A dramatic sunset sky with a bright sun partially obscured by dark, textured clouds. The light from the sun creates a glow and illuminates the edges of the clouds, transitioning from deep blue to warm orange and yellow.

PSYCHOLOGY OF EMOTIONS,  
MOTIVATIONS AND ACTIONS

# Hope

INDIVIDUAL DIFFERENCES,  
ROLE IN RECOVERY AND  
IMPACT ON EMOTIONAL HEALTH

Francis L. Cohen  
Editor

A dense field of bright green grass blades, filling the bottom third of the cover. The blades are sharp and detailed, creating a textured foreground.

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**PSYCHOLOGY OF EMOTIONS, MOTIVATIONS AND ACTIONS**

# **HOPE**

## **INDIVIDUAL DIFFERENCES, ROLE IN RECOVERY AND IMPACT ON EMOTIONAL HEALTH**

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**PSYCHOLOGY OF EMOTIONS, MOTIVATIONS AND ACTIONS**

# **HOPE**

## **INDIVIDUAL DIFFERENCES, ROLE IN RECOVERY AND IMPACT ON EMOTIONAL HEALTH**

**FRANCIS L. COHEN**  
**EDITOR**



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Additional color graphics may be available in the e-book version of this book.

### Library of Congress Cataloging-in-Publication Data

Names: Cohen, Francis L., editor.

Title: Hope : individual differences, role in recovery and impact on emotional health / editor, Francis L. Cohen.

Description: Hauppauge, N.Y. : Nova Science Publishers, Inc., [2016] |

Series: Psychology of emotions, motivations and actions | Includes index.

Identifiers: LCCN 2016028483 (print) | LCCN 2016043520 (ebook) | ISBN

9781634857031 (hardcover) | ISBN 9781634857178

Subjects: LCSH: Emotions. | Hope.

Classification: LCC BF511 .H67 2016 (print) | LCC BF511 (ebook) | DDC 152.4--dc23

LC record available at <https://lcn.loc.gov/2016028483>

*Published by Nova Science Publishers, Inc. † New York*

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## **PREFACE**

This book provides research on the individual differences of hope. It reviews the role hope has in recovery and its impact on emotional health. Chapter One describes the importance of hope in peoples' personal and professional lives. Chapter Two presents hope as a major factor in predicting the resilience of families. Chapter Three attempts to explicate theoretically the impact of hope on adolescents' optimal achievement and its impact on their emotional well-beings. Chapter Four studies the relationship between hope, spirituality and life satisfaction, using a structural equation model approach. Chapter Five examines Polish students' and how their spiritual experiences mediate between hope and religiosity. Chapter Six uncovers the emotional problems preceding an eating disorder and the main reasons and explanations for the development of these problems. Chapter Seven explores the two-sided nature of hope as it pertains to decision-making at the end-of-life. Chapter Eight examines the experience of hope in caregivers of children with CI. Chapter Nine focuses on the revisiting and re-storying of hopeful actions and practices in the face of emotional hurt, physical pain, sorrow, loss and shattered dreams.

Chapter 1 - This chapter describes the practices of doing hope together in a kaleidoscope of personal and professional narratives woven into and between people's lives. Narrative therapy practices such as compassionate witnessing and narrative documents are called on to story small steps of doing reasonable hope in everyday life and in counseling research. The chapter draws on the witnessing of a farewell ritual between a grandmother and grandsons, witnessing diners at a café and excerpts of narrative documents to produce, acknowledge and richly describe practices of care that contribute to the doing

of hope together. These small and ordinary, yet significant, incidents take place in the entangled spaces of discursive and material, between humans and humans, as well as between humans and matter-materiality. The chapter also weaves vignettes from everyday living and counseling-research data.

Chapter 2 - The goals of this chapter are to present hope as a major factor in predicting the resilience of families. Three theoretical models were integrated in order to explain individual differences in hope in the family: attachment theory (Bowlby, 1988), the family systems model (Crittenden and Dallos, 2009; Minuchin, 1985) highlighting conflict management styles, and resiliency models of dealing with family stress and adjustment (Masten and Monn, 2015). This integrated model has been used to present and review individual differences in family coping and hope by comparing the challenges and tasks of typical families with those of families with special needs children. The survey demonstrates the unique contribution of hope to family resilience. It also emphasizes the challenge of preserving future expectations among family members who struggle with disabilities in their homes. Research has demonstrated that the promotion of hopes in these families requires unique personal strength, and their construct of hopes is often qualitatively different. Families of children with disabilities often develop a different set of hopes, because they are painfully aware of the difficulties that their children may face in their attempts to reach similar goals. Interventions designed to increase hope, emphasizing their clinical and research implications were presented together with future research directions.

Chapter 3 - *Hope* is a psychological process that may yield positive educational and non-educational outcomes. Its characteristics, positive in nature, reflect a non-deficit positioning, enabling individuals to anticipate, plan, and persist in different courses of action. One inquiry that has credence for research development is the extent to which hope, as a collective entity, could facilitate and encourage the achievement of *optimal best*. The authors recently developed the *optimal achievement bests theory* (Phan, Ngu, and Williams, 2016), which has been refined to include the *continuum of achievement bests framework*, whereby five progressive achievement bests are noted: *historical achievement best*, *realistic achievement best*, *personal achievement best*, *optimal achievement best*, and *ultimate achievement best*. Optimal achievement best is a point of reference, which may serve to encourage individuals to strive for successful performance outcomes. Ultimate achievement best, differently, is more inspirational and outside the scope of capability for most individuals. Accomplishing ultimate achievement best, however, is a possibility that cannot be discounted, overall.

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The authors consider the possibility that hope, in effect, could positively relate to individual achievement bests (i.e., notably optimal outcomes) of enriched emotional well-beings, situated within the context of the period of adolescence. Emotional well-beings, encompassing a wide range of affective responses have been argued to feature centrally in human agency (Phan, 2015b; Phan and Ngu, 2015b), especially for adolescents who may experience both positives and negatives. Does hope, for example, facilitate the striving and achievement of enriched emotional well-beings in the face of difficulties and obstacles? To what extent does hope enable adolescents to experience positive affective responses (e.g., happiness) that may, in turn, counter detrimental personal functioning on a daily basis (e.g., feeling of pessimism)? The authors' conceptualization of achievement bests is significant, and may contribute substantive theoretical, methodological, and practical yields for consideration.

This chapter then, makes attempts to explicate theoretically the impact of hope on adolescents' optimal achievement bests of their emotional well-beings. This theoretical positioning may provide grounding for advancement into the study of: (i) hope as a facilitator and central mediator of achievement best in relation to emotional well-being (e.g., optimal achievement best), and (ii) the achievement best theoretical framework as reflecting the nature and characteristics of positive psychology. The authors' in-depth analysis in particular, may explain the impact of emotional well-beings as a proactive vehicle for adolescents.

Chapter 4 - The number of studies on hope and spirituality as predictive factors of youth's emotional well-being has increased over the last years. The present chapter studies the relations between hope, spirituality and life satisfaction, using a structural equation model approach, offering transcultural evidence of a scarcely studied population, the Spanish youth. A sample of 224 participants aged 18-28 completed the Spanish version of the Satisfaction With Life Scale, the Dispositional Hope Scale, and the subscales Meaning and Peace of the FACIT-Sp. A structural model was built to test variables' predictive power on life satisfaction. The a priori theoretical model fitted the data well. Results suggest that hope and meaning have strong effects on youth's life satisfaction, whereas peace is not a statistically significant predictor. The variance accounted for it is large enough to be considered relevant. The key factor associated to youth's emotional well-being seems to be hope. This new transcultural evidence obtained in a Mediterranean culture is consistent with recent literature mainly grounded in Anglo-Saxon evidence,

supports the universalism of the approach and should encourage future strategies to promote hope and spirituality in youth people.

Chapter 5 - Researchers have tried to prove that spirituality mediate between some personal traits and religiosity. The aim of this study was verification that among students from Poland spirituality mediate between hope and religiosity. The sample consisted of 115 students of University School of Physical Education in Poznań and Warsaw School of Social Psychology. The following tools were used: Herth Hope Index (HHI), Daily Spiritual Experiences Scale (DSES), The Age Universal I-E Scale, Brief Religious Coping Scale (RCOPE) and two one item scales regarding frequency of attending mass and frequency of praying. It was proven that spiritual experiences mediate between hope and religiosity. It means that among students from Poland relationship between hope and religiosity is indirect. Spiritual experiences totally mediate between hope and intrinsic religiosity, extrinsic personal religiosity as well as positive religious coping. It means that Polish students which have a higher level of hope have a more spiritual experiences and finally more using religion to struggle with stress as well as they religious are more intrinsically or personal extrinsically oriented.

Chapter 6 - In the period before the development of an eating disorder patients try to hide and suppress negative emotions for others (Fox, 2009; Noordenbos, 2013). They use their eating disorder as a coping strategy to suppress negative emotions (Jantz and Muray, 2002). However, this coping strategy is highly dysfunctional and not effective, because when they stop dieting their negative emotions are felt again.

In the first part of this chapter the results will be presented of a qualitative research about emotional problems in the period before the development of the eating disorder and the reasons for these emotional problems. In total 57 patients with anorexia and bulimia nervosa were interviewed who told that before their eating disorder they learned to hide, avoid and suppress their emotions. The main reasons they mentioned for this behavior were that they had lack of self-esteem and were afraid of being rejected by others; pleasing behavior in order to be accepted; caring for parents who had emotional problems; having parents who were not able to express their own emotions; or parents who did not allow that their children express negative emotions.

In the second part of this chapter the results are presented about the treatments which helped the eating disorder patients to develop more healthy emotion regulation strategies such as psycho-education, writing an emotion diary, mindfulness, Acceptance and Commitment Therapy (ACT), Cognitive Behavior Therapy (CBT), and role playing. In the treatment they learned to

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recognize and to accept their negative feelings and emotions, instead of avoiding and suppressing them. They learned to regulate and express their emotions in a healthy way and no longer needed their eating disorder as coping strategy for negative emotions.

Chapter 7 - When end-of-life discussions ensue, hope is a frequently summoned word. While often utilized by patients and caregivers as an optimistic oath to the human spirit and condition, some healthcare providers look upon the word with fear if not disdain. To the former, it is a buoy that energizes them to continue the defense to withstand suffering, and as death approaches, a way to define their legacy. To the latter, it may represent a form of denial that must be bolstered by unnecessary tests and procedures. In this commentary the authors explore the two sided nature of hope as it pertains to decision-making at the end-of-life. On the one hand, the authors of several publications have demonstrated that some terminally ill patients equate hope with optimism, not necessarily with cure. On the other hand, some patients don't realize that they are marshalling hope in an effort to defeat fear. When that happens, hope and fear unite as the ball-and-chain which the prisoner drags. It is this dichotomy, one that can complicate the relationship between patients and healthcare providers, which needs exploration. For it is only through this inquiry that the authors can aspire to understand and reframe hope so as to minimize suffering and assist patients stave fear as life comes to an end.

Chapter 8 - Millions of children live with chronic illness (CI), which impacts the well-being of the entire family unit. The presence of hope has been suggested as a way to improve the functioning of parents and families coping with a CI. This chapter examines the experience of hope in caregivers of children with CI residing in a Ronald McDonald House adjacent to a children's hospital in a Midwestern city. Group interviews were conducted with caregivers whose children or grandchildren were receiving medical treatment. Analyses revealed that caregivers identified faith, the care received by hospital staff, and the fighting spirit of their child as the major contributors to hope. Detractors from hope included the seriousness of the medical issue, splitting up the family during treatment, and financial pressure. In addition to the thematic findings, this study demonstrates a unique methodological approach for studying hope and well-being, which have largely been studied using quantitative research methods. The results of this study have important implications for researchers and practitioners working with caregivers who reside at a Ronald McDonald House and are coping with the stress of a child with a CI.

Chapter 9 - This chapter focuses on the revisiting and re-storying of hopeful actions and practices in the face of emotional hurt, physical pain, sorrow, loss and shattered dreams. Painstakingly slow recovery from major surgery coincided with the shocking and immeasurable loss of a beloved mother. This chapter grew out of conversations reminiscing about a graduation ceremony in the year following the loss. Memories, of a gold dress, carefully stitched together the concern, love, attention, compassion, and admiration of a mother and her support for her daughter's hope of an academic future. These memories later became the focus of an outsider witnessing practice and remembering conversations as a means by which to re-visit, re-story and remember the celebration of the graduation ceremony. Eleven years after the loss and as an aspiring academic, the small, but significant steps of speaking through the hurt of injustice, the immense loss of not only a mother, but central person in the life of a young woman living with disability, opened up the space to discuss the discursive and material practices of Ashlie's lived experiences.

*Chapter 1*

**DOING HOPE ... TOGETHER,  
IN EVERYDAY LIVING AND IN COUNSELING  
RESEARCH**

*Elmarie Kotzé\**

University of Waikato, Aotearoa, New Zealand

**ABSTRACT**

This chapter describes the practices of doing hope together in a kaleidoscope of personal and professional narratives woven into and between people's lives. Narrative therapy practices such as compassionate witnessing and narrative documents are called on to story small steps of doing reasonable hope in everyday life and in counseling research. The chapter draws on the witnessing of a farewell ritual between a grandmother and grandsons, witnessing diners at a café and excerpts of narrative documents to produce, acknowledge and richly describe practices of care that contribute to the doing of hope together. These small and ordinary, yet significant, incidents take place in the entangled spaces of discursive and material, between humans and humans, as well as between humans and matter-materiality. The chapter also weaves vignettes from everyday living and counseling-research data.

**Keywords:** discursive↔material, narrative documents, witnessing practices, practices of hope

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\* [elmariek@waikato.ac.nz](mailto:elmariek@waikato.ac.nz).

## INTRODUCTION

Hope is too important — its effects on the body and the soul too significant — to be left to individuals alone. Hope must be the responsibility of the community.

(Weingarten, 2000, p. 402)

I draw on various small strands of theories and practices to investigate examples of “doing hope” that communities actively engage in. One such strand that I draw on is narrative therapy. Narrative therapy emerged through the linguistic and discursive turns (White and Epston, 1990) and was shaped by philosophical currents including the poststructural work of Foucault, especially his analysis of power/knowledge relations, and Derrida’s practices of deconstruction. A more recent influence is the work of Deleuze and Guattari (see Winslade, 2009). I weave between witnessing practices as described by Weingarten (2000, 2003, 2010) and therapeutic practices of outsider witnessing developed by White (1997, 2007) to witness myself, other human-human interactions and intra-actions, as well as human-matter “intra-actions”, as described by the quantum physicist, feminist and new materialist Barad (2007, p. 178).

Weingarten’s (2000, 2003, 2010) practices of compassionate witnessing and doing reasonable hope, and White’s (2007) outsider witnessing practices provide counselors with tools to use in counseling with the intention of richly storying hope-full actions. Weingarten (2000, 2003) describes four positions from which a person can engage in witnessing. Her two-by-two grid of witness positions is constructed around whether or not a witness is aware and empowered, or unaware and disempowered in relation to that which the person witnesses. A person is able to witness the self and others compassionately when the person moves into an aware and empowered position (Weingarten, 2003). I apply these ideas to pause and notice how I am positioned when I witness, and to turn that witnessing into small acts of doing reasonable hope. Weingarten (2010) argues that reasonable hope becomes possible when hope is relational and consists of a practice or actions. Reasonable hope “maintains that the future is open, uncertain, but influenceable, [and] seeks goals and pathways” (Weingarten, 2010, p. 7). Such a practice seeks ways to accommodate doubt, contradictions and despair: it focuses on small but significant actions, even when a person experiences despair. “Doing” reasonable hope becomes possible when hope is re-interpreted, not as a noun, but as an action we “do with others” (Weingarten, 2010).

Michael White developed a three-stage narrative therapy witnessing practice on the basis of Barbara Myerhof's "definitional ceremonies" (White, 2007, p. 165). In this approach, client and therapist negotiate the process of outsider witnessing for a particular purpose. They identify who might be invited to hear the client's story. During the session, the client tells a significant snippet of the client's life story, while the invited outsider witness listens carefully to the conversation. After the first telling of the story, the outsider witness is invited to retell the story he/she heard to the therapist, guided by questions crafted by the therapist. In this re-telling, the person whose story was witnessed listens to the conversations between the therapist and the outsider witness. In the third stage, the person whose story was told in the first stage retells the story as witnessed and retold by the outsider witness in the second stage. The therapist carefully scaffolds all conversations.

For the purposes of this chapter I position myself as a witness and draw on the intentions of the questions that a therapist might ask a witness to shape questions to myself about the event that I witnessed:

- What stood out for you as you witnessed the event?
- What in our life prepared you to hear, experience, and witness the event?
- What image/s comes to mind?
- How will this learning guide you further in your teaching/counseling practice?
- What hopes do you hold for your practice now that you have witnessed an event?

Another narrative practice that I draw on in this chapter is the construction of narrative documents (White 2007; White and Epston, 1990). Narrative letters are often used in therapy for particular purposes (White and Epston, 1990, pp 125–126; Freeman, Epston, and Lobovits, 1997, pp.112–142). In the second example, I select a letter I wrote to an unborn child in order to connect with the hope of the child's father-to-be for a rich and meaningful relationship with his child. In the third example, I draw on a narrative document used in counseling research to capture the hope-full words uttered by member of an aging community.

I teach the theory and practice of narrative therapy, and derive intense joy from those moments when students are enchanted by this kind of work and take up these practices because the approach and practice resonate closely with their own values and hopes for ethical counseling practices. However, in the

last few years, I have begun to reflect on the invitations to engage in new ways with our universe offered by new materialism (Barad, 1998, 2003, 2007, 2010; Bennett, 2010; Hekman, 2010; Thiele, 2014). I wonder whether the discursive approach foregrounded in narrative therapy contribute to matter-materiality's fading into the background. If and when this happens, it can strengthen an unjustifiable binary between the material/discursive or discursive/non-discursive. Barad (1998, 2012, 2014), a quantum physicist, and a philosopher of science, feminism and new material feminism questions such a dichotomy:

Language has been granted too much power. The linguist turn, the semiotic turn, the interpretative turn, the cultural turn: it seems that at every turn lately every "thing" – even materiality – is turned into a matter of language or ... form of cultural representation ... Language matters. Discourse matters. Culture matters ... The only thing that does not seem to matter anymore is matter. (Barad, 2003, p. 801)

In response to this dichotomy, Barad (2007) developed a theory that requires us to rethink concepts such as subject, object, agency, causality and intra-action. Intra-action differs from inter-action. Inter-action assumes that there are separate individual agencies that precede these interactions. By contrast, intra-action is seen as a new way of thinking (about) causality, and opens up a space for "material-discursive forms of agency" (Barad, 2003, p. 826). Agency, in Barad's view, is thus "distributed" (Jackson and Mazzei, 2012, p. 113), produced in an enactment, and not as the property of a person or a thing.

In narrative therapy, matter-materiality and intra-actions with non-human or the "more than human" (Alaimo, 2010) may go unexplored and un-storied if an embedded positioning within the linguistic and discursive turn is continually re-inscribed. If I reread narrative therapy through – or in terms of – new materialism (Barad, 2003, 2007, 2010, 2012; Bennett, 2010; Hekman, 2010) or relational materialism (see Hultman and Taguchi, 2010; Thiele 2014), narrative therapy seems to be shaped predominantly by theory and philosophy from the linguistic turn. This is the situation when in fact, the under-storied matter-materiality carry and shape the narratives of our lives and make the discursive possible through "intra-action" (Barad, 2007).

Another important aspect that I want to mention briefly, because it speaks into how we teach and engage with counseling and doing-of-hope practices, is how we come to know and become on material↔discursive terms. Barad

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(2007, p. 185) explains that knowing and being are mutually interwoven and that we get to know the world from within:

[P]ractices of knowing cannot fully be claimed as human practices, not simply because we use nonhuman elements in our practice but because knowing is a matter of part of the world making itself intelligible to another part. Practice of knowing and being ... are mutually implicated. We don't obtain knowledge by standing outside the world; we know because we are of the world....Onto-epistem-ology – the study of practices of knowing in being.

Studying practices of “knowing in being” provides an opportunity to become different from what we were through our intra-actions (with and between the human and more-than-human). In the examples that I discuss below, I call on my interpretation of this practice to become different *with* hopeful practices that become possible in inter- and intra-actions. I am interested in how becoming with hope-full practices opens up possibilities of multiplicity and inclusivity. I investigate how they affect everyone/everything involved.

Deleuze and Guattari's (1987) work resonates with and contributes to Barad's (2007) stance of the “knowing-in-being” when they describe their view of a “becoming” in an in-between space and define “becoming” as “always in the middle” (Deleuze and Guattari, 1987, p. 293). They explain:

A line of becoming is not defined by points that it connects, or by points that compose it; on the contrary, it passes *between* points, it comes up through the middle... a line of becoming has neither beginning nor end, departure nor arrival, origin nor destination. A line of becoming has only a middle .... A becoming is always in the middle; one can only get it by the middle. A becoming is neither one nor two, nor the relation of the two; it is the in-between ... (Deleuze and Guattari, 1987, p. 293)

In this chapter, I use three narratives as an experiment to uncover how matter-materiality is woven into and through these stories. This tentative exploration reveals the significance of materiality in these hope-full actions and texts, suggesting that these stories embody hope-full inter- and “intra-actions” (see Barad, 2007). Drawing on very small aspects on the spectrum of “new materialism” (Barad, 2003, 2007, 2014; Hekman, 2010; Hultman and Tagushi, 2010), I see a community that does hope together becomes visible in interaction and intra-action (Barad, 2007) between humans and humans, as well as between the human and non-human or “more-than-human” (Alaimo,

2010, p.13). In re-thinking the material aspects of the three narratives, I tentatively acknowledge materiality “as an effect or consequence of discursive practices” (Barad, 2007, p. 225). In these examples I cannot yet assert “materiality as an agentive and productive factor in its own right” (Barad, 2007, p. 225). I tentatively contemplate the movement identified by Jackson and Mazzei (2012, p. 110) as a shift from a focus “on the discursive, with Derrida and Spivak; to the discursive↔material, with Foucault and Butler; to the material↔discursive, with Deleuze and Barad”.

The purpose of drawing on these ideas is to view the enactment of human-human and human-matter intra-actions (Barad, 2007) as doing-hope-together practices. These practices are acted with and within small communities.

## **EXAMPLES OF COMPASSIONATE WITNESSING AND NARRATIVE DOCUMENTS**

The three stories I tell below have been intertwined into my personal-professional life over several years. I first tell the three stories and then revisit and rethink the examples, emphasising selected threads relating to the theoretical ideas mentioned above. In the first example, I witness a farewell ritual between a grandmother and a teenage grandson. In the second example, I re-visit a narrative letter to an unborn child as an action of doing hope on paper. The third example relates how I experienced “being witnessed” in a particular timespacemattering (Barad, 2007) as I simulatenously witnessed diners in a café.

### **FAREWELL RITUAL**

In the late afternoon traffic, the bus is on its way to the international terminal at the airport. It slowly pulls into a parking bay in one of the villages along the road. Sitting in the bus, I take my thoughts back from the long flight ahead. Through the window I look down to where passengers, family and friends mill around in a kind of orderly commotion, facing each other, turning away and towards the bus, looking at their luggage stacked in a row. They turn back to loved ones. A temporary entanglement/assemblage of human and non-human matter unfolds – colourful suitcases, suitcases that show signs of being handled by many hands and machines, paper tickets, tickets on mobile phones,

name tags, bodies of adults, children, young people, mingling, talking, giving last instructions, repeating the last farewell rituals – some will get on the bus, and others will be left behind.

She stands at the edge of a small cluster of people. Her arms are spread like wings to hold her grandchildren lightly, with great care and love, captured in the embrace of her arms. Two grandsons, one a teenager and the other a young boy, are tucked snugly under her arms as they lean into her body. She keeps kissing them, whispering intimately to each of them. The teenager wipes at his tears, but does not try to hide them. The grandsons's parents stack the suitcases and for a short second the boys' arms loosen their grip on their grandmother as they look at their suitcases being loaded, and then they snuggle back into her arms. The teenager puts his arm around her. His younger brother has his arm around her waist, so the tallest boy squeezes his grandmother's body. He realises that he has touched her bosom and gently moves his hand lower. I witness this moment of leaning into her body, holding onto the care and comfort he wants. In the moving hand, I see respect, taking care not to offend her familiar body, which holds their memories. The small movement captures a tenderness between a young man and his grandmother. The bus window provides me with an opportunity to become part of these delicate actions of care. I rejoice in a young boy's taking the opportunity to perform an act of recognition of this significant relationship.

The embrace, kissing, gentle whispers come to an end when the family embark. As they take the first steps onto the bus, each family member turns to look back at the figure of their mother/grandmother, who moves slightly forward. As they are taken up in the bus and find seats on the side of the bus that faces her, she slowly takes a big, bright white handkerchief from her pocket. The driver shifts into his seat and starts the engine. He closes the doors, using a hydraulic mechanism. As the bus moves off, she comes closer and gently wipes the tears from her eyes with the folded handkerchief. She shakes the handkerchief gently and it unfolds as she lifts it to wave. A light breeze assists her in unfolding the material, which moves up and down, and then left to right. A slight, frantic movement in the two rows where her family sit produces a white facial tissue. The older of the two boys clutches the tissue in his fist and pushes it through the open window. He meets her gaze and her gesture. Their eyes measure the distance, their bodies move and the handkerchief and tissue move in waves, and the movements of bodies and matter, the handkerchief-waves and the facial tissue-waves meet in the space-in-between. Within a "relational materialist understanding" (Hultman and Tagushi, 2010), the bodies and material *come into waves* – the movement of

material and the movement of the bodies “be-come” the embodying of handkerchief-tissue waves.

The bus slowly puts more and more distance between the family and the figure at the bus stop. The light breeze, the slowly moving bus provide an extra movement and two pieces, cloth and paper, meet each other, in mid-air on a mild autumn day, as the bus turns into the traffic. It becomes one with the stream of vehicles.

The grandmother and grandson do hope together in their actions, words and small gestures. Their tears carry the anticipated loss. The whispered words speak love, care and connection, and through the nods, smiles and touching of each other’s bodies, the hope, dreams and values for this relationship materialise. These actions provide hope within a respectful relationship and for the continuation of a special bond into the future. They do relationship at a time when immediate physical contact is broken off. Within and between the small but significant gestures of the waving of material, memories are captured and narratives of connection are established.

As a teacher of counseling, I often see and hear of experiences of difficulties in many relationships. Relationships between young men and their grandmothers are often ones where more distancing is acted. This small but significant entanglement of a farewell ritual produces hopeful actions that these relationships can be acted differently and in the particular timespacemattering: the intra-actions “matter”. The boy’s snuggling, leaning into his grandmother’s body, captures his desire for connection and comfort. Their actions do hope for me as a parent, as a potential grandparent and as a counselor in my witnessing practice of the discursive↔material. I saw touching, kissing, tears, moving lips, as words were spoken. The materiality of these bodies and actions were then also captured in my look. The development of these actions invited my body to respond with “affect” for them, the ritual and the material, doing hope with them, even though they are unlikely ever to know about my connection with them.

The white handkerchief and the facial tissue extend the intra-action of the material↔discursive and make visible the possibility of an alternative story (White, 2007) for grandparent-grandson relationships for all those who witnessed what happened between them. In the closeness of their bodies, small actions of doing hope, I witnessed the movements of white material. I witnessed how the distance between her body and the moving bus grew, I saw the materiality of waving arms, visible tears on cheeks and in their eyes, smiles and hand gestures meeting each other in the spaces-in-between.

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The material of one body shapes the material of another body and the material of the handkerchief and the tissue shape the relationship through the enactment of their substance, in the movement and in expanding distance. In the material↔discursive space, the touching-leaning bodies, intimate whispering, kissing, tears, walking, stepping over the threshold, muscles, hands waving, intra-acted with the bus, doors closing, wheels turning, windows, seats, material meeting tears, material unfolding, a breeze lifting the material ....

Thinking of practices of knowing and being as mutually constituting (Barad, 2007), led me to wonder how the young man's intra-acting with the world (human and material) produced a different becoming for his grandmother, the young man himself, his brother, his parents, myself and the other passengers as witnesses. I was an active witness of the interaction and through the active witnessing became part of the ritual within a particular timespacematter (Barad, 2010). I made a decision to follow these inter- and intra-actions with a desire to connect. I am not outside of the practices of "knowing-in-being" and doing hope together that is produced in a public space. I witness and I become different from what I was before.

## **NARRATIVE DOCUMENTS AS PRACTICES OF DOING HOPE**

Charl<sup>1</sup> lost his father very early in his life. His father served a life sentence for several brutal crimes. Charl made a commitment to his mother that he would focus his life on finding good work and establishing good personal relationships. He delayed becoming committed to a serious relationship, and when he married for the first time at the age of 40, he was very careful to nurture family relationships. He experienced significant uncertainty regarding his ability to achieve this goal and questioned whether he would be a "good father".

I witnessed a particular incident and decided to story the moment so that it would not get lost in the busyness of everyday living. I wrote the letter to Charl and Deborah's unborn child. Narrative documents provided me with the material to offer a small step of doing hope in a future↔present↔past weaving.

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<sup>1</sup> Identifiable information has been changed

Dear little one

You may not yet know me. My name is Elmarie and I am your grandmother's friend. I can write about many precious incidents that your parents keep speaking you into this world but I have chosen to write about a very particular incident that caught my attention when I visit the apartment where your parents, Charl and Deborah, live. Your mother, Deborah, wanted to show us the special place they have prepared for your arrival. I went with your mother, Deborah, and Dorene, my friend and your grandmother, to have a look at the small room. Walking into the room I had a feeling the room was waiting for a small body to claim it.

When we returned to the kitchen/living room your father Charl and his friend Bill were watching something on TV. I thought it was a sport programme but then realised they were mesmerised by a DVD of you in your mother's uterus. I watched them watching this precious DVD. I had never seen two men so intrigued by every movement – the movements that you made – and captivated by the wonder of your life inside your mother's womb. I was moved by this and wanted to tell you a little about this special incident. As they were watching, your father Charl explained and commented on every move and every new development of your little body. He indicated your arms and tiny hands. They both became very excited when you moved your arms and legs and it looked like you were kicking very strongly. Charl drew Bill's attention to every minute detail of the movement. His voice carried a warmth and tenderness and spoke to me of wonderment, admiration, amazement and love as his eyes followed your every movement. What a very special experience to have witnessed this! Watching him made me wonder about connections that people build, for example your relationship with your father even before you have felt his hands or heard his voice in person. A warm voice followed you on the screen. He pointed out your heartbeats and his voice sounded what I would call really "velvety". It had a very special quality. I am not able to capture in words the tone of his voice and the emotions his voice carried at that moment. It hung in the air and touched and moved me to think about writing to you regarding this very special incident.

My guess would be that it had to do with the wonder of your existence in the womb, the excitement to get to know you and seeing your heart working to help you grow and become a person who is ready to meet him and us here in the outside world. At that moment he looked connected to you in an extraordinary way. His eyes were soft when he followed your heartbeat. He had a very special smile that touched his face as the fascination of your existence captured him. I was privileged to have witnessed this and thought I wanted to share this with you.

Your parents may decide to read this letter to you when you are still in the womb or they may wait and read this to you in a couple of years. By the

time you can read this yourself, you may already have experienced their love and care for you. If later in life, you experience a very special bond with your father, I hope this letter will be a reminder of how this bond started long before you were born.

My wish for you is that you may experience the love in his voice, his admiration for you, and that the two of you will have many hours of growing this very special bond.

Your parents are looking forward to your arrival. May you all be blessed with good health, humour, commitment and stamina to grow an extraordinary relationship.

Best wishes  
Elmarie

Narrative documents are familiar practices in narrative therapy (White and Epston 1990; White, 2007). They have been used for many purposes (Kotzé et al. 2010, Kotzé, Van Duuren and Small, 2011; Kotzé, Hulme, Geldenhuys, and Weingarten, 2012). I wrote the letter above as a narrative document with the intention of richly storying alternative practices that I witnessed. In the letter I call forward an alternative or preferred story (White, 2007) with possibilities of Carl's envisaging himself as a caring father in the life of the couple's unborn offspring. The letter serves the purpose of what in narrative therapy is called a "taking-it-back practice" (White, 2007). In the small episode I witnessed, the opportunity to engage in a taking-it-back practice (White, 2007) with a man who was to become a father, while his own history spoke of an absent father. I captured the witnessing in words on paper and offered this letter to the couple.

In typing the letters in this letter, I called on another technology-matter as materiality as I intra-acted with the computer. The computer keyboard captured the letters of the words I typed as my fingers touched, pressed and at times caressed the small squares. The computer encoded and stored the words. I read the words back as they spoke the hope I was doing in the words chosen, in the spaces between words, in sentences on and off the page. They reflected back to me the meaning that I made of my witnessing of an incident. In this intra-action with the discursive↔material the letter took shape through my fingers on the keyboard and the narrative practice of letter writing storied the entanglement of people, technology, and an unborn offspring. The letter captured my witnessing of an experience that two men engaged in and with technology and many disursive practices in a living room in a house, in a particular timespacemattering. In printed format, the paper, words, spaces,

punctuation, meanings off and on the page intra-acted with technology and the user of that technology.

Barad's (2007, pp. 216-222) nuanced analysis of the material↔discursive intra-action of the sonogram and the process of capturing images of a fetus highlights the entanglement of the technological/scientific apparatus being used, the medical gaze-practice and the political positioning that accentuates the autonomy, subjectivity and identity of a fetus. Barad argues that the political discourse of the fetus is autonomous, making it possible to "see" the unborn offspring as "free floating" on the screen, while the technological/scientific practice of focusing on the fetus makes its political autonomous identity possible (see Hekman, 2010, p. 78). The decisions or "cuts" that Barad (2014) describes, the specific focus or emphasis on capturing particular information, have far reaching consequences; for example, such technologies are only available in well resourced communities. In other communities, such technology and particular ethno-cultural and socio-political practices may be used in different ways, sometimes even culminating in termination of the pregnancy when the sex of the baby becomes known, if a particular sex is undesirable for particular reasons at a particular time.

Another effect of the distinction I made in addressing the unborn child as a person is that I ignored the body of the woman carrying the baby. On a bigger scale, such an action may have political consequences for the debate on when termination of a pregnancy is deemed (in)appropriate. The letter I wrote not only gave a specific form to the discursive practices of parenting and parent-offspring relationships, but also to the materiality of the fetus's existence somewhat "outside" of the materiality of the body of the mother. In Baradian terms, such cuts introduce differences, and such differences "matter".

## AGING

I wait at the cash register to order my food. A moment to pause and look at the lake outside the café. After a few minutes I bring my gaze back into the café. Without actively looking, I notice the significant presence of grey-haired diners. I hear the agitation in a voice before I see the owner of the voice: "Oh mum, why do you always have to ruin something special that I try to do for you?" They sit within hearing distance of the queue of people patiently waiting to be served. I slowly shift my gaze in time to witness the disappointment, pain, and agitation on the speaker's face, and slowly turn my gaze away. The words come to rest in my body and I wonder about the plates of food between

them on the table. I wonder about the hopes the speaker had entertained of enjoying time with her mother. The pain finds a place in my body.

As I slowly shift my gaze, my eyes catch an (un)familiar shape – dentures on the table. To my left ... dentures, discolored through time, smile back at me. They are uncovered, placed upside down on the small side-plate. I look away and a few seconds later I move my eyes to check that this really is what I saw... yes! I turn my head and look again. I feel the urge to gently cover the dentures with a serviette. My body is frozen in not knowing what to do. Then I look up and my eyes catch the small warm smile of a younger woman (a daughter perhaps?) sitting opposite him at the table. She witnesses my witnessing him and the dentures. I do not want to hold her gaze, but her smile holds me in the moment, and I breathe slowly. A calmness settles in my body and I slowly make a small nod, up and down, lift my eyes and look up into her eyes, and feel a faint movement of the corner of my mouth ... moving up. She witnessed my witnessing the dentures. In that moment I viscerally experience a movement towards be-coming, a be-coming other than I was before this intra-action in the space between the eye-contact, the smile of the dentures and our faint smiles meeting each other, in the space between us, across the dentures.

In that moment of her witnessing my witnessing, I meet my own aging with compassion. My own aging body comes into being, and the possibility of a failing body, a failing memory, calls on others to witness me with compassion. I turn compassionately witnessing self into the act of compassionately witnessing the diners at the table.

I order my food and leave the café, slowly looking back, and nod again to the table with the dentures. Walking in the shade of the aging oak trees, I remind myself of a renowned academic who published the book *Staring at the park* (Speedy, 2015) after she had a debilitating stroke. She resists taken-for-granted ideas about “recovery” from a stroke; she explains that she wrote the book

... against the grain of the more triumphalist ... survivor narratives that I was given to read. I wanted to privilege confusion and incoherence and old age and to express a resistance to the pioneering, more youthful myths that made coherent and linear sense of it all. (Speedy, 2015, p. 15)

The memories of the two incidents in the café, words spoken from a place of pain and irritation, dentures on the table, smiles and eyes meeting in the spaces in-between, silences, nods, and a becoming different than I was, take up

a space in my body. The visceral experience evokes the practice of “caring solidarity”, a term Sevenhuijsen (1998, p. 147) uses to ascribe political meaning to “care”. Such caring solidarity does not rely on a “privatization and moralization of care”, but reminds us that “everyone in different ways and to different degrees needs care at some point in their lives” (1998, p. 147). Resistance and caring become the hope-full practices people do, together ... with dentures, plates of food, words, smiles, silences ... in the spaces in-between.

I remember a research project by Swanepoel (2003) that I supervised. This Master’s student experienced herself being moved by the narratives of elderly people in a care facility in South Africa that she interviewed. In our supervision sessions, we talked about the identity claims the residents in the care facility had taken up. We reflected on the positions they were invited into by care-givers, their families and medical staff and how they responded to these invitations. Together we discussed the many practices that opened up and/or closed down agentic input from the residents of this facility. In the supervision, we listened to the spoken-unspoken, visible-invisible data as hopeful practice that she generated with the residents. In her research report, she held on to the participants’ desires for connection and appeal to their loved ones. After a supervision discussion she drafted the following narrative document from the data generated with research participants:

Many of our children out there believe that we are too old to change. Attempts to address longstanding issues are thus viewed as inevitably fruitless. It is true that sometimes we do not want to change or make changes as easily as you young people. However, a few of us are frequently more ready to talk about the realities of our life experiences than you might realise.

We can sometimes make amazing realistic evaluations of our lives. We can even experience it as a welcome relief to be able to talk to you freely and honestly about feelings. We may even be more ready to change than you are prepared to accept. Avoiding problems and the silence surrounding the issue may make us feel isolated and unloved. Even if it is painful to face reality, talking about problems dissolves the distance between us. Afterwards we may be able to build a closer and more meaningful relationship.

Please try to talk to us in a non-judgemental way. Try to care for us without feeling guilty. Please give us the gift of your time, attention and presence instead of physical gifts. Although we are old we still know the difference between being ignored and being cared for. As people facing mortality, please ask us how we want to be remembered and assure us that our legacy will be kept alive after we are gone; our story is not wholly our own but lives on, woven into your lives.

Please view us as unique individuals rather than as reflections of your own perceptions. As humans, we too have problems. We sometimes need affirmation and may seek it from you in inappropriate ways, expecting more than you have the resources to give. We apologise for sad misjudgements but please respect the wisdom that we have gathered in our lifetime and, if possible, pay attention to our opinions.

Please play the ‘do-you-remember-game’ with us sometimes. Remind us of the times that our actions meant a lot to you and the nice things you will always remember about us – and if you remember please thank us for these when you have the chance to do so, before the time comes when you will say: ‘I wish I could have told them, in the living years...’ (song from the group Mike and the Mechanics).

(Swanepoel, 2003, pp. 93-94)

Thinking with the theoretical strand (Barad, 2007, pp. 3-25) of the science and ethics of “mattering”, I wonder about the becoming differently than they/we were, people-material and matter-material. I wonder about the intra-action of tables, chairs, food, the different smells of food, dentures, a queue of people, the sounds of cutlery, plates, glasses, eating, drinking, laughing, talking, faint smiles, eyes meeting, words spoken and unspoken, acting together and the small and seemingly insignificant acts of “doing hope, together” between human and human and between human and non-human that “matter”.

## CODA

I wonder what brought about the entanglement of bodies, text, relationships, language in a new configuration. Was it the desire for connection, for transformation, for doing hope ... together? The woman at the table witnessed my witnessing them, and her witnessing me while witnessing “my-self” made a spectrum of identity claims available to me. In writing this chapter I witness myself witnessing self and others doing small acts of hope, together.

Barad’s (2007, p. 3) introduction to her book *Meeting the universe halfway* starts with a discussion of Frayn’s play *Copenhagen*, which represents Heisenberg’s visit to Niels Bohr in Copenhagen in September 1941. She considers Frayn’s point that “we are prohibited, in principle, from knowing our own thoughts, motives and intentions. The only possibility we have of catching a glimpse of ourselves is through the eyes of another” (p.11). These

words are heavily marked in my book. I revisit them often. Their implication invites me – forces me – to explore micro-socio-political actions that we engage in when we are doing hope with others in the many moral and ethical questions our world faces in trying to make meaning and act in ways that matters.

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## **BIOGRAPHICAL SKETCH**

Elmarie Kotzé D Litt et Phil. teaches in the Counselor Education Program, Te Oranga Human Development and Movement Studies, University of Waikato in Aotearoa, New Zealand. She supervises doctoral candidates' and M Couns students' research projects. She has co-authored several articles and book chapters with colleagues, graduates and students.

*Chapter 2*

**HOPE IN THE FAMILY:  
INDIVIDUAL DIFFERENCES IN PARENTING  
STRESS, PERSONAL RESOURCES  
AND COPING**

***Shiri Ben-Naim<sup>1,2</sup>, Michal Einav,<sup>1,3</sup>  
Roni Laslo-Roth<sup>1,4</sup> and Malka Margalit<sup>1,5,\*</sup>***

<sup>1</sup>School of behavioral Sciences, Peres Academic Center, Rechovot, Israel

<sup>2</sup>Neuropsychiatric Clinic, Hadassah Medical Center, Jerusalem, Israel

<sup>3</sup>Tel-Aviv-Yaffo Academic college, Tel-Aviv, Israel

<sup>4</sup>SCE - Shamoon College of Engineering, Israel

<sup>5</sup>School of Education, Tel-Aviv University, Israel

**ABSTRACT**

The goals of this chapter are to present hope as a major factor in predicting the resilience of families. Three theoretical models were integrated in order to explain individual differences in hope in the family: attachment theory (Bowlby, 1988), the family systems model (Crittenden and Dallos, 2009; Minuchin, 1985) highlighting conflict management styles, and resiliency models of dealing with family stress and adjustment (Masten and Monn, 2015). This integrated model has been used to present and review individual differences in family coping and hope by

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\* Corresponding Author: Dr. Malka Margalit, [malka@post.tau.ac.il](mailto:malka@post.tau.ac.il).

comparing the challenges and tasks of typical families with those of families with special needs children. The survey demonstrates the unique contribution of hope to family resilience. It also emphasizes the challenge of preserving future expectations among family members who struggle with disabilities in their homes. Research has demonstrated that the promotion of hopes in these families requires unique personal strength, and their construct of hopes is often qualitatively different. Families of children with disabilities often develop a different set of hopes, because they are painfully aware of the difficulties that their children may face in their attempts to reach similar goals. Interventions designed to increase hope, emphasizing their clinical and research implications were presented together with future research directions.

**Keywords:** family system, attachment, hope, children with disabilities, individual differences, resilience, parents

## INTRODUCTION

Why do some families faced with stressful and challenging circumstances overcome them and even thrive, while others fall apart under their weight? Researchers have identified a variety of factors that may explain these differences. For example, classic psychological conceptualizations have focused attention on the impact of past experiences on the individual's current adjustment and development (Mittal and Griskevicius, 2014). In contrast, the resilience conceptualization considers hopeful thinking and future expectations as new directions for an in-depth comprehension of the challenges, struggles and growth possibilities in families (Frazier et al., 2011). According to this premise, individuals vary in their responses to experiences, their susceptibility to adversity and their *vantage sensitivity*, what Pluess and Belsky (2013) term their positive responses to experiences. *Vantage* is short for *advantage* and refers to the "bright side" of the wide range of responses to challenging situations.

We contend that hope is a major factor in explaining the resilience of families. To support this contention, we integrate three theoretical models to explain individual differences in hope in the family: attachment theory (Bowlby, 1988), the family systems model (Crittenden and Dallos, 2009; Minuchin, 1985) highlighting conflict management styles, and resiliency models of dealing with family stress and adjustment (Masten and Monn, 2015). We then use this integrated model to review individual differences in

family coping and hope by comparing the challenges and tasks of normative families with those of families with special needs children. Finally, we discuss interventions designed to increase hope, emphasizing their clinical and research implications.

## **PARENTAL HOPE**

Hope in the family system has been often studied in relation to distress and illness. Scholars have established relationships between parenting styles and the development of hope among children (for example see Einav, Levi, and Margalit, 2012; Heaven and Ciarrochi, 2008; Lloyd and Hastings, 2009; Ogston, Mackintosh, and Myers, 2011). According to the hope theory, hope is a cognitive motivational construct that reflects individuals' perceptions of their ability to (1) identify and conceptualize meaningful goals, (2) develop specific strategies to reach these goals (pathways thinking), and (3) initiate and sustain the motivation and personal energy for using these strategies (agency thinking) (Hellman, Pittman, and Munoz, 2013; Snyder, 2002). Hopeful individuals often construct detailed strategies for attaining their goals, as well as energize themselves in pursuing the pathways to doing so. Furthermore, they do not ignore the possibility of obstacles and devise alternative pathways when they encounter barriers pursuing their goals (Snyder, 2002).

Hope starts in the family. Childhood is a critical time during which the foundations of hope are established through interactions with fathers, mothers and siblings. Children's growth and hopeful thinking reflect the influence of family-members' beliefs and behavior styles (Shade, 2006). The main role of parents is to nurture the children's hope and model how to achieve one's goals. They shape the children's inner representations of the world as a safe, dependable, stable, and trustworthy place (Goldner, Edelstein and Habshush, 2015). Snyder (2002) proposed that the development of hopeful thinking is at risk for children who are raised in environments that have few boundaries, little consistency, and limited support. In contrast, consistency in parenting style enhances the development of the structure and rules needed to determine when it is or it is not appropriate to stay engaged in goal-directed behaviors. Parental support provides the love and respect necessary for the attachment through which the children attempt to implement their goal-directed behavior.

## **ATTACHMENT AND HOPE**

Attachment theory is a key construct for understanding the different roles of hope in families. In a meta-analysis that examined the relationship between hope and attachment (Blake and Norton, 2014), one's degree of hopeful thinking emerged as an outcome of safe attachment as well as a mediator between the type of attachment relationships with one's parents and ability to adjust to life's challenges. These results are not surprising, because the attachment framework assumes that the quality of early relationships in the family predicts people's patterns of social relationships throughout their lives. Shorey and Snyder (2006) delineated a relationship between hope and attachment in which early attachment relationships predict adult levels of hope. According to their research, healthy early attachment relationships contribute to the individual's ability to maintain goal-directed thoughts and an overall hopeful approach to life (Shorey and Snyder, 2006). For instance, a study that examined 565 adolescents from five middle schools revealed that hope mediated the relations between the adolescents' attachment to a parental figure and their satisfaction with life (Jiang, Huebner, and Hills, 2013). This study established that the interactions with parents, not only during their early developmental stages, but also during adolescence, contributed to increased hope.

Other studies have also demonstrated the role of hope as a mediator between attachment and various measures of quality of life. For example, adolescents' satisfaction with life was explained not only directly by their close relationships with their parents, but also indirectly by their levels of hopeful thinking and motivation (Lavy and Littman-Ovadia, 2011). Similarly, people's degree of hope mediated the relationship between attachment and satisfaction with life (McDermott et al., 2015; Shorey, Snyder, Yang, and Lewin, 2003). To determine the exact role that hope plays within families, we will first consider the family systems model and then focus on specific coping aspects.

## **THE FAMILY SYSTEMS MODEL**

A family is far more than a collection of individuals sharing a specific physical and psychological space. While families take various forms, each one is a natural social system with unique characteristics, rules, assigned and

ascribed roles for its members, an organized power structure. By developing intricate overt and covert forms of communication, and employing elaborate forms of negotiation as well as unique problem solving approaches, they are able to perform various tasks that promote the development of their members, while preserving the family system's unique character (Goldenberg and Goldenberg, 2013). Powerful, durable, reciprocal emotional attachments and loyalties connect the family members. These connections may fluctuate in intensity over time, but nevertheless, persist over the lifetime of the family (Barnes, 2004).

In the process of growing up, family members develop individual identities but nevertheless remain attached to the family group, which in turn maintains an identity or collective image of its own. To function successfully, members need to adapt to the challenging needs and demands of other family members, as well as the changing expectations of their larger kinship networks such as the community and society in general (DeGenova and Rice, 2002). Apart from its existence as a system, a well-functioning family encourages the realization of the individual's identity and the developmental potential of its members – allowing them enough freedom for exploration and self-discovery along with supportive protection and a sense of security (L'Abate, 2013).

Constantine (1986) distinguished between “enabled” and “disabled” family systems. The former succeeds at balancing systemic needs as a family unit, while simultaneously, promoting the growth and wellbeing of all of its members as individuals. Enabling family regimes implement procedures that attempt to satisfy the sometimes conflicting interests of its members. Constantine maintains that to do less or to enable only some members of the family to prevail and not others reflects family disablement, often manifested in unstable, rigid or otherwise chaotic family patterns. Conflicts are an inevitable part of most family systems. They are amplified and demonstrated during difficult and distressful situations. However, the study of their long-term impact has focused attention on the families' ability to cope with stressors, revealed in their conflict management styles.

## **Conflict Management**

Conflict has been defined as an interaction between partners with incompatible goals (Bradbury, Rogge, and Lawrence, 2001). Disagreements between married couples often revolve around broad based, fundamental

issues such as children's needs, household chores, finances and work-related issues (Baum, 2006; Cinamon, Wiesel, and Tzuk, 2007; Fincham, 2003). However, sometimes these conflicts deal with minor incidental issues, and reflect inner and sometimes unconscious conflicting motives between the husband and wife. When conflicts are carried out in an inappropriate manner or when their frequency and intensity are high, they may become a major source of stress in the family's life and a risk factor for marital difficulties, separation and divorce. Research has reported that marital conflicts are associated with a drop in the quality and stability of the relationship between spouses (Kline, Pleasant, Whitton, and Markman, 2006). They may affect parenting and limit the children's ability to develop adjustment skills (Erel, and Burman, 1995; Grych, Fincham, 2001), resulting in the increased likelihood of conflicts between parents and children and with siblings (Grych, Fincham, Jouriles and McDonald, 2000) as well as domestic violence (O'Leary and Cano, 2001). An increased risk of depression (Whisman and Bruce, 1999) and health problems (Burman and Margolin, 1992, Kiecolt-Glaser and Newton, 2001) may also be additional results. It should be emphasized that the content of the conflicts in itself is not as harmful as the way the family members manage such conflicts (Desivilya and Gal, 1996; Gottman, Swanson and Murray, 1999).

Conflict management styles in the family refer to the manner in which couples try to find solutions to their disagreements. Research has identified several different management styles such as avoiding the conflict, giving in, or standing one's ground. Some families deal with the situation by everyone speaking their minds openly, while others are ready to compromise. In addition, collaboration, mediation and voting are additional approaches that family members may adopt in situations of conflict (Igbo, Grace, and Christiana, 2015). The use of a particular conflict management style between spouses may determine the quality of their relationship. When appropriate, it may promote the partners' goals and strengthen their relationship. However, inappropriate conflict management can delay the achievement of family goals and negatively affect the quality of the relationship (Schwarzwald, Koslowsky and Izhak-Nir, 2008). Accordingly, research has found that active and cooperative conflict management styles such as positive problem solving contribute to the quality of marital relationships (Rusbult, Verette, Whitney, Slovik and Lipkus, 1991). On the other hand, aggressive management styles may impair them. In addition, passive conflict management styles such as refraining from engaging in conflicts or denying their existence may affect the

couple's ability to develop effective conflict behavior skills and can intensify their lack of confidence in their ability to find a viable solution to their disagreements (Notarius and Vanzetti, 1983; Schwarzwald et al., 2008).

Gender and personality characteristics also play a role in the preference for specific conflict management styles in the family. For example, women tend to handle conflicts by attempting to compromise and withdraw. They tend to provide explanations and additional information as a strategy. In contrast, men use harsher styles, favoring expressions of dominance, using force, showing signs of aggression and a readiness for direct confrontation (Laslo-Roth and Schwarzwald, 2016). Individual differences in conflict management styles may also reflect personality traits such as cognitive closure, extraversion, agreeableness, conscientiousness, neuroticism, and openness (Igbo et al., 2015; Laslo-Roth and Schwarzwald, 2016).

## **HOPE AND CONFLICT MANAGEMENT**

Hope may play a unique role in determining the quality of conflict management. Studies have shown that hope contributes to the preference for a constructive conflict management pattern in four ways (Merolla, 2014). First, hopeful people tend to evaluate conflicts as controllable and resolvable, which motivates them to identify goals and constructive ways to achieve them. Second, hopeful people experience more positive emotions, which prompts the choice of effective conflict management styles. Third, hopeful people are more flexible in their choice of goals and in their preferences for a conflict management style. They tend to adapt to different situations and respond to their partners' needs in a more empathic way than those who are less hopeful. Lastly, a lack of hope is related to depressive moods that may limit the family members' ability to identify a constructive conflict management style. Thus, hope increases marital satisfaction by influencing conflict management styles (Halperin and Gross, 2011; Merolla, 2014). Therefore, when the family situation is more stressful, hope and conflict management styles are especially productive for maintaining a positive family dynamic. In addition, the families' ability to use a productive conflict management strongly depends on their degree of resiliency.

## Family Resiliency and Hope

In times of distress and crisis, the family as a system and/or some of its members may manifest dysfunctional behavior. The adjustment of some families may deteriorate while others may emerge strengthened and resourceful. Research has shown that family competencies may be utilized to promote self-corrective changes. Therefore, resilience should not be thought of as a static set of strengths or traits, but as a developmental process, unique to each family. It enables individuals and systems to create adaptive responses to stress and, in some cases, to even thrive and grow in response to stressors (Goldenberg and Goldenberg, 2013; Lebow, 2003).

Adopting a hope-based approach may support family resilience. It calls for identifying and fortifying key interactional processes that enable individuals to withstand and rebound from disruptive challenges. This approach does not assume that families will not face stress or that they are not involved in demanding situations or facing conflicts. It suggests, instead, that survival, regeneration and empowerment can occur through collaborative efforts and the ability to develop hopeful visions of future goals, even in the midst of severe personal and family adversity. Some families are more flexible and resourceful in seeking solutions to current challenges, more purposeful in pursuing future goals and satisfactions, and more adaptive to changing conditions while identifying barriers blocking their path.

Walsh (2003) identified some key factors in family resilience: (1) a consistent and positive belief system that provides shared values and assumptions offering guidelines for meaning and future-hopeful action (e.g., viewing disruptions as milestones on their shared passage through life without assigning blame and recasting a crisis as a manageable challenge); (2) the family's organizational processes (how effectively it organizes its resources) that provide "shock absorbers" when confronted with stress (e.g., remaining flexible, open to change, connected to each other); and (3) a set of family communication and problem-solving processes that are clear, consistent and congruent. These processes create a climate of mutual trust and open expression among family members, thereby maintaining a shared range of feelings, decisions and creative brainstorming.

Family resilience entails more than surviving a crisis. It offers the potential for growth and wellbeing. A resilient and hopeful family can emerge from a crisis more connected, loving and resourceful, ready to meet future challenges with renewed hope (Walsh, 2015; White, Richter, Koeckeritz, Munch, and Walter, 2004).

Black and Lobo's (2008) comprehensive review of family resilience lists several factors that contribute to the successful coping of family members in the face of adversity: (1) a positive outlook, meaning, an optimistic approach to new situations, a vision of a positive future and hope; (2) a sense of humor as an important feature in viewing crises as manageable; (3) spirituality - a shared internal value system in the family that connects it with the broader community and the universe; (4) a sense of coherence, which enhances the family's confidence that problems are comprehensible, manageable and meaningful, and that the family may emerge from the crisis better organized and adjusted; (5) flexibility, meaning the family's ability to rebound and reorganize following the challenges, while maintaining a sense of continuity and (6) communication, which refers to clarity, open emotional expression and collaborative problem solving that create direct, clear, honest and specific communications in which family members feel free to express their feelings without judgment or shame. The conceptualization of family resiliency offers a cogent lens through which we can understand why some families can confront adversity successfully, while others do not cope as well. These factors not only compensate for risk factors but also promote family harmony, balance and security (DeSimone, Harms, Vanhove and Herian, in press).

One of the most challenging situations a family faces is dealing with a special needs child. Individual differences in parents' hopeful thinking may demonstrate the unique role of hope in fostering family resilience in facing such a challenge.

## **Hope in Families of Children with Special Needs**

A child with special needs or who is diagnosed with a chronic illness or disability is a source of major crisis for a family. Hopes and expectations for the perfect child are dashed. Fathers and mothers suddenly find themselves in a world of doctors, nurses, medical institutions, endless assessments and examinations. They slowly realize the child's need for long-term care. Therefore, it is not surprising that their hope is, at least, somewhat challenged. This section will focus on the role of hope among families who are dealing with a child with a disability, demonstrating individual differences in coping and adjustment.

In this section, the term "disability" includes physical and developmental disorders, congenital or acquired. According to this definition, between 6% and 18% of children in the US are considered as having a disability

(Reichman, Korman, and Noonan, 2008). Their parents and close family members usually serve as their life-long caregivers in their homes (Lunsky, Tint, Robinson, Gordeyko and Ouellette-Kuntz, 2014).

Undoubtedly, these fathers and mothers face more challenges than typical families. They have to cope with increased and prolonged care for their children. They may face social ostracism and must learn how to negotiate the labyrinth of social services (Families Special Interest Research Group of IASSIDD, 2014). Their emotional distress reflects their need to meet increased physical and emotional demands, high care costs, and make critical decisions concerning education and childcare. They may find themselves losing their faith in the professionals' ability to provide meaningful help in the face of their children's difficulties. Emotionally, they may experience confusion and negative feelings such as guilt, self-blame or reduced self-esteem. These demands may affect their expectations of and reduce their engagement and involvement with other family members and have a negative impact on the functioning of the family (Reichman et al., 2008). Furthermore, conflicts may arise between the parents with regard to the child's care plan, diagnosis or ways to manage the child's symptoms and behavior difficulties (Phelps, Hodgson, McCammon and Lamson, 2009; Saini et al., 2015; Aylaz, Yilmaz and Polat, 2012). Thus, it is not surprising that the rate of divorce among parents of children with special needs is significantly higher compared to parents of typical children (Risdal and Singer, 2004).

However, in line with the resilience conceptualization, having a child with a disability may in fact lead to broader horizons, increase the family members' awareness of their inner strength, enhance family cohesion and encourage supportive connections to community groups (Reichman et al., 2008). Some parents of children with disabilities describe their lives as enriched with empathy, hope, love, care, compassion and value as a result of their experience of having a child with a disability. Moreover, they also report undergoing a process of personal growth, which they credit to the experience of parenting a child with a disability (Kausar, Jevne and Sobsey, 2003).

However, parents seem to differ in their assessment depending on their gender. Mothers of children with intellectual disabilities report experiencing greater parenting demands, increased levels of stress and poorer physical and psychological health (e.g., Olsson and Hwang 2002, Singer, 2006). For instance, fewer of them work outside their homes compared to mothers of typical children (Reichman, Korman and Noonan, 2004). Since mothers are often the providers of the major care needs of their children, it is not surprising

that fathers often report less psychological distress than their spouses (Olsson and Hwang, 2001).

Additionally, some family members may feel socially isolated. They maintain that their identity revolves around their being a relative of a child with a disability and an individual who has to be “on duty” all the time (for a review, see Griffith and Hastings, 2014). Adult siblings of people with severe intellectual and developmental disabilities report feeling a mixture of guilt and joy, frustration related to actual caregiving difficulties, and stress related to a sense of responsibility for their siblings (Rossetti and Hall, 2015). Similarly, parents of adolescents with autism describe their fatigue, endless burden, and intense mother-child relationships that contribute to family tensions (Mount and Dillon, 2014). Nevertheless, some families cope well. For example, some mothers of children with an autistic spectrum disorder indicate that they are able to manage well with day-to-day challenges compared to a similar control group. In addition, only less than 20% of mothers report poor mental or emotional health (Montes and Halterman, 2007). These inconsistent results emphasize the need to examine in depth the factors that might contribute to the adjustment of families of children with disabilities.

## **Coping with a Disability in the Family**

### ***Parental Mood***

Research indicates that mothers’ positivity (defined as the ratio between positive and negative emotions) predicts family adjustment when coping with a child with a severe disability (Trute, Benzies and Worthington, 2012). Margalit and colleagues (2006) examined mothers of children with developmental delay and found that those who rated their positive mood the highest also reported the strongest level of personal confidence and coherence, and viewed their families as cohesive and supportive. However, mothers who indicated having many negative moods experienced higher levels of stress and described in detail their vulnerability and depressive tendencies. They described their families as non-cohesive and themselves as having little maternal sense of coherence (Margalit, Al-Yagon and Kleitman, 2006).

### ***Attachment Patterns***

Parental distress may have a detrimental impact on parent-child interactions and attachment relations (Bowlby, 1988). Therefore, children with disabilities may find it more difficult than children with typical development

to satisfy their attachment needs, putting them at greater risk of developing an insecure attachment. Since secure attachment is based primarily on the parents' ability to accurately recognize their child's mental state and emotional needs and to respond to them, the communication difficulties of many children with disabilities may impair their ability to express their emotional needs (Howe, 2006). Raising a child with a disability involves additional attention to unclear messages, in addition to prolonged care, costs, errands and arrangements. These difficulties contribute to parental stress and may preoccupy them at the cost of reducing their responsiveness to their child. The stress associated with caregiving also activates parents' attachment-based emotional defenses and overall fatigue, making them less receptive to the child (Moran, Pederson, Pettit and Krupka, 1992).

Research demonstrates that children with disabilities are more likely to display insecure attachment (e.g., Al-Yagon, 2014; Al-Yagon and Mikulincer, 2004; Clements and Barnett, 2002; Macrae, 2003). A meta-analysis of 13 samples of children with a variety of disabilities (i.e., Down's syndrome, autism, cystic fibrosis and congenital heart disease) found lower rates of secure attachment compared to typical children (van Ijzendoorn, Goldberg, Kroonenberg and Frenkel, 1992). An additional meta-analysis that examined samples of autistic versus comparison groups reported similar patterns (Rutgers, Bakermans-Kranenburg, van Ijzendoorn and van Berckelaer-Jonnes, 2004).

An important factor that may affect attachment patterns is the degree to which parents have accepted and feel committed to the challenges of raising a child with a disability. For example, Barnett and colleagues (1999) found that toddlers with neurological and congenital problems were more likely to be classified as insecurely attached if their mothers were not able to accept their child's diagnosis. Similar results were reported with respect to children with autism (Morog, 1997), cerebral palsy (CP) and epilepsy (Marvin and Pianta, 1996; Pianta, Marvin, and Morog, 1999). Howe (2006) concludes: "To the extent that an impairment or disability increases the demands made on a parent's caregiving capacities, it challenges the emotional availability and sensitivity of the attachment figure. But if caregivers remain free-minded, reflective, emotionally attuned and have resolved states of mind with respect to attachment, children are likely to be secure" (p. 102). Moreover, the ability of these parents to develop a secure attachment with their children was related to their beliefs about hope and mediated by the personal strengths and weaknesses expressed in their individual differences.

### ***Hope and Disability in the Family***

The challenge of preserving future expectations among family members who struggle with disabilities in their homes requires endless strength. Research has demonstrated that their hopes are qualitatively different. For example, parents of adolescents with CP described in detail their worries about the future opportunities for their children when they grow up. They were afraid that their peers would not accept them and assumed that they would probably feel quite lonely. These parents also feared that their children would be ill-treated (Shikako-Thomas, Bogossian, Lach, Shevell and Majnemer, 2013). Parents of children with autism and fetal alcohol spectrum disorder expressed concerns about their children's current and future safety and overall humiliation, as well as the fear that they would have to continue caring for them into adulthood. These parents also worried about their youngsters' ability to have a fulfilling and satisfying career (Watson, Hayes, Radford-Paz and Coons, 2013). Caregivers of children with intellectual disabilities expressed similar fears about the future, focusing on their child's wellbeing when they, as parents, would no longer be able to take care of them (for a review, see Griffith and Hastings, 2014). These future challenges imperil the development of hope.

Families of typical children hope that their children will achieve socially desirable goals such as an academic education, a successful and productive career, a satisfying marriage and a family of their own. In contrast, families of children with disabilities may develop a different set of hopes, because they are painfully aware of the difficulties that their children face in their attempts to reach similar goals. Along with the disappointment, despair, sadness and grief accompanying this understanding, a reframed definition of hope may develop--the hope for one's child to live a meaningful life in dignity, to find suitable friends and a support system, to be able to ensure their security and care when parents get older, to appreciate and enjoy personal achievements, and adapt to individual abilities and disabilities.

These reframed hopes appear in several studies. For example, 51% of parents of children with autism expected major progress and clear development in their children's overall functioning (Bilgin and Kucuk, 2010). Hope for a better future was also apparent in the narratives of parents of children with autism, compared to parents of children with fetal alcohol syndrome disorder who expressed less hope that their children could live independently. A similar pattern of hope was evident with regard to their children's opportunities for marrying and raising children of their own (Watson et al., 2013).

The reframing of hope becomes a challenge following the diagnosis of their children. In a study that examined families' experiences during conversations with medical professionals, they described the emphasis put on the expected future difficulties of their children. The parents were sensitive to the lack of hope in these discussions. On the other hand, the professionals who participated in this study described their professional belief in their need to remain truthful and honest, and not to provide "false hopes." Family members of people with acute brain injury also described a rehabilitation process that did not foster hope but instead provided the worst-case scenario (Kuipers et al., 2014). This study and others called for increasing the awareness of the benefits of conveying some sense of hope such as underscoring the worth of the child as an individual, pointing to the help available for the family, and informing parents about a range of possible outcomes for their child (Harnett and Tierney, 2009).

The difficulty in defining and maintaining hope is even more pronounced in progressive medical conditions in which the patient's physical condition is expected to deteriorate. Some practitioners even tend to treat hope in terminal circumstances as "denial" (McLean, 2011). However, it should be clarified that promoting hope does not necessarily mean looking for a cure. Hope can also relate to identifying small goals such as reduced pain or enjoying the stay at home with loved ones around.

Overall, research reports that hope may play a crucial role in the quality of life of families who cope successfully with disability, whether it be an intellectual disability (Lloyd and Hastings, 2009) or chronic physical conditions such as spina-bifida, CP or chronic diabetes (Horton and Wallander, 2011). For example, parents of adolescents with CP described the trajectory they went through from an initial existential crisis to acceptance of their child's health condition and a vision of the future. It was hope that helped move them through this process from an understanding of the limited choices available for their children's physical, cognitive and academic functioning, towards focusing on abstract, metaphysical notions such as hoping for their adolescent's happiness and wellbeing. The parents regarded this transition as crucial in their adolescent's current and future quality of life (Shikako-Thomas et al., 2013).

## Hope as an Intervention

Given these studies, some researchers have begun to explore hope as an intervention. Within the family system research, reports have surfaced that sometimes individuals engaged in reframing their notion of hope within a relationship launch a cascade of positive effects on their partners that include subjective, behavioral and physiological changes. These changes occur regardless of the partner's awareness of their engagement in this reframing (Ben-Naim, Hirschberger, Ein-Dor and Mikulincer, 2013), thus underscoring the ability of this reframing to change the family system as a whole.

Several programs have been instituted to capitalize on these findings. For example, Morison and colleagues (2003) describe a community-based program for families of children with chronic illness and disabilities that focuses on empowerment and hope in the belief that such factors would enhance resilience. The program encourages family members to identify their hope and reframe it in line with the changes and dynamics wrought by the circumstances of illness and disability. As one of the parents in the group described: "Parents are not asking to be told that their kids are going to be OK, they just want a doctor to tell them – Don't give up hope, you can make this child's life a little better – no one has the right to take away all your hope" (Morison, Bromfield and Cameron, 2003, p. 129). In another study conducted among mothers of children with Down's syndrome and delayed development, the mothers' coping style and sense of coherence predicted their degree of hope (Einav, Levi and Margalit, 2012). The authors concluded that, "Early intervention efforts to empower mothers and to support their family cohesiveness and flexibility may contribute not only to the mothers' current coping, but also to future expectations and hopeful thinking" (p. 275). Therefore, their attempt to change the current situation through activities of directed coping promoted their experiences of hope.

Nevertheless, individual differences play a key role in coping abilities and hopeful beliefs. Some families are more able to cope effectively with their daily routine as well as with the additional demands of caring for a child with a disability. They are able to use the social support from family, community and institutions more efficiently, while others struggle with hopelessness and despair (Breitkreutz, Wunderli, Savage and McConnell, 2014).

## CONCLUSION AND FUTURE DIRECTIONS

Hope plays a key role in understanding the struggles of both normative and special needs families facing stressful situations. Individual differences in their levels of hope help us understand why some families remain resilient and cope effectively with daily challenges, whereas others crumble in the face of adversity. Understanding the relationships between hope, resilience and attachment in families also helps us understand family dynamics. Research on the unique role of hope as a mediator of the ability of parents to cope with the stress of having a child with a disability exemplifies how hope helps explain the differences in adjustment to the diagnosis of a child with special needs.

In addition, the existing programs that use hope as an intervention seem promising in both the short and long terms. When facing difficulties and struggling with day-to-day challenges, it may be difficult to believe in positive future opportunities. Nevertheless, maintaining a hopeful outlook replenishes people's stock of personal resources and revitalizes their coping abilities. Future studies are needed to experiment with different therapeutic approaches that include and perhaps emphasize hope as an intervention in family support programs and family therapy in general. Additional research pathways should explore individual differences in the levels of hope among families who cope with different types of challenges, focusing on possible interactions between the type of challenge and the reframing of hope. Particularly important are future longitudinal studies focused on stability and changes in the levels of hope in families that might clarify the dyadic impact of the hope narrative on mothers and fathers and their attitudes towards their children. More in-depth studies using mixed method designs may decipher the intricate, yet meaningful family dynamics between parents, children, siblings and even extended family members that promote or hinder the use of hope in family processes. Lastly, as previously noted, research has already demonstrated that hope is a distinctive personal resource. Future studies must explore and support the power of hope as a familial resource that enhances resilience and promotes effective coping.

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- Watson, S., Hayes, S., Radford-Paz, E. and Coons, K. (2013). “I’m hoping, I’m hoping...”: Thoughts about the future from families of children with autism or fetal alcohol spectrum disorder in Ontario. *Journal on Developmental Disabilities, 19*, 76-94.
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## ***BIOGRAPHICAL SKETCHES***

**Name:** Shiri Ben-Naim

**Affiliation:**

1. School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel
2. Neuropsychiatric Clinic, Hadassah Medical Center, Jerusalem, Israel

**Education:** PhD in rehabilitation psychology, Bar-Ilan University, Ramat Gan.

**Address:** 145 Karkom st., Ramat-Raziel, Israel

**Research and Professional Experience:**

The focus of Dr. Ben-Naim’s research is on psychological and marital aspects of disabilities and the role of hope, intimacy and coping in dealing with learning disabilities and other acquired and developmental disabilities. She is a registered senior rehabilitation psychologist and supervisor. She also specialized in CBT as a practitioner and supervisor.

**Professional Appointments:**

1. Director of the neuropsychiatric clinic, Hadassah Medical center, Jerusalem, Israel.
2. Lecturer in Peres Academic Center, Rehovot, Israel.

**Publications Last 3 Years:**

- Ben-Naim, S., Hirschberger, G., Ein-dor, Z. and Mikulincer, M. (2013). An Experimental study of emotion regulation during relationship conflict interactions: The moderating role of attachment orientations. *Emotion*, 13(3), 506-519.
- Feldman, D. B., Davidson, O. B., Ben-Naim, S., Maza, E. and Margalit, M. (in press). Hope as a Mediator of Loneliness and Academic Self-efficacy Among Students With and Without Learning Disabilities During the Transition to College. *Learning Disabilities, Research and Practice*.

**Name: Michal Einav, PhD****Affiliation:**

1. School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel
2. Tel-Aviv-Yaffo Academic college, Tel-Aviv, Israel

**Education:** PhD In clinical Psychology, Rutgers University, NJ ,USA

**Address:** 34<sup>th</sup> Einstein St, Tel Aviv, Israel.

**Research and Professional Experience:**

1. The focus of Dr. Einav's research is on psychological aspects of the marital and parental relationships in the family, and the way in which they relate to each other and affect key variables in both the individual and family life. Dr. Einav also focuses on the significant role hope plays in the family interactions and family members' well-being.

2. Dr. Einav is a registered clinical psychologist who teaches both undergrads and graduate psychology students classes in both clinical psychodiagnostics and child and adolescents psychotherapy.

### **Professional Appointments:**

1. Senior lecturer, Chairperson of the Teaching Committee, chairperson of the research Committee in the School of Behavioral Sciences, Peres Academic Center, Rehovot.

2. Adjunct Lecturer in the MA clinical program in the Tel-Aviv-Yaffo Academic College, Tel-Aviv, Israel.

3. Private practice for clinical psychology, Tel-Aviv, Israel.

### **Honors:**

2009 to 2015 – Every year: Outstanding lecturer awards in the School of Behavioral Sciences, Peres Academic Center, Rehovot.

### **Publications Last 3 Years:**

Levi, U., Einav, M., Raskind, I., Ziv, O. and Margalit, M. (2013). Helping students with LD to succeed: the role of teachers' hope, sense of coherence and specific self-efficacy. *European Journal of Special Needs Education*. 28(4), 427-439.

Einav, M. (2014). Psychological resources and victim blaming in sexual assaults. *Mifgash, Social and Educational Journal*. 22(40), 87-113. (Hebrew).

Einav, M. (2014). Perceptions about parents' relationship and parenting quality, attachment styles and young adults' intimate expectations: A cluster analytic approach. *The Journal of Psychology: Interdisciplinary and Applied*. 148(4), 413-434.

Levi, U., Einav, M. and Margalit, M. (2014). Academic expectations and actual achievements: The roles of hope and effort. *European Journal of Psychology of Education*. 29,367-386.

### **Chapter**

Einav, M., Rosenstreich, E., Levi, U. and Margalit, M. (2015). Coping with loneliness during childhood and adolescence. In A. Rockach and Shaked A. (Eds.), *Treating Loneliness*. NY: Routledge

**Name: Roni Laslo-Roth**

**Affiliation:**

1. School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel.
2. SCE - Shamoon College of Engineering, Israel.

**Education:** Ph.D. in Social-Organizational Psychology. Bar Ilan University, Israel.

**Address:** 7 Carmel St., Rehovot 76305, Israel.

**Research and Professional Experience:**

**Research interests:**

1. Conflict types and sources in the workplace.
2. Appropriate conflict resolution strategies for handling different types of conflict.
3. Emotion regulation and its effect on conflict resolution strategies.

**Professional Experience:**

- Organizational counselor
- HR experience

**Professional Appointments:**

- Lecturer, School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel.
- Adjunct Lecturer, Department of Industrial Engineering and Management, SCE - Shamoon College of Engineering, Israel.

**Publications Last 3 Years:**

Laslo-Roth, R. and Schwarzwald, J. (2016). Rationale and emotion in the selection of influence tactic by managers in conflict with subordinates. *Leadership and Organization Development Journal*, 37 (1), 42-70. doi:10.1108/LODJ-04-2014-0076.

**Name: Malka Margalit, Ph.D****Affiliation:**

- School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel
- School of Education, Tel-Aviv University, Tel-Aviv, Israel.

**Education:** Ph.D in Child Development, London University, London, UK**Address:** 18 Halotus St. Ramat-Efal, 5296000, Israel**Research and Professional Experience:**

**Research:** In her research, Prof. Margalit examines developmental aspects of hope and loneliness and the impact of emotions and motivation on adaptive development among children and adults with typical development and with high prevalence disabilities such as learning disabilities and ADHD. She is employing empowering models such as Hope Theory and the salutogenic paradigm to promote growth and adjustment. She is conducting research on the contributions of friends (including Internet support and virtual friends), schools and families to the adjustment of children with typical development and with special needs. Her studies identify and examine methods for promoting effective coping, enhancing personal strength and reframing difficulties into challenges including the support of technology to enhance growth and resilience.

**Professional Experience**

Prof. Malka Margalit was the Head of the School of Education, Tel-Aviv University. She was nominated by the Israeli Ministry of Education as the chairperson for the Inclusion Committee to evaluate the implementation of the Special Education Law (Margalit Committee II). The Israeli Law of Inclusion was developed following the recommendations of the committee's position

paper. In addition, she was nominated by the Minister of Science and the Minister of Education to chair the national committee that examined the needs of students with learning disabilities in Israel (Margalit Committee I). The report's conclusions were presented in 1997, and are currently being implemented throughout the Israeli education and higher education systems. Recently she was nominated as the chairperson of the experts' committee for higher education students with LD, which develops the curricular knowledge-base and educational demands from professionals specializing in learning disabilities.

Prof. Margalit is on the Coordinating Board of the International society for Research in Early Intervention. She is a Fellow in the IARLD (International Academy of Research in Learning Disabilities) and was the Vice-president for International Development in IARLD. She was a member in the Israeli Education Committee (nomination according to the Israeli Law of Education), and was Chairperson of the Israeli Council of Psychologists, director of the Sneurson Psycho-Educational Center and the representative of the Israeli Psychologists' organizations in the National Health Committee of the Israeli Ministry of Health. She was also the chairperson of the Shalem Foundation Research Committee, Chairperson of the Committee on Disability and Rehabilitation in the International Council of Psychologists, and the Vice-Chairperson of the International Association of Special Education.

### **Professional Appointments - Current:**

Dean, School of Behavioral Sciences, Peres Academic Center, Rehovot, Israel.

She is a registered senior Educational and Rehabilitational psychologist.

She is Special Issue Editor, Journal of Learning Disabilities,

### **Publications Last 3 Years:**

#### **Articles:**

Israel, N., Gur, A. and Margalit, M. (in press). Emotional aspects of eating disorders and ADHD: Comorbidity, sense of coherence, loneliness and rumination. *Mifgas* (in Hebrew).

Al-Yagon, M. and Margalit, M. (in press). Specific Learning Disabilities: The Israeli Perspective. *Learning Disabilities: A Contemporary Journal (LDCJ)*.

- Al-Yagon, M., Aram, D. and Margalit, M. (in press). Early Childhood Inclusion in Israel. *Infants and Young Children (IYC)*.
- Feldman, D. B., Davidson, O. B., Ben-Naim, S., Maza, E. and Margalit, M. (in press). Hope as a Mediator of Loneliness and Academic Self-efficacy Among Students With and Without Learning Disabilities During the Transition to College. *Learning Disabilities, Research and Practice*.
- Sharabi, A., Sade, S. and Margalit, M. (in press). Virtual connections, personal resources, loneliness, and academic self-efficacy among college students with and without LD. *European Journal of Special needs Education*.
- Rosenstreich, E., Feldman, D., Davidson, O. and Margalit, M. (2015). Hope, optimism and loneliness among first-year college students with learning disabilities: A brief longitudinal study. *European Journal of Special needs Education, 30*(3), 338-350.
- Rosenstreich, E. and Margalit, M. (2015). Loneliness, Mindfulness, and Academic Achievements: A Moderation Effect among First-Year College Students. *The Open Psychology Journal, 8* 138-145.
- Feldman, D. B., Davidson, O. B. and Margalit, M. (2015). Personal Resources, Hope, and Achievement among College Students: The Conservation of Resources Perspective. *Journal of Happiness Studies, 16*, 543-560.
- Idan, O. and Margalit, M. (2014). Socioemotional self-perceptions, family climate, and hopeful thinking among students with learning disabilities and typically achieving students from the same classes. *Journal of Learning Disabilities, 47*, 136-152.
- Levi, U., Einav, M., Raskind, I., Ziv, O. and Margalit, M. (2014). Academic expectations and actual achievements: The roles of hope and effort. *European Journal of Psychology of Education, 29*, 367-386.
- Sharabi, A. and Margalit, M. (2014). Predictors of positive mood and negative mood among children with learning disabilities (LD) and their peers. *International Journal for Research in Learning Disabilities, 2*(1), 18-41.
- Margalit, M. (2014). Learning disabilities: Neuro-developmental model – after 15 years. *Mifgas, 39*, 32-13 (in Hebrew).
- Levi, U., Einav, M., Raskind, I., Ziv, O. and Margalit, M. (2013). Helping students with LD to succeed: the role of teachers' hope, sense of coherence and specific self-efficacy. *European Journal of Special Needs Education, 28*(4), 427-439.
- Margalit, M. and Raskind, I. (2013). The experience of loneliness among children with special needs. *Psychology and education, 50*(3/4). 55-68.
- Al-Yagon, M., Cavendish, W., Cornoldi, C., Fawcett, A., Grünke, M., Hung, L. Y., Jiménez, J.E., Karande, S., van Kraayenoord, C. E., Lucangeli, D.,

Margalit, M., Montague, M., Sholapurwala, R., Sideridis, G., Tressoldi, P. E. and Vio, C. (2013). The Proposed Changes for *DSM-5* for SLD and ADHD: International Perspectives—Australia, Germany, Greece, India, Israel, Italy, Spain, Taiwan, United Kingdom, and United States. *Journal of Learning Disabilities*. 46(1), 58 - 72.

### **Chapters in books**

- Al-Yagon, M. and Margalit, M. (in press). Hope and coping in individuals with SLD. S. Lopez, and M. Gallagher (Eds). *Oxford Handbook of hope*, NY, Oxford University Press.
- Margalit, M. and Raskind, I. (in press). The social world of children and adolescents with disabilities: The loneliness perspective. In C. Kowalski, A. Rokach and J. Cangemi, (Eds.). *Loneliness and life*, NY, McGraw Hill.
- Einav, M., Rosenstreich, E., Levi, U. and Margalit, M. (In press). Coping with loneliness during childhood and adolescence. In A. Rockach and Shaked A. (Eds.), *Treating Loneliness*. NY: Routledge.
- Margalit, M. (2014). The hope theory. In Raviv, A and Boles, R (Eds.) *The educational consultation today*. (pp. 322-295). Tel-Aviv, Sifriat Hapoalim (Hebrew).
- Idan, O. and Margalit, M. (2013). Hope theory in education systems. In G. M. Katsaros. (Ed.), *Psychology of hope (pp.139-160)*. New York: Nova Publishers.
- Al-Yagon, M. and Margalit, M. (2013). Social cognition of children and adolescents with LD: intrapersonal and interpersonal perspectives. In L. Swanson, K. Harris and S. Graham (Eds.), *Handbook of Learning Disabilities* (pp. 278-292). New York: The Guilford Press.

### **Presentations at major scientific conferences**

- Margalit, M (June, 2016). Looking Forward and Back at Early Intervention and Hope: Parental Coping and Resilience. International Society on Early Intervention Conference: Children's rights and early intervention, Stockholm University, Sweden.
- Margalit, M. (July, 2015). New Trends in Resilience Research and Learning Disabilities: Challenges and Dilemmas. *Presented in the annual meeting of the International Academy of Research in Learning Disabilities*, Vancouver, Canada.

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- Margalit, M. (July, 2015). Discussant at the symposium: Self-Appraisals of Youth with Attention-Deficit Hyperactivity Disorder: Implications for Assessment and Intervention. *Presented in the annual meeting of the International Academy of Research in Learning Disabilities*, Vancouver, Canada.
- Margalit, M. (March, 2015). Loneliness, Hope and Resilience Among Students with LD: Theory, Research and Implications. Presented at the 30<sup>th</sup> Annual Learning Differences Conference, Harvard Graduate School of Education, Boston, USA.
- Margalit, M., Davidson, O. and Rosenstreich, E. (July, 2014). Conservation of Resources (COR) During the Beginning of the First Year in College for Students with LD: Optimism, hope, Academic Self-Efficacy (SE) and loneliness. *Presented in the annual meeting of the International Academy of Research in Learning Disabilities*, Vilnius, Lithuania.
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*Chapter 3*

## CONSIDERATION OF OPTIMAL BEST, USING HOPE AS A POINT OF REFERENCE

*Huy P. Phan and Bing H. Ngu*

University of New England, Armidale, Australia

### ABSTRACT

*Hope* is a psychological process that may yield positive educational and non-educational outcomes. Its characteristics, positive in nature, reflect a non-deficit positioning, enabling individuals to anticipate, plan, and persist in different courses of action. One inquiry that has credence for research development is the extent to which hope, as a collective entity, could facilitate and encourage the achievement of *optimal best*. We recently developed the *optimal achievement bests theory* (Phan, Ngu, and Williams, 2016), which has been refined to include the *continuum of achievement bests framework*, whereby five progressive achievement bests are noted: *historical achievement best*, *realistic achievement best*, *personal achievement best*, *optimal achievement best*, and *ultimate achievement best*. Optimal achievement best is a point of reference, which may serve to encourage individuals to strive for successful performance outcomes. Ultimate achievement best, differently, is more inspirational and outside the scope of capability for most individuals. Accomplishing ultimate achievement best, however, is a possibility that cannot be discounted, overall.

We consider the possibility that hope, in effect, could positively relate to individual achievement bests (i.e., notably optimal outcomes) of enriched emotional well-beings, situated within the context of the period

of adolescence. Emotional well-beings, encompassing a wide range of affective responses have been argued to feature centrally in human agency (Phan, 2015b; Phan and Ngu, 2015b), especially for adolescents who may experience both positives and negatives. Does hope, for example, facilitate the striving and achievement of enriched emotional well-beings in the face of difficulties and obstacles? To what extent does hope enable adolescents to experience positive affective responses (e.g., happiness) that may, in turn, counter detrimental personal functioning on a daily basis (e.g., feeling of pessimism)? Our conceptualization of achievement bests is significant, and may contribute substantive theoretical, methodological, and practical yields for consideration.

This chapter then, makes attempts to explicate theoretically the impact of hope on adolescents' optimal achievement bests of their emotional well-beings. This theoretical positioning may provide grounding for advancement into the study of: (i) hope as a facilitator and central mediator of achievement best in relation to emotional well-being (e.g., optimal achievement best), and (ii) the achievement best theoretical framework as reflecting the nature and characteristics of positive psychology. Our in-depth analysis in particular, may explain the impact of emotional well-beings as a proactive vehicle for adolescents.

**Keywords:** achievement bests, hope, optimal outcome, emotional well-beings, personal processes, adolescents, emotions

## **THE IMPORTANCE OF EMOTIONAL WELL-BEING: AN OVERVIEW**

Emotional well-being, as a unitary construct, has emerged in the empirical literature as central to human agency. We prefer this theoretical orientation for its positive and non-deficit emphasis. The Mental Health Foundation defines emotional well-being as “a positive sense of well-being which enables an individual to be able to function in society and meet the demands of everyday life; people in good mental health have the ability to recover effectively from illness, change of misfortune” (<http://www.belongto.org/resource.aspx?contentid=4574>). Emotional well-being, in this sense, is not simply concerned with a person's state of emotions and affective responses (e.g., happiness and responding positively to others). Rather, emotional well-being emphasizes much more, and relates to a person's ability to think, feel, and be able to relate to others (Australian Institute of Health and Welfare, 2012). Personal well-being, in a similar vein, encompasses a wide range of personal attributes that

may develop and flourish in both educational and non-educational settings (Phan and Ngu, 2015b; Soutter, 2011). The work of Van Damme, Phan and their colleagues, likewise, emphasize on personal experiences of well-being in school context (e.g., Opdenakker and Van Damme, 2000; Phan, 2016; Phan and Ngu, 2015b; Van Damme, De Fraine, Van Landeghem, Opdenakker, and Onghena, 2002). Phan and Ngu (2015), for example, describes attributes such as *appreciation, relating to others, academic striving, daily functioning, personal functioning, and emotional functioning*.

Emotional well-being, an aspect of personal well-beings, in general, is a focus of consideration for many educators, researchers and counsellors, alike (Phan and Ngu, 2016). Phan and Ngu's (In press-2016) definition of emotional well-being, concurred with the Mental Health Foundation's work, reflects a person's affective state of functioning. In particular, according to the authors, there are two major components of affective state, namely: *emotions that are general in characteristics* (e.g., "I often feel negative with life"), and *emotions that are contextualized in school contexts* (e.g., "I am always happy at school"). Individuals who are positive in their emotions at school (e.g., "I am always happy at school": Phan and Ngu, 2014), in this analysis, are more likely to enjoy schooling and report positive learning experiences. Negative emotions (e.g., a heightened state of anxiety), in contrast, reflect a sense of helplessness, and may indicate task disengagement and school withdrawal, overall.

Adolescence is a period of growth and inner turmoil (Arnett, 1999; Casey et al., 2010; Erikson, 1968; Spear, 2000). Growth, of course, may encompass a number of personal elements, such as cognition, physical and physiological development, moral reasoning, and complex emotions. It is a period of joy, discovery, and exploration. These elements, act in tandem, to ensure smooth transitioning into adulthood. Inner turmoil, in contrast, reflects a negative focus, resulting in detrimental consequences and maladaptive practices. Adolescents may, for instance, experience daily situations and experiences that are quite pervasive, in nature: economic disadvantage, homophobic bullying, physical abuse, disruptive social relationship (Onyekuru and Ibegbunam, 2014; Vasquez-Salgado, Greenfield, and Burgos-Cienfuegos, 2015). Social relationships (e.g., teacher-student: Cornelius-White, 2007; Roorda, Koomen, Spilt, and Oort, 2011), for example, have been noted to play an important role in student engagement for effective learning. Economic disadvantage, likewise, has led to some children and adolescents leaving school early to find work to support their families, financially (Phan, 2009). Indeed, an inescapable

trait, inner turmoil is paramount and may result in long-term outcomes that are negative, at best.

Emotional well-being, as a theoretical entity, we contend, can counter and assist in the alleviation of adolescents' turmoil on a daily basis. Emotional well-being, on this basis, reflects a positive positioning that focuses on personal aspects, such as: (i) instilling a sense of personal resolve and resilience to persist in the course of life, (ii) heighten self-beliefs (e.g., confidence) for improvement in performance outcomes, academic and non-academic, and (iii) transformative change in thinking, feeling, and behavior. Building on this, it is possible for us to envisage adolescents who experience positive emotional well-beings. Aside from quality learning and academic performance (Berger, Alcalay, Torretti, and Milicic, 2011; Phan and Ngu, 2015b; Urbis, 2011), in particular, an adolescent who is enriched, emotionally, may achieve the following indicators (<http://www.belongto.org/resource.aspx?contentid=4574>):

1. Understand and adapt to change on a daily basis.
2. Coping with stress and other negative-related outcomes (e.g., anxiety).
3. Develop enriched self-esteem and self-concept.
4. Be autonomous, independent, and engage in decision making in order to meet personal needs.

It is important for us to reject the deficit model of thinking, feeling, and behavior – that is, finding pathways, alternatives, and means to resolve detrimental consequences (e.g., task disengagement: Liem, Lau, and Nie, 2008). Adopting a positive, non-deficit point of view is healthier, focusing on personal growth, and identifying and building upon strengths and motivational beliefs, rather than resolution of problems and/or weaknesses. We contend, for instance, that it would be beneficial for us, as a collective society, to explore the potent influences of happiness, effective functioning, optimism, and the quality of life, in general.

Consideration of emotional well-being, positive in characteristics, requires examination of pathways, means, and strategies for implementation. How do we facilitate and enhance adolescents' positive well-being experiences? *Verbal discourse? Role modeling? Financial means? Family support?* Indeed, this question poses contemplation and thought-provoking recommendations for advancement and research development. One possible mean, we contend, may involve the use of *hope*, a psychological process that has been shown to produce positive yields (Snyder, 1995; Snyder et al., 1991).

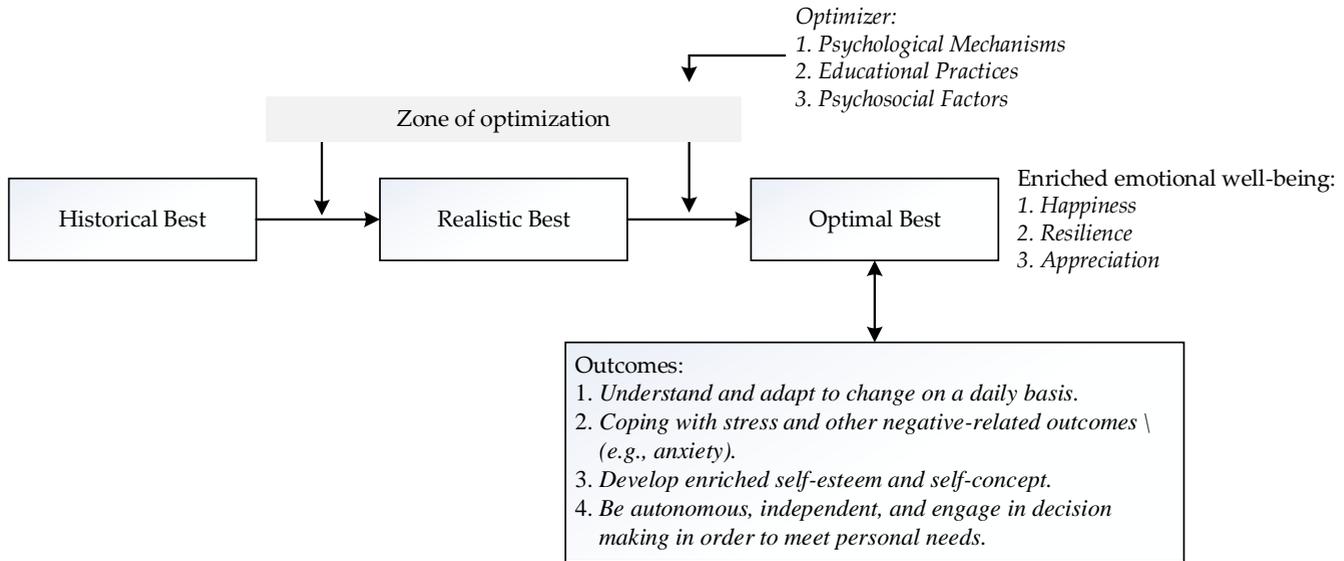


Figure 1. Conceptualization of Achievement bests, Hope, and Emotional well-beings.

Note: The achievement bests framework details five different types of achievement best, namely: historical achievement best, realistic achievement best, personal achievement best, optimal best, and ultimate achievement best. For the sake of simplicity, and for the purpose of our argument, we have included only historical, realistic, and optimal achievement bests.

Testament to the potency of this theoretical orientation in educational and non-educational contexts has been affirmed by extensive research studies (e.g., Adelabu, 2008; Bernardo, 2015; Phan, 2013, 2015a; Rand, 2009; Rand, Martin, and Shea, 2011; Wong and Lim, 2009) and the recent book by Belgium author Leo Bormans, titled *The World Book of Hope*. Hope, similar to that of optimism, reflects a positive orientation towards life – for example, what are my goals in life? On this basis, we provide an in-depth examination of a conceptualization, shown in Figure 1, that depicts the potential use of hope to facilitate positive emotional well-being experiences. This postulation is innovative, especially from a practical point of view. In our discussion of this proposition, we also introduce and focus on the tenets of *achievement bests*. This theoretical orientation, which emphasizes on the importance of personal accomplishments in a particular domain (e.g., Algebra) is integral to the functioning of society.

## THE FRAMEWORK OF ACHIEVEMENT BESTS

Recently, progressing the study of personal well-beings, we have developed the *Framework of Achievement bests* (e.g., Phan, In press-2016; Phan and Ngu, In press-2016; Phan et al., 2016). The Achievement bests Framework focuses on a person's accomplishment in a particular domain of functioning, such as his/her emotional well-being in daily situations. Our conceptualization, expanding on a previous seminal publication, titled '*Introducing the concept of Optimal Best: Theoretical and methodological contributions*' (Phan et al., 2016), depicts *five different types of achievement best* (Phan, In press-2016; Phan and Ngu, In press-2016), namely:

1. *Historical achievement best* emphasizes an individual's *past* knowledge, learning experience, and personal functioning in a subject matter. Historical achievement best, in this sense, is similar to Bandura's (1986, 1997) theorization of enactive learning experience (i.e., a person's academic accomplishment, subject to both mastery and normative criteria), which is an important source of information in the formation of self-efficacy beliefs. This type of achievement best involves an individual's reflection and recall of his/her past learning experiences, achievements, and academic standings, say (e.g., I note that I have never been good in mathematics; I was ranked 67/90 last year in Year 8). An individual's past knowledge, accomplishment,

and personal functioning, in this sense, may indicate exceptional scholarly standing. A Year 9 student, Thomas, may indicate and report a high historical achievement best for Algebra to his current teacher, Mrs. Choo (e.g., he was ranked 4/30 in the class in Year 8). Alternatively, too, of course, it is plausible that individuals' historical achievement bests may show sub-standard learning experiences and accomplishments. For example, in comparison to Thomas, another student's report may reflect a moderate historical achievement best in the area of Algebra (e.g., she was ranked a 24/30 in the class in Year 8).

Historical achievement best is an important source of information that highlights a person's current accomplishment and level of knowledge in a subject matter. At the same time, however, historical achievement best also explains levels of motivation, and one's determination and personal functioning to succeed, academically and/or non-academically. This type of achievement best is insightful for the purpose of reflection, and enabling individuals to recall and realistically report on their prior achievement bests. Inaccurate recall of historical achievement best, for example, may result in unrealistic estimation, aspiration, and expectation for current and/or future successes. Accurate recall of historical achievement best, in contrast, may serve as a source of motivation for improvement purposes.

2. *Realistic achievement best* is defined as a person's *actual* knowledge, learning experience, and personal functioning in a subject matter. This type of achievement best, differing from historical achievement best, is current and realistic, and manifests itself in the forms of test scores at school (e.g., a student may achieve a test result of 20/30 for a topic in mathematics), and personal ranking, based on social comparison. Likewise, of course, an individual may report to others (e.g., parents) of his/her current knowledge, capability, and personal functioning (e.g., this is how much I know of Algebra, right now). Realistic achievement best, intricately influenced by historical achievement best, is actual and indicates immediacy in terms of a person's knowledge, learning experience, and personal functioning. An individual whose historical achievement best is moderate, for example, is likely to report on a similar achievement best level at the present time.

Realistic achievement best, similar to that of historical achievement best, may vary between individuals. A Year 9 student, Thomas, may report high realistic achievement best in mathematics, alluding to his actual knowledge, learning experience, and personal functioning of, say, Algebra (e.g., to solve equations with two unknowns,  $x$  and  $y$ ). Another student, Melissa, in contrast, may report low realistic achievement best, which in this case involves her knowledge, learning experience, and personal functioning to solve equations with one unknown. This type of achievement best, in itself, could serve as a source of motivation for future outcomes. A high level of realistic achievement best, for example, is likely to result an individual reporting on a similar level for future achievement best. A low-to-moderate level of realistic achievement best, in contrast, may align more closely to an indication of a similar level of future achievement best.

3. *Personal achievement best* is defined as a person's *anticipated positioning to achieve a level of* knowledge, learning experience, and personal functioning in a subject matter that is comparable with others' (e.g., peers). This type of achievement best, differing from historical and realistic achievement bests, emphasizes the importance of *anticipation* – that is, one's anticipation to achieve a particular level of acquired knowledge, learning experience, and personal functioning (e.g., to be able to understand the concept of 'factorization' in Algebra) that surpasses realistic achievement best (e.g., a person's reporting that he/she is only able to demonstrate his/her competence at solving 'additions and subtractions' of Algebra problems). An individual using historical and realistic achievement best records, in this sense, may anticipate that he/she has the capability to advance further, and to produce sound outcome(s) in a subject matter. How much 'further', which we recently conceptualized (Authors, In press-2016b), is an unclear issue that requires continuing research development.

It is important to note that achievement of personal best is realistic, and situates within the realm of a person's belief, expectation, and capability to achieve concrete outcomes. We contend that social comparison of personal achievement bests indicated by others serves as a point of reference, benchmarking a particular level of anticipated positioning for an individual to achieve. A Year 9 student, in this analysis, may indicate that he/she has the potential to

achieve a more complex level of learning outcomes in mathematics (e.g., to learn about ‘multiplications and divisions’ of three variables), consequently as a result of knowing that another student previously has achieved similar outcomes. What this means then, of course, is that personal best in school contexts is realistic and achievable, depending on a student’s level of motivation, resolute, expectation, and learning experience.

4. *Optimal achievement best* is defined as a person’s *aspired positioning* to acquire knowledge, learning experience, and personal functioning that are at an optimal level. This type of achievement best differs from personal achievement best for its potential non-concrete outcomes. This type of achievement best, differing from historical, realistic, and personal achievement bests, emphasizes the notion of *aspiration* – that is, one’s aspiration to achieve a level of acquired knowledge, learning experience, and personal functioning that surpasses personal achievement best. That is, indication of optimal achievement best is ‘aspirational’, and reflects a person’s wishful thinking and desire to achieve outcomes that may be farfetched, in nature.

Optimal achievement best, in this sense, does not depend on social comparison as a point of reference; rather, a person’s own historical, realistic, and personal achievement bests, as well as his/her internal standard of belief and aspiration (e.g., what is the best that I can do?) serve as sources of information in the formation of a particular aspired positioning. A Year 9 student who is exceptional, as reflected by his/her historical, realistic, and personal achievement bests, may aspire to function at a higher level of capability, and to achieve a first place ranking in mathematics. This indication of optimal best, realistic and achievable, illustrates the student’s standing in terms of knowledge, learning experience, and personal functioning in relation to other students’. Another Year 9 student’s low-to-moderate historical and personal achievement best records, in contrast, may not necessarily produce concrete optimal achievement best (e.g., To do complex mathematics in Senior years).

5. *Ultimate achievement best*, similar to optimal achievement best, is defined as a person’s *maximum projection* to acquire knowledge, learning experience, and personal functioning that are at the most maximum level of achievement. This type of achievement best differs from optimal achievement best for its emphasis on the notion of *maximum projection* – that is, one’s projection to achieve a level of

acquired knowledge, learning experience, and personal functioning that surpasses optimal achievement best. Ultimate achievement best, in this sense, indicates self-fulfillment of goals that are extremely ambitious, distant, and grandiose per self-referenced standard. This type of achievement best is unrealistic for many individuals, as its formation is based on track record, self-comparison, personal belief, and expectation (e.g., I know that I can do this, regardless of what people say). Any individual, for that matter, may aspire and project goals for accomplishment that are extremely unrealistic, based on his/her current historical, realistic, personal and optimal achievement bests. Some individuals, of course, may flourish and achieve their project goals, consequently as a result of their track records, high levels of motivation and self-beliefs, and resolute to succeed.

The implausible nature of ultimate achievement best, in this case, indicates that variations between individuals, consequently as a result of differences pertaining to historical, realistic, personal, and optimal achievement bests. Some individuals, for instance, are resolute and believe they have the knowledge, experience, and personal functioning to achieve the level of ultimate best that they have projected. This projection of a maximum level of achievement of knowledge, experience, and personal functioning is contrary to their existing track records that do not warrant such ambitious undertakings. Students who are low-to-moderate in mathematics capability, for example, are unlikely to reach the projected maximum level of achievement best. Exceptional track records in mathematics accomplishment, in contrast, are more likely to assist in the fulfilment of a level of achievement best that is maximum in terms of knowledge, experience, and personal functioning.

Overall, the continuum of achievement bests may account and explain an individual's cognition, motivational beliefs, and behavioral patterns. A historical account, in this instance, may help educators to: (i) understand the achievement status of an individual in terms of his/her current competence, anticipated performance, aspiration, and future projection, and (ii) consider initiatives, pathways, and educational-social programs that could optimize ongoing achievement bests. One important question for us to consider is how does the achievement bests framework situate and fit in with our understanding of emotional well-being? What does optimal achievement best from the perspective of enriched emotional well-being mean?

The framework of achievement bests may account for a person's state of emotional well-being. In particular, based on the descriptions of the five different types of achievement best, it is plausible for us to surmise that the achievement bests framework reflects the *past*, the *present*, and the *future*. Progressively, in this instance, we delve back into a person's historical best of his/her emotional well-being. Has it been negative (e.g., anxiety) or positive, in general? Comparing with other individuals, for example, has there been a history of negativities, whereby the person has had profound experiences of anxiety and other negative emotional well-being experiences? What were some of the factors and/or reasons that accounted for this track record? An examination of historical achievement best of emotional well-being (e.g., +ve emotional well-being, in general) may, in turn, inform us of the person's current realistic best state. For example, in relation to an adolescent who is dealing with a social relationship, at present, it is possible that we could explain and account for his/her emotional states based on previous historical track record. Constant bouts of anxiety and difficulties in overcoming this negative affect response, in this instance, may result from his/her previous track record of low emotional well-being experiences (e.g., not being able to overcome adversity). Another adolescent's ongoing state of positive emotional well-being, in contrast, may be explained and accounted by enriched historical achievement best.

The realistic achievement best of emotional well-being for an individual, in this instance, may inform his/her future state of affair. Recognizing one's strength and constantly being happy with everyone (i.e., evidence of positive emotional well-being), at present, may facilitate in the striving of the following outcomes:

- Build upon strengths and positive emotions, such as happiness and love to ensure successful social relationships with others.
- Be thoughtful towards others who are less capable, and who may be in need of assistance.
- Develop a strong sense of personal resolve and resilience to face adversities without hesitation.
- Consider towards and develop a sense of purpose, feelings of completeness and contentment and, of course, heightened self-beliefs such as self-esteem and self-confidence.
- Be autonomous, independent and, where appropriate, to engage in decision making that may produce benefits for all.

- Adopt a positive approach to life with the purpose of enjoyment, appreciation, and self-fulfillment.
- Envisage of lifestyles that are enriching, in nature.

The achievement bests framework, overall, is insightful and may provide information regarding the progress and development of adolescents' enriched emotional well-beings experiences. The aforementioned indicators, for example, reflect a heightened state of emotional well-being that is noteworthy for consideration. The achievement best outcomes set out (e.g., be autonomous and recognizes one's strength), in this instance, may serve to motivate adolescents to live fulfilling life. Indeed, aside from historical achievement best, which is informative for the purpose of explanation and understanding, realistic, personal, and optimal achievement bests are motivational, encouraging adolescents to appreciate life and strive for maximum life experiences. More importantly, of course, such mentioning also adopts a positive psychological approach to human endeavor. This non-deficit positioning is more potent for its non-preventive measure and execution.

## THE ZONE OF OPTIMIZATION

The continuum of achievement bests to reach enriched emotional well-being, as shown in Figure 1, also emphasizes the *zone of optimization*, which is defined as the 'difference' or 'range' between achievement bests, for example: historical achievement best ↔ realistic achievement best, realistic achievement best ↔ personal achievement best, etc. (Phan and Ngu, In press-2016). The zone of optimization is intricately linked to the *process of human optimization* (Fraillon, 2004; Phan and Ngu, 2015a; Phan et al., 2016), defined as *an individual process of scaffolding and guidance that, in turn, optimize individuals to achieve their optimal best outcomes* (Phan and Ngu, In press-2016). How does an individual 'move' from his/her realistic achievement best to that of personal achievement best in a domain of functioning (e.g., a sense of shyness and uncertainty → personal resolute to deal with people, in general)? The process of human optimization, involving achievement bests (e.g., realistic achievement best → optimal achievement best) may involve differing 'optimizers'. We postulate that *psychological mechanisms* (e.g., the impact of hope), *educational practices* (e.g., appropriate instructional design for effective learning), and *psychosocial factors* (e.g., the impact of the home

environment) could all serve to optimize individuals' achievement bests and subsequent learning experiences. Optimizing individuals' achievement bests, in this sense, may involve scaffolding from external sources (e.g., a classroom teacher, a social program). The onus, however, rests with individuals to ensure that resources, programs, feedbacks, etc., are utilized appropriately to produce positive yields. Regardless of one's historical and/or current realistic achievement bests, it is important that there is free will and consideration for him/her to strive for maximum outcomes. From our previous discussion, there are three major possibilities that expand on from historical and realistic achievement bests: personal, optimal, and ultimate.

A historical account, in this instance, may help us: (i) understand the achievement status of an individual in terms of his/her current competence, anticipated performance, aspiration, and future projection, and (ii) consider initiatives, pathways, and educational-social programs that could optimize ongoing achievement bests. An individual's realistic achievement best informs his/her current level of achievement, for example: A Year 9 student, Mark, is having difficulty in coping with family pressure, and his self-confidence is quite low when compared to students in his class. Acknowledgment of realistic achievement best would enable an individual (e.g., Mark) to plan his/her personal achievement best for accomplishment (e.g., to try and develop a level of self-confidence that is sound for the purpose of dealing with others at school). This personal achievement best, if successful, would surpass current realistic achievement best. Fulfilled personal achievement best, in turn, may inspire an individual to anticipate and strive for optimal best achievement, a self-referenced benchmark that has been set and achieved by his/her peers. In the case of Mark, for instance, his personal achievement best may result in him setting forth an optimal achievement best for accomplishment, namely: (i) recognizing his own emotions (e.g., happiness) to help others whose predicaments are similar to his previous experiences, and (ii) to be authentic and positive even in the face of adversities and difficulties.

The ultimate achievement best of emotional well-being is different, reflecting a personal endeavor that may not yet be achieved by others. For adolescents, in particular, this theoretical tenet may not result in concrete and achievable outcomes, given their cognitive maturity and limited life experiences. The zone between realistic achievement best and personal achievement best is realistic and achievable. Likewise, the zone between personal achievement best and optimal achievement best is ambitious, but still accomplishable, depending on one's resolute, the availability of scaffolding, and the extent of the optimal outcome(s) for achievement.

## HOPE: A THEORETICAL OVERVIEW

*Hope* is an important psychological mechanism that has been extensively studied. Its significance, world-wide, has recently been acknowledged in Bormans' (2015) recent book of hope. *What is so significant about hope?* Hope, similar to that of the achievement bests framework (Phan and Ngu, In press-2016; Phan et al., 2016), reflects a positive approach to our understanding of life and human endeavors. Hope is defined as "a sense of determination toward reaching one's goals (i.e., the *agency* component) and the ability to generate successful plan to reach one's goal (i.e., the *pathways* component)" (Adelabu, 2008, p. 348). Hope is not an emotion at all, but rather considered as a dynamic motivational system that positively associates with self-beliefs (e.g., self-esteem), perceptions of control, optimism, affectivity, and outcome expectancies (Phan, 2013; Snyder et al., 1991; Snyder and Shorey, 2002). There is extensive research evidence, which attests to the impact of hope on both academic (Adelabu, 2008; Bressler, Bressler, and Bressler, 2010; Chang, 1998; Gilman, Dooley, and Florell, 2006; Phan, 2013; Rand, 2009; Rand et al., 2011) and non-academic (Bernardo, 2015; Bryant and Cvendros, 2004; Chang, 2003; Chang and DeSimone, 2001; Danoff-Burg, Prelow, and Swenson, 2004; Gilman et al., 2006; Hasnain, Wazid, and Hasan, 2014; Snyder, 2004; Wong and Lim, 2009) outcomes. Academically, for example, a heightened state of hope is positively associated with achievement-related outcomes (e.g., hope  $\rightarrow$  grade expectancy,  $\beta = .31$ ,  $p < .01$ : Rand, 2009; e.g., hope  $\rightarrow$  GPA,  $\beta = .25$ ,  $p < .05$ : Rand et al., 2011). Non-academically, likewise, hope is found to predict a number of personal and social outcomes (e.g., hope  $\rightarrow$  life satisfaction,  $\beta = .39$ ,  $p < .001$ : Rand et al., 2011).

Hope is positive and, we contend, reflects a number of personal attributes that could serve to influence emotional well-being. Indeed, from what we know of hope so far, it is plausible to contend that this psychological mechanism could serve to optimize adolescents' achievement bests in their experiences of emotional well-being. Is it possible for hope to act as an agent of change, and optimize adolescents' optimal achievement best regarding their emotional well-being experiences? There is empirical evidence, at present, to indicate that hope positively influences emotional well-being (Ciarrochi, Heaven, and Davies, 2007; Ciarrochi, Parker, Kashdan, Heaven, and Barkus,

2015). Referring to our previous example, an achievement of personal best for an adolescent, Benjamin, may involve: (i) recognizing the potentials of his/her positive emotions (e.g., happiness), regardless of current difficulties, and to move forward, (ii) consideration of different coping strategies, based on personal emotions, that could enable him/her to face difficulties and adversities, academically and/or non-academically, (iii) the development of a sense of purpose and to enjoy life at the present time.

In Figure 2, we present an example of the optimization of personal achievement best to that of optimal achievement best for Alison, Benjamin's best friend. Alison's case is different from Benjamin's, illustrating individual variations in the different achievement best types. Importantly, in this scenario, we have positioned Alison's personal resolute to anticipate and strive for optimal achievement best. It may well be the case that Benjamin is not able to contemplate this achievement of optimal best, and contends with his personal achievement best. Alison's case of personal achievement best is similar to that of Benjamin's, detailing three main outcomes, namely: recognition of positive emotions, the ability to develop coping strategies to deal with adversities, and the enjoyment of life, at present. What is notable, however, is that Alison's intent to achieve the following optimal best outcomes, based on her achievement of personal best:

- Aside from recognition, there is also desire to appreciate both positive (e.g., happiness) and negative (e.g., sadness) emotions.
- To assist others, based on her own experiences, to use their own emotions (e.g., happiness) to cope with difficulties (e.g., social relationship with a friend).
- To develop personal attributes that reflect her intent to be autonomous in her action and decision making. This decision making (e.g., organizing a community event to assist disadvantaged locals), which could benefit others, may, indeed, indicate her maturity.

For Alison, the achievement of optimal best of her emotional well-being may result in positive outcomes and, at the same time, reflect non-academic growth. Striving to achieve from recognition of positive emotions to that of appreciation of different types of emotions, of course, would require some personal initiatives, effort, and scaffolding. We contend that hope, in this

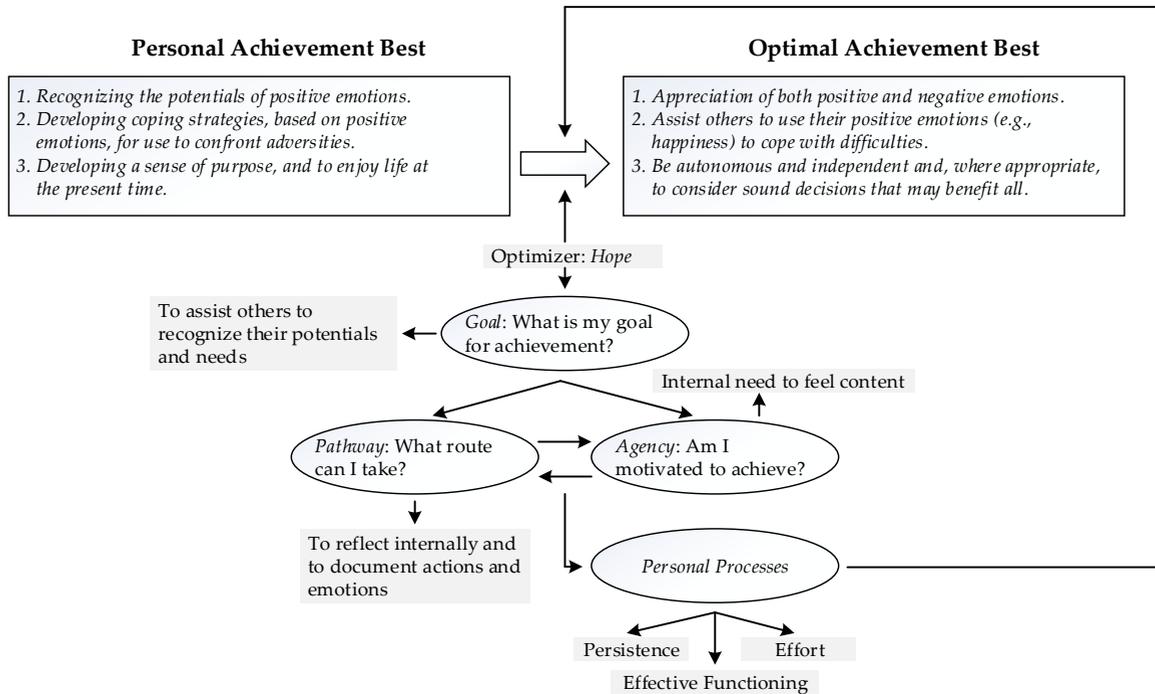


Figure 2. The Striving of Optimal achievement best.

Note: An example of the striving of optimal achievement best from personal achievement best. It is also possible, of course, to present another example, whereby an individual strives to reach personal achievement best from his/her realistic achievement best.

analysis, could serve to assist Alison to achieve the three mentioned outcomes. *What is the basis for this theoretical contention?* We argue that this is possible, given the characteristics of hope (Snyder et al., 2000), which may facilitate the following sequential process:

1. The consideration and articulation of a goal(s) that one wishes to achieve. For example, in Alison's case, she has a main goal to achieve – that is, to better herself in emotional well-being (e.g., to recognize others' needs, and to assist them in this recognition), drawing on from her current emotional well-being experiences.
2. The goal that is anticipated for accomplishment results in two consequences that is consistent with the theory of hope: (i) an individual's pathway that would enable him/her to achieve the specified goal, and (ii) an individual is required to experience a state of motivation to achieve such goal. In Alison's case, for example, she has decided that one pathway that she would take is to engage in personal reflection, and to document this reflection for the purpose of improvement. At the same time, too, Alison experiences an internal state of motivation that calls for her to achieve a sense of contentment.
3. The tandem act of both pathway (e.g., Alison's determination to engage in personal reflection) and agency (e.g., an internal need to achieve experience and feeling of contentment), in turn, results in the *facilitation of personal processes* that may enable the achievement of optimal best. This theorization of personal processes, which may encompass one's state of *persistence*, *effective functioning*, and *effort expenditure*, expands on from the theoretical orientation of hope (Snyder, 1995; Snyder et al., 2000; Snyder, LaPointe, Crowson, and Early, 1998). We introduce this concept of personal processes, as we believe that both hope and fulfilment of achievement bests (e.g., to assist others to recognize their potentials and needs) cannot exist in isolation. Hope, in this instance, would initiate a sequence of personal processes in order to ensure guaranteed accomplishments:
  - Persistence is a reflection of one's own dedication, and serves to instill self-confidence and personal tenacity, especially when original pathways are disrupted. At the same time, however, persistence is an attribute of endurance, diligence, and commitment towards the established goal(s) for fulfilment.

- Sustaining one's state of motivation to achieve such goal(s) in the achievement of optimal best also requires dedicated time and effort expenditure. One cannot expect to achieve a particular goal if there is minimum dedication and/or commitment from an individual.
  - Effective functioning (Phan and Ngu, 2015a) indicates the importance of efficiency in terms of cognition, behavior, and action. That is, from our previous theoretical contention, purposive thinking and action in a functional, structured manner is likely to guide individuals towards their goals. This functional deliberation is an antithesis of unstructured learning, behavior, and action.
4. Personal processes, arising from the combined association between pathway and agency, play a central role in optimizing achievement of one type of accomplishment to that of another. We contend that personal processes are initiated, consequently as a result of the setting of hope. Basically, from Figure 2, our theoretical contention posits a sequence of consequences that result from the initiation of hope. For Alison, the quest to achieve optimal best of emotional well-being experiences (e.g., to develop a sense of autonomy) could, indeed, initiate a sense of hope, which would help her in her accomplishment. Our postulation is that theoretically hope, encompassing both pathway and agency, cannot directly optimize individuals' achievement bests; rather, it is *the consequence of hope that then optimizes the zone of achievement bests* (e.g., realistic achievement best → personal achievement best). This premise enables us to consider a more generic model of human optimization (Figure 3), whereby different optimizers (e.g., *personal self-efficacy*: Bandura, 1997) may initiate personal processes that then scaffold individuals' achievements. For example, in a recent focus of inquiry, we proposed that *instructional designs* in mathematics (e.g., equation method), as applied educational practices, could serve as optimizers of achievement bests.

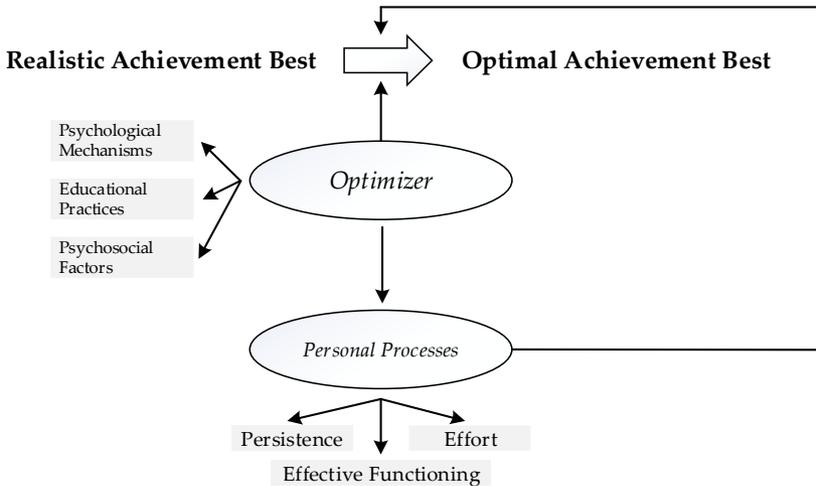


Figure 3. A General Model of the Zone of optimization.

Note: We contend that optimizers may include, for example: *psychological mechanisms* (e.g., hope), *educational practices* (e.g., instructional design), and *psychosocial factors* (e.g., the home environment). Academically, for example, it is plausible to argue that instructional designs (Ngu and Phan, 2015, 2016) could optimize students’ achievement bests (e.g., optimal best involving problem solving).

## CONCLUSION

In summary, what can we conclude from this chapter? Basically, as a recap for consideration, our theoretical discussion so far has focused on the importance of emotional well-being, situated within the period of adolescence. Adolescents experience personal growth (e.g., understanding of inner moral beliefs), but yet also face uncertainties, stress, conflict, and negative experiences. One notable facet, which arises from this emphasis, is the notion of emotional well-being. Emotional well-being experiences for adolescents, in this case, may reflect both positives and negatives. Not being able to cope, socially, and the continuous feelings of helplessness, for example, may result in long-term detrimental consequences. Acknowledging this pervasive possibility, we need to consider the positive outcomes that may arise from enriched emotional well-being experiences. Positive emotional well-being, in

this case, enables adolescents to flourish and grow, academically and non-academically. It is important than that, as a collective society, we focus on the nurturing and enhancement of adolescents' emotional well-being experiences.

There are a number of pathways and strategies that could contribute to the nurturing of enriched emotional well-being. One such pathway may involve the utilization of hope, a psychological mechanism that has been found to produce positive yields. Our postulation, in this analysis, indicates the central role of hope as an optimizer of adolescents' emotional well-beings. This is an important theoretical positioning, placing emphasis on the extent to which hope could optimize and enable individuals to reach their emotional well-being potentials. Such theorization, according to our discussion, involves close examination of individuals' achievement bests in different domains of functioning. *What is the best that I can do?* is the hallmark of this concept of achievement best. The characteristics of achievement bests are positive, in nature, focusing on the intricate analogous associations between the past, the present, and the future. Situating emotional well-being with this framework of achievement bests is appropriate, enabling individuals to benchmark their thinking, motivation, behavior, and action against individual and peer-referenced accomplishments.

We contend that our conceptualization, to date, has provided grounding for advancement and further research development. We take this opportunity to consider a few major recommendations for examination and research progress. Foremost, of course, is a requirement for educators, counsellors, and researchers to validate the conceptualized role of hope as an optimizer of achievement of emotional well-being (e.g., realistic achievement best → hope → personal achievement best). Ethnographic and/or psychobiological focus is a possibility, involving in-depth examination and documentation of the central role of hope in the development of enriched well-being experiences. Interestingly, perhaps, is a focus on adolescents': (i) views regarding the concept of hope, in general, and (ii) willingness to consider using hope to improve and enhance their emotional well-beings. Secondly, referring to Figure 3, it would be insightful for researchers to establish empirical credence regarding the association between an optimizer (e.g., hope, instructional pedagogical practice) and the subsequent personal processes that arise. For example, how does a particular optimizer influence persistence, say, to result in the heightening of the zone of achievement bests (e.g., realistic achievement best in the learning of Algebra → optimal achievement best in the learning of Algebra)?

Finally, we believe that the study of hope could also benefit from research development that explores the impact of hope on other psychological processes (e.g., self-confidence) and/or personal (e.g., daily functioning) outcomes during the period of adolescence. Aside from emotional well-being, it is noteworthy for us to consider the importance of adolescents' personal values. We recently advanced this psychosocial aspect by introducing the concept of *appreciation and value well-being* (Phan and Ngu, 2014, 2015b, In press-2016), which focuses on an individual's appreciation for life and their altruistic values. This inquiry is positive, in nature, and may serve to associate adolescents with enriched personal growth in moral, social, and emotional development. Believing that life is beautiful, for example, may assist adolescents to progress with life with a sense of conviction, hope, and optimism. Appreciation and value well-being, similar to that of emotional well-being, may come to enrich individuals' life experiences.

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*Chapter 4*

## THE ROLE OF HOPE AND SPIRITUALITY IN YOUTH'S EMOTIONAL WELL-BEING

*Amparo Oliver\**, *Laura Galiana*,  
*Davide Piacentini-Genovart and José M. Tomás*  
Universitat de València, Valencia, Spain

### ABSTRACT

The number of studies on hope and spirituality as predictive factors of youth's emotional well-being has increased over the last years. The present chapter studies the relations between hope, spirituality and life satisfaction, using a structural equation model approach, offering transcultural evidence of a scarcely studied population, the Spanish youth. A sample of 224 participants aged 18-28 completed the Spanish version of the Satisfaction With Life Scale, the Dispositional Hope Scale, and the subscales Meaning and Peace of the FACIT-Sp. A structural model was built to test variables' predictive power on life satisfaction. The a priori theoretical model fitted the data well. Results suggest that hope and meaning have strong effects on youth's life satisfaction, whereas peace is not a statistically significant predictor. The variance accounted for it is large enough to be considered relevant. The key factor associated to youth's emotional well-being seems to be hope. This new transcultural evidence obtained in a Mediterranean culture is consistent

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\* Corresponding author: Amparo Oliver, Department of Methodology for the Behavioral Sciences, Psychology, University of Valencia. Av. Blasco Ibañez, 21, 46010, Valencia, Spain. Email: oliver@uv.es.

with recent literature mainly grounded in Anglo-Saxon evidence, supports the universalism of the approach and should encourage future strategies to promote hope and spirituality in youth people.

**Keywords:** hope, spirituality, well-being, meaning, life satisfaction, structural equation model

## INTRODUCTION

Experiencing hope seems natural for every human being. It could be said that at the very moment we start being conscious about the world and about ourselves, we may also start hoping. There is not yet a great deal of literature describing hope during the very early ontogenetic stages. A hint on this matter is superficially provided in Snyder and colleagues' (1997) article "The Development and Validation of the Children's Hope Scale" (see page 402), where it is explained that an early childhood immunization process against negative outcomes could result in the development of a high-hope way of thinking that protects children for future impediments. It is impossible for almost any person to retrieve the first time she or he hoped for something. If such a complex, emotional process cannot be uttered, there is no access to that information and experience, and hence neither to the process *per se*. In fact, we may only be capable of recalling early memories such as desiring to get a good mark at school, be friends with a group of kids or see our Christmas list of presents accomplished, among several others. Even though these memories are what we could consider the closest approximation to the act of hoping, they are not accurate enough so as to build a theory upon them. Science can be done only once a common and clear method, that includes exploration, hypothetization, categorization, comparison and so on, is carried out. So let us start reviewing how hope is actually defined and studied.

Professor Richard Snyder has been a major and well-known contributor to the study and research on hope. His work has served –and it is still serving– as solid scaffolding to other researchers and clinicians for either deepening in this topic or taking hope theory to therapy sessions and interventions.

From Snyder et al.'s (1991) perspective, hope is composed of two processes: agency and pathway. *Agency* (or *agentic thinking*) is understood as the energy and determination invested in pursuing a specific goal, i.e., the will to achieve something, while *pathway* (or *pathway thinking*) is concerned with searching for feasible ways or plans to attain one's established goal (Snyder et

al., 1991). So the expression “where there’s a will, there’s a way” is no longer appropriate. From Snyder’s prism, agency and pathway constantly interact with each other during the whole goal-focused behavior, being the cumulative components of what is deemed as hope.

To date, this dual conceptualization of hope has been held in literature. Nevertheless, it is dealt differently in research endeavors. In a recent study carried out by Galiana, Oliver, Sancho and Tomás (2015), who presented the first Spanish version of Snyder et al.’s Dispositional Hope Scale (DHS; 1991), four confirmatory analyses were tested for hope, agency and pathway: unidimensional, non-hierarchical multidimensional, second-order, and bifactor models. In terms of factor validity and internal consistency, the unidimensional model was the best fit to the data, which is in line with what Brouwer, Meijer, Weekers and Baneke (2008) found when evaluating DHS dimensionality, concluding that “the best choice is to consider the scale as a unidimensional scale” (p. 314).

## **Hope and Positive Psychology**

Despite seeming alarming from our current living, not too many years ago, it was thought that having good expectations for one’s future and that being positive for one’s life plans could be understood as a sign of social and personal maladjustment; even a likely evidence of psychopathology (Alarcon, Bowling and Khazon, 2013; Peterson, 2000). Since the origins of positive psychology, that is not the case anymore. Academic research of recent years suggests quite the opposite –being positive and hopeful has been shown to reflect well-being (as examples, see Peterson, 2000; Snyder et al., 1991, 2005). From a methodological point of view, the question if hope and optimism are the same (or not) arises yet again, due to its implications in further research and its applicability.

As described by Scheier and Craver (1985), who conducted a comprehensive research on optimism and expectancy outcomes, optimism stands for the generalized tendency to believe that a person will experience more good than bad outcomes in life. By revising the definition of hope given above, the reader may see subtle differences. While optimism is conceived as the big, positive picture of one’s outcomes, hope emphasizes the role played by the individual in attaining those desired outcomes. So, from a conceptual ground, we can assert they are indeed not the same. Still, this is not the end of the story. Methodological aspects knock our door in attendance of a more

accurated scrutiny, and Alarcon, Bowling, and Khazon (2013) could be able to cast some light in this matter. They conducted a meta-analytic study whose results suggest that hope and optimism are related constructs but belong to different categories, i.e., they are not redundant. As a matter of fact, optimism showed stronger positive relation to some personality variables, such as “positive affect,” “self-esteem” and “self-efficacy,” and stronger negative relation to “negative affect,” while hope yielded stronger positive relation to “happiness,” and stronger negative relation to “stress.” Moreover, these authors also tested for distinction between optimism and hope and other well-established personality traits, as the ones encompassed in McCrae and Costa’s Five-Factor Model (1987), concluding that a) optimism differs from OCEAN: Openness to experience, Conscientiousness, Extraversion, Agreeableness, and Neuroticism; from trait Positive Affect (PA) and Negative Affect (NA), and from pessimism; b) hope differs from trait PA and trait NA; from self-esteem, and from self-efficacy (Alarcon et al., 2013).

## **Hope and Well-Being**

Up to this point, the reader may wonder why the study of the “feeling of wanting something to happen and thinking that it could happen” (Hope, 2015) has drawn so much attention, and even why it seems to be important enough as to keep on writing about it. It should be regarded as a natural question to the reader; perhaps the same question Snyder asked himself at the beginning of his career researching on this topic.

Negativism can be a settled personality trait for some people, which can automatically lead to expect bad things to happen. But the general tendency is to hope for good things to occur, and the achievement of the wanted things should take us to a higher level in our development. Therefore, the implicit, ultimate goal of both hope and hoping are enhancing our satisfaction with life, this is, improving our well-being. Yet can hope actually do so? Prior to answer this question, some constructs must be defined and explained.

Human mind seems to work at its best by creating categories for the perceived and thought world that surrounds us (Thomasson, 2004). Intellectual categories then help us compare between other categories and group of categories. This being the case, it is not surprising that humankind has been interested from his origins in defining, describing and comparing the human state or condition known as well-being. What is indeed surprising is the absence of consensus about it, existing almost as many definitions of well-

being as people in the world (Liu, 1976) or researchers studying this concept (Baker and Intagliata, 1982).

Emerson's (1985) definition deems well-being as "the satisfaction of an individual's goals and needs through the actualization of their abilities or lifestyle" (p. 282). Providing a more comprehensive perspective, Felce and Perry (1995) state that well-being "comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being, together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (p. 60).

These two definitions, picked up from many others, already declare that the focus on well-being can be placed in different facets or dimensions, what has meant breaking down the state of well-being into objective well-being, psychological well-being, and subjective well-being (Hird, 2003), having each of them more subdivisions and scales in order to measure every subcategory.

Although objective well-being has its own components (material well-being, emotional well-being, physical well-being, social well-being, and development and activity) (Hird, 2003), which makes easier to identify it as a unique dimension, it does not work the same way for both psychological well-being and subjective well-being. The reason underlying this problematic conceptualization is their intertwined nature, as noted in Hird's model of well-being (2003). Of course, this is on debate, since there are measures to test each of them; for instance, psychological well-being can be measured separately from subjective well-being by using Ryff's (1989) PWB (Psychological Well-being) Scale.

For the purpose of this chapter, we are going to focus on subjective well-being – commonly abbreviated as SWB – given its narrow relation to the idea of happiness.

SWB is a large structure that includes several elements (Lucas and Diener, 2004), being positive affect and negative affect (emotional facets), and life satisfaction (cognitive process) (Diener, Suh, Lucas and Smith, 1999) its key components. The former two refer to moods and emotions that an individual holds when evaluating events in his life, whereas the later term refers to "a globally assessment of a person's quality of life according to his own criteria" (Shin and Johnson, 1978).

In the context of humans' achievement of happiness, it is fundamental to determine the way young people perceive their lives (Proctor, Linley, and Maltby, 2009), inasmuch as youth is a period in which people have to face important decisions and develop a sense of who they are and who they want to become. In this line, O'Sullivan (2011) found a correlation between hope and

life satisfaction of .42 in a sample of undergraduates, and an increase in the explained variance of life satisfaction of 11% when hope and self-efficacy were added in a logistic regression. More recently, Marques, Shane and Mitchell (2012) also found that hope had the strongest explanatory power for life satisfaction in a sample of Portuguese students, with a maximum R-square of .28. Regarding students at high-school level, hope has also been proved to act as a buffer against difficulties children may encounter in classroom settings with their peers (Lagacé-Séguin and d'Entremont, 2010), and as a psychological strength against internalizing behavior problems and reducing life satisfaction when confronted with adverse life events (Valle, Huebner, and Suldo, 2006).

Consequently, according to what research has suggested so far, hope is proving to be 1) a strong significant predictor of well-being and life satisfaction, and 2) a protective factor against depression (Legacé-Séguin and d'Entremont, 2010; Singh, Singh, Singh, and Srivastava, 2013), dropout (Worrell and Hale, 2001), self-worth decrease and children's maladjustment (Legacé-Séguin and d'Entremont, 2010).

In this quest to unravel hope, some researchers have employed more sophisticated analyses, such as structural equation modeling. The awakening of this need for more complex methods could have its origins in the feeling that an additional meaning was being missed in the construct of hope; something that could antecede it and, at the same time, connect it with subjective well-being. Meaning in life could be the answer.

As described above when dealing with SWB's definition, meaning in life has not got an official and clear definition for itself; depending on the author describing it, it may imply more philosophical or more psychological aspects. Thus, Wong's (1989) definition is taken here due to its comprehensive view. Wong proposes that meaning is "an individually constructed cognitive system, that is grounded in values and is capable of endowing life with personal significance and satisfaction" (p. 517). The same author establishes a taxonomy for meaning, having: a cognitive component, referring to the thoughts, beliefs and interpretations a person has in relation to everyday events; a motivational component, this is, the will to achieve personal goals congruent with one's needs, values and wants; and an affective component, which represents the satisfaction or feeling of fulfillment resulting from a life worth living (Wong, 1989).

Bearing this in mind, and using the Meaning in Life Questionnaire (MLQ) by Steger, Frazier, Oishi and Kaler (2006) among other instruments, Yalçın and Malkoç (2015) have investigated the relationship between meaning in life

and subjective well-being having both hope and forgiveness as mediators in a sample of Turkish students. The results from their CFA and structural equation modeling (being Meaning in life, Subjective well-being, Forgiveness and Hope latent variables), suggested that even if both Hope and Forgiveness mediated Meaning in life and Subjective well-being, Hope turned out to have greater power than Forgiveness (.62 over .33, respectively). Therefore, experiencing an increased meaning in life could imply experiencing more hope, which in turn results in a greater subjective well-being or happiness. Existing literature supported these findings. For example, McGregor and Little (1998) found that the perception of achievable goals is connected to happiness and well-being, and the perception of goals congruent with one's values, commitment and self-identity is associated with a meaningful life.

In parallel, Demerli, Türkmen and Arik (2015), using the same statistical methods, found in a sample of Turkish college students that dispositional and state hope have a positive influence in positive affect and flourishing – cognitive evaluations of one's life–, and a negative influence in negative affect. In other words, their results suggested that hope predicts and mediates the relationship between hope and happiness strongly ( $r = .78$ ).

A general problem faced when including spirituality in any kind of research, is the difficulty in defining this construct (Ellison, 1983; King, Speck, and Thomas, 1994). In this paper, spirituality is conceived as “the way in which people understand and live their lives in view of their ultimate meaning and value” (Muldoon and King, 1995, p. 336), and is thought to include “a present state of peace and harmony” (Hungelmann, Kenkel-Rossi, Klassen and Stollenwerk, 1985, p. 151). Studies on spirituality have reported positive correlations between this and satisfaction with life, happiness, and well-being (Holder, Coleman and Wallace, 2010; Kelley and Miller, 2007; Khan, Shirazi and Ahmed, 2011; Marques et al., 2012, Zullig, Ward and Horn, 2006). Holder et al. (2010), for example, found that children's spirituality was strongly linked to their happiness, being happier those children who were more spiritual. In Australian and Chinese samples, Pan, Wong, Joubert and Chan (2008) found evidence of a strong positive contribution of meaning of life, a construct intimately related to spirituality, in predicting life satisfaction, in addition to mediating between acculturation and life satisfaction. Unwin and Dickson (2010), taking a sample from a large university in the UK, as well concluded from their study that goal focused hope was the strongest independent variable in predicting well-being; yet what they also found was that spiritual hope acted as a buffer and protective factor for people low in

hope, or low-hopers. Regarding people high in hope, or high-hopers, spiritual hope did not appear, *in lieu*, to have an additive effect in hope values.

## **The Present Study**

As it has been exposed, the number of studies on hope and spirituality as predictive factors of youth's life satisfaction and happiness has increased over the last years. However, few of them have taken into account the effect of predictors in a multivariate context, and cross-cultural research is still scarce. In particular, and as far as we know, there is no study on this topic developed in Spanish population.

The present paper aims to address these gaps on the literature, by studying relationships among hope, spirituality and life satisfaction, in a multivariate and structural context, offering transcultural evidence on the Spanish youth. The structural equation model simultaneously tests for predictive effects of hope and spirituality on youth's life satisfaction, expecting significant and positive results, as seen along the reviewed literature.

## **MATERIALS AND METHODS**

### **Design, Participants and Procedure**

Prior to sampling, a systematic review of literature was conducted in order to check for the state-of-the-art publications related to the topic of this chapter. PsycINFO and ProQuest databases were used to conduct literature searches for hope and well-being articles published in the last 10 years. We used the search term "hope" paired with the search terms: "wellbeing," "health," "protective factor" and "preventive factor."

Our search initially yielded 771 articles for "hope" and "health"; 114 for "hope and "wellbeing"; 11 for "hope" and "protective factor," and 0 results for "hope" and "preventive factor." Since the first pair of terms for the search brought a great deal of articles related to the field of medicine and health diseases and health treatments, they were excluded due to their irrelevance for our topic. The third and fourth search pairs were as well excluded because they yielded either too few or none profitable articles. Hence, the second search pair was the focus of our attention.

After a thorough scrutiny, we refused a) non-empirical articles as well as empirical articles whose main topics were neither hope nor well-being; b) articles related to work and working life satisfaction; c) articles dealing with mental disorders, physical impairments, and physiological disorders; d) articles about at-risk adolescents in different countries within Africa, and at-risk adolescents in poor contexts, due to their disparities in regard to the sample and context of the present research; e) articles regarding hope from a religious perspective, and f) articles written in other languages but English, Spanish, Italian or French, as far as we were not familiar with them.

As a result, 11 out of 114 articles were retained on their relevance to the constructs being studied, i.e., hope and well-being.

As regards the empirical work, data for this research come from a cross-sectional survey of university students. The questionnaire was distributed in the University of Valencia (Spain) class setting, where participants voluntarily participated. It took about fifteen minutes to complete the questions. The students self-completed the survey, with the assistance of researchers –who gave the instructions.

The sample consisted of 242 students whose age ranged from 18 to 28 years old, with a mean age of 20.43 ( $SD = 2.09$ ). 51.7% were women. 62.8% of the students were studying Health Sciences, 16.2% studied Social Sciences, 9% studied Technical Sciences, 8.5% studied Arts, and 3.5% studied Exact Sciences.

## Measures

The Satisfaction With Life Scale (SWLS; Diener, Emmons, Larsen and Griffin, 1985) is composed of five items assessing global life satisfaction. Items scored from totally disagree (1) to totally agree (7). The Spanish version used was validated by Atienza, Pons, Balaguer and García-Merita (2000), consisting on five items scoring from 1 (totally disagree) to 5 (totally agree). Alpha was .85. A CFA of the satisfaction with life items was estimated in order to test if a single factor solution was tenable for the scale. As seen in previous literature (Diener et al., 1985; Pavot, Diener, Colvin, and Sandvick, 1991; Shevlin, Brunnsden, and Miles, 1998), this structure had excellent fit indexes for this study ( $\chi^2(5) = 13.6391$ ,  $p = .01$ , CFI = .979, GFI = .973, SRMR = .032, and RMSEA = .085).

The Dispositional Hope Scale (DHS; Snyder et al., 1991) is a 12-item instrument, with 4 pathways items, measuring abilities to identify feasible

ways to achieve goals, 4 agency items, attainment measuring motivations for pursuing goals, and 4 filler items, ignored for the current analysis. Items scored from 1(definitely false) to 4 (definitely true) (Babyak, Snyder and Yoshinobu, 1993). Internal consistency in this sample was .83. As regards the latent structure of the Dispositional Hope Scale, and even though there is some controversy about the unidimensional structure, latest literature points out a single factor structure emerging from the eight items of the DHS (Brouwer et al., 2008; Galiana et al., 2015). Thus, a one-factor CFA was estimated for the eight items of hope, with excellent fit indices ( $\chi^2(20) = 29.497$ ,  $p = .07$ , CFI = .972, GFI = .965, SRMR = .041, and RMSEA = .045).

The Meaning and Peace subscales (FACIT-Sp-12; Brady, Peterman, Fitchett and Cella, 1999) measure meaning, a cognitive dimension of spirituality/religion, with eight items, and peace, an affective dimension of spirituality/religion, with four items, both scoring from 0 (not at all) to 4 (very much), for assessing spirituality across a range of religious traditions and also for not religious respondents (Peterman, Fitchett, Brady, Pharm and Cella, 2002). Alphas in this sample were .70 and .61 for meaning and peace, respectively. A CFA was estimated for the two factors of spirituality, with a two-factor structure, following the model used in the study presented by Canada, Murphy, Fitchett, Peterman and Schover (2008). This model adequately fitted the data ( $\chi^2(19) = 62.033$ ,  $p < .01$ , CFI = .851, GFI = .911, SRMR = .076, and RMSEA = .099).

## Analyses

CFAs were employed to test for factorial validity and reliability of the three constructs of interest (life satisfaction, hope, and spirituality), and structural equation models (SEMs) to test for the effects among these constructs, which were tested within the EQS 6.1 program (Bentler, 2005) with maximum likelihood with robust corrections being the method of estimation.

Model plausibility was assessed using several fit criteria, as recommended in SEM literature (Hu and Bentler, 1999; Tanaka, 1993): (a) chi-square statistic (Kline, 1998); (b) the comparative fit index (CFI; Bentler, 1990) of more than .90 (and, ideally, greater than .95; Hu and Bentler, 1999); (c) the root mean squared error of approximation (RMSEA; Steiger and Lind, 1980) of .05 or less (the RMSEA uses errors of prediction and measurement to assess the degree of match between the hypothesized and true models); (d) the GFI as

a measure of proportion of variance-covariance explained for the model, with values of more than .90 as indicative of adequate fit (Hoyle and Panter, 1995); and (e) the standardized root mean squared residuals (SRMR) of .05 or less (Hu and Bentler 1999). Hu and Bentler (1999) suggested that a CFI of at least .95, a RMSEA less than .06, and a SRMR less than .08 together would indicate a good fit between the hypothesized model and the data.

## RESULTS

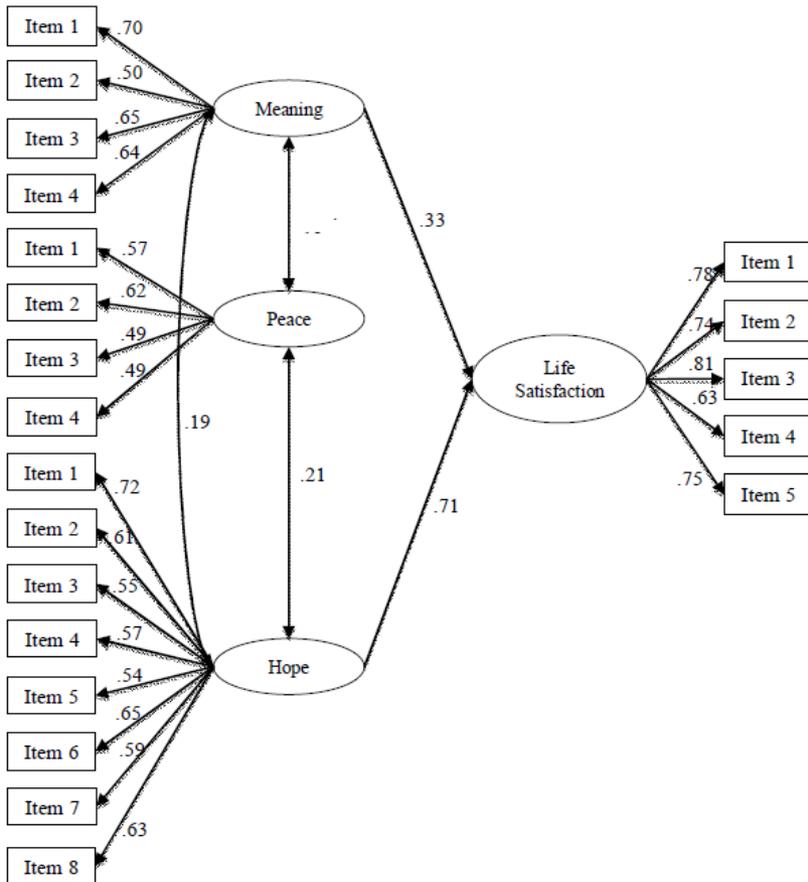
Prior to establish the structural model among the variables, several CFAs of the scales were estimated. Once the latent structure was established by confirmatory means, a structural model with latent variables was hypothesized to relate the relevant factors to satisfaction with life. The model has a clear rationale: hope and spirituality may affect or at least be related to youth's life satisfaction, and therefore may be potential predictors of well-being. These constructs are interrelated, which turns into estimated covariances in the structural model among all the exogenous latent variables with significant product-moment correlations.

This initial or theoretical model fitted the data reasonably well:  $\chi^2(183) = 293.714, p < .001$ , CFI = .900, GFI = .867, SRMR = .062, and RMSEA = .065. Only peace was not a statistically significant predictor of life satisfaction. However, no post-hoc modifications were made, specially having into account that the structural model had not salient areas of strains in the new solution (e.g., large modification indices) and that the interpretability of parameter estimates was reasonable in accordance with previous empirical results (and hypotheses) and theoretical arguments. Accordingly, the model was retained as a sufficient representation of the data, and its standardized parameter estimates are presented in Figure 1.

The measurement part of the model showed a strong link between the indicators and their corresponding latent variables (life satisfaction, hope, meaning, and peace), with factor loadings extremely large and reliable (with a minimum of .49). In terms of life satisfaction prediction, the main predictor was hope (.71,  $p < .01$ ), although meaning also had a positive and important effect (.33,  $p < .01$ ). Peace was not statistically significant. Overall, the amount of variance of life satisfaction explained by all significant predictors in the model was large ( $R^2 = .76$ ).

## DISCUSSION

The aim of this research was to study the predictive power of hope and two dimensions of spirituality, meaning and peace, in Spanish youth's life satisfaction.



Notes: All relations were statistically significant. For the sake of clarity, errors are not shown.

Figure 1. Structural model to predict life satisfaction.

With respect to the relation between hope and life satisfaction, results showed a significant and positive effect of hope on life satisfaction, which agrees with previous literature. Nevertheless, this effect represents the larger

magnitude found in studies on this topic. As this is the first study using hope as predictor of life satisfaction in a Spanish sample of young people, several hypotheses could be built on the nature of this effect, such as Spanish cultural peculiarities or the type of instruments used. In any case, more studies on Spanish youth's hope and life satisfaction are needed for a better understanding of this phenomenon.

A finding from Demerli et al. (2015) investigation that should not be readily dismissed is that income was the demographic variable showing the highest indirect effect on well-being. In relation to SES, Zhang and Postiglione (2001) suggested that individuals from high-SES families used more creativity-generating thinking than their lower SES counterparts. Simply put, a poor person will have less room for creativity-related activities if he or she has to struggle for existence (Mullainathan and Shafir, 2009). This should be taken into account when addressing well-being and hope-related problems. As noted in Maslow's hierarchy of needs, the basic needs must be satisfied in order to engage in more complex mental processes.

As regards results on the relation between spirituality and life satisfaction, these are diverse: while meaning showed a positive and significant predictive power for life satisfaction, peace did not emerge as a predictive variable of satisfaction with life. Evidence obtained for the meaning factor is in line with several researches that have found an effect of spirituality on life satisfaction (Khan et al., 2011; Starks and Hughey, 2003). For example, Holder et al. (2010) found that personal and communal spirituality explained almost a quarter of the shared variance in children's happiness, beyond any variance explained by gender, school, and temperament. Khan and colleagues (2011) also found a clear relation between spirituality and life satisfaction, quantified in a similar explicative amount to Holder and colleagues' work (2010). Nevertheless, other studies are far less conclusive on the relationship between these variables. For example, Marques et al. (2012) found a positive effect of spirituality on life satisfaction, but this effect only appeared in two of the three time frames measured. Longitudinal studies, such as the mentioned, should be welcomed, so that to gather data about the stability of these effects. Although the results reported in literature suggest a positive relationship between spirituality and life satisfaction, evidence from this research points out different relations with satisfaction with life for the different facets of

spirituality. In the current work, the affective dimension of spirituality, peace, was not a statistically significant predictor of life satisfaction. The distinction of the two dimensions of spirituality, affective and cognitive (Canada et al.,

2008), is more informative than the conception of spirituality as a single construct, being the cognitive side the most related with other cognitive processes, such as life satisfaction. An additional contribution from this paper is the suggestion for future research of a separated operative study of both spiritual dimensions: affective and cognitive.

The results of this study are compacted within a multivariate model. Multivariate structural models allow analyzing a complex array of variables; synthesizing conclusions with less error and more validity than if the variables under study were studied in isolation or as manifest variables. Therefore, the estimates of the structural model simultaneously tested all the relations among the constructs involved in the model.

It seems clear, therefore, that spirituality and especially hope are very important predictors for Spanish youth's life satisfaction. Thus, these results should help encourage the implementation of programs promoting positive strengths to achieve greater well-being.

Up to this point, it could be said that a Gestalt has been produced – we now envision the phenomenon of hope and its implications in wellbeing (in view of the evidence gathered to date). Being aware of this explicative model for hope, one could argue and speculate that making some variations in the right parts of this model, that adding a bit here and subtracting a bit there, should make it work for happiness. This conception of hope as a malleable thing is not brand-new. Some studies have already tested if hope interventions can trigger an increase in hope and, in turn, a greater sense of wellbeing and overall happiness. However, as Feldam and Dreher (2012) noted, many of these interventions have been addressed to people in clinical settings and tend to last for too long. Considering this scenario, these same authors conducted a study that aimed to find if a 90-minute intervention could significantly change hope. A sample of college students was taken and split into three groups: hope intervention group, progressive muscle relaxation group, and no-intervention group (control group). The participants were randomly assigned to any of the three groups. Participants in both first and second group were asked to think of a goal they would want to attain 6 month hence. ANOVA technique showed that participants taking the hope intervention had greater increases from pre- to post-test in hope (both agency and pathway thinking) regarding a self-nominated goal, as well as in sense of life purpose (akin to meaning in life) and vocational calling. Furthermore, the same participants in this group reported making more progress when summoned for the follow-up session (a month later) in comparison with those in both the relaxation condition and the control condition. One of the appealing conclusions of this study was that hope

scores regarding participants' self-nominated goals predicted progress at 1-month follow-up, as long as the mentioned goals were considered important to them.

Despite the mentioned results, this study should be considered cautiously. Feldam and Dreher (2012) declared that the variance in goal progress accounted for by goal-specific hope scores overlapped by 27.6% with the variance accounted for by condition; this is, much of what could have led the intervention to increase goal progress was not explained by hope.

Further research is needed on this matter in order to find more evidence that supports hope intervention programs in both hope enhancement and goal-attainment prediction. After all, considering other additional variables, such as the above-noted SES along with personal characteristics, can help professionals handle hope in either clinical or non-clinical settings, to tap those factors that are conditioning, from the background, people's happiness and life satisfaction.

A strength of the present paper is its integrative approach to relationships in a multivariate context, including latent variables free of error. The structural model has included hope and spirituality measures of youth's life satisfaction, and these indicators have explained a significant part of life satisfaction. Another highlight is the differential relation found for the affective and cognitive dimensions of spirituality with life satisfaction, which suggest further research on potential interactions between spirituality components and well-being. However, in our opinion, the main contribution of this paper is that estimates the model in an understudied population, Spanish youth, as genuine representative of Mediterranean culture. Nonetheless, future longitudinal studies in youth's life satisfaction arena would help to establish causal effects among variables. Additionally, many psychological strengths have emerged as predictors of youth's life satisfaction in samples from different cultures, as reflected in Proctor and colleagues' recent review (2009). Thus, prospective studies on new samples should deem this question by including a wider range of issues affecting or being affected by hope in the sense of self-efficacy.

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*Chapter 5*

**IN A SAMPLE OF POLISH STUDENTS’  
SPIRITUAL EXPERIENCES MEDIATE  
BETWEEN HOPE AND RELIGIOSITY**

*Marcin Wnuk\**

Department of Psychology of Work and Organization in Institute of  
Psychology of Adam Mickiewicz University in Poznań,  
Institute of Psychology, Poznań, Poland

**ABSTRACT**

Researchers have tried to prove that spirituality mediate between some personal traits and religiosity. The aim of this study was verification that among students from Poland spirituality mediate between hope and religiosity. The sample consisted of 115 students of University School of Physical Education in Poznań and Warsaw School of Social Psychology. The following tools were used: Herth Hope Index (HHI), Daily Spiritual Experiences Scale (DSES), The Age Universal I-E Scale, Brief Religious Coping Scale (RCOPE) and two one item scales regarding frequency of attending mass and frequency of praying. It was proven that spiritual experiences mediate between hope and religiosity. It means that among students from Poland relationship between hope and religiosity is indirect. Spiritual experiences totally mediate between hope and intrinsic religiosity, extrinsic personal religiosity as well as positive

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\* Address: Marcin Wnuk, Ananasowa street 27 60-185 Skórzewo. E-mail: marwnuk@wp.pl.

religious coping. It means that Polish students which have a higher level of hope have a more spiritual experiences and finally more using religion to struggle with stress as well as they religious are more intrinsically or personal extrinsically oriented.

**Keywords:** hope, spiritual experiences, religiosity, mediation

## INTRODUCTION

In the literature religiosity and spirituality have considered as a multidimensional concepts (LaPierre, 1994; Wortmann, Park, 2008). Both terms are used interchangeably. The two other approaches treat religiosity as a broader (Hill, Pargament, Hood, McCullough, Swyers, Larson, Zinnebauer, 2000; Pargament, 1999) or wider (Cawley, 1997; Nagai-Jacobson, Burkhardt, 1989) concept than spirituality.

Results of research have confirmed a positive relationship between religiosity and spirituality (Heintz, Baruss, 2001). Religiosity as a multifaceted construct is consider from the many perspectives including denomination (Abbotts, Williams, Sweeting, West, 2004), private and public religious practice like a church attendance (Levies, 2002), prayer (Francis, Evans, 1996), religious coping (Pargament, Koenig, Perez, 2000) as well as religious orientation (Allport, 1966).

Religious coping is recognized as a multidimensional process that cannot be reduced to simple behavioral indicators (e.g., prayer, going to a place of worship) or restricted to passive or defensive functions of the psyche (denial, rationalization, etc.). It incorporates active, passive, problem-focused, emotion-focused, intrapsychic (i.e., cognitive, behavioural) and interpersonal methods of managing stress (Klaassen, McDodald, James, 2006).

Religious orientation reflecting motivational aspect of religiosity according to Allport theory human religiosity can be internally or externally oriented. Intrinsic orientation toward religion is characteristic for individuals who treat religion as autotelic value and religion play a fundamental role in their life. Persons presenting extrinsic orientation toward religion treat religion instrumentally to fulfil the needs and advantages having no connection with it (Allport, 1966).

Many studies have confirmed positive relationships between hope and religiosity as well as hope and spirituality. Individuals claim that spirituality

and faith in God have a crucial role for shaping their hope (Herth, 1990; Weaver, Flannelly, 2004). A faith in a 'Higher Power' increases the hope of 92% of family members looking after their terminally sick relatives, (Herth, 1994). Cancer patients demonstrate a direct, positive relationship between inner religiousness, strength of faith and spiritual well-being with hope, (Fehring, Miller, Shaw, 1997; Herth, 1989). In a sample of terminally ill hope was related to faith in God (Buckley, Herth, 2004). Amongst members belonging to the Christian Pentecostal Community, hope correlated with a reading the bible, prayer and experiencing meeting with God, (Benzein, Norberg, Saveman, 1998).

Among Alcoholics Anonymous (Wnuk, 2008), Sex and Love Addicts Anonymous (Wnuk, Marcinkowski, Hędzielek, 2011) and Al-Anon (Wnuk, 2014) hope positively correlated with religious-spiritual aspects of life.

Despite of cross-sectional studies regarding relationship between hope and some aspects of religiosity and spirituality researchers rather trying to consider religious-spiritual sphere of live as a source of hope. In the other hand in some conceptions hope is treated as a part of spirituality (Wills, 2007). It means that hope can be simultaneously antecedent and consequence of spirituality indirectly improving religious involvement, religious coping and religious motivation.

Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which to the hoping person, is realistically possible and personally significant (Dufault and Martocchio, 1985). The causative dimension of hope has a motivational role in maintaining activity and behaviors directed toward reaching a desired goal (Kozielecki, 2006).

Among Polish students spiritual experiences can mediate between emotional aspect of hope and religious practice, religious coping as well as religious motivation. We can imagine that in sample of Polish students which belong to Roman Catholic Church denomination achieving goods is deeply rooted in a religious-spiritual sphere of live. The aim of this study was verification that in a sample of Polish students' spiritual experiences mediate between hope and religious coping, religious practice as a prayer and attending at mass as well as religious orientation.

## METHOD

### Participants

The study comprised 115 students of University School of Physical Education in Poznań and Warsaw School of Social Psychology. Students were asked to participate in a questionnaire study of psychosocial well-being and religiosity. All the subjects consented to participate in the study. Because the packet took approximately 1 hr to complete, students took the packet home and returned it the following class period.

### Research Tools

The following research tools were used: Herth Hope Index (HHI), Daily Spiritual Experiences Scale (DSES), The Age Universal I-E Scale, Religious Coping Scale (RCOPE) and two one item scales regarding frequency of attending mass and frequency of praying.

### Demographics

Mean age of the subject was 22 years ( $M = 22$ ;  $SD = 2,79$ ). 86.1% had secondary education, 13.9% had higher education. Women comprised 60.9% of the study group and men - 39.1%. All the subjects declared Roman-Catholic denomination.

### Measures

#### *Spiritual Experiences*

The Daily Spiritual Experience Scale (DSES) consists of 16 questions, each one having 6 grades ranging from 1, (i.e., never or almost never), to (6, i.e., many times daily). The more points scored the greater is a person's spirituality. The scale reliability, depending on population, ranges from  $\alpha = 0.86$  to 0.95 (Loustalot, Wyatt, Boss, May, McDyess, 2006). Short version of this measure was used which consists 6 items.

### ***Hope***

The Herth Hope Index (HHI) is a scale used for the measurement of hope based on a definition of hope as a multidimensional, dynamic life force, which can be characterized as the certainty of achieving a good result, which for a hopeful individual is possible and personally significant (Dufault, Martocchio, 1985). The participants answered 12 questions expressed on the four-step Likert scale (1-4) where total agreement with three and five number of items means 1 and total disagreement means 4. Total agreement with the other items of the questionnaire means 4 and total disagreement means 1 (Herth, 1992). The reliability of this scale has satisfactory psychometric properties - in reference to patients scores  $\alpha = 0.97$  (Herth, 1992) were evaluated with the test-retest method scores 0.91 (Herth, 1992) and in the previous research scores  $\alpha$  - Cronbach = 0,91. The reliability of this tool in the described project using  $\alpha$  - Cronbach method was  $\alpha = 0.74$ .

### ***Religious Coping***

Brief Religious Coping Scale (Brief RCOPE) comprises of 14 items regarding positive and negative religious coping. Each question has a 4 point graded scale depending on how much the subject agrees/disagrees with the question. The more points scored the more frequent individual's using religious coping. The scale reliability, per given population, ranges from  $\alpha = 0.78$  to 0.94 (Pargament, Koenig, Perez, 2000). In the study was used only the items regarding positive religious coping. Reliability of positive religious coping questions was  $\alpha = 0.9$  and for negative religious coping questions was  $\alpha = 0.78$ .

### ***Strength of Religious Faith***

The Santa Clara Strength of Religious Faith Questionnaire (SCSORFQ) comprises of 10 questions regarding strength of religious faith. Factor analysis statistically confirmed the unidimensional structure of this measure (Lewis et al., 2001). The reliability of the scale ranges between  $\alpha = 0.94$  to 0.96, (Plante, Boccaccini, 1997a, Plante, Boccaccini, 1997b). The reliability of this measure in the described project using  $\alpha$  - Cronbach method was  $\alpha = 0.95$ .

We used additionally measures reflecting religious practises as a one-item question scales on how often prayers were said and holy mass attended.

### ***Religious Orientation***

Age-Universal I-E Scale-12 were used to measure religious orientation. These constructs reflect the degree to which religion is viewed as a personal

(intrinsic) or social, either by membership in a particular group or by allowing social status and participation in a social network (extrinsic) (Maltby, 1999). This scale is a 12-item measure of intrinsic and extrinsic dimensions to religiousness, and items fall into one of three categories: intrinsic, extrinsic-personal (religion as a source of comfort) and extrinsic-social (religion as a social gain) (Maltby, 1999). Items are scored on a 3 point scale from 1 (Yes), 2 (Not certain) and 3 (No) in order to improve psychometric properties of the scale. High internal reliabilities have been shown with alpha coefficients of 0.67 for the extrinsic-social dimension and 0.73 for the extrinsic - 29 personal dimension (Maltby, 1999). Higher internal reliabilities were reported by Maltby and Day (2000) with their study demonstrating alpha coefficients of 0.72 (extrinsic-personal), 0.73 (extrinsic-social) and 0.82 (intrinsic).

## RESULTS

Noticed positive correlations between hope and spiritual experiences, strength of religious faith, positive religious coping, intrinsic religiosity and extrinsic-personal religiosity. Hope was not related to religious practices as a prayer and attending at mass, negative religious coping as well as extrinsic-public religiosity. Spiritual experiences weak correlated with extrinsic-public religiosity, moderate correlated with religious practice as well as extrinsic-personal religiosity, and strong correlated with positive religious coping, strength of religious faith and intrinsic religiosity.

Because of the very strong correlation between strength of religious faith and intrinsic religiosity this first variable was excluded from further analysis. Additional argument for this decision was that the strength of religious faith was stronger related with spiritual experiences than intrinsic religiosity.

Finally Preacher and Hayes (2004) method was using to verify mediation effect of spiritual experiences for relationship between hope and three religious indicators as an intrinsic religiosity, extrinsic-personal religiosity and positive religious coping.

Total effect of hope on intrinsic religiosity ( $c = 0.283$ ,  $p = 0.0008$ ) decreased to insignificant ( $c' = -0.057$ ,  $p = 0.4025$ ) indicating that spiritual experiences ( $Z = 5.18$ ,  $p = 0.0000$ ) totally mediated hope and intrinsic religiosity.



-.055,  $p = 0.5587$ ) because of the spiritual experiences mediating role ( $Z = 2.33, p = 0.0196$ ).

When spiritual experiences as a potential mediator were entered into the model, the total effect of hope on positive religious coping ( $c = -0.415, p = 0.0001$ ) decreased to insignificant ( $c' = -0.031, p = 0.7083$ ); indicating that spirituality ( $Z = 4.50, p = 0.0000$ ) totally mediated hope and positive religious coping.

## DISCUSSION

Hypothesis about spiritual experiences mediating role between hope and religiosity was partially confirmed. According to assumptions spiritual experiences mediate between hope and positive religious coping as well as intrinsic and extrinsic personal religiosity.

Achieving results are consistent with a recent research indicating positive relationship between hope and religious-spiritual variables (Wnuk, 2008; Wnuk, Marcinkowski, Hędzielek, 2011; Wnuk, 2014; Benzein, Norberg, Saveman, 1998; Buckley, Herth, 2004; Fehring, Miller, Shaw, 1997; Herth, 1989).

Hope improves some aspects of students' religiosity indirectly through spiritual experiences. Among Polish students hope influences spiritual experiences which finally lead to higher level of intrinsic religiosity, extrinsic personal religiosity and more frequent using positive religious coping. It means that spiritual experiences have a positive impact on shaping both religious orientations. Students which experienced spiritual movements because of hope treat religious as autotelic value or instrumental value serving personal motives. Intrinsically motivated students have a strong sense of God presence and trying to live according to religious beliefs. Among extrinsically personal motivated students attitude toward religion is based on personal benefits like a peace, relief, happiness, protection as well as comfort in times of trouble and sorrow (Maltby, 1999).

Students with high level of hope and more frequent experienced spiritual movements have a tendency to appeal to God to struggle with stress in a difficult life situations through focus on religion to stop worrying about problems, try to put plans into action together with God, look for a stronger connection with God, ask forgiveness for sins and seek God's love and care (Pargament et al., 2000).

Conducted research in a student's sample has confirmed indirect relationships between hope and some aspects of religiosity. Spiritual experiences mediate between hope and intrinsic religiosity, extrinsic personal religiosity as well as positive religious coping.

This research has an introductory character. Cross-sectional design was a main limitation of this study because we do not know for sure if hope is an antecedent or consequence of religious-spiritual facets of life. Most of results have indicated that hope is a consequence of religious-spiritual activity (Herth, 1994; Wnuk, Marcinkowski, 2012, Wnuk, 2014). I consider that in a same time hope can have a positive impact on spiritual experiences indirectly influencing religiosity. This research has confirmed this kind of assumption indicating another direction in relationship between hope and religious-spiritual aspects of life. Only conducting longitudinal study could confirm the direction of this relation.

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*Chapter 6*

**IMPROVING EMOTION REGULATION:  
A CORE FACTOR TO RECOVER  
FROM AN EATING DISORDER**

*Greta Noordenbos\**

Clinical Psychology, Leiden University, Leiden, The Netherlands

**ABSTRACT**

In the period before the development of an eating disorder patients try to hide and suppress negative emotions for others (Fox, 2009; Noordenbos, 2013). They use their eating disorder as a coping strategy to suppress negative emotions (Jantz and Muray, 2002). However, this coping strategy is highly dysfunctional and not effective, because when they stop dieting their negative emotions are felt again.

In the first part of this chapter the results will be presented of a qualitative research about emotional problems in the period before the development of the eating disorder and the reasons for these emotional problems. In total 57 patients with anorexia and bulimia nervosa were interviewed who told that before their eating disorder they learned to hide, avoid and suppress their emotions. The main reasons they mentioned for this behavior were that they had lack of self-esteem and were afraid of being rejected by others; pleasing behavior in order to be accepted; caring for parents who had emotional problems; having parents

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\* Dr Greta Noordenbos e-mail: Noordenbos@FSW.Leidenuniv.nl.

who were not able to express their own emotions; or parents who did not allow that their children express negative emotions.

In the second part of this chapter the results are presented about the treatments which helped the eating disorder patients to develop more healthy emotion regulation strategies such as psycho-education, writing an emotion diary, mindfulness, Acceptance and Commitment Therapy (ACT), Cognitive Behavior Therapy (CBT), and role playing. In the treatment they learned to recognize and to accept their negative feelings and emotions, instead of avoiding and suppressing them. They learned to regulate and express their emotions in a healthy way and no longer needed their eating disorder as coping strategy for negative emotions.

## 1. INTRODUCTION

Extreme dieting, bingeing and purging are often used to regulate negative emotions and to reduce feelings of stress (Fox, 2009). Eating disorder patients train themselves to ignore their feelings of hunger, fatigue and cold. They feel strong when they are able to ignore all the negative consequences of extreme dieting and starvation (Noordenbos, 2013). Extreme dieting helps them to suppress their negative feelings and emotions (Jantz and Murray, 2002). Patients who suffer from Anorexia Nervosa (AN) use severe food restriction in order to lose weight. The effect of starvation is not only weight loss but also the reduction of negative emotions (Noordenbos, 2013). Patients with Bulimia Nervosa (BN) or a Binge Eating Disorder (BED) use binges to reduce their negative emotions and stress (Young, Zander, Anderson, 2014).

Eating disorder patients have developed dysfunctional strategies to reduce negative emotions and stress. Dysfunctional emotion regulation is defined as the inability to recognize, accept and express negative emotions and to ignore, avoid or suppress these emotions (Spence, and Courbasson, 2012).

Recently, the question has emerged whether eating disorders are the results of *having* negative emotions, or the result of *suppression* of negative emotions (Danner, Sternheim, and Evers, 2014; Evers, Tolk, and de Ridder, 2010; Dingemans, Martijn, Jansen and Furth, 2009). It is supposed that suppression of negative emotions requires much energy and self-control whereby only little energy and self-control are left for other activities that need a certain control, such as eating (Muraven, Tice, and Baumeister, 1998). In order to test this suppression theory Muraven et al. (1998) did an experiment whereby the participants had to watch a sad video fragment. Half of the participants got the instruction to suppress their emotions, while the other part

was allowed to express their emotions. After the video both groups had to pinch in an object. The participants who had to suppress their emotions were significantly less able to pinch for a long period of time compared to the control group. This difference is explained by the lack of energy and control which is left after the suppression of their emotions while watching the video (Mulraven et al. (1998).

Also in the study of Hofmann, Rauch, and Gawronski (2007) it was found that participants who were instructed to suppress their emotions during a sad video had significantly less control over their eating behavior during the food tasting test after the video, compared to a group who did not have to suppress their emotions. Both studies support the hypothesis that *suppression* of emotions requires much energy and reduces the energy and control for other activities. An important question is why do eating disorder patients suppress their emotions?

Emotion regulation is an important factor in recovery from an eating disorder and higher wellbeing (Elburg, 2007a, 2007b; Gross and John, 2003; Noordenbos and Seubring, 2006; Zonnevillage-Bender et al., 2004). What are the most important goals of treatment in to improve emotion regulation strategies? And which treatment strategies can be used to develop healthy emotion regulation strategies? These were the central questions for research.

## 2. METHODS

### Aim of Research

The aim of this study was to uncover the emotional problems preceding the eating disorder and the main reasons an explanations for the development of these problems.

The second aim was to find out which treatments are useful to develop healthy emotion regulation strategies.

### Participants

In order to find participants for this research advertisements were published in journals, and organisations for eating disorders, such as the Dutch Foundation for AN and BN. Criteria for inclusion were that the participants have had anorexia nervosa or bulimia nervosa for more than one year or longer

and were recovered for two years or longer. In total 74 persons reacted to the advisements. They were invited to be interviewed and received an informed consent with information about the research. By signing the informed consent they gave permission for being interviewed and for using their information for publication after anonymizing the interview. In total 57 recovered patients were interviewed, 52 women and 5 men. Their ages ranged from 18 to 52 years, with a mean age of 28 years. The mean age of onset of their eating disorder was 16 years (range 12-24). All participants had started with extreme dieting, whereby 74% had a period of restrictive anorexia nervosa, while sooner or later 63% started bingeing and purging behaviour and developed bulimia nervosa. This cross over from anorexia to bulimia nervosa is described as a transdiagnostic process by Fairburn et al. (2003). In total 26% of the participants started with bulimia nervosa without having had a period of anorexia nervosa. The mean duration of the eating disorders was 7 years, in a range of 1-38 years.

## **Instruments**

In depth interviews were conducted whereby the following questions were asked:

1. Did you have emotional problems in the period before your eating disorder?
2. What was the reason that you developed these emotional problems?
3. What were the aims to develop healthier emotion regulation strategies?
4. Which treatments were useful to develop healthier emotion regulation strategies?

## **Analysis**

All interviews were anonymized and completely transcribed. The emotional problems and the explanations for these problems which were mentioned by the participants were counted and percentages were calculated. If emotional problems were mentioned by more than 30% of the participants, they were evaluated as relevant and described. Percentages were counted for the whole group of anorectic and bulimic patients. In this chapter several

quotes of former patients are described as an illustration of the emotional problems they had and of the treatments which were helpful for them. For reasons of anonymization no real names are mentioned.

### 3. RESULTS

#### 1) Emotional Problems in the Period before Their Eating Disorder

All participants who were interviewed mentioned emotional problems in the period before they developed an eating disorder. Most of them mentioned several problems such as hiding their real inner feelings from others, preventing a conflict by hiding their negative feelings, being scared to express feelings of anger and disappointment.

Debby: *“I never dared to express my feelings of anger and disappointment, and always tried to hide my real feelings and suppressed my own troubles and needs. Before my treatment I always set aside my own wishes and opinions, because I was so afraid that others would criticise me. I never dared to ask attention for my own emotions and problems.”*

#### 2) Reason for Developing Emotional Problems

The following reasons were mentioned for hiding, avoiding and suppression of their emotions:

*Low self-esteem and fear of rejection*

Behind this adjusting and pleasing behaviour of eating disorder patients they often have a deep lack of self-esteem. This reason was mentioned by 94% of the participants.

Annet: *“When I was a teenager I was very insecure about myself and for that reason I always tried to hide my real inner feelings from others. By adjusting to the expectations of my parents and teachers I hoped to be accepted and valued. I always did my best at school and tried to be the perfect daughter.”*

Margreth: “Before my eating disorder I was always very scared of having a conflict with somebody, because than they might reject me and might no longer accept me. For that reason I tried very hard to prevent a conflict by hiding my negative feelings.”

*Pleasing behaviour*

In total 92% of all participants showed pleasing behaviour in order to be accepted by others, and for that reason they did not express negative emotions or conflicts.

Jacqueline: “I was always very insecure and very afraid that people would not like me anymore when I expressed my negative feelings. For that reason I always kept up appearances by saying that I liked something, while deep down inside me I did not like it. I always said yes and tried to please others, even when I felt quite unhappy. It was not only other people that I had to keep up appearances for, but also for myself, because having negative emotions did not fit with the image I had of myself.”

*Being sensitive to the needs of parents*

In total 65% of the participants told that they were very sensitive to the needs of their parents, especially when their parents had emotional problems. They often were worried about the wellbeing of their parents and tried to cheer them up. A clear example of this is Mary:

“My mother was often depressed, and when I sometimes felt disappointed or angry she started to cry, which made me feel guilty. I never dared to express my feelings of anger and disappointment, and always tried to hide my real feelings from my mother because she already had so many problems and was so depressed. For that reason I completely lost the contact with my own feelings and emotions.”

Linda: “I remember clearly that during my puberty I worried much about my mother, who was very ill and finally died of cancer. I felt so much sorrow for her ongoing decline and her disappointment when the treatment was not successful. I also saw how my father suffered because of my mother’s cancer. I tried to fulfil their needs as much as possible

and suppressed my own troubles and need for attention. I never dared to ask attention for my own emotions and problems.”

In the period before the development of their eating disorder they were very sensitive to the needs and feelings of others and were able to register subtle signals from their parents, especially signals of sorrow, disappointment, anger, depression, fear or stress.

However by being so sensitive to the needs and expectations of their parents they learned to ignore their own needs and feelings.

*Parents were not able to express emotions*

In total 47% of the eating disorder patients told that their parents were not able to express their emotions. This could be a consequence of negative life events, being traumatized, being depressed, severe and chronic illness, or severe loss of a loving person. When their parents had severe emotional problems they were not able to pay attention to the emotions of their child. They were unable to be responsive to their emotions. The consequence was that the participants often felt emotionally ignored and “empty.” In order to comfort themselves they learned to use food as a substitute for attention. This might explain why anorectic and bulimic patients find it difficult to get in touch with their emotions and to express them.

Suzan: “My mother was often very depressed, because she missed my father who died very young. I saw how much she suffered and tried to help her and to cheer her up whenever possible. When I looked at her face I could see when she felt depressed, and then I tried hard to cheer her up. I continuously tried to improve my mother’s mood and was always thinking what I could do to help her. But she never asked me how I felt and what I wanted and I always hid my own problems and sad feelings for her. In the long run I completely lost the feeling of having a ‘self’ with its own feelings and needs.”

*Parents did not allow to express negative emotions*

Of all participants 34% of them told that it was not acceptable for their parents to have negative emotions or to be angry. For that reason they learned to hide their negative feelings for their parents as was told by Esther:

“My parents did not allow me to express negative emotions such as anger. I learned that having these emotions was bad and I could not accept them as part of myself. I always had to be in a good mood. To others I only showed my positive emotions, even when I felt disappointed or angry. But that was not my real face, it was like a mask, but under that mask I often felt irritated and angry.”

### **3) Aims for Developing Healthier Emotion Regulation Strategies**

The participants told that the following aims were important to improve their emotion regulation strategies.

#### *Learning to listen to feelings of hunger and satiety*

An important goal for eating disorder patients was to learn to listen to their physical sensations of hunger and satiety. For many years anorectic patients regulated their food intake in a cognitive way by counting calories instead of listening to feelings of hunger and satiety. They never ate enough and did no longer know when they had eaten enough and when their stomach was full. Also bulimic patients had to learn when they felt physically hungry or satisfied. They had to learn to eat when they were hungry and to stop when they felt that their stomach was full. They need to distinguish between physical hunger and emotional hunger, and to cope with negative emotions and stress.

Sarah: “In the therapy I had to learn what I really felt and needed, instead of trying to please others. In the first stage of treatment this was very difficult for me because I really did not know what I felt and needed. Only very slowly I learned to listen to my own feelings and to explore my own needs. Now I am much more sensitive to my own feelings and needs.”

#### *Recognizing and accepting negative emotions and stress*

In the treatment eating disorder patients learned that everybody has negative feelings, and that it is not at all bad to have them. They have to learn that it is important to listen to their emotions, and not to avoid or to suppress them. To recover from an eating disorder it was important to develop

healthy strategies to cope with negative emotions. In the first period when they had to listen to their emotions, some patients became completely overwhelmed by negative emotions and tried to avoid them again as soon as possible. But instead of avoiding and suppression of negative emotions, they learned to accept them. They learned that it is not bad to have negative emotions and that there might be good reasons for feeling sad or becoming angry.

Bob: “During the first part of the treatment my emotions were very negative and overwhelming, but the therapist taught me that when I became more sensitive to my feelings and wrote down what I felt, these emotions would become less threatening and intense. Slowly I learned to differentiate between various kinds of emotions. For me it was very important to learn that it is not bad to have negative emotions. It was new to me that I might be angry, disappointed, or sad. I no longer suppress these feelings but learned to accept and express them.”

*Developing adequate strategies to cope with negative emotions and stress*

An important goal for treatment was to explore and express their emotions, and to reduce their fear of being criticized or rejected when they express their own feelings and opinions. They had to learn that being criticized by others did not mean that they were no longer accepted.

Jessy: “For me it was very important that my therapist accepted me with all my emotions and I did not have to hide them from her, on the contrary. For the first time in my life I could tell somebody how bad I felt and how angry I was about all the comments I got from my mother. I felt sad for not being fully accepted by my mother, sad that she never paid any attention to my emotions. In the therapy I felt safe to explore and express my negative feelings, and I felt accepted by the therapist with all my emotions, even when they were negative. That helped me to reduce my binges. I no longer needed a binge in order to suppress my negative emotions.”

Carol: “When I learned to accept my emotions and to analyse why I felt that way, the urge to have a binge became much lower and finally I needed no longer to have a binge.”

## **4) Treatment Strategies to Improve Emotion Regulation**

Several treatment strategies were mentioned as useful to improve emotion regulation, such as psychoeducation, using an emotion diary, mindfulness, Acceptance and Commitment Therapy (ACT), Cognitive Behaviour Therapy (CBT) and role playing.

### ***1. Psycho Education***

Psycho-education about the relationship between food and emotions was very useful for 90% of the patients. They learned that it is normal have negative emotions and to express them, rather than to hide and to suppress them. They learned that it is normal to have different opinions and sometimes to have a conflict, but having a conflict does not mean that other people reject them as a person.

### ***2. Keeping an Emotion Diary***

In order to learn to explore their negative emotions it was helpful for 34% of the participants to note them in a diary, and to analyse why and when they had that emotions. To write these emotions in a diary was felt as a safe strategy. After some weeks of training with writing their negative emotions in a diary they had to discuss their emotions with their therapist. It was very important for them that the therapist reacted with appreciation and accepted their negative feelings. They learned that expression of negative emotions was not followed by criticism and rejection of the therapist.

Debby: “By using a diary I learned to listen much better to my own feelings and emotions, needs and desires.”

### ***3. Mindfulness***

Mindfulness was mentioned as a useful strategy by 42% of the participants. Mindfulness helped them to become more sensitive to their physical sensations of being tired and cold, or being hungry or satisfied. Also becoming more sensitive to the way they breathe made them more relaxed.

Jocelyn: “In the therapy I started to pay attention to my way of breathing, which was very superficial and limited to the upper part of my body. I was told to breathe with my abdomen. That was very difficult for me, because it felt as if my stomach became round and fat, while I had always trained myself to keep it as flat as possible. But I learned that

breathing with your abdomen has nothing to do with becoming fat, but only with the amount of fresh air in my lungs. When I practiced this deeper respiration I felt much more relaxed.”

Mindfulness was also useful to learn to pay more attention to all kinds of emotions. For many participants, who found it difficult to accept that they had negative emotions, mindfulness was very helpful to explore them instead of suppressing them. They learned to accept their negative emotions as a part of their personality. In order to accept and to explore negative emotions 23% of the participants told that Acceptance and Commitment Therapy (ACT) was useful.

#### **4. Cognitive Behavioural Therapy (CBT)**

Cognitive behavioural therapy (CBT) was mentioned as useful by 45% of the participants.

Mary: “During the Cognitive Behavioural Treatment I learned much about my cognitions but I could not feel my emotions. To be able to recover from my eating disorder I had to get in touch with my emotions. The more I learned to accept that I was allowed to have negative emotions, the less I needed my eating disorder to suppress them.”

#### **5. Role-Playing**

In order to learn to become more assertive and to stand up for oneself it is necessary to train the expression of emotions in all kinds of different situations. Role-playing was helpful to become more assertive by 56% of the patients.

Wendy: “I had to learn to express my own feelings and opinions instead of always listening to the opinions and expectations of others. Only after many role-playing sessions I became more assertive in real-life situations. I learned that having a different opinion did not immediately imply being rejected by others. That felt very good, and I learned to be assertive not only in the treatment but also in contacts with family and friends. Now I can express my own feelings and opinions and defend them.”

In the first period expression of expression of negative emotions the patients often had many feelings of stress and guilt.

Natascha: “In the treatment I had to practise expressing my own thoughts and opinions in role plays. In the first stage of the therapy it was very difficult for me to stand up for my opinion, and I often gave in to the views of others. But the therapist stimulated me to express my own arguments instead of agreeing with others. I had to learn to convince others of my opinion. That was quite difficult for me, because I always had been very compliant and eager to please. Now I am very glad that I dare to express my own opinions and arguments. I do not feel bad or rejected any more when others think differently.”

## CONCLUSION

Eating disorders often function as a strategy to avoid and suppress negative emotions. Some eating disorder patients had lost all contact with their own feelings, opinions and desires. The following reasons were mentioned for suppressing their emotions: low self-esteem and fear of rejection (95%), pleasing behaviour and need for support (89%), worrying about parents (72%), parents were not able to express emotions (57%), parents did not allow to express negative emotions (34%). However, by being sensitive to the needs of others they ignored their own needs and feelings.

The most important aims to improve emotion regulation strategies of eating disorder patients were learning to listen to physical sensations as hunger and satiety and to react in an adequate way, recognizing and accepting negative emotions and stress, recognizing and accepting negative emotions and stress and developing adequate strategies to cope with negative emotions and stress.

In the treatment the participants learned to become more sensitive to their own feelings and emotions. They learned that it is not necessarily a bad thing to have negative emotions or to be angry. They were able to accept these feelings and to analyse why they had these negative emotions, and which alternative strategies they could use to regulate them. They also learned to express their own opinions and to become more assertive and to stand up for themselves. Instead of regulating their negative emotions by extreme dieting or by binging and purging, they developed healthier strategies to cope with their negative emotions and no longer needed their eating disorder.

Several treatment strategies were mentioned as useful to improve emotion regulation, such as psychoeducation (Jantz and Mc Murray, 2002), healthy food intake, using an emotion diary, mindfulness (Baer, 2003; Baer, Fischer

and Huss, 2005; Kristeller, Baer and Wolever, 2006), Acceptance and Commitment Therapy (ACT) (Hayes et al. 1999; Heffner and Eifert, 2004), Cognitive Behaviour Therapy (CBT) (Faiburn et al., 2003) and role playing.

## Limitations

This qualitative research however has some limitations because the results were found in retrospective interviews whereby memory can be distorted. The treatments they had received were quite diverse which made it impossible to compare the effectivity of the treatments to improve emotion regulation. Moreover no differences were made between subgroups of eating disorder patients. It is not clear whether some treatment are more effective for anorectic patients and other for bulimic patients.

## Recommendations

In order to find more evidence for the results in this research, quantitative research is necessary with a higher number of eating disorder patients in which validated scales are used. More research is also needed to study the effectivity of treatment strategies for different groups of eating disorder patients.

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### ***BIOGRAPHICAL SKETCH***

*Name:* Greta Noordenbos

*Affiliation:* Department of Clinical Psychology, Leiden University, The Netherlands

*Education:* Ph. D. in Psychological, Pedagogical and Social Sciences

*Address:* Department of Clinical Psychology, Leiden University.

Wassenaarseweg 52,2333 AK, Leiden The Netherlands

*Research and Professional Experience:* I am a specialized researcher on the field of Eating Disorders for more than 20 years and have written several book and articles about eating disorders.

*Professional Appointments:* Assistant Professor Clinical Psychology, Leiden University

*Honors:* I am a honored member of the Dutch Academy of Eating Disorders.

*Publications Last 3 Years:*

- Noordenbos, G. (2013) *Recovery from Eating Disorders. A Guide for Clinicians and Their Disorders*. Wiley-Blackwell, Oxford.
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*Chapter 7*

## **TWO FACES OF HOPE: OPTIMISM AND FEAR**

*Lisa Humphrey<sup>1,2,\*</sup>, MD  
and Pedro Weisleder<sup>2,3</sup>, MD, PhD*

<sup>1</sup>Section of Hospice and Palliative Care, Nationwide Children's Hospital,  
The Ohio State University, OH, US

<sup>2</sup>Nationwide Children's Hospital's Center for Pediatric Bioethics, OH, US

<sup>3</sup>Division of Child Neurology, Nationwide Children's Hospital  
The Ohio State University, OH, US

### **ABSTRACT**

When end-of-life discussions ensue, hope is a frequently summoned word. While often utilized by patients and caregivers as an optimistic oath to the human spirit and condition, some healthcare providers look upon the word with fear if not disdain. To the former, it is a buoy that energizes them to continue the defense to withstand suffering, and as death approaches, a way to define their legacy. To the latter, it may represent a form of denial that must be bolstered by unnecessary tests and procedures. In this commentary we explore the two sided nature of hope as it pertains to decision-making at the end-of-life. On the one hand, the authors of several publications have demonstrated that some terminally ill patients equate hope with optimism, not necessarily with cure. On the other hand, some patients don't realize that they are marshalling hope in

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\* Corresponding author: Lisa Humphrey, MD, Section of Hospice and Palliative Care, Nationwide Children's Hospital, 700 Children's Drive, Columbus, OH 43205. E-mail: [lisa.humphrey@nationwidechildrens.org](mailto:lisa.humphrey@nationwidechildrens.org).

an effort to defeat fear. When that happens, hope and fear unite as the ball-and-chain which the prisoner drags. It is this dichotomy, one that can complicate the relationship between patients and healthcare providers, which needs exploration. For it is only through this inquiry that we can aspire to understand and reframe hope so as to minimize suffering and assist patients stave fear as life comes to an end.

*JK was a 25-year-old young man who was born with hypoplastic left heart syndrome. Early in life he underwent the Fontan palliative repair surgery, and for all intents and purposes, he had been stable for many years. This time around, things were different. JK had been admitted to the hospital secondary to progressive congestive heart failure that would not respond to medical treatment. Three months into his hospitalization, members of the palliative care service were asked to address JK's insomnia and severe pain. To the service's members' bewilderment, they were forbidden from discussing end-of-life care (EOLC) with the patient. It was the young man's and his cardiologist's, who had cared for him for 20 years, hope that the symptoms would improve. Such hope, the cardiologist argued, negated the need to discuss EOLC. Furthermore, he feared that such conversation might crush hope and mark the beginning of the end.*

## **THE DEFINITION OF HOPE**

Merriam-Webster's dictionary defines hope as a cherished desire with expectation of fulfillment [1]. Hope has also been defined as a feeling of expectation and desire for a certain event to happen or be the case. Central to these definitions is the concept of optimism. For without optimism the desired outcome might not occur. Optimism, and hence hope, is multifaceted. As defined by Dufault and Martocchio, hope is a "multidimensional dynamic life-force characterized by confident yet uncertain expectation of achieving a future good, which to the hoping person, is realistically possible and personally significant" [2]. What is absent from these definitions, but is at the center of this essay, is the role that hope plays at the end-of-life, and whether hope likens cure? The answer to the aforementioned question is a resounding "no." Patients facing EOLC do not necessarily equate hope with cure. Rather, patients with incurable cancer discuss hope in spiritual and expectant terms such as "a positive expectation that goes beyond visible facts" and "a motivating force, an inner readiness to reach goals" [3].

But not all is hopeful with hope. For as told by Perses: the Titan god of destruction - and recounted by Hesiod, hope is an evil [4]. Hope is, among others, a punishment to humankind for Prometheus' deception of Zeus [5]. Hope is an evil for as together with ills, hard toil, aging, sorrow and mischief, it was included in the jar which Pandora - the all gifted - opened while finding herself among men. And so it goes that from the jar out came grief, defiance, troubles, and sickness. Only hope was Pandora able to contain under the lid. But over millennia, hope has oozed from the jar and into humankind's fabric, for the jar's clay is porous. Hope, as explained by the stoic thinker Seneca to his friend Lucillus, is the unwitting partner of fear "Just as the same chain fastens the prisoner and the soldier who guards him, so hope and fear, dissimilar as they are, keep step together; fear follows hope" [6]. Fear and hope, continued Seneca, are ills that stop us from living in the moment. Instead, hope and fear propel us into a future with terrifying options, some of which we don't even wish to contemplate. Seneca went on to say that true happiness can only come from appreciating the present and setting aside our anxious dependence upon the future. The cure for hope, and hence fear, is to limit our desires for future events to happen. Hope is intangible, undying, and unmeasurable. In a review, Schrank et al., found 49 definitions of hope, and 32 ways to measure it [7]! Surely, if hope were not ethereal, we would at least know how to define and measure it.

## THE PURPOSE OF HOPE

Some terminally ill patients use hope to tend to important end-of-life tasks [8]. Hope allows patients to answer questions such as: What did I represent over my lifetime? Have I been an impactful person? Hope also is a tool to cope with suffering, both her own, and those whom she loves and will leave behind [9]. For many patients facing EOLC, their focus, and how they view hope, shifts from self to others. Clinicians can assist patients along this transition by viewing hope not as a binary commodity - success or failure of realizing a goal - but rather a dynamic one where the patient sets a series of attainable goals, and the clinicians provide a roadmap to reach those goals [10]. The roadmap, however, should be one without a final destination. Instead, it must have numerous stops along the way. Places to rejoice that a hoped-for goal has been attained, before continuing, if possible, on the road towards the next goal. When healthcare providers view hope as this multidimensional entity, they can deploy tactics to foster hope and thus

support their patients while providing EOLC. Such tactics include: *Interpersonal connectedness*: fostering capacity to have ongoing relationships and thus purpose to those around her; *Lightheartedness*: exposing patients to humor to validate that they share a common humanity through laughter; *Personal attributes*: identifying and augmenting patient resiliency attributes to buoy their hope activities, such as tenacity and optimism; *Attainable aims*: generating care plans that facilitate a patient complete the tasks of dying, including completion of goals, requesting and granting apologies as well as admissions of love, turning inward to prepare for a peaceful death; *Spiritual base*: identifying a patient's faith and spiritual needs and making resources easily accessible; *Uplifting memories*: encouraging story telling that defines and validates a patient's legacy; *Affirmation of worth*: giving the gift of one's presence even when cure is no longer possible to validate that the patient still has worth [3].

In the medical setting, especially at the end-of-life, hope thrives in an environment of desperation and near defeat – all is lost, and the only thing we have left to do is hope. Hope can make healthcare providers dishonest as we omit important clinical information in order to avert disrupting hope [11]. By avoiding candid conversations not only do we become deceitful, we also undermine a patient's autonomy [11, 12]. To be sure, the therapeutic effect of hope is well established. But is that also the case for false hope? Should beneficence trump autonomy? The answer should be self-evident: autonomy should be the victor [12.]

*Members of the palliative care service made adjustments to the patient's opioid regimen, and made sleep hygiene recommendations including the use of a sleep induction agent. JK's pain improved but his insomnia remained. Members of the palliative care service were concerned that JK's insomnia stemmed from a mixture of social isolation - by virtue of the protracted hospitalization - and a spiritual crisis. JK was a devout Catholic struggling to understand why he was given such disease. The service eased on JK's social isolation by facilitating visits with his family. The palliative care service's chaplain provided JK a safe outlet to question and, over time, accept his fate.*

Hope is the interaction between a giver and a receiver. Marcel.

If hope represents not a spiritual framework to face death, but a form of denial, it must be noted that patients are not the only ones deluded. Rather,

healthcare providers, including physicians, exhibit forms of denial and thus bear some responsibility when a patient cannot or will not gain insight into her mortality. Lamont ratified what has long been evident to medical students - clinicians will prognosticate one timeline outside of the patient's room, and provide a rosier picture when speaking with the patient [13]. In the same study, however, Lamont also shows that the physician is effectively lying to herself as the true time to death is shorter than what she predicted to others behind closed doors. Doctors also wield the word hope as if they can prevent sadness or death. Olsmans notes that while chaplains use hope with tones of expectations and spiritual buoying, physicians use hope as a "grip." Examples include "Hanging on to a treatment plan so as to not take away a patient's hope," and "If his hope drops, he will collapse" [14].

Such ethos may then drive physicians to incompletely disclose prognosis to patients, and as such, creates a shared story line between parents and physician - one that is untrue. Kamihara observed clinician-parent dyads discussing cancer relapse of pediatric patients. The author reported that only 16% of clinicians told families the condition was "incurable," and for 25% of the physicians, their only attempt at prognostication was to state that they were "worried" [15]. This collusive relationship, between doctor and the unsuspecting patient, can prevent a patient's transition from the denial of curative intent, to the acceptance of mortality [16].

So what is the best prospect for hope? After all, it is an integral part of the end-of-life vernacular. The best hope for hope is a balance between wishes and realistic expectations. Hope should be about possibilities, and not about reliance in a stroke of luck. Hope needs to be tempered by honesty. A good first step is to recognize that hope is not monolithic [17]. Hope can come in different shades, sizes, or strengths [18]. At one extreme is hope for a cure when one is not available. In the middle is hope for a few more days with a loved one. And at the most grounded level, hoping that a medicine will address a symptom. We should also recognize that hope can evolve. At the time the diagnosis of a life-limiting illness is made, the natural expectation for a long life is dashed. In that moment, the most common specific hope is that for a cure [19]. Over time, more realistic goals - relief of pain and discomfort, relief of sleeplessness, improving the patient's environment in the hospital - become the new faces of hope. Clinicians have the opportunity to play a positive role in that transition by maintain a measure of hopefulness that is compatible with their obligation to be truthful [17, 20]. It is also important to recognize that there are limitations to hope, and that to ignore those boundaries can lead to deception. Hope should never take the form of a lie, because when

the lie comes to light the harm it causes far outweighs that which had been its intended good. Rather than being silent or deceptive, clinicians should encourage patients to reframe unrealistic specific hopes into the more realistic understanding of generalized hopes [21]. This shift allows for preparation, which at the end-of-life allows for a more peaceful and humane death.

*Members of the palliative care service brokered a conversation between JK's and his cardiologist. Emphasis was placed on assisting the cardiologist face his grief over JK's pending death. Eventually, the two recognized the fact that the cardiologist could not improve JK's symptoms, and he was going to die shortly. Once this was clarified, members of the palliative care service worked with JK to reframe his hopes, which he translated into maximizing happiness even at the risk of shortening his life. JK's long-standing wish was to go parasailing. Equipped with a milrinone<sup>1</sup> pump taped to his leg, and strapped on to an experienced parasailer, JK flew over the shoreline. He then returned home and died within the week surrounded by his family.*

## PARTING WORDS

Healthcare providers are uniquely positioned to support hope, and deter fear, at the end of life. By viewing hope as a dynamic construct that does not necessarily include the desire of cure, clinicians can actively engage in a patient's hope journey - one that consist of multiple small yet meaningful achievable goals. Healthcare providers can nurture hope-fostering activities that show the worth of a patient's personhood, deploys laughter, supports spirituality, and honors what matters to the patient. Through this common goal, healthcare providers help prepare a patient for a good death, with hopes preserved, goals attained, and fear defeated.

Hope is not the conviction that something will turn out well but the certainty that something makes sense, regardless of how it turns out.

Vaclav Havel

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<sup>1</sup> A medication used in patients who have heart failure.

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*Chapter 8*

## **HOPE AS A SUPPORT FOR A COMMUNITY OF CAREGIVERS**

*Rachael S. Clark<sup>1,\*</sup>, Laura A. Nabors<sup>2</sup>,  
Michelle L. Burbage<sup>2</sup>, Chia-Liang Dai<sup>3</sup> and  
Vicki L. Plano Clark<sup>1</sup>*

<sup>1</sup>Research Assistant Professor University of Delaware School of Nursing  
Newark, DE

<sup>2</sup>School of Human Services, College of Education,  
Criminal Justice and Human Services, University of Cincinnati

<sup>3</sup>College of Education, Health, and Society, Miami University

### **ABSTRACT**

Millions of children live with chronic illness (CI), which impacts the well-being of the entire family unit. The presence of hope has been suggested as a way to improve the functioning of parents and families coping with a CI. This chapter examines the experience of hope in caregivers of children with CI residing in a Ronald McDonald House adjacent to a children's hospital in a Midwestern city. Group interviews were conducted with caregivers whose children or grandchildren were receiving medical treatment. Analyses revealed that caregivers identified faith, the care received by hospital staff, and the fighting spirit of their

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\* Corresponding author: Rachael S. Clark, Ph.D.

University of Delaware School of Nursing Newark, DE 19716 Contact: rsclark@udel.edu

child as the major contributors to hope. Detractors from hope included the seriousness of the medical issue, splitting up the family during treatment, and financial pressure. In addition to the thematic findings, this study demonstrates a unique methodological approach for studying hope and well-being, which have largely been studied using quantitative research methods. The results of this study have important implications for researchers and practitioners working with caregivers who reside at a Ronald McDonald House and are coping with the stress of a child with a CI.

Between 15 and 18 million children and adolescents in the United States have chronic medical conditions or illnesses, which involve limitations in cognitive, physical, or psychosocial development (Van Cleave, Gortmaker, & Perrin, 2010). More children are living longer, facing multiple medical procedures and long-term stress due to chronic illness (CI) (Coffey, 2006). The presence of a CI in the family influences multiple relationships, including the siblings' connection and the parent-child bond. Siblings of ill children may withdraw, or otherwise internalize the strong emotions associated with living with a brother or sister with CI (Knecht, Hellmers, and Metzger, 2015). Parents of children with CI carry an additional burden as advocates, caretakers, and medical decision-makers. Additionally, caring for a child with a CI can cause an erosion of hope in caretakers, who have their everyday caregiving roles to fulfill as well (Coffey, 2006; Nabors et al., 2013; Venning, Elliott, Whitford, and Honnor, 2007). Caregivers of children with CI may experience a greater amount of stress than caregivers of healthy children (Cousino and Hazen, 2013). Hope has been studied as a coping mechanism for parents caring for children with CIs (Samson et al., 2009) and has been shown to be strongly associated with happiness and well-being (Davis, 2005; Demirli, Türkmen, and Arik, 2014; Macaskill, 2012; Vacek, Coyle, and Vera, 2010). Nurturing hope may help caregivers cope in a positive manner with the stress of caring for children with CI.

Hope is typically studied as a cognition or emotion (Snyder, 1995); however, from the perspective of CI, it is helpful to conceptualize hope as a means of coping and consider the experience of hope within the context of a community (Eapen, Mabrouk, and Bin-Othman, 2008; Garrard and Wrigley, 2009; Lopez, Pedrotti, and Snyder, 2015). Qualitative and quantitative studies have explored the general importance of hope and its association with well-being (Davis, 2005; Demirli et al., 2014; Duggleby, Schroeder, and Nekolaichuk, 2013; Vacek et al., 2010). Because hope demonstrates a positive

relationship with well-being, it is important to explore this construct within the context of caring for children with CI.

A unique opportunity existed for qualitatively exploring the meaning and experience of hope in families who were caring for a child with a CI. We conducted a case study in order to understand the experience of hope for caregivers of children with CI at a Ronald McDonald House in a Midwestern city in the United States. Ronald McDonald Houses around the world serve nine million families per year. The mission of the RMH Charities is to support the well-being of children by providing a home-like environment for seriously ill children and their families during medical treatment. Housing for the ill child's family is provided at little or no cost. Many families residing at Ronald McDonald Houses travel from great distances, including other countries, so that a seriously ill child may receive specialized treatment (Ronald McDonald House [RMH], n.d.(a), para.1).

## HOPE

Having hope means that an individual has both the energy to think about one's objectives and a plan to meet them (Snyder, 1995). Neither piece is sufficient alone to create hope. Those who are hopeful see pathways to reach an end and also believe that they can reach that end point (Snyder, 1995, 2002). According to hope theory, positive emotions are the result of the successful pursuit of goals. When individuals encounter a barrier such as a CI, the CI is interpreted as an obstacle, and the experience is perceived as stressful (Lopez, Snyder, and Pedrotti, 2003; Snyder, 2000).

Hope can foster a positive emotional state that encourages action toward positive ends. Thus, nurturing hope can be critical to coping actions of caregivers of children with CI (Mecnick et al., 2007). For instance, Venning et al. (2007) examined factors related to hope in parents of children with CI. Findings indicated that higher social support, faith, and feelings of self-efficacy were related to higher levels of hope for a positive outcome for an ill child.

An added dimension to the study of hope is that the emotions of parents and children can be intertwined, which indicates the need for a family approach to coping with CI (Brown, Mangelsdorf, Agathen, and Ho, 2008; Hoy, Suldo, and Mendez, 2013). Because parent and child functioning are connected, it is essential to study the treatment of CI in families and to assist them in moving toward positive psychological well-being. Wong and Heriot

(2008) examined vicarious hope (hope parents have for the future of their child) and found that it was associated with lower levels of depression in parents, and less anxiety in parents of children with cystic fibrosis. Hope was the strongest predictor of child mental health and the impact of the illness on parents' emotional well-being in this study. Parents who receive strong emotional support and are encouraged to have high hope experience less distress than parents who do not (Wong and Heriot, 2008). Nurturing hope may help caregivers and families cope in a positive manner with the stress of caring for children with CI.

Hope is supported in scholarly research as an essential piece in coping and adapting to illness (Eapen et al., 2008; Garrard and Wrigley, 2009). Likewise, lack of hope usually indicates poor psychological well-being. Hope can sustain parents of children with serious, chronic illness when the future outlook for their child looks bleak (Samson, et al., 2009).

**Qualitative methods and hope.** Qualitative research is well suited to explore and understand individuals' perspectives and experiences of phenomena within specific contexts (Neuman, 2006). Although qualitative research studies remain relatively scarce in the field of psychology (Alise and Teddlie, 2010; Bhati, Hoyt, and Huffman, 2014; Carrera-Fernández, Guàrdia-Olmos, and Perú-Cebollero, 2013; Cromby, 2011), they have the potential to add important understandings of families' experiences with hope to the scholarly literature. Substantively, few studies of hope in caregivers of children with CIs exist. In order to explore the experience of hope from the perspective of caregivers of children with CI, a qualitative study best filled this need. A qualitative approach, especially in a residential setting, demonstrates respect for the parents/caregivers and their unique experience, and respect for the strongly unique context of living in a Ronald McDonald House during treatment for CI (Carrera-Fernández et al., 2013). Equally important in learning from caregivers about the experience of hope is the neglected intersection of illness and emotion implicit in any health-related phenomenon. Health is both physiological and psychological; hope is both a cognition and emotion (Demirli et al., 2014). These complex constructs may be explored in greater depth using qualitative research in order to allow participants to explore the emotional aspects of hope within a space that honors their experience and knowledge (Cromby, 2011). Finally, qualitative research is a strong choice for conducting research within family systems. Qualitative methods may be used to investigate contextual factors within families and to explore processes (Ganong and Coleman, 2014).

## METHOD

Because caregivers of children with serious, lifelong illnesses were our target sample, it was important to us to choose our research methods carefully. Managing the medical care of an ill child, caring for the siblings of the ill child, and maintaining relationships with family members living apart can take a heavy toll even on well-adjusted caregivers. For these reasons, a qualitative case study seemed the most appropriate choice to explore the experience of hope within caregivers of children with CI living at a Ronald McDonald House.

We chose the embedded single-case study as our qualitative research design. Case studies are appropriate when the major research question is *how* or *why* (Yin, 2009). As we were interested in understanding how caregivers of children with CI experienced hope, the case study was considered the strongest approach.

### **The Case: A Ronald McDonald House**

Participants resided at a Ronald McDonald House in a mid-sized city in Ohio while their children or grandchildren received medical care at a nearby children's hospital for their CI. Caregivers stayed at the Ronald McDonald House in order to access the high-quality medical treatment at the adjacent children's hospital. Usually caregivers stayed at the Ronald McDonald House because specialized treatment was not available in their hometown, and the treatment was lengthy enough to require an extended stay at the residence. Families make the journey to this Ronald McDonald House either after waiting months for an opening at a nearby children's hospital for treatment, or suddenly upon receiving a serious medical diagnosis that requires immediate treatment. In the latter situation, the family will often arrive at a Ronald McDonald House in an unfamiliar city with no one to rely on for support. Residents rely on the Ronald McDonald House as a source of support in a very difficult, stressful period. Notable in the many family stories on the Ronald McDonald House website is that the love and support provided by the Ronald McDonald House was thought to be just as important as the medical treatment their child or grandchild received ("Ronald McDonald House Charities," 2015).

## Participants

Purposeful sampling was used to choose participants from a population that included adults caring for children with a CI (Patton, 2002). The inclusion criteria were that the participant cared for a child with a CI and also lived in the Ronald McDonald House while the child received treatment. Caregivers of children of all ages were eligible, and ages of the children ranged from two months to 10 years. In the remainder of this chapter, we refer to “caregivers,” because not all participants were parents. We spoke with caregivers of children with CI, who included five mothers, a father, and two grandmothers. This population was chosen due to the unique nature of the experience. We wished to identify the individuals who were coping with stress in a positive manner in order to contribute to the scholarly literature in positive psychology. According to the principles of positive psychology, individuals functioning at their best should be studied in order to identify characteristics, factors, and experiences that contribute to high psychological functioning (Seligman, 2011; Seligman and Csikszentmihalyi, 2000). Despite a challenging life situation, the caregivers in our study exemplified high psychological functioning, as they dealt with a life threatening illness in the family while handling all of the other duties of a parent or grandparent.

Eight caregivers volunteered to participate in this study. A small number of participants is appropriate in qualitative research due to several important factors. First, qualitative research is designed to achieve an in-depth view of a phenomenon from the participants’ perspective (Creswell, 2014). We were interested in learning about hope from the perspective of caregivers of children with CI. Next, the scope of this study was relatively narrow (Morse, 2000). We were interested in the experience of hope in a specific population, in order to deeply examine and understand hope and CI. Finally, the quality of our data was strong. Participants readily reflected on the topic and expressed themselves well in group interviews. The elements of qualitative research, including scope and data quality are aspects of saturation, which is the point at which no new data is provided that reveals insight (Creswell, 2014; Morse, 2000). After eight interviews, it was clear that many of the participants shared the same experience with hope and we felt comfortable discontinuing the data collection at that point.

## **Ethical Considerations**

We followed the ethical guidelines that direct qualitative research, including reciprocity (Hatch, 2002). Because we asked for a time commitment from participants with very little time to give, we offered support and encouragement to interviewees, particularly if they seemed to need a listening ear. Additionally, researchers demonstrated respect for participants and assured anonymity for participating in the study. Potential participants were not pressured into participating and we followed the advice of Rubin and Rubin (2012) to “do no harm” (p. 89). We explained who we were and the purpose of our study before inviting potential participants to take part in the research (Rubin and Rubin, 2012). This study was approved by the Institutional Review Board at our university.

## **Group Interviews**

Group interviews were selected as the data collection technique because this method produces a large amount of data in little time, and because it provides a comfortable setting for participants. A group can stimulate conversation around the shared experience leading participants to share feelings and ideas about the topic (Rabiee, 2004). We conducted group interviews with four caregivers on two different evenings (n = 8). Interviews were conducted using a semi-structured guide. We created and refined interview questions through a series of face-to-face and email sessions and attempted to write open-ended questions that allowed flexibility as new insights emerged to adapt and respond to participants’ responses (Rubin and Rubin, 2012). Questions were designed using our own experience and knowledge about hope and chronic illness. Probes were used when the responses required follow-up (Krueger and Casey, 2009; Rubin and Rubin, 2012). All participants were asked the same opening question, “How do you stay hopeful with a chronically ill child?” and based on the participants’ answers, examples of follow-up questions were: 1.) Can you see hope in the medical professionals working with the child? 2.) Does [participant’s stated event] have an impact on how hopeful you feel for the child’s future? 3.) How do you stay determined? Where does the determination come from? The focus of the open-ended questions was always to learn about the experience of hope from the caregivers’ perspectives.

Those who agreed to participate sat in small groups and were interviewed one at a time, which allowed the participants to hear each other's stories, add to them, and validate their own experience. The group setting seemed to increase the comfort level of the participants, and they obviously had created strong friendships in the Ronald McDonald House. Groups were discontinued when we began receiving similar responses to questions, thus reaching saturation.

The researchers used McLafferty's (2004) model for considering methodological issues in a group. The second author gathered demographic information from participants while the first author began the group interview. Individuals answered several questions related to the child's illness and their views of hope. Other group members were able to comment as the individual responded, providing an opportunity for presenting detailed historical and personal information within the groups.

Observations were noted on the interview protocol during the groups. We noted the physical setting of the groups before data collection began, the interactions between participants during the groups, and nonverbal behaviors among the participants during data collection (Merriam, 1998).

The groups were conducted in English. One participant spoke only Spanish and used her friend (another resident of the Ronald McDonald House) as a translator. The questions were translated into Spanish by the friend, and then answers were translated into English for the researchers. The video recording was later viewed by a Spanish-speaking graduate student at Northern Kentucky University, the first author's employer, to corroborate and confirm that the provided translation was accurate. The video recordings were deleted following completion of transcription.

## **Methodological Issues**

Conducting a study of hope among caregivers of children with CI takes careful consideration, and more planning and accommodation than a typical study. The caregivers we wished to interview had numerous and competing demands on their time. Often, the child with CI required 24-hour a day care, and caregivers were not able to leave them for long periods. Sometimes the siblings of the ill child were present with the caregivers, and needed care during the time we set aside for interviews. Some of the children with CI were with their caregivers in the lobby after dinner, and had to be cared for during the interview. As an example, one mother who interviewed with us had her 10-

month old child with CI next to her during the interview. The child was lying down in a large stroller that was encased by a plastic zippered covering. During the interview, the mother ate supper, nursed her baby, and participated in the interview all at the same time. Due to these extremely challenging conditions in this research study, we decided to limit our time requests with the caregivers, and to interview them in a group setting.

We planned ahead for some of these challenges by inviting an undergraduate psychology student to bring a craft project for the children with CI and their siblings to work on while their caregivers were being interviewed. The psychology student had stayed at a Ronald McDonald House as a child and was eager to give back to the organization. The crafts on both nights were guided by the principles of positive psychology and involved having the child write character strengths on pieces of a mobile that they could place in their room at the Ronald McDonald House. Additionally, the first author brought her two children to complete crafts and play with the children and their siblings. The first author's children played ball with some of the siblings of the children with CI as well as some of the children with CI and helped with crafts. This experience was beneficial to the residents of the Ronald McDonald House as well as the volunteers, who gained a great deal of fulfillment from interacting with the children.

## ANALYSIS

Groups were recorded on a Flip camera and conversations were transcribed by the first author using Microsoft Word. Transcripts were coded individually by the first four authors on the research team using open coding (Patton, 2002). The objective of coding in qualitative research is to use inductive reasoning to simplify the data and allow for ideas to be linked (Richards and Morse, 2007). Codes were refined, condensed, and eliminated over the course of four face-to-face meetings. Investigator triangulation was used to examine the validity of the coding. Any disagreement about coding was discussed until consensus was reached. Codes were combined into themes, which involved finding general patterns among specific information (Miles and Huberman, 1994). Throughout the data analysis, salient quotes that illustrated the themes were noted (Rubin and Rubin, 2012).

## RESULTS

Results that we discuss come from our review of transcripts as well as field observations and notes concerning the nature of this study and the population on which it is based. In analyzing the caregivers' comments about hope and its relation to positive functioning, our research team discovered two specific subtopics in caregivers' stories and conversations, which were (1) contributors to hope, or supports for the child and (2) detractors from hope, or stressors that detracted from hope and family well-being. Figure 1 shows a visual depiction of the themes that participants discussed as contributors to and detractors from hope in the Ronald McDonald House.

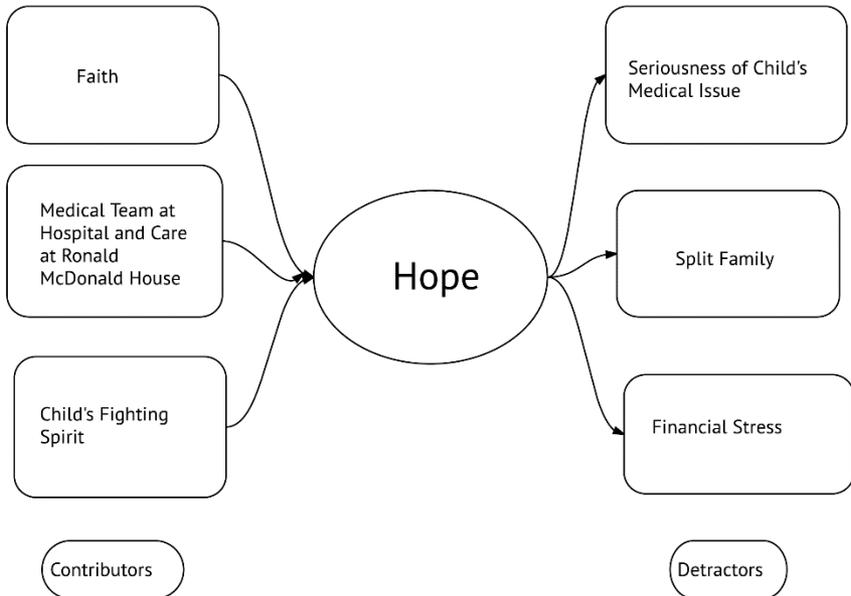


Figure 1.

### Contributors to Hope

Contributors to hope were supports that helped the parents and family remain hopeful and positive for successful treatment. Caregivers reported that

faith, support from the medical team and care at the hospital, and their child's fighting spirits helped them to remain hopeful in dealing with their child's CI.

**Faith.** Six of the eight participants reported they relied on their faith in God to maintain hope and keep them moving. One participant believed that there was meaning in the child's illness, "God gave this child a purpose and just gonna find that purpose for that child" (P2). This caregiver, a grandmother, believed that her child was "chosen" to have the child with CI because the mother of the child with CI was the strongest of her four children. In addition, by praying and talking to God, participants strengthened their determination to fight for their child's recovery. Another caregiver stated that there was a lot of faith at the Ronald McDonald House and in the hospital, and a lot of people do "a lot of praying for each other" (P3). "...my belief in God is what gets me very hopeful" (P7). One of the mothers said "God said he is taking care of her, she will be O.K....I don't know what that 'O.K.' is necessarily going to mean..." (P5).

Faith and talking to God were used as escape mechanisms on an individual basis. When talking to God, one caregiver stated that he was "off the situation" (P1). Praying seemed to allow him time to recuperate, gather strength, and come back to the present moment to deal with the immediate situation. Hope was thus described as a precursor to summoning determination to keep going.

One caregiver (P4) mentioned bargaining with God to spare her son's life. She stated that she would give up everything if only He would let her son live. The sacrifices she made to get her son to the children's hospital and to stay with him in the Ronald McDonald House paled in comparison to the thought of losing her son.

Several caregivers also mentioned that having faith allowed them to be at peace with whatever outcome resulted from the treatment of the CI. Hoping for a positive outcome was described as more surface-level emotion, while faith that the outcome was already predetermined by God allowed a deeper sense of contentment and intention.

**Medical team at hospital and care at Ronald McDonald House.** Participants shared that the strengths of the medical team and care at the hospital gave them hope during the treatment of their child's illness. The participants felt they were well informed about the medical situations of their children and treatment plans. "This hospital, and it translates over to the Ronald McDonald House, is a step above anywhere we're from" (P6) "I had never met doctors that I feel so comfortable with. They treat you like a person" (P3). Caregivers felt they were being involved in the treatment process and

were a part of the cure of their children's illness. Caregivers highlighted that positive language to convey hope for recovery of the child bolstered their resolve and helped them maintain a hopeful outlook for their child's recovery. "At the hospital and at Ronald McDonald House everyone is positive...the nurses at the hospital are very caring" (P6). Doctors, and for that matter, nursing staff needed to couch medical information within ideas for staying the course and encouraging parents to "hang in there" to help caregivers maintain hopeful attitudes. If doctors spoke negatively or acted as if there was not any hope it caused caregivers to experience pain and sadness and feel a sense of futility in terms of maintaining a positive outlook for their child's wellness and potential recovery. We should note here that when doctors indicate that there is no hope, it means there is no hope for recovery, and may indicate a loss of the child. It was as if caregivers were borrowing strength to maintain a hopeful outlook from their positive interactions with others, and that a cycle of positive words, support, and beliefs for the future could buoy flagging spirits and lift caregivers up in order for them to lift up their child.

Besides the professional and medical treatment participants received, they also reported that the resources and support provided by the hospital and Ronald McDonald House helped them to meet their psychological and basic needs. Caregivers indicated that they rely on each other every day during their stay in the Ronald McDonald House. As an example, one caregiver who spoke both English and Spanish mentioned helping out a family from Honduras who does not speak English. "I know English, they don't, so I help them out" (P7). The caregivers established strong bonds received support from each other that kept them going. The bonds created during stays at the Ronald McDonald House continued even after families left to return home after treatment. Caregivers mentioned contacting prior residents to see how their child was doing. This act seemed to create an extended network of support outside the hospital and the Ronald McDonald House that could be sustained through social media even after the families physically left the house.

Participants described that they get hope from seeing other people going through the "same thing." In addition to faith being aligned with hope, caregivers provided several other tools or variables that promoted hope for their child's well-being. For example, in terms of increasing caregivers' feelings of hope, support from other parents and caregivers at the Ronald McDonald House greatly enhanced feelings of hope for recovery of their child. Caregivers reported that the volunteers, staff and other parents at the Ronald McDonald House supported them and their child and this helped parents, and the child, to generate hope for recovery. One caregiver mentioned, "I like

being here at the Ronald McDonald House. I think it gives me hope” (P8). Another mother mentioned that she gained support from other mothers and families at the Ronald McDonald House, “I would say having her [motions to another mom in group] and being around [another family staying at the Ronald McDonald House]. You know, we give each other support” (P7).

In addition, the ill child and their siblings received support from their peers at Ronald McDonald House. Support helped relieve caregiver stress. A participant mentioned, “They’re [children] always playing together. It is hard to explain to a very young child about all those illness, treatment and doctor appointments they or their siblings have to take. But in the Ronald McDonald House, she wanted to come back, she’s not alone. She’s made friends” (P7).

**Fighting spirits.** Caregivers reported that their hope comes from their determination in treating their children’s illness and the strength of the child. One caregiver (P4) indicated that she would treat her child at any cost. Caregivers also shared that watching their children’s strength and progression during treatment procedures gave them hope. A caregiver (P8) noted, “She [my daughter] is my inspiration.” Another participant (P7) described her daughter as a “firecracker” that brought her hope.

Caregivers frequently downplayed the challenging aspects of having a child with a CI when compared to the child’s experience. The struggle to keep going and resolve evident in the child’s recovery seemed to create even more hope for recovery in the caregivers. The sense that in no way would they, as adults, be able to handle the illness in the manner the children did came through in several comments. “She glows and a spirit comes out of her. She’s my inspiration...she’s my hero” (P7).

## **Detractors from Hope**

In addition to the various supports that aided the participants in building hope, several detractors from hope were mentioned. Detractors from hope were discussed as factors that deteriorated hopeful feelings and also caused the family to function less positively, thereby experiencing lower levels of well-being. Three major detractors from hope were reviewed including coping with the seriousness of the medical procedures and life-threatening complications, financial stress due to repeated hospitalizations, and being “split” as a family.

**Seriousness of child’s medical issue.** Five of the eight participants spoke about the medical procedures their child endured and recounted the circumstances that led them to the Ronald McDonald House. The five

participants extensively recounted their child's illness, using medical terms and describing specific procedures they endured. "You'd have to do compressions, keep her heart going..." (P1) and "Sixty percent of her intestines had to be removed" (P3). One participant (P4) showed the researcher photographs of her son immediately after a car accident that resulted in a traumatic brain injury. The picture showed the young boy in a hospital bed with his skull open, exposing the brain. Although this participant stated that the pictures of her son kept her hopeful, this exchange seemed like a coping method as well.

**Split family.** Overwhelmingly, split families were reported numerous times with five out of eight participants citing this as a detractor from hope. Many participants indicated that family members could not stay at the Ronald McDonald House due to the distance from work and home. A participant explained how her daughter-in-law, the kids, and her son, "stayed the first week, but he [the father of the ill child] has to go back to work – pay the bills" (P2). Being away from the rest of the family, when one parent was with a child at the Ronald McDonald House, and missing their other children and spouse was draining for parents as well as the ill child who was missing being with (mostly) fathers and siblings.

In addition, siblings of the children with CI are commonly placed in another family member's care due to the caregivers devoting most of their attention to the ill child. One participant mentioned that her husband is currently taking care of their 5-year-old while her mother is the caregiver of their 14-year-old. She stated, "I had to split them up" (P6). Another participant stated "And you know, just ... having them completely away from me for weeks, like not even where I could see them at night. Things like that. That's huge. So if there was some way they could be here and then... would have been a huge difference" (P5). A participant also described marital problems as a strain (P3) whereas another (P4) cited worrying about siblings and family responsibilities as stressors. One caregiver (P5) called the experience being "split in half." This comment relates to the sense of not being completely present with the ill child because their mind often drifted to think about their other children and spouses that were not there. Some felt guilty about asking family members to care for their other children because "Realistically everybody has their own life. And they cannot put their life on hold because your life has been put on hold" (P7). With work schedules, school schedules for siblings of the child with a CI, and even holidays, arranging for care for the siblings of a CI child can be an overwhelming process.

**Financial stress.** Financial stress was discussed as another stressor by the caregivers. One participant (P6) shared that transportation to and from home exceeded their financial means. Another (P3) stated that her family is having difficulty moving due to financial problems and “It’s going to cost to move... You know, we have excellent credit. I just...but we’re gonna have to start all over again. I don’t know what it’s gonna be like – we’re gonna have to pay deposits and all that”. The family was considering moving to the city in which the children’s hospital was located so they could avoid traveling back and forth for treatment.

Financial stress was often intertwined with another frequently mentioned stressor, which was being apart from one’s nuclear family or family unit (i.e., “Split Family” thematic finding). When vacation and sick time had been used up, typically one of the family members had to leave the Ronald McDonald House and return home to work. This impacted the family in two major ways by removing a support for the parent or grandparent and splitting the family apart.

## CONCLUSION

This study examined the experience of hope for eight caregivers of children with CI at one Ronald McDonald House. Caregivers conveyed the importance of living in a supportive environment and their child’s behaviors and spirit during their children’s treatment and described how different aspects of the environment impacted their hope. Findings from these group interviews underscored the importance of living in supportive environments when coping with a serious illness. Participants seemed to gather feelings of hope for the future from other caregivers, professionals, and volunteers as well as from the child’s brave coping efforts.

Findings were consistent with research demonstrating the importance of hope for children and parents during hospital stays for chronic illness (Davis, 2005; Demirli et al., 2014; Garrard and Wrigley, 2009). Our study suggested that caregivers gained strength from feelings of hope toward their child. Faith that a higher power would create meaning from the child’s suffering allowed caregivers to experience hope for a recovery and a return to well-being for their child. Taking the individual experience of hope and extending it outward to encompass a community is an emerging concept in positive psychology. Lopez et al. (2015) called this creating positive communities, and specifically “collective hope” (p. 210) or the “positive psychology of us” (p. 44).

Collective hope emphasizes the group-oriented experience of hope in overcoming obstacles that are nearly impossible for one person on his or her own. Indeed, the caregivers in our group interview nearly universally shared the faith experience and support from other residents of the Ronald McDonald House as critical to maintaining hope.

Faith is an element that can be shared with others, and explored as a support in boosting hopeful feelings during treatment. Caregivers unanimously reported that hope provided them with strength to keep moving forward in caring for their child and family in times of stress related to their child's illness. A key component of hope was faith in this study. Participants consistently stated that hope was more like wishing and faith was what "really got them through." One quote in particular sums up the difference between hope and faith from the perspective of caregivers: "Hope is kind of like a candy bar, you know" (P5). In the experience of these caregivers, hope alone did not sustain them, whereas faith filled them up. Participants noted that adjusting to the illness and coping with illness-related stresses had a purpose in their own and in their child's lives. Family and community support were significantly related to feeling hopeful as well.

Financial stress and split families were major challenges to feeling hopeful. Medical bills, combined with the 24-hour a day care that children with chronic illness require, results in a situation in which little income can be generated by the family. Financial stress impacts living arrangements, the ability of a caregiver to stay with the child, and limits options. Diminishing hope through a reduction of options caused by financial stress aligns with the *pathways* dimension of hope; when individuals cannot identify a path to goal attainment, hope is weakened (Snyder, 1995). By providing free housing, the Ronald McDonald House may help alleviate some of the financial stress for families and creates a supportive environment with others sharing similar experiences. Future research should investigate the financial impact of the Ronald McDonald House for residents.

Feelings of grief were also evident, as some of the caregivers strove to find meaning in their child's coping with his or her chronic illness and the suffering the child had to endure as the course of the illness waxed and waned. When the illness was causing pain and suffering, as it was in the case of the children in the current sample who were hospitalized, hope was identified as faith that well-being would return. This notion is similar to results presented by Venning et al. (2007). Faith was thus a tool for accessing feelings of hope, as caregivers attempted to capture meaning in the pain and suffering of their child. Granero-Molina and colleagues (2014) also found that adult patients

who had cancer used faith in a higher power to assist them in finding meaning in their illness and to bolster feelings of hope for recovery. Thus, when the course of illness necessitates hospitalization or enhanced suffering faith may be even more aligned with hope in order to provide strength to those who are coping with either their own or a family member's suffering.

Although much qualitative research relies upon prolonged contact with participants through observation and in-depth interviews in natural settings, we demonstrated that research with a vulnerable population can be achieved by careful planning and respect for participants' limited time to participate in research. Group interviews were ideal for achieving depth of coverage with limited time and for allowing participants to share their voice and experience support and encouragement from other caregivers. Qualitative research methods could be considered more widely as a research method in psychology, as researchers decide which method best suits their research question(s); emotions can be studied in-depth using qualitative methods that allow participants to share their experience using their own voice. The individual perspective and subtle nuances that are inherent in emotional experiences seem a strong fit for inquiry using qualitative methods. Although qualitative methods were ideal for this study, they certainly may not best fit the needs of all studies of children with CI, hope, or positive psychology.

## **Implications**

In order to contribute to the future use of qualitative research methods with this population within a residential treatment context, the following recommendations are provided:

- Consider a method that allows for a large amount of data to be collected in a short period of time. Caregivers often are not able to leave their children alone for long periods of time, if at all. Group interviews, in which a good deal of data may be collected without infringing upon time with the caregivers is a strong choice.
- Closely aligned with the previous suggestion, residents may be accompanied by siblings as well as the caregiver in data collection periods. Plan ahead to provide activities for the siblings and even the patient while the caregivers are interviewed.
- Allow time for flexibility in data collection periods. Caregivers at times may need to leave the session to attend to other children. Build

in enough time to collect the data you are seeking, but remain flexible in case your participants are pulled in another direction and have to return to data collection later.

- To give back to the participants, consider providing a sympathetic listening ear if needed. Often, caregivers are worried and anxious about the future of their child or grandchild. Having someone to talk to about the medical procedures and stress associated with them can be a welcome support.

Several factors may limit the utility of our findings. For instance, our sample size was small, and this could have resulted in limited information, although we did reach saturation in terms of themes and we also recruited a fairly diverse sample. Conducting a study with a greater number of participants and perhaps adding information through using surveys would allow researchers to gather more information about how the length of stay at the Ronald McDonald House and types of illnesses and medical procedures faced by children were impacting hope. We relied on data from caregivers, and thus our results capture one source of information. Conducting group interviews with medical professionals, Ronald McDonald volunteers, other family members, and the children themselves may provide more information on how hope impacts family functioning and the functioning of individual family members. When transcribing information from the groups, it was noted that participants had lengthy responses to the interviewer's questions. Perhaps conducting multiple groups to allow caregivers to provide more information or follow-up interviews with parents after the group would have provided more information on all members' points of view. Investigating in more depth the importance of faith in Ronald McDonald House families and how the meditation room is used within the Ronald McDonald House would possibly have yielded more information on the role of faith for participants in the current study. Finally, the Spanish-speaking participant only responded to questions with assistance from a friend at the Ronald McDonald House who translated information for her. Having a translator may have impacted her group experience and detracted from conversations that could have occurred if a translator had not been needed.

Snyder (1995) has described hope as involving a cognitive appraisal of a situation where a person gains determination to meet a goal. This definition seems person-centered and our study extends this idea to feelings of hope for another loved one. Certainly the concept of collective hope seems to apply to our results (Lopez et al., 2015). The caregivers participating in our groups

gained hope, which transferred to determination for their child to recover and faith that this would happen from a higher power, support from others, and their child's own willpower to fight and become well. This finding is similar to findings from Granero-Molina et al. (2014) that faith was used to bolster hope when dealing with a chronic illness. Hope then was a coping mechanism, or helpful tool, to both empower caregivers and children and buffer them as they coped with stressors related to the child's illness-related hospitalizations.

In future studies, it will be important to learn more about the role of faith. Researchers need to design questions to assess how faith promotes hope and vice versa to determine how these concepts influence well-being in caregivers and children. In terms of improving caregiver support, offering support groups for caregivers, and assessing their impact on caregiver coping is an important future clinical and research activity to further determine the impact of social support on hope and well-being of caregivers. Because of the known impact of a CI on siblings and parents, (Cousino and Hazen, 2013; Knecht et al., 2014) health professionals assisting families with children with CI should continue to infuse positive messages into their conversations with parents, caregivers, and even siblings, in order to help them stay strong and strengthen hope in caring for their child and family as they cope with the extreme stress related to their child's hospitalization. Lobbying for extra "sick time" for caregivers as leave time may also be one way that social workers and other health professionals supporting families can improve their ability to remain together and have financial support as the child copes with repeated hospitalizations due to illness.

This study focused on caregivers of children with CI, a population that to our knowledge had not been included in prior research on hope. Including caregivers of children with CI in research on hope is important because they have a great deal of worry and stress to manage (Coffey, 2006; Nabors, et al., 2013). In the caregiver population, it may be worthwhile to consider offering hope intervention at the Ronald McDonald House as also suggested by findings from Feldman and Dreher (2012) and Herth (2001). Opportunities to share their child/grandchild's strengths, progress, and prognosis could help the caregiver deal with the stress of caring for a child with CI. Infusing hope into the activities at the Ronald McDonald House and in conversations at the hospital may help caregivers cope with stress and move toward psychological well-being.

## Author Note

The authors wish to thank Elizabeth Morales of Northern Kentucky University for translation assistance, and Kasey Romito of Northern Kentucky University for directing activities for the children of the Ronald McDonald House during the caregiver interviews. Most important, we thank the participants at the Ronald McDonald House for sharing their experiences with us.

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*Chapter 9*

## STITCHING HOPE THROUGH LOSS IN CELEBRATION

*Ashlie Brink\* and Elmarie Kotzé*

University of Waikato, Aotearoa New Zealand

### ABSTRACT

This chapter focuses on the revisiting and re-storying of hopeful actions and practices in the face of emotional hurt, physical pain, sorrow, loss and shattered dreams. Painstakingly slow recovery from major surgery coincided with the shocking and immeasurable loss of a beloved mother. This chapter grew out of conversations reminiscing about a graduation ceremony in the year following the loss. Memories, of a gold dress, carefully stitched together the concern, love, attention, compassion, and admiration of a mother and her support for her daughter's hope of an academic future. These memories later became the focus of an outsider witnessing practice and re-remembering conversations as a means by which to re-visit, re-story and re-member the celebration of the graduation ceremony. Eleven years after the loss and as an aspiring academic, the small, but significant steps of speaking through the hurt of injustice, the immense loss of not only a mother, but central person in the life of a young woman living with disability, opened up the space to discuss the discursive and material practices of Ashlie's lived experiences.

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\* Ashlie Brink. Email: [abrink@waikato.ac.nz](mailto:abrink@waikato.ac.nz).

**Keywords:** outsider witness, narrative documents, re-membering, loss, grief, hope

## INTRODUCTION

### A Dress, a Graduation, a Loss

A gold, lace dress with a chiffon scarf draped across its right shoulder hangs proudly in the corner of the cupboard. It hangs in wait of its owner celebrating a graduation ceremony, a celebration of new beginnings, of hope, aspiration and dreams she had for her daughter. But the owner never did wear the dress. Instead her daughter wore it in honour of its owner, her mother. When she graduated the daughter wore the dress. The dress needed alterations to fit her daughter's smaller frame, a dress stitched together by hope, love, honour, respect and gratitude to her mother.

I, (Ashlie) am the daughter - I wore my mother's dress for the graduation

Elmarie attended the graduation as a colleague and staff member and then, 11 years later, Ashlie and Elmarie shared a conversation about the graduation. Elmarie held some knowledge and small details about the story of the dress and Ashlie's loss of her mother. Elmarie asked Ashlie about the celebration day and the dress she wore to the graduation. On this particular occasion, Ashlie spoke of the conflicting and painful memories of her mother's passing. This conversation was not only around the time of the anniversary of Ashlie's mother's passing, but at a time when Ashlie was searching for inspiration in the midst of writing a PhD and thus building an academic career for herself. Through speaking the bitter-sweet relationship that Ashlie had with the dress, she revisited the occasion of the graduation. In the conversation, Elmarie and Ashlie recalled a book that launched the previous year, *The Memory of Clothes* edited by Gibson which also included a chapter by a colleague. Ashlie and Elmarie both read the moving and touching chapter titled *The Red Pashmina*. A day or two later the story invited discussions of shared memories of clothes, loss of mothers and their mothers' handy-work of sewing outfits. It was here that an opportunity and space presented itself to talk about the materiality of the graduation dress that Ashlie talks about below.

After the death of the owner the red pashmina was claimed by her daughter. Campbell (2015) very poignantly personifies the pashmina and

writes a section with the voice of the pashmina, explaining the daughter's experiences of loss.

Saturation from tears and sweat. I was repulsed. *Stop!* I wanted yell. I, who had always been worn with stylish grace by *The Reader*, had now succumbed to the wrenching and drenching of *The Daughter*.

I grieved for *The Reader* too! I had loved her for fourteen years. Her presence pulsed inside me. I had sucked at her life, hiding bits of her essence throughout my weave. Layered her laughter into my warp, secreted her scent snug-tight in my weft. I became greedy to be worn by *The Reader*; I couldn't get enough of her. I wanted to be stuffed full with *The Reader's* essence, to be her ambassador in the world. But now the horror of living with *The Daughter* engulfed me.... (Campbell, 2015, p. 5).

In the section above the pashmina speaks of the intimate relationship with the first owner and the transition to the hands and tears of the new "owner." A shift or re-positioning happens as a result of the "intra-action" (Barad, 2007) between daughter and the material of the pashmina she wrapped herself in. The pashmina continues:

I don't know what came over me, but after a few hours of more tugging and wailing from *The Daughter*, I remembered what I had been born to do – to adorn and protect. The strain of resisting *The Daughter* was tiring, so I relaxed. I loosened my weave a little, ever so slightly to reveal a scent. *The Daughter* calmed and became still. I opened my memory-laden pores a little more. A smile teetered at the corner of *The Daughter's* mouth. I relaxed further allowing more of *The Reader's* essence to float in the air. A ray crept across *The Daughter's* face, no teeth to speak of, but a smile none the less. Then, holding me close to her cheek, she whispered the word *Mum*.

I know now that I adopted the role of surrogate mother in those first few months after *The Reader's* death. *The Daughter* wore me often, mostly at home by herself. Every time I enshrouded her, I released more of my greedily stored away memories of her mother (Campbell, 2015, p. 5).

Unlike the daughter in the story of The Red Pashmina, Ashlie had conflicting views of the dress that she wore to the graduation. Ashlie did not invite the dress to envelope and comfort her body nor did she want the dress to adorn her. Ashlie had wanted her mother to wear the dress as she had always intended to. It was her mother's celebration outfit that she had chosen for herself to wear to her daughter's ceremony, not the other way around. Ashlie

recalls her mother's joy when purchasing the dress and carefully hanging the garment in the spare room cupboard for the occasion. Ashlie's mother was pleased with her 'find.' Despite the fact that her mother had not yet established a physical, 'worn in' relationship with the dress as the owner of The Red Pashmina had, the dress represented a garment of significance to her. Ashlie graduated with a Masters of Special Education for which she had interviewed young women with visible, physical disabilities for she herself had learned to live with. A common thread acknowledged in Ashlie's research interviews, were the close relationships that the participants had with their families, and particularly the bond that they shared with their mothers.

Experiencing the ongoing impact of the loss of Ashlie's mother, anger crept in as the graduation neared. Ashlie loved the dress as the dress was a garment her mom had chosen for herself to wear at Ashlie ceremony, but at the same time, Ashlie hated it because it represented the stark reality her that a pivotal person in her life was absent. The resentment and bitterness of Ashlie's mother's accident pushed itself forward and the dress became a painful reminder of what should have been, but was not.

Ashlie briefly told Elmarie about the incident of receiving the news of her mother's car accident:

This January, 11 years ago my mother called me earlier in the day to say that she would be home late from work. My mother never made it home. In an instant my life changed, dramatically.... A police car outside the drive ... A police officer... Cap in hands ... Asked to sit down ... I went numb, chilled to the bone. He expressed his deepest sympathies. I could not hear a single word that passed the officer's lips. I saw the movement of his mouth and smelt the smoky residue of a recently smoked cigarette. I sat there ... I was brought back to reality when I heard the bellowing cries of my brother. I saw the tears rolling down my father's cheeks. I got up ... We embraced, holding each other tightly as though one would fall if any of us let go. Time went both quickly and slowly. The embrace was both comforting and empty. My body both cold and numb and life shattered and unfamiliar - the feeling of my mother's love in an embrace which made all things better, absent.

Ashlie had shared with Elmarie the shock she felt on hearing the above news of her mother's tragic accident and how it was not something she often spoke about. It was through the above sharing of clothes, memories, mothers, loss and renewed dreams that an opportunity presented itself which was well timed being the beginning of January and the start of new academic year. The intention of the outsider witness practice was not for therapeutic purposes, but

an opportunity for both students in the University's Master of Counseling (M Couns) programme to bear witness and Ashlie to talk about a significant experience in her life.

## OUTSIDER WITNESSING

Elmarie teaches narrative therapy to M Couns students and one practice that she teaches is "outsider witnessing" (White, 2007). At the beginning of an academic year Elmarie introduces M Couns students to outsider witnessing practice. She sometimes invites a graduate or senior counseling student to join in the introduction of this practice. In 2016, a week after the conversation with Ashlie and hearing how Ashlie received the news of the car accident, Elmarie invited Ashlie to join the discussion with the M Couns students. Elmarie explained that the purpose would be for Ashlie's story to be witnessed by outsiders (Weingarten, 2010) and to further thicken (White, 2007) her story of her graduation and her mother's contribution to her life and studies. Prior to the session Elmarie provided Ashlie with relevant readings (White, 1988, 2007) about the process of outsider witnessing. Elmarie first consulted the group of 25 students and asked if they were in agreement to invite Ashlie into the group which they supported. Ashlie then accepted the invitation to join the group. The function of outsider witnessing (White, 2007) in this specific situation was not therapeutic, but a practice to create an audience to witness Ashlie's experiences of loss, her celebration of her graduation and the remembering of her mother.

The three-stage process of outsider witnessing was developed by Michael White, based on Barbara Myerhof's "definitional ceremonies" (White, 2007). Within a therapeutic context, a client and therapist negotiate the presence of outsider witnesses. In the first stage, the client tells an aspect of her life story while the invited outsider witnesses listen carefully to the conversation. The outsider witnesses are then invited to retell the story to the therapist, guided by the carefully crafted questions. During this stage, the person whose story is witnessed, listens to the conversations between therapist and outsider witnesses. In the third stage, the therapist returns to the person whose story was witnessed and invites them to retell the story witnessed and retold by the outsider witness. Once again the therapist carefully scaffolds this conversation with crafted questions.

The practice was audio-taped to capture Ashlie's words for her to listen to and re-visit. At the start of the session Elmarie once again set out the process

for the group and then turned to Ashlie and asked her what she thought could be the focus of the discussion. After a few moments of silence Ashlie selected to talk about the dress and said: ... *the gold dress gives me that comfort in talking about other things ... so I'm feeling I'm holding onto the gold dress, so its that, that is giving me warmth. A place to talk ...* Ashlie returned to the January conversation that she and Elmarie had.

... it was January, and an anniversary – my mom's anniversary was coming up ... I also recalled some of those memories of the graduation ... I think I had mentioned it to you at the time ... - when we [staff] queued, lined up to go up to the stage ... colleagues around me ... at that time it was something that was really warming for me. I felt cloaked [a korowai]<sup>1</sup> I felt protected ... a blanket of comfort from colleagues' presence. Also, at the time knowing that my family were in the audience, and it was a difficult time – the whole graduation ... Certainly, the whole event was steeped in bitter-sweet emotions at that time.

She continued to talk about the loss of her mother, the bitter sweet memories of the graduation, and her decision to wear the gold dress with pride.

Through the telling and questioning, a relationship with the dress and the graduation ceremony emerged. Ashlie talked about the conflictual relationship:

I think at that time there was a lot of anger, still, a lot of anger – and a lot of this was just not how it was supposed to be ... unfair. So, I had ... arguments with the dress... It wasn't my initial decision... [to wear it] it was a gradual decision, it grew with me.

After the conversation with Ashlie, Elmarie turned to the M Couns students and asked them to reflect on and relate how Ashlie's story resonated with, and transported them. Elmarie invited Ashlie to listen to the discussion. Elmarie carefully scaffolded the questions to the witnesses. For example, she asked about the particular words or expressions that stood out for them in Ashlie's story. She invited them to think of images or values that came to mind when they heard those particular words. They were requested to think about why they connected with particular aspects of Ashlie's telling and what

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<sup>1</sup> A korowai is a particular type of Māori kākahu (cloak). It is usually decorated with feathers and/or tassels and has a border along the bottom, although this can vary according to tribal custom.

it was in their own lives that connected them to those particular aspects of the story. Elmarie asked what in their own lives prepared them to hear these aspects of Ashlie's story. Towards the end of the conversation Elmarie also asked them how they might take the learning from the event into their future counseling practices. Elmarie ended the discussion and slowly returned to Ashlie. She created a few moments of silence for all to re-collect thoughts and emotions.

In the third stage, Ashlie was then invited to retell the story as witnessed and retold by the M Couns students as witnesses. Once again, Elmarie carefully scaffolded this conversation and asked Ashlie what she thought about what she had heard them speak. Elmarie asked Ashlie what meanings she had made of their re-tellings (White, 2007).

Outsider witnessing can serve many purposes (White, 2007). In this specific situation, it provided Ashlie with an opportunity to speak the loss and grief outside of her immediate family. The witnesses created an audience to listen carefully to Ashlie's experiences of loss and grief, the graduation ceremony and her relationship with a dress. The outsider witness responses were scaffolded by Elmarie and the ritual opened up opportunities for Ashlie to develop richer descriptions of her relationship with a dress and in turn remembering her mother and her mother's love and contribution to her graduation ceremony became even more richly storied.

## **A NARRATIVE DOCUMENT**

Narrative documents have been described as "expanding the conversation" (Epston, 1998, p. 95; Freeman, Epston and Lobovits, 1997, pp. 112-124) and the practice has developed to include many forms of documentation. White (2000) calls on Geertz (see also Newman, 2008) when writing about the work that a narrative document can be used for when he writes:

Practices of the written word, which have for a long time been a theme of narrative therapy, contribute significantly to the visibility, substantiation, and endurance of the sparkling events that are identified in narrative conversations – these practices of the written word document the more sparkling events of people's lives and in doing so contribute to 'rescuing the said from the saying of it,' the 'told from the telling of it.' This documentation can take many forms, including certificates, letters,

announcements, position statements, verse, song, and transcripts of therapeutic conversations. (White, 2000, p. 6)

Another contribution to the use of narrative documents came from Speedy (2005) who developed the use of “poetic documents” in narrative therapy. Speedy (2005, p. 285) writes that “poetic language speaks to that which is not fixed or known and that which ‘moves or escapes’ and appears to defy the confines of conventional language.” She provides some “suggestions and safeguards” (p. 295) in the crafting of such documents. Elmarie was mindful of these guidelines when she captured Ashlie’s words from the transcript of the outsider witness conversation. Elmarie used Ashlie’s language and captured words and phrases that Speedy (2005, p. 295) identifies as “unforeseen, evocative and resonant, that link lives and that attend to ‘particularities’ rather than generalities.” Elmarie also reached for the “talk ... that emerges out of moments of silence or reverie” (p. 295) and “‘talk’ from all sorts of places—places of struggle, and difficulty ...or more helpful moments ...talk that surprises people, comes unexpectedly to their lips, shifts ... their experiences of life’s possibilities” (Speedy, 2005, p. 295).

For the purpose of capturing the above, Elmarie studied the transcript of the interview with care and highlighted the words that stood out as speaking the relationship with the dress and the connecting and re-connecting of the dress and Ashlie’s mother. She did this with the intention to re-turn Ashlie’s words to her in order to provide her with a rich description of her experiences. This practice supported a thickening of the story outside of “established assumptions and social constraints” (Speedy, 2005, p. 285).

January

Her anniversary

I submitted my dissertation

The weekend before Mother’s Day

Graduation ceremony

Bittersweet memories

We lined up to go on stage

Colleagues – a blanket, safety, warmth, comfort

Family in the audience – bittersweet memories

I can talk the dress, *now*

Brings warmth and comfort

To talk, to remember

Bittersweet memories

She *wasn't* there ... she *was* there  
The dress spoke, my mother spoke  
The dress is my mum  
I could feel the flow – cold and warming

I argued with the dress  
The decision to wear it grew with me  
Proud to wear it, and anger ...  
She would have worn the dress,  
with pride ... and grace  
I brought her to the graduation ceremony  
In her absence, she spoke  
A bittersweet moment

The dress, re-fitted, altered, spoke  
Opened space for me to think, talk, write  
Doing hope with me ...  
For a future ceremony... celebration

## RE-MEMBERING

Ashlie remembered how she cared for her mother when she farewelled her mother's body. Spending time with Ashlie's mother before her funeral was an incredibly painful, but precious time shared together – just one last time! She carefully ran her fingers through her mother's beautiful hair, sweeping and stroking her forehead in the way her mother had done when Ashlie had been retching and vomiting after an anaesthetic. Ashlie sat with her mother for ages clasping her hand wishing her mother could reciprocate in the way she had done so many times when Ashlie would wake in pain searching for comfort and relief. Ashlie's thumb tenderly stroked her mother's cold, limp hand that at that time, Ashlie had convinced herself that the patch that she had stroked became warm, just warm enough to feel like her mother was alive and present. Ashlie's mother hated being cold and was always known to rub her hands together to keep them warm.

Ashlie sprayed both her mother's and her perfume on her mother so that the two scents would mix. Perfume was one of the many joys that bound Ashlie and her mother together and was always the height of pleasure and delight for birthdays and celebrations. On many occasions their perfumes would mix as they hugged and during the day a whiff of the other's perfume

would touch the nostril reminding one another of their ‘scent.’ Ashlie’s mother with her rich, warm, spicy, earthy notes and Ashlie with her light, spring, floral blossom tones. Both these fragrances being quite distinct and recognisable as signature scents by those closest to them. On this day and final occasion, Ashlie wanted the perfumes to mix and the vapour to dance, droplets to come together and finally settle on the body like individual hugs.

Ashlie carefully redressed her mother’s hair the way she would have worn it. Her hair felt clean but at the same time brittle and cold. Ashlie ran her fingers through a stranger’s hair – it was her mother, but at the same time it was not.

Ashlie had brought her mother’s rich burgundy lipstick to wear as she had worn so many times before. Her mother was starting to look more like the mother she had known except for the bandage on her right arm and the burgundy acrylic nails her mother loved so much that were now broken and chipped from the accident.

Detailed storying of the care Ashlie took with her mother’s body called forward memories of her mother’s care for Ashlie at times when she had surgery and other medical procedures. Ashlie remembered the love, care and commitment her mother gifted her when she was younger and needed this medical care. She recollected how as a child she would spend part of the school holidays in hospital, having most of her joints drained of the fluid build-up caused by Juvenile Rheumatoid Arthritis (JRA). The hospital visits had become so frequent for Ashlie growing up that an unspoken ritual had developed between Ashlie and her mother. “This time next week it will all be over” her mother would say. “This time tomorrow, you will be home and in your own bed, all done and all better,” her mother would remind her. The morning of the hospital visit Ashlie would seek reassurance, “In a few more hours, I will be done, hey? In my own pyjamas, hey? You will put my pyjamas on as soon as I get back from theatre?” Ashlie’s mother always came through on her promise to her daughter and after Ashlie returned from the operating theatre she would wake wearing her own pyjamas and hear her mother say “there, it’s all done now, it [the aspirations and cortisone injections] was so quick, in and out and it’s all done now and you will be so much better.”

Hospital visits were traumatic for Ashlie. The ordeal of following hospital policy and protocols were impacting on both Ashlie and her mother. Ashlie’s mother had negotiated for Ashlie to be admitted on the day she was due to go into theatre, not the night before as was hospital policy at that time. Ashlie would change into the gown just before going into theatre, not the many hours beforehand. This ritual alleviated some of the anxiety of going into the

operating room. Ashlie's mother would make sure the correct anti-nausea medication was administered in theatre after the procedure if it was an anaesthetist who did not know Ashlie's history of adverse reactions to some medications. Her mother would insist that she receive the Stemetil injection before Ashlie got back to the ward to ease the additional angst about having any further medical treatment like injections done to her already sensitive body. After waking and on return from the recovery ward, Ashlie's mother would carefully remove the theatre gown, gently washing Ashlie's face, neck and upper body with warm water and lightly scented rose soap. The ritual on occasions would take place two or three times to get rid of the vomit.

Ashlie's mother dressed her in her pyjamas and on the neckline of the garment, placed a dab of perfume to help rid the smell of anaesthetic and vomit Ashlie hated so much. Ashlie's mother advocated, even argued with medical staff to discharge her at the end of the day of surgery. She knew from experience that Ashlie would recover far quicker if she went home as soon as she was able.

Through Ashlie re-connecting with these acts of kindness and love and her mother once again became a companion on Ashlie's journey and the relationship was re-kindled. In narrative therapy's term the evoking of the presence of a deceased person is called "re-membering conversations" (White, 1988, 2007; Hedtke, 2003; Hedtke and Winslade, 2004, 2005) when storying practice of "reengagements with the history of one's relationships," through revising and revisiting the "memberships" (White, 2007, p. 129) one has with significant others in one's life. For Ashlie the outsider witness practice opened up a space to re-visit her relationship with her deceased mother through the re-membering of the care her mother provided in her life and re-storyed the role and meaning of these actions. Ashlie re-claimed her mother's membership of what in narrative therapy is called a "club of life" (White, 1988, 2007; Hedtke and Winslade, 2004). A person can introduce membership to a "club of life" to people whose presence enhance wellbeing and support what we ourselves care about and hope for in our lives. This re-membering practice was developed by White (1988) as a "saying hullo" to significant people in one's life. "Saying hullo" is a deconstruction of the readily available expected practice of "saying goodbye" to people who have passed on. A hope-full "saying hullo" provided Ashlie with the opportunity to re-claim her mother's membership of her "club of life" (White, 1988, 2007; Hedtke and Winslade, 2004). Ashlie claimed her mother's membership to her club of life when she re-visited her mother's care for her as well as her care for her mother's body. The practice of saying hullo again was called into existence by the discursive materiality of the dress.

Ashlie's relationship with the dress shifted. The golden, lace dress with a chiffon scarf draped across its right shoulder now hangs proudly in her cupboard. It hangs as testimony of the two owners' hopes, aspirations and dreams for Ashlie's forthcoming celebration of a graduation ceremony.

A Baradian (2007, p ix) statement about "memory" and remembering speaks into the significance of the "materiality" of a pashmina and a dress provided in the grieving for two mothers. Barad (2007, p. ix) writes:

Memory does not reside in the folds of individual brains ... Memory is not a record of a fixed past that can ever be fully or simply erased, written over, or recovered (that is, taken away or taken back into one's possession, as if it were a thing that can be owned). And remembering is not a replay of a string of moments, but an enlivening and reconfiguring of past and future that is larger than any individual.... The past never finished.... We never leave it and it never leaves us behind.

## CODA

The re-visiting, re-remembering and re-telling of the story of loss, grief and a graduation ceremony sustained Ashlie's hope for completion of her doctoral study. In re-storying the dress and Ashlie's previous graduation ceremony opened up a possibility for her to embark on the PhD and hearing the dress calling her to acknowledge and embrace the new possibilities of the future celebrations. The discursive materiality of the dress called forward memories of reciprocal commitment and care available to Ashlie and her mother. This relational bond beyond loss was stitched into the golden lace dress and practices of outsider witnessing, narrative document and re-remembering conversations richly described the stitching together of love, hope and care.

## ACKNOWLEDGMENTS

Ashlie would like to thank the University of Waikato's Wilf Malcolm Institute of Educational Research (WMIER) for the funding made available for transcribing and acknowledge the M Couns students at Waikato University.

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