Healthcare Clowns in Palliative Care in Chile

Healthcare Clowns in Palliative Care in Chile:

Traveling Together in a Humane Care Triad

By

Victoria Valdebenito Mac Farlane

Cambridge
Scholars
Publishing

Healthcare Clowns in Palliative Care in Chile:
Traveling Together in a Humane Care Triad

By Victoria Valdebenito Mac Farlane

This book first published 2023

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN (10): 1-5275-9289-8
ISBN (13): 978-1-5275-9289-6

Dedication to the Wonder Women

One day I visited the wonder women to ask them how they got their superpowers.

They shared their stories with me, their greatest pains, the ones that are still healing in the nature of shared dialogue.

They narrated their most sincere feelings, their truths, their deepest wounds, which as a collective they continue transforming into oceans of wisdom.

They told me about the darkness of the world, but above all about the light that each one of us can radiate towards others.

These wonder women are so transparent, pure, conscious and beautiful that they handle their pain by walking alongside their sisters.

However, they said, their most important experiences, the ones that had transformed them, are the enjoyment they take from their intuitions, their joys, their deep love, the happy moments, the pleasant laughter, those memories that they embrace and treasure because they know that the path of life is full of these delicacies.

TABLE OF CONTENTS

Introduction

Overview of the Literature

Mothers' Perceptions of HC in PC

Recommendations and Conclusions

PREFACE

This research is dedicated to the mothers and their children who experienced palliative care whose generosity made this work possible. The research presented here, following in the footsteps of these children, seeks to be a contribution both for people who will have to face this situation in the future and for defending the right to life and the wellbeing of all people, based on the study of perceptions of the period of paediatric palliative care and death.

ACKNOWLEDGMENTS

To the mothers who generously shared their and their children’s life stories.

To the healthcare clown organization Sonrisólogos in Chile for their trust in me to do this work.

To the PC unit team members who supported this project.

To my family for always being there for me.

LIST OF ABBREVIATIONS

CAM: Complementary and alternative medicines

DECEL: Online Spanish Etymological Dictionary

DG: Discussion Group

E: PC unit team member

FONOSA: National Health Fund, Chile

HC: Healthcare clown

M: Mother

PC: Palliative Care

PINDA: Childhood Cancer Program, Chile

RAE: Royal Spanish Academy

SENAME: National Service of Children, Chile

WHO: World Health Organization

CHAPTER ONE

INTRODUCTION

This book is the result of a research project with the main objective to study the relationship between children in palliative care (PC), their families, the clinical team and healthcare clowns (HC) in a paediatric palliative care unit in Santiago, Chile. At the same time, the study was developed in order to create training material for this type of professional and their particular work in an area that requires great sensitivity. In 2008 a HC organization, which uses the art of the clown as its instrument and main language, was invited to be a member of the PC team in a paediatric unit of a public hospital in Chile, being the only case that offers this service in the country.

The main aim of the studied HC organization is to improve the quality of life of children and adults through interventions to de-dramatize hostile situations, along with promoting the part of the child that is healthy. It also works to mitigate the stress and anxiety generated by the diagnosis and treatments, promoting play as a tool for communication and expression, along with autonomy for children. In this regard, it is important to say that the organization under examination also works with the entire range of human emotions, emphasizing the importance of the experience of not only joy but also sadness, anger and grief, among others. Moreover, the organization has a multidisciplinary team.

In order to be a contribution to people who suffer from the loss of children, after more than thirteen years of work as members of the PC team, along with biomedical professionals, the HC organization wanted to evaluate the effects of their intervention by exploring the perceptions of the actors involved in the process. More than sixty-five girls and boys have undergone the treatment that includes HCs. Additionally, the HC organization does specific work with grieving mothers. There was then a need to systematize the evidence accumulated over time by treating patients in PC and to generate evidence about its impact on people who had experienced paediatric PC.

Background

The studied PC unit and hospital that frame the research are part of the public-health system in Chile, one of the two sectors of the healthcare structure, the other being private. The public sector covers all the agencies of the National Health Services System (SNSS), these being the Ministry of Health and dependent institutions, the Institute of Public Health, the Supply Center, the National Health Fund (FONASA) and the Superintendency of Health. The public-health system provides coverage to approximately 70% of the country's population, including people from low socioeconomic levels in rural and urban areas, the lower middle class and retirees, as well as professionals and technicians with better incomes who voluntarily choose to join it. The public sector is funded with general taxes, mandatory contributions and co-payments that are collected under FONASA. The provision of public services is in charge of the SNSS, which has a network of twenty-nine Regional Health Services and the Municipal Primary Care System. Sometimes FONASA contracts the services of private providers. In addition, funding for FONASA comes from a mandatory social-security premium of 7% of adherents' salaries.

On the other hand, the private-health sector is mainly funded by mandatory contributions collected by the Social Security Institutions (ISAPREs), which covers approximately 18.5% of the Chilean population belonging to groups of higher socioeconomic levels (Cid and Uthoff 2017). In parallel, three security mutuals offer protection to their members, covering 15% of the population against work-related accidents and occupational diseases. Security mutuals provide care in their own facilities. The inhabitants of the country can choose between FONASA or some ISAPRE. ISAPREs provide services in their own facilities, in others in the same private sector, or even in public-sector facilities. Depending on the contracts, people affiliated may or may not choose the service providers. A small segment of the population, belonging to the upper classes, makes direct out-of-pocket payments to private providers of healthcare services. Around 10% of the population use other public agencies, mainly the Health Services of the Armed Forces. Self-employed workers can choose to join FONASA or an ISAPRE, or be part of the population that does not belong to any social-security health system (Becerril-Montekio, Reyes and Manuel 2010). The context of the phenomenon reported in this book is the public-health system in Chile.

Key Bodies of Research Literature

At the base of HC is the clown theatrical technique, originated in the style known as Commedia dell'arte Italiana (Cantieri 1965), derived from Greek comedy. The technique as we know it today developed from experiences such as the circuses of Boullevard du Temple in Paris during the second half of the nineteenth century (Ceballos 1999). Characteristic of the clown is the fact that the artist does not interpret a character but plays themselves, with their defects and virtues, communicating directly with the audience, breaking the traditional fourth wall of theatre, expressing themselves through emotions and sensations (Jara 2000). Likewise, the clown laughs at themselves, is gentle and never attacks the audience. The clown's actions are based on their own failure. Playing a clown is similar to being in a state. A distinctive element is the use of the clown's nose, the smallest theatre mask that exists, which is used by the artist to show themselves honestly (Valdebenito 2012).

In particular, clowns have been related to the field of health since the time of Hippocrates when they fulfilled the role of balancing the bodily humours that were considered essential to maintaining good health (Spitzer 2006), a vision far from the scientific method. However, HC as part of healthcare teams is a relatively new phenomenon that has risen in prominence over the last three decades. In 1986 clowns reappeared in hospitals in the United States and Canada after centuries of absence. In 1991 the Program Doutores da Alegría was founded in Brazil and Cliniclowns in the Netherlands, while in 1996 the Clown Doctors were created in Australia, and the Dream Doctors Program was created in Israel in 2002. Since then, programs of this type have been established in many countries of the world. Although each program is unique, they all prioritize professionalism, regular training and maintaining the highest possible standards (Raviv 2018). These standards include training in hospitals and respect for a code of ethics by all professionals dedicated to this work, which are basic requirements for performing as HCs in these contexts. Due to these reasons, ethics is a fundamental part of the training of those who work in this profession (Vaz and Makri 2016; Caires and Masetti 2015). In Chile, the first HC organizations began to take shape in 2007, the one studied by the research reported in this book being a pioneer.

On the other hand, PC concerns the care delivered actively and globally to patients and families by a multidisciplinary team when the disease of the former is considered not susceptible to curative treatment (World Health Organization 2020). Thus, paediatric PC generates the necessary conditions for the creation of an atmosphere of integrity in order to provide wellbeing to children until the end of life; that is, quality of life, including for their families (Castañeda de La Lanza et al. 2015).

Around the world, approximately three hundred thousand children are diagnosed with cancer annually, among which the most common are leukaemia, brain cancers, lymphomas and solid tumours. In low and middle-income countries, less than 20% of these cases are cured, while 80% are cured in high-income countries (WHO 2020). In Chile, cancer is the second leading cause of death among girls and boys. Each year, more than five hundred cases are detected in children between one and eighteen years old, and the public-health system cares for 80% of these (PINDA 2020). Currently, 78% of children and adolescents diagnosed with cancer survive in Chile, depending on the type of cancer and its risk (PINDA 2020).

It is important to note that the research reported in this book is framed in a PC unit that is also a centre for the Childhood Cancer Program (PINDA), that is, part of the coordination network of paediatric PC teams in oncology at the national level in Chile. Here children arrive with advanced cancer diagnosed by a specialist doctor and/or an oncology committee. These types of centres are located in more complex and ambulatory establishments, in both the public and private sectors (Ministry of Health, MINSAL 2011). They are also part of the National Cancer Pain Relief and Palliative Care Program, which emerged in 1994 from the National Plan for Cancer of the Ministry of Health as a response to the Continuity of Care Model proposed by the WHO’s Cancer Fight Program (2002).

The period of PC leaves a profound impact on both children and families, given the unnatural nature of the loss (Muñoz 2011; Almeda and Barbero 2009). Both quality of life and wellbeing are negatively impacted as a result of this painful experience, particularly for the diagnosed child, an impact that transcends death in the case of families. Therefore, delivering quality of life in PC is central. The study reported in this book defines quality of life as a subjective and multidimensional construct that encompasses several domains of life (Aymerich et al. 2005), specifically six dimensions: self-perception about physical activity and health, psychological state, self-esteem, family, friends and school (Pane et al. 2006; Rajmil et al. 2004).

Likewise, children’s wellbeing is understood in the study presented here as perceptions regarding the dimensions of material wellbeing, health and safety, educational wellbeing, family and peer relationships, behaviours and risks, and subjective wellbeing; that is, the opinion that they themselves transmitted about their own life in this period (United Nations Children's Fund 2007). These aspects are strongly challenged by a cancer diagnosis, and even more so when entering the PC stage.

Although the literature shows that PC is a valuable tool in any health system, its development at the international level is still precarious (Castañeda de La Lanza et al. 2015), especially in developing countries such as Chile. Even more precarious is the development of paediatric PC. Internationally, it is estimated that each year more than one million children under the age of fifteen require PC at the end of life, of which 98% live in low and middle-income countries (Caruso et al. 2014). Regarding the American continent, authors such as Williams-Reade et al. (2015) explain that, with greater efforts in this line, between five and nine thousand children could benefit from PC due to their short life expectancy after an illness.

The studied HC organization works in a hospital in a city in the south of Santiago. As some have stated (García Herrera et al. 2015), urban public space is central in the daily life of the inhabitants of a place and can act as a sphere of identification. In Chile, a public hospital can barely fund this complementary medicine. Being inserted in a city with a multidimensional poverty rate of 27.11% – higher than the 15.01% average of the Metropolitan Region, where Santiago is located, and the national average of 16.63% (CASEN Survey, 2017) – indicates that users of this health service are among the most disadvantaged in the country. The studied HC organization work also covers community aspects of identity and memory.

In 2008 this HC organization joined the studied PC unit and its multidisciplinary team, composed of an oncologist who coordinates the team of two nurses, two psychologists, two social workers, an occupational therapist and professional HCs. They meet once a week to organize work with each child according to their needs. Depending on the case and diagnosis, they visit patients within the hospital, also offering free home visits. This is available for all patients referred to this paediatric PC unit. This is a unique case in Chile and the results presented here are part of the first research in Chile about HC in PC.

Research Design and Methodology

Regarding the above, the research question that led the study presented in this book is: "What is (are) the role(s) that HCs play in the context of PC of children, their families and the unit PC team?" The themes that resulted from the analysis of the answers to the question are presented in the following chapters.

HC programs first appeared in Chile in 2007. The studied organization has worked as part of the paediatric PC unit since 2008. There is no budget in public hospitals to incorporate complementary medicines such as HC. In this case, the program has been funded by the city council where the hospital is located, being the only case of paediatric PC which includes this medicine in Chile.

Regarding the research methodology, this was underpinned by an interpretivist paradigm. A qualitative strategy was considered appropriate due to the research focus on people's perspectives about the HCs' roles played in PC, with an emerging and descriptive design. Three techniques were used for data collection: in-depth interviews; discussion groups with mothers, PC team members and professional HCs separately; and document analysis. The main researcher conducted the interviews, and had no previous relationship with the participants. The participants signed an informed consent document before the interviews. The process started face-to-face in locations that suited participants, but had to go online to the Zoom platform due to COVID-19 restrictions, while discussion groups were held live when restrictions were lifted. The fieldwork was developed between December 2019 and December 2020.

The interviews sample is composed of sixteen mothers of children who passed the PC experience, ten team members from the PC unit, and ten professional HCs. The sample of documents was selected purposively from photos and drawings that are part of the HC organization records. In the case of interviews, a successive strategy was used to reach the sample, while a point of saturation principle determined the number of participants. The inclusion criteria were for families to have lost children in PC, being over 18 years old, and for staff to have worked in the unit for a minimum of two years. The exclusion criteria were being underage, and having been diagnosed with a psychopathology. The data analysis was performed using critical discourse analysis, grounded theory and projective analysis. The themes were derived from the data. The participants provided feedback on the findings.

Quality of the research was assured through credibility, auditability and transferability criteria, along with strict ethical criteria such as confidentiality. Ethical approvals were obtained from both the hospital and the university to which the main research is associated. Likewise, interviewees are quoted using parentheses denoting the number of interviews assigned and a code to protect anonymity. The quotes were selected due to their representativeness of the thematic domain. Also, as it is a qualitative study, the positionality of the researcher must be informed. Along with her career as a PhD student and researcher, she has worked as a HC in different countries. However, she has not worked in the studied PC unit.

Moreover, the following objectives guided the research presented here:

General objective: To understand the role of HC in paediatric PC, according to the perspectives of children's families and the PC unit team members, to support the development of a HC training plan to work in PC.

Specific objectives:

1. To study the qualitative impact of HCs on the wellbeing and quality of life of children and families who have gone through the PC experience.
2. To understand how children perceived HC.
3. To describe the vision of death from the perspective of children and families who underwent the PC experience.
4. To deepen the understanding of the bond between HCs and families.
5. To identify the evaluation of HC made by parents.
6. To characterize the PC unit team members' perspectives about HC as part of that team.
7. To discover the perspective of professional HCs about their work and their relationship with children in PC.
8. To consider the unanticipated effects of HC on the paediatric PC of children, families and PC unit team members.
9. To recognize strengths in HCs to carry out this work.
10. To identify challenges of this job for HCs.
11. To generate knowledge for the development of training material for HCs working in the area of PC.

Significance

The research presented here has two types of relevance: theoretical and practical. Regarding the first, it should be noted that there is limited evidence in relation to HCs in Chile (Valdebenito 2021; Valdebenito and Sanchéz 2021; Codina and Osorio 2019; Faúndez and Moena 2014), and a scarcity of studies on the presence of HCs in PC both nationally and internationally, specifically in childhood and in relation to the issue of death. Therefore, this research is a contribution to knowledge and theory in this field. Likewise, the topic of PC has moved to a central place in the health agendas, which explains that in Chile in July 2019 the Chamber of Deputies approved a Law on PC that recognizes and regulates the rights of people with terminal illnesses to access this type of care. The results presented here contain recommendations for the design of public policies on PC for children.

Secondly, the study has practical relevance since its results have been used as evidence to develop a proposal for training future HCs to work specifically in paediatric PC. As it is an emerging field in the world, and specifically in Chile, it is necessary to define curricula for the training of this type of professional, and the work presented in this book contributes in this regard.

Structure of the Book

The book contains six chapters. The present chapter has provided an overview of what follows, indicating that the central objective of the research was to analyse the roles of HCs in a paediatric PC unit in Chile. Following this, Chapter Two provides the background and theoretical framework exploring developments both internationally and in Chile in relation to the concepts of HCs and PC.

Chapter Three examines the results in relation to the perceptions of mothers who underwent the PC process with their children, while chapter Four presents the results of the analysis of the perceptions of the PC team members regarding those roles. Chapter Five is a qualitative meta-analysis of results according to the perspectives of all studied actors on the HCs' roles in the PC context. Finally, Chapter Six provides an overview of the study and makes recommendations for theory, further research and action, practice and policy design, and concludes the book.

CHAPTER TWO

OVERVIEW OF THE LITERATURE

Introduction

This chapter is concerned with the literature informing the research reported in this book. It is organized in ten sections. The first relates to evidence around the topic of clowns and HC. The second and third consider the notions of HC training, while the fourth covers evidence on HC impacts. The fifth and sixth deal with the notions of complementary medicines and PC. The seventh focuses on the healthcare system in Chile and dying within the PC context, followed by a review of community and emotional intelligence in the last two sections.

Clowns and HC

As already stated, the clown is an archetype and theatrical technique. Its main characteristics are that the clown communicates directly with the audience, honestly expressing their emotions and sensations, protected by the red nose, laughing at themselves, being gentle, without attacking the audience, acting based on their own failure (Jara 2000). Thus, the clown is a kind of antihero with whose humanity helps people empathize. Although the presence of clowns in the field of health dates back to ancient times, HCs who work in hospitals as part of healthcare teams reappeared only in the last three decades, being a relatively new phenomenon. They all work with humour, and authors such as Van Blerkom (1995) have compared their work to shamans and traditional healers.

Over time, in diverse contexts, HCs have been increasingly accepted as valuable members of multidisciplinary healthcare teams, recognized as integral components of the healthcare delivery process (Moreira, Esteves and Caires 2015; Dionigi, Flangini and Gremigni 2012), and as agents who add a humane dimension through their work in hospitals (Brockenshire et al. 2017). However, despite the growing number of HC programs, there is a lack of research in healthcare settings (Kristensen et al. 2019; Yildirim et al. 2019; Koller 2007), especially regarding training and preparation for this type of clown. Chile is no exception in this regard.

From the above, the idea that clowns, or HCs, play different roles in society emerges. Initially, their role is to entertain and make people laugh (Jara 2000). But the clown's work is deeper, encompassing the full range of human emotions. In healthcare contexts, for example, these professionals promote awareness and sensitization of human aspects of care, thus claiming human rights (Ros 2015). Thus, in these everyday contexts, HCs play a political role through their art (King 2018).

HC training

The work carried out by HCs requires these professionals to be trained in other artistic skills such as music, movement, theatre, magic, puppet theatre, singing, dancing and play techniques. The latter element is an important tool due to its therapeutic effects. Play can create a positive experience for patients in hospitals if used appropriately, allowing children to find solace in a familiar activity and providing a safe outlet to communicate individual fears and assimilate new experiences. In addition, play can reduce stress and increase children's ability to cope and gain a sense of control (Australasia Children's Healthcare 2010). Opportunities for play, fun, recreation and creative activities for children in hospitals are so fundamental that they are recognized in standards for child and youth care in many countries (Ford, Tesch and Carter 2011). Thus, through play, HCs can benefit their patients (Anes and Obi 2014), being at the same time a therapeutic process for those who carry out this work (Lalantika and Yuvaraj 2020). Such evidence suggests that HCs need additional training, guidance and greater sensitivity to aspects related with disease (Warren 2009) compared to clowns who work in other contexts.

Regarding professional training for HC in formal education systems, at an international level the European Federation of Healthcare Clown Organizations (EFHCO) has been working on an Erasmus+ project called Healthcare Clowning Pathways, which concerns training and certification of HC education according to European standards (2022). On the other hand, in Israel from 2007 to 2015 the University of Haifa offered a first master degree in Medical Clowning (Dream Doctors 2022), to which a similar initiative was added on the other side of the world at the University of Southern California (2014). These are the only three formal instances of HC education in the world. In Israel, they are considered an essential part of clinical teams (Moreira et al. 2015). In Latin America and Chile there are no formal training programs for this type of professional, nor are there any measures of the effectiveness of such interventions.

Regarding non-formal education, another existing example is the case of the Heart and Noses Hospital Clown Troupe in Boston, United States, who designed a specific methodology systematized in a training manual (Lindheim 2005). Recently, Raviv (2018) elaborates a HC training and evaluation model, this being one of the only current and updated protocols worldwide to safeguard the work of these professionals.

Using a qualitative approach, one pioneering research project conducted in Canada examined HC preparation and existing programs in that country, seeking to discover what these professionals know upon entry and how they learn both formally and informally, examining links between these types of learning in training and practice, identifying good practices. Later, this knowledge was used in the design of HC training programs (Warren 2001). The results of this project indicated that two main approaches to the HC work in Canada were initiated in 1986, one influenced by the Winnipeg Therapeutic Clown Program and the other influenced by the Big Apple Circus Clown Care Unit, an American organization that leads the revival of this discipline and is based on the European clown tradition. Other results of this study indicate that HCs learn mainly in hospitals and receive formal and informal training that helps them prepare for their work. Likewise, HCs learn from other HCs doing this job. Globally, clown-to-clown learning occurs in three ways: formal group meetings, informal talks and discussions both inside and outside the workplace, and working as colleagues in healthcare wards. This study establishes that for these HCs the latter is the most important way of learning. Finally, HCs learn from other healthcare professionals, being the second largest source of informal learning for HCs. This is why the author proposes that it is important to develop mentoring systems in which this information can be shared (Warren 2001). Much of the information gathered by this research is already being implemented in the Windsor Fools for Health Program, which trains this type of clown.

Despite this contribution, more evidence is still needed to define what HCs should learn to practice this job in other settings. Another study (Warren 2009) points out that requirements to qualify as a HC to work in those settings need to be clarified since they are increasingly valued as members of clinical teams and an integral component of healthcare processes (Valdebenito and Sánchez 2021; Hanuka 2011; Warren 2009).

It must be emphasized that HCs in this context do not aim to cure a patient's illness. Rather, they focus on the healthy aspects of the person, reminding family members and healthcare team members that a patient is more than the disease. Thus, children, families and the clinical team can see beyond the medical problems (Warren 2009). The complexity and sensitivity required for this work highlight the importance of adequate preparation for these professionals. Since they work as part of the healthcare teams, they must be adequately prepared to function in this field. Also, as a relatively new complementary medicine (Dionigi 2020), it has many challenges and continues to be validated as such.

Formal, Non-formal and Informal Education

Since the research that supports this book had amongst its objectives the development of training materials for HCs working in PC teams, a fundamental consideration is the concept of education. In this field, some theories distinguish between formal, informal and non-formal learning, categories originated in the late 1960s, when there was an international discussion about a crisis in education policies. The latter was linked to economic and political problems that national systems experienced in expanding their traditional educational systems, that is, their formal education (Coombs, Prosser and Ahmed 1973). In this regard, at the beginning of the 1970s, many organizations began to distinguish between formal, non-formal and informal education. In practice, due to the nature of education phenomena, boundaries between categories are easily blurred, especially between non-formal and informal education. This tripartite distinction was also associated with a new concept that emerged at that time in the field of education policy, that of lifelong learning (Barreiro 2005), which others refer to as self-programmable labour (Castells 1998). These approaches are appropriate for understanding the training process of a HC.

Linking education and work, the concept of self-programmable labour takes into account the need for continuous training in the current times, understood as work that is reconverted facing new technologies, in which workers must also be self-programmable, that is, capable of adapting to new demands. In this regard, Castells states that today it is very important for people to have a "general educational capacity for general culture, capacity for association, knowing what qualifications you need for the tasks you have to do, where to look for them, how to learn them and how to apply them" (Castells 1998, 5). Thus, it is a permanent specialization and qualification that people obtain throughout their lives, who can redefine their occupations and knowledge, which would be essential for those who work as HCs in healthcare settings.

On the other hand, the concepts of social and cultural capital allow for understanding part of the training required for this profession. These concepts are used in education research, linked to the economic meaning of capital. Social capital is understood as the number of relationships and social networks that a person can generate during their education stages, but also as something granted by family relationships and friendship (Bourdieu and Wacquant 1992). Those relationships are a capital because they can produce benefits. A clear definition is the one delimited by Bourdieu and Wacquant (1992) as the sum of resources, real or virtual, that an individual or a group accumulate thanks to having a lasting network of more or less institutionalized relationships of mutual knowledge and recognition. On the other hand, the notion of cultural capital is all the knowledge, information, training and ideas that a person has.

Given the characteristics of HC, which are explained in detail later in this chapter, there is an essential need for these professionals to develop and carry out self-care strategies. According to evidence, the job of HCs is rewarding but at the same time exhausting. The literature shows that HCs can develop conditions such as “compassion fatigue” (Benson and Magraith 2005), so it is necessary to consider these aspects when designing an education program for this type of work. Likewise, other conditions such as “anxiety in the face of death” (Tomer and Eliason 1996) that affect healthcare workers such as doctors, especially in PC (Boceta et al. 2016) must be considered in an education curriculum of this type.

The Physical, Social and Psychological Effects of the HC

HCs are specially trained multidisciplinary artists and/or professionals who work in healthcare settings, such as hospitals or primary care health centres, being a combination of artists and healthcare workers. They wear a red nose and use minimal makeup, while some dress in a white coat, and generally call themselves “doctors.” They often work in pairs, making the rounds in healthcare settings, bonding with patients and their families, and healthcare staff. Their main objective is to promote wellbeing and improve the quality of life of patients and their caregivers (Warren 2008), validating all emotions (Aguirre, Daniel and Pérez-Campdepadrós 1998). Specifically, the use of the white doctor’s coats helps them to be identify as part of the clinical teams. The HC is part of a complementary medicine (Dionigi 2020).

While the job description of healthcare staff is to make medical rounds and see what is “wrong” with patients, HCs make rounds to see what is “right.” Both health personnel and HCs work together to help patients on their journey. According to evidence, this work helps to change children’s perceptions of doctors, other medical personnel, and their own treatment (Simonds and Warren 2004). HC interventions also improve the experience of families and friends who visit patients in hospitals. Likewise, this intervention is carried out with all workers in healthcare services, giving them a moment of relaxation amid the inherent tension in working in these environments, which in turn directly benefits patients and their families (Warren 2008). Thus, part of the objective of HCs is to help patients in healthcare settings with the disease process, using humour and fantasy, creating an alternative world, helping families to reduce the stress and difficulties of the situation. At the same time, their work promotes better communication between medical teams, patients and families (Raviv 2018).

One research project carried out in Chile (Faúndez and Moena 2014) indicates that the work of HCs in an oncology unit enhances faculties such as vitality and strength amongst patients, while various international evidences have shown physical, psychological and social benefits from HC interventions due to the use of laughter, amongst other tools. Others have previously indicated that the use of humour produces positive attitudes and happiness in these contexts (Scholl and Ragan 2003). A study conducted in Germany (Tagalidou et al. 2019) clinically tested humour training for people diagnosed with depression, anxiety and adjustment disorders. These results showed that humour moderates symptoms and has both personal and social benefits for this type of patient.

Particularly about HC, there is evidence suggesting that it decreases anxiety levels in children undergoing haemato-oncology treatments (Maimon 2011), as well as children and parents of different cultural origins (Gilboa-Negari et al. 2017). There is also evidence of its positive impact in the context of paediatric PC (Mortamet et al. 2014). Likewise, evidence indicates that it is a good treatment for reducing both children’s preoperative anxiety (Vagnoli et al. 2005; Fernández and Arriaga 2010) and postoperative anxiety (Newman et al. 2019; Gutiérrez et al. 2008). It also facilitates examination procedures for sexually abused children (Tener et al. 2010; Smith, Symons and Ofir 2022). Equally, this therapy positively impacts children’s experience of pain during invasive procedures such as venous blood draws, urological surgery and skin tests for allergies. It also assists when attending respiratory infections, improving mood and emotions (Karisalmi et al. 2020), having a positive effect on the wellbeing of children with severe disabilities, and helping to improve the ability to communicate and establish personal connections in children on the autistic spectrum (Stephson 2017). Furthermore, HCs have a beneficial effect on pregnancy rates after in vitro fertilization and embryo transfer (Friedler et al. 2011), and in some cases can be used to replace sedation (Goshen et al. 2011). In countries like Israel, HCs are considered essential members of medical teams (Hanuka 2011; Gomberg et al. 2020).

Regarding pain management, evidence points to the benefits of HC interventions with children in venipuncture procedures (Kristensen et al. 2018), and in reducing acute pain in procedures related to needles (Kristensen et al. 2019). Furthermore, there is evidence of its positive physical and emotional effects during chemotherapy procedures (Arriaga, Melo and Caires 2020), and during intrathecal chemotherapy (Kurudirek and Arikan 2020). The benefits of this therapy have been studied from the perspective of not only patients and caregivers but also medical professionals (Venrooij and Barnhoorn 2017), who agree with what previous evidence has shown. The systematic review of randomized studies and non-randomized controlled trials suggests that HCs have a positive influence on the psychological wellbeing of children and adolescents (Lopes-Júnior et al. 2020; Sridharan and Sivaramakrishnan 2016).

HCs also bring benefits to the overall hospital environment, helping to humanize people’s experience in these settings, improving healthcare delivery and making hospitals more accessible and user-friendly (Warren 2008). Likewise, they break the hierarchical structure of hospitals by considering all people in the same horizontal status (Valdebenito 2012); for them, there are no hierarchies. As mentioned above, HC interventions produces social benefits. It has been found that laughter allows workers in health environments to establish empathetic relationships with patients and their families, facilitating the use of intuition and sensitivity in these relationships. Likewise, it allows care staff to help patients and families with the disease process, contributing to strengthening progress made by them, preventing negative attitudes that could generate feelings of guilt, and facilitating the use of active listening attitudes (Carbelo, Rodríguez de la Parra and Asenjo 1998). Moreover, HC reduces operation cost for hospitals (Gomberg et al. 2020).

Regarding psychological effects, a semi-experimental study concluded that the presence of HCs has an impact on patients’ emotions (Kingsnorth, Blain and McKeever 2010). Likewise in the last decade, a relatively good understanding has been achieved of the wide range of direct and indirect effects that humour and laughter have on perceptions, attitudes, judgements and emotions, one of the tools that HCs use that can potentially benefit physical and psychological states (Gelkopf 2011). This knowledge has promoted research suggesting that the use of humour and laughter could be positive in the treatment of children with serious mental disorders and illnesses (Henderson and Rosario 2008). In this regard, a study carried out in Spain shows that HC activities in a psychiatric unit reduce punctuation in the Global Disruption Index (Higueras et al. 2006). However, there is still a need for more empirical research in this area (Gelkopf 2011) given its profound implications for human wellbeing.

Ignorance invites many to think that HCs should only work with children. However, there is also evidence of positive results from working with other types of patient. For example, there has been a significant integration of this complementary medicine with adults suffering from chronic illnesses (Dionigi and Canestrari 2016; Nuttman-Shwartz and Scheyer 2010) such as depression (Low et al. 2013). Likewise, another research (Wild et al. 2007) revealed that HCs generate positive attitudes in this type of patient in Germany. In addition, evidence also recognizes that not all types of patients benefit from this therapy and humour, which has relevant implications to recognize and integrate such diversity (Auerbach 2017).

Regarding the use of humour in PC, authors such as Carbelo, Rodríguez de la Parra and Asenjo (1998) have indicated that this often represents the greatest need for people in this terminal phase according to their own testimonies. In psychology, Cabodevilla (2000) has noted that the use of humour helps to improve quality of life in the last stages of life, facilitating the farewell of families in PC units. Others (Ruiz Irigoyen 2001) have indicated that humour acts so that the farewell situation is lived humanely and de-dramatized, avoiding the process becoming a horrendous and artificial one.

Regarding effects of the presence of HCs and humour in PC (Ricarte and Torres 2008), research by Santarpia, Romani-Cesaro and Simonds (2019) indicates that these bring other aspects of healing that modern Western medicine has not yet developed, that is, the most holistic treatment of the whole person. HCs work with physical, emotional, cognitive and spiritual dimensions. Despite these positive experiences, there is little understanding of their role in hospital settings, especially in PC (Brockenshire et al. 2017; Nuttman-Shwartz and Scheyer 2010). This lack was one of the motivations to develop the research presented in this book.