstand op verschillende momenten in hun proces, om zichzelf en hun relatie te beschermen. Tegelijkertijd benadrukten ze ook de noodzakelijke momenten van verbinding tussen hen, met of zonder woorden. Deze eerste studie introduceerde een kijk op koppelcommunicatie die van nature dialectisch, dialogisch en dynamisch is.

Nadien, in een tweede en derde studie, onderzochten we de verschillende betekenissen die deze ouders gaven rond het ‘niet spreken’ met elkaar. In de tweede studie (Hoofdstuk 2), deden we twintig diepte-interviews met zesentwintig rouwende ouders, en deden we hier een thematische analyse op, op basis van een ‘Grounded Theory’ methodiek. Onze analyses toonden vier basis betekenissen voor het ‘niet spreken’ over hun rouw met de partner. Het niet spreken (1) omwille van de ontoereikendheid en zinloosheid van woorden in rouw, (2) om afstand te creëren tegenover de pijn, (3) als een expressie van een persoonlijk en intiem proces, en (4) omdat de partner eenzelfde verlies heeft maar een ander rouwproces (met 4 subcategorieën: 4a. Respect en het niet belasten van elkaars rouwproces, 4b. de zinloosheid van woorden binnen de relatie, 4c. onvoldoende afstand tegenover de pijn van de partner, en 4d. een verschillende manier of timing van rouwen.

Voor vele rouwende ouders startte het complexe proces van spreken en ‘niet spreken’ over de angst om het kind te verliezen in de periode van de kanker diagnose en behandeling. Daardoor besloten we om onze onderzoeksgroep te verbreden, en onderzochten we hetzelfde proces van koppelcommunicatie bij ouders wiens kind in behandeling was voor kanker. In deze studie (Hoofdstuk 3) deden we eveneens een thematische analyse op basis van een ‘Grounded Theory’ methodiek. De analyses werden uitgevoerd op negen diepte-interviews met zestien ouders. Meteen werden we geconfronteerd met de verschillende context van deze ouders (in vergelijking met de rouwende ouders). Hun primaire focus tijdens de behandeling lag geheel bij het welzijn en de genezing van hun kind, in een leven dat gedomineerd en gestructureerd werd door behandelingen en regelmatige opnames. Als ouders voelden de meesten van hen zich gesteund door de partner, en hadden ze de ervaring hier samen in te zitten. Echter, allen spraken heel erg weinig met elkaar over hun emoties en gedachten rond de ziekte van hun kind. Onze analyses toonden drie basis betekenissen: niet spreken (1) omwille van de ziekenhuis- en behandelingscontext, (2) uit zelfzorg/zelfbescherming en het afblokken van emoties, en (3) omwille van elkaar (met 3 subcategorieën: 3a. elkaar sparen, 3b. een verschillende manier van ermee om te gaan, en 3c. omdat er geen woorden nodig waren tussen hen.

Deze drie studies toonden dat de ouders in onze interviews hun koppelcommunicatie ervaren als iets wat erg complex is, met daarbij zowel de waarde van het spreken alsook de waarde van het niet spreken.

Dit leidde ertoe dat we, in een vierde studie, verder gingen met de exploratie van *een dialectische benadering van communicatie* bij een koppel na het verlies van hun dochtertje (Hoofdstuk 4). Gericht op het beter begrijpen van de complexiteit van het dialectische proces, onderzochten we heel nauwgezet een metafoor die gebruikt werd door deze ouders: "*We spreken er eigenlijk nooit over, of toch niet expliciet. We fietsen er altijd wat rond, niet te dicht maar zeker ook niet te ver…".* Op basis van verschillende interviews deden we een thematische en metafoor analyse. Dit gaf ons de kans om het relationele proces meer in de diepte te bestuderen. Inderdaad, het samenspel van de dialectiek was ook aanwezig *in* hun dialoog met elkaar, op een interpersoonlijk niveau. Het concept '*afstemming*' *("Het is altijd een kwestie van afstemmen, op onszelf en op elkaar")* bleek van grote waarde in het verbinden van het intra-persoonlijke en interpersoonlijke niveau.

Met onze vijfde studie hebben we ons onderzoeksdomein verbreed naar de communicatie tussen ouders en hulpverleners die werken op een afdeling kinderoncologie (Hoofdstuk 5). We waren vooral geïnteresseerd hoe het proces van afstemming ook speelt in deze context. Daartoe deden we vier focusgroepen met twintig hulpverleners (psychologen en verpleegkundigen van UZ Leuven, UZ Brussel, UZ Gent en UZ Antwerpen) in combinatie met de negen interviews uit de derde studie, maar nu met de focus op de communicatie met de hulpverlener. We deden een afzonderlijke thematische analyse op de transcripten van de focusgroepen en op de transcripten van de interviews. Zowel de hulpverleners als de ouders spraken over een gestegen spanning in de partnerrelatie van de ouders tijdens de behandeling van het kind. Echter, in deze context voelde een expliciete aandacht voor de partnerrelatie niet gepast, niet voor de hulpverleners en niet voor de ouders. Het kind was hun voornaamste focus nu. Verder benadrukten zowel de ouders als de hulpverleners het belang van een openheid tot gesprek vanuit de hulpverlener, en een afgestemde respons op de parterrelatie van de ouders.

Samengevat vonden we tijdens ons onderzoeksproject dat het proces van afstemming centraal is in het begrijpen van hoe partners, geconfronteerd met de dood of een levensbedreigende ziekte van hun kind, met elkaar spreken en tegelijk bepaalde dingen (tijdelijk) onuitgesproken of in stilte laten.
Dit stemt overeen met *een dialogisch perspectief* op het spreken met elkaar. Aldus beschrijven we een model van afstemming dat onze bevindingen weer geeft. Het proces van afstemming is een interactie van moment naar moment, en behelst verticale en horizontale processen. Deze processen zijn inherent verbonden met elkaar en maken deel uit van een groter geheel (of proces), het ene inherent verbonden met het andere. Voortkomend uit deze afstemmingsprocessen worden bepaalde dingen in de externe dialoog gebracht en andere niet (of nog niet).

Het concept afstemming bracht ons tegelijk ook bij een beter begrijpen van de samenhang tussen spreken/niet spreken en verbondenheid/niet verbondenheid (of afstand/nabijheid) binnen de partnerrelatie.

We sluiten dit doctoraatsmanuscript af met een algemene discussie over onze voornaamste bevindingen, en hoe deze kunnen bijdragen aan de bestaande literatuur rond rouw en psycho-oncology. Tot slot bespreken we de methodologie van deze studies en de beperkingen van onze studies, toekomstig onderzoek en wat dit alles kan betekenen voor de klinische praktijk.

ENGLISH ABSTRACT

“It’s a matter of attunement”: exploring couple communication in times of child loss and child cancer.

Confronted with something as fundamental as a cancer diagnosis or death of one’s child, it is generally assumed that sharing the emotional impact of it, in the form of talking about it with the partner, is helpful and necessary in order to cope as an individual and as a couple. Undoubtedly, being able to talk to one another can be a way for connecting emotionally with the partner and supporting each other through difficult times. However, couple communication in the context of childhood oncology or grieving the loss of a child is often challenging. Moreover, contemporary research is far from consistent about the presumed beneficial effects of talking and social sharing about painful emotions.

The overall aim of this doctoral research was to deepen the understanding of couple communication, talking and not talking, in the context of child cancer and the loss of a child. Therefore, we explored the *experiences* of bereaved couples and couples confronted with childhood cancer, including the meanings they gave for ‘not talking’ with one another about their emotions, or being silent in each other’s presence. In addition, we explored the experiences and views of professionals working with parents whose child is in cancer treatment.

A qualitative research design was used to meet this overall aim. In qualitative research the starting point is usually not a specific hypothesis that needs to be tested empirically. Rather, the phenomenon under study is systematically explored, resulting in a rich description of the phenomenon that is grounded in the data. Such rich descriptions can then lead to fundamental reflections on conceptual issues.

We conducted five studies, each presented in a chapter. Chapters 1, 2 and 4 relate to the exploration of couple communication of bereaved parents, while chapters 3 and 5 are conducted in the context of childhood cancer, including the views of professionals at a child oncology department (Chapter 5).

First, we conducted an exploratory pilot study (Chapter 1) with a bereaved mother and her partner. Based on an in-depth interview, a book she wrote and a text of a presentation she gave, we did a thematic analysis. Following this, we did a narrative analysis where we focused on the evolution of this couple’s sharing and not sharing of grief experiences since the loss. The main storyline involved the need for silence and distance at several points in the process, to protect themselves and the relationship. At the same time, they stressed the necessary moments of connection between them, with or without words. This study introduced a view on couple communication which is dialectic, dialogic and dynamic in nature.

Then we explored meanings related to ‘not talking’ in a second and third study. For our second study with bereaved parents (Chapter 2), we conducted and analyzed twenty in-depth interviews, with twenty-six parents, and did a thematic analysis based on grounded theory methodology. Our analyses revealed four main meanings related to ‘not talking’ about their grief with the partner: not talking (1) because of the inadequacy and pointlessness of words in grief, (2) to create some distance from the pain of grief, (3) as an expression of a personal, intimate process, and (4) because the partner has the same loss but a different grief process (with 4 subcategories: 4.1. Respect and not burden each other’s grieving process, 4.2. The uselessness of words, 4.3. Not enough distance from the pain of the partner, and 4.4. Different grieving styles or moments).

For many bereaved parents, the complex process of talking and ‘not talking’ about the fear of death and loss of their child started from the moment of the cancer diagnosis. Therefore, we decided to broaden our group of research participants, and explored the same research topic with parents whose child was in cancer treatment in our third study. In this study (Chapter 3), we equally did a thematic analysis based on grounded theory methodology. The analysis was done on nine in-depth interviews with sixteen parents. In this study we were immediately confronted with the different context of these parents. Their primary focus during treatment period was the wellbeing and recovery of the child, in a life that was dominated and structured by treatment procedures and frequent hospitalizations. As parents, most of them felt supported by the partner, as a way of “being in this together”. However, they all talked very little with each other about their emotions and thoughts related to their child’s cancer during treatment. Our analysis revealed three main meanings: not talking (1) because of the hospital and treatment context, (2) for selfcare/self-protection and blocking of emotions, and (3) because of each other, (with 3 subcategories (3a) to spare one another, (3b) a different coping, and (3c) because no words are needed between them).

These three studies showed that the parents in our interviews experienced their communication with each other as subject to a lot of complexities, representing both the value of talking *and* not talking. This led us to explore a *dialectical approach to communication* in a fourth study with a bereaved couple (Chapter 4). Aiming at a deeper understanding of the complexity of the dialectical process we meticulously investigated a metaphor used by one of the bereaved parents. We used multiple data collection for this study and conducted a thematic and metaphor analysis. This gave us the chance to examine the relational process more in depth. Indeed, the interplay of dialectics was also apparent *in* their dialogue with each other, on an interpersonal level. The concept of *attunement* showed extra value in connecting the intrapersonal and interpersonal level.

With our fifth study we broadened our research topic to the communication between parents and professionals working at a child oncology department (Chapter 5). We specifically wondered about how attunement processes operated in this context. Therefore, four focus groups were organized with twenty professionals (psychologists and nurses), in addition to the nine in-depth interviews (study 3), now with a focus on the communication with the professionals. Thematic analyses were done separately on the transcripts of the focus groups and interviews. Both professionals and parents talked about an elevated tension in the partner relationship during oncology treatment of the child. However, explicit attention for the partner relationship in this context felt inappropriate to professionals and parents, as the child is their primary focus now. Furthermore, both professionals and parents emphasized the importance of the professional helpers' openness for conversation and an attuned response to the parental couple relationship.

Taken together, during our research process we found that the process of attunement is central in our understanding of how partners, confronted with the death or life-threatening illness of their child, talk with each other and leave certain things (temporarily) unspoken or in silence. This corresponds with *a dialogical perspective* on storytelling. Consequently, a model of attunement reflecting our findings is described. The process of attunement is a moment-to-moment interaction, which includes vertical and horizontal processes. These processes are inherently connected and part of one process, the one resting on the other. Based on these attunement processes some things are brought in the outer dialogue, while others are not (yet). The concept of attunement also brought us to a deeper and broader understanding of the relatedness of talking/not talking and connecting/not connection (or closeness/distance).

We conclude this doctoral manuscript with a general discussion of our main findings and how they might contribute to the existing grief and psycho oncology literature. Finally, we discuss methodological issues with the limitations of our studies, future research and clinical implications.

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Chapters

Integrative Discussion

FOREWORD

It all started from clinical practice with bereaved parents. *"Do we really need to talk about it?"*, and *"Is it really necessary to involve my partner in these conversations?"* My own background in psychology and psychotherapy from a systemic approach was rather convincing: "*Yes, it would be good to talk about your grief, in order to give words and meanings to the emotions and thoughts connected to your grieving process".* And "Y*es, people don't grieve in isolation from each other. You're partner has lost the same child and is going through a grieving process too, so sharing your grief might be very important to be a support for each other, and to make meaning together, as a couple*". Some clients agreed and came together. They found ways to express their grief and share it with one another. Although this process was often difficult and they needed to grow into this conversation as a couple, the value of talking about their grief with each other was apparent. However, some clients tried, with my help, but did not find a connection with each other in their grief. Sometimes their partner relationship became even more strained. Some parents repeatedly told me this was not useful for them, as they were looking for something else. And some clients disregarded my view and found reasons for their partner not being present for every session, or ended the therapy (and maybe looked for an individual therapist).

I started to doubt my views and systemic beliefs and searched for more nuanced answers than the one I gave. I looked for differentiation. When, and for which couples, would it be useful to talk with each other about their grief? How can I better understand that for some talking about their grief with the partner was so difficult, or something they did not consider as helpful, or even considered harmful for themselves or their partner relationship? How could I understand their hesitations, or even reluctance to talk with their partner?

I talked with many colleagues, marital therapists, family therapists and grief therapists from all over the world, and dived into the psychotherapy literature and research on grief, family grief, couple therapy, communication, disclosure, emotional expression and so on. There was ample support for the importance of expressing one's emotional reactions to the loss as a vehicle to find meaning and as a central component of adaptive grieving. Moreover, some scholars strongly advocated for involving partners and family members in grief therapy as a way to co-create meaning together, mutual support, and an increased understanding and connection.

However, empirical research also raised some doubts on this generally assumed beneficial effect of emotional disclosure and social sharing of an emotional event. Studies failed to show a recovery effect following the sharing of emotions in the context of bereavement, as the expression of emotions can intensify distress and interfere with one's active coping. For some families it appeared better not to talk. Moreover, not expressing grief could function as a resilient way of being able to distract oneself from the loss.

Then, my colleague Peter Rober advised me to stop reading, but instead ask it to the parents themselves, interviewing bereaved parents about my main question: *How do you experience the talking about your grief with your partner?*

Taken together, my repeated questions from clinical practice initiated a search for better understanding the process of talking and not talking with the partner about grief emotions. Over time, these questions resulted in a doctoral project, aimed at a deeper understanding of couple communication of bereaved parents and, in a next phase, parents confronted with childhood cancer.

INTRODUCTION

Confronted with something as fundamental as a cancer diagnosis or the death of one's child, it is generally assumed that sharing the emotional impact of it, in the form of talking about it with the partner, is helpful and necessary in order to cope as an individual and as a couple (e.g., Porter et al., 2009; Shapiro, 2008; Stroebe, Stroebe, Schut, Zech, & Van den Bout, 2002; Walsh & McGoldrick, 2004, 2013). Undoubtedly, being able to talk to one another can be a way for connecting emotionally with the partner, and supporting each other through difficult times (e.g., Albuquerque et al., 2017; Bergstraesser et al., 2015; da Silva et al., 2010; Hall, 2010; Lavee & Mey-Dan, 2003; Manne & Badr, 2008; Wiener, 2016). Consequently, not talking with one another about how one feels, is commonly assumed to be unhealthy, associated with pathological physical as well as psychological symptoms. Most often this is conceptualized as 'avoidance', or 'experiential avoidance', to distract from painful emotions and other internal experiences (e.g., Fisher et al., 2016; Shear et al., 2007). Attachment theory is at the base of this assumption, as this theory has traditionally held that emotional avoidance is indicative of poor psychological adjustment (Fraley & Bonanno, 2004). Therefore, avoidant individuals are believed to have difficulties recovering from the loss—difficulties that may manifest themselves later (Shaver & Tancredy, 2001).

Controversy

Despite general assumptions, contemporary research is far from consistent about the presumed beneficial effects of talking and social sharing about painful emotions (e.g., Goldsmith & Miller, 2015; Rimé, Finkenauer, Luminet, Zech, & Philippot, 1998; Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002; Zech & Philippot, 1998; Zech & Rimé, 2005). Indeed, the association between avoidance and maladaptive or delayed grief has recurrently been called into question by many bereavement scholars (e.g., Boelen et al., 2006; Bonanno, 2004; Bonanno et al., 2005; Fraley & Bonanno, 2004; Znoj & Keller, 2002). Surprisingly, it was found that people who exhibit seemingly defensive or avoidant approaches to loss suffer less in the long run than those who actively express or 'work through' their grief. In addition, studies failed to show a recovery effect following the sharing of emotions in the context of bereavement (Meads & Nauwen, 2005; Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002; Zech & Rime, 2005). Indeed, the expression of emotions can intensify distress and interfere with one's active coping (Kennedy-Moore & Watson, 1999). In grief research, a review on the effects of disclosure (Stroebe, Schut, & Stroebe, 2005) found no evidence that expressing and sharing emotions facilitates adjustment to loss in normal bereavement. Consequently, rather than a pathological process, avoidance has sometimes been portrayed as an 'ability' to distract oneself from the loss and redirect attention to other aspects of life, reflecting the resiliency of the bereaved (e.g., Boelen, Van den Bout, & Van den Hout, 2006; Fraley & Bonanno, 2004). Moreover, it has been argued that the specific relational context determines the efficacy of family communication (Kissane et al., 2006). For example, in families characterized by anger and hostility, communication between family members can be detrimental rather than connecting, even in the presence of a skilled therapist attempting to facilitate the interaction. Equally, in the context of cancer, open communication is typically advised as it would be associated with healthier outcomes (e.g., Figueiredo et al., 2004; Hilton, 1994) although there is only limited theoretical, empirical or intervention research to justify the assumed benefits of open communication (Donovan & Farris; Goldsmith & Miller, 2015).

Related to our research topic of couple communication in the context of child loss or childhood cancer, some scholars have argued that conclusions drawn about the adaptiveness and resilience of avoidance does not hold true for the severe experience of the death of a child (e.g., Wijngaards-de Meij et al. 2007). In addition, Stroebe and colleagues (2013) examined the impact of avoidance of talking about the loss and remaining strong in the partner's presence ('Partner Oriented Self Regulation', POSR). They found that holding in one's own grief in order to protect one's partner from pain was actually associated with greater grief for both the partner and the self later on.
Research on the communication of parents confronted with the cancer of their child is limited (e.g., da Silva et al., 2010; Hall, 2010; Lavee & Mey-Dan, 2003; Wijnberg-Willams, 2015), and a review on couple functioning after pediatric cancer diagnosis indicates that there are no qualitative reports about the parents' communication (Van Schoors et al., 2017). In a quantitative longitudinal study, Wijnberg-Williams (2015) found that the parents' use of communication appeared to have only limited effects on their marital dissatisfaction and no effect on their distress five years later. The topic of couple communication where one partner is in oncology treatment received a lot more attention in the psycho oncology literature (e.g., Beach & Anderson, 2003; Boehmer & Clark, 2001; Goldsmith et al, 2008; Manne & Badr, 2008). In a mixed method analysis of couples' talk, Goldsmith and Miller (2015) found that participants who reported talking about feelings also reported more distress and poorer quality of life and functioning. However, in studies examining 'protective buffering' (e.g. hiding worries and denying concerns) they found that the adoption of buffering did not have the intended impact, reducing the partner's distress (e.g., Langer et al., 2007; Manne et al., 2007).

A more balanced view: the value of both talking and not talking (or silence)

Today, this scholarly discussion related to avoidance of communication, in both grief and psycho oncology literature, remains controversial, and suggestions are made to adopt a more nuanced view related to couple communication, as we still know little about how and why and when communication works (e.g., Goldsmith & Miller, 2014), and research on interactional patterns remains limited (e.g., Beach & Anderson, 2003). A more balanced view on couple communication after the loss of a child was described by Rosenblatt (2000a, 2000b), and also Kissane and his colleagues (2006), who found that the specific relational context of the bereaved family determines for the efficacy of family communication about grief. In addition, the desire to talk about the loss with others, and the perceived benefits in doing so can change over time (Kamm & Vandenberg, 2001; Luminet, Bouts, Delie, Manstead, & Rimé, 2000; Zech, Rimé, & Pennebaker, 2007). Therefore, the use of multiple and flexible coping strategies was considered as more important than concentrating merely on grief processing or grief avoidance as beneficial or detrimental (Zech, Ryckebosch-Dayez, & Delespaux, 2010). This multidimensional view can also be found in literature related to communication in the context of cancer. Indeed, the degree to which someone fosters openness (about their cancer experiences), and developed norms and patterns within a couple or family, can vary across people, couples and families, and across time (Fisher et al., 2016). This fits with a family communication patterns theory (Koerner & Fitzpatrick, 2006), which recognizes that *"different families function well by employing different types of behavior"* (p. 61).

Surprisingly only sparse attention is given to the meanings of not talking with the partner about one's emotions. It is rare that researchers address silence in families in an appreciative way (Baddeley & Singer, 2009, 2010; Rober & Rosenblatt, 2013; Rober et al., 2011). Baddeley and Singer (2009, 2010) propose silence can have its own identity and function, and Rober and colleagues (2012, 2013) explored the concept of 'selective disclosure', referring to some information that is shared, while some is not shared within families.

A theoretical model emphasizing the value of both talking and not talking in a tense relationship with each other is the dialectical perspective on communication in personal relationships (Baxter, 2011; Baxter & Montgomery, 1996). This perspective is inspired by the work of the Russian philosopher Mikhail Bakhtin, who stated that in the uniqueness of every moment there is a continuous tension between two opposing forces, the centrifugal force (openness) and the centripetal force (closedness). Both forces are continually present, as they co-exist in a constant tension that is never resolved (Bakhtin, 1986). According to this perspective, people feel the wish to be open and share with others, while at the same time they also want to keep thoughts and feelings private. What is actually said between people is the moment-to-moment result of the interplay between these opposing forces, simultaneously present and inherently connected.

Similarly, in grief literature, **the Dual Process Model** (DPM, Stroebe & Schut, 1999) extends the conceptualization of grief adaptation by the incorporation of both loss and restoration oriented coping strategies and the core feature of oscillation between them. Loss orientation refers to attention to aspects of the death itself, such as confronting feelings of grief and confiding in trusted others, whereas restoration orientation refers to confronting the need to reengage in life and adapt to a changed life following the loss. The DPM postulates that, for the bereaved individual, attention to both is needed for favorable psychological adjustment after bereavement. An important aspect of this model is the dynamic regulatory mechanism of oscillation between the two coping strategies. At times the bereaved will confront aspects of the loss/restoration, while at other times avoid them. As the authors of the model postulated, “coping with bereavement thus is a complex regulatory process of confrontation and avoidance” (Stroebe & Schut, 2010, p. 278). Since the introduction of the Dual Process Model, many scholars have been stimulated to empirically test and refine its key propositions (for a review, see the DPM a decade on, Stroebe & Schut, 2010; Stroebe & Schut, 2016). For example, incorporating insights from the DPM, Shear (2010) further explored the concept of avoidance from an attachment theory perspective. With the concept of experiential avoidance she referred to the distancing of the bereaved from painful emotions and other internal experiences. However, in partial distinction from the DPM model, she proposed that the bereaved do not oscillate between loss and restoration focused coping, but rather that these processes overlap, occurring in tandem. She stated, “What oscillates is the private experience of thoughts and emotions. Oscillation progresses through use of experiential avoidance” (Shear, 2010, p. 363).

Another model in grief literature, greatly influencing our work and also related to expressing or sharing grief, is a **meaning making – meaning reconstruction** model (e.g., Neimeyer, 2001). Over the past years, many scholars have contributed in supporting the outlines of this model (e.g., Bellet, Neimeyer, & Berman, 2017; Burke et al., 2015; Coleman & Neimeyer, 2010; Holland, Currier, & Neimeyer, 2006; Keesee et al., 2008). The main thought is that a central process in grieving is the attempt to reaffirm or reconstruct a world of meaning that has been challenged by loss (Neimeyer, 2006). When our sense of self and our worldview, and the basic assumptions about how life is or should be, are threatened by loss (Janoff-Bulman, 2004), when the basic plot and theme of one’s life story are profoundly shaken or shattered (Neimeyer, 2001), the bereaved often needs to re-establish a changed sense of self and world (Neimeyer & Wogrin, 2008). Under such circumstances, telling one’s story in the presence of responsive others is thought to be one major vehicle through which meaning reconstruction and healing occurs (e.g., Bosticco & Thompson, 2005; Neimeyer & Levitt, 2000; Romanoff & Thompson, 2006). Indeed, confronted with death, we need to create stories to make order of disorder and to find meaning in the meaningless (Gilbert, 2002; Holland & Neimeyer, 2010; Keeley & Koenig Kellas, 2005; Riches & Dawson, 1996a, 1996b, 1998; Weber, Rowling & Scanlon, 2007; Wheeler, 2001; Woodgate, 2006). As such, meaning reconstruction is both a process and an outcome (e.g., Romanoff & Thompson, 2006).

One of the core principles of a meaning reconstruction approach (Neimeyer, 2007) entails that narrative methods can play a role in restoring or re-storying a sense of autobiographical coherence, in oral narrative or storytelling, formulated in private reflection (like writing letters or poems (Neimeyer, Van Dyke, & Pennebaker, 2009)), or in public discourse to close others, social networks or a therapist (Refs?). As such, meanings are co-created with others in the dialogue (e.g., Baxter, 2011; Koenig & Trees, 2006; Nadeau, 1998, 2001, 2008; Neimeyer, Klass, & Dennis, 2014; Walsh & McGoldrick, 2004). However, rather than only explicit or verbal, the process of meaning making is largely implicit or tacit (Neimeyer, 2001), emerging in, for example rituals (e.g., Neimeyer, Prigerson, & Davies, 2002; Romanoff & Thompson, 2006) or expressive arts (e.g., Thompson & Neimeyer, 2014).

PhD OBJECTIVES

PhD OBJECTIVES

This PhD project has the objective of exploring the process of couple communication, talking and not talking, in the context of child cancer and the loss of a child. More specifically we want to better understand the meanings related to not talking with each other. In addition, our project includes the exploration of experiences and views of professionals working with parents whose child is in cancer treatment.

This qualitative research is framed within a dialectical view on communication and therefore adds to the recent but limited literature on silences in grief and in parents confronted with a child's cancer.

A qualitative design

As we aimed to explore the lived experience of couples related to the complexity of couple communication, we chose a qualitative design. While qualitative research has a lot of limitations (e.g., Flick, 2006) it sometimes allows empirical access to domains that are difficult to reach with the established quantitative methods. Qualitative research has its own logic, that is different from the logic of quantitative research in some important ways (e.g., McLeod, 2010). In a qualitative design, the starting point is usually not a specific hypothesis that needs to be tested empirically. Rather, the phenomenon under study is systematically explored, resulting in a rich description of the phenomenon that is grounded in the data. Such rich descriptions can then lead to fundamental reflections on conceptual issues. Furthermore they can lead to the development of hypotheses that can eventually be tested empirically within a quantitative design.

Our research can be framed within the approach of *Consensual Qualitative Research* (CQR), which is an integrative approach to qualitative research (Anderson et al., 2014) and incorporates elements from phenomenology, grounded theory and comprehensive process analysis (Hill et al., 1997; Hill et al., 2005). The essential components of CQR are (1) the use open ended questions in semi-structured data collection techniques which allow for the collection of consistent data across individuals as well as in-depth examination of individual experiences, (2) several judges throughout the data analysis process to foster multiple perspectives, (3) consensus to arrive at judgments about the meaning of the data, (4) the use of external auditors who have the task of challenging interpretations and checking if these interpretations are sufficiently grounded in the data, and (5) domains, core ideas and cross-analyses in the data analysis (Hill, et al., 2005; p. 198). As such, the research process is considered as teamwork as it involves a rigorous method that allows several researchers to examine data and come to consensus about their meaning.

Studies: collection and analyses

We conducted 5 studies. Studies 1, 2 and 4 relate to the exploration of couple communication of bereaved parents, while studies 3 and 5 are conducted in the context of childhood cancer treatment, including professionals at a child oncology department (study 5).

In a **first phase** we explored the accounts of bereaved parents after the loss of their child to cancer, about their experiences of talking and not talking with each other about their grief. We were especially interested in learning more about the fears of disclosing, the desire to keep emotions private and the perceived benefits of not talking with each other (study 1, 2 and 4).

Our research with bereaved parents showed that the complex process of talking and not talking about the fear of death, and loss of their child, started from the moment of the cancer diagnosis. Therefore, in a **second phase** we broadened our group of research participants, and studied the same research topic with parents whose child is in cancer treatment (study 3). In addition we explored the communication not only between partners but also with the professionals at the department of child oncology, through the accounts of the parents and the professionals (study 5).

Note that the studies are not named in the chronological order as we studied them. For this manuscript we choose to re-order them with the purpose of intelligibility for the reader. As such, we assume that the flow of our findings is easier to follow in terms of our research focus, and subsequently, the discussion and integration in theoretical frameworks and concepts.

Different study methodologies in qualitative research were used, with 3 different groups of participants. See Figure 1 for an overview of the studies, Figure 2 for an overview of the participants in the interviews in study 2 (bereaved parents), Figure 3 for an overview for an overview of the participants in the interviews in study 3 and 5 (parents confronted with childhood cancer), and Figure 4 for an overview of the participants in the focus groups in study 5 (professionals at child oncology).

For the ***collection of the data*** we used the following methods:

- In-depth interviews (in all studies)
- Tape assisted recall interviews (in study 4)
- Focus groups (in study 5)

For the ***analyses of the data*** we used the following methods:

- Thematic analysis (in all studies) according to Grounded theory principles (Charmaz, 2006) (study 2 and 3)

We used MAX QDA software version 2 (2007) for the thematic analyses. Based on the video recordings, the interviews were transcribed verbatim. In preparation for the analyses, we watched the video files of the interviews several times in order to be fully immersed in the narratives. Simultaneously the transcripts were completed with notes about nonverbal behavior and silences. Statements and sentences that seemed essential, revealing and/or surprising were identified. We identified descriptive categories by using line-by-line coding and the constant comparison method, assessing meaning units and categories for similarities and differences (Charmaz, 2006). This resulted in a hierarchical category structure, with categories and subcategories. During the coding process the hierarchical code system became more complex. In addition, at several stages in the reporting and writing about the codes and categories (for the external auditor reports and during our writing for peer reviewed journals) we continued to interact with our data, resulting in modifying the code system and new emerging connections and concepts (Charmaz, 2006).

According to *Grounded Theory* (GT) core tenets include minimizing preconceived ideas about the research problem and the data, using simultaneous data collection and analysis to inform each other, remaining open to varied explanations and/or understandings of the data, and focusing data analysis to construct middle-range theories (Charmaz, 2008, p. 155). More than describing categories in the data, the objective of GT is to generate emergent theories from the data. Therefore we systematically scrutinized the data with a successive development and checking of categories during the whole research process. However, although we followed most of the defining features of GT (like coding, memo writing and theoretical saturation) described by Charmaz (2006, 2008), our research process differs from it in the fact that, for the separate studies, we collected all our interview data before analyzing. This means that we did not do a theoretical sampling, returning to the field and gathering more data to check and refine our categories, which is a essential component in GT. But as in, in studies 2 and 3 we reached theoretical saturation, which means that the last coded interviews did not yield new categories and gathering more data shed no further light on the properties of the theoretical categories.

- Narrative analysis (in study 1)

Narrative analysis takes as it object of investigation the story itself (Riessman, 1993). In our narrative analysis we listened carefully to the family's story, and sought to articulate key implicit meanings from within the story (Giorgio & Giorgio, 2003). In study 1 we focused very directly on the evolution of this couple's sharing and not-sharing of grief experiences within their family (Crossley, 2007).

- Metaphor analysis (in study 4)

Metaphors are weaved through our daily language as powerful ways to convey complex feelings and behavior. The analysis of a metaphor allows us to map someone's experience in depth, especially in a context of bereavement where words often fail to express the complexity (Umphrey & Cacciatore, 2014).

To enhance the ***validity and credibility of the studies*** we made use of several procedures (Cresswell & Miller, 2000):

- Triangulation

In our studies we used triangulation across data sources (Study 5), across methods (Study 1, 4, and 5), and among different investigators (Study 5).

- Member checking

We used member checking in three ways. First, in Study 1, we sent our analysis and interpretations back to the couple. Their feedback gave us the chance to modify our story of their experiences. Secondly, in Study 2 and 4, we used an additional narrative approach, called 'restoried stories' (McCormack, 2004). For the first 4 couples interviewed we made a report of our understanding of their story, focused on our research question. This 7-page long narration, which had the form of a poem, only used their own words and phrases and is structured in titles and subtitles on many levels. In a second interview we talked about this restoried story, which gave us the opportunity to adjust some of our interpretations of their story. Thirdly, in Study 5, we organized a focus group with three psychologists of the oncology departments (Brussels and Leuven) to review the code system. We discussed both the process and the product of the inquiry. All categories were discussed and agreed upon as fitting what they encounter in their practice. Their feedback was then incorporated in the paper.

- External auditing process

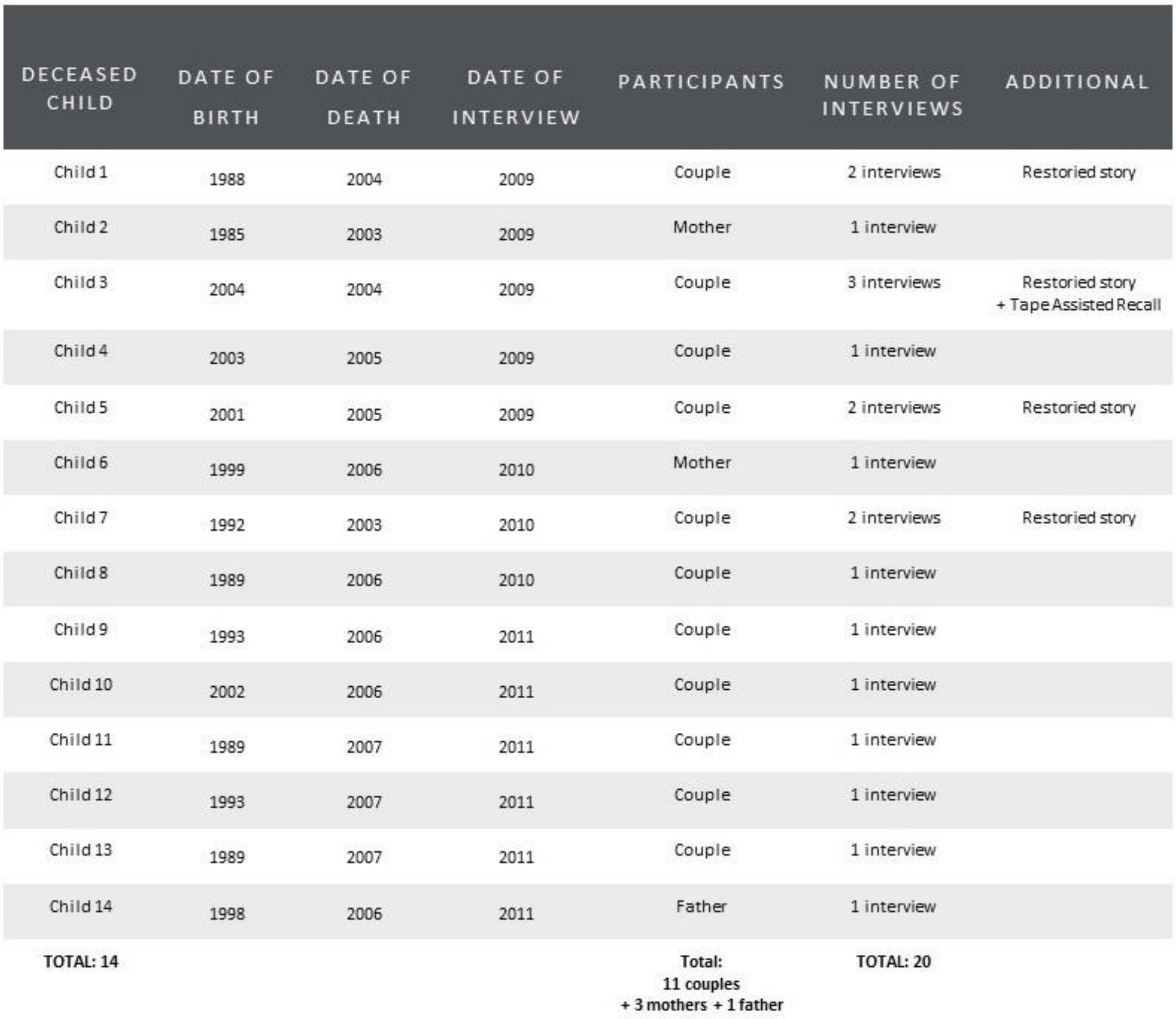
Using an external auditing process means that the researchers turn to individuals external to the project. The external auditor examines this documentation with the following questions in mind: Are the findings grounded in the data? Are inferences logical? Is the category structure appropriate? Can inquiry decisions and methodological shifts be justified? What is the degree of researcher bias? Through this process of documenting a study and a review of the documentation by an external auditor, the narrative account becomes credible.

In Study 1, 2, 3 and 4 we incorporated an extensive auditing process (Hill, Thompson, & Nutt-Williams, 1997). Independent of one another, 3 auditors (different auditors for each study) read the report and reviewed the overall category structure for coherence⁄consistency as well as elegance⁄ nonredundancy. All meaning units were audited for their fit into the category to which they were assigned. All three auditors then provided feedback to the first author, who used this to modify the category system and the assignment of meaning units.

Note: All interviews were conducted, transcribed and analyzed in Dutch. For the first study the researcher translated all coded meaning units from Dutch to English, in order for the co-promotors to follow the research process and analyses. In the fourth study these co-promotors (Prof. Neimeyer and Prof. Rosenblatt) also served as external auditors, and thus also for this study the main researcher made an external auditing report in English, with all codes and meaning units translated to English. In the translation process some words were difficult to translate (for example, ‘zwijgen’) and so they were also described.

	PARTICIPANTS	DATA COLLECTION	DATA ANALYSES	VALIDITY CHECK
STUDY 1	1 Bereaved couple	1 In-depth Interview + Book + Presentation	Thematic Analysis + Narrative Analysis	Triangulation (method) + External audit + Member checking
STUDY 2	26 Bereaved parents	20 In-depth Interviews	Thematic Analysis (Grounded Theory)	External audit + Member checking (Restoried Story)
STUDY 3	16 Parents (Child cancer)	9 In-depth Interviews	Thematic Analysis (Grounded Theory)	External audit
STUDY 4	1 Bereaved couple	3 In-depth Interviews (1 Tape Assisted Recall)	Thematic Analysis + Metaphor Analysis	Triangulation (method) + External audit + Member checking (Restoried Story)
STUDY 5	16 Parents (Child cancer) + 20 Professionals	9 In-depth Interviews + 4 Focus Groups	Thematic Analysis	Triangulation (data source, method, investigators) + Member checking (Focus Group Professionals)

Figure 1. Overview of the five studies.



DECEASED CHILD	DATE OF BIRTH	DATE OF DEATH	DATE OF INTERVIEW	PARTICIPANTS	NUMBER OF INTERVIEWS	ADDITIONAL
Child 1	1988	2004	2009	Couple	2 interviews	Restoried story
Child 2	1985	2003	2009	Mother	1 interview	
Child 3	2004	2004	2009	Couple	3 interviews	Restoried story + Tape Assisted Recall
Child 4	2003	2005	2009	Couple	1 interview	
Child 5	2001	2005	2009	Couple	2 interviews	Restoried story
Child 6	1999	2006	2010	Mother	1 interview	
Child 7	1992	2003	2010	Couple	2 interviews	Restoried story
Child 8	1989	2006	2010	Couple	1 interview	
Child 9	1993	2006	2011	Couple	1 interview	
Child 10	2002	2006	2011	Couple	1 interview	
Child 11	1989	2007	2011	Couple	1 interview	
Child 12	1993	2007	2011	Couple	1 interview	
Child 13	1989	2007	2011	Couple	1 interview	
Child 14	1998	2006	2011	Father	1 interview	
TOTAL: 14				**Total: 11 couples + 3 mothers + 1 father**	**TOTAL: 20**	

Figure 2. Participants in the interviews, bereaved parents (study 2).

INTERVIEW	HOSPITAL	DATE DIAGNOSIS	DATE INTERVIEW	TREATMENT PHASE	INTERVIEWED TOGETHER/ALONE	TYPE CANCER
1	Leuven	May 2015	Sept 2015	Active treatment	Together	Bone tumor
2	Leuven	May 2015	Oct 2015	Active treatment	Together	Bone tumor
3	Leuven	Febr 2007	July 2016	Checkups	Alone	Leukemia
4	Brussels	June 2016	Aug 2016	Active treatment	Alone	Leukemia
5	Brussels	April 2015	Aug 2016	Checkups	Together	Brain tumor
6	Leuven	April 2015	Sept 2016	Active treatment	Together	LCH
7	Leuven	Febr 2014	Oct 2016	Checkups	Together	Leukemia
8	Brussels	May 2015	Oct 2016	Checkups	Together	Brain tumor
9	Brussels	Sept 2013	Oct 2016	Checkups	Together	Leukemia

Figure 3. Participants in the interviews, parents child oncology (study 3 and 5).

FOCUS GROUPS	HOSPITAL	PSYCHOLOGISTS	NURSES
1	University Hospital Leuven (L)	2	2
2	University Hospital Brussels (B)	2	2
3	University Hospital Ghent (G)	2	4
4	University Hospital Antwerp (A)	1	5

Figure 4. Participants in the focusgroups, professionals (study 5).

Note: The raw data of the interviews (anonymous), the analysis (MAX QDA files, meaning units, code structure) and external auditor reports can be requested from the researcher by email: an.hooghe@upckuleuven.be

CHAPTERS

The complexity of couple communication in bereavement: An illustrative case study.

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ABSTRACT

Sharing grief experiences, or “storying” grief, can be a key resource in adapting to loss, one that can contribute to stronger bonds and relational intimacy within the family. In this paper we conceptualize communication between grieving family members in terms of three *“D processes,”* emphasizing the extent to which such communication is *dialectic*, *dialogic* and *dynamic* in nature. We will illustrate the complexity of sharing about a mutual loss, focused on these three features, by referring to a case study of a couple coping with the death of a child in the context of a newly formed family. Rather than unilaterally advocating the promotion of open communication, we suggest that therapists working with bereaved families first discuss the complexities of communication with the family members, specifically those concerning talking and keeping silent, and explore the different meanings associated with sharing grief experiences with each other.

INTRODUCTION

When families are confronted with the death of a loved one, it is generally assumed that the expression of one's emotional reactions to the loss is an important component of adaptive grieving (Stroebe, Stroebe, Schut, Zech, & Van den Bout, 2002). Moreover, clinicians argue that open and honest communication about one's grief experiences with family members enhances couple and family relationships (e.g., Shapiro, 2008; Walsh & McGoldrick, 2004). Accordingly, *not* sharing grief, or remaining silent, is seldom addressed in an appreciative way.

In the first part of the paper we will describe this dominant paradigm of approaching communication in grief. In the second part we will draw on several (related) theories on relational dialectics (Baxter & Montgomery, 1996) and dialogue (Bakhtin, 1986, Morson & Emerson, 1990) to propose a more complex view of communication, specifically focused on the *dialectical*, *dialogical* and *dynamic* features of family communication in bereavement. Drawing on a clinical case study, we will conclude by illustrating the implications of these three "*D processes*" for consultation with grieving families.

The dominant paradigm of communication in bereavement

Storying grief experiences

The notion of the necessity of 'grief work' has long dominated grief literature and practice (e.g., Freud, 1917; 1957; Lindemann, 1944; Worden, 1991, 2002). The traditional grief work hypothesis postulates that the bereaved need to confront and express their feelings of grief in order to be able to work through their loss and adjust to the changed life without the deceased. Giving words to grief in a relationship with a trusted other could serve more than an expressive function, however. From a narrative and meaning making perspective, 'storying' one's experiences is a way to create coherence and to make sense of our lives through connecting the elements of experience in time (Bruner, 1990; White & Epston, 1990). When our sense of self and our worldview is threatened by loss (Janoff-Bulman, 2004), when the basic plot and theme of one's life story are profoundly shaken or shattered (Neimeyer, 2001), the resulting inability to "make sense" of the loss emerges as a powerful predictor of the intensity of the bereaved parent's grief symptomatology (Keesee, Currier, & Neimeyer, 2008). Under such circumstances, telling one's story in the presence of responsive others is thought to be one major vehicle through which meaning reconstruction and healing occurs (e.g., Bosticco & Thompson, 2005; Neimeyer & Levitt, 2000; Romanoff & Thompson, 2006). Confronted with death, we need to create stories to make order of disorder and to find meaning in the meaningless (Gilbert, 2002; Holland & Neimeyer, 2010). Considerable empirical research, both quantitative (e.g., Harvey, 1996; Keeley &

Koenig Kellas, 2005; Smyth, 1998) and qualitative (Riches & Dawson, 1996a, 1996b, 1998; Weber, Rowling & Scanlon, 2007; Wheeler, 2001; Woodgate, 2006) has found support for the beneficial effects of narrating one's experiences related to the loss, or storying grief.

The social sharing of grief

To understand the phenomenon of storying we need to consider the interactive context in which it takes place (Gilbert, 2002; Gudmundsdottir, 2006; Nadeau, 1998; Neimeyer, 1998). From a social constructionist perspective, the act of storytelling is an interactive co-constructive process resulting in a dialogue between people (Ellis & Bochner, 1992; Gilbert, 2002; Nadeau, 1998, 2008; Rosenblatt, 1994). The sharing of grief experiences with others is important for the bereaved individual as it contributes to the testing and exploring of one's view of the world in relation to the views of others (Gilbert, 2002) and to receiving validation and social support for one's loss (Gilbert, 1997; Neimeyer & Jordan, 2002; Walsh & McGoldrick, 2004, Walsh, 2007). Furthermore, it reduces emotional distress and facilitates coping with loss (Rosenblatt & Elde, 1990; Rubin, 1986; Sedney, Baker, & Gross, 1994). The sharing of grief also has an impact on social contexts, particularly on couple and family relationships (e.g., Byng-Hall, 1991; Kissane & Bloch, 2002; Penn, 2001; Shapiro, 2008; Walsh & McGoldrick, 2004). Shared stories can bring family members closer together (Rober, van Eesbeek & Elliott, 2006; Sedney et al., 1994), create stronger bonds (Cook & Oltjenbruns, 1998), and enhance their sense of togetherness and relational intimacy (Gilbert, 1989; Gottlieb, Lang & Amsel, 1996; Hagemeister & Rosenblatt, 1997). Numerous quantitative studies have demonstrated strong associations between concepts such as social sharing, family communication, family cohesion, marital satisfaction, social support and grief outcome (Greeff & Human, 2004; Kissane et al. 2002; Nolen-Hoeksema & Davis, 1999; Sandler et al., 2003; Traylor, Hayslip, Kaminski, & York, 2003; Yelsma & Marrow, 2003). Based on the repeatedly occurring association between family communication and grief outcome, the importance of open and honest communication within the family is often highlighted (e.g., Greeff & Human, 2004; Kissane & Bloch, 2002; Rynearson, 2001; Walsh, 2007; Walsh & McGoldrick, 2004). Qualitative studies have shown that the sharing of feelings through conversation with the partner is experienced as a key factor in both parents' grief resolution. Furthermore, marital discourse is perceived by grieving partners as important for constructing and maintaining self identity (Riches & Dawson, 1996a, 1998), shared reality and mutual support (Gilbert, 1989; Rosenblatt et al., 1990), and an increased sense of security, togetherness and understanding of each other (Gilbert, 1989). Within the family context, Nadeau (1998, 2008), Gudmundsdottir (2006) and Koenig and Trees (2006) stress the importance of communication and interaction in the creation of family meanings around the death.

The meaning of silences and not sharing grief

In most studies on family communication and grief, both the sharing of grief experiences and communicative openness are implicitly favored. Sparse attention is given to the importance of remaining silent or the possible risks associated with sharing grief experiences with others. Concepts like '*withholding*', '*keeping experiences to oneself*', *'remaining silent'* and '*not sharing'* have a negative connotation in Western culture. Not sharing painful emotions in the family is sometimes referred to as a '*conspiracy of silence*' (Helmrath & Steinitz, 1978; Johnson, 1987) and is described as a 'communication problem' (Schwab, 1992). It is often associated with a "cut-off" in meaningful communication, intimacy and emotional engagement (Gilbert, 1989; Rando, 1984; Schwab, 1992; Silverman & Silverman, 1979), and with increases in blame, guilt and conflict (Vess, Moreland, & Schwebel, 1985). Furthermore, family secrecy is believed to contribute to instability in family dynamics, mystification, emotional disconnect and the formation of factions (Sedney et al., 1994). In recent years, however, empirical research has raised doubt on this generally assumed beneficial effect of emotional disclosure and social sharing of an emotional event (Rimé, Finkenauer, Luminet, Zech, & Philippot, 1998; Stroebe, Schut, & Stroebe, 2005; Zech & Rimé, 2005). Studies have failed to show a recovery effect following the sharing of emotions in the context of bereavement (Meads & Nauwen, 2005; Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002; Zech & Rime, 2005). On the contrary, the expression of emotions can intensify distress and interfere with one's active coping (Kennedy-Moore & Watson, 1999). Researchers studying the association between grief and avoidance found some indication that not expressing grief could function as a resilient way of being able to distract oneself from the loss (Boelen, van den Bout, & van den Hout, 2006). Moreover, from a family perspective, Kissane and his colleagues (2006) , found that the specific relational context of the bereaved family determines for the efficacy of family communication about grief. For families characterized by anger and hostility, communication between family members can be detrimental rather than connecting, even in the presence of a skilled therapist attempting to facilitate the interaction.

A more complex view of communication in grief

Looking closely at any case of grief following the loss of a loved one, the dominant approach to grief communication fails to attend to the specific context of the bereaved. Several authors have pointed to the importance of the context to be able to understand stories or the act of storytelling (Gilbert, 2002; Fiese & Wambodt, 2003; Neimeyer, 2001; Rosenwald & Ochberg, 1992; Sedney et al., 1994). A more contextualized view would, at minimum, entail the consideration of the combination of contextual factors such as the uniqueness of the bereaved individual (e.g., Davis, Lehman, & Silver, 2000; Stroebe, Schut, & Stroebe, 2006), the person of the listener as a co-narrator (Bavelas, Coates, Johnson, 2000; Burke, Neimeyer, & McDevitt-Murphy, 2010), the relational context in which one shares with others (e.g., Kissane et al., 2006; Kissane, Lichtenthal, & Zaider, 2008), the moment of communication (e.g., Kamm & Vandenberg, 2001) and the content of what is being shared (e.g., Capps & Bonanno, 2000; Finkenauer & Rimé, 1998). Considering these contextual factors, the adequacy of storying or sharing grief might sometimes be questioned, whereas maintaining a discreet silence about one's loss experience might well be an adaptive response in some instances, much as moments of silence in psychotherapy have been found to be adaptive as well as obstructive to the therapy process (Frankel, Levitt, Murray, Greenberg, & Angus, 2006).

In this paper we want to approach communication as a process between people over time. We specifically will focus on the meanings of talking and silences in a *dialectical*, *dialogical* and *dynamic* approach. These features are undoubtedly intertwined with each other. However, for purposes of discussion, we chose to discuss them separately. As an illustration of this view of communication, we will make use of a case study of a newly formed family experiencing the loss of a child. As the family lives in the Flemish portion of Belgium, the interviews, letters and journal entries on which we draw were originally in Dutch, and translated by the first author, who was also the interviewer.[1]

An illustration: The case of Hilde and Koen

Hilde, a 44 year-old grieving mother, lost her son Jasper to brain cancer 11 years ago when he was 13 years old. Five years before his death, Jasper's parents divorced. Both Jasper and his sister Emma, who is two years younger than Jasper, lived with their mother. One year after the divorce, Hilde started a new relationship with Koen and together they had another child, Julie, a third child for Hilde, a first child for Koen. Three years later Jasper was diagnosed with brain cancer. During the period of chemotherapy and surgical operations, Hilde tried to be with her son as much as possible, while Koen mainly took care of the household and the two other children. It was a difficult period for the family, but they kept hoping and they tried to have family life continue on as usual. After approximately 18 months of anguishing efforts to defeat the illness, Jasper died.

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[1] The story of Hilde and Koen (pseudonyms) has been the subject of an intensive case study comprised of both a thematic and a narrative analysis of the experiences of this family after the loss. This case study is based on an in-depth interview, supplemented with letters Hilde wrote to Jasper during the first years after his death. This study is part of a broader institutionally reviewed and approved research project on the experiences of parents sharing grief with each other after the loss of their child to cancer. Although our research question involves the partner relationship, in this case study we will mainly focus on the mother because of her position as a single mother to Jasper. The family has given informed consent for the (disguised) use of their interview responses.

Grief communication as a dialectic process

“I controlled what has to be controlled in our culture: raw emotions are not nice to look at, expressive pain is annoying to others. We tried hard to spare each other. Mainly, we remained silent about the unspeakable. It is one of the most persistent paradoxes that I keep struggling with during all my reflections: the stereotype that "words fail" is completely right in my opinion, but on the other hand (at least in our culture) exactly those same words are the only way not to disconnect from everyone… I do remember attempts to describe the 'wasteland' on the inside. ... The only intention [of talking] is that bridges are made, that moments of connection can be created”.

With these words Hilde expresses the internal conflict she feels about verbalizing her emotions. On the one hand she draws on metaphors to express how she feels, to feel connected with others (attempts to describe the “wasteland” inside, so that “bridges are built” between her and others), and, at the same time, there are things that restrain her from doing so. She does not want to annoy other people. She wants to spare her family members from this pain, a stance that for her expresses core Flemish values of “being strong” and managing ones own emotions, a cultural attitude widely shared in northern European, North American, and other English-speaking societies. More than that, she acknowledges that “words fail to express the unspeakable.” How can one express such a devastating experience as the loss of a child? Grief, as a multifaceted phenomenon, is beyond words.

Viewed in a dialectical framework, the phenomenon of self disclosure is broadened to focus on the inherent tension between ‘openness’ and ‘closedness’, in an ongoing interplay with one another (Baxter & Montgomery, 1996; Toller, 2005). There is a natural and ongoing tension between the wish to be open and share with others, and at the same time the desire to keep thoughts and feelings private. The same dialectical contradiction between being open and being closed can be found in Toller’s study (2005), examining how bereaved parents experience communicating about their deceased child with individuals in their social network. The parents in Toller’s sample chose to share their grief with friends and family members, and at the same time most of them were hesitant to be open as they were afraid of the potentially negative reactions of others, a very real and painful prospect as research by Burke and her colleagues (2010) documents. This internal conflict or ‘ambivalence over emotional expression’ (King and Emmons, 1990, 1991), which is better characterized by the competing goals of wanting to show how one is feeling yet fearing the consequences of such self expression rather than the simple absence of emotional expressiveness, has been shown to be detrimental to subjective well-being in several studies (Katz & Campbell, 1994; King, 1998; Mongrain & Vettese, 2003; Tucker, Winkelman, Katz, & Bermas, 1999).

Grief communication as a relational dialogical process

Based on the work of the Russian social philosopher Mikhail Bakhtin (1986), the relational approach of Baxter and Montgomery (1996) situates the unfinalisable tension between openness and closedness on a relational level. From a dialogical perspective, the contradiction is situated not only in the individual persons, but also in the communication between relationship parties (Baxter, 2004). Baxter recognizes a constant tension in relationships between the two contradictory needs: the need for disclosure (openness) and the need for secrecy (closedness). She relies on some of Bakhtin's (1981, 1984) concepts, especially his idea that language is the product of dynamic, tension-filled processes in which two tendencies are involved: *centripetal* (centralizing, unifying) forces and *centrifugal* (decentralizing, differentiating) forces. Contrary to Hegelian dialectics that prescribes the finalization of dialectic tensions in a synthesis, Bakhtin contends that these dialogical processes are unfinalisable, and the tension between the two opposing forces never finds a solution. As Baxter writes, "This view stands in sharp contrast to dominant approaches to relational communication…[that] have articulated the grand narratives of connection, certainty and openness" (Baxter, 2004). In these traditional "modernist" approaches to relational communication, autonomy is linked with distance and secrecy between partners. Openness is linked with relational intimacy and closedness is viewed as problematic and unhealthy. From a dialogical perspective, however, these traditional ideas underestimate the importance of the continuous dynamic interplay of centripetal and centrifugal forces in relationships, as well as the uniqueness of every moment and the shaping force of the time and place of the dialogical exchange.

In the case of Hilde and Koen, Hilde remembers attempts to describe what she feels, to make a connection with Koen in her grief, not to be alone in this suffering, to create a communal story, but at the same time this grief often felt like *her* grief. *"It was no subject of conversation anymore, it was my inner life… it was my territory…."* Remarkably, while struggling with what she called her "*internalized grief*" (in Dutch: "*verinnerlijkte rouw*"), both Hilde and Koen wrote letters to each other. In one letter Hilde asked Koen's permission to find a way out of her grief on her own. She proposed to Koen: "*Let me find a way out, I ask you to allow me the freedom and the space…*". In turn, Koen wrote a letter to Hilde in which he asserted that he had "*faith in her heart and in her mind*", and that he trusted her ability to find her own way to cope with her grief. The freedom she needed to be able to concentrate on herself, and not connect with others, was a freedom they negotiated in connection with each other. For Hilde, Koen's trust was important: *"Maybe [your trust] will save me: it makes a difference if there is someone who believes that it will get better*". In a sense, they connected in their agreement not to connect in this grief.

When dialogue about the loss does occur, the listener is viewed as actively present in the moment (Bakhtin, 1986). The act of storytelling is an interactive co-constructive process, in which the listener could be considered as a co-narrator (Bavelas, Coates, & Johnson, 2000). All interact with one another, both verbally and nonverbally (Gilbert, 2002; Nadeau, 1998, 2008; Riches & Dawson, 1996b; Rosenblatt, 1994). All utterances are connected with past utterances and invite other utterances in a dialogical chain (Bakhtin, 1986). In contrast to a traditional understanding of emotional disclosure, in which the emotion 'to be told' is already a completely formed story that can be articulated to a neutral listener, from a dialogical perspective the story unfolds in the moment and all participants (storyteller as well as addressees) in the dialogue contribute to the unfolding story. In an ongoing dialogue, a story is being made together; meanings are being co-created, resulting in a new story, that is unique and unrepeatable (Bakhtin, 1981; Gergen, 1999; Nadeau, 2008).

Referring to the interaction and interdependence between the interlocutors, Baxter and Montgomery (1996) use the concepts of 'openness *to*' and 'closedness *to*' to specify the degree of receptivity and responsiveness toward another's disclosures. One person's 'openness with' is interdependent with the other person's 'openness to' (Baxter & Montgomery, 1996). Similarly, in the bereavement literature, various authors have pointed to the importance of the responsiveness of the listener for the bereaved to be able to emotionally disclose his or her feelings of grief (e.g., Burke, Neimeyer, & McDevitt-Murphy, 2010; Mancini & Bonanno, 2006). Perceiving the listener as receptive, supportive and willing to help (Kelly & McKillop, 1996) or discreet and non-judgemental (Mancini & Bonanno, 2006) is crucial in explaining the beneficial effects of sharing one's grief.

For Hilde and Koen, talking with each other was often difficult. Sometimes one of them wanted to start a conversation about the difficult time since Jasper died, while the other was hesitant or was not receptive at that time. In one of her letters to Koen, she regrets the moments that he was unable to listen: *"Sometimes I tried to ask you to be with me in my pain, to listen and watch my pain. You couldn't" (p 49).*

The first years after Jasper's death, the couple described a relational climate that was '*suffocating*' for all family members, making it very hard or even impossible to talk or listen. Hilde stated: *"A family is very small, very closed…. We couldn't breathe in our house… there was no air…. Sometimes I think grief is suffocating."* Explaining what she means by this suffocation, she added: *"It is suffocating inside, for each of us…. We did not succeed in [talking], we could not clear the air in a way that we could talk about it".* Pointing to the interactional dynamics in this, Koen replied*: "When [the silence] lasted too long, you [Hilde] got nervous. When you [Hilde] wanted to talk, she [her daughter] shut down."* Clearly, the interactional process was much more complex than one person simply wanting to share her/his grief with the other, while the other was not willing or able to listen. In their relationship with each other, they all struggled with a continuous interplay between unifying and differentiating forces in the context of a ‘grief-suffocating climate’.

Grief communication as a dynamic process

Every dialogue takes place in a specific temporal-spatial context. Referring to Bakhtin’s notion of ‘chronotope’ (Bakhtin, 1981), Baxter states: “Communication is always situated in historical, environmental, cultural, relational, and individual chronotopes, or contexts. The chronotopic nature of communication obligates researchers to take both sociospatial and temporal contexts into account” (Baxter & Montgomery, 1996, p 44-45). Every act of communication or silence must be understood in its context of time and space. When and where do they occur? What was said previously? What is anticipated to happen next? Who is present, who is not? What is the relational context? And so on.

Grief and grief communication is a process in time. The intensity of grief processing (thinking about the deceased, searching for meaning and positive memories of the deceased) declines with time (Holland & Neimeyer, 2010; Pressman & Bonanno, 2007). The desire to talk about the loss with others and the perceived benefits in doing so can change over time as well (Kamm &Vandenberg, 2001; Luminet, Bouts, Delie, Manstead, & Rimé, 2000; Zech, Rimé, & Pennebaker, 2007).

Hilde and Koen, looking back on their grief communication, portray a search process that unfolded over time. How they approached each other was different in the beginning than it is now. Hilde recounts that in the beginning, when Jasper was hospitalized, *“I didn’t have much to say. I could not talk about it. Nor did it do me any good….”* After Jasper died, they describe some very difficult years struggling to stay emotionally connected with each other. Hilde needed time on her own, “*to be able to breathe*”. When she was on her own, in silence, she didn’t feel the “*pressure to be whole*” as much. “*Being on my own, I could just be broken*”. At times though, Hilde felt lonely and regretted the difficulties in sharing their grief with each other. At other times, they both felt inner calm not expecting the other to be the conversational partner any longer, “*adjusting the expectations… a kind of frustration about unmet expectations faded away*”. Instead of talking, she started to write letters to her dead son. Koen had built an attic room for her so she could be on her own with Jasper, undisturbed. In this room, Hilde felt the space and peace she needed. This was a place where she could stay connected with Jasper. She experienced her monologic communication with her son as helpful: “*Verbalizing unspoken thoughts and feelings… to create some space for the chaos in my head*”. After some time though Hilde felt the pressure to go on with life and to connect with her family: "*Being torn [between Jasper and my family] and the incompatibility of the love for a dead child with the love and care for a living family*." In recent years Hilde and Koen have started to reconnect again. After almost ten years Koen states: "*By now, fortunately, we've come that far to be able to talk in a serene way about [the loss]".*

More than simply an evolution in their *way* of sharing, they also experienced an evolution in the *meanings* given to their sharing and not sharing over time. What was painful and disappointing at one time, was experienced as meaningful and constructive at another time. Not being able to share her feelings with her husband, Hilde early on felt lonely and frustrated. "*Back then, the decision to internalize my grief was born out of frustration"*. However, looking back, Hilde says, this decision was also a strategic one, to save their couple relationship. She describes how it was important for their relationship that she found a way to stop expecting Koen to be there for her as a conversational partner. By internalizing her grief she saved the family from the burden of her unspeakable sorrow. Remaining silent about the pain and the grief over the loss of Jasper, Hilde let daily life take its course, omitted the grief as an obstacle from family life, offering space for her family to start again and to heal. As Hilde noted in the interview: *"For us, [internalizing my grief] was the best way to go on living as a family, and to give our relationship and our family a future."* New opportunities were created for them as a couple to connect. In spite, or maybe because of remaining silent or not sharing grief with each other, they felt that they succeeded in saving their relationship.

DISCUSSION

Ironically, perhaps, communication traditionally has been approached in a monologic way. Most often, scholars have only studied communication, expressiveness and self-disclosure without considering the dynamic interplay with other forces pulling towards silence, withdrawal and closedness. Therefore, Baxter and Montgomery (1996) propose to 'rethink communication' and argue for the 'both/and' interplay of openness and closedness in personal relationships. "The utterance is a complex phenomenon in which the said and the unsaid, the free and the constrained, and the inner and outer of speaking come together in a moment of interaction" (p. 151).

Equally, studies in the field of bereavement on the effectiveness of self-disclosure (e.g., Zech, Rimé, & Pennebaker, 2007) and communication between family members (e.g., Walsh & McGoldrick, 2004) have not considered those forces leading the bereaved towards remaining silent or *not* communicating with others. While many scholars in the bereavement and family literature point to the importance of sharing grief in order to create a stronger bond, a sense of togetherness and relational intimacy (Cook & Oltjenbruns, 1998; Gilbert, 1989; Gottlieb, Lang, & Amsel, 1996; Hagemeister & Rosenblatt, 1997; Sedney et al., 1994), only few of them also mention the importance of taking a balanced view of the degree to which talking or not talking is beneficial for individual couples or families (Kissane et al., 2006; Rosenblatt, 2000a, 2000b).

In this paper we argue for considering the complexity of the process of couple communication in the context of bereavement. Rather than approaching grief communication as a necessary condition for all grieving couples at all times, we propose to consider the contextual factors, ambivalences and relational tensions at a specific moment in the grieving process of the individuals and relationships involved. Describing the dialectic, dialogic and dynamic features of grief communication, we have concentrated on the act of verbalizing one's grief towards the partner. However, we could reasonably question the necessity of the spoken word in order to connect with others in grief. Emotions also obviously can be expressed in nonverbal ways (Hughes, 2009), which might be as crucial to emotional connection with relevant others as the spoken word. As in the case of Hilde and Koen, words can fail to express the unspeakable. What it feels like to lose a child is beyond words. Still, it was important for them that moments of connection were created. Koen's expression of trust in Hilde's way of grieving, verbally, in a letter to her, and nonverbally, by building an attic for her where she could connect with her dead son, were most important.

Additionally, we could wonder about the cultural aspect of grief communication and emotional communication. Would it be more typical for bereaved Flemish people specifically, or people of northern European descent more generally, to connect in a nonverbal, silent way, than it would be for bereaved parents from other cultures? Regretfully, little is known about the way one's sociocultural context shapes and informs the social sharing of emotions (Singh-Manoux & Finkenauer, 2001). Although no significant differences are found for the rate of social sharing across European, Asian and North American samples (Rimé, 2009), Singh-Manoux & Finkenauer (2001) found that cultural background was reflected in the social sharing patterns of English and Indian populations. "Macro" dynamics in the social construction of bereavement clearly deserve greater attention on the part of scholars, researchers and clinicians (Neimeyer, Klass, & Dennis, 2010).

CLINICAL IMPLICATIONS

A traditional approach, unilaterally promoting the expression of grief, fails to acknowledge the dialectic, dialogic and dynamic features of grief communication. For therapists working with bereaved families it might be useful to try to create a space and opportunity to explore with family members the possibility of sharing their grief experiences with others, while simultaneously acknowledging the difficulties of sharing and the good reasons family members might have to not share their experiences (Rober, 2002, 2006). This would mean that the clinician makes room to 'talk about talking' (Fredman, 1997) and attend to the possible tensions and hesitations (Rober, 2002, 2006) involved in sharing. How would it be to share your grief with others? Whom would you like to share your grief with? Which grief experiences would be helpful for you to talk about, and which wouldn't? How would you like to share and what ways of sharing would be more difficult for you? What do you feel you might gain from not talking about your feelings?… and so on. In this exploration it could be important to recognize that it might be valuable for them not to share some (or all) feelings or thoughts, some (or all) of the time, with some (or all) 'listeners'. This corresponds with Toller's study (2005) in which bereaved parents taking control of communicative situations and being selective in their disclosure is central. In families, different members often take opposing positions on the usefulness of sharing their grief. This highlights the tension between sharing and not sharing within the family. This tension is constantly present as an important undercurrent of daily family life. Rather than encouraging all family members to share, and thus exclusively joining with those who predominantly feel the need to share, we propose that therapists explore the complex dialectics of expression and non-expression (Baxter, 2004) and attend to the different viewpoints of the family members. A better understanding of the possible risks associated with sharing as well as of the wish to remain silent about some things towards some people may lead to an increased tolerance for the differences within the couple or family.

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“We hardly ever talk about it”: emotional responsive attunement in couples after a child’s death.

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ABSTRACT

Within Western cultural traditions, the idea that parents should talk about the death of their child with each other is deeply rooted. However, across bereaved parent couples there are wide variations in communication about their grief with each other. In this study we explored the experiences of bereaved couples related to the process of talking and not talking. We used a thematic coding approach to analyze twenty interviews with twenty-six bereaved parents (eleven interviewed as couples, four as individuals). Four main meanings emerged out of our analysis: not talking because of the inadequacy and pointlessness of words in grief, not talking as a way to regulate emotions in daily life, not talking as an expression of a personal, intimate process, and not talking because the partner has the same loss but a different grief process. In addition, we found that the process of talking and not talking can partly be understood as an emotional responsive process on an intrapersonal and interpersonal level. In this process partners search for a bearable distance from their own grief and their partner's, and attune with their relational context. A better understanding of this process is sought in a dialectical approach, emphasizing the value of both talking and not talking in a tense relationship with each other. Implications for clinical work are described.

INTRODUCTION

“We tried hard to spare each other. Mainly, we remained silent about the unspeakable. It is one of the most persistent paradoxes that I keep struggling with during all my reflections: the stereotype that ‘words fail’ is completely right in my opinion, but on the other hand exactly those same words are the only way not to disconnect from everyone” (Hooghe, Neimeyer, & Rober, 2011, pp.910-911).

With these words a bereaved mother pointed to the complexity of grief communication. While words are needed to connect with the partner in the grief process, still something seems to pull towards silence and withdrawal.

The general presumption that talking about grief experiences is a necessary part of everyone’s grief process and that not talking is harmful fits within our Western cultural traditions. In Western cultures encouragements like ‘you’d better talk about it’ or ‘silence kills’ are ubiquitous and deeply rooted. However, across bereaved parent couples there are wide variations in communication about their feelings and the child who died (Rosenblatt, 2000a, pp.88-95)

A theoretical model emphasizing the value of both talking and not talking in a tense relationship with each other is the dialectical perspective on communication in personal relationships (Baxter, 2011; Baxter & Montgomery, 1996). This perspective is inspired by the work of the Russian philosopher Mikhail Bakhtin, who stated that in the uniqueness of every moment there is a continuous tension between two opposing forces, the centrifugal force (openness) and the centripetal force (closedness). Both forces are continually present, as they co-exist in a constant tension that is never resolved (Bakhtin, 1986). According to this perspective, people feel the wish to be open and share with others, while at the same time they also want to keep thoughts and feelings private. What is actually said between people is the momentary result of such dialectical processes.

The dialectical perspective has also been introduced in the grief literature (e.g., Hooghe, Neimeyer & Rober, 2011, 2012; Toller, 2005; Toller & Braithwaite, 2009). For example, in a study of bereaved couples Toller and Braithwaite (2009) found two dialectical contradictions: one between trying to grieve together as a couple and apart as individuals, and another between being both open and closed when talking with one another about their child’s death. Openness to one another was perceived to be essential, but embracing closedness in order to give space to grieve as individuals was found to be equally necessary. Similarly, Hooghe, Neimeyer and Rober (2011) argued for considering the complexity of the process of couple communication in the context of bereavement, acknowledging the dialectic, dialogic and dynamic features of grief communication. They found these opposing forces in a case study of a bereaved couple (Hooghe, Neimeyer, & Rober, 2012). The interaction of both forces resulted in dynamic ways in which the bereaved couple tried to stay close to the memories of the child and at the same time found some distance from agonizing pain. Finally, Rober and Rosenblatt (2013) questioned if simple dichotomies (openness - closeness; talking - not talking; etc.) can capture the complexity of family communication. They proposed the concept of ‘systemic emotion management’ to describe the way the dialectical process of speaking and keeping silent is enacted in family communication about loss.

Our study

In this study we aimed at a deeper understanding of the different meanings and processes related to not talking with the partner about personal grief experiences after the loss of a child. While we acknowledge the importance of open communication, we don’t want to underestimate the importance of not talking and silences in the grief process. Both talking and not talking are seen as part of a dialectical process. We defined ‘talking’ as verbally communicating with one another. We defined ‘their individual grief process’ as all the thoughts, emotions and behaviors related to the death of their child.

METHOD

Participants and Data Collection

For this study we collaborated with the child oncology department of the University Hospital in Leuven, Belgium. Thirty Dutch speaking couples who lost their child to cancer in this hospital between 2003 and 2007 were contacted by letter asking if they would be willing to be interviewed about their grief process. Two weeks after they received the letter they were contacted by phone by one of the psychologists from the oncology department. The purpose of the study and confidentiality were explained. Twelve couples agreed to be interviewed, in addition to two mothers who wanted to take part even though their partner did not want to participate, and one couple only wanted to participate if they could do the interviews separately. They agreed to have their names and contact information given to the researcher, who then contacted them to arrange a first interview. In total, twenty-six parents participated, fourteen mothers and twelve fathers, between age 36 and 53, all living in the Flemish part of Belgium and culturally Flemish. Three of the couples were interviewed twice and one was interviewed three times, so in total the eleven couples and four individuals provided a total of twenty interviews. In sixteen interviews both parents (married) were present, in three interviews only the mother participated (one divorced mother, one mother was interviewed alone because the father chose not to participate, and one mother was interviewed alone because this couple chose to be interviewed separately), and in one interview only the father was present (whose wife was also interviewed separately). The deceased children were between 6 months and 18 years old, after a time of sickness between three months and eight years, and all died of cancer (brain tumor, leukemia, kidney cancer).

Between May 2009 and Dec 2011, the first author carried out all the interviews. All but the first interview was at the home of the interviewees. The first interview was carried out at the university hospital, and in that interview both the first and third authors were the interviewers. For each of the first four couples we made a restoried story (McCormack, 2004) based on what they told us about the subject of not talking. We contacted them again asking them if they would be interested in receiving this story and we requested a second interview. They all agreed and gave feedback on the story we made. One couple was interviewed for a third time. In this third interview, a Tape Assisted Recall Interview (TAR, Elliott, 1986, 2004), we looked back at the video recording of the interview from the previous evening. Both partners as well as the interviewer stopped the tape at times they wanted to add/ask about unspoken reflections at a certain moment. These reflections yielded insights into the meaning of their interactions, including silences. These second and third interviews are also part of our data, and analyses. All interviews started with their story about the deceased child, how they learned about the diagnosis, how the treatment evolved and the ultimate dying. Gradually we asked for relational dynamics in their grieving processes, and more specifically how they could talk to each other, or how we could understand why they chose not to. Examples include, "how was it during those first days to share your grief with each other?" or "can you help us understand why you prefer to go to the graveyard by yourself, in silence?" or "what makes it difficult to talk to each other at moments like that?"

Analyses

In this study we aim for a better understanding of the process through which partners construct and interpret their own social reality in the context of shared realities, fitting a social constructionist underlying epistemology (Reczek, 2014). Rather than testing specific hypotheses, we inductively coded the data. All categories emerged out of the data and no predetermined categories were used.

Based on the video-recordings, the interviews were transcribed verbatim in Dutch. In preparation for the analyses, the first author watched the video files of the interviews several times in order to be fully immersed in the narratives. Simultaneously the transcripts were completed with notes about nonverbal behavior, and silences. Statements and sentences that seemed essential, revealing and/or surprising regarding the theme of talking and not talking about grief experiences with the partner were identified and marked. Subsequently, a thematic coding was done on all transcripts, one by one, using MaxQda software Version 2 (2007). The first author identified descriptive categories that emerged through the line-by-line coding and the constant comparative method, assessing meaning units and categories for similarities and differences (Glaser & Strauss, 1967; Strauss & Corbin, 1998). This resulted in a hierarchical coding structure, with categories and subcategories reflecting the meanings related to not talking with the partner about grief experiences. During the coding process the hierarchical code system became more complex. New codes were created, and categories became more nuanced, resulting in a hierarchical structure with 6 levels of coding/subcoding. Often, meaning units were assigned with more than one code. For example, a father explains that he mostly avoids talking about his grief because "*then I feel sad, and then she gets sad too. Then we are both sitting here in a sad atmosphere*". This meaning unit was coded with three different codes and subcodes: 1.'Not talking to create some distance from the pain of grief' with subcode 'Talking makes me feel bad', and 2. 'Not talking to create some distance from the pain of grief' with subcode 'Talking creates a negative atmosphere', and 3. Not talking because the partner has the same loss but a different grief process, with subcode 'Not burden each other's grieving process'. We achieved theoretical saturation after analysing the transcripts of eighteen interviews (fourteen interviews with nine couples, and four interviews with four individuals). Two more interviews were coded but these data did not yield new categories, which confirmed the theoretical saturation (Charmaz, 2006).

In order to verify the credibility and trustworthiness of this analysis, we incorporated an extensive auditing process (Hill, Thompson, & Nutt-Williams, 1997; Rober, 2004). When the coding was finished, the first author gave a detailed report to three external auditors (all experienced psychologists and family therapists). Independent of each other these auditors read the report and reviewed the overall category structure for coherence⁄consistency as well as elegance⁄nonredundancy. All meaning units were audited for their fit into the category to which they were assigned. All three auditors then provided feedback to the first author, who used this feedback to modify the category system and the assignment of meaning units. Then a second report of the category structure was made and again sent to the three auditors. After this second round in the external auditing process we reached an overall consensus about the report. A total of 471 meaning units were coded, and 117 codes were given.

While in the process of writing this paper we went back to the data of the interviews, and carefully re-examined the meaning units and codes previously given. This resulted in a reordening and renaming of some categories.

FINDINGS

All parents who were interviewed differentiated between talking about the child (or reviving memories of the child) and talking about their grief process. They all emphasized the importance of remembering the child and keeping their child present as life continues. However, talking with each other about how they felt in their grief was subject to much more complexities.

Our analyses revealed four main meanings related to not talking: 1. not talking because of the inadequacy and pointlessness of words in grief, 2. not talking to create some distance from the pain of grief, 3. not talking as an expression of a personal, intimate process, and 4. Not talking because the partner has the same loss but a different grief process.

Not Talking Because of the Inadequacy and Pointlessness of Words in Grief.

Several parents said that for the horrendous experience of losing a child words fail: These parents said that the experience of losing a child cannot be conveyed in words:

> Father: "*I can express how I feel, I can show it, but the feeling that is beneath my tears is something impossible to convey*." *"I would not know how to put it in words."*

Moreover, most parents also mentioned the pointlessness of words. Some parents said that there was no point in talking about their feelings again and again. The feelings do not change.

> Mother: *"His life stopped. What's more to say? You can't keep saying it. All the things are said so many times already."*

Many also expressed the fact that talking will not bring the child back:

> Mother*:"…so, what's the point in talking about it? It doesn't help."*

Not Talking to Create Some Distance from the Pain of Grief.

All the parents talked about a tension between the enormous pain of the loss and the inevitability of ongoing life (in which there is a need to protect oneself from the pain in order to go on).

> Father*: “… I’m working, and then she wants to say something, … I don’t want that at that time, because … there’s no way I can keep on working [if we would talk] …”*

For both mothers and fathers, talking is often experienced as the stirring up of painful things. This disturbs the rhythm of daily life and therefore it is avoided. Talking about it is “too painful,” “too confronting;” ‘too exhausting” and “makes it all harder.” One father compared his grief with an emotional core, protected by a crust. He said “Imagine that you would ask me to talk about the time when my daughter was sick, or the moment of death or something, then I feel I am piercing through that crust.” Another father used the metaphor of a full bucket “as long as the lid is on it, it’s ok. But if the lid goes off, then it splashes out.” Often in order to move on in daily life, grieving parents prefer not to pierce through the crust, or take the lid off the bucket.

Some parents talked about avoiding the pain of the loss because they don’t know how they will end up, maybe not being able to function for a few hours or days. More than only a moment of disturbance, the confrontation with the pain of loss was also described by some as something that can reverberate for hours. Father: “When we talk about it in the evening, and then we go to bed, then that’s a hard blow. When you wake up in the morning, then again you think about it. Then you keep thinking about it all day long.” Talking brings the deep pain to the surface, and then some parents need time to recover. Therefore, not talking about their grief is experienced as a way to regulate emotions in daily life: to keep the pain at a bearable distance. A continuous search for this bearable distance is something that some bereaved parents said they needed to do for themselves, not being burdened by the grief process of the partner.

Furthermore, for some parents, this keeping away from their most painful feelings, also represents a basic philosophy, or like a father says, “we need to go on, there is no use in standing still.” This way of thinking is often strengthened by the memories of their sick child courageously struggling with the illness. Or as one mother expressed it “Our daughter fought, she fought tremendously. And all the messages she gave were positive. On her last card for Mother’s day she wrote “my love will keep growing”. That’s what we wrote on her grave. So, yes, that was her motto “Stay positive!” And yes, that is something from her I want to carry along…”

Not Talking as an Expression of a Very Personal, Intimate Process

While at times these parents feel the need to avoid the grief in order to go on with daily life, at other times they feel drawn to feel closer to their child, and immerse in grief. This intensive grieving over the loss of their child is experienced as something very personal.

> Mother: *"And then, at night, when I'm in my bed, then I can let myself go. Then I cried, when nobody was around. I rather do that on my own, just like he [the father] does."*

Many parents described how they often physically isolated themselves because they preferred to grieve on their own, when they are home alone, or a place where they can cry on their own. One father explained: "It's not like we have to hide something from each other, but often one is so much in one's own realm of thought." Withdrawing from others and shrinking into oneself was described as a personal and preferred choice:

> Father: *"I like to grieve on my own, while I am cooking or while I'm in my car or so."*

Some bereaved parents used possessive pronouns to describe their grief.

> Mother: *"This is MY pain, this is MY grief."*

Grieving moments were then described as private moments, something they felt entitled to. Some parents said that they felt more in control of their grief process (for example, being able to control the moment and the intensity more) when grieving in this isolated and private way, "Asking questions to myself at the moment I feel ready for it, being able to dose it myself." At some point, this father added, "You become your own partner in the dialogue." Sometimes having a moment in which one could feel lonely and sad was a deliberate choice. Like a mother said, "Sometimes it's a choice. Then you choose to feel lonely, just shutting out everybody.", and she added "I need these moments to be involved in it, even if it makes me feel bad." The grief was experienced as something deeply inside and too intimate to share with others, or as a father expressed it "I think that is too intimate, so intimate, it's really something deep inside yourself." Some parents especially need isolation from their partner. For them, talking to others is easier, as they are not in the same pain.

> Mother: *"Then we are here with the two of us, both having tears in our eyes. That doesn't work. For me it's easier to talk to others."*

Importantly, these private moments were described as moments they shared with their deceased child:

> *"This is MY moment with [deceased child]."*

One mother talked about her daughter's room, where she has put a cd player, and *"then I listen to her cd, and that is my moment. My moment with her."*

Not Talking because the Partner Has the Same Loss But a Different Grief Process.

Both partners were confronted with the same process of their child's illness and the eventual death. Talking about their grief with each other was often experienced as very difficult precisely because both parents went through a similar experience (Gilbert, 1996). In our study four subcategories reflect different meanings of not talking with each other related to the fact that they both were grieving the same loss.

Respect and not burden each other's grieving process

According to the parents we interviewed, not talking with each other can be understood from a position of respect for each other. Some partners said that they wanted to respect the grieving process of their partner without interfering in it.

> Mother: *"I often sense what he is feeling, and then I'll leave him to it. I mean, I don't need to be there; he doesn't need me there, so I'll just leave him to do his thing."*

Moreover, they wanted to grant private grieving moments to their partner. Or as a mother said: "I think you need to grant each other the sadness."

In addition, all parents said they took care not to burden the other with their own grief, but instead they tried to spare the partner.

> Mother: *"We often protected each other, not talking about it not to hurt the other."*
> Father*: "We try to spare each other. You know each other's pain, but we don't say it."*

In addition, some parents said that they felt worried that the expression of their own grief would cause the grief of the partner to surface.

> Father: *"When I start to cry, maybe she'll start crying too. We don't want to burden each other with it."*

The uselessness of words

As both partners were grieving the same loss, talking about it was often experienced as useless, because words would not add anything to their communication. They knew each other's expressions and behaviors, and no words were needed to explain how they felt.

Mother: *"We don't always make those awful things explicit towards each other… I don't need to explain, he is the father."*

Sometimes the parents we interviewed found ways to share grief without explicitly talking about it. As the grief was often experienced as too raw, they sometimes addressed it indirectly. They hinted at it without going into it, both knowing they were talking about the pain of grief. For example, one couple talked about the urn of their deceased daughter, "Always when it snows I think 'Oh wouldn't she be cold in her little vase?' and then he says 'No dear' (Both laugh)… In that way we talk about her (Silence). … I think that is just a way to say something else."

Importantly, more than verbally sharing their grief, which they scarcely do, many parents emphasized the importance of an emotional connection to share grief with the partner. One couple, for example, described how they often sat in the room of their deceased child together, both doing their own things (he reading his paper, she ironing), without saying anything, but somehow connected to each other. Then the mother added, "We often understand each other without saying one word. Then we look at each other for just one moment, like, yes, again we are thinking about the same thing." Moreover, the silent physical contact can be of great value. Or as one father expressed it: "It's partly a matter of attunement. When one sees that the other is having a hard time, … a hand, a shoulder. Physical contact says a lot more than words." With these words, this father emphasizes the importance of an emotional attunement with the partner, communicated in a nonverbal physical way. Also, some parents expressed that they feel confident that, if needed, they would talk to one another.

Not enough distance from the pain of the partner.

Talking with the partner about one's own grieving process was experienced by some parents as difficult or even undesirable. Both partners are grieving the same loss and feel that the partner's process comes too close to their own grieving process

> Mother: *"I couldn't cope with someone else's grief, (to her husband) I cannot comfort you, I'm sorry, I would have liked to be able to, but no, I actually still need to go through my own things."*
> Father*: "I think we were not able to help each other…"*

Because of this lack of distance, some parents said that they felt that they could not help each other. The intense personal grief sometimes makes it impossible to be there for the partner.

Different grieving styles or moments

Many of the bereaved parents talked about the difficulty of talking with each other about their grief because of the different ways or times in which they grieve.

> Mother: *“When I’m feeling bad, he often is not. And when he is having a hard time, sometimes I’m not, so we both grieve on our own.”*

For some parents, such differences made it hard or even disruptive to share their grief. Both partners had their own moments in which they were intensely immersed in grief, while at other times they tried to go on with daily life and distanced their grief. Obviously these moments were not always in parallel for both partners. Talking about their grief with each other required some synchronization, or observing the partner and looking for some attunement to each other’s process.

> Mother: *“It has to match a little. It’s not because I am feeling bad that I need to involve her, because maybe she is busy and not struggling with it at that moment.”*

More than the differences in moments of grieving, some parents also pointed to the differences in communication styles, which made it hard or disruptive to talk to each other.

> Father: *“We just have a different way of communicating.”*
> Mother:*“It’s not always easy of course. I am a very open person and he is very closed.”*

Parents often experienced differences in the way they focused on the loss of their child or the way they avoided focusing on it.

> Father:*“I’m not saying that she has no pain anymore, but she can cope with it in a more objective way.”*
> Mother:*“I want to keep my son alive… while he [husband] finds it hard [to keep the child alive]; he cannot talk about it.”*

Because of these differences, some couples struggled. Talking about their grief with each other sometimes led to conflicts, which made it all even more painful.

> Mother: *“We start a conversation and it goes well until the point that the other says something which gives me the feeling: ‘No, this is not what I think or feel, not at all!’ I hope to feel listened*

> *to and have my own opinion without someone saying that it isn't ok, without getting that aggressive reaction. … Then I feel not listened to, and that hurts."*

In these arduous conversations, like this woman describes, one often did not feel listened to or understood by the other. What follows may become a painful fight,

> Mother: *"…a silent fight. No words are said anymore, and we don't talk to each other for the rest of the day."*

Another mother talked about her feeling of, at times, not wanting to live anymore since her son died. She used to talk about this feeling with her husband, but then he became angry.

"How can you say this, having three other children?" he said. Then she stopped telling him when she felt that way. *"I'm not telling him, because I know, well, that you (to husband) don't think that way. I don't want to be confronted with that, the fact that you don't understand that some things are difficult for me."* Not feeling respected in one's own way of grieving, or not getting the responses one hopes for, resulted, in time, in avoiding conversing with each other about their grief.

> Mother: *"Maybe, because I have felt misunderstood so many times, then I try, yes, to keep it for myself."*

Interestingly, some of these parents also described how they did not feel the emotional space to be able to listen to their partner.

> Mother*: "To be there for each other, both thinking so differently, requires that we can put our own feelings aside for a while, to listen to the other, and go with his feeling. I cannot go into things which I feel so differently, and I don't want to do it either, because I feel so much need to be listened to myself."*

Over time, for some partners, these differences and difficulties resulted in accepting the reality of not being able to talk about their grief with each other.

> Mother: *"I think we came to the point that we both gave up talking about it with each other. It's too hurtful and exhausting. … It's a pity, but I think I need to accept it."*

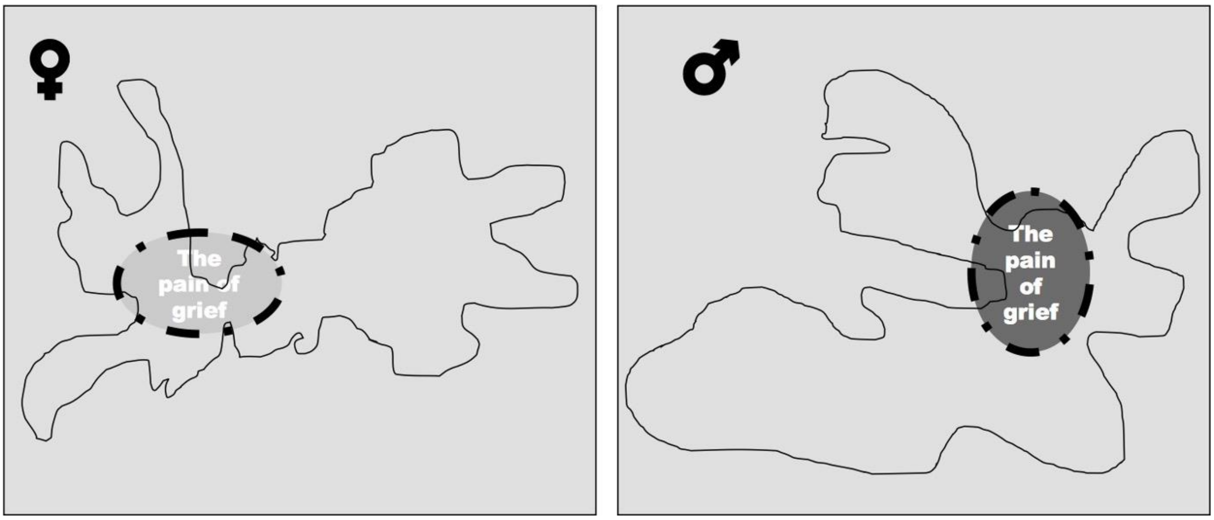
DISCUSSION

Our study contributes to a model of couple grieving in which talking and not talking are part of a dialectic process encompassing a continuous tension between the two. As the value of openness is widely recognized, in our study we were particularly interested in what bereaved parents told us about the meanings and circumstances of not talking to each other about their grief experiences. Many scholars in the grief literature have pointed to the challenges and difficulties in communication for the marital relationship of bereaved couples after the loss of a child (e.g., Oliver, 1999; Rogers et al., 2008; Rosenblatt, 2000a, 2000b; Schwab, 1992). The difficulty of grieving together and the challenges faced by grieving partners were also described by Toller and Braithwaite (2009). Although the participants in their study stressed the importance of grieving together, they also found this was difficult due to the different ways they approached and expressed their grief. Research on gender differences in bereavement has shown that woman generally confront their emotions more than men, while men use more avoidant coping strategies (Stroebe, 2001).

But the challenge of grieving together is not only a question of different grieving styles. It may also have other grounds. Some researchers for instance examined the avoidance of talking about the loss with the partner from the perspective of protecting the partner (Stroebe et al., 2013), in terms of conflict avoidance (Rosenblatt, 2000a, pp. 50, 91-92), avoiding blaming and pain (Rosenblatt, 2000a, pp. 68-69), and in terms of not feeling ready to talk (Rosenblatt, 2000a, p. 69).

In our study, we found that the process of talking and not talking could partly be understood as an emotional process of attunement on an intrapersonal and interpersonal level. On the intrapersonal level, attunement is a process of emotional regulation in which each partner continuously searches for closeness to the deceased child, while remaining at a bearable distance from the unspeakable pain to make life possible. For instance when a parent feels threatened to be overwhelmed by grief in a way that is too intrusive, or does not fit the here and now circumstances, feeling too close to the pain, then he/she may start to do something practical, or he/she may focus his/her attention on something that is not so emotional. In one of our interviews, one couple used the metaphor of “cycling around an emotional core of grief” to refer to this process of emotional regulation. For them it was a continuous search for the right distance: close enough but always careful not to come too close to the core or to stay close too long (see Hooghe, Neimeyer and Rober, 2012 for a description of this metaphor analysis). It is a continuous and restless process of moving closer and farther, never finding the right distance. It is always too close or too far. The word “attunement” used by one of our participants seems to capture the essence of this never-ending process, as it expresses its searching, trial-and-error character. It is a search for a balance never to be found, but responsive at every moment.

Figure 1



To be able to do this individual emotional attunement, these parents said they sometimes need some kind of withdrawing or isolation from the outside world. Not talking was a way to attune with oneself, and protect their own grief which felt too intimate to share, and too vulnerable to be intruded and possibly disrupted by someone else’s thoughts or emotions. Just because most partners were in a close attunement with each other (knowing each other that well that they could easily read each other’s emotion, and be influenced by it) they especially needed to distance from their partner, therefore choosing not to talk (too much) with each other. In this way they respected their own and each other’s need to withdraw, and tried not to burden, or be burdened by, the partner. One father, for instance, explained that whether they talked or not was often determined by how they assessed each other’s emotional state: “It depends where each of us is in the (emotional) roller coaster.”

The intrapersonal process of emotional regulation rests on an interpersonal process. In the couple, there was an emotional attunement on a relational level at times when they did talk about their grief, or interact with each other. Then, they were oriented towards each other and they attuned to each other. Our data suggest that each partner observes the other, and, in response, they attune to each other. Often, the observation and assessment of the other makes the partner hesitant to say something. Or a conversation may be stopped, because, for example, they want to spare each other, or because they feel like they need to respect the other in his/her emotional process. Like a father said: “…then I feel concerned that because I’m sad, that she would become even more sad then she already was at that time, and that we would intensify each other’s pain.”

Figure 2

Interestingly, sometimes partners can explicitly describe their own processes of relational attunement, but most often it seems to happen outside of awareness. Because most of the interviews we did were couple interviews, we could often observe this process during the interviews. For example, we could see how one partner kept an eye on the other and took over the conversation when the partner seemed to be having an emotionally difficult moment.

Remarkably, a similar attunement process could be observed in the way our participants initially responded when we invited them to be interviewed. Many parents immediately explored the circumstances of the interview, such as the place (most of them did not want to come to the hospital where their child died, because that would be too close to their pain), or the particular moment (often participants mentioned a timing that would be better or not appropriate, for example, not around an anniversary date, or close to a holiday or party), or those being involved (like some decided only to participate if the interview was not in the presence of their partner, and most couples mentioned that they would rather not have the interview when their other children would be around).

LIMITATIONS OF THE STUDY

Given our interest in better understanding the not talking of bereaved couples, it would have been particularly interesting if we would have been able to interview those who chose not to participate. If we would have had an extensive talk with them maybe they could have provided us with even more reasons why talking about grief may not be preferable. While we of course accepted their decision not to participate, we briefly inquired for their reasons.

Interestingly, the reasons they gave us correspond with the main findings from this study. For example, some non-participating parents said that they were not used to talking about it and that participating in an interview to talk about their grief did not fit with their way of coping with the loss, individually and as a couple. Moreover, some parents told us that they did not see the benefit or usefulness of this interview for their own grief process, or considered their words inadequate to express what they felt. Furthermore, most non-participating parents explicitly noted that they feared it would stir up too much of the pain around the loss. Finally, some parents also mentioned the fact that because this interview would be in the presence of their partner, it would be awkward or too difficult, as most of them hadn't talked about it with each other for a long time, or ever.

Another limitation may be the choice for predominantly doing couple interviews. We did 16 couples interviews (with eleven couples) and 4 individual interviews. There were some obvious differences between the two. For example, in couple interviews they often addressed the partner directly, and even asked questions to each other. Moreover, they sometimes took over the conversation at times when one started to cry. Maybe doing only individual interviews would have led to other findings. On the other hand doing couple interviews gave us the opportunity to witness the processes of talking about grief in couples. Furthermore, the use of couple interviews had the extra value of allowing us to observe the co-creation of the account, and partners eliciting accounts from one another (Reczek, 2014).

In this qualitative study we did not focus on gender differences. However, when we checked all the quotes in the different meanings, we could not note an explicit gender difference. Interestingly, this absence of gender differences was also found by Stroebe and colleagues (Stroebe et al., 2013) in their study on the avoidance of talking about loss and remaining strong in the partner's presence. They found similar patterns of avoidance of talking and holding back grief for the sake of the partner.

During this study we often wondered how the subject of not talking, and the tension between talking and not talking experienced by our participants, is also a cultural issue. Flemish people are generally known as not overly verbal or rather limited in emotional expressions. When asked about the meanings regarding not talking with each other about their grief, the bereaved parents often referred to a more general way of dealing with emotions as an individual and as a couple, namely being silent about one's emotional life. Although it would be very interesting to better understand how the cultural context may affect our findings, our study does not compare cultures, so it does not allow for any statements regarding the specific influence of culture. Perhaps there are cultures in which the dynamics of couple interaction are quite different from what was seen in these Flemish-speaking couples. Future research would have to explore that. However, the ideas in this paper may be helpful in understanding non-talk or little-talk in bereaved parent couples from many cultures.

In addition, we can also wonder about the possible dialogical dynamic between the interviewees and the interviewer (a psychologist), who is most likely perceived as someone who believes in the value of talking. It was remarkable how many of the parents in our interviews talked about not talking in an almost remorseful way. For example, one woman said apologetically at the start of the interview: "We actually never talk about it; maybe we should, but we actually don't." It is conceivable that this apologetic stance points to a cultural aspect of what is considered the preferred way of grieving in Belgium, as it is often voiced by psychologists and social workers.

CLINICAL IMPLICATIONS

Family therapists often try to help bereaved families and couples to create a safe space in which to explore and share meanings related to the loss (e.g., Hooghe & Neimeyer, 2013; Kissane & Bloch, 2002, Kissane & Hooghe, 2011; Nadeau, 2008; Shapiro, 2008; Walsh & McGoldrick, 2004). A better understanding of the multitude of meanings related to not talking about grief experience can help therapists to think about the challenges related to grief therapy for couples confronted with the loss of a child. As psychotherapy is in many respects a 'talking cure,' we believe that for a lot of grieving couples there may be an ambivalence regarding the quest for psychotherapy itself. Often, in clinical practice our clients tell about their hesitations to come into therapy to talk about their loss, because they fear they would be encouraged to share their most intimate grief experiences with the therapist and perhaps the spouse. They might well fear the surfacing of the pain as a consequence of talk. Moreover, they might doubt the usefulness of talking about their loss, realizing that this will not bring back the deceased.

As therapists, working with grieving parents, and the intensity and powerlessness that we often feel, we are also in this process of emotional attunement. Firstly, there is an attunement with our own emotions we need to regulate. Secondly, we need to attune with the processes of both parents and with the emotional climate in the couple.

Strengthened by the findings of our study, we think that it might be useful for therapists to presume the presence of this dialectic tension between talking and not talking in grieving couples. Rather than urging couples to be open about their experiences and talk about their feelings, or address the avoidance by confrontation, our study suggests that, in dialogue with our clients, therapists need to explore with both partners the meanings of both talking and not talking about their grief experiences, and the value of it in terms of connection. Moreover, we suggest that therapists should make room to reflect on the process of the individual and relational emotional responsive attunement as a dynamic way of grieving, rather than something that should aim for a fixed balance in all moments. This suggestion for psychotherapy equally comes from the feedback of the interviewees, who, after the interview, often reflected that the interview was a helpful conversation for them because, as one father said, "We actually never thought about how we do this, for ourselves and with each other. We just do it. We go on, without thinking about 'the how.'" A few weeks after the interview, one mother asked us for the videotape of the interview, so she could listen again to what her husband had said about his process, and the way he restrains for her sake. Also for this couple, the mother said, their talking during the interview about their processes of emotional attunement was new and helpful.

Thus, for some couples, grief therapy with both partners could be very valuable to help partners to speak and listen to each other in relation to their unique grief experiences and grieving styles. Often, when there is a lot of tension in the couple subsequent to the loss, it's helpful to offer them the time and space to listen to each other's experiences and meanings, creating an enhanced connection in talking and grieving together and/or in the greater validation and acceptance of the need to grieve apart. Sometimes merely the presence of the partner, with only one partner talking about their own grief experiences while the other one is primarily listening, can meet both partners grieving styles, while also contributing to a greater understanding and connection in the couple relationship.

Although we strongly believe in the added value of the presence of the partner or other family members as the natural support system in the grief process (Kissane & Hooghe, 2011), therapists should also make room for hesitations of the bereaved to talk to the partner. The findings of our study can also help us understand the dynamics of the frequent quest for individual, rather than conjoint, grief therapy, and the hesitations to bring one's partner or other family members to the sessions. Often grief experiences feel too intimate to share, or one or both partners want to avoid setting off conflict or one partner is protective of the other or one doesn’t feel this is the right time and so on. Importantly, as our findings show, often other people than the partner are easier to talk to, just because the partner is the one they automatically attune to. While being in a therapy session with one’s partner automatically draws one to a relational attunement, the absence of the partner can be experienced as a relief and opportunity not to keep an eye on the other. Or, as a bereaved mother says, “Here, on my own, I can cry out loud, with sound. I never do that while he (husband) is present, because then I’m immediately looking at his response and wonder how that affects him.” As a consequence, individual therapy is sometimes experienced as a safe, isolated bubble, away from their daily life and connections. One father conveyed this in relation to the interviewer: “I can talk to you [about my grief] because I will not see you in my daily life, and there is no need for further contact between us.” The hesitations to bring others, such as one’s partner, into therapy can thus be understood as an expression of being burdened by the grief of the other and their own attunement to it, or as an expression of the respect for the partner’s own grief process and the concern of burdening the other with one’s own grief. Consequently, therapy might usefully be carried out at times with both partners together, and at times with them separately.

Finally, our study points to the importance of sharing while words often fail. Sometimes partners said that they do not talk to each other about the loss of their child because words fail to express their pain. This illuminates the powerlessness of grieving parents to express in words what they experience, while at the same time they need to find ways to not feel alone. Indeed, our findings point to a distinction that needs to be made between talking about grief experiences in relationships and sharing grief as a way to connect with another. All bereaved parents in our interviews stressed the significance of sharing their grief with each other in a non-verbal way, without the necessity of spoken words. Holding hands, embracing each other, or just being together in silence is often experienced as a way of grieving together.

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"It's Hard to Talk When Your Child Has a Life Threatening Illness": A Qualitative Study of Couples Whose Child is in Cancer Treatment

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ABSTRACT

Confronted with something as fundamental as a cancer diagnosis of one's child, it is generally assumed that sharing the emotional impact of it, in the form of talking about it with the partner, is helpful and necessary in order to cope as an individual and as a couple. However, couple communication in the context of childhood oncology is often challenging. In this qualitative research, we aimed for a better understanding of how partners experience their couple communication during treatment of their child. Thematic coding was done on in-depth interviews with sixteen parents (seven couples interviewed together and two mothers). We found that the circumstances of this period ("Our life was on hold") were the background to understand couple communication in that period. The well-being of the child was their primary focus. In addition three main meanings were found related to the limited talking (1) because of the hospital and treatment context, (2) for self-care/self-protection related to the value of blocking of emotions, and (3) because of each other. Taken together, talking with each other was subject to an individual and relational attunement to what is contextually, emotionally and relationally feasible for these parents in this time. This research, framed in a dialectic approach, emphasizes the value of both talking and not talking in a tense couple relationship and adds in an important way to the existing literature, broadening the intra and interpersonal level, with implications for clinical work.

INTRODUCTION

A child's diagnosis and treatment for cancer has an impact on all family members (Kazak, Rourke, & Crump, 2003; Rolland, 2005). Families need to adjust to a new reality of an unexpected and life threatening illness and reorganize family functioning to the increased care needs, hospitalizations and aggressive treatments (Long & Marsland, 2011; Van Schoors et al., 2015). For parents, being the most important and present persons in the child's life, having a child with cancer is extremely challenging and emotionally traumatic. Ample research investigated the effects of childhood cancer on the individual adaptation of parents, their functioning and psychological distress (e.g., Gibbins et al., 2012; Grootenhuis & Last, 1997; Klassen et al., 2007; Van Schoors et al., 2017; Vrijmoet-Wiersma et al., 2008). Although it is clear that the couple relationship of parents becomes strained in this stressful time, research on the impact of pediatric cancer on the subsystem of the couple relationship is rather limited (e.g., Burns et al., 2017; Lavee & Mey-Dan, 2003; Silva-Rodrigues et al., 2016; Steffen & Castoldi, 2006; Wiener, 2016). Mixed results have been found in both quantitative and qualitative studies on the effects on marital satisfaction, emotional closeness, role changes, intimacy and couple communication. In their review, Van Schoors and colleagues (2017) concluded that overall most couples adapt well to the crisis of pediatric cancer in most domains, with an exception of the domain of sexual intimacy.

A recurrently studied domain in the couple relationship, indicated as a critical determinant of the impact of childhood cancer on the relationship, is communication between the partners (e.g., da Silva et al., 2010; Hall, 2010; Lavee & Mey-Dan, 2003; Wijnberg-Willams, 2015). Research is sparse and does not allow strong conclusions regarding the changes in communication patterns during the child's illness, nor its impact on the couple relationship (Van Schoors et al., 2017). Undoubtedly, being able to talk to one another can help a couple to connect emotionally, handle stress and know they can cope with difficult situations together (Wiener, 2016). However, communication between partners during the child's treatment can be challenging. This is in part caused by the physical distance between the partners, as one parent typically stays at the hospital and the other at home for the remaining family members and household chores. Moreover, the expression of affect in times of chronic illness may be suppressed, as one may be afraid to exacerbate tense feelings in other family members (Patterson, 1991).

But how do partners react to suppressing or avoiding conversations about their emotions? Manne and colleagues (2003) assumed that avoidance of communication between parents in the context of a child's illness would be detrimental to mothers' psychological adaptation, as it may inhibit the cognitive processing that may derive from talking with others. However, contrary to their predictions, they found that perceived partner avoidance was associated with decreases in maternal anxiety.

The complexity of couple communication in times of emotional stress has been addressed before in the grief literature (Hooghe, Neimeyer, & Rober, 2011, 2012; Toller, 2005; Toller & Braithwaite, 2009). A dialectic perspective on communication shows promise, as the value of talking and not talking in a relationship with each other is emphasized (Baxter, 2011; Baxter & Montgomery, 1996). In previous research related to the communication of parents after the loss of a child to cancer (Hooghe, Rosenblatt, & Rober, 2018) we found several meanings of not talking. The dialectical process of talking and not talking could partly be understood as an emotional process of attunement on an intrapersonal and interpersonal level (Hooghe, Rosenblatt, & Rober, 2018). In the same way, Rober and Rosenblatt (2013) questioned if simple dichotomies, like talking and not talking, can capture the complexity of family communication.

To our knowledge, no qualitative research has been done to explore the experiences of parents related to their communication with each other in times of a severe illness and treatment of a child.

Our study

In this study we focus on communication in couples who are challenged by the cancer of one of their children. We inquired with parents about their experiences related to their couple communication during cancer treatment of their child. With communication we mean the verbal exchanges with one another related to their emotions (e.g. fears and hopes) and thoughts about the child's cancer and treatment.

METHOD

From a social constructionist perspective (Reczek, 2014), partners construct and interpret their individual social reality in the context of shared realities. Our research can be similarly framed in a social constructionist perspective (Hill, Thompson, & Nutt-Williams, 1997), based on the idea that doing qualitative research is teamwork. In accordance with that philosophy our analyses were checked by independent external auditors who challenged our interpretations and checked if our interpretations were sufficiently grounded in the data.

Participants and Data Collection

For this study we initially collaborated with the child oncology department of the University Hospital in Leuven, Belgium. The psychologists of the department selectively invited parents whose child was in cancer treatment to participate in our study. Their first concern was with the well-being of their patients and their families, so they only invited couples for whom they thought an interview would not be too disturbing in their process. Other criteria were being Dutch speaking, both biological parents of the child, and living together. They gave the potential candidates a letter from the first author with more information about the study. In case they agreed to participate, the parents gave the hospital psychologist permission to share their names and contact information with the first author. Initially we wanted to interview both parents of a child who was in active treatment for a first diagnosis. In addition, we decided that we wanted to do the interviews at least two months after the moment of diagnosis, as to ensure the parents had already had time to reflect on their process. However, in a period of ten months only eight couples were invited by the psychologists and only two couples were willing to participate. Therefore we changed some of the selection criteria. We also invited parents whose child was not in active treatment anymore, and individual parents whose partner chose not to participate. In addition, we also collaborated with the University Hospital in Brussels, and posted an invitation on a Facebook page (Kikov) for parents whose child had been in cancer treatment. In total nine interviews with 16 parents (seven couples interviewed together and two mothers) were conducted in a period of fifteen months (August 2015-October 2016). See Table 1 for a description of the nine interview cases. All lived in the Flemish part of Belgium and were culturally Flemish. The time since their child's diagnosis ranged from 2 months to three and a half year. For half of them treatment was still going on; for the other parents active treatment had stopped and they were now in a period where their child needed to go only for checkups. Diagnoses included brain tumors, bone tumor, leukemia, and Langerhans cell histiocytosis (LCH). All parents with the exception of one couple and one mother, had other children besides the one that was in treatment. The interviews were planned at the time and place of their choice (8 interviews at their homes, 1 in the hospital), and lasted between 1 and 2 hours. Open-ended questions were asked related to their experiences, and more specifically about their couple communication. Examples include "*How did you talk about your emotions with your partner during that time?*" or "*Can you help us understand why you say you sometimes preferred not to talk about it with your partner?"*

Table 1: Interview Participants

Interview	Hospital	Date Diagnosis	Date Interview	Treatment phase	Interviewed together/alone	Type of cancer
1	Leuven	May 2015	Sept 2015	Active treatment	Together	Bone tumor
2	Leuven	May 2015	Oct 2015	Active treatment	Together	Bone tumor
3	Leuven	Febr 2007	July 2016	Checkups	Alone	Leukemia
4	Brussels	June 2016	Aug 2016	Active treatment	Alone	Leukemia
5	Brussels	April 2015	Aug 2016	Checkups	Together	Brain tumor
6	Leuven	April 2015	Sept 2016	Active treatment	Together	LCH
7	Leuven	Febr 2014	Oct 2016	Checkups	Together	Leukemia
8	Brussels	May 2015	Oct 2016	Checkups	Together	Brain tumor
9	Brussels	Sept 2013	Oct 2016	Checkups	Together	Leukemia

Analyses

The interviews were transcribed verbatim in Dutch based on the video-recordings. In preparation for the analyses, the first author watched the video files of the interviews several times in order to be fully immersed in the narratives. Simultaneously the transcripts were completed with notes about nonverbal behavior, and silences. We identified and marked all statements and sentences that seemed essential, revealing and/or surprising regarding the theme of talking and not talking with the partner. Subsequently, a thematic line-by-line coding (Charmaz, 2006), grouping codes into clusters around similar and interrelated ideas or concepts, was done on all transcripts, one by one, using MaxQda software Version 2 (2007). Hence, we inductively coded the data, rather than testing specific hypotheses. No predetermined themes were used, and all themes emerged out of the data. This resulted in a hierarchical coding structure, with themes and subthemes reflecting participant experiences of couple communication. During the coding process the hierarchical code system became more complex. New codes were created, and themes became more nuanced, resulting in a hierarchical structure with 7 levels of coding/subcoding, 1203 segments and 145 codes. Often, meaning units were assigned with more than one code. For example, a father said *"At those moments you don't have the time to be angry at each other, as you hardly see each other*". This meaning unit was coded with three different codes and subcodes: 1. Our life is on hold, with subcode 'No time for the partner relationship', and 2. Our partner relationship, with subcode 'No room for conflicts', and 3. Our couple communication, with subcode 'No time to talk, hardly together'. We achieved theoretical saturation after analyzing the transcripts of seven interviews (five couple interviews and two interviews with a mother). Two more interviews were coded, but these data did not yield new categories, which confirmed the theoretical saturation (Charmaz, 2006).

The credibility and trustworthiness of the analysis was verified by incorporating an extensive auditing process (Hill et al., 1997; Rober, 2004). Therefore the first author gave a detailed report, made anonymously, to the psychologists of the oncology department in Leuven and Brussels (third, fourth and fifth authors). Independent of each other these auditors read the report and reviewed the overall category structure for coherence⁄consistency as well as elegance⁄nonredundancy. All meaning units were audited for their fit into the category to which they were assigned. All three auditors then provided feedback to the first author, who used this feedback to modify the theme structure and the assignment of meaning units. As an additional validation check the first and last author had a meeting with these psychologists to review the new code system, and discussed what they found recognizable or surprising. All themes were agreed upon as fitting what they encounter in their practice.

FINDINGS

All couples talked extensively about the impact on their lives of their child's cancer diagnosis. All stressed the importance of this context to be able to understand their partner dynamics and communication. Therefore, in our coding, three main categories arose: 1. Our life during the treatment of our child, 2. Our couple relationship, and 3. Our couple communication.

In this article we focus on the first and third category.
Related to the first category it struck us that most parents used remarkable metaphors to describe their experiences related to the cancer diagnosis of their child and being a parent during oncology treatment. Metaphors are commonly used, especially in relation to illness (Spall, Read, & Chantry, 2011), as they offer a powerful language device for expressing complex thoughts and feelings. First, we relate to the three most frequently used metaphors as a context for their couple relationship and communication in that period. The metaphor of a train was used 14 times in 4 different interviews, all mentioned by the parents first, and 11 times by the interviewer as paraphrase. The metaphor of a pause button was used 8 times by one couple, and 13 times by the interviewer. Related to this was the word 'a standstill', which was used 6 times by parents in 3 different interviews.
Second, we focus on the experiences related to the couple communication, and more specifically on the meanings related to their limited talking about emotions with each other.

The Context

"The train of life suddenly stopped. A pause button was pushed. We were thrown on another train"

When parents were confronted with the cancer diagnosis of their child, they felt as if the train of their previous life was called to a halt, or a pause button was pushed. This happened in an instant, unexpected, without having any choice. Their pre-diagnosis life, with attention and time for self, for each other, and for their social and professional life drastically changed. All seemed to have disappeared.

> Father: *"Everything is gone."*
> Mother: "*Yes, really, everything is gone.*"
> Father: "*Friends, social stuff, it's all gone.*"
> Mother: *"Yes, we needed to step off that train, and that train went on, without us."*

There was no time for oneself and emotions were put on hold to be there for the child.

> Mother: "*All of a sudden your life comes to a standstill. A pause button has been pushed….Our selves are suddenly of subordinate importance. As a parent you don't count anymore, all the attention goes to your son."*
> Mother: *"When you're confronted with a life threatening illness of your child, everything else doesn't count anymore."*

Metaphorically speaking they felt as if they were thrown on another train, where everything was different. In the beginning everything went very fast. Or, like a mother said "*We needed to jump on that train, like the doctors told us to,"* and her partner added "It*'s almost out of your consciousness, it all goes so fast.*" On this train there was a need for other organizing principles, without having choices.

For all parents who had other children, planning and a tight organization to run a family combined with a lot of time in the hospital, were central in this period. "*It's a matter of organization and schedules, trying to get your life on those rails.*" Most of them often travelled between the hospital and home. There was no time to lose, and at the end of the day they were exhausted from taking care of all the children and household chores. Treatment rules, and lots of time and care went to the sick child. It was a time of survival, in which many of them held on to hope or found ways to block their anxious, sad or angry emotions. Not thinking too much, just following treatment plans, looking forward, day by day. Everything that could possibly take energy was fenced off, like for example social or professional responsibilities. In addition, these parents told us that during times of hospitalization they were alone most of the time, separated from their partner, each partner struggling in their own ways of coping. Conversely, between hospitalization periods, many parents told us they were isolated as a family, on their island, at a distance from the world outside. Then, the possibility to spend time together as a family, with all the children, was more important than time for the couple relationship.

In the interviews we specifically focused on the couple relationship during that time and we learned that for all of them there was little or no room for it. In some way the partner relationship needed to be put on hold. Most obviously, they were rarely together. Or, as a mother said "*You can't take care of a couple relationship if you're hardly together.*" Moreover, the couple relationship was not a priority, and energy needed to be saved.

> Father: "*Our couple relationship really was the last thing on my mind. It's a matter of 'battle for survival', straight focus on him (child), everything else doesn't exist anymore."*
> Mother: "*You just know that you need to go to bed and sleep, because otherwise you can't go on the day after."*

Even though most parents expressed that the partner relationship was under some kind of tension, there was no room for discussion or questioning the relationship.

> Father: "*If you start a discussion then, it just stops right away. That's impossible, you can't handle that. Because at that time you're working on something together."*
>
> Mother: *"If I would have had a partner saying 'Hello, I'm here too! Do you still love me?' that wouldn't have worked."*

Although all couples felt their partner relationship was 'on hold', most couples felt close in another way, as a parental team working towards the same goal, being in the same railway carriage. "*We're in this together*" some parents said. This was true in several meanings. First, and most visible, in an organizing way, where they tried to help and spare the partner as much as possible.

> Father: "*You just go on and you try to help each other."*
>
> Mother: "*Yes,* to *make it easier for one another, because you know how hard it is."*

In many ways, practically and emotionally most partners felt supported by the other. They were concerned about each other and encouraged one another to hold on and stay hopeful.

> Mother: "*In some way one took care of the other. If he had a bad time, then I tried to make myself stronger, and then I said 'come on,' and the other way around."*
>
> Father: "*That was really necessary, otherwise we wouldn't have survived."*
>
> Mother: "*And sometimes we hugged because we wanted to support each other. That's a very different kind of hug then an 'I love you' hug."*

Most couples explained this special relating to each other in terms of the partner being the only one who really could understand what they went through, or as a father framed it, "*She actually was the only one who could feel how I felt, because she is the only one with whom I have this child*."

In this period, parents told us that trust was crucial. Trusting each other, and trust in the relationship to be able to endure a period of pause.

> Mother:"*You have a base and you know we'll get through this, even though you don't feel each other, or see each other. I know he's there for the full 100 percent to take care of our other child, and vice versa….And when it was crucial, he was there for me."*

For most parents this experience of being put on hold, or their train being called to a halt, was frustrating. They observed how others are still on that train. Especially when treatment ended, they noticed how for them things had been put on hold while for others life just went on. It was not always easy to catch that train of their former life again.

> Mother: *"At a certain point it was very difficult to realize how that train has been going on for others, and how I tried to run after it, but couldn't catch it. Slowly I'm on the platform again, and partly I'm riding that train again. But for a long time that train was far out of my sight."*

Couple Communication

The couples were asked about their communication with each other, specifically related to the verbal sharing of emotions like fears or ways they each struggled and coped with the stressful time of having a child being treated for cancer. Some couples clearly differentiated between the time around diagnosis and the time following, with hospitalizations of the child and treatment. At the time of diagnosis, some couples said they talked a lot with each other, in a very intense way. They cried together and shared their anguish with each other. Some couples said they were used to verbally share emotions with each other as they believed it was important to talk about how they felt so it would not stay suppressed. However, all couples also talked about the difficulty of talking about their emotions with each other during this period, as it was subject to much more complexities.

Our analyses revealed three main meanings related to the limited talking: 1. Not talking because of the hospital and treatment context, 2. Not talking because of self-care/self-protection related to the blocking of emotions, and 3. Not talking because of each other.

Not Talking Because of the Hospital and Treatment Context

During the time of hospitalizations and treatment there was limited time for parents to be together or talk with each other. In the sparse moments they were together, a lot of organizational or factual things about the treatment or related to the other children at home got priority. Some couples found more time together during hospitalization, but then the hospital setting was not conducive to talk in private, just the two of them. Others said that the times in between hospitalizations, at home, gave more space to talk. Then, only sparsely, they sometimes shared how they felt. Or like a mother said when the interviewer specifically asked for these moments,*"…mainly when we were in our bed, when we finally could sleep together after so many weeks, then we started to talk, when the lights were out."* However, at home or in the hospital, all parents wanted to spend as much time as possible with the children, and in the presence of them they found it inappropriate to talk about their own emotions, not to worry them.

> Mother: "*I was always with her....I did not want to show that I was afraid. I did not want her (child) to see that.*"

Not Talking Because of Self Care/Protection and Blocking of Emotions

Most parents told us that they needed to block their own emotions in this period, to be able to stay strong and function, for the sake of their child. Their own emotions were subordinate to their parental role. Some parents said they did not feel their emotions, as if they were functioning in an automatic mode because their emotions were not useful in that time.

> Mother: "*I didn't really have a lot of emotions. They were not going to help me. Afterwards I realized that I just functioned on automatic pilot….Now I know that back then I parked the emotions that were not helpful at the time.*"
>
> Mother: "*You just try to push them away, because what's the point of crying all day?*"
>
> Father: "*I think we moved our fears in front of us….We did not want to think about it.*"

Others said they were afraid that if they would allow their own feelings to come, they might not stand up again, and it would undermine their functioning. Related to this, statements like "*Not being able to move forward,*" "*getting stuck,*" or "*then it's impossible to function*" were frequently expressed by all parents.

For some, their anguish and sadness was clearly present at times, but then it was too hard to express it in words, out loud, or share them verbally with their partner.

> Mother: "*I just couldn't say anything about it….Then you called me and I started to cry. I could not say one sentence.*"
>
> Father (smiled): "*Yes, two words, and then it stopped, she just couldn't*."

Not Talking Because of Each Other

Because we wanted to spare each other

For some partners, not sharing what they felt, had to do with taking the well-being of the other into account. They knew how hard it was for the partner and they did not want to burden him or her with their own emotions. A mother who was mostly in the hospital with her child told us she tried not to call her partner at difficult moments, *"because I didn't want to make him feel bad too."* Knowing their partner, some adjusted their words about how they really felt.

> Father: *"When I was afraid…I tried to stay positive when we talked, because I know she is more pessimistic than I am."*

Some partners shared their sadness or fears only after it passed. In one interview a couple talked about how he told her about the moments he had been very anxious only a long time after he felt that way, when the child was back home and treatment had stopped.

> Mother: *"You only told me afterwards. There you spared me, right? Because we coped with it in a different way."*

In most interviews parents talked about their different ways of coping with their emotions while their child was in treatment. Some told us about how this difference resulted in limited talking.

> Father: *"Sometimes we felt we were in a different phase or so. In the beginning she searched for information about treatments, and then I said 'I just don't want to know.' And the other way around, then I asked her 'What if this ends bad?' and then she said 'I don't want to think about it.' So sometimes you can't talk."*

This different coping was most explicit in the two interviews where only the mothers were present. Both mothers explained how their husbands were very different than they. Both men were described as listening, but never saying a word. *"He lets me talk, and he listens, but he won't react."*

Because no words were needed between us

Although our focus in the interviews was on the verbal communication between these couples, many emphasized how they often did not need words to share how they felt. Sometimes there was nothing that could be said, or as a father said after their child drastically weakened, *"Then we were lying in our couch, in each other's arms, and I think that at that time there just wasn't anything to say."* Moreover, many couples told us that they often observed each other and knew how their partner was feeling, or they just assumed they knew.

> Mother: *"We've known each other for years already; that's a long enough time to read each other's faces. When I look at him, or he looks at me, then I can see what he's thinking. I just know when he has something on his liver. We don't need words for that."*

DISCUSSION

We aimed for a better understanding of what a child's cancer diagnosis and treatment means for partners and their couple communication. Can they share their fears and hopes with each other, as a couple? If so, how do they experience their talking? And how can we better understand possible hesitations or barriers to talk with one another?

In our interviews, inquiring about their experiences related to their couple relationship and more specifically their communication with each other, they all first explained the circumstances of this period, as a background needed to understand the context of their couple communication. To describe the complexity of this experience, the parents in our interviews frequently referred to metaphors. Indeed, metaphors are often used for experiences that are beyond words (Spall et al., 2001). Families confronted with childhood cancer have been reported to describe their experiences as, for example, "a broken life world" (Björk et al., 2005), or "feeling drained" (Björk et al., 2009). For the parents in our interviews it felt like "their life was put on hold," "a pause button had been pushed," "or the train of their previous life had been called to a halt." As a couple they felt forced, without having any other choice, to step on another train, where other priorities and different organizational principles reigned. Everybody needed to adjust to a life that was dominated and structured by treatment processes and frequent hospitalizations. Their primary focus during treatment was the well-being and recovery of the child (see also Hooghe et al., in press). For these parents it felt as if their main identity was reduced to parenthood, while being marital partners became subordinate. Similarly, Van Schoors and colleagues (2017) pointed to the difference between parenthood and partnership as an important distinction, as the two imply different roles, responsibilities and behaviors.

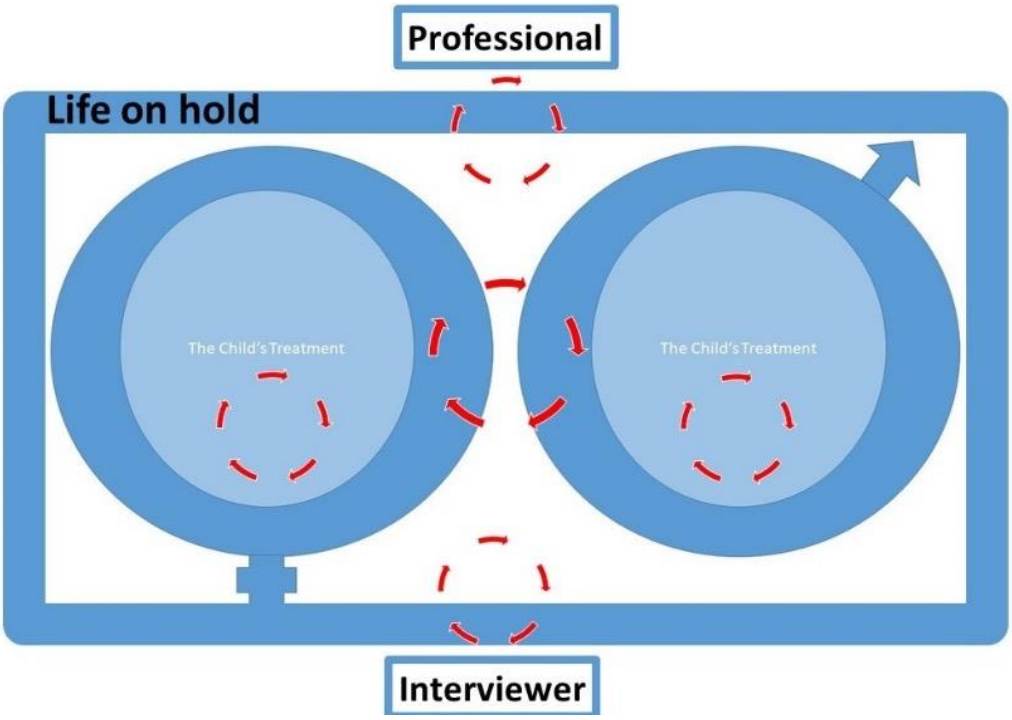
Others have reported that the demands of cancer tend to push families toward augmented cohesion (Rolland, 2005), with an increased emotional closeness (Van Schoors et al., 2017). In our study we also found that most parents felt closely connected to the partner, because they were "in this together." Nevertheless, our interviewees talked about a very limited talking with each other about their emotions and thoughts related to their child's cancer during treatment. Our analysis revealed three main meanings: not talking (1) because of the hospital and treatment context, (2) for self-care/self-protection related to the blocking of emotions, and (3) because of each other, to spare one another (3a), a different coping (3b) and because no words are needed between them (3c). The context of the child being treated in a hospital setting makes it hard for parents to talk to one another. There is hardly any time together, and the oncology department is not well suited for emotional conversations in private. In addition, these parents experienced this time period as an acute phase in which they were in a survival mode where emotions were blocked. Talking about their own emotions or difficulties could make things worse while they needed to stay strong and function for the sake of the child. Finally, because the partner is going through the same experiences, talking with each other was often more difficult. Although some said that the partner was really the only one who could understand how they felt, these parents often prioritized not burdening each other even more than was already the case. They observed each other and saw how their partners struggled, sometimes in a different way or with different timing, and tried not to add to his or her struggle.

Our study invites us to rethink the equalization between emotional closeness and frequent or intense emotional communication in couples. Indeed, our findings suggest that a limited talking can sometimes serve the couples' cohesion and closeness. Or put differently, how not talking can be part of a good couple communication. As a way to survive and stay strong for the sake of their child, these parents needed to attune to themselves, as an individual and as a couple. On an intrapersonal level, attunement is a process of emotional regulation in which each partner tries to hold their head up and focus on daily chores and treatment procedures while blocking emotions of fear or sadness. Not talking about their own emotions and thoughts is a way to attune with oneself and stay focused on the child. As both partners are in the same situation, they also need to attune with one another, not to undermine but support and respect the intrapersonal attunement of the partner. Moreover, the limited talking is also a way to protect their partner relationship, trying not to argue or fight, or putting relational issues on hold in this time of endurance. In this period of time there seems to be little or no room for the couple relationship, or as a father said, "O*ur couple relationship was the last thing on my mind.*"

Framed in a dialectic perspective on communication in which the value of talking and not talking in a relationship is emphasized, our study contributes to the understanding of couple communication as an emotional process of attunement on an intrapersonal, interpersonal and contextual level (Hooghe et al., 2018).

As a final point, the research process and our findings taught us how also for the interviewer it always has been important to attune to the processes of all parents in all interviews. For example, the arrangements for all interviews persistently involved a dialogue related to the timing and setting of the interviews (e.g. not in the hospital because there was no private space to talk, or they did not want their child to be present, nor to be away from the child). Also during the interviews we needed to attune to their dialogue (e.g. sometimes the focus of the conversation needed to be altered because one of the partners became overwhelmed, explicitly asking not to go deeper into the subject we were talking about). Accordingly, the interview context and the interviewer needed to support their survival mode, taking care not to undermine their strength they needed to go on. In a previous study in which we also inquired with the professionals of child oncology departments (Hooghe et al., in press), we found that there was a similar process of attunement between hospital staff and the parents. Often attention for the parents or the partner relationship is minimal in order to support the parents in their survival, not intruding in the complex process of attunement these parents are in. However, an attuned response from the staff towards the parents was crucial at times when emotions spilled over or relationship issues surfaced. Figure 1 shows the attunement processes on an individual, relational and contextual level (with the professional and interviewer).

Figure 1: Attunement processes on an individual, relational and contextual level



STUDY LIMITATIONS

In this study we interviewed sixteen parents about their couple communication during the oncology treatment of their child. These couples were invited by the psychologists of the oncology department based on their assessment related to the emotional and relational strength of the couple to take part in these interviews. Possibly the parents who were invited and willing to participate in our interviews had fewer couple issues than average. Given our interest in better understanding not talking, it would have been interesting if we could have been able to interview those couples who were not invited or who chose not to participate.

Although this study does not aspire to generalize our findings to all couples confronted with a cancer diagnosis of their child, maybe in a sense our selection bias even validates our findings. For couples who had more difficulties, or had to try harder not to let their couple conflicts intrude in this challenging time, participating in an interview about their couple communication might be too disturbing in their process. This was also confirmed in our meeting with the psychologists of the oncology department (Leuven and Brussels) where we discussed our findings. All affirmed that what we found was highly recognizable in their experiences with parents, but some couples don't manage to regulate their emotions or attune with each other, or put relational issues aside during treatment. These couples were not invited, as a way to protect them, or they did not participate, possibly as a way to protect themselves and their partner relationship (assumed by the psychologists based on the reasons given not to participate).

In this study we did not focus on gender differences. It is generally assumed that in Western culture women have a higher tendency to talk about difficult emotions than men (Brody & Hall, 2008), and have a different coping style related to stressors in general (Badr, 2004). An overview on gender differences in bereavement has shown that woman generally confront their emotions more than men, while men use more avoidant coping strategies (Stroebe, 2001). However, some studies, like Stroebe et al. (2013) note the absence of gender differences in their study on the avoidance of talking about loss and remaining strong in the partner's presence. In our interviews with the couples, talking about the context of childhood cancer and the meanings related to their couple relationship and communication, we could not note an explicit gender difference. However, in the two interviews we did with the mothers whose husband chose not to participate, these women explicitly mentioned how they were more inclined to talk about their emotions and experiences than their male partner.

In our broader research project on communication in couples confronted with the loss of a child (Hooghe et al., 2011, 2012, 2018), or childhood cancer (Hooghe et al., in press; this study), we often wondered about the possible cultural influence. Related to emotional expression Flemish people are generally known as not overly verbal. A recent paper on the dynamics of spousal relationships after the loss of a child among bereaved Malay parents (Hussin et al., 2018) found that avoidant communication was helpful in preventing disharmony in the spousal relationship, which echoed the influence of Asian culture emphasizing the importance of preserving harmony rather than being expressive. However, our research does not compare cultures, so it does not allow for any statements regarding this issue.

CLINICAL IMPLICATIONS

Some scholars have advocated for health care that attends to the psychosocial needs of all family members, or family centered care (e.g., Campbell, 2003; Kazak, 1989; King et al., 1999; Meyler et al., 2010; Rolland & Walsh, 2005). However, most often little is specified related to what this entails, or how this should be translated to e.g. the psychosocial or therapeutic interventions related to couple dynamics or couple communication during childhood treatment. It is clear that, generally speaking, a clinical guideline stimulating couple communication is advocated. Or like Patterson (1991) put it, *"In the resilient family, open expression is associated with better child and family outcomes. This includes the opportunity to express anger about the impact the illness is having on family life, fears about the future, resolving conflicts about role allocation with other family members, and sharing positive feelings of caring and commitment"* (p 495). However, rather than unilaterally advocating the general promotion of open communication, our findings point to the complexity of couple communication for parents whose child is in cancer treatment. Indeed, it might be useful to consider possible hesitations to talk at certain time points in the process. Probably the timing for couple interventions is important for these couples. In the process of data collection we noticed that it was a lot easier for parents to participate in the interviews once treatment had ended. Then, they could reflect and talk about the process they went through as a couple. Some couples even made it very explicit that they would never have participated in an interview in the time their child was still in active treatment, when their focus was exclusively directed to things that would benefit of the child' recovery. Talking about their relationship in that time was contextually, emotionally and relationally not feasible for these parents. Even more, they experienced their limited talking not as a subject of strain, nor subject of their attention, but rather as helpful to be able to go on, as a parent and as a couple.

Therefore, it could be useful to consider the degree of marital difficulties in offering interventions aimed at improving couple communication. To what extent do their difficulties have an impact on their ability to care for their ill child and maybe other children? Some couples, like the ones we interviewed, might consider their partner relationship solid enough to be put on hold for a while in the interest of the demands related to the ill child. Or as one of the fathers in our interviews put it metaphorically, "*It's like food and sports: the care for our child is like food, it's a daily necessity. Our couple relationship is like doing sports, in times of crisis you can put that on hold for a while."* But what about those couples who experience relational issues that cannot be put aside? Aimed at distressed couples with chronically ill children interventions have been studied (Cloutier et al., 2002; Walker et al., 1996) with significant results at 2 year follow up. Based on their results, they advocated for referring couples who encounter marital and/or psychological difficulties, helping them to enhance their ability to parent their chronically ill child.

Taken together, a better understanding of the possible risks associated with couple communication, and the relational value of not talking, might better aim our interventions, in timing, and in selecting those parents who are in need and are in a place to make use of an intervention. In that way we can better attune to what specific parents need at specific times in their process.

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“Cycling around an emotional core of sadness”: Emotion regulation in a couple after the loss of a child.

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ABSTRACT

In contrast to the traditional view of working through grief by confronting it, recent theories have emphasized an oscillating process of confronting and avoiding the pain of loss. In this qualitative study, we sought a better understanding of this process by conducting a detailed case study of a bereaved couple after the loss of their infant daughter. We employed multiple data collection methods (using interviews and written feedback) and an intensive auditing process in our thematic analysis, with special attention to a recurrent metaphor used by this bereaved couple in describing their personal and relational experience. Our findings suggest the presence of a dialectic tension between the need to be close to the deceased child and the need for distance from the pain of the loss, which was evidenced on both individual and relational levels. For this couple, the image of “cycling around an emotional core of sadness” captured their dynamic way of dealing with this dialectic of closeness and distance.

After the loss of a child, most parents safeguard the continuing presence of the child in their lives. In one way or another, by silently reminiscing or verbally sharing experiences, parents adhere to and cherish the memories of the child (e.g., Klass, Silverman, & Nickman, 1996). Indeed, the grief and the pain themselves can be treasured, because they can serve as the representation of the continuing connection with the child (e.g., Moules et al., 2004; Rosenblatt, 1996). However, feeling intense and protracted grief over one’s child can be so anguishing and overwhelming that distancing from such memories is often necessary to go on with daily life. In that sense, the regulation of their intense emotions is a central process in the parents’ grief process.

EMOTION REGULATION IN BEREAVEMENT

For several decades the assumption prevailed in the grief literature that the bereaved need to engage in intensive “grief work” to go on with life after the death of a loved one (Freud, 1917; Worden, 2002). In this long-established view, the bereaved need to confront the pain of the loss, express grief and adjust to a changed life without the deceased. Accordingly, avoiding the intense feelings of grief traditionally has been linked to denied grief, associated with pathological physical as well as psychological symptoms. In recent years numerous scholars have called this assumption into question (e.g., Bonanno, Moskowitz, Papa, & Folkman, 2005; Boelen, van den Hout, & van den Bout, 2006; Stroebe, Schut & Stroebe, 2005; Wortman & Silver, 2001; Znoj & Keller, 2002). Generally it has been found that intensive grief processing does not unequivocally bring the assumed salutary effects for the bereaved, and moreover, that there is no clear association between the avoidance of grief and grief symptomatology. Subsequently, it has been suggested that the avoidance of grief might reflect the resiliency of the bereaved, the ability to distract oneself from the loss and redirect attention to other aspects of life (Boelen et al., 2006; Bonanno, 2004).

On a theoretical level, the Dual Process Model (DPM, Stroebe & Schut, 1999) extends the conceptualization of grief adaptation by the incorporation of both loss and restoration oriented coping strategies and the core feature of oscillation between them. Loss orientation refers to attention to aspects of the death itself, such as confronting feelings of grief and confiding in trusted others, whereas restoration orientation refers to confronting the need to reengage in life and adapt to a changed life following the loss. The DPM postulates that, for the bereaved individual, attention to both is needed for favorable psychological adjustment after bereavement. An important aspect of this model is the dynamic regulatory mechanism of oscillation between the two coping strategies. At times the bereaved will confront aspects of the loss/restoration, while at other times avoid them. As the authors of the model postulated, “coping with bereavement thus is a complex regulatory process of confrontation and avoidance” (Stroebe & Schut, 2010, p. 278). Rather than concentrating merely on grief processing or grief avoidance as beneficial or detrimental coping strategies, it is assumed that the use of multiple and flexible coping strategies is optimal (Zech, Ryckebosch-Dayez, & Delespaux, 2010). Since the introduction of the Dual Process Model, many scholars have been stimulated to empirically test and refine its key propositions (e.g., Bennett, Gibbons, & Mackenzie-Smith, 2010; Lund, Caserta, Utz, & de Vries, 2010; Richardson & Balaswamy, 2001; Richardson, 2007, 2010), and grief treatment programs have carried its implications into practice (Lund, Caserta, de Vries, & Wright, 2004; Shear, Frank, Houck & Reynolds, 2005). Incorporating insights from the DPM, Shear (2010) further explored the concept of avoidance from an attachment theory perspective. With the concept of experiential avoidance she referred to the distancing of the bereaved from painful emotions and other internal experiences. However, in partial distinction from the DPM model, she proposed that the bereaved do not oscillate between loss and restoration focused coping, but rather that these processes overlap, occurring in tandem. She stated, “What oscillates is the private experience of thoughts and emotions. Oscillation progresses through use of experiential avoidance” (Shear, 2010, p. 363).

Although perceived as the most important feature of the DPM, the process of oscillation has been acknowledged as difficult to conceptualize and operationalize (Stroebe & Schut, 2010). Because oscillation is a dynamic process that varies depending on contextual factors, traditional questionnaires often fail to assess its nuances. Therefore, Stroebe and Schut (2010) recommended other data collection techniques to provide rich descriptive information. A qualitative case study, rigorously exploring the complexity of the lived experiences of the bereaved, might render such a deeper understanding (McLeod, 2010; Yin, 2009). Indeed, to advance theoretical understanding, the interaction of different factors can best be observed at the level of the case. Moreover, investigating a specific case, combined with the use of systems theory (Anaf, Drumond, & Sheppard, 2007), allows for the real-life context to be incorporated (McLeod, 2010).

Following Znoj and Keller (2002), we assume that the regulation of emotion is a highly challenging coping task for bereaved parents. It might even be the case that deficits in emotion regulation are crucial factors leading to complications in bereavement (Gupta & Bonanno, 2011). Consistent with the general literature on emotion regulation (e.g., Gross, Richards & John, 2006; Snyder, Simpson & Hughes, 2006), we presume that successful emotion regulation is a prerequisite for adaptive functioning, and that it serves as a foundation for more complex forms of social engagement (Gottman, Katz, & Hooven, 1997).

Unfortunately, empirical studies concerning these emotion-regulating processes in grieving parents are lacking, and therefore warranted. A deeper understanding is needed of how bereaved parents themselves experience the regulation of emotion in the course of grieving (Shear, 2010). Moreover, there is an explicit need for future research to include interpersonal processes in the study of emotion regulation (Snyder, Simpson, & Hughes, 2006). Within the context of a partner relationship, the regulation might not be limited to one’s own emotions, but might also entail strategies to provoke or contain the partner’s affect. In addition, encountering the emotions of the partner, here feelings of grief, might also affect one’s own feelings of grief and thus the process of emotion regulation in bereavement. Taken together, inasmuch as mourning occurs in a social field, and most intimately in the family, the study of emotion regulation in grief requires the inclusion of relational and interactional processes (e.g., Rimé, 2009).

In light of the studies reviewed above there is a clear need for further research documenting how emotion regulation processes might play out within and between individuals suffering a critical loss, such as that of a child to death. Therefore we drew on multiple sources of data and conducted a meticulous analysis of the process of emotion regulation as described by a bereaved couple after the loss of their child.

THE PRESENT STUDY

This study is part of a broader research project on the experiences of parents sharing grief with each other after the loss of their child to cancer. In conformity with the ethical board guidelines (of the University Hospital Leuven in Belgium), a hospital psychologist first contacted all parents before their identities could be given to the researchers. In cooperation with the Department of Pediatric Oncology we randomly selected thirty couples who lost their child after cancer treatment between 2002-2007. We sent them an information letter about the rationale of the study, with notification of the potential emotional impact of possible participation to the interview. We emphasized that they were free to stop participation at any point in the research process. In case they wanted more information or emotional support they were free to contact the psychologists of the department.

Throughout the data collection by means of in-depth interviews with bereaved parents and subsequent narrative analyses, it surprised us that parents recurrently referred to not talking about the loss with each other and with others as a way to create some distance from the intensive pain, protecting themselves against the ripple effects this distress might have on their functioning in the following days. To gain a deeper understanding of this theme, we thoroughly explored a metaphor used by one of these bereaved couples. They used this metaphor, which they articulated as “an emotional core of sadness inside, surrounded by a crust, around which we cycle,” to convey their grief and the way they carry it closely with them, and, also, at a bearable distance. In this article we describe and discuss this metaphor. We attempt to reach toward a better understanding of the complexity of the process of emotion regulation in grief. Special attention is paid to the talking and not talking about the child and the pain of the loss as one way to regulate their emotions. We specifically focus on the dynamic ways in which these parents deal with the dialectical forces of closeness and distance, for example by making “a detour” around the pain. To protect the privacy of the participants we changed their names. The couple gave informed consent for the disguised use of their interview responses.

A Case Study: Els and Gunter, Parents of Flore

Els and Gunter, a Belgian couple in their early 30’s, lost their daughter Flore when she was six months old. Flore was only nine weeks old when she was diagnosed with leukemia. An intensive period of chemotherapy followed. For months the three of them lived closely together in a small hospital room. During these months Flore fought through a few infections, but the last one was too strong and thus fatal for this little girl. Flore was a first child for Els and Gunter. The interviews took place six years after Flore died. Meanwhile they had two other children and are expecting a fourth child.

Data Collection

We used multiple data collection methods for this study. In a first interview we explained the purpose of the study and confidentiality procedures and both Els and Gunter gave their informed consent for participation. During the interview they both talked very openly about Flore, her struggle and her death and the way they cope with their loss as parents and as a couple. The day after this first interview Els sent an email to add a story that she forgot to tell in the interview. One month after the interview, we called them to inquire about their experiences related to the interview. After eight months we contacted this couple again, explaining the subsequent steps in the research and asking them if they would be prepared to further participate in our study. Both Els and Gunter asserted that they were pleased to engage in this research, which gave them the opportunity to help other bereaved parents with their experiences, and to learn from this experience themselves.

Based on a narrative approach to in-depth interview conversations, called “restorying stories” (McCormack, 2004), we sent this couple a restoried story, a report of our understanding of their story, focused on our research question, the sharing and not sharing of their grief as a couple. This 7-page long narration, which had the form of a poem, only used their own words and phrases and is structured in titles and subtitles on many levels. We sent this restoried story to them together with a letter explaining our intention, this narration being a starting point for further dialogue. In a second interview we talked about the way they had experienced the first interview (the impact this had on each of them and on their couple relationship), and their experiences related to receiving and reading the restoried story. Next, we further explored some of the themes they talked about in the first interview that were “given back” to them in the restoried story.

To grasp some of the complexities of human interaction (Pistrang, Barker, & Rutter, 1997), we wanted to explore unspoken reflections during the interview. Therefore we used a Tape Assisted Recall procedure (TAR, Elliott, 1986, 2004) the day after the second interview. In this third interview (TAR), we looked back at the video recording of the interview from the previous evening. Both partners as well as the interviewer stopped the tape at times they wanted to add or ask about unspoken reflections at a certain moment. These reflections yielded insights into the meaning of their interactions, including silences.

All interviews lasted around two hours. We videotaped the interviews and audio recorded the telephone call. A master’s thesis student made the transcripts under supervision of the first author. During analyses we used the video files and continually adapted the transcripts, and added nonverbal behavior noticeable on the video. Furthermore, we included notes of the inner dialogue of the interviewer, which were made shortly after the interviews. The transcripts, email, restoried story and notes were included as primary data in this study. Because this family lives in the Flemish part of Belgium, the interviews and the restoried story on which we drew were originally in Dutch.

Data Analysis

We conducted a qualitative thematic analysis on the transcripts of the interviews and email. A first step in the analysis process consisted of identifying and selecting all passages in which they referred to their ways of dealing with the loss of their child in their daily lives, as individuals and as a couple. We specifically focused on those aspects related to talking and not talking about their deceased child and the pain of the loss. In a next step, we concentrated on a central metaphor the couple used to convey their experience: they said it was as if they were constantly “cycling around an emotional core of sadness inside, which is surrounded by a crust.” Gunter initially generated this metaphor in the first interview, and they recurrently further elaborated on it in the following interviews by both partners in dialogue with the interviewer. This is consistent with a dialogical view of language according to which meanings are co-created in the interactional context of the interview (Bakhtin, 1981, 1986; Mazeland & Ten Have, 1996). In this perspective the metaphor was not an image pre-existing, fully developed in the inner world of the participants, but rather it unfolded and developed through the dialogue between Gunter, Els and the interviewer.

We performed a thematic coding using MaxQda software 2 (MAXqda, 2007), identifying descriptive categories by using line-by-line coding and the constant comparison method, assessing meaning units and categories for similarities and differences (Glaser & Strauss, 1967; Strauss & Corbin, 1998). This resulted in a hierarchical category structure, with categories and subcategories, reflecting the experience of proximity regulation in the grief process, captured in metaphorical language. To check the trustworthiness of this analysis, we incorporated an extensive auditing process (Hill, Thompson, &

Nutt-Williams, 1997; Rober, 2004). Specifically, when we finished the coding, the first author gave a detailed report to three external auditors, researchers at three different universities. Independent of one another, these researchers read the report and reviewed the overall category structure for coherence⁄consistency as well as elegance⁄nonredundancy. They audited all meaning units (in Dutch with English translation) for their fit into the category to which they were assigned. All three auditors then provided feedback to the first author, who used this to modify the category system and the assignment of meaning units. Then we made a second report and again sent it to the three independent auditors. After this second round in the external auditing process we reached an overall consensus about the report.

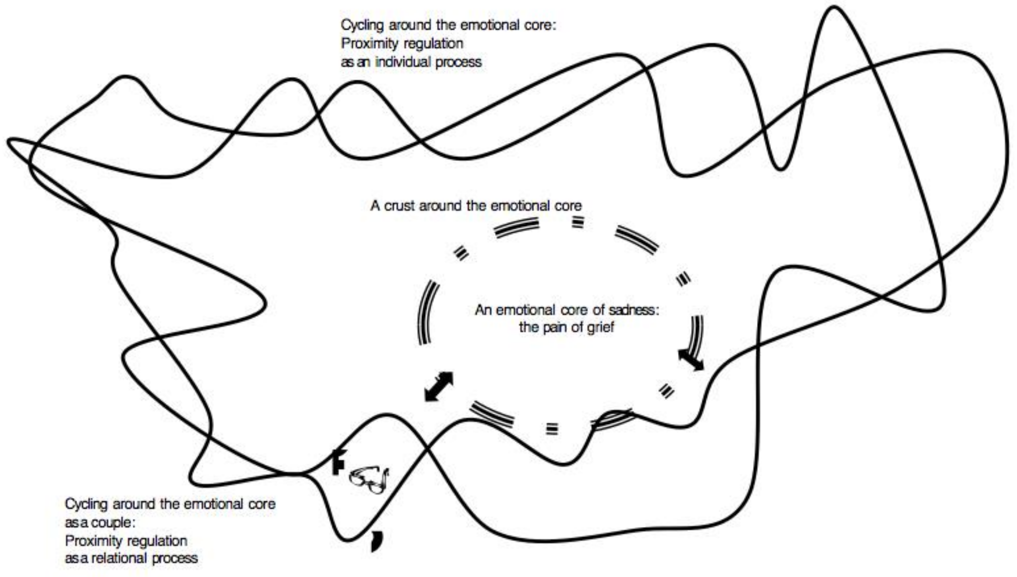
RESULTS

The thematic analysis resulted in a taxonomy of 107 different codes with 223 meaning units coded. We labeled the overall theme “Proximity regulation in a grief process.” In the hierarchical tree structure we distinguished four general domains of categories, all four connected with a part of the metaphorical image (see Table 1 and Figure 1): (a) An emotional core of sadness: the pain of grief; (b) A crust around the emotional core: a dynamic protection from the pain of grief; (c) Cycling around the emotional core: proximity regulation as an individual process; (d) Cycling around the emotional core as a couple: proximity regulation as a relational process.

Table 1. Proximity Regulation in a Grief Process: Hierarchical Tree Structure

Metaphorical image	First order categories	Second order categories	Third order categories
An emotional core of sadness	The pain of grief		
A crust around the emotional core	A dynamic protection from the pain of grief		
Cycling around the emotional core	Proximity regulation as an individual process	The need for closeness	
		The need for distance	
		Dynamic ways of dealing with the dialectics of closeness and distance	Not directly talking about it Talking in the context of research Talking in another language
Cycling around the emotional core as a couple	Proximity regulation as a relational process		

Figure 1. Proximity regulation in a grief process



The Emotional Core of Sadness: The Pain of Grief.

The metaphor of "an emotional core of sadness" is used by Els and Gunter to describe something that is filled with sadness, and is experienced as something inside, as something essential, emotional and vulnerable. While talking about this core Els and Gunter often gestured, showing something round that is held by two embracing hands. They both experienced this core as existent ever since their daughter died and as something that would never go away.

> Gunter (G): *"(. . .) that is, that's something very fundamental, since Flore died, in which we are hit as a person. It really is like a first layer, which is there. "*
>
> Els (E): *"What do you mean?"*
>
> G: *"Uhm [thinking], like an emotional core [shows something round, held with his two hands], around which one always cycles."*
>
> E: *"Yes, yes."*

Since this moment in the first interview, when Gunter created the metaphor for the first time, Els also began to use it in the following interviews. Generally this metaphor seemed to have the same meaning for both partners. A slight difference in meaning, however, was that for Els this core was filled with memories, though this was not so for Gunter. He sometimes referred to this emotional core with other metaphors, like a little pitcher filled with sadness, or a knot. For us, the metaphor of the pitcher suggested something full of feeling that might at times be poured out, just as the knot evoked an image of something that was tied together, twisted, and perhaps invited loosening or untangling.[1] Although Gunter used these metaphors interchangeably, each image could illuminate a different aspect of the same experience. However, the fact that for all these metaphors Gunter showed the same gesture with his hands, something round which is held with two hands, strengthened the view of these different images as having a similar meaning for him.

> G: *"For me these are not memories. It really is, there is a knot [shows something round held with his two hands], a knot that is inside there. By actively thinking about it, it comes closer and closer, closer to the surface."*
>
> Interviewer (I): *"That knot?"*
>
> G: "*Yes. A little pitcher filled with a lot of sadness. But nothing concrete actually. It's not that, then, I'm thinking back about something concrete. I don't know if that is the case for you too [to E]?"*
>
> I: *"Is that the same image as you used in our previous interview, an emotional core that is there?"*
>
> G: "*Yes, that's that.* "

For Els and Gunter it was hard to share this emotional core with people who did not go through the same kind of loss, partly because such people did not ask about it. With some parents who also had lost a child they could sometimes share this core, because they also knew what it is. Although the couple also could share this feeling with sensitive professionals, the core of their grief eluded narration. The struggle to give voice to the experience was evident for this couple:

> G: "*I wouldn't be able to, in a way it's confronting. I really would not know how to put it into words.*"
>
> E: "*Hmm, I don't know."*
>
> G: "*But yes, that's [shakes his head]."*
>
> E: "*But not, not spoken words."*
>
> I: "*Not spoken?"*
>
> E: "*Not, not out loud. Well, maybe that would be okay, but I never dared to try.*"

When they thought about their daughter, this brought the emotional core closer. When they talked spontaneously about Flore, or were asked to do so as in the context of the interview, they experienced this as a difficult confrontation because of the emotions it created. Therefore, not talking was often a way not to evoke the painful emotions.

A Crust Around the Emotional Core: A Dynamic Protection From the Pain of Grief.

Around the emotional core, a crust had grown, which was variable: it had become thicker over the years, and it varied in thickness depending on the situation. In Figure 1 this is represented by an arrow, indicating the variable thickness of the crust.

> G: "*There is a core of great sadness, uh, yes, around which there is a crust, which gets thicker every year, which, when one is tired or sick, or if things are not going well, or at a certain point."*
>
> E: *"or disturbed by hormones. [E was pregnant at the time of this interview.]"*

The crust had a protective value because it shielded the emotional core. One could pierce through the crust, and in so doing, come closer to the core. Piercing through the protective crust was usually associated with talking about the child or the loss.

> G: "*Imagine that you would ask me to talk about the time when Flore was sick, or the moment of death or something, then I feel I am piercing through that crust."*

Gunter and Els both emphasized that this was something they did themselves, but some situations also gave rise to this piercing through.

> E: "*Sometimes people say a lot without it happening. Well, I don't feel like anybody is doing this to me, like you [to G] say, piercing through that crust, sometimes that happens, and sometimes it doesn't. It's a little like piercing and picking, as you [to G] would say it."*
>
> G: "*Yes*."
>
> E: *"But not like you [to interviewer] are doing that, it's just something is coming too close for me."*

Although they usually preferred not to pierce through the crust, it was tolerable when it was in a controlled way, not being forced to.

> I: *"Are you saying now that piercing through that crust is not always something that you experience as negative?"*
>
> G: *"That's right. Uh, rather not, but especially when it is in a controlled context, or uh, ultimately we gave you the permission to talk about it, then it's okay. [E nods]"*
>
> I: *"Oh, yes."*
>
> G: "*That's very different than being forced to bring it to the surface."*

Consequently, not talking about it could be a way of controlling the proximity to the core, avoiding piercing of the crust when the context seemed inappropriate for them.

Cycling Around the Emotional Core: Proximity Regulation as an Individual Process.

Cycling around the emotional core was one of the metaphors Els and Gunter used to describe the way they dealt with the dialectic of closeness and distance. It was depicted as a dynamic activity of proximity regulation: approaching the core, but always careful not to approach too close, or for too long. In the following, we first describe the two opposing dialectic forces: the need for closeness to Flore, and the need for distance from the pain of the loss. Subsequently, we briefly describe how this couple deals with these dialectic forces. In Figure 1 this cycling is represented by two dynamic lines (one for Els and one for Gunter), each following their own course, sometimes closer, sometimes further from the core.

The need for closeness

In their grief process it was important for Els and Gunter to keep a certain closeness to their deceased daughter in daily ongoing life. Flore was in the background of everything they did, and she would always remain their daughter.

> G: *"(…) and memories also fade a little."*
> E: *"Which is regretful, of course."*
> G: *"Yes, yes, also the positive sides."*
> E: *"Yes, well, that is your child, you also want to keep her close. [silence]"*

They sometimes sought out her memory and pursued projects related to her (e.g., lighting candles in churches when they were on a holiday). Talking about Flore was also a way for Gunter and Els to keep their daughter close to them, to honor the child's memory, to keep her present in their lives and in the life of the children. They often found it enjoyable to talk about her, and it was important to them that she kept being mentioned by others too. When the first author talked to Gunter on the phone one month after the first interview inquiring about the way he had experienced the interview, he told her how he liked the opportunity to talk about his daughter, and compared it with the remembrance day of the hospital where Flore died, which they went to every year.

> G: *"(…) then we mostly have that same feeling, it's nice to talk about it again. Well, not really like that is a pleasant thing, but just to be able to talk about Flore. Like, well, which is, well, pleasant, yes."*

The need for distance

Besides the importance and need for closeness to their daughter, there was also a need for distance from the pain of the loss, not to be overwhelmed by it in daily life. In the interviews they often showed this distance with their hands, making a movement with their hand away from their body. One strategy to create some distance was by avoiding the confrontation. They would rather not think about it, avoiding confrontation with reminders, or searching for other contexts, not to be reminded of the pain. In the third tape assisted recall interview, they described how, even in the interview, they had their ways of creating some distance, as by laughing at what the partner was saying.

> G: *"And for you it's a, well, a kind of, uh, defensive reflex."*
>
> E: *"Yes, yes, absolutely."*
>
> G: *"to create some distance."*
>
> E: *"Yes, yes."*
>
> G: "*Well, that is very shortly after the emotional part, so that's very, that's a part of it."*
>
> E: *"Yes, of course."*
>
> I: *"And you [to G] know it too, that, at times, she uses humor, some laughing, and some, that that is something for her, to, oops this is coming close for her, and she tries to create some distance for herself? Do I understand correctly?"*
>
> G: *"Yes."*
>
> E: *"Yes. That is a strategy that we have used very often."*

Another strategy is not talking about it, with each other, and with others.

> E: *"Mostly I ask others how they are doing, and I sort of avoid talking about myself [hand movement: going around it]."*

Dynamic ways of dealing with the dialectic of closeness and distance

To deal with this dialectic of closeness and distance, Gunter and Els used several metaphors to describe this dynamic of simultaneously approaching the core of sadness, while also preserving a certain distance by not approaching it too closely or for too long, like "cycling around the emotional core," "dosing" (balancing the amount of time and intensity in which they approach the emotional core), and "detours." All metaphors were described as active ongoing processes in their grieving process.

> E: *"I recently talked about it with a friend. About yes, that you do both things. You need some distance, but not a distance that is too much. But you need to find a balance in this [G nods]. It's clear to me, that it, that it is not cycling away from it, really."*

In the following we look closely at what Els calls "a detour" around the pain, which was most apparent in "talking with some distance." We discuss three different illustrations here (a) not directly talking about it; (b) talking in the context of research; (c) talking in another language, as presented in Table 2.

Not directly talking about it.

Sometimes it was easier to talk about the pain of the loss in ways that did not explicitly verbalize it. Instead, metaphorical language or stories were used to talk about the child. Talking about a rubber band, monkeys and bananas, or the fear of Flore being cold in her urn, were ways for Els to speak indirectly about her grief for her child. This way she could feel close to her child, and at the same time protect herself from overwhelming feelings of grief.

Talking in the context of research.

For Gunter and Els it made a difference that their talking about Flore and the loss of Flore was in the context of a research project. Their participation in the interviews gave them the opportunity to talk about their daughter, to feel close to her again, while at the same time they experienced the research context as a way to create some distance in speaking about her.

Table 2. Dynamic Ways of Dealing with the Dialectics of Closeness and Distance, Examples

Talking with some distance	Examples
Not directly talking about it	E: Two weeks ago it was Flore's birthday, and I emailed it to one of the other mothers and she said, 'I hope you have a strong rubber band (E starts to cry), to keep her close to you (brings her hand to her heart) (7 sec silence). She understood. And she always wants bananas, because monkeys eat bananas and they are happy. And in the mean time we both say how sad it is (shows a detour with her hands). E: Always when it snows I think, "Oh, wouldn't she be cold in her little vase?" And then Gunter says, "No, Els." (Both laugh) G: Yes, but that is… E: In that way we talk about Flore. (Silence) E: I'm very easily overwhelmed by my emotions. I fear that she would be cold in her little vase. I think that is just a way to say something else.
Talking in the context of research	G: This (research interview) is actually a safe context. Sometimes there are moments that we are more troubled by [the memories], and if we can express them in this research context, then that is safe. E: Yes, a little distance. E: The fact that it's your doctoral study, that creates a distance again, well, [we] can actually look at what [we]'re doing in the context of your research. That is more I: Oh, that creates some distance? E: Again a detour, actually (laughs).
Talking in another language	E: I also did my therapy in English. I looked for, yeah, it is a little strange. I was looking for a therapist. I just told an English friend, and she she told me, "I am going to a sweet person, who is English". And I thought, oh, that was, that was just so much to the good, that was like (arm distance from body). Then, you can be easier, tell it like a story, with a little distance. I: That is special. (Els laughs, shows a detour with hands.) E: All tricks from the fair, everything that might help a little. I: Oh, these are tricks that can help you apparently to create some distance in your talking, so that it doesn't come too close? E: I really think so, not too close.

"E" = Els, "G" = Gunter, "I" = Interviewer

Talking in another language.

Some months after the loss of Flore, Els decided to seek psychotherapy, mainly because she wanted to talk about her new pregnancy and the fears related to having a new child. Remarkably, she did not choose a therapist who spoke Dutch, which was her first language, but instead chose to pursue therapy in another language, in English. Talking about the pain of the loss in another language was a way for Els to speak about her grief while at the same time preserving some distance needed so as to not approach too closely the overwhelming pain.

Cycling Around the Emotional Core as a Couple: Proximity Regulation as a Relational Process.

Cycling around the core also had its relational aspects. Generally, Gunter and Els described this proximity regulation as an individual process, such that the partner stood at a relative distance at times that this regulation process was satisfactory. They were not really focused on the other in this and trusted in the other’s ability to regulate his or her own proximity from the emotional core. They tried not to disrupt the other’s attempt to manage this process by drawing too close. However, they did not describe this process as entirely individual. Instead, they kept an eye on each other and guarded each other’s boundaries. While talking about how this regulation was a continuing individual quest, they both remarked that it was not entirely personal or subjective:

> E: *“Until the moment you say something about it…”*
>
> G: *“A little margin, uh, keeping an eye on the edges, I would think [Els smiles].”*
>
> I: *“Keeping an eye on each other’s edges?”*
>
> G: *“Yes, or being alert for it.”*

In Figure 1 we represented this cycling around the emotional core as a couple by spectacles, suggesting that they kept an eye on each other.

In general, Gunter and Els only sporadically talked about their grief with each other. Not talking, they tried not to affect, and not to be affected by, the other. However, when, at times, there was not enough distance from the pain, they would approach the other. Then, they trusted they could relate and rely on each other.

> E: “*Yes, if I would have a hard time, if I would have the feeling that I got stuck, then I would say that.”*

Gunter added that he thought the most important thing was that as partners, they could be the first support figure for each other in times of need: *“Being the first confidant, if needed. I think that is important.”*

In this proximity regulation the couple also described an existing relational dynamic of counterbalancing for each other. When one partner noticed that the other was too close to the emotional core and was having a hard time with it, the other tried to create some extra space, for instance by taking over the conversation, so that the partner could recover and move back again. In Figure 1 we represented this by the lines that occasionally cross each other. Sometimes these lines simply cross because each is going his or her own way, but sometimes these lines cross because one adjusts his or her route to create some space for the other.

Reflecting on a part in the second interview in which Els had a hard time and Gunter was talking, Els pointed to such a moment where they take care of each other:

> E: *“Here you are making a little space for me, right?”*
> G: *“Yes, I am, absolutely.”*
> I: *“You are making a little space?”*
> E: *“Yes, that’s, I also recognized it at that moment.”*
> G: *“Yes.”*
> E: *“You sometimes do that.”*
> G: *“I try to sell some rational theories.”*
> E: *“Gunter takes over then and is just talking until I’m back in.”*
> G: *“Whereby Els slowly comes back on board [gesture: pulling on a rope to get someone into a boat].”*
> I: *“Oh, yes.”*
> G: *“Right [to Els]? That’s true, right, we do that. Then we catch each other a little.”*
> E: *“Yes [both laugh].”*

DISCUSSION

In this study we attempted to gain a deeper and fuller understanding of the challenges of emotion regulation faced by bereaved parents after the loss of their child. Therefore, we focused on one bereaved couple and carefully analyzed multiple data from several interviews we had with them, carrying out a systematic thematic analysis. We gave special attention to a metaphor used by this couple to convey some of the complexity involved in the process of regulating emotions in their grief process: “cycling around an emotional core of sadness.” In this analysis we mainly focused on the aspect of proximity, the distance and closeness from this core, and the way this couple dealt with the simultaneous need for both. Although we could easily have chosen to explore a different metaphor, for example, the meanings of “dosing intensity over time” or the meanings of “coming on board again,” we chose the “cycling around” metaphor because our interviewees gave this metaphor a central place in their accounts.

Even though we did our analysis systematically, some issues remain open for discussion. For instance, we could question if Gunter and Els were talking about one core or two cores. Did they both have their own core, or were they talking about the same shared core? In our data we found no evidence referring to two cores, but, on the contrary, they referred to “that” core, as if they were both talking about that same core. So it seemed that in their view, there was but one core.

Another issue that remains open for discussion is the question of what exactly did this core comprise? Did the core include the memories of Flore, to which they wanted to stay close? Or did the core represent the pain of grief, the loss of Flore, from which they needed some distance? Or maybe these two meanings were merged into a single core? Or was this core comprised of different and perhaps overlapping parts? Our data did not unequivocally answer these questions. It seemed that for Gunter and Els too there was some confusion and it seemed that it was difficult for them to disentangle Flore, and the pain of the loss of Flore. As Els said: *“It really belongs together. I can not think about my daughter without being very sad that she is dead.”*

Another question that remains unanswered is, what did they mean by a core inside? For Gunter and Els this core was experienced as situated inside their body, as something that could be approached by talking or thinking about it. Still, this was not like a concrete substance somewhere in the body, but rather was meant as a metaphorical way of speaking. Stories of “embodied grief” are common in talking with the bereaved (Gudmundsdottir, 2009, Hentz, 2002). Some experience their grieving body as fundamentally changed since a profound loss. Although some bereaved experience real physical pain, often metaphorical language is used to point to a burden that needs to be carried inside their body, as for example “a heavy heart,” “a hole inside” or “a strangled throat.”

This case study has serious limitations. Although we meticulously executed this study, it was an analysis of only one specific Flemish couple’s struggle with their emotion regulation in the process of grief over the death of their baby daughter. Therefore, it does not lend itself to any generalizations across bereaved couples or across cultures. One could wonder to what extent “cycling” around an emotional core, and maybe also "talking with some distance" is a typical Flemish way of dealing with intense emotions. Therefore, at most, our findings only illustrate the central importance for some couples of relational-dialectical dynamics of dealing with emotions of grief.

A traditional formulation of "grief work" emphasizes the importance of approaching anguishing emotions and encouraging the bereaved to "work through" the grief. In contrast, our qualitative study suggests that at least in some grieving couples there is a dynamic of emotional regulation, which entails an oscillation between maintaining closeness to the deceased child and establishing a functional distance from the pain of grief. Similar to the Dual Process Model (DPM, Stroebe & Schut; 1999, 2010), our findings suggest that the couple we interviewed engaged grieving as a dynamic process balancing confrontation and avoidance. However, our case study of this couple suggests a process that differs from the oscillation process in the DPM, insofar as it points to the simultaneous attempt to ensure closeness to the child and distance from the pain of the loss. Most explicitly in their account, the couple captured this dynamic of opposing forces in analogical ways through their use of metaphors like "cycling around" an emotional core of sadness, making "detours" around the pain, and "talking with some distance."

Conceptualizing the processes of "confrontation" and "avoidance" in terms of "closeness" and "distance" fits with a relational dialectical view on personal relationships, in which both processes are considered to be opponent forces that are co-existent and in no need of resolution in one way or another (Baxter, 2011; Baxter & Montgomery, 1996, Hess, 2002; Lavee & Ben-Ari, 2007; Toller, 2005). For the bereaved couple in this study, "cycling around an emotional core of sadness, shielded by a crust" was a way to deal with these dialectics, to stay close to their deceased child, while at the same time staying at a bearable distance from agonizing pain associated with the loss of their child. This continuing quest was a challenge for both parents individually, but also one that played out at the level of the couple relationship. They kept an eye on each other, at times relying on one another, to create some distance for the other. At other times, when the pain was too great, they sought out one another as confidants. In this way emotional regulation was also a relational process.

Looking through this lens of relational dialectics, we might also gain a deeper understanding of the need of the bereaved to talk or not talk about their grief. Bereavement counselors typically emphasize the importance of expressing grief openly. However, our findings join those of others pointing to the complexity of the dialectic tension between openness and closedness (Baxter, 2011; Hooghe, Neimeyer, & Rober, in press). For Gunter and Els, talking about their child was an important way to keep her present in ongoing life, even though doing so risked piercing through the protective crust around the emotional core of sadness. Not talking, or talking with some distance (such as talking in another language, or talking indirectly) then was a way to detour around the core, not cycling away from it, not approaching it too closely.

This flexibility in regulating one's emotional expression has also recently been found to be a core capacity in the grief process of bereaved spouses (Gupta & Bonanno, 2011). The ability to both enhance and suppress emotional expression might be important in daily functioning in the wake of loss. Although both Els and Gunter seemed to have found their own ways of regulating their emotions, we also noted the imperfection and vulnerability of this regulating dynamic. It is likely that people do not always notice when they go into areas beyond what they want to talk about. Els, for example, generally protected herself by not approaching the painful topics too closely in the interview, but also recounted that, to her surprise, she had some sleepless nights following its conclusion. Apparently, only afterwards she experienced that talking about her daughter this intensively brought her closer to her grief in the days that followed. Hence, although Els and Gunter continued their search for a bearable distance, and adjusted their talking and not talking about it, it seems that sometimes the effect of talking, and the proximity to the core could only be felt afterwards.

Looking through a relational dialectical lens of emotion regulation, our findings might carry implications for research practice, in particular for scholars conducting interviews with the bereaved. We wonder whether the choice to participate in this kind of research for some bereaved might be a way to search for some kind of closeness with the deceased child in a safe context. Often intense and unexpected emotions are experienced during the interview (Dyregrov, 2004), which might generate the need for a dynamic movement toward more distance from the painful story. When the interview is conducted with partners or families, we might even be aware of the relational dynamics in this regulation, family members taking care of each other. Moreover, consistent with our dialogical perspective (Bakhtin, 1981, 1986), we should not forget that the interviewer is also part of the interactional dynamics related to emotion regulation during the interview. An illustration of this was found in the interviewers' notes made shortly after the interviews with Els and Gunter. The interviewer asked herself, for example, "Am I coming too close now to this question?" "I don't want to be the one who is piercing through the crust," "How can I respect their boundaries?" and "I'll just trust their own decisions; they'll tell me if this is too much."

All of this points to the importance of creating a safe dialogical space to conduct interviews with bereaved research participants. Being able to determine both the place and content of the interview has been shown to be important for bereaved interviewees (Hynson, Aroni, Bauld, & Sawyer, 2006).

Moreover, it might be important that the interviewer indicates a time frame for the interview to enhance the feeling of safety and control for the couple. In this way, they can estimate how long the conversation will last, and perhaps, how long they need to bear the emotional intensity, or perhaps modulate it throughout.

For psychotherapy practice, we suggest creating a dialogical space to explore with the bereaved how it would be to talk about the pain related to the loss of their loved one, while simultaneously acknowledging the hesitations the bereaved might have to speak, as well as their good reasons to choose to be silent and maintain a safe distance, at least for the time being (Rober, 2002). Through this “talking about talking” (Fredman, 1997), the dialectical tensions related to openness and closedness and to closeness and distance in relation to the child and the pain of the loss can be explored (Hooghe, Neimeyer, & Rober, in press). This careful and respectful therapeutic approach acknowledges bereaved people’s own ways, as individuals and as couples or families, to search for a bearable distance in their psychological and social lives following a profoundly emotional loss.

Notes

1. During the analyses process these different metaphors were the subject of discussion with the external auditors.

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“The child is our focus”: On couple issues in child oncology treatment

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ABSTRACT

Objective: This study explored the perspectives of child oncology professionals and parents about the attention professionals should give to the parent couple relationship during treatment of the child.

Methods: We employed a qualitative research design, framed within the approach of Consensual Qualitative Research (CQR), gathering data from four focus groups with twenty professionals, and from nine in-depth interviews with sixteen parents. Thematic analysis of the focus group and interview data was done with MaxQda software, using two coders and member checks to strengthen confidence in the analysis.

Findings: Both professionals and parents talked about an elevated tension in the partner relationship during oncology treatment of the child. However, explicit attention to the partner relationship in this context felt inappropriate to professionals and parents. All emphasized the importance of the professional helpers’ openness to conversation and an attuned response to the parental couple relationship.

Conclusion: During treatment the child is the primary focus for parents and professionals. The parents’ focus on supporting their child makes talking about their own emotions or about issues in the partner relationship potentially disruptive and unhelpful. Therefore it is crucial for professionals to support the parents in their parents’ role, but with an openness to converse about issues in the partner relationship at the moments when these issues might threaten their focus on the child.

INTRODUCTION

A child's cancer diagnosis and oncological treatment have significant impact on the child's parents[1-4]. Reviews[5,6] focusing on the effect of childhood cancer on the parents' marital satisfaction found both positive and negative changes. A growing body of literature emphasizes the importance of assessing relationship quality as part of routine psychological care throughout the treatment trajectory[5,7,8]. Moreover, some argue for identifying parents at risk and implementing interventions aimed at strengthening the marital relationship of the parents[5,9-11].

Such a psychosocial focus on the parents' marital relationship is not well established in routine pediatric care. Although one review concluded that health providers recognize emotional distress, they feel unable to address psychosocial issues due to lack of time, lack of confidence in their own skills, and the perception that parents prioritize child physical care over parental psychosocial care[11]. That review went on to say that "for patients and their families the main issue was that the healthcare system was focused on physical care with little opportunity to talk about psychosocial concerns"[11]. But do parents and professionals who work with them say that parents want such talk?

To our knowledge, no qualitative research has been done to explore the views of parents and professionals concerning attention given to the parent couple relationship while their child is in oncology treatment. In our study we inquired with both parents and professionals about their views concerning attention to parent couple relationships during this time.

METHODS

Design

We conducted four focus groups with professionals, one at each of the four child oncology departments in Flanders (the Dutch speaking part of Belgium). In addition, nine interviews with sixteen parents whose child was in cancer treatment were conducted. We combined what started out as two independent studies because both projects were looking at the same phenomena. Combining them gave us the perspectives of the parents and the professionals in a single analysis and report. Both focus groups and interviews were audio and videotaped. Our research can be framed within the approach of Consensual Qualitative Research (CQR)[12]. CQR is an integrative approach to qualitative research, based on the idea that doing research is teamwork, and that analyses should be checked by independent external auditors who have the task of challenging interpretations and checking if these interpretations are sufficiently grounded in the data.

All couples provided informed consent and the research protocol for studying couples and professionals was approved by the Medical Ethics Commission of Leuven University (B322201627096).

Focus groups with the professionals

In Flanders there are four child oncology departments (in Leuven, Brussels, Ghent and Antwerp). At each of these departments a focus group was organized with professionals. Inclusion criteria were being close to the families and having a minimum of 5 years of experience in child oncology. In total seven psychologists and thirteen nurses participated (Table 1). All but one were women. Each focus group was conducted at the professionals' workplace, and lasted between 1 and 1,5 hours. Beforehand, the professionals were provided with a document with three fictional cases in which professionals encounter marital communication difficulties or conflicts between partners during their stay in the hospital. At the start of each focus group these cases were discussed by the participants, with only minimal structuring by the researchers (first and third author). Examples of questions asked by the researcher are: "*How do you understand parents not talking with you about emotional or relational difficulties*?", and "*How do you see your own task or engagement related to marital difficulties of the parents*?".

Table 1: Professional participants.

Focus Groups	Hospital	Psychologists	Nurses
1	University Hospital Leuven (L)	2	2
2	University Hospital Brussels (B)	2	2
3	University Hospital Ghent (G)	2	4
4	University Hospital Antwerp (A)	1	5

Parent interviews

Parents whose child was in cancer treatment at the child oncology department in Leuven were invited for an interview as a couple about their experiences. Recruitment for these interviews was done by the psychologists of the oncology department at the University Hospital in Leuven. They selectively invited Dutch speaking couples (both biological parents of the child, living together) whose child was in active oncological treatment (at least two months after a first diagnosis) and were considered to be willing to participate in the study. Between August 2015- August 2016 eight couples were invited, and only two couples chose to participate. The other six couples considered an interview too exhausting in this time of treatment and did not see the value of this interview for their child. As recruitment turned out to be difficult, we decided to post an invitation on a Facebook page for parents whose child is in Oncology treatment. One mother volunteered and we interviewed her. Afterwards we decided to collaborate with the child oncology department in Brussels, and changed some of the inclusion criteria: we also invited parents whose child was not in active treatment, and parents who were willing to participate individually. Over fifteen months (Aug 2015 – Oct 2016), sixteen parents participated, seven couples (interviewed together) and two mothers (Table 2). The time since their child’s diagnosis ranged from 2 months to three and a half years. For half of them treatment was still going on, the others were in a period where their child needed to go only for checkups. Diagnoses included brain tumors, leukemia, bone tumor, and Langerhans cell histiocytosis (LCH). The ages of the children were between 9 months and 15 years. Most parents had other children besides the one that was in treatment. The interviews were planned at the time and place of their choice (8 interviews at their homes, 1 in the hospital), and lasted between 1 and 2 hours. Open-ended questions were posed related to the conversations with health care professionals at the hospital about themselves and their partner relationship. Examples include “*How was it for you to talk with the professionals about your emotions or your partner relationship*?”, and “*Can you help us understand why you say you sometimes preferred not to talk about it with them*?”

Table 2: Parent participants

Interview	Hospital	Date Diagnosis	Date Interview	Treatment phase	Interviewed together/ alone	Type of cancer
1	Leuven	May 2015	Sept 2015	Active treatment	Together	Bone tumor
2	Leuven	May 2015	Oct 2015	Active treatment	Together	Bone tumor
3	Leuven	Febr 2007	July 2016	Checkups	Alone	Leukemia
4	Brussels	June 2016	Aug 2016	Active treatment	Alone	Leukemia
5	Brussels	April 2015	Aug 2016	Checkups	Together	Brain tumor
6	Leuven	April 2015	Sept 2016	Active treatment	Together	LCH
7	Leuven	Febr 2014	Oct 2016	Checkups	Together	Leukemia
8	Brussels	May 2015	Oct 2016	Checkups	Together	Brain tumor
9	Brussels	Sept 2013	Oct 2016	Checkups	Together	Leukemia

Analysis

Qualitative thematic analyses were done separately on the transcripts of the focus groups and interviews. The interviews and focus groups were transcribed in Dutch and were inductively coded. The first author was the main researcher and primary data analyst for the interviews, the third author for the focus groups. Statements and sentences that seemed essential, revealing, and/or surprising were identified and marked. Subsequently, a thematic coding was done by grouping codes into clusters around similar and interrelated ideas or concepts using MaxQda software Version 2[13]. Descriptive themes were identified using line-by-line coding and the constant comparison method, assessing meaning units and themes for similarities and differences[14,15]. This resulted in a hierarchical coding structure with themes and subthemes reflecting the meaning structures in the transcripts related to the conversation between parents and professionals about the couple relationship.

Credibility and trustworthiness of these analyses were verified by an extensive auditing process[12,16]. For the analysis of the focus groups three independent auditors (an experienced psychologist and family therapist, an experienced psychologist working in palliative care, and the fourth author) gave feedback about the overall theme structure for coherence/consistency as well as elegance/nonredundancy. All meaning units were audited for their fit into the theme to which they were assigned. This feedback was then used to modify the theme structure, and was subsequently returned to the auditors, until consensus about the report was reached. To check the trustworthiness a second meeting was done with three psychologists of the focus groups. All themes were discussed and agreed upon as fitting what they encounter in their practice.

RESULTS

In the focus groups of professionals, as well as in the interviews with parents, two main themes stood out with respect to the partner relationship. First, explicit attention to the partner relationship in this context feels inappropriate, as the child is their primary focus now. Second, there should be offered an attuned response to the partner relationship.

"The child is our primary focus now"

The professionals in this study expressed how their professional commitment and engagement always needs to be associated with the wellbeing of the child. For that reason, emotional difficulties in the partner relationship are beyond their mandate, focus and skills.

FG A

Nurse 1*: "I think we mainly look at the relationship with the child.*

Nurse 2*: "Mainly the child, we don't look at the relationship between the partners. Is there an effect on the child? Is the child burdened by it? Not the couple."*

Moreover, the professionals assume this is also the case for the parents. Indeed, the parents in our interviews stated that in a child oncology department with professionals specialized in childcare the focus is on the child. All are there because of the child, and they don't expect any offer of psychological treatment for themselves or their partner relationship.

> Mother 5*: "I think that they are there for (the child), and of course that's logical, it's a child department, …. That's the most important."*
>
> Mother 9*: "I did not expect them asking how we were doing, because they are child psychologists, they are there for the patients."*

The professionals in our focus groups saw most parents trying to keep their heads up, to survive and stay strong for their child. This often includes that parents don't give priority to their own emotions. Sometimes talking about their own emotions or difficulties in the partner relationship can make things worse at a time they need to be stable and function for the sake of their child.

> **FG B**
>
> Psychologist: "*Sharing emotions is a nice basic assumption, but it needs to be helpful. If, because of that, he (father) can't function anymore at a time where he feels he needs to function, than that's not good."*

Similarly, all parents in our interviews emphasized that they would find it inappropriate to receive too much attention from the professionals to their emotions or partner relationship. In these circumstances they feel they need to put their own emotions 'on hold' to be able to stay focused and strong for their child.

> Mother 8: *"If they would have invited us for a conversation, in another room, about ourselves, No, that would not be the right moment! … I wouldn't have wanted to talk about myself at that time."*

Both professionals and parents recognized that the hospital setting is not inviting and appropriate for emotional conversations about their own emotional status. During the time in the hospital, all parents want to be with their child as much as possible. They don't want to cry in front of their child, or be invited to another room away from the child. If the tension between partners becomes high, and a professional is in the room, often the only 'way out' is the hallway, which of course is not suitable for a conversation.

Moreover, as the professionals reported in the focus groups, it's also a matter of time. Often there are other pressing practical, medical and organizational issues that need their attention. Although some might like it to be different, often there just isn't time for longer conversations with the parents.

In the interviews with the parents, this observation, that the professionals did not have the time for longer conversations, was a recurrent theme. Although some of them missed having somewhat more time with the professionals, they also largely appreciated their efforts.

> Father 2: *"The nurses and psychologists here, they all work very hard, but they are shorthanded, even at a department for child oncology."*

For some parents the time schedules at the hospital are inconvenient. Many parents, especially fathers, can only visit in the evenings, when the psychologists are not present. In addition they all mention the discontinuity in care, having many professionals coming in at different times.

"An attuned response to the partner relationship."

The professionals in our focus groups emphasized the importance of a safe environment for the parents in which they try to embody openness for conversation in case the parents would want to talk. Rather than initiating conversations, they observe and try to trust the process and the coping abilities of the parents and support the things that may come up.

> **FG B**
>
> Psy 1*: "I think it's about creating the space for a good balance in those things, and leaving parents in their strength, …. but always creating the space to share difficult emotions.*
>
> Psy 2: *"I agree, it's up to the parents to ask for a conversation, but we need to create the space to make that possible."*
>
> **FG G**
>
> Nurse*: "Sometimes they just want to ventilate some of their emotions, and then we just offer a listening ear. Sometimes just a few words is enough for them to pick up their strength again and go on."*

In the interviews with the parents, trust in the availability of the professionals in case they need it is one of the main themes. They had the feeling that the professionals kept an eye on them. All parents said that there was little or no conversation about themselves or how their partner relationship became tense in this context, but they felt trustful that there would be an openness to have a conversation about it if they would need it.

Sometimes emotions spill over or relationship issues surfaced. Then, the professionals (mainly psychologists) see it as their duty to respond in a way that helps parents to go on and focus on their child again. They listen and try to frame relational tensions as normal in this stressful time.

Parents talked about moments during treatment that it was just not feasible to put their emotions on hold. Sometimes their emotions overflowed, or issues in the partner relationship demanded their attention. At these moments they were very appreciative of those professionals who noticed and took the time to listen to them. Importantly, these moments needed to feel attuned to their own process, at the time when they needed it, and in a way that felt spontaneous.

> Interviewer: *"Would it be of extra value to you if the psychologists would invite you as a couple and explore how things are going for you, as a couple?"*
>
> Mother 4: *"Yes, I think so, but maybe not like an appointment, but rather as a spontaneous act. You are sitting there and you start to talk… If you need it, you can go to them, or they come and sit with you."*

In these moments they don't want to deepen or reflect on their emotions, but instead need a supportive and encouraging response to enable them to go on and focus on their child.

Some parents indicated that it would be of value for them to get the explicit offer of a psychologist to be available for them, as adults and as a couple, in case they need it. Finally, many parents noted that they might need attention from professionals for their partner relationship when treatment ends. The partners for whom this was already the case admitted that their partner relationship needed some kind of rebuilding after a long time of inattention.

DISCUSSION

The impact of childhood cancer on parents and their marital relationship is evident, and some studies have advocated for an enhanced attention for it in routine pediatric care[5-11]. In our research we aimed for a better understanding of the perspectives and experiences of parents and professionals at child oncology departments related to the attention given to parents and their marital relationship.

Most importantly , we found that attention to the partner relationship during treatment of the child is not a priority. Everyone has a similar focus: the child's illness and medical treatment . For professionals the main task and mandate concerns the child's illness, and for parents the child is their dominant focus. Therefore, everything else, including the emotions of the parents and any difficulties in the couple relationship, are put on hold. The marital relationship loses its importance[17], as one is a parent all the time[7]. As the parents in our interviews reported, talking about the partner relationship could distract them and undermine their focus on the child. Accordingly, professionals are very careful not to destabilize the parents, who are trying to survive and stay strong for their child. Moreover, in this setting where medical care is prioritized, people feel that there is little or no room, nor time, for conversations about side issues like marital difficulties.

Notwithstanding what they see as the inappropriateness of an explicit attention to the partner relationship during the child’s treatment, professionals and parents also acknowledge the elevated tension in partner relationships during the child’s treatment. Consequently, our findings point to the need for a more complex approach related to the attention given to the parents and their relationship. The analysis of all four focus groups with the professionals showed some kind of implicit working model they employ in their approach toward the parents and potential partner relationship tensions. Most importantly their efforts concentrate on creating a safe environment for the child and the parents, in which they try to embody openness for conversation, in case the parents would want to talk. Rather than initiating conversations, they accept, observe and support the things that may come up. Therefore they try to trust in the process and the coping abilities of the parents. This can be understood using ideas of containment as a working model. This concept of containment was introduced in psychoanalysis[18], and implies the creation of a safe ground, from where the client can maintain strength, and grow. When emotions of the parents or relationship issues surface and might threaten the child, there is a need for an attuned response. Similarly, Davies and colleagues[19] conclude that best practices in psychosocial care for parents of children with life threatening conditions is comprised of the ability to attune to what is present at the time. An important aspect of this attunement involves timing and spontaneity.

CLINICAL IMPLICATIONS

In light of our findings it is useful to reconsider the recommendations for professionals to include interventions aimed at the partner relationship during pediatric oncology treatment. Our study points to the complexity inherent in the attention given to the parents and their partner relationship in this time, with a focus on attunement. Consequently, we might wonder about the impact of, for example the setting aside of a private parent “lounge” hat is better suited for private, informal contacts between parents and professionals. Or, as some parents mentioned the fact that there were only child psychologists, how it would be different for professionals and parents if –instead of only child psychologists - there were also adult psychologists at the department who were exclusively available for the parents? Extending their attention to the broader system around the child can be challenging for professionals. As it is often difficult to assess the dividing line between focus on the child and focus on the relationship of the parents, they struggle with their position and mandate. Also, some reported that they felt wary of creating even more tension in the couple. But what if professionals were more trained in giving attention to couple issues? Possibly not much would change for some parents, because the child's illness so captures the situation. However, there might be parents who would be quite responsive to the availability of resources for helping with couple issues.

Related to that, it is possible that our sample of parents was biased in the direction of having parents who did not want much help with couple relationship issues while the child was in treatment. Since the parents we interviewed were selected by hospital staff, it is possible that the staff chose parents who seemed accepting of the limited attention staff was able and inclined to give to the parental relationship. But even for the parents in our study, those for whom active treatment had ended pointed to the value of psychosocial care once they were back home with their child. Perhaps more attention for the parents and their partner relationship is needed in preparation for the transition to the end of treatment in the hospital[20].

FUTURE RESEARCH

Future research could aim to explore what happens when there are dedicated couple and family therapists available to work with parents of child patients. Perhaps what we report in this paper is driven in part by the constellation of what kind of professional help is available to parents. There also seems to be a need for research exploring how what goes on or does not go on between parents affects a child cancer patient physically and psychologically, both in the moment and in the long run. Even with the focus on the child, we need to know more about what is happening to the child when, for example, parents bicker, communicate poorly, seem not to be talking with each other, or have long standing difficulties. We also need to develop a broader cultural perspective on what the issues are regarding parent couples in cases of pediatric cancer in disparate cultures. How much of what we report here is about Flemish culture and how much is it about child oncology treatment and couple relationships everywhere in the world? Our study does not compare cultures, so it does not allow for any statements regarding the specific influence of culture.

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INTEGRATIVE DISCUSSION

In this final chapter we aim to give the reader insight into our research process and what we have learned along the way. During the almost ten years that we searched for answers we learned that we needed to refine our questions, discovered and explored new concepts and literature, and took unexpected pathways. This is common or even essential in qualitative research (Charmaz, 2006; 2008; Morse, 2006, Rober, 2005 (p 315)): you follow the things that are most surprising compared to your initial thoughts. Furthermore, we had the chance to check and better understand our findings and their clinical implications in our simultaneous work with clients confronted with illness and bereavement.

We first give an overview of the five studies with our main findings on couple communication in the context of bereavement and childhood cancer (1). In this overview we integrate our own thinking process along the way, discovering new concepts that helped us to understand what we found, and guided us in next steps in our research project. Following, we elaborate on the central concept of attunement, which led to a model reflecting our findings (2). Next, we reflect on the connection between existing theory and our findings (3): what we have learned, and how our findings relate and contribute to the existing literature. Subsequently, we discuss the methodological issues of our research, noting its limitations (4). In a fifth paragraph we consider the clinical implications of our findings (5). Finally, we make suggestions for future research (6).

1. Overview of the studies and main findings

This research project aimed at a deeper understanding of couple communication of bereaved parents and parents confronted with their child being diagnosed with cancer. We conducted five studies. Studies 1, 2 and 4 relate to the exploration of couple communication of bereaved parents, while studies 3 and 5 are conducted in the context of childhood cancer treatment, including professionals at a child oncology department (study 5).

In this overview of our studies we will only briefly refer to the theoretical frameworks that have inspired us along the way, but rather focus on what we have found in our studies. Later, in the reflection on our studies, we will elaborate on the existing literature in more depth.

1.1. A broad exploration of couple communication

Study 1 - Bereaved parents

At the start of our research project our exploratory quest was very broad related to the couple communication of bereaved parents. *How do they experience talking about their grief to one another? If they talked, how did this go? Were there things that hindered their communication? And, if so, how did they experience these hindrances? Were there contexts or times when talking was easier or more difficult? And how, if so, did their communication change over the years since the loss?*

We defined 'talking' as verbally communicating with one another. We defined 'their grief' as all the thoughts and emotions related to the death of their child.

Our first study was an exploratory pilot investigation with a bereaved mother and her partner who was not the biological father of the deceased child but had raised him from a very young age. The narrative analysis of this case study (based on an interview, this mothers' diary in the form of a book, and a text of a public book reading), reflected the story about their communication in the 10 years since the loss. The main storyline involved the need for silence and distance at several points in the process, to protect themselves and the relationship. However, at the same time they stressed the necessity of moments of connection between them, with or without words. In this mothers' experience, on the one hand there was a desire to talk about the loss with her partner, and at the same time there were things that restrained her from doing so. On the one hand she longed for silence and distance, and on the other hand she feared the disconnection that came with it. This process not only resided in this mother, but was also situated between the couple, in their dialogue with each other. Moreover, this was a dynamic process, as their communication portrayed a search process over time. Thus, in their experiences, not only was there the importance of talking, but also not talking with each other about their grief to protect themselves and their partner relationship over time.

With this first study we found that talking about their grief was a lot more complex than we initially presumed. It was clear that there were no simple answers to our initial questions (as described in the introduction): '*Is it a good thing for people to talk about their grief? Is talking better than not talking about it?' 'Is it best to stimulate people to talk with their partner about their grief in therapy?, 'Should we invite the partner in therapy to share their grief?*' and so on. We came to realize that the literature that we had read so far in the grief and family therapy field largely presented a one-dimensional view on communication. In this view communication is described as a transmission from one person to another, and openness and self-disclosure is privileged for the development and maintenance of relational closeness and intimacy, while not talking or silence are often associated with poor adjustment to grief, or relational difficulties (Baxter & Montgomery, 1996; Baxter, 2004).

However, the findings of our first study introduced a view on communication where both talking or openness with one another as well as not talking or silence are valued, a **both/and approach.** Therefore, in our second (bereaved parents) and third study (parents confronted with childhood cancer), we explicitly focused on the meanings related to *not talking* with each other. In these interviews we thus inquired about the times and contexts when talking to one another about their emotions was not so easy, or maybe difficult, not desired or not possible. And how did they experience this, or give meaning to it? In addition, this study also showed that there is not only the value of not talking or silence, but also that there is **a complex and dynamic interplay** between talking and not talking. How do they relate to one another? This was the subject of our fourth and fifth study.

1.2. Exploring meanings related to not talking

First, we need to note our slight discomfort with the concept ‘not talking’. During our research process we often discussed the concept of ‘*not* talking’, which is the absence or negative form of talking. Regretfully no English word seems to capture the equivalent for what we call ‘zwijgen’ in Dutch, or ‘se taire‘ in French, or ‘schweigen’ in German, which all have their own qualities (Rober, 2010, personal communication). The complexity and ethics related to cross language research have been described in qualitative research before, as the meanings of words sometimes carry cultural connotations or subtle nuances in different languages (Shklarov, 2007; Rosenblatt, 2001). We considered words like ‘keeping silent’, ‘withholding words’, ‘closedness’ (Baxter & Montgomery, 1996) or ‘nondisclosiveness’, but none of these words seemed to capture the broadness we wanted to study in this second and third study. In discussing our findings related to the meaning of ‘not talking’ (placed in quotes to indicate the overarching meaning), we will therefore sometimes denote alternative words that better represent the specific meaning, as articulated by the parents in our interviews.

We first discuss the second and third study separately. Subsequently we reflect on the similarities and differences between the two study populations. Then, we reflect on the first 3 studies and how they brought us to explore the communication *process* in the two following studies (4 and 5).

Study 2 - Bereaved parents

For our second study with bereaved parents, we analyzed twenty interviews, with twenty-six parents, and conducted a qualitative thematic analysis based on grounded theory methodology (Charmaz, 2006).

All parents who were interviewed differentiated between talking *about the child* (or reviving memories of the child) and talking about their grief process. They all emphasized the importance of remembering the child and keeping their child present as life continues. However, talking with each other *about how they felt in their grief* was subject to many more complexities. Our analyses revealed four main meanings related to 'not talking'. For an overview, see Figure 5. Note that there is some overlap between these meanings but for purposes of clarity, we chose to discuss them separately.

First, parents said they do not talk about their grief because of the **inadequacy and pointlessness of words in grief** (1). For most parents, the experience of losing a child cannot be conveyed in words *("ge kunt dat niet uitleggen" (in woorden)*). Grief, like love, is beyond words and, as many bereaved parents said, only those who have experienced this deep feeling know how it feels. Moreover, the parents in our interviews described how words don't change the reality of the death, so "*what is the point of talking about it, as it doesn't change her death"?* Here 'not talking' is not a withholding of words, or holding off a conversation, but expresses the inability to give words to it, or the uselessness of these words for their grief process.

Second, 'not talking' about their grief was also a way **to create some distance from the pain of grief** (2). Sometimes (directly) talking about the enormous pain is just too painful, and makes it all harder. Giving words to it, making it explicit, or talking about it, would make the pain surface. Then daily life, with its responsibilities and the need to go on, can be hindered by the emergent pain. 'Not talking' can thus also be conceptualized as 'not making things explicit' for themselves and the partner.

Third, 'not talking' was considered an expression of **a personal and intimate process** (3). Many parents described how they often physically isolated themselves because they preferred to grieve on their own. Withdrawing from others and turning into oneself was described as a personal and preferred choice. In those moments, they could feel **closer to their deceased child**. Interestingly, some parents especially needed to isolate from the partner to feel more in control of their own grieving process. 'Not talking' was a way to protect their own grief, which felt too intimate to share, and too vulnerable to be intruded on, and possibly disrupted by someone else's thoughts or emotions. Just because most partners said they could ‘read’ each other’s faces and body language they particularly needed to distance themselves from the partner, therefore choosing not to talk (too much) with each other. Here, rather than ‘not talking’ these parents often used the word ‘silence’, or ‘being on my own’ as a way to be closer to themselves and to their deceased child.

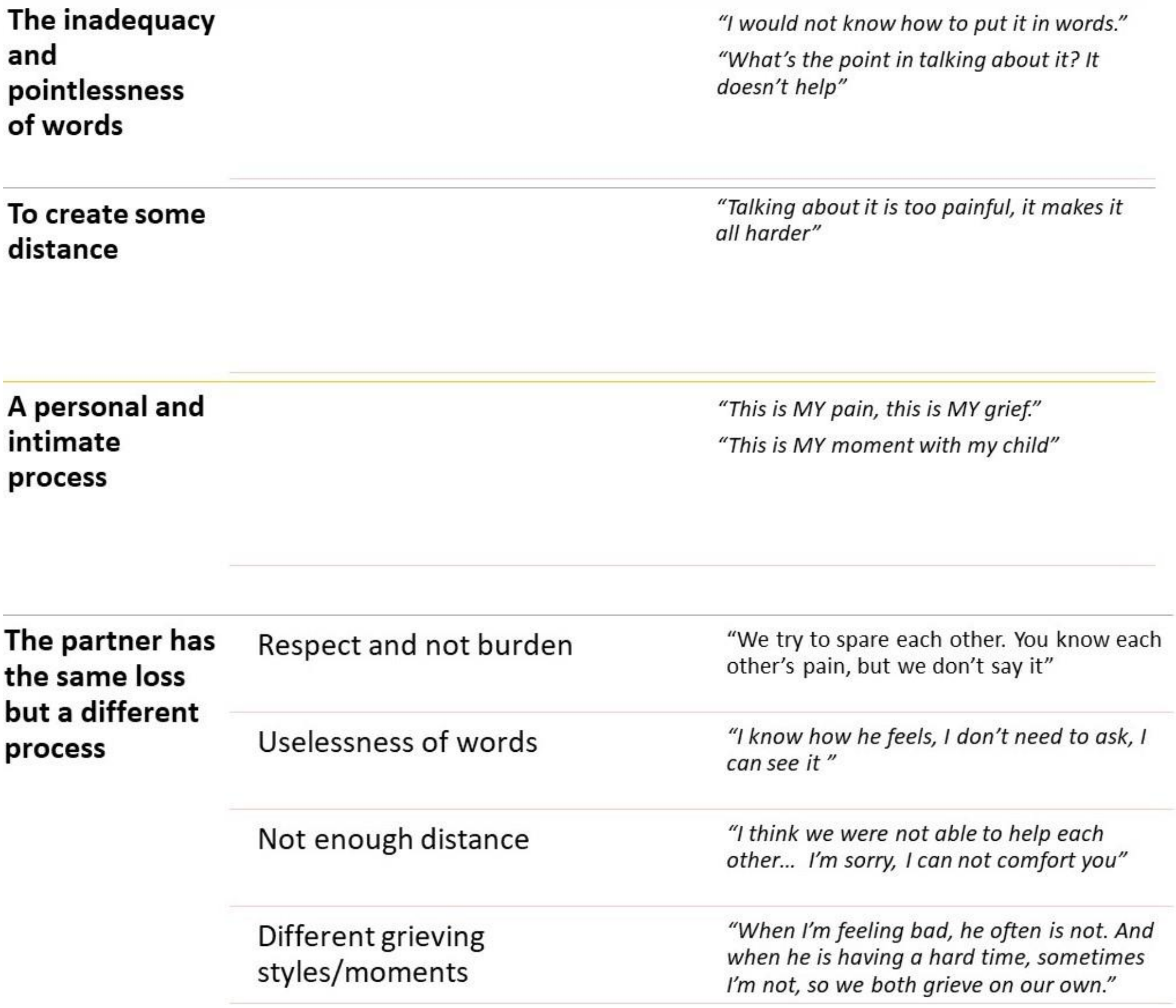
Fourth, the parents in our interviews said they did not talk with the partner because this partner has **the same loss but a different grief process** (4). Talking about their grief with each other was often experienced as very difficult precisely because both partners went through a similar experience. Four subcategories emerged from this meaning.

A first subcategory relates to ‘not talking’ as a way to **respect and not burden each other’s grieving process** (4.1). They granted each other their own private moments and took care that their own expression of grief would not cause the grief of the partner to surface. A prominent theme here was that almost all couples talked about wanting to spare their spouse from more suffering than was already the case. Here, rather than ‘not talking’ many parents referred to ‘not expressing’ their grief, as a way not to intrude on, or burden the partner with their own grief process. Indeed, with this meaning we found that talking about one’s grief was only one part of the communication process, which also includes nonverbal communication. For example, many parents talked about incidents where they somehow ‘withheld’ their own thoughts or feelings, taking care not to express them in any way, to grant the partner his or her private space, not burdening the other (like crying in the car on the way home, then drying their tears before entering the house with a smile).

In addition, ‘not talking’ was also related to the **uselessness of words in their partner relationship** (4.2). Knowing each other that well, they could speak without words to understand one another. Here many emphasized the importance of a connection through nonverbal sharing (lighting a candle in each other’s presence, going to the grave together while holding hands), and the confidence that one would say something if needed. Again, ‘not talking’ did not fully capture this meaning, as ‘silence’ and ‘not giving words to it’ were used more frequently in this context.

For some, ‘not talking’ has to do with **the pain of the partner coming too close to one’s own grieving** (4.3). In a way, their own intense grieving process took all the available emotional ‘space’, without any space left for the emotions of the partner. Hence, they expressed their inability to listen or be there for each other if they would have a conversation. Talking to one another was thus rarely initiated, or conversations quickly ended. Here we found the inherent connection between talking and listening.

Finally, ‘not talking’ with each other was also related to **a different grieving style, or moments** (4.4). Talking with each other thus required some kind of synchronization. Therefore, they needed to observe the partner and search for some kind of adaptation to each other’s process. Sometimes this entailed that words were kept inside or not spoken, or conversations were aborted, waiting for a better moment to express them. In addition, some couples also pointed to differences in communication styles. Sometimes this difference made it hard or even disruptive to talk to each other, at times leading to conflicts, in which both partners didn’t feel listened to or understood by the other. For some, over time, these differences and painful conflicts resulted in accepting the reality of not being able to talk about their grief with each other.



The inadequacy and pointlessness of words		*“I would not know how to put it in words.”* *“What’s the point in talking about it? It doesn’t help”*
To create some distance		*“Talking about it is too painful, it makes it all harder”*
A personal and intimate process		*“This is MY pain, this is MY grief.”* *“This is MY moment with my child”*
The partner has the same loss but a different process	Respect and not burden	“We try to spare each other. You know each other’s pain, but we don’t say it”
	Uselessness of words	*“I know how he feels, I don’t need to ask, I can see it ”*
	Not enough distance	*“I think we were not able to help each other… I’m sorry, I can not comfort you”*
	Different grieving styles/moments	*“When I’m feeling bad, he often is not. And when he is having a hard time, sometimes I’m not, so we both grieve on our own.”*

Figure 5. Meanings for ‘not talking’ (bereaved parents).

For many bereaved parents, the complex process of talking and 'not talking' about the fear of death and loss of their child started from the moment of the cancer diagnosis. Therefore, we decided to broaden our group of research participants, and explored the same research topic with parents whose child was in cancer treatment in our third study.

Study 3 – Parents confronted with childhood cancer

In our third study we also explored the meanings for 'not talking', but now in the context of parents confronted with childhood cancer. Similar to our second study, a thematic coding was done, based on grounded theory methodology (Charmaz, 2006). The analysis was done on nine in-depth interviews with sixteen parents. Seven couples were interviewed together and two mothers alone. Four interviews took place during treatment and five when treatment had recently ended and they were now in a period where their child needed to go only for checkups.

In this study we were immediately confronted with the different context of these parents. All parents first explained the circumstances of this period, as a background needed to understand the context of their couple communication. Everybody needed to adjust to a life that was dominated and structured by treatment processes and frequent hospitalizations. The contextual situation seemed to be determining, as these parents appeared to be in a time of survival with an exclusive focus on (the recovery of) the child, and the sense that life is on hold. As parents, most of them felt supported by the partner, as a way of "*being in this together*". However, they all talked very little with each other about their emotions and thoughts related to their child's cancer during treatment.

Our analysis revealed three main meanings related to 'not talking' with each other. Again, we will note different namings or concepts as alternatives for 'not talking'. For an overview, see Figure 6. Similar to the meanings we found in our second study, there is some overlap between these meanings.

First, parents told us that they hardly talked with each other because of **the hospital and treatment context** (1). During the time of hospitalization and treatment there was limited time for parents to be together or talk with each other. In the sparse moments they were together, a lot of organizational or factual things about the treatment or related to the other children at home had priority. At home or in the hospital, all parents wanted to spend as much time as possible with the children, and in the presence of them they found it inappropriate to talk about their own emotions, not to worry them. Here, 'not talking' was described in its contextual limitations, as a factual picture of the situation they were in. However, although this context was experienced as very difficult for most of the parents, the inability to talk to one another was not presented as one of the main struggles of this context.

Second, for **selfcare/protection and blocking of emotions**, most parents choose not to talk, or not too much (2). To be able to stay strong and function for the sake of their child, they needed to block their own emotions in this period. Many parents said they were afraid for their own feelings to come, as they would undermine their functioning. Some parents said they did not feel their emotions, as if they were functioning in an automatic mode. Their own emotions were not useful in that time and subordinate to their parental role. For some, their anguish and sadness were clearly present at times, but then it was too hard to express it in words, out loud, or share them verbally with their partner. Here, 'not talking' was expressed as a way of not concentrating on their own emotions. They kept their emotions at a distance, fended them off, and tried not to give meaning to them. This implied that they did not have words or did not search for words for themselves or initiated a conversation with the partner.

And third, these parents told us that they did not talk with each other, **because of each other** (3). We found three subcategories in this main category. The parents in our interviews wanted to **spare one another** (3.1). Therefore, they did not want to burden their partners with their own emotions, or only talked about it after it passed. 'Not talking' was described as a 'holding in' of whatever surfaced for themselves. This included words as well as the expression of their emotions in other, nonverbal ways. For instance, many talked about moments when they were feeling very afraid their child might die, but tried not to show the partner, trying to transform their tone of voice when talking about daily chores. Hence, not showing what they were feeling or thinking appeared to be a lot broader than only the inhibition of words. In addition, some couples told us that **no words were needed between them** (3.2). Often they knew how they felt without words, and sometimes there was nothing that could be said. 'Not talking' was described as 'silence', or 'sharing without words'. Lastly, most parents had a **different way of coping** with the situation (3.3), which sometimes made it hard to talk, or resulted in limited talking. For some this was depicted as 'holding in words' towards the partner, or not initiating a conversation, or stopping the conversation as they saw they had another way of coping. For others this was more described as a silence they accepted and respected between them.

The hospital and treatment context		*"We hardly saw each other. I was in the hospital and he was at home with the other children"* *"When we were together, she (child) was always there with us"*
Self care, **Self protection** **Blocking emotions**		*"I didn't really have a lot of emotions. They were not going to help me."*
The partner is in the same situation	Spare one another	"I didn't want to make him feel bad too"
	No words are needed between us	*"When I look at him, or he looks at me, then I can see what he's thinking. We don't need words for that."*
	Different coping	*"…then I asked her 'What if this ends bad?' and then she said 'I don't want to think about it.' So sometimes you can't talk."*

Figure 6. Meanings for 'not talking' (parents whose child is in oncology treatment).

Summarizing, in this second and third study we found different meanings related to 'not talking' to the partner about ones feelings or thoughts related to the loss or illness of their child. These meanings point to contextual factors and the inadequacy of words, or to a way of coping as an individual and within the partner relationship. Although we used the concept 'not talking' as an overarching concept, the diverse meanings we found also suggested alternative understandings and concepts, each with their own nuances, like 'silence', 'withholding words', 'holding off a conversation', 'not making things explicit in words', 'awaiting', and so on.

Study 2 and 3: similarities and differences

What surprised us most in these two studies was that, in general, all parents (in both studies) hardly talked with one another about how they felt. Probably this surprise is rooted in our therapeutic way of thinking: the belief that giving words to emotions is a vehicle to create meaning (Neimeyer, 2001; White & Epston, 1990), and sharing stories within the partner relationship is an important way to connect with each other (Gilbert, 1989; Riches & Dawson, 1996), and co-create meaning (Nadeau, 2008). However, at least in the couples we interviewed, this did not seem to go hand in hand with how they experienced the closeness in their partner relationship (we further elaborate on this in our reflection).

In both studies we found that ‘not talking’ was often a way for partners to spare each other, not to burden the other with their own pain or anguish (4.1 in study 2; 3.1 in study 3). In a way they all tried not to express their own experiences too much, while also imagining that ‘not giving words to it’ would not change the fact that they somehow can read each other without those words (4.2 in study 2; 3.2 in study 3). In addition, they often noted that they trusted that the partner would speak if necessary. Moreover, most parents in both studies referred to a different coping style as one way to understand their limited talking with each other (4.4 in study 2; 3.3 in study 3). For some this was a source of frustration and then their ‘not talking’ was more like a ‘holding in of words’, avoiding or terminating a conversation. For others this was more described as a difference they had encountered earlier in their relationship, which they had found a way to deal with through a not uncomfortable silence.

However, there were also important differences between the bereaved parents and those confronted with childhood cancer. Although the broadening of our research group to parents confronted with childhood cancer seemed to be a logical step in our research project at that point, we immediately noticed the different context in which these parents were in compared to the bereaved parents. In our third study we found that the context of treatment was described as one main reason why these parents were often unable to talk with each other (meaning 1, study 3). This is of course very different with the context of bereaved parents, who often spend a lot of time together, or at least are in the same house, and obviously have more time than those parents whose lives are now organized by treatment plans, hospital visits and taking care of a sick child. In addition, although we found, in both studies, that the parents we interviewed did not make their thoughts and emotions explicit to prevent the pain or fear from surfacing (meaning 2 in study 2; meaning 2 in study 3), looking closer, there is a different nuance to it in the two studies. The parents taking care of their sick child (study 3) held their own emotions *‘on hold’* as much as possible, to be able to function and be there for the child. Talking about their own emotions was mainly pushed forward to a time where the child would be healthy again, and the context would allow for a conversation with each other, away from the hospital setting, and without the presence of their children. In this context they tried not to concentrate on their own feelings, or some said they did not have feelings during the time their child was in treatment. Consequently, they did not have words and did not try to find words in a conversation with the partner.

In contrast, for the bereaved parents (study 2) not having words for how one feels had a different meaning: their grief was *beyond* words (meaning 1, study 2). Interestingly, preventing the grief to surface was much more explicitly subject to a *process*, searching for a bearable distance towards the pain of the loss. At times they did not talk about it to create some distance from their grief (meaning 2, study 2), but at other times they were drawn to be closer to their deceased child and thus their grief. So, while there were meanings related to not talking, at the same time there was also the importance to talk about the child, to remember, to say his or her name out loud, not to (let anyone) forget. Some described this process as 'balancing', 'dosing', or 'cycling around'. As a consequence, the bereaved parents talked about the asynchronicity in time (being closer to/more distant from ones grief at certain times than the partner) as a reason for their limited talking with each other (meaning 4.4 in study 2). This was not found in our third study, where both partners were in an acute phase of fighting for the same cause: the recovery and wellbeing of their child and family.

Study 1, 2 and 3: an evolution in conceptual and theoretical frameworks

Summarizing these studies (1, 2 and 3), we found that the parents in our interviews experienced their communication with each other as subject to a lot of complexities, representing both the value of talking *and* not talking. Exploring the meanings related to 'not talking' in our second and third study, we noticed that 'not talking', as a broader concept, was experienced as valuable for a variety of reasons. Accordingly, our concept of 'not talking' was refined into several distinctive concepts, each holding their own nuances. In addition, our findings so far also indicated the complexity of the communication ***process,*** in two interrelated ways.

First, we found that **talking and listening** are inherently connected (most explicit in 4.3 (study 2)). Preventing the pain from surfacing can be attained by not giving words to it, but also by not listening to the grief expressions of the partner. Second, we found that talking and 'not talking' are not in isolation from one another, but that they are part of **one process of communication, or dialogue** (most explicit in study 1, and meaning 4 (study 2) and 3 (study 3)). For instance, when one wants to talk or even starts a conversation, one can feel threatened to feel overwhelmed by grief in a way that is too intrusive, and so one may restrain from starting to talk or stop the conversation, trying to focus on something else. Or, often the observation and assessment of the other makes the partner hesitant to say something, or to proceed with the conversation.

These two elements brought us to a broadening of our understanding of the communication *process*, and led us *to explore a* ***dialectical and dialogical approach*** to communication (Baxter & Montgomery, 1996, Baxter, 2004, 2011; Rober, 2017). In this approach 'openness' and 'closedness' are in a continuous interplay, in an unfinished, ongoing dialogue. This is similar to what we found: talking and ‘not talking’ as part of one process. Moreover, ‘openness/closedness with’ (disclosing/nondisclosing) is interdependent with the other’s ‘openness/closedness to’ (the degree of receptivity and responsiveness that a person displays toward another’s disclosures) (Baxter & Montgomery, 1996). Related to this, Rober (2017) puts it, “*storytelling is inconceivable without the other; without someone who listens*” (p 107). Indeed, in our studies interviewees talked about the importance of listening, as inherently connected to talking. Additionally, in accord with our findings, the dialectical/dialogical approach posits that communication entails more than verbal exchange, but *“… implicates the full range of human actions: verbal and nonverbal, vocal and nonvocal, intended and not intended, sincere and contrived*” (Baxter & Montgomery, 1996, p. 42). Or, “*Each expression is responded to in some way: implicitly or explicitly*” (Rober, 2017, p 107).

A central element in the Relational Dialectics Theory (RDT) of Baxter and Montgomery (Baxter & Montgomery, 1996, Baxter, 2004, 2011) is the concept of ‘contradictions’ or ‘interplay’ between contrary or opposing forces (like openness and closedness), enacted in interaction. This interplay is neither positive nor negative but necessary for change in relationships (Baxter & Montgomery, 1996). We will elaborate on this theory in more detail in our reflections. For now, in this overview of the studies, we touch on this theory because the element of interplay between opposing forces (openness/closedness, and closeness/distance) was what we had encountered in most of the interviews with bereaved parents, so we wanted to study this more in depth.

In one of the interviews a bereaved couple made this tension explicit in a metaphor, so we decided to further explore this in a fourth study, giving us the chance to better understand this interplay of opposing forces.

1.3. Exploring the simultaneous presence and interplay of talking/not talking

Study 4 – Bereaved parents

In our fourth study we concentrated on a metaphor brought up by one of the bereaved couples in our second study. In the first interview with this couple the mother said:

“*we actually never talk about it, or not explicitly.*

We always somehow cycle around it,

not too close, but certainly not too far either”

(In their own language: “we spreken er eigenlijk nooit over, of toch niet expliciet. We fietsen er altijd wat rond, niet te dicht maar zeker ook niet te ver…”).

Interested in this metaphor of ‘cycling’, I asked her what she had meant by this in a second interview. She replied:

> *“well, one does both,*
>
> *(I) need distance but not too much distance.*
>
> *But you need to find a balance in it.*
>
> *Yes, that’s something I know by now, it’s not bicycling away, really.*
>
> *It’s more like staying in the neighborhood,*
>
> *and doing something with it, but taking care that it is not too intrusive ”*

(In their own language: “Ge doet de twee hé. Ge hebt afstand nodig maar ook geen te grote afstand. Maar ge moet er wel een evenwicht in vinden. Ja, dat is iets waar ik wel uit ben, dat het niet wegfietsen is, echt. Meer, in de buurt blijven en er iets mee doen, maar zorgen dat het niet te intrusief is”).

We were intrigued by these sentences because they emphasized the need for some closeness, and at the same time the need for some distance, which was also reflected in their communication with each other. Most interesting, they pointed to the simultaneous presence of these needs, and their search for ways to find some balance in this interplay. Therefore, we decided to do an analysis on this metaphor, because it might give us a deeper understanding of the process of talking and not talking, closeness and distance, all interrelated to each other, and with a continuous tension between these forces. The analysis was based on three interviews with this couple (one of which was a Tape Assisted Recall Interview). Doing the analysis we noticed that the metaphor of ‘bicycling’ was first used by the husband in the first interview, and both partners recurrently further elaborated on it in the following interviews, in dialogue with the interviewer. As such, this metaphor was not already fully developed by the participants, but rather unfolded and developed through the dialogue between the couple and the interviewer, which fits a dialogical understanding of communication (Rober, 2017).

Interplay on an intrapersonal level

Our analysis resulted in a main metaphor we labeled “*We both cycle around an emotional core of grief, surrounded by a crust”*, with different aspects to it. Related to their talking (and thus also not talking) about their grief with each other, they described (in their metaphorical language) that sometimes talking about the painful aspects of their daughter’s death was like ‘*piercing through the crust’,* the crust that protects them in daily life and enables them to go on. Therefore, they often don’t make their emotions explicit, or don’t initiate a conversation about her dying, the loss, or their grief (similar to meaning 2 in study 2). But sometimes, they said, they chose to be closer to the pain and to their child, and pierced through the crust. However, rather than making a choice between talking OR 'not talking', they somehow blended their talking and 'not talking'. Indeed, they portrayed dynamic ways to simultaneously ensure the closeness to the child and distance from the pain of the loss in specific ways or contexts of talking. More specifically, they described that in their talking they had "*detours*", in which they safeguarded some distance in their talking, for example 'not directly talking about it' (but using stories or metaphors), or talking in another language, or talking in a controlled situation (as in the interview context). These dynamic ways were described as a protection for themselves and for their partner relationship.

Interplay on an interpersonal level

Interestingly, our analysis also indicated that this process, the interplay between talking/not talking, and closeness/distance, was not merely an intrapersonal dynamic, but also resides in relationship to the other, in the ongoing dialogues with each other. What was said and not said was related to how they observed their partner in their interactions. In some way they assessed their partner in terms of the 'space' or openness for a conversation, verbally and nonverbally. Similarly, they experienced the assessment of the partner, and how he or she adjusted at it in the (initiation of a) dialogue.

In our previous studies the couples had *described* this relational process. In our first study the couple had talked about how their search related to their couple communication was also something *between* them. And exploring the meanings for not talking in our second and third study also showed important meanings connected to the interpersonal level. For example, sometimes one felt like talking about something related to the (deceased) child, but then saw the other one was doing something else (working, watching television, reading,…) and did not start the conversation. Or sometimes one started to talk but then felt that the partner was not emotionally available. Or partners would be in a conversation but then one partner said something that did not feel right to the other, or got overwhelmed by emotions of sadness, fear, or the pain of grief, and they would end the conversation (sometimes one partner turned around or walked away, or closed his/her eyes,…). This all happened in a moment-to-moment continuous interaction. Moreover, during all couple interviews (and afterwards on the video recordings), we had been able to *observe* the communication between the partners. Although not meticulously studied in the strict sense of an observational study, it was very clear that the partners observed each other during the conversation. Often they smiled at one another, or gently touched each other (as a way to support the partner in their talking to me as an interviewer?), or they finished each other's sentences when one would get too emotional to continue talking.

In this fourth study we had the chance to examine this relational process more in depth, based on two interviews and an additional Tape Assisted Recall Interview where this couple *reflected* and commented on their dynamics in the previous interview. For example, they explicitly pointed to moments where their silence or talking had to do with taking into account the nonverbal signals of the partner. Like this father said, "*Here* (pointing at a sequence in the previous interview*), I'm trying to create some room for her, as I notice she's having a hard time, so that's why I'm taking over the conversation here*".

Interpreting what this couple said from a framework of Relational Dialectics Theory (Baxter & Montgomery, 1996, Baxter, 2004, 2011), and a dialogical understanding of communication (Bakhtin, 1986; Linell, 2009; Rober, 2017), helped us to better notice and understand their interactions, as what is actually said between people is the momentary result of such dialectical and dialogical processes between people. We further elaborate on this in more detail in our theoretical reflections.

Attunement

Of particular value, at this time in our research process we found the concept of 'attunement'. Exploring the dynamics of their couple communication, the mother in this study somewhat summarized their process by saying:

"*It's always a matter of attunement,*

to ourselves and to each other"

(In their own language: "Het is altijd een kwestie van afstemmen, op onszelf en op elkaar").

It was evident that this concept of attunement was used in an intrapersonal ("to ourselves") and interpersonal context ("to each other"), as an ongoing and never ending process ("always"). As far as we know, the theory of Relational Dialectics (Baxter & Montgomery, 1996, Baxter, 2004, 2011) does not refer to this concept of attunement, but their view on communication as a continuous interplay and bi-directional process corresponds closely to what we found with this additional concept. Rober (2017) used this concept of attunement in his dialogical view on family therapy. He describes attunement as "a process of responsive interaction in which the participants of the dialogue in their (mostly unspoken) interactions intuitively (without much explicit reflection) adapt to each other in a search for ways to live together…" (p 41-42). In his description he clearly notes 'the unspoken' as part of the dialogue in the interpersonal interplay between people, in their search with each other. We further elaborate on this dialectical/dialogical view, and the concept of attunement in our reflections.

Taken together, in this study, we broadened our understanding of couple communication with, and inspired by, a dialectical/dialogical view. Although we had found the complexity of the communication process earlier in our pilot study, we now had the chance to meticulously explore the different dialectical forces (openness and closeness, related to closeness/distance), simultaneously present, in a dynamic interplay. More specifically, we found that there was the desire to talk about the deceased child (and thus the loss) with the partner, and at the same time the hesitations of doing so. Moreover, this interplay of dialectics was also apparent IN their dialogue with each other, on an interpersonal level. The concept of attunement showed extra value in connecting the intrapersonal and interpersonal level for our research.

With these findings and the concept of attunement in mind we proceeded with our fifth study, broadening our research topic to the communication between parents and professionals working at a child oncology department. We further wondered about this process of attunement, and how it plays out in the process of talking and 'not talking' during child oncology treatment.

1.4. Exploring the communication between professionals and parents

Study 5 – Parents confronted with childhood cancer & Professionals

In our fifth study, we were interested in the experiences of parents and professionals related to the communication process between them during the treatment of the child, related to the emotions of the parents. We specifically wondered about how attunement processes operated in this context. Therefore, we analyzed data from four focus groups with twenty professionals, and from nine in depth interviews with sixteen parents. These sixteen parents were the same as in study three, but now we explored a different research question.

In this study we found that for both parents and professionals the child is their primary focus during the treatment of the child. Although the professionals often noticed an elevated tension between the partners, they saw that most parents tried to keep their heads up, to survive and stay strong for the child. Often this included the parents not giving priority to their own emotions. In the views of the professionals, talking about their own emotions as parents could make things worse at a time when they needed to be stable and function for the sake of their child. As described in our third study, this relates to the experiences of the parents themselves (study 3, meaning 2: not talking because of selfcare/protection and blocking of emotions). From the perspective of the professionals this also implied that for them, explicit attention to the partner relationship in that context felt inappropriate.

Indeed, in their view, their professional commitment and engagement always needed to be associated with the wellbeing of the child. For that reason, emotional difficulties in the partner relationship were beyond their mandate, focus and skills. Similarly, the parents told us that they would find it inappropriate to receive too much attention from the professionals to their emotions or partner relationship. We found this blocking of emotions from the parents already in our third study, and apparently this also held true for their communication with the professionals.

Both parents and professionals added that the hospital setting was not inviting and appropriate for these conversations. More than time and architectural limitations, they all pointed to the fact that in the hospital most parents wanted to be with their child as much as possible, leaving no room for a private conversation between hospital staff and the parents (or between the partners, as described in meaning 1 of our third study: not talking because of the hospital and treatment context).

So, although it was not surprising that we found the same focus on the child in this study from the perspective of the parents, and apparently also from the professionals, we further wondered about this specific context of long hospitalizations and intense treatments. What about the moments that emotions spilled over? What was their approach when they noticed that parents were having a hard time, on their own or with each other? Carefully exploring these questions, and analyzing the data afterwards, we found that the parents and the professionals emphasized the need for a careful response to strong emotions in individual parents or in the partner relationship. This response involved the creation of a safe environment for the parents in which they tried to embody openness for conversation in case the parents would want to talk. Indeed, also for the parents this careful response was important: the scarce conversations they had with the professionals about their own emotions or their partner relationship needed to be attuned with their own process, at the time when they needed it, and in a way that felt spontaneous. This was interesting, because, again, we found the importance of the attunement process, now between the parents and the professionals. Therefore, the professionals needed to observe the parents closely. Most of the time this implied that they would not deepen or reflect on the emotions of the parents, but instead gave them a supportive and encouraging response to help them transcend their emotions, enabling them to go on and focus on their child again.

The bi-directional nature of the interpersonal attunement process was less explicit in this study. However, some parents also noted that they hardly talked about their emotions with the professional because they were clearly *child* psychologists, who usually initiated conversations with the parents about the child, and not about the parents or their relationship. Moreover, often parents mentioned the limited time they had with the professionals, not suitable for a longer conversation where one would have the time to transcend possible difficult emotions that might arise during a conversation. Therefore, we also assume that the parents somehow observed (not necessarily very consciously) the professionals closely and attuned with them in terms of what was possible to have a conversation about. We are strengthened in this assumption based on the slight contrast between the four oncology departments involved in this study. The child oncology department in Brussels is very differently structured than the others three (Leuven, Ghent and Antwerp). In Brussels the structure and architecture of the department is built around a kind of living room with kitchen, where the children and their parents, and also the professionals 'live' together. Rather than the psychologists visiting the parents in an isolated room (for a moment limited in time), the psychologists in Brussels can relate in a different manner to the parents of the children hospitalized in their department. Here, according to the parents and the professionals, sometimes spontaneous conversations developed between the parents and the professionals about the parents' own emotions and partner relationship. Although we did not explicitly compare the different departments in our study, it was obvious that the contexts and the availability of the professionals was different, with its implications on the conversations that took place.

Taken together, this fifth study showed that in the communication between parents and professionals, parents blocked their own emotions as a way to keep their heads up and focus on the child in this time of treatment. Correspondingly, professionals respected this stance as necessary coping behavior of the parents, and rarely initiated a conversation beyond the focus on the child. However, their openness to converse about issues in the partner relationship at the moments when these issues might threaten the parents' focus on the child, was equally important. Consistent with a dialogical view on communication, this interaction between the parents and professionals can be understood as an attunement process in the dialogue.

2. Attunement – A model reflecting our findings

During our research process we found that the process of attunement is central in our understanding of how partners, confronted with the death or life-threatening illness of their child, talk with each other and leave certain things (temporarily) unspoken or in silence. This corresponds with a dialogical perspective on storytelling (Rober, 2017).

To portray the process of attunement, Rober (2017) used the metaphor of playing the guitar, which needs to be attuned to have a good sound. Imagine this guitar playing in an orchestra (like in a couple relationship), then all instruments constantly need to find attunement with one another to create good music. Similarly, the metaphor of dancing can be used to enhance our understanding of the complex process of attunement. This metaphor was also brought up by one of the bereaved parents when she described how they needed to find ways to go on after the loss of their child. The dancer needs to feel 'in tune' with oneself and with the music to move in a fluent and smooth way. When two people, like a couple, dance together they also need to attune with each other. Most couples have created their own dance over the years together. But then, confronted with a diagnosis or death of a child, the music changes. Like an African proverb says, "*When the music changes, so does the dance*". All need to adapt to the changed music, and find ways to dance again, on their own and together. Learning a new dance involves new steps and is not possible without stepping on each other's toes at times, or movements where one interrupts the other, and so on. To be able to dance together the partners also need to trust each other. Maybe the partners hear the sounds of the music in a different way. Maybe, at times, they both need their individual space on the dancefloor to dance their own dance. When closer to each other, they both need to attune with the partner. This requires the close and constant 'sensing' of the other.

In general, **attachment theory** is at the base of most studies related to attunement and shows the intrinsic connectedness between the intra and interpersonal attunement processes. In essence, attachment theory, built on the work of Bowlby (1980), proposes that patterns of early life interaction between infants and caregivers, produce internal working models that serve as templates guiding interpersonal relations in later life. The dialogical attunement of the parent with the child has a crucial influence on the development of the child's ability to regulate emotions, manage stress and experience a sense of self agency (Fonagy et al., 2014; Hughes, 2007). Put differently, "*Through sequences of attunement, misattunement, and re-attunement (between caregiver and child), an infant becomes a person, achieving a ''psychological birth''* (Mahler et al., 1975). Similarly, other scholars argued that attachment theory is fundamentally an affect regulation theory (Mikulincer et al., 2003; Schore, 2000) with its impact on the intrapersonal attunement capacities in further life. Indeed, one could say that secure attachment in early childhood provides the child with a foundation for adaptive self-attunement, and helps the individual to modulate, inhibit, and/or enhance emotional experiences and expressions (Calkins & Hill, 2007). This process of self-attunement is an ongoing process and happens mostly outside one's awareness (Fogel, 2011). The ability to attune with oneself is essential to psychosocial wellbeing (Calkins & Hill, 2007). We further elaborate on this in the Clinical Implications.

However, according to what we found, attunement processes are more than affect regulation. Here the **dialogical perspective** can help to make explicit the attunement process as an intrapersonal process, as well as and interpersonal process. Interestingly, Rober (2017) makes the distinction between the *vertical* and *horizontal* process of attunement, inherently connected, the one making the other possible in a dynamic interaction. The vertical process indicates the reflectivity of a person, in a responsive interaction with another person (In his model this refers to a client and therapist (see Rober, 2017, p 44), but in our research project we can apply this to the partners in our study). In addition, in his dialogical perspective on storytelling, he refers to the work of Rogers and colleagues (1999) about unspoken stories: from the unsaid (what is simply not said), to the unsayable (what is difficult to say), to the unspeakable (which points to a knowledge that is dangerous or taboo) (Rober, 2017, p 107). Connected to this is the dialogical distinction between inner and outer dialogue (e.g., Baxter & Montgomery, 1996; Rober, 1999, 2017; Rober, Elliot, Buysse, Loots & De Corte, 2008; Vygotsky, 1962).

We used these ideas of vertical/horizontal attunement, unspoken stories and inner/outer dialogues, and combined both Rober's figures (p. 44 and p. 108) to illustrate the findings in this research project (Figure 7).

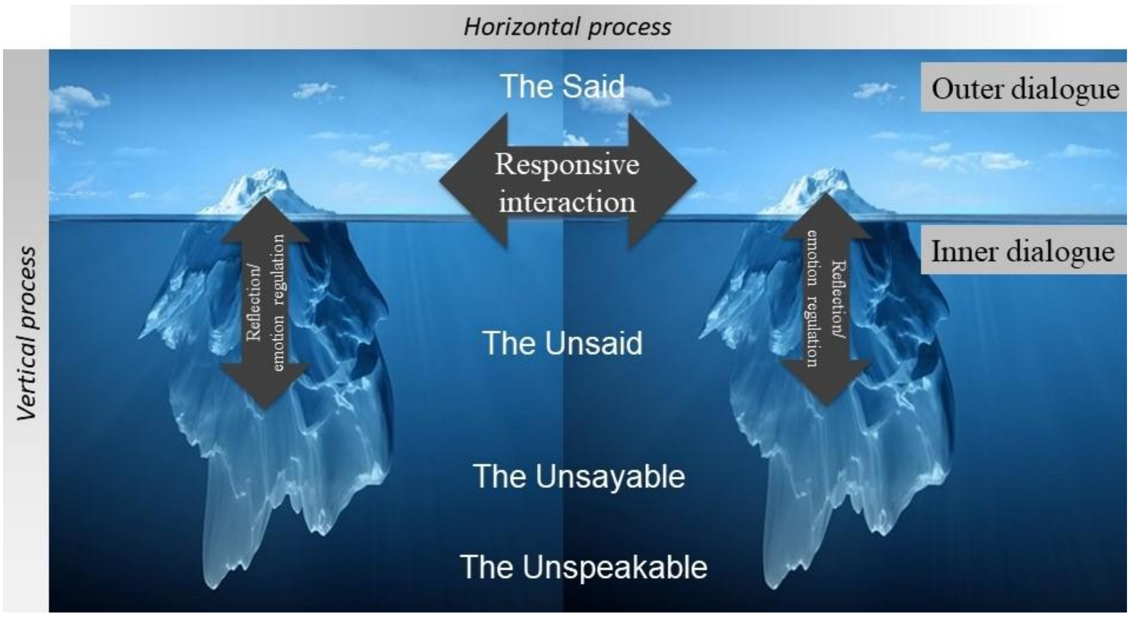


Figure 7. Horizontal and vertical processes of attunement: the said and unsaid.

In this simplified figure we illustrate both partners (as icebergs). The tip of the iceberg represents what is perceptible IN the interaction: what is said (or perceptible expressed) between two people (the outer dialogue). Beneath the surface represents what is not said (or unexpressed) (the inner dialogue).

The *horizontal process of attunement* is a responsive interaction with each other, based on what is in their outer dialogue (above the surface). Sometimes words are given to one’s experiences, spoken out loud and shared with the partner. In these conversations the partners responsively interact with each other, and attune with each other in the outer dialogue. For example, partners are talking about the treatment of the child, and then at a certain point one starts to talk about the fear of the possibility that their child might die, and the other answers that he/she does not want to think about that, and so they both stop the conversation (Study 3, meaning 3.3). Though more than only verbal interaction, there is also a horizontal attunement with one another in what is expressed in the presence of the other, without words. For example, one coincidentally finds the partner in their child’s room and silently goes away, leaving the other his/her private grieving time (study 2, meaning 3), or, as many partners told us, sometimes one wants to talk with the partner but then assesses the other’s bodily signals as not the right time to talk (study 2, meaning 4.4 and study 3, meaning 3.3). Accordingly, it is important to note that these expressions are not always deliberate or even conscious. Indeed, sometimes one partner believes he or she does not express his or her feelings, but the other attunes with what he or she assesses. Looking back at our video tapes, we found this horizontal attunement between the partners in all our interviews. When one partner was talking and suddenly started crying, the other partner often took over the conversation or changed the subject to a less emotional and more factual story. More explicitly we found this with the Tape Assisted Recall procedure in our fourth study. Then they explained some of these moments in terms of what was going on for them when they smiled at each other, touched the partner or took over the conversation. As described earlier, these interactions between the partners can be understood as horizontal attunement processes.

Equally, this horizontal attunement was found between the partners and the professionals (and the interviewer, see further in the methodological reflection). In Figure 7, the professional can be represented as one of the icebergs, in relation to the couple as another iceberg. Indeed, also in this relationship there is an attunement with each other based on what is said/not said/expressed and not expressed (study 5).

As Rober (2017) suggests, this horizontal attunement is inherently connected to *the vertical process of attunement.* In our studies we found that this vertical attunement, with oneself, is often a way of emotion regulation, which happens through the attunement with the other. Therefore, some things are not made explicit, left unsaid, or kept in silence (the unsayable, what is difficult to say). For example, to protect oneself from too much emotional intensity (meaning 2, study 3) or to create some distance from the grief for themselves (meaning 2, study 2), one will not initiate a conversation, or silence is kept as a way to 'be' with their own, intimate grief process, possibly connecting more closely to the deceased child (meaning 3, study 2). Finally, these parents described the 'unspeakable', because their grief was beyond words (meaning 1, study 2), or because their emotions were blocked and not accessible (meaning 2, study 3). Then, no words can be reached or found, and don't come to the surface (or above the surface in Figure 7).

Importantly, Rober (2017) emphasizes that these vertical and horizontal processes go hand in hand, in a moment-to-moment interaction. Actually, this involves one process, but here we discuss them separately for didactic purposes. So, in our studies we found that some things are said, or expressed, and based on the interaction with the partner and on their own reflection, other things are not said, or expressed. For example, a conversation might stop when one or both partners have the feeling that no more words are needed (meaning 4.2 in study 2, meaning 3.2 in study 3), or threatens their own distance needed from the pain (meaning 3, study 2), or when they encounter different views about what is talked about (meaning 4.4 in study 2, meaning 3.3 in study 3).

Conceptualizing the process of talking and not talking as a process of attunement helps to understand why sometimes partners talk with one another, or express their emotions and thoughts, while sometimes they don't talk or give words to their emotions and thoughts. Moreover, it adds to our understanding why partners sometimes withdraw or distance from the partner, for example, to focus merely on themselves (for example, meaning 2 in study 2). In one of our interviews with bereaved parents (study 2), a mother said "*sometimes I just need silence, and be on my own, to cry, because in the presence of my husband I also take care of him in some way, and then that is disturbing for myself*". Here she makes the explicit link between silence and being on her own, not connecting with her partner in that moment, because in the presence of each other there is always some kind of attunement with the other.

So, we could say that, based on what we found, talking/not talking is related in complex ways to connecting/not connecting, with oneself, the partner and for the bereaved parents also to their deceased child. Indeed, at times talking with each other is experienced as a way to connect in their partner relationship, while at times talking with the partner might also feel like a threat to their connection (for example, when the conversation does not go smoothly, or one does not feel listened to in their own particular and maybe different view or experiences). The same holds true for how *not* talking is sometimes experienced as a way of disconnecting from each other (silence or withholding words as a threat for their partner relationship), but also as a way to stay connected with each other, respecting their differences and each other's coping behavior (e.g. meaning 4 in study 2 and meaning 3 in study 3), and/or as a way to connect more closely with oneself (and maybe the deceased child (meaning 2 in study 2)).

Summarizing, the process of attunement is a moment-to-moment interaction, which includes vertical and horizontal processes. These processes are inherently connected and part of one process, the one resting on the other. Based on these attunement processes some things are brought in the outer dialogue, while others or not (yet). The concept of attunement also brought us to a deeper and broader understanding of the relatedness of talking/not talking and connecting/not connection (or closeness/distance).

3. Theoretical reflection

In this part of the discussion we elaborate on how our research relates, and adds, to existing research. Here we will discuss two main points of how we think our studies contribute to the grief and psycho oncology literature. First, our research might give an alternative perspective on the communication of couples confronted with the loss or illness of their child (3.1), with a focus on the meanings of avoidance of communication (3.1.1), meanings for silence in communication (3.1.2), both talking and 'not talking': the interplay of openness/closedness (3.1.3). Second, understanding couple communication as a process of attunement, we made a small contribution in bridging intrapersonal, interpersonal and interactional perspectives in the field of grief and psycho oncology related to couple communication (3.2). Finally, we wonder how our research might add or enrich the Dual Process Model (3.3).

3.1. Re-thinking couple communication

As we comprehensively described in the introduction of this manuscript, open communication (disclosing feelings and experiences) between parents about the emotional impact of child loss or childhood cancer has generally been put forward in grief and psycho oncology literature. Accordingly, 'not talking' (avoidance or keeping things to oneself) is assumed to be associated with negative outcomes related to individual and relational functioning. However, contemporary research, in both literatures, is far from consistent about the presumed beneficial effects of talking about painful emotions, or the detrimental effects of avoidance of communication (e.g., Goldsmith & Miller, 2015). Therefore, to date, scholars are incorporating multiple factors such as attachment style differences (e.g., Stroebe, Schut, Stroebe, 2006), or the nature of the emotion, the timing of possible sharing effects, and the multicomponential character of emotions (Brans, Van Mechelen, Rimé, & Verduyn, 2014), to unravel the complexity of the relation between social sharing and emotional processing, and to come to enriched integrative models to explain possible gains and losses from not expressing emotions.

With our research, we did not specifically add to the unravelling of the relationship between avoidance and the adaptive or maladaptive nature of grieving or coping with cancer. Indeed, our qualitative studies do not allow for any statements regarding the necessity of emotional disclosure/sharing emotions or dysfunctionality of avoidance in terms of psychological symptoms or measurable relational qualities. Instead, we explored the partners' ***experiences*** related to their couple communication, including the meanings they gave for 'not talking' with one another, or being silent in each other's presence. This is in line with a growing number of scholars arguing for a more nuanced view and open-mindedness about communication, exploring how and why and when communication works, also considering the desirability of talk about feelings, or what a particular couple most needs at a particular time (e.g., Goldsmith & Miller, 2014, 2015). Similarly, Rober (2002, 2006) talks about the 'good reasons' people might have not to talk, and the value of attending to their hesitations to talk (Rober, 2017).

In addition, a recent review on interpersonal communication and coping with cancer (Donovan & Farris, 2018) recommended scholars to explore the richness of interpersonal communication *processes*. This is in line with a new emerging perspective in the field of family therapy, where the focus is not on the stories themselves, but on the process of telling of stories (e.g., Rober, 2017). Equally, Baxter and Montgomery (1996) have argued that there is a need to rethink fundamental issues in the study of communication and personal relationships. They posit that the real challenge for scholars is to contribute to the understanding of the communication *process* (p 44). Moreover, from a relational dialectical view, "*rather than studying communication in relationships*" it would be of value to "*study relationships in communication*" (Baxter, 2011, p 15) (further elaborated in point 3.1.1.). Following this view, we studied the parents' experiences related to their communication *process* and the interplay between talking and not talking.

Taken together, our research contributed to the existing grief and psycho oncology literature related to the *meanings* for avoidance of communication (see 3.1.1.) and the *meanings* for silence in communication (see 3.1.2). Moreover, our findings add to the understanding of the communication process as interplay between talking and not talking (see 3.1.3), which we came to understand as a process of attunement.

We believe, and hope, that this additional and alternative view on couple communication in times of grief or coping with a life threatening illness of one's child enriches the field of grief and psycho oncology.

3.1.1. Meanings for avoidance of communication

People may avoid talking to one another for many reasons, and numerous scholars have studied these reasons in a variety of contexts (e.g., Afifi et al., 2005, 2007; Petronio, 2002). Overall, avoidance often has to do with the protection of self or others (e.g., Afifi et al., 2005; Petronio, 2002). This protection can be about minimizing psychological distress and emotional pain, or the concern that the other person would not be appropriately responsive, or to avoid overly emotional encounters or unwanted conflicts, which might lead to deterioration of the relationship (e.g., Afifi & Guerrero, 2000; Caughlin & Afifi, 2004; Caughlin et al., 2011; Roloff & Ifert, 2000).

In the grief literature the most commonly cited reason for avoidance relates to the fear of intensifying sadness and yearning for the person who died (Shear et al., 2007). In terms of avoiding or limited talk between grieving partners, Rosenblatt (2000a) notes that couples sometimes avoid conflicts and blaming, or they might not feel ready to talk. Equally, in more specific literature pertaining to the avoidance of communication in families confronted with cancer, family members avoid talking about feelings because those conversations evoke strong emotions, or they want to maintain a sense of hope or normalcy and a fighting attitude, preserve well-balanced lives, focus on enjoyable topics during what may be a limited remaining lifespan, or because some people have the feeling that the disease is a private issue, or they just don't know how to talk about it (e.g., Caughlin et al., 2011; Goldsmith et al., 2007; Goldsmith et al., 2008; Goldsmith & Miller, 2015; Miller, 2014).

In our research we found meanings related to not talking that are consistent with this literature on topic avoidance: the protection of self, the other and the relationship - for example, not talking as a way to create some distance from the pain of grief, or block emotions to protect oneself. We also found that partners did not want to burden, but spare, each other. In addition, partners often did not talk because their partner has a different grieving style, or way of coping, assuming that talking with one another could be harmful for their partner relationship.

A different approach to avoidance

Although in our research we found similar meanings related to not talking as what has been described before in literature, we were also confronted with a different framework in which the parents in our interviews approached not talking and silences (see chapters 1-4), adding another perspective to the existing literature. In the following we describe three aspects of this.

First, the couples in our interviews did not only talk about why they 'avoid' couple communication, but also sometimes *questioned the reasons why they should talk, or did not see the value of words*. This might be an important difference. In our research this related to three specific meanings: words fail to describe the experience, giving words to the experience does not change the reality, and words have no extra value for the relationship. For example, the grieving parents in our studies (see Chapters, 1, 2 and 4) frequently noted that there were no words that could explain how they feel. It's not like they wanted to talk but avoided talking because they had no words, but rather that they did not see the value in talking when words fail to describe their grief. Moreover, words were experienced as pointless, as they did not contribute to anything new, or reality would not change by giving words to it. In addition, both bereaved parents and parents confronted with childhood cancer (see Chapters 1-4) emphasized that words did not have an extra value in their partner relationship. They knew each other that well and could 'read' one another without words. Related to the first meaning (words fail) many other grief scholars have pointed to the fact that our conventional language often falls short of conveying the deep feeling of grief (e.g., Rosenblatt, 2000; Thompson & Berger, 2011; Thompson & Neimeyer, 2014). This might be related to the frequent use of metaphors used in the narratives of the bereaved and cancer patients to communicate otherwise inexpressible experiences (e.g., Graves, 2009; Nadeau, 2006; Rosenblatt, 2000; Skott, 2002).

Second, the bereaved couples we interviewed did not only question the reasons why they should talk, but also highlighted *the value of not talking or silences*. For example, being by themselves, withdrawn from others, in silence, sometimes brought them closer to the deceased child. Similarly, they valued their partner's private space and silence to grieve. We elaborate on this in point 3.1.2.

Third, in our studies all parents were not only describing their *thoughts* about 'why they did not talk' with each other, but also explained this *not talking as a process that happens between them, in a moment-to-moment interaction.* Not talking was often a part of a process between them, where they interacted with each other, sometimes said something and then attuned with what happened next (in themselves, or in how they perceived the partner and their interaction at that time). For example, when one partner starts to talk and the other partner joins in the conversation with his or her own emotions, the initiating partner sometimes withdraws from the conversation because he or she does not feel enough distance from the pain of the other, and gets overwhelmed by it. So in our research we did not only find information about why couples would avoid talking, or do not talk, but also how not talking was sometimes part of a conversation, or the end of a conversation. Therefore, our research was not so much about avoidance, as it was about the communication *process*, or *attunement*. We elaborate on this further on.

3.1.2. Meanings for silence in communication

Literature or research describing or exploring the meanings of the opposite of talking about emotions with one another, not talking or silence, is minimal. This is also true for the grief and psycho oncology literature. Applying a social interactional model of bereavement narrative disclosure, Baddeley and

Singer (2009) reviewed the multiple factors that may have an effect on what they call successful bereavement narrative disclosure. They considered the influence of the relationship of narrator and listener, their personality characteristics, the type of loss and the time since loss, and the content and structure of the narrative. In addition, they examined ‘unspoken memory’ in the context of bereavement (Baddeley & Singer, 2010) and proposed that silence can serve a function of maintaining or reconfiguring the narrative identity of each individual, as well as the family narrative as a whole. They argue that silence can have multiple meanings and effects on family members, depending on the contextual application of that silence. “*If silence is defined as a way of shaping narrative identity, then it is framed not as a form of denial, but as a way of striving to accomplish developmental tasks that are important after a major loss”* (Baddeley & Singer, 2010, p 206). As such, silence can have its own identity and meanings, rather than framing it as the opposite or absence of talking, or even as the avoidance of talking. This connects to what we described earlier, related to our slight discomfort with the concept of ‘not talking’ (p.140) and links with a dialectical view on communication (e.g., Baxter & Montgomery 1996; Baxter, 2004, 2011) (further elaborated in point 3.1.3).

In our interviews (see chapters 1-4), related to silence as a separate entity, we can identify several different contexts in which the parents talked about it. First, parents often said they needed ‘silence’ described as an environment quality (no noise, tranquility) to achieve some rest in this turbulent time of cancer treatments, or an exhausting grief process. Therefore, they needed to be on their own, distant from others (possibly creating a meaningful moment of private bonding with the deceased child for the bereaved parents). Second, ‘silence’ related to the unspeakable (Rogers et al., 1999) silence being an alternative for an experience beyond words. Third, words that were kept in silence also related to an intimate and personal process, where some things are shared and other things are not. This connects to Petronio’s model of *Communication Privacy Management* (Petronio, 2002), where one needs privacy boundaries, preventing others from invading one’s own intimate experiences. Deciding whether to keep things secret or disclose them involves complex processes (Petronio, 2002). Similarly, exploring silences in a first conversation about a family death, Rober and Rosenblatt (2013) referred to these processes, and pointed to the value of *selective disclosure*, as some sensitive information is shared within a family, and some is not (yet). In addition, Rober and colleagues (2012) made use of this concept to understand how families construct an emotionally acceptable and supportive story, a story to live by. Essentially, ‘selective disclosure’ refers to the complex process involved in dealing with the dialectic tension between openness/closedness, referred to by Baxter as ‘segmentation’ (e.g., Baxter & Montgomery 1996; Baxter, 2004, 2011) (further elaborated in point 3). Finally and fourth, more explicitly related to the dialogue between the partners, ‘silence’ was also a quality of their communication with each other, as in sharing without words, or being connected with each other while (or caused by, or as a consequence of) being verbally closed to one another. In his work on parents grief, also Rosenblatt (2000a, 2000b) found that couples did not always need words to make a shared narrative.

Additional things to consider related to avoidance and silence

Interestingly, some scholars propose to also consider the multiple goals involved in communication (Goldsmith, 2001). Indeed, the impact of avoidance can be influenced by the perceptions of the intentions for that avoidance (Caughlin & Afifi, 2004).”*… avoiding conversations about cancer probably has a different meaning if the reason for doing so is to protect another family member compared to the expectation that the other family member would not welcome a discussion… or avoidance attributed to focusing on optimistic thoughts would not have the same meaning to family members as avoidance with the perceived goal of denying what is really happening*” (Caughlin et al., 2011, p. 411). Indeed, the ways avoidance and also silence is experienced, or put differently, the subjective interpretations of interpersonal communication behaviors (Donovan & Farris, 2018), are important to consider, as couples can give different meanings to ‘open communication’ (Goldsmith & Domann-Scholz, 2013), and attributed motives for topic avoidance has been found to mediate relationship satisfaction (Caughlin & Afifi, 2004). Moreover, the norms families (or couples) have developed across their relational history, or their ‘conversation orientation’, the degree to which they foster openness, should be considered, as this informs their expectations of one another’s behavior (Fisher et al., 2016).

Likewise, in most of our interviews parents referred to the way they are used/not used to talk (with one another) about their emotions in general (See Chapters, 1, 2 and 3). In addition, their intentions related to not talking (or avoid conversing about their feelings) made their limited communication acceptable and even valuable for both partners. Like one couple explicitly said “w*e both know why we sometimes don’t talk. I know she wants to spare me, and she knows I need my own space… So, that’s ok*”. This means that the way they gave meaning to their own and their partners intensions for talking or not talking (avoidance or silence) was somehow related to what was ‘ok ‘or ‘not ok’. In the few individual interviews we did with only the mother (See Chapter 2 and 3), most of them said their partner was not present because he was “*not able*” to talk about these issues, where some framed it as acceptable, while for others this perception caused more frustration.

Based on what we found related to the meanings of avoidance, as also the meanings for silence, we came to a more *process* focused perspective on couple communication. Indeed, we came to understand that it would be valuable to approach couple communication with a both/and perspective, also considering the interplay between talking/not talking, or openness/closedness.

In the next point we elaborate on what we believe can be of additional value for grief and psycho oncology scholars in approaching couple communication.

3.1.3. Both talking and 'not talking': the interplay of openness/closedness

In this research project we used the dialectical framework of Baxter and Montgomery (Baxter & Montgomery, 1996; Baxter, 2004, 2011) to look at couple communication of parents confronted with the loss or illness of their child (See Introduction for a description of this theory). This view was valuable as a lens with which to look at, and better understand, what we encountered in our data. In the following we briefly describe their theory, *Relational Dialectics Theory* (RDT), as this was one of the influential theories guiding our research process. We focus on some of their core premises that have been relevant to our research, and in that of other scholars.

Relational Dialectics Theory (Baxter & Montgomery, 1996; Montgomery & Baxter, 1998; Baxter, 2004, 2006) is grounded in the theory of dialogism developed by Russian theorist Mikhail Bakhtin (e.g., 1986). It theoretically connects the work of Bakhtin to the study of interpersonal and family communication (Baxter, 2011). RDT holds the core premise that social life is a dynamic knot of contradictions, and "*relationships are organized around the dynamic interplay of opposing tendencies as they are enacted in interaction*" (Baxter & Montgomery, 1996, p. 6). Examples of these opposing tendencies are 'autonomy – independence', or 'closeness – distance', or 'openness – closedness', all in some kind of continuous tension or interplay with one another. In other words, the dialogue between people is the moment-to-moment result of the interplay between opposing forces, where some discourses are centered and others are marginalized (or silenced). In this perspective, openness and closedness function in ongoing interplay with one another, and concerns the need to share information with a relational partner and, simultaneously, the need to retain some degree of privacy. Or, put differently, people feel the wish to be open and share with others, while at the same time they also want to keep thoughts and feelings private. These simultaneous forces are in a continuous tension with one another (and with the interplay between other contradictions), which is voiced in the dialogue. Importantly, these tensions are regarded as neither positive nor negative, but as part of life and necessary for continuity and change in a relationship. As such, they do not need to be resolved, but instead are managed and enacted through communication. Related to this, they describe several communicative strategies, or praxical patterns, to somehow manage contradictions. These can take either synchronic (the simultaneous equality of opposing voices) or diachronic forms (where one voice is privileged at a given time/space, while opposing voices are relatively muted, and this with a cyclical quality) (Baxter, 2004). For example, in the dialectic tension openness/closedness, this can be privileging one pole of the tension based upon the topic or subject matter (segmentation), or tacking back and forth through time, alternating an emphasis on one dialectical voice with an emphasis on another dialectical voice (spiraling inversion). Overall, these struggles needs to be regarded as a dynamic process, "*in which the struggle at one point in time sets in motion the nature of the struggle at a subsequent point in time*" (Baxter & Montgomery, 1996, p 8). What is said (or not said) at one point invites what is said (or not said) in a next moment.

We acknowledge that this summary of the *Relational Dialectics Theory* is a huge simplification of their refined and complex theory. In addition, we have to note that RDT has evolved in recent years, which reflects their research and writings. The main author of this theory, L. Baxter, speaks of RDT 1.0 and RDT 2.0 (Baxter, 2011), the latter underscoring that contradiction is a discursive struggle, not a psychological tension within an individual between competing needs or motivation. However, for this discussion, we want to focus on how this framework (mainly RDT 1.0), with its general core premises and concepts, can be of value in looking at couple communication between parents confronted with the loss or illness of their child.

To our knowledge, the dialectical view, with its emphasis on the value of both openness and closedness, and the inherent tension between them, has not been described in grief literature before. However, in the field of communication research, Toller and Braithwaite made use of *Relational Dialectics Theory* to look at the communication of grieving parents (Toller, 2005; Toller & Braithwaite, 2009). In one study, Toller (2005) examined the communication between bereaved parents and their social network. In this study two dialectic tensions emerged: between being open /closed to others about their deceased child, and between the physical absence of their child and the continuing presence and emotional bond with their deceased child. In another study (Toller & Braithwaite, 2009), examining the communication of bereaved parents with each other, their analysis revealed that bereaved parents experienced two dialectic contradictions: one between grieving together as a couple and apart as individuals, and another between being both open and closed when talking with one another about their child's death. Openness to one another was perceived to be essential, but embracing closedness in order to give space to grieve as individuals was found to be equally necessary. The bereaved parents in their study negotiated the dialectic tension of openness/closedness by 'being open with others, closed with spouse', and/or 'closed verbally, open nonverbally', and/or 'accepting each other's communication'. In addition, Umphrey and Cacciatore (2014), referred to a dialectical view to look at couples communication as they explored the relational and metaphorical themes embodied in bereaved parents narratives. One of these metaphors, related to couple communication was ‘the elephant in the room’, which expresses the obvious presence of their grief but is avoided or ignored. These authors suggest that the metaphor reflects the dialectal struggle parents have in talking/not talking about their deceased child.

As described earlier, the bereaved parents in our study also described this tension between openness/closedness with the partner, and the interplay between these forces (See Chapters 1, 2 and 4). Moreover, we found that this tension was inherently connected to the dialectic closeness/distance with the partner (see p. 160), and with the deceased child (as also Toller (2005) observed the dialectic absence/presence of the child). Indeed, most parents did not really want to talk about their grief emotions with their partner, but they did want to stay connected with the child. One way to continue this bond with the child was to keep the child alive in their conversations, in talking about the child, which was hardly inseparable from talking about the pain of the loss. A dynamic way of dealing with these tensions was found in our fourth study, where the parents described how they talked about their child ‘with some distance’, in an attempt to keep the pain of grief from surfacing too much. For example, rather than talking directly about the loss of the child, they talked in metaphorical language, or they talked in another language (See chapter 4 for more details or examples). As such, in these specific ways of talking they simultaneously ensured the closeness to the child and distance from the pain of the loss.

We know of no research applying this dialectical view in relation to parents whose child is treated for cancer. However, communication scholars have referred to, or adopted, a relational dialectics framework in the study of family communication in the context of one adult family member diagnosed with cancer (Caughlin et al., 2011; Wolf, 2015). In a study about family communication and coping in response to a parent’s diagnosis and eventual death from lung cancer (Caughlin et al., 2011) family members expressed the desire for openness, as a means of navigating the cancer experience, while at the same time participants saw avoidance as useful to serve prosocial purposes (such as protecting others). Some people stated that they valued open communication, but then talked about all the issues they never talked about. This ‘*being open while avoiding*’ was not considered as a contradiction or tension for the family members. The authors postulate that their findings connected with a dialectical perspective, although also distinct from it in important ways, as they found little, if any, evidence for inherent contradiction between avoidance and openness in their participants. Accordingly, they suggested conceptualizing openness and avoidance as two separate dimensions of communication, which may or may not be inversely related in different circumstances (Afifi et al, 2007; Caughlin et al, 2011). This is interesting, because it seems that in some contexts there is the value of both talking and not talking (as theorized in the dialectical framework), but without the presence of a tension (differing from the dialectical framework).

Equally, in our studies with parents whose child was in cancer treatment the dialectic tension between openness/closedness was less apparent. Mainly, these parents were fearful of getting too emotional to be able to function, as they would be confronted with the fear and sadness of what is happening to their child. There was trust in the fact that they could put their emotions and relational life on hold. We might say that because they blocked the access to their emotions in this time the force pulling towards openness about their emotions was (temporarily) neglected or also blocked (spiraling inversion, Baxter, 1996, 2011). However, sometimes emotions spilled over and then there was a need to ventilate, but not to deepen the conversation for themselves and not to burden the partner. Nevertheless, considering the dynamic knot of not only the dialectic between openness/closedness but also closeness/distance, we found that these parents did speak about their desire of connection with the partner, mostly without words. Some also mentioned the fear of disconnection that might be caused by not talking about their emotions with each other.

It is clear that both talking and not talking (as two separate entities) go hand in hand. Indeed, communication research shows that people often look for strategies to achieve some openness but also some protection (Goldsmith et al., 2007). Most frequently these strategies involve the balancing between talking with some limitations or selections (diachronic forms, Baxter, 2004): e.g. limiting the frequency of talk, or talking about certain topics (e.g. talking factually about the cancer) but not about certain other things (like the prospect of death) (segmentation, Caughlin et al., 2011), or refraining from talking until the other partner brings up the topic. As described earlier, in our research we also found the *simultaneous* presence of talking and not talking (synchronic form, Baxter, 2004), in ‘talking with some distance’.

What the parents in our interviews told us about their couple communication (See Chapters 1-4), and the dialectical view we used to interpret what they said, brought us to the understanding of couple communication as a process of attunement. Again, this is merely a model or (alternative) lens to look at couple communication, and thus does not allow for any statements about whether the attunement processes these partners described are associated with adaptive or maladaptive coping or grieving. However, other scholars have found that talking about feelings among couples dealing with cancer can be relieving or distressing depending on whether couples successfully negotiated the interaction between them, or could coordinate differences between them. For example, partner responding with empathy and understanding was found to be crucial for talking to be beneficial, while if the partner did not reciprocate then both patient and partner reported greater depression a few months later (Goldsmith & Miller, 2015).

In the following, next point, we describe how this understanding can somewhat contribute to bridge intrapersonal, interpersonal and interactional perspectives in the field of grief and psycho oncology related to couple communication. Finally, we wonder about how our research could possibly extend or enrich two influential models/approaches in the grief literature: grief as a process of meaning making, and the *Dual Process Model*.

3.2. Parent grief and coping with childhood cancer is relational and interactive

Research on grief and cancer has traditionally focused on individual processes (e.g., Stroebe & Schut, 2015; Van Schoors et al., 2017, 2018). Indeed, many have contributed to the examination of individual reactions, coping strategies and health consequences (see Stroebe, Schut, & Finkenauer, 2013 for a review related to bereavement; Vrijmoet-Wiersma et al., 2008 for a review related to assessment of parental psychological stress in pediatric cancer). For example, how does one adapt to the cancer diagnosis or death of a child? Or who is most at risk for complications, and why? What are risk factors for the individual? However, many have advocated for a long time to include a relational and family perspective (e.g., Rosenblatt, 2000; Manne & Badr, 2008; Nadeau, 2008; Gilbert, 1996; Shapiro, 1994; Kazak et al., 2003; Rolland, 2005; Kissane & Bloch, 2002, Walsh and McGoldrick, 2004). Equally, Rosenblatt (2006) referred to the metaphor of a dance of closeness-distance in couples after the death of a parent, and suggested that this dance was also connected to their sharing or not sharing after the loss. Undoubtfully, in the last years there have been increasingly more efforts to examine interpersonal factors, both in the field of bereavement and cancer (see Donovan & Farris, 2018 for a review related to communication and coping with cancer; Schoors et al., 2017 for a review on couple functioning after pediatric diagnosis; e.g., Kamm & Vandenbergh, 2001; Wijngaards-de Meij et al., 2008; Stroebe, Schut, & Finkenauer, 2013 for a review related to bereavement).

Still, these individual and interpersonal studies have largely been researched independently from one another, and although evidence is growing that the integration of intra and interpersonal perspectives could deepen scientific understanding, research on interactional patterns remains limited (Albuquerque, Pereira, & Narciso, 2015; Beach & Anderson, 2003; Beach, 2009; Stroebe, Schut, & Finkenauer, 2013; Stroebe & Schut, 2015).

Related to our topic of couple communication in the context of grief or cancer, some scholars contributed greatly to the understanding of this interactive process. For example, Stroebe and colleagues (2013) examined the impact of avoidance of talking about the loss of their child and remaining strong in the partner's presence ('Partner Oriented Self-Regulation', POSR). They found that holding in one's own grief in order to protect one's partner from pain was actually associated with greater grief for both the partner and the self later on. They noted that they would not have found this had they not included both individual and family levels of analysis, or in their words "*the whole picture that emerges is more than the sum of the parts*" (Stroebe & Schut, 2015, p 874). Equally, Bergstraesser and colleagues (2015) studied dyadic coping of parents after the death of a child. With their mixed methods design they found that sharing emotions helped them in their grief processes, both as a couple but also individually. In addition, a study examining 'protective buffering' in the context of breast cancer (e.g. hiding worries and denying concerns for the partner) (Manne et al., 2007) found that the adoption of buffering did not have the intended impact, reducing the partner's distress.

With our research, concentrating on the way partners experience their couple communication, we contributed to the interpersonal literature on parental bereavement and relational dynamics of parents confronted with childhood cancer from a qualitative design. Similarly, other scholars did qualitative research on parental grief (Gilbert, 1989; Klass, 1988; Riches & Dawson; Rosenblatt, 2000), and on couple functioning when one's child is treated for cancer (e.g., Lavee & Mey-Dan, 2003; Patterson et al., 2004; Silva-Rodrigues et al., 2016; Steffen & Castoldi, 2006). Their studies, and ours, suggest that an exclusive focus on individual bereaved parents or on individual parents with a very sick child might miss very important areas of the lives of these parents, making it harder to understand what they do about, for example, emotional control, talking, and private reflection.

Moreover, as we came to understand couple communication as a process of attunement, both vertical and horizontal, we also contributed to the understanding of an interaction between individual and relational aspects. Although not measured within a quantitative design, exploring the communication *process* through the experiences of these couples related to their communication, an inherent connection between self-reflection, self-regulation, and responsive interaction with the partner emerged. Or, in the metaphorical image we used earlier, the dialogue between the partners was reflected in a dance of two individuals, dancing together, in words and movements, in the said and unsaid. Indeed, with our focus on their communication we saw that, in a moment-to-moment interaction, they simultaneously attuned with themselves (self-reflection, self-regulation) as with each other (responsive), leading to the expression or withholding of words in the ongoing dialogue.

Understanding couple communication as a process of attunement might thus contribute to bridging intrapersonal, interpersonal and interactional perspectives in the field of grief and psycho oncology related to couple communication.

3.3. A contribution to the *Dual Process Model*?

To bring this discussion to an end, we wonder about how our research could possibly enrich or extend the Dual Process Model (Stroebe & Schut, 1999), which is an influential model in the grief literature. Initially this model was formulated from an individual approach, but increasingly it has incorporated more relational and interactional aspects (Stroebe & Schut, 2015; Wijngaards- de Meij et al., 2008). In addition, other scholars have applied this model in the context of childhood cancer (e.g., Carpenter, Wittkowski, Hare, Medford, Rust, Jones, & Smith, 2018; Eaton Russell, Bouffet, Beaton, & Lollis, 2016).

Almost two decades ago Stroebe and Schut (1999) introduced their *Dual Process Model*, which suggests that the most effective adaptation to loss involves oscillation between loss oriented (attention to aspects of the death) and restoration oriented coping (reengage in life and adapt to a changed life following the loss) (see introduction for a more detailed description). Central in this model is the process of oscillation, which is regarded as a dynamic regulatory process of confrontation and avoidance. Broadening the DPM to an interpersonal level, the relationship between the coping strategies of a bereaved parent and his/her partner and the adjustment of the parent was examined, thereby taking both partners' reactions into account (Wijngaards- de Meij et al., 2008). They found that for fathers having a partner who coped in a similar way was helpful for them, but for women the husband's coping was unrelated to their adjustment. More recently, they proposed a family level extension to their DPM: DPM-R (Stroebe & Schut, 2015), which integrates loss orientation and restoration orientation tasks at both the individual and the family level.

As suggested by others (e.g., Carpenter et al., 2018; Eaton Russell et al., 2016) this model also offers a lens to look at the experiences of parents confronted with childhood cancer. These parents also experience grief over impending and actual losses (such as separation from other family members, loss of independence, missing their previous lives). In a recent study on experiences of children with brain tumors and their parents (Eaton Russel et al., 2016), the balancing between grief and survival emerged. Indeed, most parents feel pulled in the direction of uncertainty and grief, but pulled themselves toward maintaining hope and a positive outlook, using strategies as 'reclaiming health' and 'redefining normal' to balance their grief by focusing on survival.

Although the DPM is much broader than focusing only on the avoidance of communication, or confronting the loss through communication, we might relate to it with our own research on couple communication.

Our research could enrich, or add to the DPM in three ways:
First, we suggest that in communication processes loss and restoration oriented coping go hand in hand and happens simultaneously. In their DPM-R they formulate two tasks at the family level that involves communication in the broad sense: 'share pain of grief with family members' (loss oriented tasks at the family level), and 'family level distraction and non-grief related interaction' (restoration oriented tasks at the family level). However, family members or families can confront the loss (e.g. talking about the loss, or sharing grief together) in a way that also builds in some avoidance (e.g. not talking directly about the pain of loss but talking in metaphorical language, or talking in a context where there is more distraction or the simultaneous presence of non-grief related interaction). Similarly, Shear (2010) argued that the bereaved do not oscillate between loss and restoration-focused coping, but rather that these processes overlap, occurring in tandem. In addition, an equalization between 'loss oriented coping' and 'talking/sharing', or between 'restoration oriented coping' and 'not talking/distraction' asks for more differentiation. Indeed, not talking about the loss can also be a way of a loss oriented coping (e.g. being close to one's grief, not wanting to be disturbed by words failing to describe how one feels), while talking about the loss can be experienced as a way of distancing from the intense pain of grief residing inside. Similarly, Baddeley and Singer (2010) describe how telling the story about the loss fits into loss-oriented coping, where restoration oriented coping involves an avoidance of ruminative concern with grief. However, they note, silences can also be involved in loss oriented coping, as it can contribute to the griever's own identity growth or stability, or the stability of the family system.

Second, our research adds to the relation level of the DPM, as we found that the regulatory process is indeed not merely situated on an individual level. Both partners contribute to a process of attunement in which they regulate their own emotions, while interacting with the partner. In the interviews (See Chapter 4) the parents described how they kept an eye on each other, at times relying on one another, or creating some distance for the other. In this way emotional regulation was clearly also a relational process. We captured both processes in the concept of (vertical and horizontal) attunement. Now we could wonder if the dynamic oscillation process in the DPM could be better understood as a process of attunement. Stroebe and Schut (2010) have acknowledged that the process of oscillation is difficult to operationalize. Because oscillation is a dynamic process that can change from moment to moment and varies depending on contextual factors, traditional questionnaires often fail to assess its nuances.

Therefore, they recommended other data collection techniques to provide rich descriptive information. Maybe our research provided this.

Third, looking through a lens of the DPM to our findings with parents confronted with childhood cancer, we can imagine that not (or limited) talking about their feelings with one another serves their efforts of pulling away from their grief emotions, in order to focus on their own survival to continue functioning for the sake of their child. Parents are mostly immediately forced on some kind of 'restorative' coping (Carpenter et al., 2018), rather than the presumed oscillation between loss and restoration oriented coping. The concept of 'overload', or having more to cope with than one feels one can manage', was recently added by Stroebe and Schut as a missing link in their model (2016). During treatment too much is happening in the lives of these parents to be able to balance between loss and restoration, while taking action to gain control over the overload is the only possible way to survive in these circumstances. In this time talking with each other about their feelings can feel unsafe in their modes of survival, while not talking can be a way to keep control, safety and the ability to function.

Taken together, our research possibly adds and enriches existing research in the grief and psycho oncology literature by providing an alternative perspective on the communication of couples confronted with the loss or illness of their child. Moreover, viewing the process of couple communication through a lens of attunement processes might contribute to the necessary bridging of intrapersonal, interpersonal and interactional perspectives in this field, related to couple communication.

4. Methodological Reflections and Study Limitations

The methodological approach for this research project was entirely qualitative. This is consistent with the exploratory and descriptive nature of our research question, regarding the lived experiences of the participants themselves (Van Manen, 1990): how do couples experience their communication with each other? Therefore, our findings do not allow for any statements fitting a quantitative research design, examining research questions regarding, for example, the association between couple communication and couple functioning in terms of psychological symptoms or distress. From a clinical perspective we have learned a great deal about couples interactions in times of emotional pain and stress (we further elaborate on this in the Clinical Implications) but, in the strict sense, our research and its findings cannot give an 'evidence based' answer to questions like 'What are the most adaptive coping strategies within the couple relationship to deal with loss or illness?', or 'Does one exhibit more or less psychological symptoms over time when they have talked about their emotions with the partner in difficult times?'.

Moreover, as qualitative research attempts to illuminate the particulars of human experience occurring in a context of its own (Van Manen, 1990; Sandelowski, 1996), it cannot generalize its findings to a broader population beyond the research sample. However, this statement is controversial (e.g., Polit & Beck, 2010; Sandelowski, 1997, 2004), as a growing number of qualitative scholars suggest that the rich and highly detailed nature of in-depth interviews is especially suited for revealing higher-level concepts and theories that are not unique to a particular participant or setting (e.g., Glaser, 2002; Morse, 2004; Polit & Beck, 2010; Misco, 2007). Indeed, more than providing a list of themes or key categories, the qualitative researcher needs to develop an interpretation or model which applies across the different accounts (Ayres et al., 2003) and "those themes that have exploratory force both in individual accounts and across the sample are most likely to apply beyond the sample" (p. 872). In qualitative research the concept of 'transferability' is used to indicate the possibility for study findings to be 'transferred' to other people and situations (Polit & Beck, 2010). Transferability is a collaborative enterprise between the researcher and the reader. The researcher needs to provide a thick description (Lincoln and Guba, 1985) (providing detailed descriptions of the participants' accounts, information about the research setting, the participants, the study context and so on), so the reader can make the transfer (Polit & Beck, 2010), possibly replicating findings to a new situation or in varying conditions.

In our research project, we studied the same topic in two different contexts: parents who grieved the loss of their child, and parents whose child was in cancer treatment. The specific meanings related to 'not talking' in these two contexts (study 2 and 3) appeared to have similarities but also differences (see p. 146). However, the overarching concept of attunement as a lens or model to look at the process of couple communication applies to both contexts and is possibly of use in many other contexts wherein marital partners relate to one another. Moreover, the process of attunement also appeared to be useful in the understanding of the communication process between parents and professionals (study 5), similar to what Davies and her colleagues (2017) found in their research in pediatric settings, and Rober's use of the concept of attunement in the context of psychotherapy, or the dialogue between therapist and the client, couple or family (Rober, 2017).

4.1. Rigour in qualitative research

We think of our research project as carried out in a reflective and meticulous way, fitting the high level requirements for rigorous qualitative research (e.g., Barbour, 2001; Seale & Silverman, 1997). We made use of different study methodologies (in data collection and analyses), with different participant groups and several procedures to enhance the validity and credibility of the studies (Cresswell & Miller, 2000) (See Phd Objectives). Moreover, our research is framed within the approach of *Consensual Qualitative Research* (Hill et al., 1997), based on the idea that doing research is teamwork. Indeed, during the almost ten years we worked on this project, a lot of scholars, both qualitative and quantitative, have collaborated with us in an intense reflection: from the design to the collecting of data, conducting the interviews and focus groups, analyzing our results and reporting on our findings in various forms (seminars, conferences and peer reviewed papers). They all contributed in an important way to our study, and to the reflectivity of the researcher. More specifically, in order to verify the credibility and trustworthiness of the analyses we worked with an extensive external auditing procedure for each study. This means that we sent a detailed report with all the codes and their meanings units, the category structure and substantial context information (like our research questions, the participants, methodological choices or shifts) to individuals external to the project. All meaning units were audited for their fit into the assigned category, the overall category structure was reviewed, and our interpretations were challenged. Independent of one another they then gave written feedback to the researcher. In all studies their feedback gave rise to a re-ordering of the code system. In the first study these were three members of our research team (fellow qualitative researchers and practicing family psychologists). The second study was audited by the promotor (Rober), in addition to an experienced family therapist from the Netherlands, and a quantitative scholar who also was a practicing family therapist. For the third study three psychologists working at a child oncology department (who also participated in our focus groups in study 5) conducted the audit. Our analysis of the fourth study was audited by the promotor (Rober), and two co-promoters (Neimeyer and Rosenblatt) of this research project, all experts in the field of qualitative research

(Rober and Rosenblatt), or the field of bereavement (Neimeyer and Rosenblatt). For this external audit, all meaning units were translated to English. And finally, for the external auditing of our fifth study we made use of a videotaped meeting where we discussed our findings, with the same three auditors as in study three. This way, the 'external' auditors were most often external (not involved in this research project) but sometimes (in the case of the promotors and professionals at child oncology) they were only external to the interviews and analyses.

4.2. Limitations of our research project

Our research has important limitations to mention. These concern the limited focus on our research question, data collection, and the use of retrospective interviews to study couple communication.

4.3. Research questions guided us

First, it must be clear that our research studies were guided by our research questions, which led us to neglect other important issues that would, in their own right, be very interesting to study. For instance, we did not focus on gender differences. However, in our couple interviews we could not note an explicit gender difference. But, in the four interviews we did with the mothers whose husband chose not to participate, these women explicitly mentioned how they were more inclined to talk about their emotions and experiences than their male partner. Also, although we often wondered about the possibility of cultural influence, we cannot make any claims about how our findings would be similar or different in another culture. In the following we discuss two of what we found were our main limitations: our data collection and the use of retrospective interviews to study couple communication.

4.3.1. Data collection

An important note has to be made regarding the data collection in this research project. In all our studies we only had the chance to interview the parents who were prepared to participate, and thus 'to talk' about their experiences. Moreover, as we invited them for an interview as a couple, most of the parents who participated also agreed with 'talking with their partner' about their experiences. Given our interest in better understanding the 'not talking', it would have been particularly interesting if we would have been able to interview those who chose not to participate.

The selection procedure was different for the bereaved parents (study 1, 2 and 4) than for the couples confronted with childhood cancer (study 3 and 5). For the pilot study (study 1) this was based on the fact that I was intrigued by the story of this bereaved mother who brought up the complexity of couple communication. This fits with a purposeful sampling or initial sampling to address initial research questions (Charmaz, 2006). For the second and fourth study we needed to conform to the ethical board guidelines (of the University Hospital Leuven in Belgium), which required that the hospital psychologist first contact all parents before their identities could be given to the researchers. To ensure maximum variation sampling, they randomly selected thirty couples who lost their child after cancer treatment between 2002-2007. In total, twelve couples, two mothers and one couple who chose to be interviewed separately, participated. We were not allowed (in accord with ethical board guidelines) to further insist on participating for the ones who chose not to. Although research participation has been demonstrated to be perceived as beneficial for most participants, and even has a therapeutic value (e.g., Dehaene, 2010; Dyregrov, 2004; Riches & Dawson, 1996; Rosenblatt, 1995; Romanoff, 2001), this is in contrast to the guidelines of most research ethics boards (e.g., Buckle et al., 2010). In addition, Akard and collegues (2014) found that more phone calls to participants who refuse to participate does not make a significant difference in participation. Therefore, our studies with bereaved parents were limited to the ones who were willing to participate (in the following we further elaborate on this).

Even more recruitment challenges were present in our studies with parents confronted with childhood cancer. Indeed, where in our studies with bereaved parents only the parents needed to consent, in study three and five also the professionals of the child oncology department needed to consent. In doing ‘sensitive’ research, like involving parents in paediactric care, this is generally referred to as ‘gatekeeping’ (e.g., Melville & Hincks, 2016; Stevens et al., 2010; Tomlinson et al., 2007). Indeed, for these interviews the psychologists of the child oncology department did the selection of the partners based on their assessment of how these interviews could be harming or distressing for these parents or their relationship. We don’t know how many parents they invited for our research, but the process of data collection was clearly difficult. As a result of that we also collaborated with the University Hospital in Brussels. Over a period of more than one year we finally found sixteen parents who were prepared to participate. We conducted nine interviews, four during the treatment of the child, and five when the child only needed to go to the hospital for checkups.

Taken together, we can easily assume that the parents who were invited and willing to participate in our interviews were more ‘talkative’, and had fewer couple issues than average. However, also the ones who did not participate taught us important things, as they helped us to better understand ‘not talking’, even validating our findings in some way. This was possible because the psychologists reported on some of the reasons why some parents chose not to participate. For example, some non-participating bereaved parents said that they were not used to talking about it and that participating in an interview to talk about their grief did not fit with their way of coping with the loss, individually and as a couple. Moreover, some parents said they did not see the benefit or usefulness of this interview for their own grief process, or considered their words inadequate to express what they felt. Furthermore, most non-participating parents explicitly noted that they feared it would stir up too much of the pain around the loss. Finally, some parents also mentioned the fact that because this interview would be in the presence of their partner, it would be awkward or too difficult, as most of them hadn't talked about it with each other for a long time, or ever.

Equally, for the parents confronted with childhood cancer, reasons mentioned for not participating were similar to what we found in our study: the limited time these parents were together (and thus the chance to talk with one another) and not wanting to reflect on their own emotions to protect themselves and their partner relationship. In contrast to the bereaved parents (whose recruitment was easier), these parents did not want to talk about their child with a strange researcher to keep their child's story alive, but instead tried to put their own emotions on hold to be able to function for the sake of the child.

In addition, while we recognize that we were initially frustrated about the difficult data collection for our third and fifth study, our findings may also help to understand why the psychologists chose not to invite some couples to participate. Or, put differently, the underlying motives of the psychologists in deciding which couples to invite (or not), correspond with what we found related to the process of attunement between the professionals and the parents. This was also confirmed in our meeting with the psychologists of the oncology department (Leuven and Brussels) where we discussed our findings. All affirmed that what we found was highly recognizable in their experiences with parents, but some couples don't manage to regulate their emotions or attune with each other, or put relational issues aside during treatment. These couples were not invited, as a way to protect them, or they did not participate, possibly as a way to protect themselves and their partner relationship (assumed by the psychologists based on the reasons given not to participate). So it was only later in the process that we realized that also the professionals were equally in a process of attunement with these couples. First, the selectivity in inviting people for participating in our research was guided by their attunement to the parents, and second, as described in study five, in their professional activities in relation to the parents, attunement appeared to be central in their daily communication with them. Interestingly, also as a researcher I experienced this attunement process in relation to these parents (we elaborate on this further on).

4.3.2. The use of retrospective interviews to study couple communication

A major limitation of our research project concerns the use of retrospective interviews to study the experiences of bereaved parents and parents confronted with childhood cancer about their couple communication. Such methods of data-collection lead to narratives that retrospectively give sense and meaning to what happened. Or, referring to the metaphor of dancing we described earlier, such methods of data collection approach the dance from the perspectives of the dancers, and such accounts offer necessarily a distorted reflection of what the dance looks like from an outsider perspective. Observations from an outsider perspective might offer additional important information of what the attunement process of couple communication around grief or coping with cancer might look like.

Actually, we must say that we did not study the communication process, nor the process of attunement, but only the meanings these parents gave to it afterwards. This caveat has also been put forward by Baxter (2011), pointing to the heavy methodological overreliance on interview data in which participants construct the meanings of their relationship by talking about them, which gives us “talk about relationships rather than relationships in talk” (Baxter, 2011, p. 122).

Moreover, in an effort to describe their communication, the parents adopted an experiental perspective and relied on psychological concepts like ‘motivations’, ‘fears’ or ‘intentions’. The use of such concepts “psychologized” the description of the process of attunement, while in essence the attunement process is embodied and mostly out of awareness. However, because we only relied on the retrospective interviews for our research it might seem that people or couples control their attunement with each other, or that the process consists of different processes (vertical and horizontal), both regulated consciously, while actually they are all part of one automatic process that happens between people. In our discussion of future research perspectives we further elaborate on this.

4.4. Attunement with the researcher/interviewer

From the very beginning, we immediately experienced the vulnerability of the population we wanted to study, and the ethical challenges related to it. It was evident that we needed to ‘adjust’ to what these parents found appropriate for their process. For example, the arrangements for all interviews persistently involved a dialogue related to the timing and setting of the interviews. For example, most of them preferred that the interview not take place in the hospital because it triggered too much of the pain for the bereaved parents, or did not want to plan the interview in the evenings because then they would not have time to distract before going to sleep, or wanted to find a moment when their children were at home because that might disturb them, and so on. Equally, other scholars researching families confronted with illness and grief (e.g., Stevens et al., 2010), found how sensitivity and flexibility of the researcher in scheduling and rescheduling the interview was an important aspect in accommodating to the (changed) needs of the families.

Moreover, during the interviews there was a process of attunement, between me as a researcher/interviewer and the couples. For example, sometimes the focus of the conversation needed to be altered because one of the partners became overwhelmed, explicitly asking not to go deeper into the subject we were talking about. More than the explicit messages, interviewing these couples often felt like dancing together (cfr the metaphor we used earlier to describe the process of attunement). Sometimes, based on their tone of voice or glance in their eyes, I was afraid of coming closer (asking more delicate questions), or sometimes smaller steps were needed to come to a certain point. In all interviews we first needed time to ‘sense’ one another, creating some kind of trust and a platform to talk about their emotions and experiences, by taking the time to introduce the deceased child to me (sometimes showing me pictures or the child’s room), or telling me the story of the treatment trajectory of their child in detail. Indeed, qualitative research with vulnerable populations requires a balance “between allowing participants freedom of expression and pursuing domains of interest on which the study was based” (Stevens et al., 2010, p. 502). As an interviewer I often realized the thin line between these interviews in the context of research, and the conversations I have with couples in a therapy setting (Dehaene, 2010; Romanaff, 2011), where in both contexts profound conversational expertise is needed to create a dialogical space. In almost all interviews I felt the vulnerability of the parents sitting in front of me, which always invited me to dance slowly and attuned to their process. Put differently, it was obvious that I needed to create an interview context that supported their survival mode or grieving process, taking care not to undermine their strength they needed to go on, which was only possible through an attunement process between me and them.

5. Clinical Implications

It all started from clinical practice with bereaved parents. *“Do we really need to talk about it?”*, and *“Is it really necessary to involve my partner in these conversations?”*. These were the first sentences in the foreword of this manuscript. My background in psychology and systemic oriented psychotherapy made me convinced of my answers: Yes, and Yes, to both questions. The last ten years I conducted more than fifty interviews with bereaved parents and parents confronted with childhood cancer, analyzed all, thought and wrote about it, and talked with numerous colleague professionals in this field. Today, the answers to my initial questions are a lot more nuanced and substantiated, and therefore more complex. First we discuss the good reasons people have not to consult a psychotherapist. Next we elaborate on the implications of our research findings for psychotherapy.

5.1. Good reasons not to consult a psychotherapist

During this research project, meeting a lot of parents dealing with child loss or childhood cancer, it was remarkable that almost all these parents said they have not consulted a psychotherapist, and did not see the value for themselves or for their couple relationship to do so. Although there was probably a selection bias in our research (see Limitations, p. 178), this finding might be in line with research showing that most people and couples adapt well to the crisis of a pediatric cancer diagnosis (e.g., Vrijmoet-Wiersma et al., 2008; Van Schoors et al., 2017), or to the death of a loved one (e.g., Bonanno, 2004; Hooghe & Neimeyer, 2013), and don’t need professional help.

Moreover, all five studies in this research project made clear that parents dealing with the loss or illness of their child can have ‘**good reasons’ not to talk**, or not to talk with their partner (or others), about how they feel. For example, because talking makes it more painful or because words are inadequate or pointless (See Chapter 2). For some people ‘not talking’, or ‘selective talking’ (selective in topic or timing, or selective in people whom they talk with) might correspond with adaptive coping or grieving, attuned with themselves. Indeed, the central process of meaning making can also take place in a nonverbal way: in silent private reflections, art, making or listening to music, rituals, and so on. In addition, one can create or find meaning in silence even with the use of words, although not spoken out loud, like writing letters to oneself or others, or writing songs. And sometimes, when people are in extreme situations with stressors demanding all their attention, or when they feel they don’t have enough strength to reflect, some meaning making can, or needs to be, put on hold to be able to function. Then ‘not talking’ can serve as a protection, not to reflect, or not too much (See Chapter 3 and 5).

In a similar way, some *couples* do not find value in talking (a lot) with each other about how they feel. Sometimes that's how they are used to interact with one another in their unique couple dance, attuned with each other. For them, giving words to their feelings might not have extra value in their couple relationship (See Chapters 2 and 3). However, even if they don't talk, or don't talk a lot, a co-construction of meanings around the loss or cancer of their child emerges in their interaction. Some couples even find more connection to each other in a mutual agreed silence about some topics, and share their grief or anguish in other ways, like going to the grave together without speaking, lighting a candle in each other's presence, standing at the bedside together while they squeeze the partner's hand or offer a tissue to the partner. For many, these nonverbal means of sharing are experienced as a way to go on apart and together, attuned with themselves and each other. "*We're in this together, we don't need to say how we feel"* is one of the many expressions of the parents in our interviews.

Taken together, simply advising or encouraging all parents to talk, or to consult a psychotherapist, merely based on the fact that they lost a child or their child has cancer, would be overly simplistic and unfounded. Rather than pathologizing 'not talking' or 'silence', we suggest that it would be good for professionals in general to value different resilient ways of coping, including silence.

5.2. Implications of our findings for psychotherapy

In the following we discuss what the findings of our studies might imply for psychotherapists working with bereaved couples or couples whose child is (or has been) treated for cancer. We relate to two main implications: first, exploring hesitations and good reasons not to talk, and second, working with threatened connections.

5.2.1. Exploring hesitations and good reasons not to talk

For those who do consult a therapist the approach of the therapist regarding talking and sharing of emotions should be nuanced. Preferably the dialogue between therapist and client involves a profound exploration of good reasons not to talk, or hesitations to talk or to share their experience with others (Rober, 2002, 2006) and the possible values of talking *and* not talking in terms of connections (we elaborate on this further on). For example, people might fear they would be encouraged to share their most intimate grief experiences with the therapist and perhaps the spouse, or they might well fear the surfacing of the pain as a consequence of talk, or they might doubt the usefulness of talking about their loss or the cancer of the child, since this will not change the situation they are in (See Chapters 2-5). This means that the therapist makes room for '*talking about talking'* (Fredman, 1997; Hooghe, 2012), not only in a one-time assessment, but during the entire process of therapy. For example: "*What do you expect would, or can happen if you talk (about this, now, to me or to your partner)*?" or "*What do you feel you might gain from not talking about your feelings (at this point)*"? This exploration could be broadened to questions relating to 'what', 'when', 'how' and 'to whom', and the combination of these elements? For instance: "*what would you like to talk about, and what would you rather not talk about with me/your partner?*' (e.g. talk about our difference in coping or grieving, but not about the pain or fears), "*when is a good time for you to talk with your partner*?" (e.g. not in the presence of our children, or not right before we go to sleep), "*how would you like to share and what might be more difficult*? Or "*how do you usually share how you feel with your partner?"* (e.g. not sitting in front of each other and looking in each other's eyes, but rather if we walk or sit in the car together), and "*Whom would you like to talk to or share your experiences with*?" (e.g. with people who know how it feels, or listen carefully without judgements or advice).

Often these hesitations and meanings related to 'not talking' are not 'already known' by the clients themselves, but rather they emerge during the exploration with the therapist, becoming more 'visible' for themselves and the therapist. Indeed, also in our interviews the meanings for 'not talking' often emerged through the conversation with their partner and the interviewer. The feedback we received from the participants after the interview, was that it had been a helpful conversation because it made them think about their couple communication, their reasons for talking or silence, or the reasons why they chose for a certain way of dealing with the loss or illness. One mother even asked for the videotape of the interview, so she could listen again to what her husband had said about his process, and the way he restrains for her sake (See Chapter 2). Indeed, working with couples, this exploration of their hesitations, or the good reasons they have not to talk (or to limit talk) with one another, can be very valuable for the partners and their couple relationship. We therefore suggest that therapists make room for this exploration, and potentially help and encourage partners to talk with each other about why they sometimes prefer not to talk, or why they need to end a conversation or withdraw at times. For instance, if one says that not talking about emotions serves his or her own intimacy preferences, or that he or she just can't talk about it because then too much pain would surface, than that has a different meaning than when, for example, the partner says that his or her limited talking sometimes has to do with protecting the couple relationship because he or she feels they cope very differently. Possibly, being able to understand why the partner sometimes stops a conversation or does not talk a lot, can make a difference for both of them, and for their relationship.

The same holds true for professionals working with childhood cancer. Although their main focus is on the wellbeing and recovery of the child (See Chapter 5), arguments have been made to broaden psychological care to include the parents and their partner relationship (e.g., da Silva, et al., 2010;

Silva-Rodrigues et al., 2016; Wiener et al. 2016). Consequently, it might be important to explore the value, meanings and hesitations for parents to talk (and not to talk) about their own experiences, with each other or with the clinician. Based on this continuous assessment, they can act accordingly (respect the limited talking, make time for a conversation and/or refer to outside counseling or psychotherapy). However, all the parents we interviewed were mainly preoccupied with their sick child and did not request therapy at the time of treatment. This fits with the idea that often parents dealing with childhood cancer only seek therapy when treatment is ended (e.g., McKenzie, 2012).

It is our belief that a better understanding of the multitude of meanings related to ‘not talking’ (and thus being able to listen to the different nuances), and a dialectic view on communication (assuming that there is a value in both openness and closedness, and that these opposing forces are in a tense interaction with each other) can help clinicians and therapists to explore their clients’ hesitations, and thus better attune with them.

5.2.2. Working with threatened connections

In all our studies we found that talking and not talking often has to do with three different connections: connection with oneself, with the deceased child, and with the partner. These connections are inherently connected to each other. However, in the process, over time, one connection might be more prominent than the others. Or, put differently, at certain points in time, people can have the feeling that a certain, or all, connections are threatened or lost. Or, in terms of attunement, people or couples might feel their attunement process with themselves and/or with the partner is disturbed. For example, the bereaved mother in our first study talked about her process, and the process of their couple relationship over the past ten years since the death of her son, and explicitly referred to times when she felt she had lost herself and needed to withdraw from others. Then she started writing letters to her deceased son, to feel closer to him. Therefore, her husband had built an attic room for her, where she could be alone, and with her deceased son, in silence. At other times, maybe as a consequence of the enduring silence between them, she felt the connection with her partner was in danger. Then they needed to talk with each other. However, most remarkable was the fact that she also said that her withdrawal and the silence between them for some time, had saved their relationship.

This relates to the vertical and horizontal process of attunement, inherently connected, but sometimes one of the elements can feel disturbed, which, for some, results in a quest for psychotherapy. Then, we suggest that the therapist works with what is most present for the clients at that time in their life, always realizing that these connections are ultimately tied to one another. Sometimes this requires a greater focus on the attunement process with themselves (in an individual therapy, whether in the presence of the partner or not), on the interaction between the partners (preferably in a couples therapy), or on the connection with the deceased child.

Several procedures or strategies have been described which relate more explicitly to one or more of these connections (e.g., Neimeyer, 2012, 2015). For example, narrative techniques in psychotherapy like '*narrative retelling'* (Neimeyer, 2018), '*Chapters of our lives'* (Neimeyer, 2014), or '*directed journaling'* with 'sense-making' or 'benefit-finding' instructions (Lichtenthal & Neimeyer, 2012) can have great value when people struggle with whom they have become since the loss or cancer diagnosis of their child, not recognizing themselves in a psychological mirror, as if the thread of continuity in their self-narrative is disrupted (Neimeyer, 2001). Equally, the importance of the continuing bond with the deceased (e.g., Klass & Steffen, 2017; Neimeyer & Hooghe, 2017) has been translated into many innovative practices, like '*introducing the deceased*' (e.g., Hedtke, 2015) or '*the life imprint*' (Neimeyer, 2015). And, from an *Emotionally Focused Therapy* approach for couples (e.g., Johnson, 2012; Johnson & Williams-Keeler, 1998), some scholars suggested to explore the negative relational cycles and make underlying emotions of both partners visible (Lagrou & Hooghe, 2018), or to enhance the connection between the partners by exploring 'my grief', 'your grief' and 'our grief', with attunement and difference being the core elements (Migerode, 2018). In this couple work, the therapist helps the partners to attune with themselves and with each other, and at the same time the therapist needs to attune with the processes of both parents and with the emotional climate in the couple. In terms of attunement processes this is thus more complex in couple or family therapy (Rober, 2017).

Here we want to make two additional notes. First, sometimes merely the presence of the partner, with only one partner talking about their own grief experiences while the other one is primarily listening, can meet both partners grieving styles, while also contributing to a greater understanding and connection in the couple relationship. And second, some couples might seek our help to look for other, nonverbal, ways of sharing their experiences with each other (e.g., Cacciatore & Flint, 2012; Chang & Fong, 2015; Kosminsky & Jordan, 2016; Odgen et al., 2005, Stang, 2015; Thompson, 2012; Zech & Arnold, 2011), as a way to connect in what they are going through, without the necessity of spoken words.

Summarizing, the findings of our research gave rise to more complex and nuanced answers related to the communication process of individuals and couples and what it implies for clinical practice. People might have good reasons not to talk and not seek professional help. If they do come to therapy, we suggest that therapists make room to explore the process of talking and not talking, recognizing that both openness and closedness are part of a continuous process of attunement. Finally, although we strongly believe in the added value of the presence of the partner or other family members as the natural support system in the grief process (Hooghe & Migerode, 2015; Kissane & Hooghe, 2011), we think therapists should sometimes consider individual work, based on the exploration of the connections which might feel most threatened at a certain point in time. Consequently, therapy might usefully be carried out at times with both partners together, and at times with them separately. However, based on the findings of our studies, we suggest that therapists always are mindful that ultimately these connections are all related to one another.

6. Future research questions

As communication is a moment-to-moment interaction which, retrospectively, can only be explained in meanings given to certain behavior, or in terms of psychological concepts one attributes to the behavior (like inner motivations, or desires), additional research using observational methods would be very helpful to study this interpersonal domain. Based on our findings of attunement processes, it would be of great value to observe closely what happens between people when they converse with one another, incorporating nonverbal behaviors like silences, eye contact, sighs, tears, looking up or down, holding hands, and so on. All of our interview tapes hold this information but we did not do an analyses of those moment to moment interactions. For example, in one of the interviews a mother was telling about the last days of treatment of her baby daughter, when I asked her “and what happened when she died? Where you both there?”. The conversation abruptly stopped. She looked down for about half a minute, then looked to her husband (who was also looking at his lap), and then he looked up and looked at her. He nodded and smiled at her. She looked back to her lap and suddenly she looked up, excused herself, and said that she had not expected this question. She looked at her husband and he touched her shoulder for a very short moment. Then she shook her head, stood up, filled her glass of water and restarted the conversation “yes, we were both there. It was in the middle of the night…”. Looking back at our video tapes after all analyses were done, we knew this was an illustration of what we had found: the process of couple communication viewed through the lens of an attunement process. In addition, as was the case in what we described here, many parents excused themselves when they started to cry, and many parents who talked about their limited talking did this in almost an apologizing tone to the researcher. For example, one of the fathers said ““We actually never talk about it, maybe we should, but we actually don’t”. It would be interesting to explore the little words like “actually”, or “maybe”, or “I guess you could say that…”. This is in line with what Baxter (2011) proposes, to study the interplay of contrasting discourses in spoken or written texts. In her ‘contrapuntal analysis’, which is a specific kind of discourse analysis, competing discourses and how meanig is constructed through their interplay, are examined.

In a larger context, it would be interesting to study this topic of couple communication in the context of bereavement or childhood cancer for couples where only one of the partner is the biological parent of the child (as in our first study), or couples where one or both partners are from another culture, or homosexual couples.

7. General conclusion

During our research process we found that the process of attunement is central in our understanding of how partners, confronted with the death or life-threatening illness of their child, talk with each other and leave certain things (temporarily) unspoken or in silence. This corresponds with *a dialogical perspective* on storytelling. The process of attunement is a moment-to-moment interaction, which includes vertical and horizontal processes. These processes are inherently connected and part of one process, the one resting on the other. Based on these attunement processes some things are brought in the outer dialogue, while others or not (yet). Consequently, our research might bring an alternative perspective on the communication of couples confronted with the loss or illness of their child, thereby making a small contribution in bridging intrapersonal, interpersonal and interactional approaches in the field of grief and psycho oncology literature.

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