

The Ethics and Values of Tele-Care Technology in Palliative Care

- A Discourse Analysis -

Alexander Sandhof
M. Sc. "Philosophy of Science, Technology, and Society"
University of Twente
29.01.2016

Supervisor: Marianne Boenink
Co-Supervisor: Johnny Sørraker

Table of Contents

Chapter 1 - Introduction.....	6
Chapter 2 – A Comprehensive History of Palliative Care.....	10
2.1. The Christian Roots of Palliative Care.....	10
2.2. Modern Palliative Care – The Early Years (1950's - 1967).....	12
2.3. Interlude I – Pain Conceptions and Pain Research.....	15
2.3.1. History of Concepts.....	15
2.3.2. Pain Research Efforts.....	16
2.4. The year 1967 - St. Christopher Hospital and the Scientific Refinement of Modern Palliative Care.....	17
2.5. Interlude II – Hospital vs. Hospice, Know the Difference.....	19
2.6. Recent European and International Development of Palliative Care.....	21
2.7. Anesthetics and Technology in Palliative Care.....	22
2.7.1. Pain Relief Medications – The Roots of Anesthetics.....	22
2.7.2. The History of the Syringe Driver and its Significance in Palliative Care.....	24
2.8. Attitudes towards Technology in Palliative Care Experts and Settings.....	28
Chapter 3 – Medical and Palliative Care Ethics.....	30
3.1. Medical Ethics – Preliminary Distinctions.....	30
3.2. Deontology and Utilitarianism in Medical Ethics.....	31
3.2.1. Utilitarianism.....	31
3.2.2. Deontology.....	32
3.3. The “Georgetown Mantra” – The Four Pillars of Medical Ethics.....	32
3.3.1. Beneficence and Non-Maleficence.....	33
3.3.2. Non-Maleficence.....	33
3.3.3. Beneficence.....	34
3.3.4. Autonomy.....	34
3.3.5. Justice.....	35
3.4. Care Ethics.....	36
3.5. Palliative Care Ethics.....	38
3.5.1. Palliative Care Ethics - Preliminary Differentiations.....	38
3.5.2. Intrinsic and Extrinsic Goals in the Pursuit of Non-Maleficence and Beneficence.....	39
3.5.3. The Role of Phronesis - The “Practical Wisdom” in Palliative Care.....	40
3.5.4. The Autonomy of the Patient – Shared Value, Different Practices.....	41
Chapter 4 - The Palliative Care Stakeholders - Practices, Ethics, Research & Experimentation, and the Introduction of TCT into Palliative Care.....	44
4.1. Introduction to Palliative TCT.....	44
4.2. Technological Development - The TCT Devices and their Capabilities.....	46
4.3. My Methodology of Analyzing the Relevant Research Literature.....	49
4.3.1. Interlude III - Text Analysis Examples.....	51

4.4. The Stakeholders within the Palliative TCT Engagement.....	54
4.4.1. The Primary Stakeholders - Patients & Doctors.....	54
4.4.1.1. The old Patients.....	55
4.4.1.2. The young Patients.....	56
4.4.2. The Medical Doctors.....	57
4.4.3. The secondary Stakeholders - Informal Caregivers, Palliative Nurses, and Hospital Administrators & Managers.....	58
4.4.3.1. The Palliative Nurses.....	59
4.4.3.2. The Informal Caregivers.....	59
4.4.3.3. The Hospital Administrators & Managers.....	60
4.4.4. The Tertiary Stakeholders - TCT Manufacturers, Designers, and Policy Makers.....	61
4.4.4.1. The TCT Device Manufacturers & Designers.....	61
4.4.4.2. The Policy Makers, Public Health Programs & Institutions.....	62
4.5. Value Constitution, Assessment, Recognition, and Neglect of the Relevant Stakeholders within the Quantitative Experimental Discourse.....	63
4.5.1. The Values of the Patient within the Quantitative Discourse.....	63
4.5.2. The Values of the Medical Doctor within the Quantitative Discourse.....	65
4.5.3. The Values of the Nurses within the Quantitative Discourse.....	66
4.5.4. The Values of the Informal Caregivers within the Quantitative Discourse.....	67
4.5.5. The Values of the Hospital Admin & Manager in the Quantitative Discourse.....	68
4.5.6. The Values of the TCT Device Manufacturers & Designers in the Quantitative Disc.	68
4.5.7. The Values of the Policy Makers, Public Health Programs & Institutions in the Quantitative Discourse.....	69
4.6. Interlude IV – The Explicit Methodologies of Questionnaires and Semi-structured Interviews within the Quantitative Research.....	70
4.6.1. The Questionnaires.....	70
4.6.1.1. The Drawbacks of Questionnaires.....	70
4.6.2. The Semi-structured Interviews.....	71
4.6.1.1. The Drawbacks of the Semi-structured Interviews.....	71
4.6.3 The Direct Observation.....	72
4.7. The Prominence of the Ethics & Values of the Doctor Stakeholder in Quant. Research.....	72
4.7.1. The Enframing of Value Realization within the Quantitative Research.....	72
4.8. An Academic Meta-Analysis of the Research Efforts into TCT in the Palliative Care Context - The Shortcomings of the Quantitative Methodology and Accepted Discourse so Far.....	74

Chapter 5 - The Qualitative Methodology of J. Pols - A Refined Way of Assessing Quality in General and Palliative Telecare Research.....75

5.1. How is Care via Device and at a Distance Constituted ?.....	75
5.2. The Methodology of Pols.....	76
5.2.1. The "White Box" Experiment.....	77
5.2.2. The Webcam Experiment.....	79
5.3. A Contrasting Stakeholder Analysis to the Quantitative Discourse.....	80
5.3.1. The Medical Doctors.....	81
5.3.2. The Second Primary Relationship - Nurses and Patients.....	82
5.3.2.1. The Nurses.....	82
5.3.2.2. The Patients.....	83
5.3.3. The Secondary Stakeholders – Informal Caregivers and Hospital Managers & Admins.....	84
5.3.3.1. The Informal Caregivers.....	84

5.3.3.2. The Hospital Managers & Admins.....	84
5.3.4. The Tertiary Stakeholders - TCT Manufacturers, Designers, and Policy Makers.....	85
5.3.4.1. The TCT Manufacturers & Designers.....	85
5.3.4.2. The Public Health Managers, Policy Makers, and State Institutions.....	86
5.4. The Ethnographic Methodology - Practices and Values	87
Chapter 6 - Conclusion of the Thesis.....	90
Chapter 7 - Source Material.....	100
7.1. Appendix A.....	110

Chapter 1 - Introduction

The “Leitmotiv” for this master thesis derives from a project I was fortunate enough to participate in during my Bachelor studies, called "Death and the Dead Body"¹. A long standing personal interest in the topic of death derived from this initial encounter, eventually found its academic expression in searching for a PSTS thesis topic - circling the question of what happens when therapeutic measures have run their course and it is time to die, and what role do technological artifacts play in our dying process as it is expressed in the medical field of palliative care. In digging for the answers to some of the questions surrounding the way we deal with the death of a human being I plan to sate the discussions for myself on a personal level and also provide an academic contribution to palliative care and the larger context of the end-of-life philosophical edifice, modest as my contribution may be.

Beginning research into the field of palliative care as a discipline within modern medicine, I assumed it to be a very rich and rewarding field to investigate, especially when it comes to ethical investigations into it. Aside from the deep philosophical issues that are attached to palliative care; for example what constitutes “Death”, how can/do we perceive a dead human being, when or where does identity end, am I my organs, or is there more to me ?, etc., there is also merit in investigating the more practical, empirical aspects of palliative care practices. The unique feature that defines the practices in palliative care is the value set of this medical discipline, which seemingly puts it at odds with the values of the other medical fields, colloquially subsumed as the “Hippocratic Oath” of established medicine – with the most memorable ethical prescription being the task of preserving life and the obligation to help. As we will see during the thesis, this simple delineation is too strong, as both medical and palliative care ethics share the same underlying ethical values with very minute detailed differences in interpretation.

As an initial picture; palliative care as a field and medical activity values life, even though it deals with the dying – which essentially (or ideally) means everyone in the end - after the other disciplines “failed” in their therapeutic measures, after longer and longer periods of time as medical technology gradually prolongs life expectancy averages. Unlike the focus on prolonging life in the other medical disciplines, palliative care ethics & practices aim is the improved quality of life for the dying, to neither hasten or postpone death², and to include needs other than the purely medical/therapeutic ones in the treatment – most prominently psychological, spiritual, and bereavement care in addition to competent physical pain relief, forming the "total care" approach.

In addition to the aforementioned philosophical points of interest, palliative care is a very dynamic field when it comes to the technological aspects; any technological-procedural, therapeutic invention or advancement within other medical fields shifts the practices, place and time of palliative care interventions around. It is a discipline which relies very little on technology for itself to conduct its business, but which at the same time is subjected to the fallout of technological interventions in its neighboring fields of specialized medical practices. The technological shifts within palliative care are not limited to the innovations of medical devices and practices. Since anyone can become a patient for palliative care specialists, palliative care practices have to adapt to the changing technological life world of the societies at large in a rather total, nay holistic fashion. Within the context of the western world, in which this master thesis is inherently framed, this means for example that practices in the medical disciplines gradually adapt to multimedia tools, like the now seemingly ubiquitous smart-phone of the third – digital – revolution.³ One such adaptation

1 "Tod und Toter Körper" at the University of Marburg see : <http://www.todundtoterkoerper.eu/projekt1.php>

2 in accordance with the WHO definition, see: <http://www.who.int/cancer/palliative/definition/en/>

3 See: Y. Park & J. V. Chen: “Acceptance and adoption of the innovative use of smartphone” in H. K. Chan (eds.):

which is introduced into the palliative care field is the technology, development and eventual refinement of tele-care technologies (TCT). Just as previous developments in the field have been adaptations of existing technologies from other medical fields, which were already tried and tested in their native setting.

The central research question that is guiding this master thesis is how the introduction of the TCT devices into the context of palliative care does (or if it) influences, shapes, modifies, enables or disables ethical value realization and attitudes specifically in the relevant stakeholders affected by the technology. Flanking this main research question is a set of sub-research questions aimed at the particulars that compose the answer to this big question in of itself: who are the relevant stakeholders involved, how do stakeholders react to the introduction of TCT devices into palliative care scenarios, are there conflicting values and practices between stakeholders, and are there shared values or “blind spots” between stakeholders. In addition I formulated an observational hypothesis to complement the discourse analysis of this central research question and set of sub-questions. The hypothesis is, that from the very long dealings with the dying patients and Death in the cultural contexts, palliative care ethics is to have had an impact on the attached values & realizations of TCT in modern palliative care and the stakeholder attitudes. With the strong histories of faith-based palliative caring, the development of palliative care ethics as a distinct set of values, the emergence as a medical discipline and the focus on academic, empirical research since the 1960's, etc. I presume that palliative care ethics is playing a decisive part in the TCT care practices. A rich ethical context, deeply rooted in a discipline and its professionals facing off against modern digitization efforts in a highly sensitive context.

To answer the sub-questions and eventually the main research question the thesis is set up in the following fashion. First, as a starting point comes the history of palliative care, the development of modern palliative care as a medical-scientific discipline out of a very long faith-motivated, Christian tradition in the western world. As a background for the research to come, the chapter also contains not only the general history but also brief escapades of historical actors relevant for the development as well as an example of previous technology adaptation into the low-tech field of palliative care. The reason for this historical chapter is not only to conform to a standard of academic precision in providing the context of a topic because that is how it is done - but also give the unassuming reader a proper contextual awareness of the very extensive history palliative care has had. Not only as the modern medical discipline but also in regards to human experiences of Death as well as the decisive attachment of the discipline to faith-based ethics and theological conceptions. It also serves as a backdrop for the development of modern palliative care ethics in proximate chapter afterwards, as this set of ethics shares a baseline value lineup with the medical ethics, the historical sections helps with a clear cut and precise delineation of the discipline and why it is in fact a discipline/medical field in its own right and how it emerged. This historical chapter contains also two interludes, one serves to explicate the changes in pain theory relevant to the changes in palliative care provisioning and the physical side of the total pain concept, while the second interlude is to clarify the concept of the hospice as an institution in contrast to a regular hospital to understand the difference in practical approaches & arrangements of institutions.

Following this comprehensive history is a chapter discussing and defining the relevant differences between medical ethics, care, and palliative care ethics - as these moral-ethical guidelines all share the same baseline values, but differ in the approach as how to best resolve them for the relevant

“Industrial Management & Data Systems” Vol. 107 No. 9, Bingley, Emerald Group Publishing (2007) pg. 1349 – 1365 also see: P. Codyre: “Will an App fill the Gap ? Innovative Technology to Provide Point-of-Care Information” in “Frontiers in Public Health” online source: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3914210/#_ffn_sectitle (retrieved 23.07.2014)

stakeholders in a palliative care trajectory. The very foundation of these ethical sets is a combination of deontological and utilitarian baseline elements as towards the ethical value enframings, which then built up to four distinct pillars of the so called "Georgetown Mantra". An almost axiomatic code to be followed by the modern medical professionals it is a combination of the older Hippocratic elements of beneficence and non-maleficence with more modern distributive justice deliberations and the overall imperative of respecting the patient-centered autonomy. The nuances between medical, care and palliative care ethics are precisely explicated as to serve as references throughout this thesis. Combined with the historical knowledge this chapter will set us up for the main course of this thesis - the stakeholder-focused, discourse analysis of TCT in palliative care.

Methodology wise the thesis is set up to be a discourse analysis, as if the subtitle to it is not obvious enough, targeted at the stakeholders deemed relevant to the scientific treatment of TCT in the palliative care scenario. As a first step the textual level of the research literature was assessed and scanned towards elements of ethical relevance in the research discourse as it unfolds. Collating relevant research literature emerged as a bit of a daunting task, as research literature pertaining to this obscure set of investigations is rather scarce. Nonetheless the set of literature used is representative enough of a specific way of empirically engaging the usage of TCT in palliative care - hence dubbed the "quantitative discourse" in the chapter to delineate the focus on quantifiable data-sets, random-control-trialed questionnaires, and codified interviews conducted with the relevant stakeholders. As a result of this focus on empirical-methodical verifiable data, the literature rarely engages in discussing ethical issues, or if engaging not too deep, and the initial hypothesis regarding the influence & importance of palliative care ethics on the practical level of conduct is falsified as we will see in Chapter 4. One step removed from the textual level I shift the methodology of the thesis towards a hybridization of thematic analysis on the one hand - operating with an observational hypothesis, contrasting it against the actual thematic topics present & shaping the discourse. Second element of the hybrid approach is the utilization of inter-textual analysis, as meta level issues of research methodology become clear across the literature used - a subsequent characterization and contrast emerges.

My observational hypothesis of the influence of palliative care ethics does not hold up when dealing with this specific sub-sector of technology adaptation into palliative care at large. As palliative care ethics has made inroads into general care and nursing, the technology component of TCT and the research setups utilized predilects the situation towards a very strong position of medical ethics and the attached attitudes and prescriptive expectations towards the relevant stakeholders, even the considerations as to which stakeholder is actually relevant to begin with. In addition to addressing stakeholder composition and value realization on the level of the papers and a content discursive approach to analysis - supplemented by the Interludes III and IV pertaining to textual analysis and dissecting the quantitative research methodologies - I engage in a meta level analysis of the research methods of dealing with TCT in palliative care.

Contrasting the quantitative approach in researching TCT with a quality focused methodology reveals the shortcomings and methodological shortcuts taken as to yield usable results in the very difficult environment of palliative care. The differentiation is setting up the final sections to each methodology, the final conclusion regarding the methodology selection for TCT in palliative care emerging as a final normative remark to this otherwise descriptive master thesis. As the quantitative methodology is unable to account for the contingent, subjective elements of a TCT mediated palliative care trajectory there is a perceivable need to supplement the "proper" research with more narrow, context bound qualitative approaches (or at least elements of it). Foregoing general statistical relevance (which is also rarely achieved in the quantitative narrative to begin with due to

sample size issues) and the empirical makings of research success in favor of a much more realistic assessment of the TCT in palliative care trajectories.

Chapter 2 – A Comprehensive History of Palliative Care

In this introductory chapter I will retrace the history of the modern palliative care movement – from its roots in early Christianity, the troubles of the Reformation era, and its eventual resurfacing in the 19th century – to provide the reader with a comprehensive context in which modern developments of the field are to be placed, a thorough understanding of what palliative care is in its specific European context and place of origin. It contains but a little glimpse into the long and varied history of religious morals, theological conceptions, and individual actions that shaped and continue to shape modern palliative care ethics, policies, and practices.

As an informative chapter the content will be a broad reconstruction of main events along a timeline interspersed with the occasional, yet decisive actions of a big name historical figure. As a disclaimer before we get into *medias res*, the chapter is a comprehensive paraphrase of D. Clarks: *“From margins to centre: a review of the history of palliative care in cancer”*⁴ combined with a variety of personal and scientific papers written by Dame Cicely Saunders cited accordingly, and additional original sources of more specific, arcane knowledge for the inclined reader to peruse.

Between the general flow of historical facts and events there are two interludes woven into the narrative to give specific context to: (I) the understanding of pain as expressed in different pain conceptions through the ages, as well as the impact on pain research, and (II) the definition of a hospice in contrast to a hospital as to clarify terms. The chapter ends with an exposition of the attitudes towards technology within palliative care; from a historical perspective with special attention to the last game-changing device in the field - the syringe driver. Equipped with this knowledge I will then continue the thesis in Chapter 3 with the philosophical-ethical history and contexts of palliative care ethics.

2.1. The Christian Roots of Palliative Care

Palliative care's history begins in the 4th century when Christianity had risen to be the dominant religion throughout the Roman Empire, displacing a polytheistic religion with a monotheistic one. During this time of the early Christians we find the concept of *“hospice”* first to emerge. It is derived from the Latin root word *“hospes”* which initially just meant *“host”*; though over time the word *“hospes”* gradually took on to also mean *“stranger”*, or more precisely *“guest”*, and the term *“hospitium”* was an expression of a sanctified relationship between guest and host – what we today would understand as guest rights⁵. *“Hospices”* were simply the place for strangers, travelers and pilgrims to exercise guest rights and be welcomed, which of course also included the sick and dying.

This practice of taking in strangers asking for help translated eventually into the medieval conception of hospices, which had a distinct theological foundation attached to it, derived from the Book of Matthews, Chapter 25:35 - 37⁶. The work in a hospice is an expression of the *“corporal seven works of mercy”* of Christian faith which are: to provide food, water, clothing, and shelter to those in need, to visit the sick, to visit the prisoner, and to bury the dead. This last, crucial aspect to the modern hospice of taking care of the dying and dead is a 13th century addition to the original

4 D. Clark: *“From margins to centre: a review of the history of palliative care in cancer”* in D. Collingridge (ed.): *“The Lancet Oncology”* Vol. 8 No. 5 Philadelphia, Elsevier (2007)

5 In its simplest form it would mean that the host observes a moral obligation to assist someone asking for help and that the guest bears no ill intentions towards the host.

6 see: H. Wansbrough (trsl.): *“New Jerusalem Bible – Standard Edition”* New York, Doubleday Religion (1999)

corporeal works of mercy that are listed in the Book of Matthews and were derived in turn from the Book of Tobit⁷.

The societal role of the medieval hospice was to do charitable work towards the sick and the dying, also orphans, cripples, etc. - essentially for all the downtrodden that had no place to go. For the time these institutions were the next best thing to a public health service Europe saw from roughly the 11th to 19th century⁸. The most common knowledge of hospices remains associated with the crusades; for example the "*Order of the Hospitallers*" initially was tasked with provisioning hospitals for pilgrims traveling in the Holy Land. Over time they took on the additional practice of providing armed escorts to pilgrims and eventually emerged as a fully fledged military order⁹.

In the U.K. the service of hospices came to an abrupt end under the reign of infamous king Henry the VIII., as in his founding of the Anglican Church he split from papal authority and issued the dissolution - or suppression depending on which theological-political narrative you prefer - of all monasteries in the English Kingdom, which at the time of his reign (1509 – 1547) were the main institutions serving as hospices for the common folk. The dissolution of the monasteries effected a great decline in provisioning for the poor, sick and dying, and the term "*hospice*" appears less and less in the writings of the immediate time after. The Reformation movement initiated by Luther and consorts had the same effect for the rest of northern Europe, with the dissolution and ransacking of monasteries during as well as after the events of the Thirty Year War¹⁰ contributing to the decline.

The 19th century saw a first resurgence of hospice-like institutions, motivated by Christian beliefs of individual activists rather than being attached to or embedded within a specific church institution. One of the earliest example of such an initiative was the German pastor Theodor Flieder who founded a hospital and deaconess¹¹ training institute in 1836 located in Kaiserswerth which was dedicated to performing all the seven works of mercy. In 1842 Mme. Jeanne Garnier, a catholic widow and leading member of "*L'Association des Dames du Calvaire*"¹², opened hospice-like institutions in Lyon, which cared explicitly for the diseased and dying – the modern Calvary Hospital in Brooklyn, New York is an excellent center for palliative care and can trace its historical ties to these early initiatives of the "*Dames du Calvaire*"¹³.

Finally, in 1879 the hospices resurfaced in the U.K. as the "*Irish Sisters of Charity*", founded by Mother Mary Aikenhead, opened "*Our Lady's Hospice*" at Harold's Cross in Dublin, Ireland. In the following years a number of similar institutes were founded by adherents of a variety of Christian denominations in the U.S. and Europe - though as compassionate in their care, these institutes had no professional contact or exchange between them and largely were unaware of each others existence¹⁴.

7 *ibid.* Tobit Chapter 2: 6 -8 and 14

8 For a good example of the emergence of the medieval hospice system see: J. Kerr: "*Monastic Hospitality – The Benedictines in England, c. 1070 – c1250*" Woodbridge, The Boydell Press (2007) pg. 23ff and pg. 121ff

9 For this particular historical time of hospices in the Middle East see: D. Nicolle: "*Knights of Jerusalem – The Crusading Order of Hospitallers 1100 – 1565*" Oxford, Osprey Publishing (2008)

10 Further reading: E. Duffy: "*The Stripping of the Altars: Traditional Religion in England, 1400 – 1580*" New Haven, Yale University Press (1992); G. W. Bernard: "*The Dissolution of the Monasteries*" in E. Griffin (ed.): "*History*" Vol. 96 No. 324 Oxford, Blackwell Publishing (2011); R. G. Asch: "*The Thirty Years War: The Holy Roman Empire and Europe, 1618 – 1648*" London, St. Martin's Press (1997)

11 To clarify; these deaconess were non-ordained women whose tasks were a mix between social worker and midwife. Their training generally aimed at being able to prepare women for married life at the time.

12 see: <http://www.jeanne-garnier.org/dames-du-calvaire/histoire/> (retrieved: 18.10.2014)

13 see: <http://www.calvaryhospital.org/site/pp.asp?c=ktJUJ9MPIsE&b=3266481> (retrieved: 18.10.2014)

14 C. Saunders: "*The Modern Hospice*" in F.S. Wald (ed.): "*Quest of the Spiritual Component of Care for the Terminally Ill: Proceedings of a Colloquium*" Yale, Yale University School of Nursing (1986) pg. 41 - 48

The first institution that employed practices resembling the workings of a modern day hospice was founded by D. Howard Barret in 1893 - the “*St. Luke's Home for the dying Poor*”. Even though he founded the hospice with the help of the “*West-London Methodist Mission*”, the religious component in the treatment of the patients was kept non-denominational, less preaching and more compassion, and physical and mental-spiritual care was given equal weight in treatment design in accordance with patients desires/requirements.

Cicely Saunders worked as a volunteer nurse at *St. Luke's* starting in 1948. In her personal recollection she expressed her admiration for the efficiency and efficacy of the continuous palliation techniques employed there. At the same time she also noted that the hospice was not engaged in any form of professional interaction with other established hospitals and health care institutions and remained an isolated, small drop on a hot stone.¹⁵

This initial impression of the status of palliative care practices deepened during her medical studies¹⁶ at *St. Joseph's Hospice* in Hackney, East London, an institution founded by five sisters of the “*Irish Sisters of Charity*” in 1905, on the plea of a Father Gallwey¹⁷. Cicely Saunders read medicine for seven years at St. Joseph's - beginning in 1958 - and eventually developed the plans for St. Christopher's as a way to bring academic research and teaching, and compassionate care together. In her concept scientific research and religious virtues are complementary, as both are aimed to improve the ethics, tools and practices that are necessary to treat terminal patients in a holistic fashion.

2.2. Modern Palliative Care – The Early Years (1950's - 1967)

Beginning in the 1950's the development of palliative care in the modern sense really kicked off, its development eventually speeds up during the 60's and culminates in the eventual acceptance of palliative care as a specialization into mainstream medicine in the 70's.

As with all fledgling fields of research and interest, the initial situation of palliative care was very much in flux and the future unclear. A snapshot perspective of 1959: Cicely Saunders is about to publish her first academic contribution to palliative care - “*The Management of Patients in the Terminal Phase*” - summarizing her experiences at *St. Luke's* and *St. Joseph's*. The majority of care for the dying is conducted by few religiously motivated hospices across the UK which, as mentioned previously, have not established professional relationships between themselves. Little to no academic research into the care for the dying is conducted, terms are yet undefined and there is no professional representative society that focuses research efforts and promotes the field – a veritable tabula rasa, yet strangely enough people still insisted on dying.



Dame Cicely Saunders

15 Saunders, Clark (2006) pg. 206f

16 The head surgeon she worked for in St. Luke's actually recommended her to study medicine to understand pain better and also to have the academic weight to talk to medical professionals. (Saunders, Clark (2006) pg.252)

17 see: <http://www.stjh.org.uk/Resources/StJosephsHospice/Documents/Other/The%20History%20of%20St%20Josephs%20Hospice%20Hackney.pdf> (online source | retrieved: 10.10.2014)

In addition to the problem of the field being very young itself, oncology specialists¹⁸ showed little interest in the care for patients who they could not help anymore, as the oncology practices of the 1950's focused exclusively on therapeutic treatments. Terminal patients were told to go home and get as comfortable as they could, since any help that the doctors, as professional specialists, could give was exhausted and they relinquished responsibility of their patients. The goal was therapy or bust - physical healing, full stop.

The end of the 1950's saw the initiation of a range of exploratory academic studies into a variety of loosely connected fields which would eventually form the discipline of palliative care. Aside from Saunders and other medical professionals, social scientists and social workers also took to the field and conducted their separate investigations. For example Margaret Bailey¹⁹ conducted a research project into the social needs of lung cancer patients at the Brompton Hospital. Other researchers were interested in the public opinion and attitude towards cancer, delayed help-seeking by patients, and the way specialists understood terminal care²⁰. Research conducted in the U.S. added further issues to the fields such as understanding the practical conditions of social workers as well as how to address psychosocial issues of bereavement management, anxiety, depression, etc. in the stakeholders involved. The first stumbling steps towards resolving the piss-poor conditions of the dying were made in that period.

Mid 1960's researchers had gathered a good stock of practical studies out of the initial, exploratory phase of palliation practices, and shifted their focus more towards policy issues and promotion of good palliative care in society at large. Separate studies conducted by Eric Wilkes²¹ and John Hinton²² both reprimanded the lack of adequate hospice facilities in the U.K., citing that there is no valid reason why the care for they dying has to be so insufficient and ineffective. As a contributing factor Hinton points us to the disparate numbers of publications dealing with the treatment techniques of terminal patients (a lot) compared to the numbers of publications dealing with overall success/failure rates of treatment options in relation to patient well-being (very little).

A steady, broader exposure of the issues in palliative care in societies at large reinforced research interests even more towards the end of the 1960's; when not only medical professionals and few interested academic oddballs conduct investigations but a wider variety of sociological experts enter the field. A crucial contribution with regards to gaining more exposure for the field is the work of Glaser & Strauss of 1965²³ which was a large-scale ethnographic study of patients dying in U.S. hospitals and highlighted pressing issues in care for the dying in the U.S.. An equally important work of the time was conducted by Anne Cartwright in 1969, who conducted an even larger scale (900+ sample size) survey into the experiences of relatives of terminal patients and how they dealt

18 Oncology being a somewhat young discipline itself as well at the time (1959); medical-scientific oncology practice was only developed since the advent of pathology in the late 19th century by the works of Rudolf Vichow. see: <http://www.cancer.org/acs/groups/cid/documents/webcontent/002048-pdf.pdf>

19 see: M. Bailey: "A survey of the social needs of patients with incurable lung cancer" in "The Almoner" London, Institute of Almoners Vol. 11 (1959) pg. 379 - 397

20 see: R. Paterson & J. Aitken-Swan: "Public opinion on cancer: a survey among women in the Manchester area" in R. Horton (ed.): "The Lancet" Vol. 264 No. 6843 Amsterdam, Elsevier (1954) pg. 857ff as well as: J. E. Finesinger et. al.: "Managing the Emotional Problems of the Cancer Patient" in O. Webb-Brawley (ed.): "A Cancer Journal for Clinicians" Vol. 3 No. 1 New York, Wiley (1953)

21 see: E. Wilkes: "Cancer outside hospital" in R. Horton (ed.): "The Lancet" Vol. 283 No. 7347 Amsterdam, Elsevier (1964) pg. 1379ff as well as: E. Wilkes: "Terminal care at home" in R. Horton (ed.): "The Lancet" Vol. 285 No. 7389 Amsterdam, Elsevier (1965) pg. 799ff

22 see: J. M. Hinton: "Problems in the care of the dying" in R. R. Gaiser (ed.): "Journal of Chronic Diseases" Amsterdam, Elsevier Vol. 17 No. 3 (1964) pg. 201ff

23 see: B. G. Glaser & A. L. Strauss: "Awareness of Dying" New Jersey, Aldine Transaction (1965)

with their bereavement as well as the way they experienced the dying process of a loved one²⁴.

In 1960 Saunders shifted her medical studies towards patients in the final stages of cancer – a disease which lends itself well to palliative care efforts due to the prolonged, chronic, painful, and outright demeaning nature of it. The specific focus of her effort was aimed at the actual terminal stage of the patients, usually considered outside the domain of the therapeutic-minded medical professional of the time. She conducted a long-term study of the dying patients – reaching the respectable sample size of ~1100 cases by the year 1967. Within this research she began linking together the different pain types usually expressed by her patients; physical, emotional, psychological, and social, into the total pain concept.

Pain, in the “*total pain*” concept, is to be understood in an absolute way, debilitating the patient, and as such must be treated in a holistic fashion – for example it is not enough to just treat the physical symptoms of pain and leave the patient to e.g. fend for himself in a complicated family situation of blame, guilt and unvoiced regrets caused by the disease. This change in the way treatment was approached necessitated a change in practice, instead of administering analgesics on a need-only basis when the patient was already in visible, physical agony, Saunders advocated the constant monitoring and application of preventative analgesics to improve the overall disposition of the patient – as she so succinctly put it: “*constant pain calls for constant control*”²⁵.

A parallel development took place in the U.S. with the activities of Elisabeth Kübler-Ross positioning her as an equally important figure in shaping palliative care services in the Americas. Albeit working in the same field as Saunders, Kübler-Ross's approach differed from the practical nursing perspective of Saunders, in that her work was primarily geared towards the psychological impact of death and dying and how humans deal with death when exposed to it - culminating in her most important contribution to the field with her development of the “*five stages of grief*”²⁶ in 1969.

On a larger scale the U.S. government increased its efforts to tackle cancer related health issues in 1971 when President Nixon declared a “*War on Cancer*”²⁷. This initiative raised the public profile of cancer as a disease and made it - cynically speaking - “fashionable” enough as to promote broader and more thorough investigations into its pathology, countermeasures, treatment, and nursing practices. This marks the initial phase of cancer emerging as a broadly known and central sickness; the disease of modernity only being beaten in death statistics by cardiovascular-related diseases at present. As mentioned above, the usual prolonged trajectory of the sickness makes it an ideal vector to spread palliative care approaches, and to garner support for palliative care initiatives. Up to today palliative care and palliative care research remains closely tied to, and focused on, cancer as the primary disease, with outlying developments towards Chronic-Obstructive Pulmonary Diseases (COPD's) and other chronic diseases taking place in most recent times (last ~10-15 yrs.).

24 see: A. Cartwright et. al.: “*Life before Death*” London, Routledge (1973)

25 see: C. Saunders: “*The Management of Terminal Illness*” in J. Tinker (ed.): “*British Journal of Hospital Medicine*” Vol. 35 No. 1 London, Hospital Medicine Publications Ltd. (1967) pg. 12

26 the five stages are: Denial, Anger, Bargaining, Depression, and Acceptance see: E. Kübler-Ross: “*On Death and Dying*” New York, Scribner (1997) Chp. III - VII

27 see: M. B. Sporn: “*The war on cancer*” in R. Horton (ed.): “*The Lancet*” Vol. 347 No. 9012 Amsterdam, Elsevier (1996) pg. 1377ff

2.3. Interlude I – Pain Conceptions and Pain Research

Throughout history the conceptions and the perceptions of pain have changed considerably. In this first interlude I will briefly reconstruct the broad evolution of pain conceptions through the ages, with the help of D. Santoro²⁸, and then elaborate a bit more on the advancement of pain research due to the rising interest in, and influence of, palliative care.

So, you are in pain - but what is pain exactly? The "International Association for the Study of Pain" (IASP) gives us the following definition: "*an unpleasant and emotional experience associated with actual or potential tissue damage or described in terms of such damage*"²⁹. Well, thank you for that obvious statement, but when it comes to pain, aside of the physical pre-condition, an important factor is the cultural, socio-temporal interpretation of pain in conjunction with the way pain is expressed towards others. For expressing pain the language we speak and the words we have available do play a role. The more and differentiated terms for pain are available for language acts, the more nuanced pain conceptions are and the better a patient can relate his pain to the doctor at hand³⁰. Even though a fascinating topic in itself and worthy of academic interest, the focus of this section is on the pain conceptions in the context of the western world with assumed, relatively stable language acts at hand.

2.3.1. History of Concepts

Let's have a quick rundown of the history of pain concepts; first up, good old Hippocrates. For Hippocrates and his peers³¹ pain was caused by an imbalance of humors and lack of harmony within the patients being; it took Seneca the Younger³² in ancient Rome to introduce "*dolor corporis*", the pain of the body, as a necessary condition for pain experiences.

With the advent of Christianity in ancient Rome the interpretation emerged that pain is a direct experience of the suffering of Jesus, and by suffering the faithful would get closer to God and have divine experiences³³. This perspective would eventually be contrasted by recovering the Stoic traditions³⁴, that to be human we are to endure and outlast pain, shaping the figure of speech of a stoic person or stoic demeanor, as remaining unfazed by adversity. Pascal³⁵ eventually concluded that to experience pain and suffering is the natural condition and mode of operation of a Catholic and nothing can be done about it (ask anyone who went to a Catholic school about getting the whole guilt thing hammered into their heads). For Hegel³⁶ experiences of pain are of the highest order, a privilege really, and a confirmation that we as intelligent human beings are special and at the top of things. For others like Scheler pain is necessary to not end up being superficial, fitting into a

28 D. Santoro: "Development of the concept of pain in history" in G. Gamvbaro (ed.): "Journal of Nephrology" Vol. 24 Suppl. 17 (2011) pg. 133ff

29 H. Merskey & N. Bogduk (eds.): "Classification of Chronic Pain – Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms" Seattle, IASP Press (1994) pg. 210

30 for example, see: A. Harrison: "Arabic Pain Words" in F. J. Keefe (ed.): "Pain" Vol. 32 No. 2 Philadelphia, Lippincott Williams & Wilkins (1988) pg. 239ff

31 E. Astyrakai et. al.: "References to anesthesia, pain, and analgesia in the Hippocratic Collection" in S. L. Shafer (ed.): "Anesthesia & Analgesia" Vol. 110 No. 1 Philadelphia, Lippincott Williams & Wilkins (2010) pg. 188ff

32 Seneca, R.M. Gummere (trns.): "Ad Lucilium Epistulae Morales" Vol. II London, Harvard University Press (1920) Epistle LXXXVIII

33 L. J. Elders: "The Metaphysics of Being of St. Thomas Aquinas in a Historical Perspective" Leiden, Brill Academic Publishers (1993)

34 M. L. Colish: "The Stoic Tradition From Antiquity To The Early Middle Ages" Leiden, Brill Academic Publishers (1985)

35 B. Pascal, A. Levi (ed.): "Pensées and Other Writings" New York, Oxford University Press (2008)

36 G.W. F. Hegel: "The Science of Logic" Cambridge, Cambridge University Press (2010) §266ff

narrative of humans needing to be truly tested in order to have genuine, valuable experiences in the first place³⁷.

Enter Descartes³⁸, he gives us the one conception of pain experience that has had considerable influence on the early days of modern medicine and yes, it has to do with the mind-body dualism. Descartes dual mind-body conception was the first to explicitly link the physical symptoms of pain, say a bleeding wound to the mental experience of said pain in the brain. His meditations on the mind-body duality and attached problems was the precursor to what eventually would grow to be the “hard-wired”-system understanding of the experience of pain in modern medicine. Basically the presumption of the system is that nervous inputs are hard-wired, in that every same input elicits the same response in the brain, say stubbing a toe always gives “stubbed toe”-response in the nerve and is perceived as “stubbed toe” pattern in the brain everytime you stub your toe, with the important condition/assumption that the extend of the physical damage is related to the intensity of the pain experience in a fixed fashion.

This model has come under scrutiny since the work of Melzack and Walls³⁹ and their proposed system of the “*gate theory of pain*”, tied to the biological aspects of thick and thin nerveous fibres and they way they interact – namely dynamic integration and modulation of nociceptive (harm/danger/injury) impulses into sensory experience and signals. Very roughly speaking; every pain experience is unique in that transmission and inhibitory fibres meet in the spinal column and mediate the pain signals between them, with the thick fibres transmitting touch, pressure impulses and the thin transmit sharp pain. For example, if you rub your stubbed toe, the broader impulses for touch and pressure overwhelm the sharp, specific, thin pain impulse - thus reducing the pain signal reception and perception in the brain. The non-nociceptive impulses “gate” the access of nociceptive pain signals to the brain, hence the apt moniker of “*gate theory of pain*”. This mediation is context-specific, and gave rise to the conceptualization of specific pain types and the accompanying development of pain-type specific analgesics⁴⁰.

2.3.2. Pain Research Efforts

Before the 1970's cancer associated pain was given little attention by professionals and was treated as something inevitable that came with any disease really. This monolithic understanding of pain in practice has changed due to the efforts of the early palliative care experts.

The expansion of hospices and their new ideas regarding treatment solutions of pain prompted oncology experts to hold a conference specifically to address cancer pain types in Venice in 1978. In cooperation with palliative care experts they determined that the means to relief cancer pain were readily available to the medical practitioners but were not employed due to a distinct lack of knowledge combined with legal barriers surrounding the continuous use of Opioids. Academic, multidisciplinary investigations into specific pain types were of interest to the palliative care

37 M. Scheler: “*The Nature of Sympathy*” New Haven, Yale University Press (1954)

38 R. Descartes, T. Steele-Hall (trns.): “*Treatise of Man*” Amherst, Prometheus Books (2003) also: H. O. Handwerker: “*Von Descartes bis zur fMRI*” in L. Radbruch (pub.): “*Der Schmerz*” Vol. 21 No. 4 Berlin, Springer (2007) pg. 307ff

39 see: P. D. Wall, R. Melzack: “*Pain Mechanisms: A New Theory*” in D. Wolffe (ed.): “*Science*” Vol. 150 No. 3699 Washington D.C., AAAS (1965)

40 for example: Treatment of cancer-related bone pains with Bisphosphonates - with secondary benefits of retarding decalcification processes. Which usually shows as hypercalcemia in blood tests as bone cancers can release bone calcium into the blood stream, simultaneously weakening the skeleton as well as messing up soft tissue organs with the excess calcium causing immense, differential pain receptions throughout the patients body.

professionals, and Saunders and her fellows cooperated in a variety of investigations into pain; resulting for example in the aforementioned “total pain” concept (experience of pain) and “gate theory of pain”⁴¹ by Patrick Wall (physiology of pain).

The combined forces of palliative care and pain specialists were enlisted by the WHO in 1982 to deliver a comprehensive system for cancer pain relief on a global scale. The result was a system of three stages⁴² which included the continuous use of Opioids in its final stage, attempting to evoke a change in policies regarding the application of Class I substances⁴³ in terminal scenarios. Even though the WHO stakeholders set out to tackle the legal sanctions surrounding the production, distribution and use of Opioids on a global scale they had only limited success. Examining the situation in 1993, the use of Opioids in cancer pain treatments had increased in the industrialized world, but with differing policy backgrounds the global situation was a far cry from the improvement in use envisioned in the initial stages of the project in 1982. Still the efforts undertaken helped the broader recognition of palliative care and cancer related treatments emphasizing again the close connection of palliative care to this particular disease.

2.4. The year 1967 - St. Christopher Hospital and the Scientific Refinement of Modern Palliative Care

In 1967 Saunders opened the “*St. Christopher Hospice*” in South London, which was the first hospice in the modern sense of integrating scientific research with clinical practice and palliative care teaching. It quickly became a center of excellence for palliative care in the U.K. - and eventually abroad - when researchers conducted a series of studies into pain control with specific attention to the pharmacology of Opioids and their utilization in nursing practice. An early success was a large scale analysis of the so called “*Brompton Cocktail*”⁴⁴ and development of better alternatives⁴⁵. In short, the result of this study was the rejection of the cocktail as the standard device for palliation as more effective ways for continuous palliation were developed, as well as refined adjuvants allowing the addition of patient-comfort oriented care treatments⁴⁶.

In this early phase, to no surprise, the immediate palliative treatment was best at St. Christopher as a specialized hospice – especially when psychosocial needs were concerned. In addition the teaching activity of the staff at St. Christopher's gradually improved the conditions for palliative care in general hospitals across the U.K., spreading the important notion that the early admission of a patient into a palliative care program results in good care being provided. As a prototype St. Christopher's stimulated the emergence of similarly structured hospices across the U.K., boosting the availability of palliative care with a peak during the 1980's in which 10 new hospices were

41 see: P. D. Wall, R. Melzack (1965) pg. 971ff

42 see: <http://www.who.int/cancer/palliative/painladder/en/> as well as: G. Vargas-Schaffer: “*Is the WHO analgesic ladder still valid ?*” (online publication: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2902929/#!po=25.0000> | retrieved 01.11.2014)

43 The same classification as LSD, PCP, GHB, etc. due to the high potential for addiction and abuse of the substance.

44 A mixture, as given by Saunders, contained: Morphine Hydrochloride, Cocaine Hydrochloride, Cannabis tincture, Gin, Chloroform water and a shot of sugar syrup to mask the bitter taste. C. Saunders: “*Dying of Cancer*” in “*St. Thomas's Hospital Gazette*” Vol. 56 No. 2 London, St. Thomas Hospital (1958) pg. 9

45 see: R. Twycross: “*The Brompton Cocktail*” in J. J. Bonica, V. Ventafridda (eds.): “*Advances in Pain Research and Therapy*” Vol. 2 New York, Raven Press (1979)

46 Especially the development of Antiemetics – medication countering the fairly common side-effects of nausea and vomiting in cancer/palliative care patients. see: M. Tonato et. al.: “*Antiemetics in cancer chemotherapy: historical perspective and current state of the art*” in F. Ashbury (ed.): “*Supportive Care in Cancer*” Vol. 2 No. 3 Berlin, Springer (1994) pg. 150ff

opened every year⁴⁷.

Aside from teaching basic palliative care, Saunders & Co. pioneered an additional improvement to general hospitals – the introduction of palliative care specialist teams for large hospitals, or “*Hospital Support Teams for Terminal Care*” as was their official title at the time. Beginning in 1976 these teams were part of a more pro-active effort to bring palliative care closer to mainstream medicine in a planned, efficient manner⁴⁸. These prototypical, support-only group setups were further integrated with the introduction of centralized departmental guidelines, resulting in the eventual, official inclusion of palliative care practices into the general medical catalogue of the U.K.'s National Health Service (NHS) in 1987. The number of specialist teams climbed from 5 at the time of inclusion to 175 in 1996, spread across the whole U.K.. Studies conducted in 2002 show that the main feature of these team setups evolved to be the interfacing of oncology specialists and the palliative care specialists, with the teams precise responsibilities, range size, etc. varying considerably between institutions and their specific needs. There remains room for overarching improvements with regards to closer interaction, mediation, actor inclusion, and care management⁴⁹.

Concerning organizations, aside from St. Christopher, there are two major cancer charities that played a defining role in shaping modern palliative care. The first is the “*Macmillan Organization*” founded in 1911, which during the 1970's expanded their activities on a large scale to include nationwide palliative care training programs as well as funding professional and academic research posts to further advance palliative care. The organization recently shifted their activities towards more direct support and care for afflicted patients. The second is the “*Marie Curie Memorial Foundation*” which initially geared its efforts towards establishing nursing homes and to further laboratory-based research into cancer and pain treatment. During the 1980's this organization broadened its focus as well, and began to finance palliative care centers as well as public education efforts. In addition the foundation is also involved in the policy design of the end-of-life care in the U.K. as well as serving as a central lobbying platform for better palliative care in general.

Due to these organizational setups the situation of palliative care in 2004 looked as follows: there were 196 in-patient units across the U.K. providing 2730 beds for patients, of which only 19% were being provided by the NHS – the rest being provided by selected hospices. Aside from hospice care there were an additional 341 home care units, 237 daycare units, 324 hospital-based units and 97 hospice-at-home (24hrs. Support) units⁵⁰.

This boom in numbers of palliative care services is the result of three factors coming together. The first was the establishment of a dedicated scientific journal⁵¹ for the field that helped collecting and centralizing research efforts and their respective results for a broader, academic audience. The second factor was the foundation of an organization which served the same centralizing and collecting purposes for interested researchers and stakeholders as did the journal for literature contributions. The first organization to emerge was the “*Association for Palliative Medicine for Great Britain and Ireland*” in 1985, its program was geared towards developing appropriate palliative care training programs and it collaborated towards this end closely with the Royal

47 Clark (2007) pg. 432

48 Notice the title of the specialist team, consciously named as “Support”.

49 see: I. J. Higginson et. al.: “*Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?*” in R. K. Portenoy (ed.): “*Journal of Pain and Symptom Management*” Vol. 23 No. 2 Amsterdam, Elsevier (2002)

50 All these types of palliative care share the foundation laid by the initial hospice concept when it comes to the nursing aspects, they do differ however in scope and intensity of the care provided. Daycare units for example have an ambulant character while hospice-at-home is much more intense, prolonged, and costly.

51 “*Palliative Medicine*” first published in January 1987 see also: <http://pmj.sagepub.com/>

Colleges. Third and last, the most deciding factor in the aforementioned boom was the recognition of palliative care as a distinct medical specialization by the mainstream medical institutions.

Initially in 1987 the discipline was put on a seven year novitiate, and after its successful conclusion palliative care became officially part of medical canon in the U.K.. Similar recognition processes followed internationally, though considerably varying in timing. For example; Australia and New Zealand picked up palliative care for its national medical syllabus in 1998 whereas the U.S.A. introduced concerted palliative care efforts as late as 2009⁵². Official or provisional recognition of palliative care as a medical discipline is given in almost any European country, gradually following the example set by the U.K., albeit the respective national dialogues are invariably enriched with distinct characteristics, for example the framing of palliative care almost always in conjunction with euthanasia in the Netherlands, whereas in Germany palliative care practitioners actively disassociate their efforts from euthanasia due to the obvious historical implications.

2.5. Interlude II – Hospital vs. Hospice, Know the Difference

In order to provide some conceptual clarification as to what a hospice is, here is the second interlude with a comprehensive reconstruction of the initial hospice concept of Cicely Saunders which she developed in 1967. The concept underwent some permutations since the initial opening of St. Christopher, though the core concepts elaborated on here are still valid and still utilized in shaping palliative care efforts irrespective if they are undertaken as a “proper” hospice or only in parts.

The hospice as envisioned by Saunders is to bridge the gap between research and teaching on the academic side of palliative care efforts and the skilled, long-term relief practices on the nursing side of things. Both approaches are to be united in an active and practical effort towards improving the situation of the dying patients and their relatives/friends. Saunders and her colleagues developing the hospice concept were motivated by a strong sense of Christian morals of compassion and mercy, and looked at the historical iterations of hospices as a template. In addition to the religious motivation the “*total pain*” concept is the second crucial, conceptual element in understanding the hospice concept, again; the different types of physical, mental, social and spiritual pain and distress are to be treated as equally severe and skilled, long-term relief is to be provided.

As for the organizational structure of the hospice as an institution, there are four distinct elements setting it apart from the hospitals at the time of writing (1967): (1) The continuity of care, as in even though the patient is dying he or she is still in need of qualified care and relief; opposed to the hospital doctors which basically said: go home, we can't do shit to heal you, (2) The active involvement of relatives and friends in the treatment process if possible, (3) The emphasis on researching and teaching the most current techniques and thus improving the level of competency in palliative care for doctors, and (4) The refinement of the interdisciplinary staff within the hospice, meaning that nurses, doctors, social workers, priests, laymen, etc. are all invited to contribute to the knowledge of the field - a conscious effort against elitism and academic blindness.

Lets investigate these four aspects further: (1) The idea of the continuity of care makes it necessary that the hospice provides ample rooms for in- and outhouse patients to frequent the institution in an easy to access fashion. If a patient is incapable to travel to the hospice, the staff is on call via phone, day and night, to deal with the worries of patients and relatives alike. The idea is that relatives feel

52 see: “*Clinical Practice Guidelines for Quality Palliative Care – Third Edition*” pg. 6 (online resource: http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf retrieved 03.11.2014)

comfortable enough to care for the patient in his/her home as long as possible if they can call upon qualified help when feeling overwhelmed. Even at this initial stage, Saunders envisioned the eventual development of a home care service to replace the phone-only services, which is to be run by the same staff working the hospice and thus provide a continuous standard of care. She was also aware that the initial small size of the hospice and staff would have to be closely monitored in order to guide/ensure a growth over years to match the goals set up above. For that it is necessary that the continuity of care is also continuously assessed in a critical self-reflection done by the staff as well as the stream of students and patients going through the institution.

(2) The involvement of relatives is to be done in an active, positive fashion aimed at improving the quality of life of the patient and relieving anxieties, true or imagined, of the family members and friends. To that end the visiting hours of the hospice are to be held frequent and flexible enough to enable the patients to continue social relations almost undisturbed. In addition there are community rooms to be provided for patients and families - literally "giving room" for contacting opportunities and self-help efforts. Thirdly, the staff of the hospice is to open their communication efforts to be approachable in an informal setting, an important distinction to the normal hospital in which the doctor only has so much time to allocate for a patient, the hospice doctor and nurse is to be allowed a lot of time taking care of the issues of patient and relative. The active involvement of patients relatives under the guiding and supporting supervision of the hospice staff requires the staff to be exceptionally skilled in a variety of relief techniques as well as communicating well, and being able to emotionally endure deep, intimate relations with their patients for prolonged periods of service.

(3) The need for teaching stems from Cicely Saunders experience gained during her time at St. John's, in which the staff used to do informal ward rounds with nurses, doctors, students, priests, and social workers – the feedback in terms of what the participants learned was overwhelmingly positive and all participants cited it as a unique learning opportunity. The hospice is to provide these experiences on a regular basis to a broad, interdisciplinary audience embedded in the supportive atmosphere of the qualified staff present. Students of all medical disciplines especially are to learn skilled relief techniques and update their skills when faced with the inevitable end of their efforts - greatly relieving the feeling of helplessness when a patient does not respond to therapeutic efforts any more. These research and teaching endeavors are to be undertaken with a global mindset present, meaning the explicit, active cooperation between the hospice with universities, hospitals and other hospices – enabling concerted large scale efforts towards improving and updating palliative care⁵³.

(4) The specialized staff of the hospice is tied closely to the previous point; in order to provide good, interdisciplinary teaching it is necessary to have staff on hand that can fulfill these steep requirements. For Saunders the solution to the demanding job of providing not only physical but mental and spiritual care for the dying is of course a strong sense of Christian faith and a conviction to do the works of mercy – a continuation of the medieval hospice traditions. Though the hospice is kept non-denominational regarding the patients and staff in general, Saunders was convinced that having a strong faith helps with the constant closeness to death, and that the confidence stemming from the beliefs held translates to compassionate care and feelings of hope and security for the patients. The patients are left to find their own meanings and answers in the religious dialogues offered and the staff is expected to work in interdisciplinary/inter-faith situations if adherents of a different or no faith ask for consultation, and not to proselytize. As for the routine necessary to develop a secure and confident grip on the varying situations possible, the initial staff of the hospice

53 At the time Saunders perceived a sharp increase in demand for palliative care lectures and envisioned St. Christopher's specifically to be a hub of coordinating and planning international co-operations with Yale, Harvard and the Colleges of the London City. Nursing and Theology faculties especially.

worked with Saunders in the seven years leading up to the opening of St. Christopher in 1967. During this long cooperation they developed a community-based approach to palliative care, meaning the informal congregation of them as professionals mixed with the in-patients themselves, allowing those of the patients willing to participate into decision making processes.

In addition to the organizational differences explicated in (1) – (4), the crucial difference between a hospital and a hospice is the success criterion of their work. The success of a hospital depends on the efficiency and efficacy of their therapeutic efforts in relationship to a patients “*becoming*” - that is, the activity of the patient getting better, an actual presupposed activity on the patients end that is enabled if they are just treated with the right therapeutic tool. The therapy is successful if the patient becomes a healthy human being again - this being the implication in the Hippocratic oath condition of maintaining life whenever possible for as long as possible. Saunders project was criticizing the above attitude, since it allows the doctors and nurses to easily fall prey to a sort of functional-technological determinism, the human being as an object, a machine in need of maintenance; capable of being restored in its functional capabilities if the right therapy, the right tool is applied. A concern also expressed by the patients in the palliative care ward, on one such occasion a patient asked Saunders: “*Will you turn me out if I cannot get better ?*” - a remark that stuck with her⁵⁴.

The success of a patients treatment in palliative care hinges not on regained or maintained capabilities, but on the person itself “*being*” . A successful palliative care treatment happens, when the patients quality of life is maintained to the extent his or her deteriorating condition allows it, and the total pain felt is alleviated with all the professional skills available. The criterion of success in this conception is removed from the objective, quantifiable therapeutic measures of medicine and rests on the experience of the subjective; the idiosyncratic pain relief felt by the patient and relatives. Death is not something to be fought, but embraced as the logical conclusion of a life well lived - the “well living” conditions being enabled up to the individuals death is the success marker of palliative care. Yes, the success does hinge of efficient and effective medical procedures, but they are just the tools, full stop. The perceived and experienced quality of human interaction and the respect for ones existence is the true measuring stick. Close attention is to be paid to signals of grief, guilt and unresolved conflicts that in combination with the impending death of a person can lead to withdrawal from human interactions and in the end dying a bad death.

2.6. Recent European and International Development of Palliative Care

Following the groundbreaking work in palliative care conducted in the U.K. the rest of Europe eventually joined in on the efforts, consolidating palliative care efforts throughout the 1980's via international academic cooperation. 1976 saw the first international congress on the topic of caring for the terminal ill being convened in Canada, 1988 marks the founding year of the “*European Association for Palliative Care*” and in 1990 the “*Hospice Information Service*” of the St. Christopher hospice began the publication of its international newsletter for palliative care.

After the collapse of the block powers of the Cold War era in the early 1990's, an “*Eastern and Central European Palliative Care Task Force*” assembled in Geneva to tackle long neglected palliative care treatment options in the states emerging from the Soviet Union. Only then these states began the large scale implementation of adequate palliative care policies and practices, with Poland taking the lead in numbers of hospice provisions. Of the all the palliative care services available in the former states of the U.S.S.R. about half are provided in Poland alone. A possible

54 C. Saunders: “*Training for the Practice of Clinical Gerontology: The Role of Social Medicine*” in L. Gitman, E. Woodford-Williams (eds.): “*Interdisciplinary Topics in Gerontology*” Vol. 5 Basel, Karger pg. 73

contributing factor to this concentration of palliative care provision might be the strong Catholic tradition of Poland, emphasizing faith, the works of mercy and rejecting euthanasia despite the long period of Communist rule. On a global scale we saw the emergence of the “*Latin American Association of Palliative Care*” in 2000, the “*Asian-Pacific Hospice Palliative Care Network*” in 2001 and the “*African Association for Palliative Care*” in 2003.

The years 1989 and 1992 saw the adoption of palliative care resolutions on the level of Pan-European politics, though the resolutions did only concern certain aspects of counseling and supporting care for the dying rather than tackle palliative care provision on a broader level. In 1999 the European Parliament eventually got around to give proper recommendations regarding all aspects of palliative care to its member states, calling to action for adequate provisioning of palliative care services⁵⁵. In 2003 we see the publication of a guideline describing the basic, essential elements of palliative care that ought to be accessible for every European citizen⁵⁶, while at the same time the “*European Society for Medical Oncology*” officially gave greater recognition to the importance of palliative care in cancer treatments. In 2004 then the “*European Federation of Older Persons*” campaigned for palliative care issues becoming a priority topic on the European Health Care agenda⁵⁷. As for current developments; from 2012 to 2014 the “*European Association for Palliative Care*” ran a task force which developed a toolkit for the European countries geared towards greater recognition of palliative care, as well as giving country-specific recommendations as how to broaden and improve palliative care provision⁵⁸.

2.7. Anesthetics and Technology in Palliative Care

In this last segment of the chapter I will give a broad history of the plants and chemicals that have been used for pain relief in the past - a history of the palliative care toolkit if you will - followed by a brief outline of the main refinements of pain medications. After this, we will continue with a more detailed and nuanced reconstruction of the last great, non-anesthetic technology/device to be adapted into palliative care - the syringe driver. In conclusion of this historical chapter we will review the attitudes towards medical technology in modern palliative care, revealing the misconception of competent palliative care and sophisticated medical technology as exclusive/opposite to each other – explicating the difference in goal setting and success criteria as the cause for the misunderstanding of the role of technology in palliative care.

2.7.1. Pain Relief Medications – The Roots of Anesthetics

For the longest time pain relief efforts of humans have relied on the application of natural plants known to have a pain-killing properties; though in addition to the beneficial effect of relieving pain, these plants usually came with some caveats attached: they were quite powerful, unreliable to dose due to natural growth impurities & unrefined refinement methods, and if taking or administering too much of the substances they proved reliably deadly. An early drug to be discovered was the sap derived from *Papaver Somniferum* – Opium - and was considered to be a good pain killer since antiquity, and probably even pre-historic times⁵⁹; alcohol of course being an all time favourite too

55 see: Recommendation 1418: <http://assembly.coe.int/main.asp?link=/Documents/AdoptedText/ta99/EREC1418.htm>

56 see: Recommendation Rec (2003) 24: <http://www.eapcnet.eu/LinkClick.aspx?fileticket=3KJ5U3BQLVY%3d&tabid=1709>

57 see: http://www.apcp.com.pt/uploads/Cons.Europa_EURAG_PalliativeCareProject_2004.pdf

58 see: <http://www.eapcnet.eu/LinkClick.aspx?fileticket=zePII8IRIQ%3d>

59 P. G. Kritikos & S. P. Papadaki: “*The history of the poppy and of Opium and their expansion in antiquity in the eastern Mediterranean area*” in “*Journal of the Archæological Society of Athens*” Vol. 19 No. 4 (1967) pg. 17ff

across cultures and times⁶⁰. Other plants with a long history of cultural use by humans⁶¹ include: mandragora (mandrake) extracted from *Mandragora Officinaria*; a species of nightshade that in addition to having painkilling properties contains a high volume of varied alkaloids and thus is massively hallucinogenic and toxic; Belladonna, also an extract from a highly poisonous species of nightshade (*Atropa Belladonna*), and an all time favourite since pre-historic times: Cannabis India.

One central technology developed to administer these natural analgesics was the so called “soporific sponge”; being used since at least the 9th century up to the 17th century (over time counterindications regarding the sponge became more and more apparent)⁶². Specifics of the recipes vary somewhat over time but the general principle involves cooking the aforementioned highly noxious, poisonous and numbing plants into a sud, in which then a sponge is soaked and stored. The sponge is to be placed under the patients nose as a primitive version of inhalation anesthesia. For example one recipe reads as follows: “[...] to soak a sponge in the juices of unripe mulberry, flax, mandragora leaves, ivy, lettuce seed, lapathum and hemlock, to which was added hyoscyamus – one ounce of each mixed I a brazen vessel and put into a new sponge.”⁶³.

The first modern medical composition of analgesics to be widely produced and utilized were laudanum tinctures which came into widespread use around the 1680's. Laudanum was a mixture of Opium and Sherry introduced by a certain Thomas Sydenham⁶⁴ - the aptly named “English Hippocrates” due to his profound medical achievements. Laudanum was for a long time the only reliable sedating substance available to the early medical professionals until in 1803 Friedrich Sertürner isolated a powerful analgesic, a crystalline substance out of crude Opium – which he called “Morphium” or “Morphine” after Morpheus, the Greek god of dreams⁶⁵. Pierre Jean Robiquet⁶⁶ experimented with Opium and Morphine, extracting Codeine out of Opium in 1832, further cementing the importance of Opium as a source material for the generation of pain killers, since Codeine as opposed to Morphine does not have an adverse effect on the liver and also makes a good cough medicine (Tuberculosis and dust lungs being somewhat of an issue at the time). Codeine was initially marketed as “Antikamnia Tablets” a general pain relief medication, displacing laudanum tinctures, until in 1897 Felix Hoffmann extracted “Acetyl-salicyl-säure” (ASS) from the bark of the willow trees – marketed by Bayer as Aspirin⁶⁷, this painkiller can be used by a wide variety of people with no adverse effects, providing not only pain relief, while also possessing anti-inflammatory and anti-thrombotic properties to be utilized.

With the emergence of more refined and reliable painkillers available, the medical professions stance towards anesthesia gradually began to change, eventually establishing the field of surgical

60 P. McGovern: “*Uncorking the Past: The Quest for Wine, Beer, and Other Alcoholic Beverages*” Oakland, University of California Press (2009)

61 See: R. Rudgley: “*Essential Substances: A Cultural History of Intoxicants in Society*” New York, Kondasha USA (1994); also: G. K. Tallmadge: “*Some Aenesthetics of Antiquity*” in G. Rosen (ed.): “*Journal of the History of Medicine and Allied Sciences*” Vol. 1 No. 4 New York, Henry Schuman Publishers (1946) pg. 515ff

62 <http://www.ncbi.nlm.nih.gov/pubmed/10861170> also :

<http://www.sciencedirect.com/science/article/pii/S0306987703001130>

63 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1864551/pdf/procrsmed00027-0023.pdf>

64 Laudanum is first described in: T. Sydenham: “*Medical observations concerning the history and cure of acute diseases*” (1676) translation in: R. G. Latham: “*The works of Thomas Sydenham*” Vol. 1 London, Sydenham Society (1848)

65 F. Sertürner: “*Darstellung der reinen Mohnsäure (Opiumsäure) nebst einer chemischen Untersuchung des Opiums*” in J. B. Trommsdorff (pub.): “*Journal der Pharmacie für Ärzte und Apotheker*” Band 14, Leipzig, Crusius (1805) pf. 47ff (Digital scan of the actual paper in the Bavarian State Online Library: <http://reader.digitale-sammlungen.de/de/fs1/object/goToPage/bsb10288901.html?pageNo=57> | retrieved 25.12.2014)

66 P. Robiquet: “*Nouvelles observations sur les pricipaux produits de l'opium*” published by V. Thuau (1832)

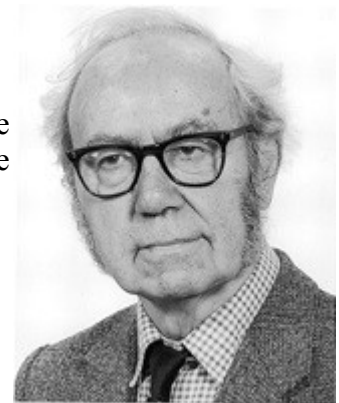
67 H. Levesque, O. Lafont: “*Aspirin throughout the ages: a historical review*” in J. Pouchot (ed.): “*La Revue de Médecine Interne*” Vol. 21 Suppl. 1, Amsterdam, Elsevier (2000) pg. 8ff

anesthesia as a professional skill ~1846⁶⁸. Initially, and oddly exact opposite to today's interpretations, medical professionals refused anesthesia administration on the grounds of ethical reasoning. For the early doctors considered operating on an unconscious person unethical, since the patient could not perceive the operation and the actions of the doctor onto their body, thus being unable what we today would consider giving informed consent to the extant measures of the operation. There was also considerable debate about potential adverse effects that anesthesia chemicals could have on the healing process, namely presumed retardation of said healing process.

The need for administering anesthetics was subjected to the so called "calculus" of the doctor, weighing the pros and cons of the patients loss of senses and pain relief against each other. The practice though never entered broad application or had universal appeal - though historically it could be considered a precursor to the modern practice of differential diagnoses. Still, great discussions of the ethics and the use of "calculus" remained up into the 19th century⁶⁹, until the technological refinement of general anesthesia and reliable breathing machines shifted the ethical stance towards the necessity of anesthesia for ethically acceptable conduct of surgery - the eventual revival of local anesthesia⁷⁰ trailing somewhat behind - caused by the research of localized anesthesia running into a lot of even more and nastier toxic substances than the researchers in the matter of general anesthetics.

2.7.2. The History of the Syringe Driver and its Significance in Palliative Care

As with all medication, aside from the primary concerns of chemical purity and reliability, logistics are a key component. This section is to explicate the history of the syringe driver systems that lead to the current emphasis on the CSCI⁷¹ alternative route for analgesic administration in palliative therapy. This development that I will retrace was the last great, game-changing technological development in the field of palliative care and provides a glimpse into the ethical problems and stakeholder dispositions during the adaptation phase. This is to sketch the issues that telecare devices will have to face in an "eternal recurrence" situation during their own development – to mis-quote Nietzsche here.



*Dr. Basil Martin Wright:
Inventor of the Syringe*

The crucial historical event, if we want to pinpoint a singular event, was the use of a Thalassaemia⁷² syringe driver in the year 1979 by a certain Dr. P. Russell, adapting a Grasenby Syringe driver to administer analgesics for palliation via the

68 For more on the fascinating history of anesthesia in medicine see the seminal work of T. E. Keys: *"The History of Surgical Anesthesia"* Park Ridge, Wood Library – Museum of Anesthesiology (1996, reprint); also: J. C. Trent: *"Surgical Anesthesia, 1846 – 1946"* in G. Rosen (ed.): *"Journal of the History of Medicine and Allied Sciences"* Vol. 1 No. 4 New York, Henry Schuman Publishers (1946) pg. 505ff

69 M. S. Pernick: *"A Calculus of Suffering: Pain, Professionalism, and Anesthesia in Nineteenth Century America"* New York, Columbia University Press (1985)

70 <http://www.ncbi.nlm.nih.gov/pubmed/12766665> also

<http://oxfordmedicine.com/view/10.1093/med/9780199586691.001.0001/med-9780199586691-chapter-001>

71 Continuous Sub-Cutaneous Infusion

72 An inherited blood disease triggering deformities in the patients red blood cells, causing anemia amongst other symptoms. As a blood disease similar to Sickle-Cell Disease, Thalassaemia provides enhanced resistance to Malaria. A disease most prevalent in the Mediterranean (hence its name), with mandatory genetic screenings of couples in effect (e.g. in Cyprus) to eradicate it. Commonly treated with regular blood transfusions, causing the patient to build up excessive iron deposits – constant administration of Deferoxamine et. al. is required to prevent severe organ damage in the mid to long term ranges.

alternative (CSCI) route. Before that event the administration of continuous analgesics was done via the oral route, which comes with inherent drawbacks if utilized for a prolonged time; most notably nausea and loss of appetite in the patient and general difficulty of swallowing due to deteriorating conditions of the patients. The possibility of having the alternate CSCI route available in a safe and easy fashion meant a substantial improvement in patient conditions and quality of life.

Following the experimental use, the device caught quickly on and established itself, with some added creature comforts for handling and safety, as the preferred route of palliation across the world during the 1990's – becoming the “standard alternative systemic route”⁷³. How exactly did this device of rather simple make attain such an important artifactual status within palliative care ? To answer that question I will reconstruct D. Clark et. al.: “*The Syringe Driver and the Subcutaneous Route in Palliative Care: The Inventor, the History and the Implications*”⁷⁴ in a comprehensive fashion. Again further, more specific reading is provided in appropriate footnotes.

The inventor of the syringe driver, Dr. Martin Wright intended to study engineering yet his father persuaded him to take up medicine as a more respectable profession, qualifying as an M.D. in 1938. After serving in the Royal Army Medical Corps during W. W. II, in which he served as a pathologist, he was recruited by the Medical Research Council, which at the time (1947) was tasked with evaluating health conditions and diseases amongst miners. Dr. Wright's penchant for engineering and tinkering found an outlet in constructing machines to experimentally recreate dust conditions and aerosol influence in mining shafts. One of these early works was the peak flow meter intended to provide accurate lung volume data for the researchers, yet the device was quickly adopted for the assessment of bronchitis and asthma pathologies by respiratory specialists. Other devices he produced were the first refinement of the peak flow meter into the “Wright's Mini Peak Flow Meter”, a device still used today and his best know invention, as well as the Respirometer which is a monitoring device for oxygen intake utilized by anesthesiologists. He also developed and prototyped the first device capable of measuring alcohol levels in breath samples – no doubt a device for which police forces around the world are grateful for.

He developed the first version of a syringe driver during his time serving in 1945; it was an improvised device to provide a quick way of delivering antibiotics to wounded soldiers – the finest in jury-rigging it was an alarm clock from which the hour hand was set to mechanically turn a screw which in turn was connected to the plunger of a syringe. This device eventually was refined by H. Ruben and H. M. Mohelsky⁷⁵ in 1954 to incorporate a spring loaded system which was controlled via pulleys attached to the alarm clock. Neither design saw a broad introduction into the medical field and remained as systems for local, impromptu use.

During the 1960's new systems were developed which were the first electrified syringe pumps for the administration of cytotoxic drugs in hospital settings, though these devices came with the inherent drawback that they had fixed flowrates per device, meaning that a new device was needed for any change in dosage or medication intended for the patient. During this time the need for flexible systems that allowed constant/continuous administration of drugs became more and more pressing as the diversification of pharmaceuticals and the refinement of the discipline of pharmacology meant that the devices had to be adaptable for a variety and/or combination of medications, as well as the needs of different fields of medicine.

73 S. Mercadante, F. Fulfaro: “*Alternatives to Oral Opioids for Cancer Pain*” in J. O. Armitage (ed.): “*ONCOLOGY*” Vol. 13 No. 2 London, UBM (1999) pg. 215ff

74 D. Clark et. al.: “*The Syringe Driver and the Subcutaneous Route in Palliative Care: The Inventor, the History and the Implications*” in R. K. Portenoy (ed.): “*Journal of Pain and Symptom Management*” Vol. 29 No. 1 Philadelphia, Elsevier (2005)

75 see: H. Ruben & H. M. Mohelsky: “*A Simple Automatic Syringe*” in S. M. Yentis (ed.): “*Anaesthesia*” Vol. 9 No. 1 Hoboken, Wiley-Blackwell (1954) pg. 38f

The design of the flexible system came at the hands of the esteemed Dr. Wright as the 1970's saw the preconditions emerge which made the development possible in the first place; most notably the introduction and subsequent broad adaptation of disposable plastic syringes in hospitals. In addition medical policies and regulations in the U.K. at the time advised against drug administration via IV (IntraVenous) drips⁷⁶. First the technical director of Pye Dynamics⁷⁷, Allan Ellson approached Dr. Wright to design an infusion device to administer synthetic Oxytocin, used to induce labor. At the same time he was also asked by the pediatrician B. Modell to come up with a device that enabled Deferoxamine treatments in childhood thalassemia, based on successful tests of the alternative subcutaneous route in administering Deferoxamine at the Children's Hospital Medical Center in Boston. Deferoxamine enables the body to excrete the excessive iron deposits caused by the repeated blood transfusion treatments for thalassemia⁷⁸.

Wright conceptualized the driver as a flexible and lightweight device that should be easily operated and adjusted by the medical professional and not unduly bother the patient due to size, noise or lack of wearing comfort. The crucial aspect was that the prescribed run-times of milliliter (ml)/time units of the medication could be converted via a scale fixed to the device into millimeters (mm)/hrs. (on the MS16A) and into mm/day (on the MS26), allowing the different flow-rates of different medications to be adapted to the same driver. In addition the devices boasted an all-purpose mount to enable



A MS16A-type syringe driver

With the help of Pye Dynamics Wright produced a range of prototypes which underwent trial by the end of 1976. The final device was small (190x53x30mm) and light (300g) powered by a dry cell battery allowing for the patients mobility to be unimpeded - given proper training on how to handle the device. The trial phase was met with great interest in the U.K. as well as Mediterranean countries which led eventually to the widespread adoption of the syringe driver and the subcutaneous route for the treatment of Thalassemia in 1978. With the minor modification of adding a light to indicate whether the device is on or not, the syringe driver was quickly adapted into post-operative analgesic administration as well as treatment of Myasthenia Gravis and as an insulin pump.

So far we have a somewhat standard history of medical device invention, yet how did the syringe driver make the jump into palliative care and became one of its most crucial devices? Why by pure chance, what else. During his work for Pye Dynamics, Wright was neighbor and a friend with a certain Dr. P. Russell – his own general practitioner eventually - who was involved with setting up a local hospice (Michael Sobell House⁷⁹) geared for palliative care, motivated by witnessing the death of an aunt of his wife in St. Christopher's. During one of their neighborly discussions, Wright suggested to utilize a syringe driver and the subcutaneous route in treating a cachexic⁸⁰, nauseous patient with terminal lung cancer, who was incapable of continuing treatment with the Brompton Cocktail. The impact on the patient was staggering, formerly bedridden and in agony due to lacking

76 see: Department of Health and Social Security: "Health Circular" No. 9 (1976)

77 Later known as Grasenby Medical, producing syringe driver systems – you see where this is heading.

78 see: R. D. Propper et. al.: "Continuous Subcutaneous Administration of Deferoxamine in Patients with Iron Overload" in A. S. Relman (ed.): "The New England Journal of Medicine" Vol. 297 No. 8 Waltham, Massachusetts Medical Society (1977) pg. 418ff

79 see: <http://www.michaelsobellhospice.co.uk/>

80 Latinized Greek: Kakhexia – "bad habit of body", meaning a general deterioration of the body - weight loss, loss of musculature, etc. An accompanying symptom of a chronic disease; usually associated with cancer, as rapid weight loss without change in lifestyle, or despite increased caloric intake, is indicative of an undiagnosed tumor (amongst other factors).

analgesics, the patient regained and retained his mobility and was pain free until his eventual demise.

Impressed by his results Dr. Russell eventually published his results in the *British Medical Journal* in 1979, citing the success of the syringe driver and also arguing for the abolition of the Brompton Cocktail as the standard route of palliation⁸¹ - shortly after his publication the lack of efficacy of the cocktail over pure morphine treatments became apparent⁸², providing an additional promotional effect for his device. The hospice community expressed great interest in the new technology and its initial presentation at a conference at the Michael Sobell House was met with positive feedback, even though some established colleagues deemed the device nothing more but a passing trend. Well, it turns out that the supposed trend was utilized by a large proportion of the palliative care community resulting in 96% of palliative care institutions in the U.K. using Wrights syringe driver by the end of 1989⁸³.

Despite the overwhelming success of the device, the design did bring some inherent drawbacks and flaws with it. The most obvious came with the conversion scales from ml/time to mm/time and the complicated calculations that had to be done every time the device was recalibrated for a different user or medication. Initially dismissive of the issue of unit-conversion, citing that professionals incapable of such simple calculations should not be administering potentially fatal drugs anyway, Wright later advised producers of the syringe driver to include a linear variable capacitor to automatically convert ml/time unit inputs into mm/time unit movement of the plunger. Another more drastic failure came to light during the aforementioned state of having different devices per medication, leading to cases of nursing personnel confusing the MS16A and MS26 devices and administering 24hrs slow-release diabetes medication over the course of one hour, killing off patients⁸⁴.

In general user-error remains the most prominent issue with the device, despite Wrights effort to perfect just one driver and produce only this variant – mechanical failure on the other hand is rare due to the rugged design of the device. In addition to the medical professionals problems with the device, the end user has long been assumed to be positively attuned towards the device, yet anecdotal evidence remains that patients see the syringe driver as the physical manifestation of a “harbinger of death”, bearing the evidence that they entered the dying phase and triggering feelings of hopelessness and despair. Despite this, there have been no investigation into patient disposition in choice of palliative care devices, which ties into criticism levied at the device during the 1980's - that the success of the driver stimulated the eager use of syringes, the uncritical, widespread adoption of a technology as a symptom of over-technification of a (presumed) low-tech specialty⁸⁵. With the added, unwanted feature that palliative care provisioning became associated and

81 see: P. S. Russell: “*Analgesia in terminal malignant disease*” in F. Godlee (ed.): “*British Medical Journal*” Vol. 1 No. 6177 London, British Medical Association (1979) pg. 1591ff

82 see: R. Melzack et. al.: “*The Brompton mixture versus morphine solution given orally: effects on pain*” in J. Fletcher (ed.): “*Canadian Medical Association Journal*” Vol. 120 No. 4 Ottawa, Canadian Medical Association (1979) pg. 435ff

83 see: P. C. Milner et. al.: “*Ownership, availability, and use of portable syringe drivers among hospices and home-care services*” in P. Mackie & F. Sim (eds.): “*Public Health*” Vol. 103 No. 5 Amsterdam, Elsevier (1989) pg. 345ff

84 see: “*Hazard Notice – HAZ(SC)96/01*” from 21.02.1996 (www.hfs.scot.nhs.uk/publications/PHAZ9601.pdf | retrieved 05.11.14) the issue persists even today, see: R. S. Murphy & S. J. Wilcox: “*A New Approach in the Design of High-Risk Infusion Technology*” in M. Chyu (ed.): “*Journal of Healthcare Engineering*” Vol. 1 No. 2 Hockley, Multi-Science Publishing (2010) pg. 155ff as well as: “*Rapid Response Report NPSA/2010/RRR019: Safer ambulatory syringe drivers*” pg. 5ff (online source: <http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=92961&type=full&servicetype> | retrieved: 07.11.2014)

85 see: W. M. O'Neill: “*Subcutaneous infusions – a medical last rite*” in C. Walshe (ed.): “*Palliative Medicine*” Vol. 8 No. 2 London, Sage UK (1994) pg. 92

intertwined with the provisioning of syringe driver devices. The association between discipline and device has gone so far, that in professional everyday lingo British doctors especially use syringe driver as analog to the utilization of CSCI measures, irrespective of context⁸⁶.

The adaptation of the syringe driver system into palliative care sketches some of the problems we will find in the investigation into telecare systems, albeit in an updated form if you will. For example the discrepancy between expected and real end-user stakeholder attitudes on the professionals and the patients side; which in the case of the syringe driver has not been resolved for the patient, leaving questions of quality of life and self-determination unanswered. Insufficient design of, and training with, the device leading to user failure is also a potential source for ethical conflicts – in the case of the driver, we really should try not to kill people accidentally. Another issue that emerges is how far are the producers willing to adapt to stakeholder demands in light of economic pressure if weighted against a constricted marketplace situation. Also, how far can the involvement of the initial designer reach, or how much responsibility is placed on him by policy design in the ever-present face of creative ab-use problems.

As for the inventor, Dr. Wright continued trying to improve his driver, aiming at weight reduction, ease of use, and overall cheaper production costs to be able to provide the device in developing countries with sub-standard palliation measures in effect. Retired by 1981, but still being a visiting worker to the Clinical Research Centre in London, he returned to refine the alarm clock driven prototype from his army days, but official efforts on mechanical, low-cost alternatives were abandoned by the CRC in 1983. Suffering from dementia during his waning years palliative care provided with a device of his own making helped him during his terminal phase, a fitting end to his life.

2.8. Attitudes towards Technology in Palliative Care Experts and Settings

Now for the last section: the attitude towards sophisticated medical technology in palliative care experts and settings. Generally speaking the attitude towards technological devices in palliative care is difficult to excise, since rarely do the professionals of this field deal explicitly with their own presuppositions when it comes to hardware. Since ethical considerations, if they take place to begin with, concern mostly the relationship to, and human(e) engagement of the patient, the technology and devices usually associated with medical treatment are engaged in a more background relationship on a need to use basis. The primary change in perspective on the patient effects a secondary (rarely explicated) change in the attitude towards devices.

A sketch of the situation presumed at hand: instead of the objectifiable technology-driven treatment of the patient as a slab of meat to be repaired, technology in the palliative context serves the quality of life (QoL) of the patient and the individual goals of success of a good care trajectory. The technology of the established medical sciences is seen as impersonal and as predisposing the involved stakeholders towards inhumane thinking and acting; defined in opposition to that palliative care enters to save the day. This conception is often reinforced between the specialties, due to the fact that as a very young discipline palliative care still is entrenched in a “fighting for recognition” mindset, and on the established medical side a stubborn adherence to the therapeutic maxime is palpable, “[...] a sense of therapeutic impotence frequently leads to therapeutic excess”⁸⁷. This lack

86 see: A. Dickman et. al.: *“The Syringe Driver – Continuous subcutaneous infusions in palliative care”* Oxford, Oxford University Press (2002)

87 see: J. F. Seely & M. M. Balfour: *“Palliative medicine and modern technology”* in J. Fletcher (ed.): *“Journal of the Canadian Medical Association”* Vol. 161 No. 9 Ottawa, Canadian Medical Association (1999) pg. 1120

of informational interaction and preservation efforts towards ones own importance reinforces the stereotypes of medical treatments of the 1960's, with capital "T" therapy being the single concern in the mind of the stakeholders - relegating the patient yet again to passive recipients of care. On a sociological-conditional side we are also still dealing with the "death avoidance" mindset of doctors that want to help their patients with therapeutic measures and are ill-equipped to deal with the inevitable, leading to a marginalization or outright avoidance of the topic of death⁸⁸.

Well the true situation is of course not as bleak and morally rousing as the sketch above suggests, yet we have to account for the attitude in the stakeholder analysis further down of course; since it is important to keep even imagined (or presumed) conflicts in mind when trying to establish a new technology within a field. As for the situation of technology as it is de facto in palliative care – medical devices are crucial to the proper administration of palliative care, and yes they are sometimes very sophisticated technologies despite the mindset of “*low-tech and high-touch*”⁸⁹. Not only does the relatively low tech device of the syringe driver plays an important role, other technologies are important for palliative care are⁹⁰; CAT and fMRI scanners to look for the physical causes of pain, localizing pain sources allows the refinement of the analgesics and application of stents to combat localized obstructive lesions; palliative radiotherapy⁹¹ relies on highly sophisticated devices in its application. And of course the generation of “*designer drugs*”⁹² for target/pain-specific symptom management is one of the central technological developments that palliative care pursues. Extending from the direct technologies, changes to the way medical research is conducted also means the adaptation of palliative care to the newest research standards (something Saunders definitely approved of).

The emergence of modern IT systems enhanced research efforts in palliative care and allowed the objective refinement of pain scales and assessment tools to equip the professional with. In that the co-dependent progress between technology and palliative care becomes apparent, since we still struggle to objectively assess the subjective experience of pain, the relation to technology is exposed when the lacking capabilities of technology have an impact on palliative care quality. As technology deals with the physical, tangible and objectifiable “*reality*” it is easy to see its effects as de-humanizing when assessments of subjective quality fail to produce reliable results. The palliative care professional is confronted with the task of mediating between, and giving good subjective, highly demanding care with the help of a sophisticated tool set, with the chief criterion being to not give into the seductive technological deterministic view of the devices but to keep the messy, involving, and potentially emotional draining human engagements of the patient in mind - “*Technology must be tempered by unconditional respect, empathy and compassion.*”⁹³. The issue is not the perceived "should we apply technology in palliative care at all" but "how do we apply technology in a ethical justified, human(e) way".

88 See: R. G. Twycross: “*Palliative Care: An International Necessity*” in A. G. Lipman (ed.) “*Journal of Pain & Palliative Care Pharmacotherapy*” Vol. 16 No. 1 New York, Informa Healthcare (2002) pg. 63 and 67

89 *ibid.* pg. 67

90 Seely, Balfour (1999) pg. 1120f

91 Palliative radiotherapy is intense radiotherapy to reduce growth size of tumors and control symptoms in a palliative care trajectory, a common tool in treating the intense pain associated with advanced bone cancers. For more see: D. Hoegler: “*Radiotherapy for palliation of symptoms in incurable cancer*” in K. P. MacMullen (ed.): “*Current Problems in Cancer*” Vol. 21 No. 3 Amsterdam, Elsevier (1997) pg. 129ff

92 For example Bisphosphonates for managing bone cancer: K. Mannix et. al.: “*Using bisphosphonates to control the pain of bone metastases: evidence-based guidelines for palliative care*” in C. Walshe (ed.): “*Palliative Medicine*” Vol. 14 No. 6 London, Sage UK (2000) pg. 455ff ; or Somatostatin Analogues for managing nausea due to prolonged medication: S. Mercadante: “*The role of octreotide in palliative care*” in R. K. Portenoy (ed.): “*Journal of Pain and Symptom Management*” Vol. 9 No. 6 Amsterdam, Elsevier (1994) pg. 406ff

93 Seely, Belfour (1999) pg. 1120

Chapter 3 – Medical and Palliative Care Ethics

This chapter will serve to establish the similarities and discrepancies between medical ethics, care ethics and palliative care ethics, providing the ethical-conceptual context for the stakeholder analysis of TCT within palliative care scenarios in the next chapters. These three ethical conceptions do share fundamental values that govern human medical interventions, while at the same time the current palliative care ethics are defined in contrast to the medical ethics conception of the stakeholders involved, the necessary skills, and the goals to be pursued in interventions – exemplified by the work of Saunders, as outlined in the previous chapter.

Whereas in care ethics we find a non-palliative, not strictly medical-only context reaction to the traditional moral backgrounds of utilitarianism and deontology governing medical ethics. We will take brief look at this parallel development to palliative care ethics and explicate the relevant issues within as to set up the stakeholder ethics analysis of this thesis.

The chapter will be organized in the following fashion: first some establishing presuppositions about the moral theories and ethics described, followed by an outline of the two relevant big moral theories for medical ethics, deontology and utilitarianism, concluding with the four pillars of the affectionately so called “*Georgetown Mantra*”⁹⁴, which are axiomatic for present day medical ethics. Followed by a short descriptive outline of the care ethics conception, highlighting the relevant aspects that puts it in parallel to palliative care ethics. After that I will give a contrasting description of current palliative care ethics and the differential definition of it against medical ethics, and some of the practical implications of this conception. Concluding the chapter with a concise line-up of the theories discussed, we are equipped to face the main part of this thesis – the analysis of stakeholder attitudes, ethics, and values in the introduction of telecare devices into palliative care scenarios.

3.1. Medical Ethics – Preliminary Distinctions

Before we get into the discussion of the great moral theories relevant to medical ethics and the subsequent moral concepts, I want to outline some necessary presuppositions regarding medical ethics that play a role within the theory as well as in care and palliative care ethics as a reaction to medical ethics. Medical ethics is a set of normative ethics to be followed by a group of professionals and is geared towards being a guide in practical situations that a health care professional could encounter in his or her professional function(s). This sets it apart of course from non-normative, or descriptive ethics which are observant of an ethical conflict/dilemma but do not prescribe actions. Medical ethics do aim to modify the behavior and actions of the relevant stakeholder groups of medical professionals in context sensitive scenarios, and thus is more often than not being criticized, analyzed, and refined over and over again. To frame it in a philosophical understanding: medical ethics is always practical ethics, not theoretical ethics - “*Theoretical ethics is to applied ethics as physics is to engineering*”⁹⁵.

Current medical ethics are also secular ethics, grown from the understanding of rational value judgments in human interactions⁹⁶, as opposed to divine-order type of morals that is the trademark

94 First developed in: T. L. Beauchamp, J. F. Childress: “*Principles of Biomedical Ethics*” New York, Oxford University Press (1979), the term was coined to succinctly describe their ethical conception and the impact it had on the medical profession.

95 J. L. Bernat: “*Ethical Issues in Neurology*” Philadelphia, Lippincott Williams & Williams (2008) pg. 4

96 *ibidem*, for further reading on the matter see: H. T. Engelhart: “*Bioethics and secular humanism: the search for common morality*” London, SCM Press (1991), R. M. Veatch: “*Hippocratic, Religious, and Secular Medical Ethics: The Points of Conflict*” Washington D.C., Georgetown University Press (2012)

of religious ethics, which usually contain some tenets and scriptures that are regarded as holy, are enshrined, and thus removed from ethical review and reassessment in the medical context of guidelines for the professional caregiver. Religious ethics re-enter the picture on the patients side, that is aspects of autonomy and patient self-determination/-understanding can and are being derived from religious ethical notions the patient might hold (especially when it comes to facing death and finding meaning in a life lived); if the patient in question is a very religious person conflicts can stem from the clash between religious and the secular medical ethics⁹⁷ when choosing treatment options and therapies, and finding resolutions for them can be a very challenging task for the stakeholders involved⁹⁸.

3.2. Deontology and Utilitarianism in Medical Ethics

As for big philosophical, moral-ethical traditions governing medical ethics, two are the most relevant to the current medical ethics, the great oldies-but-goodies: Deontology and Utilitarianism. A brief reconstruction of the two big schools of thought follows, if not marked otherwise, I chose J. L. Bernat: "*Ethical Issues in Neurology*"⁹⁹ as a source of the descriptive reconstruction for two reasons, first as a neurosurgeon with considerable experience he is well suited to give a practically schooled perspective on these moral theories, and second his book is targeting the unsuspecting medical student with some weapon-grade philosophy, forcing him to be concise and clear in his formulation making it in turn easier for me to paraphrase and stay comprehensively in the limits of a master thesis size requirements.

3.2.1. Utilitarianism

Utilitarianism as a moral theory of school of ethical thinking was mainly conceptualized by Jeremy Bentham and John Stuart Mill¹⁰⁰. The central tenet of utilitarianism is the singular concern for the outcome of peoples actions, and the balance between beneficial and maleficent effects that the interactions end up having – thus it is also referred to as Consequentialism. Actions are to bring the maximum amount of “good”¹⁰¹ to the maximum amount of people; as far as philosophical concepts go, utilitarianism is not really complicated nor sophisticated.

Employing pure utilitarian thought to situations is where it gets tricky, since almost any singular action comes with a complex net of benefits and harms for inter-acting groups and persons that tend to get impossible to track. Still, trying to anticipate the outcomes there are two schools of thought; (1) act-utilitarianism and (2) rule-utilitarianism. Simply put; act-utilitarianism is the analysis of every action done under the rule/demand of shifting the net balance of the outcomes towards “good” every time one does act. Rule-utilitarianism is the school of moral thought that from analyzing enough similar, single actions and their outcomes, we can derive rule-sets to be followed in a utilitarian fashion. To no surprise the utilitarian thinking, the balancing of “good” and “bad” outcomes, is broadly entertained in the medical field - as the decision making regarding therapeutic

97 Simple example would be the well known refusal of blood transfusions for religious reasons by Jehvoha's Witnesses. For more on the topic see: R. E. Ashcroft et. al. (eds.): "*Principles of Health Care Ethics*" New York, John Wiley & Sons (2007); especially "*Part I: Methodology and Perspectives*" pg. 3ff

98 See previous chapter for the attitude towards religion in palliative care; specifically the conception of the hospice as a space for free stakeholder mediation, as devised by Saunders.

99 J. L. Bernat: "*Ethical Issues in Neurology*" Philadelphia, Lippincott Williams & Williams (2008)

100 For a comprehensive reading on utilitarian thought see: J. Bentham, J. S. Mill, A. Ryan (ed.): "*Utilitarianism and Other Essays*" London, Penguin Books (1987, 2004)

101 Definition of “good” is up to the socio-temporal context and mediation between the people at hand of course.

measures is usually done in an economic fashion of how much physical good for example an operation would provide for the patient, in relationship to the dangers of anesthesia, frailty of the patients body, life expectancy added by therapy, etc¹⁰². This particular aspect of modern medicine is one of the chief reasons why Saunders initially tried to distinguish palliative, hospice care from the practices in the hospital due to the perceived objectifying, economical way of thinking being the prevalent mindset deciding over available, "useful" therapy options.

3.2.2. Deontology

Next up, Deontology or "Do your duty!"- type ethical thinking. Most famously of course developed by Immanuel Kant and his concept of the "*categorical imperative*"¹⁰³, this ethical theory forgoes the outcomes of actions and focuses purely on the intent of the relevant stakeholder. The judgment between "good" and "bad" is derived from the moral righteousness of the intent of the acting person. With the actors following their duty, the moral obligation of an action, being the highest expression of proper moral behavior. A doctor that follows the moral imperative to cure his patient and better their physical condition is doing a morally good thing from a deontological standpoint - the way and the outcome of following this imperative is of almost no concern. A direct criticism employed by the deontological position usually refers to the impossible task of utilitarian positions to reliably assess the total outcome of any action. Proper utilitarian reasoning hinges on an impossible ideal-information situation for the acting person; thus we would be better served if we assess peoples intent and moral intuitions¹⁰⁴, not actions.

Modern medical ethics entails aspects of both theories outlined above, since none can reliably cover all the ethical conflict situations that might arise in a medical setting. Both, intent of actors and the consequences of said actions, are relevant when we deal with medical scenarios that almost always entail a hierarchic patient-doctor relationship. The intention of the doctor for example plays a significant role, just looking at the long history of the Hippocratic oath for example as a deontological rule-set to be followed. As for the ethical consequences of an action, we encounter advanced health care directives¹⁰⁵ and the impact they have on the actions of medical personnel for example.

3.3. The "Georgetown Mantra" – The Four Pillars of Medical Ethics

Deontological and utilitarian aspects are both relevant to the ethical discourse in medicine, they enter the conceptions not as the pure moral theories outlined above, but are usually derivatives present in the four major ethical tenets in medical ethics: (1) Beneficence, (2) Non-Maleficence, (3) Justice and (4) Autonomy. These four aspects, summarily also known as the "*Georgetown Mantra*"¹⁰⁶, is the more prominent defining guideline for medical practitioners and I will consequently outline their concept in the following sections, still building on Bernats instructional work with additional reconstructive efforts derived from L. Sandmans book: "*A Good Death – On the Value of Death and Dying*"¹⁰⁷.

102 G. Mooney: "*Economics, Medicine and Health Care*" Harlow, Pearson Education Ltd. (2003)

103 I. Kant: "*Groundwork of the Metaphysics of Morals*" Cambridge, Cambridge University Press (1997)

104 Regarding moral intuitions, see: M. Huemer: "*Ethical Intuitionism*" Basingstoke, Palgrave MacMillan (2008)

105 Best example of an advanced health care directive would be a Do-Not-Resuscitate order (or an Organ Donor Card), signed by the patient when he or she still had all their physical and mental faculties in order.

106 Beauchamp, Childress (1979)

107 L. Sandman: "*A Good Death – On the Value of Death and Dying*" New York, Open University Press (2005)

3.3.1. Beneficence and Non-Maleficence

The two oldest principles governing medical ethics and interventions, non-maleficence and beneficence, make up what L. Sandman calls the “main tradition” of medical ethics - the necessary moral conceptions. Both concepts are at the heart of one of the earliest and most invoked rule-sets in a deontological sense humans came up with: the Hippocratic oath¹⁰⁸.

3.3.2. Non-Maleficence

First one on the table: Non-Maleficence - along with Beneficence one of the oldest moral principles in medical ethics. Usually cited as “*primum non nocere*” - “*first, do no harm*”, though also available in the direct translation from Hippocrates writings as: “*at least, do no harm*”¹⁰⁹ putting a certain twist on the whole phrase – shaping it as a minimum moral, rule-based requirement. In the modern medical scenario therapeutic measures usually come with multiple beneficial and detrimental effects for the patient, and at its core the principle of non-maleficence simply tells the medical practitioner to avoid those therapies which net effect would be hazardous to the patient¹¹⁰.

A derivative of catholic moral doctrine¹¹¹ plays into the modern conception of non-maleficence in the context of palliation – the “*double effect*” principle. Double effect is when the therapy devised by the doctor comes with an intentional, beneficial effect and an unintentional (accidental) detrimental effect at the same time. As an ethical guideline double effect is a variation of utilitarian thinking about outcomes, coupled with specialist knowledge - privileged access to potential outcome information - and a deontological “intent” criterion. The most practical example of the double effect comes from palliation efforts; in that if the intended pain relief medication also shortens the expected life span of the patient, the risk of this shortening is accepted due to the intentional relief of pain for the already short rest of the patients life is considered a reasonable trade off. The same applies to the medical professional in that employing therapeutic measures, he or she has to consider the potential of the treatment choices falling under the double effect principle. How are double effect actions assessed ? (1) The act committed is not intrinsically wrong; as in killing someone intentionally, you do remove any disease symptoms as well - you are not allowed to retroactively redefine maleficent actions as intended, “good” effects. (2) The intended effect has to be the beneficial one, even though the drawbacks can be anticipated. Example above, the pain relief is the intentional good effect, even though it could shorten the remaining life span of the patient. (3) The bad effect must be an end to gain the good effect; as an inevitable side effect of the only available treatment option left. (4) The act is proportionally reasonable for the situation at hand - you are not going to amputate a hand when you can pull a splinter. (5) The net effect has to be more good than bad (non-maleficence minimum criterion, beneficence ideal both in effect). Lastly it is always implied and sometimes explicated that the informed consent (oral, written, and/or by proxy) of the patient is a criterion for morally permissible double effect actions.

108 See L. Edelstein: “*The Hippocratic oath, text, translation and interpretation*” in E. L. Minar Jr. (ed.): “*The American Journal of Philology*” Vol. 66 No. 1, Baltimore, Johns Hopkins University Press (1945) pg. 105ff

109 *ibid.*

110 As in; principally speaking if you kill someone, the patient can also be considered free of pain...permanently.

111 See: Thomas Aquinas: “*Summa Theologica*” Notre Dame, Ave Maria Press (2000), specifically Question 64. See also: Thomas Aquinas: “*On Law, Morality, and Politics*” Indianapolis, Hackett Publishing (2003)

3.3.3. Beneficence

Second one up; beneficence. As non-maleficence is a normative rule not to be violated, beneficence on the other hand is a moral ideal to be pursued - very much in a utilitarian fashion of getting the most beneficial effects for the most patients in light of limited resources, more on that under the "Justice" section further down the chapter. It is a positivistic complement/mirror of the non-maleficence principle, articulating the intuition that medicine is supposed to bring about beneficial, "good" effects for the patient in practice.

The duty of the doctor is to have the patients health and well-being in mind, and to guide him or her to the right treatment options, heeding the patients autonomy and accounting for the vulnerable state of a sick person of course. The challenge here is the balancing act in every patient-doctor interaction, between the doctors expert choice of right treatment options and the patients autonomous (usually shitty) decisions/rights, more on that in the next section.

3.3.4. Autonomy

The medicine ethical concept of autonomy largely concerns the patient in the doctor-patient relationship; with the rights on the patients side and following out of these rights, duties for the physicians. So, what does autonomy mean? In its most basic sense to not deprive a person of his or her own freedom and not to disable a person to pursue their freedom. There is some emphasis within the medical setting on the freedom of choices of the patient as autonomy, over the more fundamental freedom/autonomy of the patient as a whole person (being).

Now what is necessary for the patients choice as an autonomous action moral-conceptual wise? The action/choice is made with intent, simple enough. But intent requires two presuppositions to be fulfilled: (1) a solid, truthful understanding of the situation the patient find him or herself in – as in access to true, good information about the available choices of treatment, and (2) for the patient being free of any determining influences, which means in the medical context the often problematic necessity of being consciously awake and mentally sound - or having provided contingency measures in written form when the patient was last responsible for his or her actions in a legal sense.

Autonomy, in the context of our modern, western understanding, is individualistic and utilitarian at its core. Everyone has the right to live what they consider a good life in accordance with their views and values, within a justice system that preserves individual freedoms until they infringe upon others. The responsibility for ones life lies squarely with the singular person living it. In order to get to this very liberal, secular attitude in medicine, the so called "patient-centered rights"¹¹², there were historical breaks necessary with the previous paternalistic model of medical ethics¹¹³. These revolutions in medical attitudes were provided within the context of the civil rights movements emerging in the U.S. over the 1950's and 60's, which challenged broad societal consensus and paved the way to fundamental changes which eventually found their way into international (or maybe at least western world) medical ethics; the loss of the paternalistic attitudes¹¹⁴ in the doctor-patient relationship co-developed out of the societal change in attitudes towards authority¹¹⁵.

112 Bernat (2008) pg. 10

113 See J. F. Childress: *"Who Should Decide?: Paternalism in Health Care"* Oxford, Oxford University Press (1982)

114 G. B. Weiss: *"Paternalism modernised"* in J. Savulescu (ed.): *"Journal of Medical Ethics"* Vol. 11 No. 4 London, British Medical Journal (1985) pg. 184ff

115 See J. J. Chin: *"Doctor-Patient Relationship: From Medical Paternalism to Enhanced Autonomy"* in T.E. Kiong (ed.): *"Singapore Medical Journal"* Vol. 23 No. 3 Singapore, Singapore Medical Association (2002) pg. 152ff

An accompanying negative effect of this development is that the doctors recommendations are seen as vestigial paternalism of the past and the treatment decisions have to be justified to a larger extent than before. Any treatment developed by the specialist in the patients best interest is under scrutiny, up to the point that even when provided with adequate and accurate information, the primacy of the patients decision leads to long-term detrimental effects for the patient. Studies did show that patients under physical and psychological stress, being responsible for their own treatment options do tend to disregard the advice given as paternalistic and still commit to bad decisions¹¹⁶, caused by a mixture of miscommunication/-interpretation of medical facts and irrational thinking. Cultural bias can play an important role, for example the emphasis towards self-sufficiency and self-determination in the U.S. can skew perspectives; but for health care and medical ethics this concept of autonomy outlined above has axiomatic status for at least the western world - you are entitled to have your decisions respected even if they are utterly stupid.

Regarding the reliability or stability of the patient as an autonomous actor; patients under distress tend to shift their values and preferences around¹¹⁷ - they might even conflict - as the disease trajectory takes hold, there is the philosophical argument that we are confronted with the absence of a stable autonomous agent, and that for the time being the doctor can and should assume a more assertive, read paternalistic, attitude and intervene on behalf the patients health. There is additional criticism levied at the purely singular, autonomous conception of the patient, in that rarely do people ever make decisions just for themselves. Especially in medical scenarios family and friends almost every time do enter the equation/calculations on the patients side. To better grasp this situation the argument for an interactional-relational model¹¹⁸ of autonomy over the singular conception of the individual remains to be made.

3.3.5. Justice

The last pillar of medical ethics are considerations regarding “justice”; in the medical context this almost always concern the assessment of distributive justice from the utilitarian perspective of health care systems in general (macroeconomics) and from the deontological perspective of specific cases at hand for the practitioner (microeconomics)¹¹⁹. Simply put: how do we distribute the finite resources, or “medical goods”, fairly amongst the sick and to an extend, should we be at all concern with a fair and just distribution in the first place ? And how can practitioners balance economic pressures and necessities with their moral obligations like non-maleficence and beneficence ? Practically speaking the doctors have to stick to the legal frameworks, guidelines and laws, policies etc. in place in their respective society and hospital. There are a variety of deontological and utilitarian theories dealing with justice; Bentham, Mill, Nozick, Rawles; all with their respective focus ranging from neo-liberal to egalitarian approaches in distribution of goods. Since justly

116 See: C. E. Schneider: *“The Practice of Autonomy: Patients, Doctors and Medical Decisions”* New York, Oxford University Press (1998)

117 On the topic of stability in patient decisions see: N. Kohut et. al.: *“Stability of treatment preference”* in E. G. Howe (ed.): *“The Journal of Clinical Ethics”* Vol. 8 No. 2 Hagerstown, The Journal of Clinical Ethics (1998) pg. 124ff, also: R. M. Gready et. al.: *“Actual and Perceived Stability of Preferences for Life-Sustaining Treatment”* in E. G. Howe (ed.): *“The Journal of Clinical Ethics”* Vol. 11 No. 4 Hagerstown, The Journal of Clinical Ethics (2000) pg. 334ff, and: P. H. Ditto et. al.: *“Stability of Older Adults' Preferences for Life-Sustaining Medical Treatment”* in A. E. Kazak: *“Health Psychology”* Vol. 22 No. 6 Washington D.C., American Psychological Association (2003) pg. 605ff

118 See: J. M. Breslin: *“Autonomy and the role of the family in making decisions at the end of life”* in E. G. Howe (ed.): *“The Journal of Clinical Ethics”* Vol. 16 No. 1 Hagerstown, The Journal of Clinical Ethics (2005) pg. 11ff

119 Regarding the conflict between the perspectives see: G. Garbutt, P. Davies: *“Should the practice of medicine be a deontological or utilitarian enterprise ?”* in F. Godlee (ed.): *“Journal of Medical Ethics”* Vol. 37 No. 5 London, BMJ (2010) pg. 269ff

representing all these theories would take at least a thesis of its own, it suffices to say there are socio-temporal, legal and economical constraints within which the medical professional has to navigate and act, while ideally still observing his moral duties and ideals. Irrespective of theory preferred the usual assessment of just distribution hinges on the following aspects of the patient: individual effort, individual societal contribution, merits or deserts, personal contribution to desirable effects in the societal market (your economic worth to a society).

3.4. Care Ethics

Before outlining the contrasting position of palliative care to the mainstream model of medical ethics above, I want to explicate a third ethical system: Care Ethics. Care ethics, in the same vein as palliative care ethics, is a criticism of an established set of ethics¹²⁰. Methodologically similar to palliative care ethics, Care ethics is focused more on the practical aspects and contextual circumstances rather than abstract moral theories and conceptions. The initial criticism of care ethics was levied towards the justice conceptions of the established moral theories¹²¹, as the early proponents of care ethics perceived a distinct lack of moral elements usually associated with feminine and feminist ethical principles – chiefly care and compassion as the name indicates.

It is important to note that when Saunders started to conceptualize the early palliative care ethics and practices, care ethics was not yet around. From a historical perspective palliative care ethics and care ethics run in parallel – both a similar reaction towards the weaknesses of the established ethics of their field, with care ethics having ties to nursing ethics in the medical context¹²², thus making an comprehensive explication of the theory necessary in preparation of the stakeholder analysis of this thesis.

The usual time of emergence for care ethics as a moral theory is placed in the 1980's and its initial conception and explication is attributed to the works of Milton Mayeroff¹²³, Carol Gilligan¹²⁴ and Nel Noddings¹²⁵. At its core the theory emphasizes care, compassion, emotional attachment and active motivation as crucial elements of moral assessments and actions, and the theory maintains close historical ties to with feminist ethical writings. Now the re-emphasis on the more subjective-centered spectrum of ethical theories brings with it certain similarities to palliative care ethics, and differences as well – first and foremost care ethics is aimed at therapeutic patients, not the terminal – and that is only if we constrict it to the hospital scenario; as mentioned before in those circumstances care ethics can be considered interchangeable with its medical forerunner/twin of nursing ethics.

120 When positioned as a full moral theory and model Care Ethics is usually grouped with/contrasted against Deontology and Utilitarianism.

121 see: G. Clement: *“Care, Autonomy and Justice: Feminism and the Ethic of Care”* Boulder, Westview Press (1996)

122 It stands to reason that strictly for the medical context, care and nursing ethics are complementary or even interchangeable to an extent. See for example: S. D. Edwards: *“Is there a distinctive care ethics?”* in A. Gallagher (ed.): *“Nursing Ethics”* Vol. 18 No. 2 Thousand Oaks, Sage Journals (2011) pg. 184ff

123 M. Mayeroff: *“On Caring”* New York, HarperCollins (1972)

124 C. Gilligan: *“In a Different Voice: Psychological Theory and Women's Development”* Cambridge, Harvard University Press (1990 reprint, 1st edition: 1982) and: C. Gilligan et. al. (ed.): *“Mapping the Moral Domain: A Contribution of Women's Thinking to Moral Theory and Education”* Hoboken, Harvard University Press (1988)

125 N. Noddings: *“Caring: A Relational Approach to Ethics and Moral Education”* Oakland, University of California Press (2013 revised edition, 1st edition: 1984)

Care ethics is employed on larger scales and does rarely engage in the medical setting¹²⁶, efforts are undertaken to establish it as a general, all purpose moral approach to human interactions, akin to Deontology and Utilitarianism – with specific interests of the proponents ranging from macro scale politics, over economics, to linking care ethics with eastern thought¹²⁷. Its status as full-blown moral theory remains debatable¹²⁸, and argumentations remain as to how close to the threshold of being a recognizable theory it is or not; or if in fact it should not be considered a theory but an expression of a fundamentally different mindset, paradigms of a priori-esque deliberations before we engage in any moral discourse.

The basis of care ethics is the interaction between humans and an emphasis on inter-actional and relational moral values and assessments. Though different specialists pay attention to varying issues and areas of application of care ethics, as well as considering vastly different size/scopes, there are shared basics throughout the works which could be considered the core tenets of care ethics.

First the caring relationship between a “carer” and a “cared-for” is identified as the basis for any human interaction that doesn't involve perpetual hitting each other over the head. The principle of “Caring” is the identification of caring relationships, which form a primal experience that allow humans to have engaging social relationships, and is the first step into building culture/civilizations. Between the carer and the cared-for there is reciprocal commitment to each others well-being, with a intent and activity on the carers side; motivated out of previous experiences of being cared for and the capability to recognize the need for care in another human being. The carer enters a “problem solving” mode concerned with the contextual, real necessities of the cared-for rather than the more abstract forms of artificial, theoretical, moral problem solving as we find for example in the utilitarian or deontological theories and debates.

From interpersonal care experiences care ethics abstracts the so called “ethical caring” as an outgrowth of this “natural caring” instinct and organic actions described above - a duty component extends the basic disposition of the human being into a larger scale societal context. There is a certain twist on this duty component though, when we compare it to the deontology conception of Kant; whereas in Kants moral theory the duty comes before the inclination to help and compassion - in care ethics the compassionate component comes first, then comes the duty, derived out of the primacy of care. By switching these primacies around care ethics allows to address one crucial issue of deont./util. ethical doctrines – that you cannot care for everyone with the same efficiency and efficacy, which is what absolute moral statements imply by their very conceptional nature, nor even personal attachment and emotional closeness.

Care ethics allows for the limitations as to whom to help with ones own capacities and abilities, i.e. a much more realistic conception for concrete moral actions in practice. To put it into a simplified image: for every person there are concentric circles of attachment (family, friends, colleagues, proximate and total strangers) radiating outwards. The task of the human being is to cultivate these circles and care attachments to people in a similar fashion to the ethical virtues first described by Aristotle. There is considerable debate between proponents of care ethics as to how much one should subsume care ethics into virtue ethics¹²⁹, or not¹³⁰, due to the differing emphasis of their

126 And even then it is still in the context of large scale health care provision systems.

127 See: C. Li: “*The Confucian Concept of Jen and the Feminist Ethics of Care: A Comparative Study*” in L. L. McAlister (ed.): “*Hypatia*” Vol. 9 No. 1 Hoboken, Wiley-Blackwell (1994) pg. 70ff

128 see: M. Hammington: “*Embodied Care: Jane Addams, Maurice Merleau-Ponty and Feminist Ethics*” Champaign, University of Illinois (2004) pg. 2ff

129 see: R. Halwani: “*Care Ethics and Virtue Ethics*” in H. Lindemann (ed.): “*Hypatia*” Vol. 18 No. 3 Hoboken, Wiley-Blackwell (2003) pg. 161ff

130 See: M. Sander-Staudt: “*The Unhappy Marriage of Care Ethics and Virtue Ethics*” in H. Lindemann (ed.):

respective agendas on politics, macro scale policies and gender issues emphasizing that care ethics should not be mixed into such an old patriarchal conceptualization.

So, how can Aristotelian virtue ethics be linked to care ethics? It all hinges upon the roles care and compassion play as central virtues. If we accept this premise, proponents of care ethics emphasize the importance of cultivating one's personal virtues (care & compassion) in the concrete circumstances of one's own life and towards the people surrounding us. In parallel to Aristotle's conception the importance is on balancing these virtues, since: (1) the vice of deficiency, only care for the self and exclusion of the others, leads to selfishness and hedonism; whereas with (2) the vice of excess, caring only for others while neglecting the self, we arrive at unhealthy co-dependant situations and eventually pure deontology – what we need is (3) balance of the humors: while caring for ourselves and for others in the proper way we find combined, intertwined, realistic care, well-being and meaningful relationships with others; (some of) the components of a good life (according to Aristotle and Care Ethics).

3.5. Palliative Care Ethics

Now that we have established the frames of reference for palliative care ethics we can get down to the business of discerning the particular way palliative care ethics is intertwined with medical ethics. Once in the way palliative care ethics is contrasted against medical ethics, as well as the way medical and palliative care ethics share certain aspects between each other (chiefly, the pillar/value of Autonomy). This is the last section of this thesis dealing with preparations and explications, giving us the current status of palliative care ethics that is the moral background knowledge necessary for the stakeholder analysis beginning in the next chapter.

3.5.1. Palliative Care Ethics - Preliminary Differentiations

Inherent in palliative care ethics is a change in conceptualizing specific terms as well as in the understanding of relevant stakeholders involved in the ethical discourse. To account for that I turn to F. Randall & R. S. Downie's work: *"Palliative Care Ethics – A Good Companion"*¹³¹ and *"The Philosophy of Palliative Care – Critique and Reconstruction"*¹³² to help exemplify these changes. Before we get to the descriptive details, we need to clarify some terms used in the palliative care ethics, since these nuances are a contributing factor to the larger contrast picture of palliative care ethics going up against medical ethics.

The terms are: "morals" and "ethics". In the medical ethics conception, the medical professionals are presumed to have privileged principles and access to moral actions as doctors and nurses, framing their "morals" as somewhat superior to the lay folk (source of paternalism). In the palliative care ethics conception they become experts with the non-moral, specialist knowledge to treat the diseases of physically ill people and better their condition. When it comes to morals they are just as any other human being, having the same access to/capacity of being a moral upstanding person/being.

"Hypatia" Vol. 21 No. 4 Hoboken, Wiley-Blackwell (2006) pg. 21ff

131 F. Randall and R. S. Downie: *"Palliative Care Ethics – A Good Companion"* Oxford, Oxford Medical Publications (1996)

132 F. Randall and R.S. Downie: *"The Philosophy of Palliative Care – Critique and Reconstruction"* New York, Oxford University Press (2006)

The term “Ethics” can generally be segmented into: (1) the philosophical discussion of concepts and principles in a fundamental, theoretical fashion - “moral philosophy”, (2) common knowledge, daily value judgments of persons in a particular context [socio-temporal] - the moral intuitions of the general populace, and (3) ethics as a pre-agreed code of conduct, policy or set of guidelines for action assessment within an institution or field - born out of repeated conduct of (1), say the Georgetown mantra for example. In palliative care ethics we find (2) mixed into (3); allowing a shift from the deontological-utilitarian, rule-ideal ethics of medicine towards the holistic care ethics and flattening of hierarchies in conjunction with a more pro-active patient value understanding – again, see previous chapter for the palliative care conception of Saunders for the historical roots. Accompanying this development is the introduction of intrinsic and extrinsic goals into the therapy, changing patient-doctor stakeholder understanding, actions and attitudes while still being embedded in a practical scenario. The next section will detail what intrinsic and extrinsic goals are in the context of palliative care.

3.5.2. Intrinsic and Extrinsic Goals in the Pursuit of Non-Maleficence and Beneficence

In palliative care we find a different approach to the role and understanding of the medical professional – the development of intrinsic and extrinsic goals. These goals are fundamental to the pursuit of non-maleficence and beneficence as moral values for the benefit of the palliative patient. To understand these ideas, the work of L. Sandman¹³³ again provides us a good source for the following conceptualization.

Now what are these goals ? Intrinsic and extrinsic defined goals serve to integrate palliative care into a medical health care system that works in accordance with the medical ethics outlined in the first sections – medical and palliative care ethics do share the four pillars as moral values to be pursued¹³⁴ - and are an important and necessary component of palliative care - since ideally palliative care specialists eventually end up treating all the patients of the different disciplines and field of medicine.

Intrinsic goals are what makes palliative care...well palliative care really. The collection of necessary actions that everyone being active in the field inherently agrees upon as worthy of doing: the provision of a medical good/“good” for the patient - same as in the medical ethics, these actions serve the concrete, contextual realization of the moral values of non-maleficence and beneficence. They concern the application of non-moral specialist knowledge, for example pharmaceuticals, to improve a patients condition (pain). As the name suggests, they are intrinsic to the field and are an apriori necessity in the debate of palliative care technology. As mentioned above, palliative care and its ethics are embedded in a medical ethics driven system (to a large extent), the intrinsic goals are the connecting point to medical ethics in that the values of non-maleficence and beneficence are the same and are pursued in the same vein.

But palliative care aims at more than just fulfillment of intrinsic goals. As palliative care ethics extends the value pursuit of non-maleficence and beneficence - the propagation of these two values is to serve the betterment of the patient as a whole person. This conceptual change necessitates the introduction of extrinsic goals, anything unrelated, any action of the professional, to the “techne” aspects of the practice/intrinsic aims. Nurses and doctors have a unique (read: privileged/intimate) access to the patients fears, hopes, wishes, etc. with the patient being in a situation of distress – thus

133 Sandman (2005)

134 As palliative care ethics evolved out of the medical context, the baseline ethical concepts are shared, as opposed to say Deontology Morals versus Hedonistic Morals which are conflicting in a fundamental fashion.

they are confronted with a large potential to really fuck things up or to substantially improve patient dispositions and affecting the outcomes of the intrinsic goals to a large degree.

So why consider what could be construed the psychological condition of the patient as an extrinsic goal, and not an intrinsic one from the get go ? Strictly speaking the palliative care professional in the pursuit of extrinsic goods does not treat the disease, the primary cause, but symptoms, the secondary and tertiary effects of the disease - within the symptoms are included social relationships (family, friends, etc.) as treatment targets¹³⁵. Conceptually intrinsic goals all relate to the primary effects of the disease which require the attached professionals qualification, whereas extrinsic goals are aimed at alleviating secondary and further effects of the primary cause, improving the patients condition as a whole person, from primary to tertiary, etc. causes, problems, effects and so on. To reiterate a previous point: it is important that for the palliative care context, the intrinsic goal is conducting the pain management until death – keep in mind the inherent presupposition that “therapy” in palliation is pain relief, not removing the cause of the disease.

3.5.3. The Role of Phronesis - The “Practical Wisdom” in Palliative Care

Facing the pursuit of extrinsic goals, the professionals are moved outside of their training and taught skills, as they have to engage the patient as a human being in an existential fashion. So, what help is there available to assist in these difficult tasks, since we do not have a comprehensive skill book to be able to teach the nurses and doctors what to do when engaging patients in this extensive, exhausting fashion ?

We can provide them with experiences of practical wisdom in action – one of Saunders chief reasons to build St. Christopher's aside from concerting academic research interests & efforts. Palliative care ethics in pursuit of extrinsic goals very much subscribes to what Greek philosophers called the development of “*phronesis*”¹³⁶ for the individual practitioner – the type of wisdom/knowledge a person can only gain by living a full life and the complete development of ones character. “We need a whole person to provide whole person care” - think of a long experienced ward nurse for example: no special qualification or certificate, yet if it comes to human(e) interactions with patients and their family they tend to be the preferred partner over say a doctor who just got his degree and is simply inexperienced.

Phronesis is derived from the total sum of a persons life experience, and the way they developed their personality and character over time; inherently this is not something that can be taught but needs to be gained in action. The crucial point of phronesis is that professional-only experiences, even though handy in the medical scenario are not enough to generate true phronesis.

Example: The doctor and nurses have excellent non-moral knowledge on how to treat the patient physically, but if they never experienced say a loving, deep relationship in their lives, it most likely is very hard for such a person to relate to, and care for, a wife while the husband of 30+ years is dying. The challenge towards the professional is to bring all his human experiences to the table, while still remaining a capable palliative care specialist.

135 Again, see previous chapter.

136 Further reading on phronesis: A. W. Frank: “*Asking the right Question about Pain: Narrative and Phronesis*” in R. Charon, M. Spiegel (eds.): “*Literature and Medicine*” Vol. 23 No. 2 Baltimore, Johns Hopkins University Press (2004) pg. 209ff, also: D. Thomasma: “*Aristotle, Phronesis, and Postmodern Bioethics*” in M. G. Kuczewski, R. Polansky (eds.): “*Bioethics: Ancient Themes in Contemporary Issues*” Massachusetts, MIT Press (2002) pg. 67ff

From a medical professional standpoint, only the intrinsic goals of palliative care can be expected to be fulfilled by the professional (in a justice/duty moral fashion) - the potential emotionally challenging pursuit of extrinsic goals and the level of human interaction required is learned along the way - in the best case scenario phronesis is learned from and with someone experienced in a conducive environment¹³⁷.

From a total, whole person care perspective, phronesis and the development of it helps when dealing with the specifics of a case and is a good protection from being too objective about treatment and care options. As a caricature; the anonymous medicine of an ICU comes to mind the doctors just following standards, procedures, flowcharts and so on, while treating meat¹³⁸. When confronted with a range of intrinsic treatment options, phronesis can also help - always in conjunction with the patient of course - to pick the right course of action for the patient at hand, and to decide in which manner the treatment is implemented. Phronesis also entails how the communication of treatment solutions is done, some patients may prefer matter-of fact, no nonsense consultations, others may want to feel safe in what they experience as an exposed, weak personal situation. To cite Randall & Downie: "*Techniques are blind and require the guidance of the ethical concept of practical wisdom*"¹³⁹ and it is "*our moral duty to develop all our talents*"¹⁴⁰.

3.5.4. The Autonomy of the Patient – Shared Value, Different Practices

Aside from sharing the same basic respect and appreciation for the values of non-maleficence and beneficence for the patient – one other particular value of the shared value foundation between medical ethics and palliative care ethics has been emphasized very strongly in practice: the respect for the autonomy of the patient. Similar to medical ethics, palliative care ethics takes the consent/choice of the patient as the most crucial and decisive controlling influence over the care trajectory. Even more so than medical ethics, in which context the consent of the patient is primarily concerned with the choice of treatment options, the patients consent to the care approach in palliative care scenarios has more severe, far reaching consequences – since it involves intrinsic and extrinsic goals that rely on a much more intense and holistic, active involvement of the patient. Thus treatment of, and expectations towards, the patient as a stakeholder in the medical scenario at large changes drastically within palliative care ethics, while still being in alignment with the foundational values explicated in the Georgetown mantra.

In the palliative care scenario the patient and the care team of specialists is engaged in a mutual, equal-authority relationship¹⁴¹, and thus the pursuit of the extrinsic goals, by the phronesis-equipped professional that has a privileged access to the patient. This, to some extent extreme, focus on the patient and the revision of doctor-patient relationship makes the task on the professionals side much more challenging than "only" to consider employment of therapeutic measures within the medical ethics of the established setting. Aside from the postulated increase in beneficial effects for the patient as a whole person the intimacy of the situation also entails, that unwanted incursions of the expert into the emotional, psychological and social domains of the patient holds the potential for even greater damaging effects for the quality of life of the patient.

137 Again, this is one of the main goals and accomplishments of St. Christopher's as an institution.

138 Hyperbolic terms for clarity, a well-meant RAA if you will.

139 Randall & Downie (1995) pg. 17

140 *ibid.* pg. 23

141 Of course always contingent upon the precondition of having a conscious, sound-minded patient at hand as well as good information available and distributed between the stakeholders.

Informed consent, or dissent for that matter, regarding psychological or emotional problems however tends to not enjoy the same respect, and commands not the same authority as physical intervention consent and usually means the application of a more detailed informed consent process in which the patient is often on the defensive, and more paternalistic attitudes are still prevalent in the professionals and their actions¹⁴². The “*well-meaning presupposition*”¹⁴³ of helping the patient - especially in palliative care in which the professionals often carry a strong sense to help at all costs, has to be closely scrutinized when the professional gets involved in the pursuit of extrinsic goals. As well-meaning the initial conception of Saunders was for the hospice as an equal, mediating place between patients, doctors, nurses, relatives and visiting students; the whole person care presumes the patients active and willing inclusion, “[*whole person care*]....*implies a willingness to assist the patient to overcome psychological, social and spiritual barriers to well-being, by using our relationship with them as fellow members of a community*”¹⁴⁴.

The patients relatives though possess also a privileged relationship and access to the patient, ideally they come with a long history of healthy emotional attachment and a loving, supportive disposition. Though more often than not the inclusion of relatives within an already economically constricted care trajectory brings in just more problems, especially when it comes to dying, questions of inheritance, emotional distress, unvoiced regrets etc.. The role of the professional is to keep his or her distance to these secondary and tertiary conflicts, and mediate on the patients behalf, if no consent is given, relatives are not to be involved at all, making the care trajectory much easier. It stands also to argue that despite schooling and complexity induced fragmentation of disciplines we should question whether it is a good idea to medicalize a basic, inherent human experience – Death¹⁴⁵ when it comes to the patients relatives, or if the engagement should be a reduced, hands off approach leaving the autonomy of the relatives in conjunction with the patient intact and not interfere with human grief and coping mechanisms.

Between medical ethics and palliative care ethics we find a shift in the two primary stakeholder conceptions - the doctor and the patient – caused by the inclusion and pursuit of extrinsic goals, in addition to the already present intrinsic goals, within palliative care. The medical professional is exposed to higher, more personal demands in dealing with the patient; motivated by whole person care he or she has to be a capable caregiver schooled in techne and a capable person possessing phronesis. All the while facing the patient not from a standpoint of authority but on equal terms in a team setting. The patient has increased rights as an autonomous person, which entails that the active shaping of the palliative care trajectory falls within the patients responsibility. Instead of passively choosing between treatment options as in medical ethics, the patients being is called into action, participating in shaping his or her end of life with even more self-responsibility in a distress situation – requiring more strength and attention from the patient than before.

142 See psychologists struggle: P. S. Appelbaum & T. Grisso: “*The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment*” in M Bull Kovera: “*Law and Human Behavior*” Vol. 19 No. 2 Washington D. C., American Psychological Association (1995) pg. 105ff, as well as: W.T. Carpenter et. al.: “*Decisional Capacity for Informed Consent in Schizophrenia Research*” in J. T. Coyle(ed.): “*Archives of General Psychiatry*” Vol. 57 No. 6 Chicago, American Medical Association (2000) pg. 533ff, also: C. W. van Staden, C. Krüger: “*Incapacity to give informed consent owing to mental disorder*” in F. Godlee (ed.): “*Journal of Medical Ethics*” Vol. 29 No. 1 London, BMJ (2003) pg. 41ff

143 Randall & Downie pg. 20

144 *ibid.*

145 If the changing DSM standards are any indication, defining normal from abnormal psychiatric states appears to be a fucking mess. see for example: S. Vanheule: “*Diagnosis and DSM: A Critical Review*” Basingstoke, Palgrave Macmillan (2014)

Summarily, in medical ethics the patient has the autonomy of choice, whereas in palliative care ethics the patient has the autonomy of a whole person to deal with. Adding care ethics to the mix we find that aside from the implementations of the shared values we should also investigate the presuppositions and the paradigms of the ethics, as to how are the actions motivated in a fundamental fashion and if there is need to explicate these hidden values. Despite the difference in stakeholder conception and implementation of action directives, the basic moral values at stake between medical and palliative care ethics are shared. The emphasis does shift, but when it comes to the moral values these two ethical conceptions are not that far apart as it might seem due to the drive of palliative care ethics to establish its take as a serious contender, and other separating effects on the level of professional fields. To put it into one sentence; medical and palliative care ethics are two different ethical conceptions rooted in the same moral values, and are not mutually exclusive in a fundamental fashion as say deontology is to hedonism.

Chapter 4 - The Palliative Care Stakeholders - Practices, Ethics, Research & Experimentation, and the Introduction of TCT into Palliative Care

4.1. Introduction to Palliative TCT

After initial research of the topic "TCT usage in palliative care" - and the field of palliative care in general - one is left with two broad avenues of research open to pursue. One option is to engage in practical research, for a master thesis meaning the attachment of the student, yours truly, to a specific project and to engage the TCT within the projects, to investigate while being suspended in narrative constraints as well as research parameters to be able to have specific results of the effort. The second option entails what I have done in this master thesis proper, an attempt at the effects of TCT introduction into the field with relevant stakeholder groups of palliative care identified - combined with an understanding of its history and ethical backing between the stakeholders as to map the changes in ethical values, their constitution and modification, as well as the potential for moral & ethical conflicts and their resolution. An ethical-moral focused discourse analysis if you will.

Guiding this attempt was the set of sub-research questions as postulated in the introduction - Who are the relevant stakeholders involved ? How do stakeholders react to the introduction of telecare devices into palliative care scenarios ? Are there conflicting values and practices between stakeholders ? Are there shared values and/or "blind spots" between stakeholder ? and finally, is there a perspective to resolve the eventual differing values and practices ? The combination of which gives us the answer to the central research question as a mosaic of human interactions.

The literature forming the backbone for the descriptive reconstruction and the analysis to follow below was collected by a rather straightforward process that has to do with the overall scope of the field itself and the scope of this thesis. Simply put, I utilized any text which combined the quite small field of palliative care (which can be quite young depending on the country location of the research conducted – see Chapter 2 for more) with the even smaller field of TCT research aimed at this specific context of palliative care.

As most proper attempts only date back about ~20 years, the research data to be used within the size of a master thesis was limited to begin with. Search terms were any variation of terms like "Telecare", "Palliative Telecare" and "Remote Care" via Google Scholar, and subsequent searches within publishers databases to get behind those damn pay walls. "Science culture"-wise speaking the result was a lot of material coming out of the U.K. context of palliative care research, unsurprising given the aforementioned history - conforming to international standards of research, empirical imperative, statistical significance, and RCT-styled setups if possible.

The specific set of papers used – see Appendix A – range in publication date from ~2000 to 2014 – covering research that goes back as far as ~1988 (that is, in their references). Their content being specific to TCT in the following applications/ways: pediatric home care, palliative home care, hospice and hospital bound care, and general digitization efforts in nursing and palliative care, as well as in medicine in general. Method-wise these papers mostly consist of small scaled experimental setups, while their assessments were based on two major quantitative techniques – in addition to first hand observations - the semi structured interview with codified answer forming the statistical backbone, and standardized questionnaires for a variety of stakeholders that were of interest to the study/chosen aspects in question.

A subset of papers utilized are literature reviews and analysis, aiming to provide comprehensive overviews over research progress and attempting to explicate issues that are being worked on, have been solved or just recently arisen and or neglected. In combination with the different foci set within the papers some deal with clinical appropriateness of the devices, others with the practicalities of provision or haptics, or integration into existing clinical structures, etc. etc.. The papers selected give a broad perspective of the issues TCT has an impact on; in addition they also provide a semi-stable stakeholder set. You add some or lose some depending on the extant focus, for example one paper dealing mostly with TCT integration aims at the professionals crowd at the expense of the patient being “the target audience” in the most passive way. And lastly they are not too long, not too specific as to break the size limits of a master thesis regarding their total volume.

Now in practical terms for this chapter, I will first give an outline of the technological development that took place within the what I call the "quantitative discourse" - papers which research designs utilize empirical, objective methodologies - like RCT's - to obtain verifiable data pertaining to the different, previously identified, relevant stakeholder groups. And of course before diving from the technology description into the stakeholder analysis I will outline my research approach towards the literature and the guidance of the central research question it provided. Explicating my methodology as to how reading and engaging the relevant research literature as to satisfy academic full disclosure. Following this I will get into the stakeholders presented as relevant within the literature researched in accordance with my methodology. The first two stakeholder groups are the most varied in terms of the constituting people that form them and also the most important, since their interaction is at the very center of palliative care - the patient and the medical doctor - a.k.a. "the primary care relationship". From these central two stakeholder interactions all other stakeholders are suspended on either side - adjuncts to either the patients or the doctors. Included are the most important secondary stakeholders; the informal caregivers on the patients side - usually a varied ensemble of family members and close friends. And the hospice, hospital, and on-site care nurses on the doctors side of things, whose inter-actional relation is largely predetermined by the immediate, discrete, contingent interactions & relations between patient and doctor. One further step removed are the tertiary stakeholders, consisting of the technology manufacturers, the designers, hospital administrative staff and health care managers. They add non-medical, economic dimensions to the TCT in palliative care-scenarios and relate mostly to secondary ethical issues like distributive justice - which are important, but do not stem from the primary care relation between doctor and patient directly. This is the stakeholder line-up for the mainstream, quantitative discourse I will reconstruct in the following sections. These characteristics that follow are also relevant for the qualitative methodology of Pols in Chapter 5, differences in the relevant stakeholders will be outlined within the end section when appropriate.

After the stakeholders, this chapter contains an analysis of what the expected and real outcomes are in terms of value constitution and realization – attempting to answer my main ethical research questions about the modifying potential & influence that TCT might have had on the stakeholders ethics. I will find that within the boundaries of the quantitative methodology, the experimental, prototype setups - and on its own terms of scientific quality/veracity even - the answers gathered are insufficient & falsify my hypothesis regarding the impact palliative care ethics I presumed has had - in that it hardly had any impact at all & conflicts/mediation remain unrealized. Reflecting on the quantitative methodology as such the last section of this chapter contains a meta analysis of the quantitative methodology and its specific shortcomings dealing with TCT & TCT ethics in palliative care – engaging the research contextualized in anticipating the example of a qualitative, alternate approach of Pols that is covered in Chapter 5.

4.2. Technological Development - The TCT Devices and their Capabilities

The development of TCT technology is tied inevitably to the change in communication tools and behaviors in society in general. The curious part is, that all technologies utilized for TCT palliative care have been adaptations of consumer devices into the medical-palliative context. There has been no original development of devices within palliative care, but akin to the syringe driver, using modified gear to serve their needs is oddly fitting for a discipline that is so entrenched between fields to adapt societal developments of communication tools.

Now the progress of the telecare devices as it mirrors social communication developments started with the closest modification of the precursor technology - the telephone. Simply enough the earliest TCT trials and experiments utilized video-telephones marketed to the general public¹⁴⁶ - those emerged in the mid 1990's out of their precursor technology of room sized video-conferencing technology utilized mostly in large, multinational companies. Though the technological roots go even further back¹⁴⁷, these variants were the first large scale permeation of end users by this type of communication technology - and subsequently the first to enter into the palliative care setting due to having achieved this critical market saturation. With this first usage of the technology comes of course the prototype status and associated issues that need to be worked out along the lines, a first learning experience for palliative care professionals facing a high-tech device in their low-tech field.

The video-phone technology rests on using the existing phone lines in order to not necessitate a new infrastructure to be built for an untested technological product, though later iterations switched to ISDN¹⁴⁸ systems due to the stress the video-signals had put on the plain old telephone system (POTS) in the earliest models. The quality of the compression algorithms as well as the pure amount of data meant that the POTS was unable to handle the stress and frequently the trials of POTS-based videophones broke down even over short distances. In one experiment two rooms on opposite ends within the same building were to be connected for a demo setup, and the lines buckled under the data volume¹⁴⁹.

In addition to these reliability problems, the end users took issue with the devices themselves. First off, the screen size was adequate for most people at the time, but due to the utilization in an assisted living facility, visually impaired seniors were disproportionately challenged by the screen size. Patients with hearing aides reported feedback issues triggering high pitched noises in the aid, and subsequent attempts at lip reading to compensate were unsuccessful due to lag spikes and general choppy conversational style caused by the overworked phone-lines, making it necessary for the participants to repeat themselves and wait for confirmation, eliciting an awkward conversation flow.

One positive aspect voiced by all users of this first version of TCT was the easy handling of the device, not surprising since it was a normal telephone that the users were familiar with, which had a screen bolted onto it. Lastly, the first generation TCT's were subject to strong economic considerations; as an unproven technology facing break-even and constrained budgets of hospices and hospitals with about 500\$ per unit prices, an issue recurring in the adaptation of the second generation of TCT - the workstation coming up next. Though eventual bulk discounts & price drops

146 see: D.R. Park et.al.: *"The usability of videophones for seniors and hospice providers: a brief report on two studies"* in E. Ciaccio (ed.): "Computers in Biology and Medicine" Vol.35 No. 9 Amsterdam, Elsevier (2005) pg. 782 - 790: as well as: http://www.eetimes.com/document.asp?doc_id=1273559

147 see: <https://www.google.co.in/patents/US2079880> the earliest patent for what we would call a video-phone, in that it transmitted video and audio simultaneously. It is from 1937.

148 D.R. Park (2005)

149 *ibid.*

resulting from Moore's law¹⁵⁰ impact on microchip designs and TCT device retail prices solved the issues eventually for the most current, tablet-based TCT designs available (e.g. Apple iPad).

The second iteration of TCT was the so called workstation setup, these systems were stationary computers mounting videoconferencing equipment plus software¹⁵¹. The reliability of the devices that eventually ended up using ISDN and early DSL systems was improved significantly over the video-phones, and with refined compression algorithms and better throughput the video and audio quality improved as well. Still user issues remained, as the workstation was to provide proper telecare - and not serve as a somewhat gimmicky replacement of the telephone - and the stationary nature of the device made it difficult for a majority of its targeted patient population to use it to full effect. Elderly diseased people tend to be on the physical frail side of things and were often incapable of getting in front of the workstation and sit upright for prolonged periods of time, while also being awake and alert throughout the contact. As in the video-phone systems, the workstation computers were off-the-shelf consumer devices with common web-cams and communication software installed and sometimes mounted on a chassis of sorts for easy movement within an assisted care facility or patient homes.

Despite improving the technological reliability, the workstation setup came with the drawback of being a very bulky, very present device, and if utilized in patient homes it tended to reinforce the feeling of a medical invasion of the home setting that could unsettle the patient and impact anxiety scores in a negative fashion. Also the improved audio and video quality came with increased technological prerequisites - needing ISDN or DSL access points to be utilized, the TCT devices were challenging the overwhelming majority of TCT recipients home infrastructure. By virtue of being old, the patients were not really what one could consider early technology adopters, and frequently TCT programs had to face this absence of minimum technological capacity, and to somehow make it work, getting broadband access ports out there in a timely fashion. More often than not this led to frequent losses in patients trust as they had to wait for technicalities to be resolved as two or more institutions had to coordinate - lengthening the utilization of common care in the meantime and foregoing TCT's potential impact/benefit. This aspect is much less present if dealing in all things pediatric palliative care, where the younger generation is more likely inclined to be using cutting edge communication technology already. More on this special subgroup of patients and the "escalating factors" relevant to them in the respective section below.

Additionally the workstation is the first system in which the doctors could leave material for the patient to peruse on their own time, increasing self-care competency in patients and informal carers alike. As well as having the option to leave remarks and data for other medical professionals involved in the patients trajectory, i.e. the on-site nurse having access to most recent blood tests from the clinic, providing seamless and near-instant conveyance of critical patient data. This second TCT generation is also the first in which researchers experimented with remote telemetry readouts like blood pressure cuffs and oxygen meters as to broaden the clinical applications of the device¹⁵². Adding to the clinical perspective that the camera already provided for the doctor to be able to assess the patient's disposition and their living conditions in situ at home.

150 more on the impact of Moore's law: <http://cc.sjtu.edu.cn/G2S/eWebEditor/uploadfile/20130912204854152.pdf>

151 A. Stern et.al.: *"Use of home telehealth in palliative cancer care: a case study"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 18 No. 5 New York, Sage Publications (2012) pg. 297 - 300

152 A. Stern et.al.: *"Use of home telehealth in palliative cancer care: a case study"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 18 No. 5 New York, Sage Publications (2012) pg. 297 - 300

The third iteration of TCT that is distinct enough to warrant that label is the shift from the immobile workstations towards the semi-mobile laptop setups¹⁵³. Reduced in size and weight, the laptop form of TCT allows the previous functions of the workstation to be continued, with improved mobility and haptics added. The camera and audio quality keeps further improving due to the refinement & advancement of the consumer electronics that are being adapted; and the software side keeps pace with even better compression, lag elimination and generally improved haptics (“App” software concept). Semi-mobile the laptop improves usability in the home bound patient - though still hardwired - it is portable enough to be used in a variety of spaces and configurations within a house; most notably of course this benefited patients that are bedridden and could not get in front of a fixed workstation up to this point.

Later generations of the laptop setup started using wireless ports, allowing for even more increased flexibility. Aside from the mobility increase that the laptop systems provided over the stationary ones, the devices were still large enough that patients perceived them as intrusive in their home environment, and their weight was heavy enough to cause some issues with feeble and bedridden patients in using them for the prolonged time of a teleconsultation - averaging in duration of one hour. Also the haptic requirement and the level of minimum technological competency necessary to successfully operate the device increased with the workstation and the laptop setup, making it necessary to give extensive introductions to patients that when dosed with palliative medication are not exactly the most attentive and responsive crowd to begin with. This high entry barrier for correct use was/is a contributing factor to under-utilization of this TCT in elder patient populations, while in younger, more tech savvy patients the TCT providing institutions had to institute contracts limiting laptop usage to an acceptable level¹⁵⁴.

The fourth and latest iteration of a distinct TCT device is the adaptation of the pad/tablet PC concept, popularized by the market success of the Apple iPad¹⁵⁵ for example. Again, a common consumer communication tool is eventually utilized by the palliative care TCT undertaking. The main advantages of the tablet design are the size and weight. It easily disappears into a bookshelf or next to a newspaper/books, and the low weight allows even frail and bedridden patients to use the device effectively and for extended periods of time if necessary. Apps like “Skype” or “Facetime” with the big buttoned layout and intuitive touchscreen haptics reduces the necessary technological competence down from what was needed in workstation or laptop setups in a significant way; so that the majority of the patients, that are late adopters usually, can handle it. The intuitive aspect and responsiveness of the touchscreen scored very high in both primary end-users - patients and doctors - for utility, and the option to add informational material and direct links, available since the workstation devices, was taken more seriously and was better utilized. In part caused by the deep impact that the wireless broadband availability had on the distribution and consumption patterns of information technology.

153 see for example: A. Reis et.al.: *"Information and Communication Technologies in Long-term and Palliative Care"* in M.M. Cruz-Cunha et.al. (eds.): *"Procedia Technology"* Vol. 9 Amsterdam, Elsevier (2013) pg. 1303 - 1312 as well as: B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 - 161

154 N. Bradford - Australian failure study

155 see: J. van Gorp et.al.: *"How audiovisual teleconsultations between hospital-based palliative care specialists and outpatients challenge interdisciplinary collaborations between primary and tertiary care providers"* presented at the EAPC World Research Congress 2014, 5- 7 June, Lleida, Spain as well as: J. van Gorp: *"How outpatient palliative care teleconsultations allows for empathetic and intimate care relationships"* in *"PloS One"* Vol. 10 No. 4 (2015) (online publication)

The success on the tech side of things is largely owed to the smart-phone boom - of which the pad/tablet design is an offshoot - and the subsequent provision of the necessary infrastructure of wireless broadband access points for the palliative care TCT to use - mirroring the generation one efforts in avoiding the need for a specialized infrastructure for the video-phones. The advances of the broadband wireless system meant that instead of having to utilize hard-wiring like in generation two and three devices - and the attached scheduling issues - now all you need is a SIM card that has one contract attached to the hospice or care institution rather than the individual patient - allowing for quick seamless changes & handover of devices with no loss in provisioning density. Despite being not a native development of the medical sector it is used in, the pad/tablet design by chance and by well-designed haptics is the best technological device, best “fitted”, for telecare in palliative care presently available.

4.3. My Methodology of Analyzing the Relevant Research Literature

Before diving into the specifics of stakeholder conceptions and the subsequent delineation of values constitution and realization between them, I want to explicate my research approach to make clear to the reader how I engaged the researched material and of course to satisfy academic requirements of full disclosure pertaining to research setups in the general sense & the idea of reproducibility.

Guiding the stakeholder analysis and assessment thereof was of course the central research question regarding value realization in TCT usage in the field of palliative care, as how to read the texts and what particulars of ethics were payed attention to. Most obviously the first step was, and always is, to scan the texts while reading for any explicit mentioning of ethical assessments by the researchers - literally looking for papers that might have dealt with my central research question before as a form of textual assessment. Within the explicit content the literature researched rarely addresses ethical issues related to the TCT, almost all of the mentions that are being made are superficial, "here be ethical issues" statements. This is compounded by the fact that save for one paper¹⁵⁶, all of the literature was very positive and promotional in their attitude towards the technology. In a lot of the cases the researchers were conducting the TCT trial and writing about the impact it has on the care at the same time, leaving the uncomfortable impression of a certain bias, or hidden presuppositions of promotion. Due to the embedding of the experiments within certain larger telecare initiatives and policies¹⁵⁷, the researchers followed these policies to the letter when it came to the technologies necessity as such, reasoning that digitization is in a fundamental way (1) necessary for quality improvement in modern medical care and (2) that TCT is actually a desirable technology to have, distribute, analyze, and promote.

Before progressing further, I would like to position my research approach within the varieties of discourse analysis methodologies. As a good as ever a recommendation, one should not reinvent the wheel if all possible. Though I very much used a personal approach towards the discursive elements of the relevant literature, a characterization might help the esteemed reader to better appreciate and understand the thesis at hand & allow me to fulfill the academic requirement of reproducibility of this thesis¹⁵⁸. Past the more descriptive, textual analysis first step as explicated above, the second layer of discourse analysis utilizes elements of thematic analysis, themes and topics around which the discourse is developed. my observation hypothesis aimed towards a topical analysis of the ethical impact of palliative care ethics. With the assumption that it had any impact on

156 Bradford et.al. (2014)

157 For example; the ePCS system trialed in Scotland is part of a much larger NHS initiative for digitization in the U.K. healthcare system. ee footnote 29 above.

158an excellent primer on discourse analysis methods written by J.R. Ruiz can be found here: <http://www.qualitative-research.net/index.php/fqs/article/view/1298/2883>

the stakeholder constitutions - yet it emerged that the core topics were much more in line with medical care ethics provisions, since medical ethics allows much better fitting of the quantitative research methodologies to the research conducted. This thematic analysis is combined with inter-textual analysis¹⁵⁹, leading up to the meta topic of research methodology in general, as it eventually emerged in contrasting the quantitative with the qualitative methodology. The notion that within the quantitative discourse the elements of accepted science have to be fulfilled and are propagated as in order to be admitted into the larger, overall discourse. In essence the researched relevant stakeholders become somewhat pawns to the veracity and efficacy claims of the quantitative methodology.

Aside from the obvious step of looking for and analyzing the explicit, textual statements in the relevant literature literature, it helps to also engage the researched papers from a historical perspective, tracing the stakeholder attitudes, values and practical embedding over time as the discourse progresses (collated papers used: Appendix A). This is to be done in parallel to the content-leveled, literal search for ethical issue statements. Being able to identify the time-line - the steps - of the TCT development and assessment between the papers enables the proper alignment of the central piece that is the stakeholder analysis. Within this historical perspective of development, there is much knowledge to be gathered by - as a third step - also collating those stakeholders that do not explicitly show up - or show up too little despite being very numerous (informal caregivers) - indicating under-researched, neglected, or ignored stakeholders in preparation for the lineup to follow. Larger trends emerge in the stakeholders that are treated as relevant and investigated due to the over-watch position the historical approach provides; for example the somewhat stable conception of the nurses as the helping hands to the doctors and their (presumed) total authority across papers, or the fuzzy defined activities of the informal caregivers and their impact on the patients quality of life.

The methodological challenge is how do we actually trace changes in ethical attitudes in those papers that do not explicitly make this aspect a focus of their work - which entails almost all of the relevant papers used. Easily enough, since of interest is the observance of change, the essential aspect of "changes in ethics", the very foundation of stakeholder action planning and attitudes, is something that never goes of without a hitch. Conceptually no change in ethical compositions within a fixed group ever went out swimmingly, there are always hiccups, foul-ups, attempts at keeping the status quo, and extremist positions of revolutionary (and counter-revolutionary) quality to be observed and traced, tough not all at once or to the same extent depending on context. Now in palliative care embedded in the very strict medical ethics with the long history attached any change to the ethical foundation should be easy to observe, even indirectly in research literature touching up it - in a poetic picture: the more rigid/brittle the ethical system under "evolutionary" pressure, the easier to see the fine cracks in its surface. Important to keep in mind is while looking for said cracks in the development and adaptation of the technology under question modifying the stakeholder setup the way it is presented can give us clues as towards the realization or disappearance of the ethical conflicts.

Another good indicator of these "cracks" we are looking for, is the escalation of organizational disconnect, between the stakeholders, indicating different ideas of use patterns, or what is deemed acceptable technification and what is not. Which has to be put in combination with the relevant agenda that this technological attitude is embedded in, for example: the prime concern of the hospital managers is classical economic efficiency, the distributive justice value is an accidental adjunct to this. In organizing a hard data driven distribution of nurses schedules and TCT access, the

¹⁵⁹an exemplar for the intertextual analysis is the work of N. Fairclough: *"Language and Power"* Harlow, Addison Wesley Longman Ltd. (1989)

manager in this example is always expressing and modifying a distributive justice value set, even if he/she might not be aware of it. allowing us to see the expression and modification of ethical values even if they are not explicitly addressed on their own.

In contrast to this stark numbers-driven approach we can position the nurses actions, they tend to know the patient better and more intimately, say regarding the extend to which they desire or reject TCT project advances in practice, thus being able to provide better alignment at the cost of objective precision; the researchers for example assume that the patient is a stable stakeholder, with fixed baseline attitudes, whereas any palliative nurse could provide the extant feedback that even over the course of a day patients attitudes vary wildly depending on the disease trajectory/flares. For these implicit aspects, it is necessary for me to abstract from the stakeholders action in the above explicated way, as to reach proper alignment with my research interest - which is odd, since topic-wise the TCT experimentation is conducted in a highly ethical environment that has very strong and partially old, tried and tested positions, yet these are not engaged/challenged¹⁶⁰, staying in terms of scope on the level of the (presumed) neutral technological device. An example for this type of assessment is explicated in the Interlude III further down in the chapter, serving as a practical reminder in preparation of the value section of the stakeholder analysis - the veritable heart of this thesis.

4.3.1. Interlude III - Text Analysis Examples

Two studies conducted by Bradford et.al. express some of the issues I want to highlight, so I will use them as practical example for what I mean regarding the search for methodological- practical(-ethical) disconnects in the literature's relevant study designs. In general, the baseline pain conception that was employed in the researched papers was limited to the analysis and alleviation of physical pain symptoms in the patient - the efficiency and efficacy of which determined the overall success of TCT as a medical-technological intervention. The care as it is phrased to be delivered via TCT was aimed at the assessment of physical indicators of pain, and the conversations were build on the treatment of physical pain. Other pain types that were explicated sometimes; social, psychological, etc. as they are conceptualized in the total pain concept as intricately context bound by the specific patient stakeholder, were less emphasized to begin with, and treated as separate, secondary effects in the stakeholder interviews and questionnaires - complex, subjective issues reduced into quantifiable numbers in favor of statistical analysis, losing/precluding the potential for deeper, more realistic depictions and discussions of relevant moral-ethical issues of the stakeholders.

A practical example for this can be found in the Bradford et.al. 2012 pilot study (which was eventually abandoned due to attrition rates), with the utilization of a specific questionnaire, the "Quality of Life in Life-Threatening Illness - Family Carer" questionnaire - QOLLTI-F in short - that warrants a close look; since it ended with such sophisticated conclusions as: *"We found caregivers equally satisfied with the provision of palliative care [pain medication only] and the location of that care, regardless of the use of HTP [telecare project] or not. Two domains of caregiver quality-of-life require further study: their finances and their emotional and physical state."*¹⁶¹. This is the only time the caregiver is engaged as a more or less whole person is in the very last sentence of the conclusion as "here be distributive, emotional, and physical issues...eventually" - spoiler alert, the result is so abstract/sub-par due to the compression loss of the complex socio-emotional, personal issues of the carer, who are forced to express them as an abstract number

160 (heraus-)gefordert

161 Bradford et.al. (2012) pg.

ranging 0-10.

The designers of the questionnaire, Cohen et.al.¹⁶², were confident as to the proper usage of it would result in the correct depiction of: state of carer, patient well-being, quality of care, outlook, environment, finances, and relationships¹⁶³. A multistage development of the questionnaire took place, with multiple 40+ professional teams reviewing the phrasing and topical cohesion of the questions. Additional checks were made for the relevant time-frame of the questionnaire (2 days, as to actually account for a somewhat unstable caregiver stakeholder!), and the application window of the questions (last months of patients life, grouped under "terminal phase" by the researchers) - with the usage guidelines being a point in time process over the course of the disease trajectory. Phase 2 of the project clarified terms further, deleted some items and made explicit that the patients death is not to be mentioned at all, "*We expect that the question about preparation for the future [...] is interpreted within the context of the imminence of the patient's death for those who are aware of it.*"¹⁶⁴. Which makes utilization contingent on doctors information policy variations, coupled with the idiosyncratic attitudes of the actual family carer being relevant, but not depicted in the questionnaire, since the researchers felt that "*Items that decreased the interpretability of the principal components analysis or that had poor distribution were eliminated*"¹⁶⁵. Of course, with such a handy adjustment, the statistical check for internal consistency for correlations of the questionnaires responses was accordingly good, with the far spread across seven very different topical factors the questionnaire exceeded the necessary value of 0.70 of the Cronbach alpha¹⁶⁶ for its correlating sub-questions, even across multiple applications of the questionnaire to the same carer group.

The questionnaire was also translated back and forth into French, since it was to be used in Canada primarily, and the result was that the French version was answered on average with more distress, helplessness and less time for self care of the carers. Sadly it remains undetermined if this was caused due to the translation, cultural attitudes, or baseline more extreme/escalated conditions in the cared for patients - indicators are present, but not analyzed, that it was presumably due to overall worse patients conditions. Testing for consistency of the questionnaire between applications, the researchers found stable enough values for the topics, with intraclass coefficients of the items going up, save for patients assessment by the carer which went down from 0.58 to 0.50, despite which the researchers felt "*It is also reassuring that most carers rate their relationships with the patient and others very highly. Again, we do not know if this reflects problematic items or realities*"¹⁶⁷.

The compression of the relevant issues to the carer as a deciding stakeholder in the patient care within this questionnaire is so high, that the minimum complexity and subsequent attention that these issues warrant is lost due to the expression of said issues as a number between 0 and 10, making the resulting overall statistics in an experimentation like Bradford's, which additionally faces low recruitment and high attrition utterly meaningless past general constitution of "here are potential, complex ethical issues".

162 R. Cohen et.al.: "*QOLLTI-F: measuring family carer quality of life*" in C. Walshe (ed.): "*Palliative Medicine*" Vol. 20 No. 8 New York, SAGE Publications (2006) pg. 755 - 767

163 *ibid.* pg. 756

164 *ibid.* pg. 759f

165 *ibid.* pg. 760

166 A statistical, psychometric evaluation, its calculation expresses the consistency and intensity of correlations of a list of items, usually utilized in psychology and social sciences statistics. 0.70 is the minimum value needed to consider the statistic at hand good enough to be acceptable/reliable. For a short primer on the Cronbach alpha see:

<http://www.bmj.com/content/bmj/314/7080/572.full.pdf>

167 Cohen et.al. pg. 763f

Now for an example of the semi-structured interview variety: in a second, more extensive study of Bradford¹⁶⁸ they forewent the questionnaire in favor of a self designed interview guide for semi-structured interviews as a more intense and potentially more yielding methodology, lets take a gander at those then. Even with the self-designed questions the researchers did not break out of the pure technological enframing of the TCT, the questions in question's phrasing is an indicator for that, coupled with the guideline of what the expected answers are, and the "why did it not work ?" reflection following of both; question 1: "*what do you consider the most important interventions to support a child receiving palliative care and their family at home ?*" (relevant usage situations), questions 4&5: "*do you think there are any benefits/limitations for using home tele-consultations to support families ?*" (what it says on the tin), or question 7: "*what do you think the barriers are to home video-consultation for palliative care ?*" (expected practical example)¹⁶⁹. The answers of the interviews were compiled and codified into three distinct blocks: Technology factors, service factors, and individual factors. The one relevant for addressing bona fide ethical issues was "individual factors" which exhausted itself with general assessments of cultural, socioeconomic speculations of preference of face-to-face over telecare conversations, the primacy of in-hospital patients over TCT contacts, and the general rejection of the replacement narrative¹⁷⁰. And culminating in the discussion of the techno-logical feedback of the professionals, the researchers indicate that they knew the questioned professionals from previous experiments/co-operations, "*This may have biased the process of data collection. [...] Other types of evidence are required to fully understand this problem, and it would be helpful to understand this issue [TCT under-utilization] from the perspective of the families also; those who used the HTP and those who did not.*"¹⁷¹.

Some other citations and literature elements pointing towards the "cracks", the technological fixture of promotional attitudes, and lacking structures of the TCT research when it comes to holistic, realistic approaches: "*Telehealth can provide faster access to health care professionals, better use of time and improved efficiency of service delivery. [...] The community for which the process or system is targeted needs to be ready to accept telehealth and requires strong leadership and perceptions of the need to improve practice.*"¹⁷²; as well as the difficulty in assessing Quality of Life and the subsequent focus on anything remotely quantifiable: "*Historically, studies have proved difficult in this area [pall. care] due to low recruitment and a subsequent inability to show effectiveness. Measuring the effect of telehealth in palliative care is challenging as outcome measures such as quality of life are not easily attributable to the telehealth intervention. [...] There are however, a number of small but successful studies that demonstrate home telehealth to be a useful and feasible method of providing support to families. These studies have found a reduction in anxiety scores, enhanced communication between clinicians and families, and a decrease in unplanned admission rates to hospitals and health care utilization.*"¹⁷³.

And some more citation gems to drive home the point (highlights by me): "*What remains unknown is whether within these populations [pediatric oncology, pediatric cardiology, adult oncology, adult palliative care], there are intrinsic differences that affect the acceptance or use of telehealth applications. Variables such as **goals of care**, access to alternative modes of care, **perceived need for care, comfort with using technology**, and even the physical location of the technology within either the home or health care facility may also influence use.*"¹⁷⁴; "*In pediatric palliative care*

168 Bradford et.al. (2014) Australian failure study

169 Bradford et.al. (2014) Table 1

170 ibid. Table 3

171 ibid. pg. 9

172 L. Kidd et.al. (2010) pg. 7f

173 Bradford et.al. (2013) pg. 11f

174 ibid.

particularly, there is little known about barriers, benefits and limitations, factors influencing use and the economic implications of telehealth applications to support home care."¹⁷⁵, and the veritable nail in the coffin for any realistic assessment of TCT via the quantitative discourse: "Over the last decade a number of studies have attempted to measure the outcomes of telehealth applications in the home setting for this population. The inability of these studies to establish effectiveness demonstrates the difficulty of measuring an effect of an intervention such as telehealth in palliative care"¹⁷⁶.

4.4. The Stakeholders within the Palliative TCT Engagement

The following three sections will address the stakeholder conceptions as they are present in the specific discourse pertaining to the last ~20 years of TCT device development outlined previously. The main line of reasoning is along the primary care relationship (see below) and rests on the functionality of the quantitative, empirical methodology. The following sections are to explicate exactly how the stakeholders are enframed within the research papers and how their interactions are positioned within the parameters set by the experimenters. After which follows my value analysis of this particular discourse, attempting to answer my own research questions regarding the value modifications I expected regarding the introduction of TCT into the palliative care trajectory and the subsequent changes in stakeholder conceptions and interactions.

4.4.1. The Primary Stakeholders - Patients & Doctors

Central to the discourse of TCT in palliative care is the constitution of two stakeholders and their linear relationship to each other - the patient and the doctor. According to the papers investigated, the relationship between these two stakeholders is shaped in a very particular way, a procedural trajectory, possibly ranging from initial engagement at the beginning of the disease up to the very end of the terminal phase. Understanding the constitution of these two groups (and respective subgroups on the patient side) is critical for success in promoting TCT and palliative care in general as well as within the quantitative discourse that is to be traced and analyzed in this chapter.

In addition to being of said central importance, these primary care stakeholders involve one of the most complex, varied, and infuriatingly hard to grasp stakeholder group - the patients. Due to the inherent, essential aspect of palliative care - the care for the dying - literally any person in a society can become part of this stakeholder group, if contracting the "right" disease. Making it a wee bit challenging to give a satisfactory outline in terms of cutting edge precision. Nevertheless, the papers investigated and reconstructed in the following undertake attempts by looking at the two groups of patients that make up the vast majority of this grouping. The (very) young and the very old patients respectively. The terminal disease phase as participation criterion for the group of patients follows a Gauss bell curve, shifted towards old age, with an additional bump towards the zero point of the x-axis accounting for exotic, high-death-rated birth defects and genetic diseases (see Illustration 1) – so from a statistical point of view, which the quantitative methodology claims,

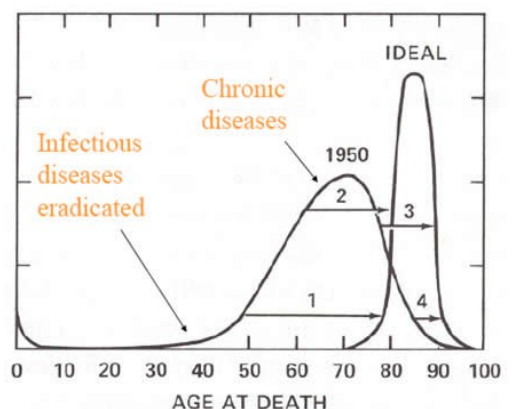


Illustration 1

175 *ibid.*

176 Bradford et.al. (2013) pg. 12

pretty much all the patients are included.

4.4.1.1. The old Patients

The standard target audience since the earliest TCT efforts and still the ruling champions in terms of participation in palliative care efforts, is the old patient. The papers begin at the mainstream medical conception of the patient within the medical encounter for the longest time having been that of a passive recipient of the medical professionals activity. The patient faced recommendations and directives drafted by the doctor in a clear cut, top down hierarchy: "Take this medication, undergo this surgery and it will make you healthy again". With the refinement of disciplines in the medical sciences, the advent of the palliative care movement, and general increase in treatment complexities the patients inclusion and active participation in mediating their own therapy and care trajectory eventually emerged within mainstream medicine. The long standing hierarchies and the top down recommendations of the doctors have been replaced, thanks to the patient rights movement and the emergence of the aforementioned Georgetown mantra of Chapter 3 - and infused a need to respect the personal idiosyncrasies of the patient, rather than framing them as a piece of defective meat in need of fixing. Following this development, the next step in terms of patient inclusion is depicted in the investigated literature coming up now - due to the specialized circumstances of palliative care as a medical discipline. As previously mentioned the attention of palliative care is almost exclusively focused on cancer patients due to the "good" fit of the disease trajectory in general. Being a chronic disease with a gradual deterioration of capacities - this focus in the papers applies to both patients groups, with most recent efforts attempting the inclusion of other chronic conditions, like Chronic Obstructive, Pulmonary Disease(s) (COPD)¹⁷⁷.

As a group the old patients are framed to be late adopters of technology in general, and any productive approach in terms of TCT should address this particular circumstance -providing a combination of easy to use technology, haptics, and good, simple instructions is key in terms of the direct, techno-logical interactions with(-in) this stakeholder group. Demand for TCT and its combination with traditional care interventions is existent, the earliest experiments¹⁷⁸ show that there are high hopes for the technology in the old patient group and a positive attitude all around towards the devices concept¹⁷⁹.

Despite their late adopter status, the patients intuitively mapped out the intended utilization for themselves: ability to see friends and family despite physical limitations, connect with other palliative patients as a group and socialize, and to contact ones personal physician and nurses for consultations and counseling¹⁸⁰. The possibility of the devices allowing them to stay at home longer, without loss of quality in terms of care and provisioning, as well as a normal life to be lead is the main selling point/angle of the quantitative narrative. These desires towards the technology are mapped as the key to this user group – in a marketing sense, the end-user the narrative aims at - and any issue with the background infrastructure and technological reliability will have severe impact on the positive attitude towards the device and the concept of palliative TCT.

177 R. Gaikwad & J. Warren: *"The role of home-based information and communications technology interventions in chronic disease management: a systematic literature review"* in R. Procter (ed.): "Health Informatics Journal" Vol. 15 No. 2 New York, Sage Publications (2009) pg. 122 - 146

178 D.R. Park (2005)

179 N. Coyle et.al.: *"Audio-Visual Communication and Its Use in Palliative Care"* in R.K. Portenoy (ed.): "Journal of Pain and Symptom Management" Vol. 23 No. 2 Amsterdam, Elsevier (2002) pg. 171 - 175; G.C. Dolittle et.al.: *"Hospice care using home-based telemedicine systems"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 4 Suppl. 1 New York, SAGE (1998) pg. 58 - 59

180 D.R. Park (2005) & A. Stern et.al. (2012)

The technical demands voiced by this user group in the experiments are simple, but deceptively so: reliability is an assumed given, as a basic as a requirement towards technology can get, but earlier TCT devices utilized disappointed in that regard¹⁸¹ and dampened the initial positive attitudes to a more realistic attunement to technological progress. Ease of operation, haptics, size, and weight complete the set of core requirements of the old patient towards the device.

4.4.1.2. The young Patients

The younger patients are postulated as the second major subgroup for the patient stakeholder formation, though smaller in total numbers, and are sharing most of the issues in terms of disease and palliative attitude with the older patients.¹⁸² Same as in the old patients, the focus of the papers dealing with young patients is also most exclusively on cancer trajectories - though due to the circumstance of age there is a prevalence of more exotic, rare and often more aggressive forms of cancer that usually lead to tighter & faster escalating palliative care trajectories and higher attrition rates. A close second sub-disease grouping researched is that of exotic birth defects with severe impact on life expectancy, though the TCT in this context tends to be remote surveillance and contacting for parents, as to have more flexibility in reaction to personal life obligations and medical isolation procedures - while important these aspects of TCT are not the core concern of this section of the chapter nor thesis.

Setting apart the young patients from the old, is the relationship to the informal care givers as the most obvious, and jarring difference described in the papers. In the old patients the informal carers tend to be framed as either spouses, children and to a lesser degree friends and neighbors that engage a fully developed human being with a life well lived - ideally that is. In pediatric palliative TCT experiments the informal carers are depicted as being uniformly worried, distressed parents, siblings and relatives. The need and overall desire as well as the appropriate attention on the professionals side for the home environment during palliation is taken as the prime imperative in drafting care trajectories. Generally speaking, in the papers the existing issues of the old patient are intensified in the pediatric patient, akin to an ethical magnification glass, which also makes research into this subset of palliative patients extremely difficult, as ethical barriers for research approval are appropriately high in addition to high attrition rates and low initial recruitment possibilities¹⁸³. The young patient is poised in the papers as to engage the technology in a different way than the old patient; as the TCT devices are derivatives of consumer communication tools and their modification of behaviors and cultures, the younger patient is framed as the polar opposite of the old patient - they are deemed early adopters.

Due to the massive numbers advantage on the old patients side, the adaptation of the TCT tends to be done the conservative, easy to use way - thus clashing with the communication behavior and desires of the younger patients. The base demands are the same of course, like accessible haptics

181 D.R. Park et.al. (2005)

182 M. Bensink et.al.: *"Paediatric palliative care with Internet-based video-phones: lessons learnt"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 10 Suppl. 1 Thousand Oaks, SAGE (2004) pg. 10 - 13; N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic review"* in I. Pala (ed.): "BMC Palliative Care" Vol. 12 Article No. 4 Berlin, Springer (2013); N. Bradford et.al.: *"Home telemedicine for paediatric palliative care"* in A.C. Smith & A.J. Maeder (eds.): "Studies in Health Technology and Informatics" Issue 161 Amsterdam, IOS Press (2010) pg. 10 - 19; as well as: S. Levy et.al.: *"End-of-Life and Living Technologies, The role of Telemedicine in palliative care of children and young people"* presented at Pervasive Health, Dublin, Ireland (2011)

183 a good example: M.E. Bensink et.al.: *"Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study"* in C. Walshe (ed.): "Palliative Medicine" Vol. 23 No. 3 New York, SAGE (2009) pg. 228 - 237

and a baseline reliability of the device. Yet research shows potential for a schism in communication conduct, as young patients add desires like: unlimited internet capacity, unhindered, deeper reaching control over a laptop or tablet PC, as well as a desire for privacy and the aversion of the clinical eye. As an anecdote; one experimental setup in Australia had to implement contracts with the young patients regarding proper usage of the TCT laptop¹⁸⁴. A necessary disclaimer of course is that akin to the older patient subgroup the individuals disposition towards technology is a decisive wild-card element and that to address every potential combination of individual disposition was not possible within the papers investigated.

4.4.2. The Medical Doctors

The second half of the primary care relationship is the medical doctor facing the patient. Positioned in the research papers as strict adherents of the medical ethics outlined in Chapter 3, they are to play a crucial role along any patient trajectory¹⁸⁵. As the patients stakeholder group changed over time, so did the doctor with it. The classic relationship for the longest time was described as that of the doctor giving top down strict hierarchical organized advice and treatment recommendations to the patient. To a large extent they were also the ones immediately executing said recommendations respective to their professional specialization. The content of the medical trajectory was not something the patient was involved in and the patient was relegated to the passive role outlined¹⁸⁶. Similar to the patient stakeholder group, the doctor stakeholders are positioned as a very varied group in terms of personal experience regarding palliative care trajectories and TCT devices. The vast majority of doctors has only tangential knowledge of palliative care efforts and ethics in particular - with the attitudes propagated being that the death of the patient is the failure of the doctors actions rather than the logical outcome of life itself. This prevalence of marginalizing death leads to specific impact of the doctor stakeholder group onto the TCT trials in palliative care - the authority of the medical ethics standard over anything related to the care trajectory options and measures undertaken as we will see later on in this chapter.

As for their evolution before and during the investigated TCT trials, the doctors had to adapt to the patients more active involvement in their own trajectory - part patient driven demands, part medical reformation in the disciplines, the hierarchies that used to govern this stakeholder group have changed towards a patient-centered approach over a treatment-centered one. The idea of patient control as it is embedded in the ethical obligation regarding autonomy emerged as crucial in governing the doctors stakeholder groups efforts in any given direction as a precondition for the experimentation. The patients interests, as however they are constituted, hinges more on mediating skills than medical, objective ability within the doctors – essentially the doctors have to market their recommendations more and more to the patients disposition. Previously equipped with implicit competency the doctors turned from an unopposed, specialist of his trade into a mediator and manager for a medical good he or she is providing to a clientele with opinions and power. The

184 N. Bradford et.al.: *"Home telehealth and paediatric palliative care: clinician perceptions of what is stopping us ?"* in J. Mockridge (ed.): *"BMC Palliative Care"* Vol. 13 Art. 29 Berlin, Springer (2014)

185 see: P. Whitten et.al.: *"Addressing telehealth's foremost barrier: provider as initial gatekeeper"* in M. Mäkelä (ed.): *"International Journal of Technology Assessment in Health Care"* Vol. 21 No. 4 Cambridge, Cambridge University Press (2005) pg. 517 - 521; *"Providers' acceptance of telehospice"* in C.F. van Gunten (ed.): *"Journal of Palliative Medicine"* Vol. 8 No. 4 Larchmont, Mary Ann Liebert (2005) pg. 730 - 735; and *"An analysis of provider perceptions for telehospice"* in R.E. Enck (ed.): *"American Journal of Hospice & Palliative Care"* Vol. 15 No. 5 Thousand Oaks, SAGE (1998) pg. 267 - 274; as well as: G. Demiris et.al.: *"Telehospice tools for caregivers - a pilot study"* in D.E. Gallagher-Thompson & L.W. Thompson (eds.): *"Clinical Gerontologist"* Vol. 31 No. 1 Abingdon, Taylor & Francis (2007) pg. 43 - 57

186 a prime example: B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 - 161

doctors as a stakeholder group experienced a communicative model shift, attached and derived from the shift to patient-centered care.

The classic one way communication with the doctor as the sole communicator and the patient as the recipient changed in favor of specialist team approaches to disease management. This, conjoined with the evermore growing complexity of medical interventions making the coordination of specializations necessary even from an overcome treatment-focused mode of communicating. The doctors end up being embedded and engaging in a two stage communication model: (1) the inter-professional specialist care team (SPCT) that discusses on a professional level the disease of the patient. Potential avenues of treatment, pros and cons of a chosen treatment, and in general engage in a swift, closed counseling of the leading physician that is in the end responsible. (2) The second stage is when the doctor consults with the patient, an added layer of negotiations with the doctor as the medically informed professional presenting options and recommendations - the actively involved patient giving feedback. The task proposed is that the doctor has to bring together a team of specialists with their own nuanced language and coordinate them successfully; and then having to break down the medical aspects and lingo towards the patient who is to make an informed decision, give consent etc., thus sticking to the ethical directives of the medical ethics.

The communicative escalation described in the discourse also means that the educational aspects of what is actually good communication becomes more and more emphasized in the doctors curriculum - or at least it should, according to the papers¹⁸⁷ - mirroring the fact that it takes up more and more time in a practice setting. The TCT mediated encounter is now the latest modification of the doctors communicative modes that needs to be integrated into the aforementioned two stage approach to patient doctor communication. As with the patients group prevalence for cancer-form trajectories as the chief disease of its population, it is most often the cancer/oncology qualified doctors leading SPCT's that are exposed to TCT and palliative care efforts and experiments.

4.4.3. The secondary Stakeholders - Informal Caregivers, Palliative Nurses, and Hospital Administrators & Managers

All the groups discussed in this section, the secondaries are all stakeholders whose constitution is derived from the immediate constitution of the primary care relationship and their impact can be seen directly in the primary care relationship. Making them powerful adjuncts to palliative care trajectories, though not to their full potential as they are an under-researched group¹⁸⁸ within the experimental discourse outlined in the papers. Later in this chapter, and in Chapter 5 as well, I will discuss the extant circumstances and issues faced by this set of stakeholders in that regard, with most of the attention going towards the nurses and the attached set of palliative care ethics.

187 an example for communicative shifts in TCT and telecare in general see: A. Reis et.al.: *"Information and Communication Technologies in Long-term and Palliative Care"* in M.M. Cruz-Cunha et.al. (eds.): "Procedia Technology" Vol. 9 Amsterdam, Elsevier (2013) pg. 1303 – 1312

188 S.V. Browning et.al.: *"Telehealth: Is Your Staff Ready To Implement ?"* in M. Anthony (ed.): "Home Healthcare Nurse" Vol. 27 No. 4 Alphen aan de Rijn, Wolters Kluwer (2009) pg. 242 - 248; G. Demiris et.al.: *"Hospice staff attitudes towards telehospice"* in R.E. Enck (ed.): "American Journal of Hospice & Palliative Care" Vol. 21 No. 5 New York, Sage Publications pg. 343 - 347 as well as: G. Demiris et.al.: *"Ethical considerations for the utilization of tele-health technologies in home and hospice care by the nursing profession"* in K.D. Sandford (ed.): "Nursing Administration Quarterly" Vol. 30 No. 1 Alphen aan den Rijn, Wolters Kluwer (2006) pg. 56 - 66

4.4.3.1. The Palliative Nurses

Differentiating nurses from the doctors as a specialized sub-set of medical personnel as far as the dualistic primary care relationship is concerned, this secondary stakeholder group did not undergo significant changes over time – that is according to the researched papers. The educational requirements in terms of medical competency follow the medical ethics mandated conceptions of beneficence and non-maleficence close enough, and the added layer of holistic care and warm, hands-on care is intrinsic enough to the discipline as it emerged historically from distantly attached Christian values of compassion and the role of playing foil to the cold, objective doctors orders "from above" in the practical care provisioning for the patient.

Contingent on dispositions of course, the nurses are literally and figuratively the closest professional & ally to the patient, with the juxtaposition in modern team-focused and patient-centered trajectories serving as a departure point for nurses to engage in mediation between patient and doctors should the need arise. Regarding this, TCT can be a valuable asset in strengthening the nurses contact to the patient and to include the doctors in a more informal fashion. Also the nurses as being on-site when it comes to necessary care measures being executed have also the added communicative layer with the informal caregivers, providing support, instructions and a dual translation between doctor lingo and patient/informal carers informational needs to further QoL in the patients surroundings - as well as making them very adept in fitting into SPCT's. Nurses and informal caregiver relationships in the research literature mirror the primary care engagement in that they are concerned with the execution and shaping of the immediate patients surrounding - nurse and informal carer are both mirrored adjuncts to the practical implications of the doctor and patient relationship respectively.

The impact of the nurses as secondary stakeholders is somewhat muted in terms of quantification in the research investigated and also in validation of practices. Since doctors operate within an intact empirical imperative, and with the nurses in the end having to defer to their medical judgments as to uphold intra-field clear cut hierarchies in the interest of responsibility definition, the impact that quick, informal, hands-on care can have is diluted by the inability of the papers/metrics/research setups to assess them correctly, and is often relegated to an abstract "human" engagement without deepening the discussion or to drill for discrepancies in ethical enframings.

4.4.3.2. The Informal Caregivers

A varied group of people the informal caregiver stakeholder group is described as a collection of patients family members, close and distant relatives all with their contingent relations to the patient, as well as assorted personal friends & neighbors. In the TCT mediated encounters and the palliative care trajectory in general to which they are attached, their primary value is constructed as that they can serve as a remote pair of hands - in trials with the remote monitoring device informals were instructed in proper application of the readout devices - and to an extent they can conduct lighter care duties when a nurse visit is not exactly warranted or necessary¹⁸⁹. The TCT adds the benefit of being able to directly instruct informal carers for prolonged periods of time in situ and build up their competency in care procedures, improving the QoL of the patient by empowering a close and personally appreciated actor. This is as far as doctors are concerned with the informal caregivers, with nurses and their inherent mediating disposition the informal carer can build - personal-idiosyncratic attitudes permitting - build a better relationship. Largely due to the simple spatial fact that the nurses are more often in the proximity and are usually much more attuned to assuaging

189 A. Stern et.al.. (2012) pg. 298f

fears and building confidence in patients and their surroundings. According to the researchers, the TCT in this relation increases efficiency, in some cases being so successful as to make itself obsolete after the training of the informal caregiver was advanced enough¹⁹⁰.

One differentiation has to be done in terms of the escalating circumstances of pediatric palliative care, in which the informal caregivers are the parents of the patient. Positioning them into a much more prominent role in the research trajectory, as they hold the decisional authority over the usually under-aged patient. In terms of relationship they are effectively promoted to primary stakeholder with the attention being directed towards "good" decision making¹⁹¹. The TCT pediatric experiments in that capacity served to provide a communicative tool to allow more frequent checks and balances in the patients home setting. This is of course in addition to being able to educate the patients parents in care techniques as in the other informal interactions explicated above, but the pediatric experimental setups put a lot more emphasis on this TCT usage.

There is not much more to say regarding the informal caregivers as the researchers stop at the conceptions outlined above. Their interest coordination is either bound up in self-help groups for mutual support and thus outside of the interest of the papers investigated - or their role is critically under-appreciated. From the doctors side they are positioned as somewhat passive components¹⁹² in the palliative engagement that have an unspecified influence on patient disposition via normal, everyday human engagements, framed as beneficial to the patients QoL (under ideal circumstance). Yet the researchers are interested in the quantitative, objective effects, thus neglecting the "informal carer - doctor" relation & investigative angle. With the nurses the informal carer becomes more active in that provided with the individual empowerment of the necessary care techniques, and engaging in the diffuse "human interaction" the nurse alleviates patients issues indirectly in addition to their own work – and it is an assumed given in the literature that the informals do just that. Other than that the contingency and massive variety of the dispositions, which is already very difficult to grasp in the patients alone, makes it nigh impossible for the quantitative method to assess their impact onto the patients QoL outside of very basic assessments of their personal relationship to the patient as "good" or "bad".

4.4.3.3. The Hospital Administrators & Managers

This particular secondary stakeholder group brings a new dimension into the field that tends to be marginalized in the academic discourse about palliative care efforts due to the overwhelming importance attached to the medical procedures and communicative engagements of SPCT's - the economic dimension¹⁹³. To dig up an old time favorite saying "There is no such thing as a free lunch", and the hospital & hospice admins and managers are engaged as being solely responsible to provide the necessary economical and financial backing for any TCT to work, nay to exist to begin with in some cases. Earliest experiments into TCT implementation actually did consider the managerial side of things a lot, as an unproven technology at the time trials with first generation video-phones were geared in their implementation setup to specifically convince the stakeholders

190 N. Bradford et.al (2014) Australian failure study

191 N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic review"* in I. Pala (ed.): "BMC Palliative Care" Vol. 12 Article No. 4 Berlin, Springer (2013)

192 B. Johnston et.al. (2012) pg. 155f

193 Dolittle et.al.: *"A cost measurement study for a home-based telehospice service."* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol 13 Suppl. 1 New York, Sage Publications (2000) pg. 193 - 195; D.J. Cook et.al.: *"Administrator and provider perceptions of the factors relating to programme effectiveness in implementing telemedicine to provide end-of-life care"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 7 Suppl. 2 New York, SAGE (2001) pg. 17 - 19

responsible for resource allocation - making the chief ethical contribution and concern of this group one of distributive justice.

The initial phase of any technology shows of course concern when it comes to convincing the stakeholder with control over the necessary resources; in TCT the earlier trials were usually two-pronged: for once the experiments were to establish a market to begin with, ergo the patients were the first questioned about principal attitude towards the technology, second then the admins and managers were the target group to be convinced to get funding – the research was set up aiming at their financial gatekeeper functionality. This earliest iteration is important for two reasons: (1) the doctors did not play the important role they do today. Even though it seems they always have in the way they are represented in the majority of the research papers of recent times. And (2) as a departure point it highlights how much the device side of TCT is contingent on market forces in alleviating issues of distributive justice, due to being consumer technology co-opted into medical usage.

As adaptations of consumer electronic goods the TCT in palliative care has profited from market forces like Moore's law when it comes to the pricing of the hardware, making the ethical concerns about distributive justice largely a main concern of earlier TCT experiments - that is for now. As almost all trials investigated are so small in scale that the issue does only come up when the provisioning of access ports or devices falls short due to inferior scheduling, rather than fundamental price issues as it was in the early phases. With the role of distributive justice as a value somewhat diminished, the admins and managers as secondary stakeholders are currently marginalized as a group in the discourse, as well as in their financial gatekeeper function. The budgeting and financing of a TCT program is taken as a given, due to prevalence of small sample sizes as well as financial incentives due to some policy mandate or funding available via grant money, making the TCT cost efficient until quantitative, statistical significance in market permeation can be achieved - or becomes a serious problem.

4.4.4. The Tertiary Stakeholders - TCT Manufacturers, Designers, and Policy Makers

This will be a relatively brief section and serves to contextualize the embedding of the TCT in larger technological developments as well as to outline the emerging change in public health and digitization of the medical field in general; the development is simply not isolated from outside influences, though the aspect is glossed over in the small scaled experiments into TCT that form the backbone of the investigated discourse – often taking the form of one or two sentences stating that funding and state approval was gained, full stop.

4.4.4.1. The TCT Device Manufacturers & Designers

One of the more muted stakeholders in the discourse, the influence of the designer and manufacturers is mostly of accidental nature, at least as (barely) present as they are in the literature. The TCT adaptation of consumer goods makes them more of an implicated stakeholders in the technology, the manufacturers due to the market attractiveness of consumer electronics in total, tied up in the aforementioned economical narrative and the solving of distributive justice issue via market forces like Moore's law.

The designers on the other hand are experiencing a creative end user (ab-)use of their devices, progressing through the TCT generations a certain increase in complexity and increased demands

towards the end user leading to an increased misfit with elder patients, suddenly gives way for the pad/tablet-design basis which is an accidental near perfect fit for TCT application - stemming from a pure consumer design effort.

4.4.4.2. The Policy Makers, Public Health Programs & Institutions

A more diluted stakeholder grouping within the papers, in terms of precision of composition as well as influence, due to macroscopic efforts, the policy designers and public health institutions (the State) have a more direct, but larger scaled influence on TCT in palliative care, and the primary care relationship, than the designer's accidental one. Large scale provisions and research grants are shaping the field as a whole – and the papers used here in particular, on the merit of them being exploratory studies - resolving distributive justice issues as well as being a contributing factor to the empirical imperative requirement which strengthens the doctors position and ethical enframing due to the inherent necessity for hard, empirical data-sets as a basis for drafting national policies.

The promotion of TCT and palliative care as the overarching field is subsumed in the papers under general digitization efforts within national policies¹⁹⁴, the example referred to in this section will be the NHS (National Health Service) policies in the U.K. of the last decade approximately. Simply because the U.K. is the first nation to have started with palliative care and have been at the forefront of policy integration of the field into the public health sector. The ePCS (electronic Patient Care System) project¹⁹⁵ itself, a general digital effort for improved patient record keeping, is setting a precedent on how to deal with the attached classic ethical issue of privacy. The important part is how these larger programs struggle to address the issues by tampering with a fundamental aspect of a running system; namely the responsibility in record keeping is getting more diffuse and the ePCS program has had issues with reworking a capable system of patient record keeping responsibility and fidelity. An issue often found in the TCT research investigated, and as such important; since the idea is to link TCT devices with the ePCS in the end to create a seamless integrated, digital network of information and counseling capacity for improved - and cheaper - care provided by the NHS¹⁹⁶.

In ethical terms this issue of privacy is at an advantage since there already are good guidelines towards patients medical data and confidentiality in place, the challenge is the educational effort within the professionals to respect the severity these devices carry in practice regarding this value. Example: the consultation via TCT has to have the same relevance as a personal visit to the doctors office, in the past this has been an issue where nurses interrupted the TCT consultation for menial aspects like getting a signature from the M.D. - highly disruptive to the presumed one-on-one intimacy of a TCT encounter. For the stakeholders of this group the interest in something like this little concrete example is how far the consumer electronic goods and especially the software solutions can be utilized without issue. The latest trials with fourth generation TCT, the iPad studies in the Netherlands¹⁹⁷, utilize the commercial application of Facetime, making patient-doctor encounters run across the servers of a commercial entity/company that has certain access to the

194 B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 – 161 | see also: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303

195 S. Hall et.al.: *"Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient, carer and professional perspectives"* in V. Neale (ed.): *"Family Practice"* Vol. 29 No. 5 Oxford, Oxford Journals (2012) pg. 576 – 585

196 That conjunction is not a typo, see: http://www.scottishneurological.org.uk/content/res/quality_strategy.pdf pg. 27ff

197 J. van Gorp (2014) and J. van Gorp (2015)

data. In this regard there is presumably need for a digital data protection act, or the design of a public healthcare exclusive, and state controlled system to maintain the public interest in the privacy of medical data. This also includes the necessity of the policy makers to address changing informational behavior in the population, the voluntary openness about personal data that say Facebook enables, and general different conception of what constitutes data security we can find in younger citizens. Past this particular issue, the policy makers are part of the target audience for the research papers as well as a source of grant money, period.

4.5. Value Constitution, Assessment, Recognition, and Neglect of the Relevant Stakeholders within the Quantitative Experimental Discourse

Now, with the stakeholders firmly established let us turn towards the value constitution and assessment thereof as it occurs in the quantitative discourse for the relevant stakeholders - the extent, respect, and even neglect as it occurs in the relevant research literature

4.5.1. The Values of the Patient within the Quantitative Discourse

Idiosyncrasies in constitution aside - as they are outlined previously, derived from the literature recognizing the old and the young patient - lets have a gander at the values underlying the patient stakeholder group and how the research addresses them (or not).

The patients, old and young apparently are very positive towards the TCT in general, as their diseases often carry limiting effects in mobility and socializing options the improvement of their communicative means is a welcome addition to the regularities of their palliative treatments. Ever since the first experiments¹⁹⁸ the patients have shown instinctive mapping of the possibilities of the TCT; the contact between patients, to their family and friends as well as contacting their physician on issues regarding the care and disease are expressed¹⁹⁹. They seem to follow the experimental outlines set by the researchers as well as the intended usages by the doctors/providers in such a fashion that these positive attitudes are all the promotional effect needed, with very little encouragements beside recommending general usage needed from the medical professionals for the patient to engage in TCT²⁰⁰. The only discontent towards the TCT introduction from the patients, old and young is in fact technological breakdowns, or catastrophic material failures²⁰¹ [fail to connect, choppy/blurry images/sounds, feedback in hearing aids²⁰², etc.], as the technological capacities cannot advance fast enough for them to use.

As for value constitution and realization, the patients are second only to the doctors in terms of them actually getting what they want regarding practical values, like economic benefits (or at least no drawbacks from utilizing the device), utility of the devices and overall respect for their personal ethical alignment - most commonly faith based prescriptions regarding medical treatment/care options [e.g. the sex of care nurse when facing Muslims]. In short, the primary stakeholders value realization is largely up to choice, and personal idiosyncratic alignment of values (different

198 POTS demo in: D.R. Park et.al.: *"The usability of videophones for seniors and hospice providers: a brief report on two studies"* in E. Ciaccio (ed.): "Computers in Biology and Medicine" Vol.35 No. 9 Amsterdam, Elsevier (2005) pg. 782 - 790 [one of the earliest demos showed that patients liked TCT, even in a very unstable form tech wise, and that 80+% would accept the device if their doctor thought the usage beneficial]

199 D.R. Park et.al. (2005) pg. 784ff

200 *ibid.*

201 A. Stern et.al.: *"Use of home telehealth in palliative cancer care: a case study"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 18 No. 5 New York, Sage Publications (2012) pg. 299

202 D.R. Park et.al. (2005) pg. 784

emphasis on autonomy between patients for example) as the patients right movements achievements are the definite ethical imperative all other stakeholders in the TCT experiments have to subject to. Patients know best if the technology utilized is not properly attuned to them, regarding the value and ethical imperative of non-maleficence being that the device does at least not impair care trajectory²⁰³. Yet depending on personal attitude and disposition of contingent nature the patients are quite disturbed by the device, especially material or organizational shortcomings on the providers side can lead to value deterioration and discontent with the TCT and then quickly to dissatisfaction with the care trajectory in general.

What is odd and almost schizophrenic about this constitution is that the patient is assumed to be a stable actor, with stable value configurations over the whole trajectory, when especially palliative care patients are subject to vast swings in attitude, expressing shifting values and considerations over time – something none of the papers did address. More so, the respect for the patient autonomy is derived from the classic medical ethics set of values that are eligible to be considered, and here we find a contentious issue. The values that are recognized as legitimate part of ethical concerns – the macro headers of beneficence, non-maleficence, etc. that are expressed in detailed, idiosyncratic micro actions between specific patient-doctor constellations – are determined by the classic medical ethics and in essence by the doctors. Which would not be as big a problem if not the professional adherents of said ethical set, the doctors were not also responsible for advising the patient on the choices that they can make.

The patients value alignment and choice is depending on the quality and degrees of freedom that the doctors information about available choices entails. Meaning that there is the possibility that their value alignment is curtailed by at least some potential sins of omission on the professionals counseling side – as the doctors have to submit to the patients choice, but regulate access to or at least the understanding of medical professional choices by the patient. In a simple sentence, the factual authority of the doctors has to yield to the decisional authority of the patient - that is assuming an active, capable patient which values over the trajectory are somewhat stable that has to rely upon, and trust the medical expertise of the medical doctor advising him/her.

There is close coordination and an odd absence of fundamental conflict of values between the patient as the chief stakeholder and the doctor as the medical consultant, that is regarding the transformative effects of TCT as a high-tech, open ended communication device. Mirroring the doctor-nurse absence of conflict – which is more severe regarding ethical systems, see further below – the patient contingency on the doctors recommendations regarding TCT utilization and the experimenters. Allowing the doctors a somewhat privileged influence on the specific usage of the TCT – see following paragraph – seems to indicate an unresolved (-able?) aspect of power distribution within the primary care interaction. That is one apparently insoluble aspect of regaining/re-invigorating doctors authority by virtue of control that the experimenters subscribe to as a hidden presupposition in engaging the patient with TCT – which appears also as part of their implicit promotional stance on the technology.

203 N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic review"* in I. Pala (ed.): "BMC Palliative Care" Vol. 12 Article No. 4 Berlin, Springer (2013) pg. 8f

4.5.2. The Values of the Medical Doctor within the Quantitative Discourse

Despite the patient centering and team specialist approaches the doctors experience a certain renaissance of their hierachichal top dog position - not exactly reverting the achievements of the patient centered approach but the research conducted and the setups used are aimed to convince the doctors²⁰⁴ as the go to decisional authority regarding the TCT researchers veracity of claims. Hence they are allowed a certain first pick of the technology, as well as their position shaping capabilities before the devices even reaches the patient. The researchers consulting with the doctors beforehand and including them in large part in the implementation and setup process for their research awards the doctors a power position reminiscent of their once held authority over the patients.

This setup in the quantitative methodology has to do with the fact that the doctors are the ones closest to the patient, equipped with the medical necessary knowledge for evaluation and a very stable, long traditioned value system, and are the ones consulted (or their organizations more precisely) when it comes to statistical evaluations by the researchers and policy makers²⁰⁵. Simply put, they are central to a variety of stakeholder interactions, hence this ideal crossroads position and the experimental nature of the TCT used awards them power to no end in terms of shaping the introduction of TCT into their respective patient populations and the distribution of control.

As such they react very positively to the devices capacities themselves, seeing the benefits in a similar fashion, and similarly instinctive as the patient stakeholder group, though their focus is on getting the „clinical eye“ functionality out of it, closer and more frequent supervision of the patient in order to improve objective care delivery. This clinical eye function, as an important incentive for the medical professionals to engage in TCT experiments is strenghtening to an extent the traditional power position of the medical doctor, since the researchers have to make it attractive to engage in, they might on occasion tailor the research setup to the presumed doctors needs/empirical demands of the medical research methodology - being guided by objectifiable, empirical data and classic medical ethics - *"It was discussed there was a need for an individual approach when planning any intervention or interaction; control of the relationship between clinicians and families was guided by needs of the family but it was the actions of the clinicians that determined how needs were met."*²⁰⁶

By training and circumstance of the modern, western-typed medicine engine their ethical values and the realization they pursue is tied to the Georgetown mantra. In terms of reflection on those values in practical alignment with human(e) engagements, their initial training is lacking across the board, with elements of contingency to the value alignment caused by the specifics of the individual doctors experience. This underlying, diluted, and not conducted task of reflection and the attached contingency of the individual clinician harks back to Saunders, who succinctly summarized the demanding circumstances as follows: *"At times the work [palliative medicine] will cause pain and bewilderment to all members of the staff. If they do not have the opportunity of sharing their strain and questions, they are likely to leave this field or find a method of hiding behind a professional mask. Those who commit themselves to remaining near the suffering of dependence and parting find that they are impelled to develop a basic philosophy, part individual and part corporate. This grows out of the work undertaken together as members find that they each have to search, often*

204 P. Whitten et.al.: "Addressing telehealth's foremost barrier: provider as initial gatekeeper" in M. Mäkelä (ed.): "International Journal of Technology Assessment in Health Care" Vol. 21 No. 4 Cambridge, Cambridge University Press (2005) pg. 517 – 521 | G. Demiris et.al.: "Telehospice tools for caregivers - a pilot study" in D.E. Gallagher-Thompson & L.W. Thompson (eds.): "Clinical Gerontologist" Vol. 31 No. 1 Abingdon, Taylor & Francis (2007) pg. 43 - 57

205 German example: „Marburger Bund“

206 Bradford et.al. (2014) pg 4

painfully, for some meaning in the most adverse circumstances and gain enough freedom from their own anxieties to listen to another's questions of distress."²⁰⁷

Individual experience contingency aside, the doctors value set is well defined, has a long history, they are in charge & are to be convinced by the TCT experimenter/producer - hence, the doctors value realization is as good as it gets while also potentially reinforcing the white spots of medical ethics that palliative care ethics and care ethics try to address. Even before the experiments begin and they are engaged, the doctors occupy the TCT shaping, since all experiments conducted in this quantitative methodology investigated cater to the doctors value alignment even before the researchers interact with the patients - in the way they set up the empirical parameters or even the questions asked. Some research tailors their approach very much to the primary care interaction without other considerations due to the exploratory nature of their research grants aimed at statistical significance. Hence there is a lot of data on the primary care relation stakeholders, some more accidental-natured data on the secondaries, and fuck all about everyone else or the contextual embeddedness. Due to this data situation/focus there is a certain element of exclusivity to the doctors that in researching them as a group the TCT researchers focused a lot on the attitudes and the attunements of the doctors, neglecting the aspect that irrespective of the personal and professional motivations for the appliance of TCT, there is no need to take over the doctors main medical narrative in which those motivations are embedded.

4.5.3. The Values of the Nurses within the Quantitative Discourse

Initial reactions towards TCT by the nurses are split, attitudes are positive regarding the potential for more frequent contacts and interventions, and negative in that the nursing techniques of caring are very reliant on physical proximity – lit. „hands on“ care and the immersion in the patients home environment to gather sixth sensed impressions of living conditions and general, circumstantial disposition of said patient. They eventually have to subsume to the doctors authority though. No, more precisely they are assumed to work alongside the doctors as the grunts of the medical system, in which they are no doubt embedded, though nursing, palliative care, or care ethics are not considered in the construction of the pre-experiment parameters so necessary in the quantitative methodology. As they are under the doctors authority and are bound to extend by the care and treatment recommendations - nurses value stance and attitudes towards the device are subsumed by the researchers under the mainstream medical systems parameters/boundaries. Therefore their attitudes towards TCT are enframed as being part of the established medical system by the quantitative papers, and are explicated as dynamic adaptation to the devices introduction in practice by practical usage with the patient, under guidance and order by the medical doctors that are ultimately responsible. A major part/evidence is due to the phrasing and language use; the nurses are only mentioned separately in the literature when it comes to the practical changes that is caused by the technology, when talking about the patient as such engaging professional medical personnel - it becomes a simple duality of clinicians vs. patients; with the nurses being subsumed under the header clinician²⁰⁸.

Adjustments in terms of technology utilization are done in accordance with the nurses feedback due to their access to the practical dimensions of micro-care interactions using the TCT. Yet the feedback is processed through the medical systems enframing of what is to gain by the utilization.

207 C. Saunders: "Foreword" in D. Doyle et.al. (eds.): "Oxford Textbook of Palliative Medicine - 3rd edition" Oxford, Oxford University Press (2004) pg. XVII - XX

208 see: Bradford et.al. (2014) pg. 4ff The text does discern the clinician stakeholder conglomerate only to lump them together in the end result.

Large parts of the myriad and contingent practical adjustment knowledge that nurses generate in the care trajectory in which they get to know the patient personally are not recorded in the papers, nor investigated as a worthwhile aspect of care. The personal touch elements that the hands-on care entails is muted in its presence within the palliative care TCT investigations/papers - most likely due to the experimental nature of the technology the main focus is on integration of the devices into the medical routines of care - with the human element/touch enframed within the face to face communication that the technology promotes.

The nurses feared a sizable loss of contact and sensory immersion with the patients situation should the hospitals and hospices shift to only a TCT care model - the so called replacement narrative that is present in earlier TCT research papers. Due to the resistance of the nurses, on the practical grounds of monetary loss²⁰⁹ for them as a profession, as well as on account of the potential loss of care quality in the patient population - the total absence of the "human touch" element is simply not feasible - this replacement narrative was abandoned in favor of complementary TCT setups²¹⁰ - TCT and common (palliative) care interlinked for mutual quality improvement.

4.5.4. The Values of the Informal Caregivers within the Quantitative Discourse

Akin to the patients they are attached to, the informal carers stakeholder group values are even more diverse, since we are talking various degrees of relations to the patient - family, kids, friends, etc. combined with various personal attitudes regarding palliative phases, and attitudes towards medical interventions, and so on and so on. This escalation in the complexity, due to the simple increase in the number of stakeholders - patient and doctor are singular, contingent entities whereas informals range from potentially none to many - means that to get a good picture of this group the researchers of already constrained, prototyped TCT's would have to expend a disproportionate research capacity to capture a proper image of the group.

The approach to their (inferred) specific, varied values within the researched literature is that they are doing "informal" stuff, they are involved on the patients side and influence their quality of life in their interaction. Hence they are kept in the loop of the care trajectory as passive information recipients or a spare set of hands for the telenurse. The texts do not go more in-depth with regard to the informal stakeholders than this, they are, after a brief cursory treatment, assumed as adjuncts to the primary care stakeholder of the patient - the focus on the patient-doctor interactions via an empiric methodology is very specific for this emerging medical technology, so this setup of the research is, from a conceptual-logical point of argument/reasoning, ill equipped at least to address the informal caregivers. Essentially to include the exponential magnified informal carer attitudes there would need to be a sociological research running in parallel. Which is simply not feasible nor aligned with the immediate research goals of the papers/experiments investigated here.

For the methodology utilized it made sense, the patients as the most nerve-wracking diverse and idiosyncratic-dispersed groups is already enough to content with – especially when one is targeting the whole experiments to yield objective, quantifiable results, hence the secondary stakeholders informals are assumed to have actual secondary effects derived from primary effects of the palliative care trajectory being exposed to the TCT. Its dynamic, chaotic, interesting and utterly not targetable with the methodology, or more precisely it was never data even considered worth

209 P. Whitten et.al.: *"Telehospice: reasons for slow adoption in home hospice care"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 15 No. 4 New York, Sage Publications (2009) pg. 187 - 190

210 example citation: *"The presence of primary care clinicians is an important factor in the model of care for the HTP [Home Telehealth Program], as the program is not intended to replace home visits, but to improve equity of access to specialist care"* Bradford et.al. (2014) pg. 2

gathering past the point of the informal carers doing informal stuff.

4.5.5. The Values of the Hospital Admins & Managers in the Quantitative Discourse

The last of the secondary stakeholders, they still possess the value limitation as expressed in their reconstruction section outlined above with regard to managing the financial and managerial side of a hospice/hospital²¹¹. Yes, their decisional strength and recognition within the quantitative assessments has been diminished by the market forces that enables cheaper and more capable TCT, that does not mean the problem of distributive justice and resource allocation magically went away. They are still very much in the business of providing and organizing a logistical infrastructure on which TCT relies and are under-appreciated in the way they realize this for the researchers. Especially the latest TCT that comes with capacities past direct face to face contact requires a lot of logistics on the admins parts²¹², the integration of data processing capabilities into existing digital frameworks of the hospital/hospices for example is a professional manager challenge that these stakeholders will face in the immediate future – as it is tied in the western world into state-driven pushes for general digitization of societies.

As for realizing the value, monetary logistics is pretty much their exclusive value, with the distributive justice not being an issue since the experiments are all prototypical, small scaled with lengthy pre-screenings of participants never triggering any real ethical issues of just, large scale distribution²¹³, even less so with projects that run on state research grants, thus freeing up the hospital managers and admins to basically concern themselves with secondary distributive effects – the time the experiment takes out of their staff, nurses and doctors alike, that needs to be compensated somehow to run the daily business as uninterrupted by the experiments as is possible. Hence their value realization is actually traceable with the quantitative methodologies inherent in their managerial education combined with their specialist orientation towards health care provisioning, practically in the experiments they only show up to curtail any given excessive drain on the personnel, for example limiting nurses hours available to deal with the added workload of managing centralized patient TCT data-sets.

4.5.6. The Values of the TCT Device Manufacturers & Designers in the Quantitative Discourse

As for the designers/producers, they are already only in this because someone somewhere designed (and produced) the webcams computers laptops and the tablet devices, but the connection is purely accidental, since all the TCT prototype experiments used the devices off the shelf without having particular, specialist development done for the field of palliative TCT. Thus the value assessment is outside of the range of either medical, nor palliative care ethics but is to be constructed along the product valorization assessment inherent in the market driven economy the devices ultimately come from. So, in that regard, and the perceived success of the market forces for (1) to lower the device prices continuously in light of competing products, and (2) to be actually so successful as to alleviate distributive justice issues whilst (3) making the technology so ubiquitous in society to begin with, as to prompt the medical field to incorporate the designs, the values regarding

211 N. Bradford et.al. (2013) pg 9f

212 an early study addressing this issue of organizational readiness is: D.J. Cook et.al.: *"Administrator and provider perceptions of the factors relating to programme effectiveness in implementing telemedicine to provide end-of-life care"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 7 Suppl. 2 New York, SAGE (2001) pg. 17 - 19

213 even though attempts were made, see for example: B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): "Palliative Medicine" Vol. 26 No. 2 New York, SAGE (2012) pg. 152 – 161

monetization of the designers/producers are realized.

As for the element of ethical value alignment of say the designer, they might very well range from idealist, “I want to provide the best product in order to enhance peoples communication” to the very profit oriented, “hey lets build in back-doors and behavioral trackers type of designer” with not practical impact on the TCT in palliative care, since they are already trailing established marketed technologies on the societal level, thus making the designers future choices irrelevant for the quantitative experiments – which really just poses the them as a fixed variable and might point to the issue of needing a more wholesome societal debate regarding digital communication before the next step in privacy curtailing effect takes place, conducted via the latest Apple gadget.

4.5.7. The Values of the Policy Makers, Public Health Programs & Institutions in the Quantitative Discourse

The policy makers, responsible political institutions are really only entering the discourse as some sort of background noise and edifice from which you get the grant money for the prototype experiment you have in mind. The allocation of research funds if of course a value-laden activity, expressing the larger, dispersed decisions of a society as such as to what research in medical science is deemed valuable, “adding value” to the disposition of the single citizen living in said society by virtue of interest guided solutions/suggestions of distributive justice for any given commodity. The problem is exactly that, dealing with large scale, dispersed, counter-intuitive value desires of a society requires a lot of data, meaning quantifiable, statistical significant data in order to draft national policies when it comes to TCT integration in the public health sector²¹⁴.

They are easy to convince since they are reliant on statistical methodologies to actually make their decisions. to an even larger extent these are key stakeholders due to the sheer size and representative weight of their decision making (simply put: political power), but they are so reliant on the researchers that value realization is done by just handing out research grants and see what falls out of it – tied into the still early experimental stages of the TCT adaptation into the field, following larger societal shifts towards digitization. They do concern themselves of course with non-maleficence and beneficence (forbidding of unethical research proposals for example) – those being contingent on doctors input in national and regional review boards, hospital ethics committees, etc. etc. resulting in national laws governing medical sciences - but the mainstay is and will be distributive justice, after all that is the task of the state and the institutions regulating and shaping medical research, full stop.

As for the main interaction we can read out of the experimental papers used for this chapter, there is pure mentioning of passing said review boards and getting grants, hence giving it the outlook of being an ethical objectively assessed project, despite biases in the researchers. For example all carry with them a promotional attitude towards TCT – tailoring their parameters towards an assumed added value of the technology as in order to obtain grants from drafted national research endeavors that address the need for general research into digitization and the digital revolution occurring - those are of course not drafted out of the goodness of heart and adherence to values ideal, but to maintain competitive advantages of a society.

²¹⁴http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303

4.6. Interlude IV – The Explicit Methodologies of Questionnaires and Semi-structured Interviews within the Quantitative Research

The knowledge generation within the papers, regarding stakeholder constitution and attitudes, as fixed over time as they might appear, is done via specific methodologies of quantitative nature. This interlude serves to explicate them as well as start a reflection on their inherent flaws/drawbacks on their own terms – serving as a precedence for a following meta-leveled criticism regarding the quantitative scientific methodology as a whole, and eventually to contrast it to a more qualitative approach.

4.6.1. The Questionnaires

The first and foremost in delivering explicit, tangible evidence for empirical investigations that concerns humans, the questionnaire is easy to design, apply and analyze – making it one of the two methodological weapons of choice, aside from direct observation, for the quantitatively inclined researcher. Every research paper that was not a review of some sort had one or more questionnaires within their tool-set, with some papers publishing the extant processes of designing, compiling, and codifying the questions and their respective answers. The questionnaires were strictly technique only - used without any deeper reflections regarding the methodology shaping the answers collected.

For my analysis it was important to look into the codification of the idiosyncratic answers given by the stakeholders taking any given questionnaire. Due to the prototypical nature of the experiments, and the lack of communication between researchers, each questionnaire was codified with a different goal/subset/application in mind. As such, the data these questionnaires yielded is not exactly up to one of the logical/conceptually implied requirements of the quantitative methodology – the reproducibility of results. The high attrition rates being a deciding factor in general, cohort size is an issue regarding fidelity to the quantitative methodology claims which seems unavoidable in palliative research.

4.6.1.1. The Drawbacks of Questionnaires

The questionnaires are punctual events dotted over the care trajectory as a process, with the added layer of sometimes the papers not being explicit if they checked repeatedly with the same questionnaire or applying a single use one (sometimes they are explicit, for example in giving questionnaires after a study has ended). As they are done at a particular point of the whole palliative care trajectory, the researchers did not include at what stage they conducted them, obviously the patients were responsive but with good palliation that can mean any time before the actual terminal phase.

Furthermore, only a few studies revealed the extant question catalog they applied/used for the questionnaire, meaning that for all the studies that did not, there remains the shadow of doubt concerning loaded, or leading questions being part of the investigation, possibly in conjunction with a suspicion of researchers taking on TCT promotional attitudes as to enforce positive results. And lastly, the delivery of the questionnaire is rarely explicated - is the researcher present and oversees (exacting stress, test condition, look over shoulder issues in the patients, etc.) or is it a letter sent to patients to resolve at their own leisure. The question there is how daily idiosyncratic constitution, is it a good or bad day for the diseased patient, did the disease flare up/escalate a step, was there a family issue, etc., affects responses – which clashes with the assumed stable stakeholder conceptions which is needed for the statistical analysis of comparability of the responses to general,

and or tailored questions. Despite these drawbacks, the questionnaire is still the best thing in objective accuracy and one of the strongest tools in quantitative assessments [if done correctly], and for the methodology the most closest objective-ish approach to the patient. Ideally a standardized piece of paper in front of a presumed stable stakeholder is filled out completely and regularly.

4.6.2. The Semi-structured Interviews

The second favorite technique to get proper objective, quantifiable data from and about stakeholders for TCT in palliation is the semi-structured interview. Same as the questionnaire they are used in almost all studies that are not a literature reviews.

As methodologies go, the interview requires more preparation and setup from the researchers that engage the stakeholders, meaning that in practice the sheer mass of interviews is lower in comparison to the amount of stakeholders you can get with a questionnaire. The advantage of this is of course that with a smaller cohort/level of methodical sophistication you can get more into depth regarding the chosen issue to investigate and adjust more precisely to personal idiosyncrasies as well as for example get the reasoning of the stakeholder for their attitudes – something that a questionnaire cannot do, due to the lack of interaction between patient and the the researcher proper.

The semi-structured aspect of the interviews is also wonderfully fuzzy enough that, even if we have access to the question catalog, like with the questionnaires, we cannot assess the amount of modified questions and follow ups that the researcher asked. More often than not what one is presented with as a result is the already codified result of the interviews – made comparable via statistical methodologies like the N-Vivo 9 utilized by Bradford et.al.²¹⁵ for example.

4.6.1.1. The Drawbacks of the Semi-structured Interviews

Well, leading questions as already mentioned are an issue – more precisely loaded follow-up questions during a dynamic interview setting; semi structured inherently implies a fuzziness uncannily convenient for such experiments that run on quantitative significance and precise terminology and numbers. The odd part is that the details as to what the “semi” entails are not explicated. For example dynamic follow up questions are fine and dandy when digging deeper and a fixed script is not applicable/feasible – but what about the situation where to ask; research facility/anonymous meeting room at university/ patients homes or just follow up telephone interviews.

The patients state of mind within the interviews is depending on the locational arrangement, as well as the for the quantitative methodology crucial element of timing said interview. Assuming the same disease type and roughly the same trajectories with phase length variation, the interview should take place at roughly the same spot in the trajectory, though no paper offered details as to if this was achieved in practice with explicit regards to the reproducibility and interchangeability of the results. Other than that there is not much to say about the drawbacks, still like the questionnaires its a tried and tested methodology to gain proper first source data from the patients in a compact way if done correctly, albeit not presenting it correctly has the drawback of undermining the scientific veracity of the claims. Even more so that the interviews in questions pertain to limited scale prototyped experimental setups.

215 N. Bradford et.al.: *"Home telehealth and paediatric palliative care: clinician perceptions of what is stopping us ?"* in J. Mockridge (ed.): "BMC Palliative Care" Vol. 13 Art. 29 Berlin, Springer (2014)

4.6.3 The Direct Observation

The last methodology and the most obvious and scientific (as in natural science - comparable to observing bacteria under a microscope) is the direct observation of TCT interactions as they happen. Less utilized as the interviews and questionnaires, some studies do attempt to have the researcher immerse in the patient and professional ends of a TCT conversation. The presentation of the results from direct observation the follows similar encoding procedures like the questionnaire and interviews, with the researcher being the investigator and investigatee. A more detached observer might engage also in the care procedures of then nurses, though never to the extent as we will find in chapter 5 with J. Pols ethnographic methodology. What the few direct observations do not address is how far the researcher is concealed as to not disturb the TCT engagement by observing it, also difficult since the papers that did research directly were also the ones providing the TCT engagement in the first place – meaning the researchers are first engaging and training the patient and professional and then shifts to a passive observer [probably not really as concealed as they'd like to think].

4.7. The Prominence of the Ethics & Values of the Doctor Stakeholder in Quantitative Research

The key criterion for my assessment of my research questions was, since the TCT is such a transformative device configuration there should be ample conflicts between at least the doctors and nurses regarding its utilization – with the expectation that the TCT strengthens the nurses position within the care trajectory and also strengthen their values within said trajectory. What I found was an absence of conflict, with two possibilities as to why that might be so: (1) there is actually no conflict and TCT as an emerging, ill-researched technology with highly modifying characteristics has been seamlessly integrated into a complex care provision on multiple instances – yes I am being sarcastic here. And (2), and much more realistic a proposition/reasoning from a logical stance, is that the methodology of quantitative empirical research is not capable of tracing said conflict, or at least conflict potential of the TCT to its full extent, and that the true way the TCT integration is happening in the minuscule collections of practical, routine handling of the TCT device is not being depicted/challenged/appreciated within the research done so far.

4.7.1. The Enframing of Value Realization within the Quantitative Research

The important bit regarding the palliative states impact/effect is that the patients change in condition should elicit a specific change in the ethical foundation/motivation within the doctors - see chapter 3 for palliative care ethics. In the practice traced by the research papers this is not the case, the doctors facing the palliative patients, mediated by a new technology like TCT, the situation is most often resolved in favor of the doctors position of power and the need for empirical, quantifiable data generated in the process/experimental setups. The issues faced by the setup of quantitative typed interventions are that in order to function, the research setup pre-defines variables way in advance of the actual practical conduct of the research. That is the core of empirical research, the postulation of assumptions and parameters to be verified or falsified by empirical activity, and also a reason why empirical, quantitative research fits so well into the paradigm of acceptable data of the medical doctors - their knowledge generation works in exactly the same way, think medical double blind, RCT trials for a new kind of drug. This leads to the embedding of these presumed stakeholder conceptions and values in accordance with the researchers attitude towards them, as well as with assumed role conceptions that in terms of practical research outcomes provide inflexible.

The TCT should have an impact in terms of triggering a re-negotiation about which values and ethical conceptions are relevant and important between the stakeholders while also redistributing interpretative, issue-setting authority between the stakeholders, most significantly with the doctors experiencing yet another deterioration of their paternalistic vestiges – the one outlined above in my research questions/assumptions. Also since we investigate the introduction of a high-tech, networking device into a very low-tech field of action between people the assumption was made that we would find a renewed iteration or fragment of the eternal freedom vs. security narration.

Oddly enough in all the research conducted for this thesis and all the papers examined for this thesis, there is a peculiar absence of a proper ethical conflict between at least medical ethics and palliative care ethics as their respective stakeholders interact and develop the field – running counter to the previous sections explication of my research assumptions & questions regarding value formation and realization.

The derivative state of the technology itself might have some influence on the conflict situation - that is absence thereof: all the devices are adaptations of outside the field, consumer electronic goods, way after their market saturation/hype phases: ergo the stakeholders in their roles as doctors, nurses and patients are not independent actors suspended from thin air. They are part of society and are exposed to large scale developments in communicative tools as they take place, and how these devices reshape communicative behaviors - what is deemed an acceptable ethical set in dealing with this technology is derived from this macro-scale societal evolution.

This lack of a conflict has an impact on nursing disciplines as their role in the total care and team approaches is not what it could be – at least concerning the quantitative discourse analyzed here. A future conflict once one TCT approach has stabilized and permeated the field of palliative care seems inevitable from today's status of the field and effort of promoting TCT. Unspecified remnants of the low-tech attitude that shaped the nursing discipline, and the palliative nursing in specific, might linger in the nurses at present, coupled with realistic fears of reduced working hours and pay due to the TCT consultation eliminating "unnecessary" nursing visitation - one of the key economic and personnel allocation narratives/arguments that makes TCT so attractive for hospices/hospitals. Also the inherent distance of the TCT is something nurses with their expressed hands-on focus in practice have a hard time adapting to.

The primacy of the medical ethics narrative and its stabilization due to champion/gatekeeper status attached to the doctor means that the to be expected conflict simply is not realized, and only technology driven mediation is conducted within the primary care engagement between doctor and patient. With the added caveat that a terminal diagnosis tends to shift/suspend "minor" issues aside in the patients perception, leaving the background of technology utilization in terms of ethical appropriation to the professionals only. In that regard the nursing discipline is at a disadvantage despite the flattened hierarchies and team approaches. In absence of a stabilized TCT narrative as a tipping point, there is just a diffuse, unresolved issue subsumed under practicalities. Once QoL of the patient re-enters the discourse in light of failed attempts at quantitative attempts with small sample sizes, the nursing disciplines ethics and procedures might emerge strengthened.

4.8. An Academic Meta-Analysis of the Research Efforts into TCT in the Palliative Care Context - The Shortcomings of the Quantitative Methodology and Accepted Discourse so Far

Part of the absence of conflict outlined above and the less than sufficient answers to my research questions, is of course to do with the type of research methodology used in the field and application of TCT - which is for starters presupposed or at least predisposed to a promoting stance for the technology; as it is relatively unproven the papers and research setups are geared towards convincing the key stakeholders taking part. These key stakeholders are the doctors, and to a lesser extent the patients, but not the nurses or informal carers; in terms of presumed power structure and authority over decision-making in the process all the papers utilized are very quantitative, classic "properly scientific". The academic efforts into the TCT distribution in palliative care, save for one paper all of the efforts were geared towards this promotion of the technology irrespective of circumstance: the one paper that did not was an explicit failure study²¹⁶ of a TCT integration in Australia, that failed - in that the device was effectively abandoned by all end-users - despite possessing the presumed necessary characteristics and building blocks for success: good co-operations, long standing experience, positive attitudes, willing tech providers and receptive patients embedded in an ideal rural setting for TCT to take hold. The unspoken assumption is in all the others that TCT is good and that a push towards the technology is desirable; adding to the invasive perception of technology and reviving old fears in the nursing population for example that inherently is accustomed to the low-tech nature of their palliative specialization.

The academic work and quality of investigation becomes skewed by aiming to convince the doctor stakeholder group - caused by the research setup and imperatives of RCT's styled quantitative work - and, to a smaller extent than in the earlier phases, the administrators. Which means the engagement in quantitative studies aiming for statistical significance due to the empirical imperative of the gatekeeper stakeholders that defines what is relevant science and what not, as the researchers perceive it beforehand - foregoing any attempt at assessing "true" QoL in patients for example that is not quantifiable. The problem in practice is that it is all good and fine to aim for quantitative, statistical significance, yet all the papers dealing in this are utilizing fragmented and untested experimental setups²¹⁷ which all suffer from issues with cohort recruitment: the patients insist on dying, and that is after the setups have to overcome high ethical approval barriers to begin with - nothing eliminates statistical significance like small cohorts to begin with, and the additional high attrition rates escalating the impact on research quality even further²¹⁸. In addition the scientific enterprises as small as they are, are distributed around the world, do not stand in exchange with each other, thus we find localized clusters that do not profit from the potential of larger scale peer review and exchange²¹⁹, while at the same time also employing specific methodologies inadequate to their little grouping that makes comparative attempts in analyzing the status quo very difficult, if not utterly impossible/senseless. So what could/should/might change in order to fix this situation? Enter J. Pols approach towards TCT as a modified ANT/scripting-based ethnographic study methodology.

216 N. Bradford et.al (2014) Australian failure study | also there is a brief sketch of a refined quantitative methodology in N. Bradford et.al. (2013) pg. 11f

217 N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic review"* in I. Pala (ed.): "BMC Palliative Care" Vol. 12 Article No. 4 Berlin, Springer (2013) pg. 11f

218 M.A. Hebert et.al.: *"Potential and readiness for video-visits in rural palliative homecare: results of a multi-method study in Canada"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 12 Suppl. 3 New York, SAGE (2006) pg. 43 - 45; and *"Successes and challenges in a field-based, multi-method study of home telehealth"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 10 Suppl. 1 New York, SAGE (2004) pg. 41 - 44

219 L. Kidd et.al.: *"Telehealth in palliative care in the UK: a review of the evidence"* in V. Wade (ed.): "Journal of Telemedicine and Telecare" Vol. 16 No. 1 New York, Sage Publications (2010) pg. 1 - 9, pg. 8f

Chapter 5 - The Qualitative Methodology of J. Pols - A Refined Way of Assessing Quality in General and Palliative Telecare Research

The shortcomings of the quantitative efforts as presented in the previous elaborated narrative/discourse are to be addressed. The obvious question is how can we structure research efforts into TCT devices being used in palliative and care scenarios, with meaningful results for the stakeholders involved and of improved academic quality. As an alternative way of doing science in this field there is a proposed refinement of an ANT/script approach outlined by J. Pols in her book "Care at a distance"²²⁰. In this chapter I want to reconstruct the general methodology of doing science differently as well as to explicate the changes this methodology enables in stakeholder conceptions and ethical enframing. Following this, a final discussion about the advantages that the reframing of the research conditions and criteria have in addressing the "white spots" in the quantitative methodology, and the subsequent rethinking of ethical values necessary to make this work. Without further ado, onto the show.

The current research situation in telecare Pols determines is full of "*noise and dust*"²²¹, with hope and despair narratives engaged, the quantitative attempts at generating more tangible and reliable data having little effect to alleviate the discussions shortcomings of substance. She points towards the fragmented research community and small scale efforts as a main contributing factor for the lack in scientific rigor and quality of research - rarely we face projects that go beyond the prototype/trial stages. Her basic proposal of changing towards a more quality-focused research activity is build around the theoretically informed observer engaging the end-users and devices in practice from a distancing observer standpoint - an ethnography - as opposed to the active researchers in RCT-styled engagements that predispose the situation very much into a particular direction by virtue of having to assume parameters in order to function. On this practical level of assessment, where quantitative efforts have to pre-define variables, the ethnographies make them up as they go in practice, deriving them from the contingent end user interactions and volatile, malleable discourse they engage with each other and with the devices, establishing new routines. Before diving into the qualitative approach of Pols, one small disclaimer of limitation: she does not investigate the telecare/TCT potential for inter-professional communication, which is a possible additional layer of communication that could be of use for quality improvement of treatments and thus be of interest for future qualitative research. In addition her focus is not on the palliative care circumstance but about care in general, and in conjunction with the use of telecare²²².

5.1. How is Care via Device and at a Distance Constituted ?

Pols engages with a specific dichotomy, that the patients and nurses actions, when engaged in a care trajectory, are tied up/enframed in a warm-cold narrative/language use. According to her the human touch of the carer is considered "warm"; a comforting, empathetic gesture between human beings, while medical interventions and tools are considered "cold"; calculated, functional procedures of flesh-and-bones-material engagement only. The classical medical system is associated with this cold aspect, the patient as a piece of meat with curious conditions for doctors to tinker with. In modern terms the delineation is between "care" as a discipline and "biomedicine management" - care concerns the patients life world, and bio-medical management deals with the system world of techno-medical interventions.

220 J.Pols: " Care at a distance - On the closeness of technology" Amsterdam, Amsterdam University Press (2012)

221 J. Pols (2012) pg. 14f

222 hence the rather straightforward title of the book....

Pols gives us a philosophical context for this, drawing on Foucault's interpretation²²³ of medicine as a discipline of surveillance – like the Panopticon of Bentham, the patient is gradually observed only via the accepted lens of medical sciences up to the point where the patient and everyone else in the care engagement is subjected to the logic of medicine; factual, objective, cold empiricism leaving a lot to be desired in terms of true “care”. Coined as the “Heideggerian inheritance”²²⁴ by Pols, it explicates the sentiment that technology somehow gets between the world and the human, insinuating itself as a controlling mediator; technology as such is not to be considered part of the intrinsic human life world to begin with.

Now, how are the machines and devices constituted within these attitudes? For this Pols turns to Sparrow & Sparrow²²⁵ who postulated three factors, representative enough for the warm/cold dichotomy to serve as an exemplar: (1) machines cannot improve the control over true “care” - as they are limited in their pre-programmed functions, (2) machines cannot care about or even love the patient – intrinsically unable to express true concern/affection their care is limited to technical interventions, and (3) machines cannot relate to the contingent, individual human – tech. Devices are one-trick ponies that ideally can be turned off at whim, their functional criteria cannot take other humans into account as ends in themselves. By these three postulates of Sparrow & Sparrow are firmly in the camp of the doom&gloom crowd: the patient as an abandoned person, alone surrounded by sterile, uncaring technology.

Pols postulates in her work that this black and white dichotomy between care and intervention does lead us nowhere in terms of care innovation and technology integration, and thus proposes to properly differentiate these intuitions as a first step towards progress in care quality. The “warm” intuition relates to the ethical relation to and between patients: empathy, caring, personally getting involved, etc. are ethical goods, demanded from the medical professional engaging a patient. The “cold” intuition is actually about the epistemological relations towards the patient: detached, objective, empirical, verified, etc. interventions of the medical professional acting as a scientist formulating the best treatment option available. This differentiation is not done properly according to Pols by the practitioners in the care trajectories, who often assume that in addressing the epistemological, “cold” issues they would also resolve any ethical issues in one stroke. This can happen, depending on the disposition of the patient especially, but does not necessarily always follow.

5.2. The Methodology of Pols

The book of Pols is explicitly concerned with the constitutions and actions of the stakeholders regarding qualitative issues of TCT utilization in care trajectories (including palliative) as they crop up in a practical context of application – the “white box” and a webcam setup respectively, more below. Somewhat antithetic in its conception to the qualitative discourse, the “data” that is of interest to Pols and made relevant in her conception, is the one that the questionnaires and semi-structured interviews did not consider relevant (see Chapter 4)

Though Pols is clear about the fact that the knowledge that practice generates compared to scientific, laboratory-esque methods is not fundamentally different as to warrant its own category, nor is it the same, since then it would be relevant to the quantitative methods - it is simply differently generated knowledge on the same matter²²⁶. This specific focus on the way of knowledge

223 J. Pols (2012) pg. 25

224 J. Pols (2012) pg. 26

225 R. Sparrow & L. Sparrow: "In the hands of machines? the future of aged care" in J.H. Moor (ed.): "Minds and Machines" Vol. 16 No. 2 Berlin, Springer (2006) pg. 141 - 161

226 J. Pols (2012) pg. 80ff

generation yields a new type of explicit, qualitative data that the quantitative methodologies discussed in chapter 4 failed to pick up - a type of data relating to the organic interactions between the nurse and the patient primarily.

Since Pols does not care much about empirical parameters like interchangeability or reproducibility – in her concept of the “uncontrolled field study” done in an ethnographic fashion, see further down – it is easier to engage the influence of TCT in palliative care scenarios in a more limited fashion scientifically speaking, and subsequently the claims of a smaller, non-statistical significant study are easier to defend and ultimately more valuable for ethical investigations like this master thesis.

5.2.1. The "White Box" Experiment

In an attempt to resolve the dichotomy mentioned in the introduction, Pols investigates a particular care setup, utilizing the so called “white box” monitoring gear, this setup was used in the Netherlands to monitor cancer palliative care patients in home care settings (living in the region of Friesland), supplementing traditional home visit care by a local nursing facility.

The device: a small, white box - a health companion that prompted the patient daily to answer a set of questions relating to their disease: water intake, general feeling, issues with breathing, are you feeling cold, hot; aside from the physical stuff it also asked general questions about disposition and mental states. The question set was designed by a medical professional team and psychologists at the manufacturers point. They also determined at what data point cutoff values needed to be put into place for answers to raise red flag alerts. If a red flag was raised, telenurses contacted the patient for follow ups. The codification is purely automated, and frequently red flags with patients that nurses had known for a long time were actually false alarms, so the nurses adjusted their procedures and contacting protocols accordingly. Functionally the device also allows the patient to contact the nurses or their G.P. and reminded them on occasion that the option exists - that you can not over-but always under-report.

For the patient the white box served as a *memento mori*²²⁷, a regular, intermediate and repetitive time investment allowed the patient to deal with their disease in 5-10 min everyday, answering the questions and engaging in self surveillance, after which they freed up the rest of their day to go on living. The main advantage of the device is that they did not have to wait for the nurse to come around and then to list their complains that might have stacked up during the last 2-3 days, so the nurses visit after the device took care of the negative, complaining side of things became something positive to look forward to, like having a coffee and discussing positive aspects, affirmative, active opportunities to improve the care and life situation; rather than handling crises. The device enables more pro-active care by enabling for once the patients much closer supervision in terms of disease factors and facts, freeing the nurses to actually design a positive, affirming care trajectory with the patient. Also as a more removed effect, the device promoted a change in the patients communication behavior, the constant prompts of the daily questionnaire eventually giving them the words/language and opportunity to open up about issues they otherwise might have kept to themselves, be it within the nurse or their own family communicative behavior. As Pols points out the communication via the white box and with the nurses exhibited a combination of warm and cold issues. More precisely it was “warm” communication about “cold” matters at hand – nursing techniques and practical stuff about their respective medical conditions. The contact was welcome though since the nurse are initiated into what the disease entails, the white box alleviated the need for the patient to constantly explain themselves and their disease – as one participant in Pols study

227 J. Pols (2012) pg. 31

put it: “...you get sick of being ill.”²²⁸. Being freed from socializing only under the guise of their disease the patients were very positive towards the white box device. The presence of the disease is taken as a given but the scale, shape and time spent addressing it in what positive or negative fashion is not. The task for the nurses is to find the right frequency of interaction in conjunction with the device to neither overburden or abandon the patient. Some patients did in fact report deterioration in their relationship with the carers, indicating the issue that TCT cannot establish good contact from scratch but builds from existing relationships – which incidentally determine the goodness or badness of the technological fit. As the nurses and doctors can be uncaring or engage in a sub-par relationship with the patient, the same goes of course too for the relatives and friends of the patient, TCT cannot generate goodness of interpersonal reactions there. Now but what about the criticism explicated earlier of Sparrow & Sparrow with regards to technologies inabilities ?

First off, Pols outlines the limitations of the warm/cold dichotomy, though still a very good and easy image about care issues, both elements are actually necessary to have good care. As a better way of describing the technologies introduction into care scenarios Pols proposes the process of “fitting” of the technology; a derivative/modification of Aristotelian phronesis as individual excellence it is “[...] the creation of a practical and aesthetic relation of making something fit needs both ideas”²²⁹.

Now how does Pols address the issues outlined by Sparrow & Sparrow; regarding the issue that devices do not love us. Yes, intrinsically the dead matter that makes up devices are incapable of this very specific human trait, but the devices can enable better and more loving, caring relations between those that use them. See the aforementioned example of the patient having finally the words to express their issues and concerns surrounding the disease being provided by the white box for them to talk to their loved ones. According to Pols it also lowers the engagement barrier for asking for help, before they had to dial the number of the nurse/doctors – combined with the Dutch proclivity not wanting to bother the doctors this led to under-reported issues all around. The white box is set up in a way that literally the nurse is just a button push away, and the box also reminded the patients when red flags were registered that they are not bothering anyone but take proper care of themselves in calling the nurse.

The patients, aside from “caring for the nurse”²³⁰ as above, also do care for the device itself and engage it on an emotional level. Obviously to Pols they do express their concerns through the device in answering the questions on a regular basis, over time the device becomes familiar, via the personal questions the perception changes as one patient put it: “*that buddy wants to ask me something*”²³¹, and some gave the box even a name. The device is flexible enough that the patients can tailor their engagement with the box. Emotionally needy patients could have a much more intense contact as people who were more distant or reserved in their care dealings.

Even within the reframed technology adaptation of “fitting” that Pols developed, there is of course room for mistake and for “mis-fitting” the device in practice. One mainstay of misfitting was to do with the design of the questionnaire for the patients. Since it was aimed at the general population it contained a set of questions that did not match the exact circumstances of each and every patient down to the letter. Questions regarding sexuality were perceived as very intrusive and invasive by the patients investigated by Pols, leading to a disrupted care state – a loss of confidence in the care effort via white box - since the patients got quite upset and delivered their feedback accordingly. Even some phrasings in the patients provisions triggered such a response when the patient got to the

228 J. Pols (2012) pg. 30

229 J. Pols (2012) pg. 34

230 *ibid.*

231 J. Pols (2012) pg. 36

ill-worded part asking for their “preferred place of death” - technically correct but formulated obviously in a very objective manner. This particular phrasing was quickly replaced by “preferred place of living” with the hidden presupposition that this is in fact the last place they will stay. More severe were questions of potential medical conditions that could not be changed since they were applicable towards the patient population, one instance the white box asks the patient about bedsores; leading to a healthy participant to think down the road ahead, and the possibility that this might apply in the future leading to a spike in anxiety scores during Pols investigation. Adding to the anxiety was the daily grind to get through the questions, as the amount of questions was quite exhaustive. Patients admitted to Pols as to sometimes just skimming them or giving the average rating they gave the day before without engaging their condition, though some patients were happy to count their blessings everyday so the grind aspect of it comes down to personal disposition. Still despite the potential for misfitting and failure in general, Pols metaphor of “fitting” serves to rectify the warm/cold dichotomies shortcomings towards a relational, unified, intra-/inter-care evaluation of the care efforts conducted with a focus on the integration of TCT into the field – in Pols own words: “*Elements of warm and cold, ethics and epistemology, subjectivity and objectivity are entangled.*”²³².

5.2.2. The Webcam Experiment

The second experiment discussed by Pols contained two sub-groups, the researched patients were all suffering from forms of COPD's²³³, one group being recently discharged patients from a clinic were enrolled in a webcam project for three months fixed, while a second group was equipped with TCT for an indeterminate amount of time, supplementing conventional home care efforts - both groups were not in palliative care but underwent care for rehabilitation/convalescence. The interest of Pols ethnographic approach lies with observing the modifying effect of the webcams. Usually the quantitative approaches endorse the device as value neutral and passive - simply utilized technology, with the human interaction being the sole focus of TCT contacts, not going beyond a background relation with the device and not engaging the mediation aspects of it according to Pols. In ANT/scripting the devices are enframed as having a modifying influence on the human end user, enabling or inhibiting certain behaviors and routines. The device and the human co-shape the new and emerging utilization routines in practical back and forth experimentation and failures.

The results in observation do mirror to some extent the results of the quantitative studies, no surprise really since Pols observations were gathered while being embedded in a quantitative styled trial phase of TCT in the Netherlands. Patients and nurses across the study reported much more personal contacts and intimacy than phone only conversations enabled. Literally and figuratively speaking, the nurses had a better picture of the patient, both participants engaged in a much more intensified contact. The device demanding more concentration within a digital, specific locus; sitting in front of a camera, engaging the other with fixed gazing - usually a very intense and aggressive behavior, confrontational subtext is avoided since the users end up looking at a fixed screen rather than directly into the camera.

As Pols shows, the capacity for conveying non-verbal communication and interpersonal subtexts allowed also for nurses to become better listeners, being forced into an attentive position and mindset due to the visual layer; though this was mostly limited to the head, with some hand gestures making guest appearances - most other body parts are excluded from the setup investigated here. The negotiated communication behavior of the encounter is enframed by Pols in two distinct

232 J. Pols (2012) pg. 42

233 Chronic-Obstructive Pulmonary Diseases.

conceptions, the "topologically reversed telepresence" and the "topologically congruent telepresence" - essentially this a reframed addressing of the issue of the clinicians "medical gaze" into the patients home. In the reversed state the patient and nurse look at each other and their backgrounds through the device, the standard relation that the device enables is that of a face to face conversation within each others specific loci made indeterminately digital. Patients socialize, show off craft projects²³⁴, have a cup of coffee with each other or with the nurse. The congruent configuration is a shift occurring when the clinicians gaze becomes too intent for the patient, where then the patient immediately and seamlessly becomes hyper aware of their background, their home situation which then is invaded by the clinician. The assumed insignificance of flattened hierarchies that seemed fixed in the quantitative research catering to the medical imperative, are much more fluid in this enframing. They remain contingent on agreeing on the communication model for both, patient and nurse could either engage in an almost absence of hierarchies (that is communication strictly, the nurse always engages the clinical gaze). Or if the communication model was not sufficient the malleable and fuzzy digital room of the TCT encounter re-enabled them quickly and decisively - a volatile state of indistinct loci as Pols puts it²³⁵, meaning that *"the carer has the power to turn indicators into symptoms and clinic visits"*²³⁶.

In the qualitative enframing of the observation it was even more noticeable than in the quantitative attempts, that the TCT cannot generate the initial trust between users that is necessary to kick off the telecare and mutual interactions, it can only strengthen and modify what is already there. As the end users negotiate their communication behavior in a back and forth modification between them and the device, the capacities attached to the device socialize the patient to the technology in a way that some patients having used chat programs like MSN previous to the webcams continued to use them over the technological dimension of the visual that more sophisticated devices offered. They felt more comfortable with a seemingly old, outdated or backwards technological dimension. The derived qualitative dimension is that fitting the communicative dimension to the actual personal relational distance is key to the fitting discourse between end user and device. In matching the actual relational distance that the end users perceive to the personal relational distance enabled by the device the best fit for TCT in palliative and care in general can be found. One patient described it as only using the webcam setup to call people he/she would actually invite into their home²³⁷.

5.3. A Contrasting Stakeholder Analysis to the Quantitative Discourse

This section of the chapter is to serve as a complementary methodological take on the stakeholder analysis that I have conducted in the previous chapter. Obviously it treats only a single source as opposed to the kaleidoscopic selection of Chapter 4 but it is extensive enough by merit of being a whole book dedicated to a qualitative attempt of researching the TCT introduction into care trajectories, while also being comprehensive enough for a master thesis.

The first aspect is that researcher and stakeholder-wise nothing much has changed with regards to the circumstantial embedding and stakeholders of interest. Pols research is facing the introduction of telecare technologies into the same medical ethics and goal oriented context of palliative care and provisions, meaning simply that the stakeholders that were of interest in the quantitative analyses in the previous chapter are also of interest for the work of Pols.

234 J. Pols (2012) pg. 103

235 J. Pols (2012) pg 106f

236 J. Pols (2012) pg. 108

237 J. Pols (2012) pg. 109/110

The relationships of the primary care interaction stakeholders are still intact, as is the the lineup of secondaries and tertiaries that are depending on the primaries constitution. The main difference between the quantitative and the qualitative methodology relates to what knowledge about the same set of stakeholder is generated and how.

The quantitative methodologies analysis and the value/Ethics analysis of said research is evident in the previous chapter, for this part I will use the pre-existing analysis and contrast Pols efforts against them. Before I dive into the specifics of the primary, secondaries, etc. relationship and the way the ethnographic method differs, it is important to note that the stakeholder set being the same does not entail that the assumptions about the stakeholders are the same. Crucial to the ethnographic results and the routine practice elements that we will see emerge is that the patients (and to lesser extent all other stakeholders, though not investigated as in-depth) are actually unstable stakeholders, with vastly differing attitudes and desires depending on daily, weekly, monthly swings in disposition, mainly brought on due to the variables of the disease trajectories in conjunction of the care quality aimed to alleviate said variations as well as the potential for interpersonal deterioration of relation between the patient and family, friends and care nurse due to personal idiosyncrasies. This unstable configuration of the patient as the main stakeholder of interest of course also extends to the secondaries, most notably the family and friends, and tertiary stakeholders as well. Depending on attitudes of all the relevant individuals of the stakeholder group, the unstable patient configuration has rippling effects outwards.

It is important in the qualitative methodology and in extent to all research methodologies to have a realistic grasp of the humans involved in whatever medical research one is engaging. Thus a realistic depiction has to take into account that across even a day the disposition of chronic pain patients, like the cancer patients, can change dramatically depending on correct analgesic dosage, personal events, flaring up of the metastasis, secondary disease effects, nutrition, etc.. Tracing this is of course a messy and time consuming business. Hence the quantitative methodology did settle for stable stakeholder configuration assumptions over time. Without the necessity to adhere to quantitative and statistical significance the qualitative attempt allows a much more realistic, anecdotal look into the practice and micro-level machinations of the daily care interactions. This is enhanced by the passivity of the ethnographic observer as opposed to most of the quantitative resources. Pols was not the researcher pushing the telecare and analyzing it at the same time, but was attached to existing TCT projects that she as a researcher had no stake in to begin with. The notions of quality, as in the quality of the scientific work conducted, are vastly different. The reduction to a smaller sample, intensely observed by a most passive participant in the room on both ends of the TCT gives us the following stakeholder modifications over the quantitative method.

5.3.1. The Medical Doctors

The primary care relationship is intact and flourishing - in the sense and nature as it was positioned in the quantitative discourse - with the patients being home bound and the patient doctor interactions being relegated to weekly or monthly interactions/check-ups. The experiments that Pols engaged in were aimed at primarily strengthening the contacts of the care/on-site nurse executing care and medical orders in conjunction with the patient and the technology helping along. Hence the primary relationship despite essentially remaining unmodified in itself, is of a more muted nature in part also due to the way Pols focus is set²³⁸ in combination with the change in methodology, taking the spotlight away from the doctors and shining it on the nurses²³⁹.

238 J. Pols (2012) pg. 94f

239 see J. Pols (2012) Chapter 3, fittingly entitled "The heart of the matter - Good nursing at a distance"

Against the backdrop of the single patient organizing and engaging his or her care, the doctors become more distant in the way their ethical/professional relation is engaged by the patient and Pols as a researcher. The medical ordering and the position of informational supremacy/control is still intact and for all intents and purposes the primary care relationship that was true for the quantitative attempts depiction remains true in the context of a qualitative research. Since the embedding has not changed for the palliative care, the supremacy of the medical ethics, in the patient-doctor engagement remains intact as well. [Caused (logical-conceptual) by Pols passively embedding herself in line with the ethnographic approach within an existing infrastructure that was delivering care within the established parameters of conventional medical care setups of the Dutch healthcare system - her research actions do not modify the context she chose to embed in.]

One necessary disclaimer is that there were only old patients participating in the white box and webcam experiments/support structures respectively, hence there is no option for Pols to engage these specific subgroup of young patients with the qualitative methodology as the researchers have in the quantitative discourse depicted in Chapter 4.

5.3.2. The Second Primary Relationship - Nurses and Patients

Resulting from the focus towards the practice and daily routines, there is a new primary relationship that I cannot fit exactly into the mold of the previous analysis of chapter 4, the contact between nurse and patient. The premise of the nurse as a secondary stakeholder is still intact, they depend on the primary interactions between patient and doctors, but the practice-bound analysis elevates their interactions into a primary-esque status due to the direct influence they have over the patient. This setup resembles the desire of nursing and palliative care ethics that formulates the nurse as a companion on the patients side, warm caring facing off against the more objective and sterile medical environment and doctor. In combination with Pols interest in the practice-generated knowledge and interactions the nurse and nursing actions & ethics are given the much needed/deserved attention.

5.3.2.1. The Nurses

This is the most crucial and differing section as contrasted to the quantitative methodology before, the prominence of the nurse as a stakeholder and the proper respect for the practical intervention level as a point for research into TCT. This is further cemented by the core research question that Pols formulates in chapter 3 of the book, fittingly entitled "The heart of the matter", regarding what is it that makes good nursing and what role TCT plays in that context²⁴⁰.

According to Pols, the aspect of care routines is the most crucial modifying point, since TCT enters and renegotiates the possibilities of care from a reactive to a pro-active engagement with the patient²⁴¹. Building from the warm-cold dichotomy, with the nurses being on the patients side, engaging in a human fashion and warmth=goodness - the Heideggerian inheritance in full effect. The TCT devices help the nurses to reinvigorate these aspects in their daily care activity. Operating usually in a time and resource constricted environment of hospice/hospitals the white box and webcam allowed vast improvements in the degree of attention that the nurses can pay to an individual patient as well as giving much more, and more frequent, data entries, smoothing out the care trajectory with daily reports of patient dispositions²⁴².

240 J. Pols (2012) pg. 45f

241 J. Pols (2012) pg. 53ff "From health status to process"

242 J. Pols (2012) pg. 53f, 117f & pg. 136f

This is the actual, very simple core of the TCT effect, an increase in check-up frequency accompanied by more patient specific data about daily dispositions rather than hard medical data - although medical data is still a part of the equation, it is no longer the sole concern. The frequency shift allows for a pro-active nursing intervention, and if done correctly the nurses attain such intimate knowledge of the patient that they easily improve the quality of life in the patients disposition towards the disease - as instead of just acutely dumping the main issues on them during the weekly/monthly visitations to the hospital.

The task for the nurses that was crucial when facing the change brought by TCT was to attune each patient to the right frequency of feedback. With patient autonomy being as compelling an ethical imperative as ever, the nurses as a stakeholder group had to negotiate and adapt the now sudden malleable attention frequency to their patients needs, marking an increase in competency demands towards them - adding to/strengthening the mediator position of the nurses between patient and doctors. As well as making their interpretative competency of the patients verbal and other responses a much more important skill in conjunction with the absence of touch as a sense it forced nurses to intensify and redevelop their practical ways - or as Pols puts it: "*...the creation of a practical and aesthetic relation of making something fit needs both ideas*" - "*... mixed to different tastes and concerns, depending on the situation at hand.*"²⁴³, referring back to the classical notions of "phronesis" as the main capability that needs to be developed - rendering the nurses as the main adapting stakeholder - the one that has to change the most - facing TCT over the doctor's role in the quantitative discourse.

5.3.2.2. The Patients

Due to the focus on the nurse-patient relationship, the neglected aspect of care routine is of course also relevant to the patient, who as a stakeholder group has to be properly educated/attuned/"fitted" to the TCT technological capabilities as to avoid sub-par or even worse care trajectories to manifest. The main aspect of this fitting process is that it ideally happens in conjunction with the nurse, over the doctors, as a stakeholder group. the divide between the generation of scientific knowledge and that of practical knowledge in immediate and obvious presence to the patient as the core "target audience" if you will of both.

The patients as a group benefit from the renegotiated knowledge generation in that the practical help of actual actions and processes with the nurse are addressing the feelings of being overwhelmed and helpless that often crop up after the initial diagnosis of being shifted to palliative rather than therapeutic care. The TCT supports the daily management of the disease, freeing up time for life after dealing with the disease in the morning as in the white box experiment - regaining certainty and purpose: "*The device made him analyze and articulate how he was doing, and made him take specific action*"²⁴⁴ .

Even events of misfitting the device to the patient can have beneficial care consequences, for example patients were prompted to reflect on the further trajectory by questions of the white box that did not pertain to their acute situation but potential avenues, making them contact and confide into the nurse that then could adapt care protocols and counseling appropriately. In that regard the patient becomes an even more active and more complex stakeholder in the care trajectory than in the quantitative discourse, by opening up about aspects of care that usually were considered less

243 J. Pols (2012) pg. 34

244 J. Pols (2012) pg. 31

than socially acceptable/desirable²⁴⁵ by the patients themselves.

A potentially negative effect of the TCT emerged in the qualitative patient study as a stakeholder, in that when properly fitted/attuned to the device in an ANT fashion the patients on occasion did grow very fond and attached to the potential of the device to the point of bordering on dependence, highlighting that if the practice is dominated by the potential agency of the device the patients could actually lapse back into a more passive disposition as compared to even the most classical medical ethics enframings of a piece of meat to be treated²⁴⁶. In one case a patient became angry after suffering a heart attack despite having meticulously used the white box to provide data feedback²⁴⁷. Indicating that there is a potential for the patients to grow to relaxed/complacent in terms of attitude towards the disease.

One final aspect is that in the webcam setup, possibly tied to the dutch predilection for "gezellig", the patients actually engaged in telecare contact between each other, sharing knowledge and little tips and tricks for everyday disease management in an organic fashion, not exactly like group therapy, exchange sessions the technology was used for informal learning experiences not accounted for in the quantitative discourse²⁴⁸.

5.3.3. The Secondary Stakeholders – Informal Caregivers and Hospital Managers & Admins

5.3.3.1. The Informal Caregivers

The conception of informal carers is pretty similar between the quantitative discourse and the qualitative ethnography, they do get bound up a bit more in the daily care practice opportunities due to the frequency increase, though the caveats still apply, for example a baseline positive attitude towards the patient to begin with. In terms of quality of life they still are relevant in improving said QoL of the patient, though the study of Pols does not venture much past the "remote hands" and "they do informal stuff" that we already face in the quantitative discourse. This aspect becomes more clear if we look back at the central issues to be researched in her book, namely the technological modification of care at a distance, with a specific focus on the professional-interpersonal relationship and constitution of primary care interactions between the nurse and the patient, full stop. If already a big stakeholder segment like the doctors is marginalized in favor of giving the nurses the professional first row seat in the analysis it should be no big surprise that the informal carers as a bona fide secondary stakeholder group are marginalized yet again.

5.3.3.2. The Hospital managers & Admins

The hospital managers and administrators enter the qualitative analysis in the same fashion as they did in the quantitative narrative, as chiefly concerned in engaging distributive justice via the monetary budget planning and allocation of resources like the nurse's duty roster. The way they are engaged though is modified a bit, that has to do with actually getting the proper attunement of the managers towards the TCT done. The manager grouping engaged in the Pols study did labor under false assumptions towards the technology in that the nurses would just gain another tool in their repository to engage the patient and care trajectory in the same fashion - discounting any and all

245 e.g. salt intake in heart failure patient J. Pols (2012) pg 57

246 J. Pols (2012) pg. 55f

247 *ibid.*

248 J. Pols (2012) pg. 71 and pg. 75f

ANT-styled modification potential of the devices, and they were firmly entrenched in thinking of the device towards an unchanging end.

There is a need for the nurses to be able to properly fit the device within the changed care routine of the pro-active nature triggered by TCT. The managers being the ones responsible for the properly sized working space in which to do it, while also being clearly envisioning that there is actual proper usage - lest the device improperly financed and allocated by the resource controlling stakeholders that the managers are, slowly dying a "social death".

In practice the managers quickly realized that their replacement narrative and drive for unchanged care routines would not be viable for long²⁴⁹, e.g. there were still physical log books kept at the patient's home location that were inaccessible leading to fuzzy reporting of care outcomes and confused nurses. Setting up a shared information point is crucial, focusing reporting and information gathering activities in a centralized fashion while lessening the impact for example that research queries like that of Pols have on the practical organizational²⁵⁰.

5.3.4. The Tertiary stakeholders - TCT Manufacturers, Designers, and Policy Makers

Again, the same stakeholders apply as in the quantitative discourse, and even in the same fashion. Their position as tertiary stakeholders once again means that there is scarcely any information to be gathered to give a satisfying picture of their value alignment. With the investigated experiments taking place in the Dutch context, it is reasonable to match the extra findings of Pols in this section to the extrapolations of the quantitative discourse section in chapter 4. Facing Pols study the stark, crucial difference is in the new primacy of the nurse-patient relationship, retaining much of the emphasis positioning of the empirical studies.

5.3.4.1. The TCT Manufacturers & Designers

As mentioned above, the attitudes and value positional expectations and requirements of this stakeholder group match that of the previous analysis. One point of difference though is at least sketched in Pols, and that has to do with the "white box" being not an off the shelf adaptation of a consumer electronic but a purpose built device specifically for palliative and therapeutic care interventions that require a daily oversight and data gathering. This means the designers and producers as a stakeholder group are tied to a much more targeted agency of their activities, being much more aware of the design requirements of the relevant end-users and most importantly they are burdened with a much more direct and immediate responsibility for their device.

Thus with the element of awareness and agency any shortcomings of the design should be easier to be taken up with the designers to begin with²⁵¹ (end user feedback) as well as increase the responsibility for ethical and usability shortcomings of the technology – for example the issue of “one questionnaire fits all” which led to intrusive questions regarding sexuality and raising fear/anxiety scores across the board by mentioning conditions that some patients did not (yet) have.

249 J. Pols (2012) pg. 122

250 J. Pols (2012) pg. 124f

251 J. Pols (2012) pg. 144: *"Tinkering could be encouraged by involving designers and technicians in the innovative practices, to adapt the devices to make them fit better with the aims and interests of the practices in which they are used. They may explore new uses for the devices together with the nurses, to make the devices work better."*

On an interactional level the producer stakeholder conception did not change aside from this increase in responsibility and common sense interactions of fixing/patching their product to the end user needs in the particular practice contexts. Questioning the participants also highlighted that the expectations regarding diminished care quality due to the machine were unfounded and nurses and patients showed great satisfaction regarding the device and the new routines it brought on²⁵², making them successful stakeholders in the correct way of implementing TCT and capable in a sense of craftsmanship.

5.3.4.2. The Public Health Managers, Policy Makers, and State Institutions

In terms of internal understanding and dispositional requirements this stakeholder grouping also remains largely unmodified from the ones we engage in chapter 4, though in the specifics of this book the experiments operate under research grants from the Dutch government, tied to the concerted large scale efforts to bring the digitization of the health sector about, see for example the electronic patient record keeping system that was introduced in ~2009²⁵³.

As they still rely on quantitative data and research analysis, they are the stakeholders with the smallest stake if you will in the ethnographic method of Pols. As she operates as an embedded observer her financial investment is small enough in terms of research grants that there is no big interest as say compared to the experimenters that proposed the medical readout devices and require a more substantial justification of their research spending. As for the scientific interest, the qualitative approach does away with exactly those methodological requirements that admits data to be used by large scale state institutions while also being so focused on micro-scaled interactions that it runs counter to the need for macro-scaled content and data for this particular stakeholder group.

In terms of external representation, the Dutch context of a market economy allows for competitions amongst TCT providers as overseen by the state - assertive consumers meet competing providers. The base assumption of the market model is of course that competition and end user preferences would bring about the best distributive and economic fit of the technology, with quantity and quality of said product emerging without the direct intervention of the state - enframing the patient as a political actor for all intents and purposes of the institutional stakeholder.

Now, as companies pay for the conduct of prototype experimentation the effect that is detectable on the micro, practical level is that the scientific data of the TCT implementation is turned into a trade secret to be protected²⁵⁴, the infrastructure of grants and company money keeping up a public health experiment that if stopped, the whole TCT development would stop - hinting at the largely promotional top down incentives of TCT research even in a presumed market situation the project survival rates are iffy, sustained by marketing strategies that engage in "soapbox posturing" and classic doom/gloom narratives²⁵⁵. The market situation is in fact, as Pols positions it, at a standstill, the promises of quality and quantity not manifest and every economic stakeholder interlocked waiting to see what happens with only minor motivation from the state stakeholder to change it - crippling further research efforts.

252 J. Pols (2012) pg. 30f

253 for an interesting take from a privacy and security perspective on the patients records as well as for a decent overview of the topic, see: <http://d1sx0yagqoiea4.cloudfront.net/epd/Techreport-VWS.pdf>

254 J. Pols (2012) pg. 14f

255 J. Pols (2012) pg. 135ff

5.4. The Ethnographic Methodology - Practices and Values

The research method by Pols, inspired by ANT/scripting concepts, rests on shifting the fundamentals of approaching any field of research and observance of human-technology relations. The basic necessary way of thinking about this approach is about not having objectively measurable "good" or "bad" TCT practices, but to observe practice first; being a theoretically informed observer embedded among the stakeholders - hence the "ethno-" in ethnographic study - and be ready for a process of dynamic/volatile fitting between the human and the device. Critical is that human and device are both co-shaping how things are going to pass; not that technology has an independent agency and activity but enables and inhibits certain behaviors and usages. "Fitting" - as in the sense of "material semiotics"²⁵⁶ - as a concept rests on the presupposition that we cannot preset and predetermine many of the variables in advance - the aforementioned essential/necessary component in RCT's.

The concept of fitting also includes the notion that practices can change before values and stakeholder attitudes do - in a kind of random, user-dependent bottom up movement of technology adaptation due to necessity or curiosity. The end-user is integral to this approach in that their creativity in using the device is key to the practice - the continuous use of the device by the end users, patients and nurses can develop into new practical routines, which then eventually solidify into new guidelines and revamped values during and after the shifts happened.

The single point assessments for parameters of the quantitative methodology is replaced the observance of a process. By shifting to process rather than point in time observations, one very crucial aspect of the users comes into light - the user attitudes and stakeholder disposition/"being" is unstable, something the quantitative method cannot account for at all. The necessary contingency of the quantitative method on stable stakeholder configurations is one of the central aspects which makes it so ill-fitting to researching unstable stakeholder configurations and values. Less deterministic, the fitting approach is then rolled into what Pols calls the "uncontrolled field study", juxtaposing her concept with the mainline, traditional assessment methodology. The quantitative method's issue is that it really is tailored to assess medical scenarios, for example a drug efficiency test, meaning it rests on stable preconditions, stable stakeholders, randomization, data that can be quantified to begin with, and a statistical significance in terms of participation/cohorts/control groups. The way it is enframed, the choice of theory, predetermines the kind of questions you can ask, and what answers you will get.

Pols lines out "four stages of heuristics"²⁵⁷ that govern this volatile process in practice:

1. Letting the technology out of the box: The effect and working of this initial phase is essentially unpredictable. A versatile stakeholder melange engages the devices and ends up with different attempts in initial "domestication" of the technology. [I would frame it as creative (ab-)use of the end user, the device is out of the designers hands and things happen.]

2. Mutual adaptation and taming: The users start to make the device fit the circumstance of ones personal, contingent use, for example: the PC has a lot of functions and capacities, but users have a particular set of programs they know and use in a semi-fixed manner.

3. The device unleashes creativity and imagination: After an initial congruent usage of the technology, the invention of new applications by users happens; like a chemist using substances to new ends, the central nurses of webcam experiment wanted monitoring data for heart failure research instead of individual patient telecare.

256 J. Pols (2012) pg. 18

257 J. Pols (2012) pg. 18f

4. The devices taming humans: though not active agency, the devices by virtue of being constituted in a discernible fashion are enabling or inhibiting certain functions and utilization, shaping use via inherent device configuration, for example a TV with the capacity for only 10 channels of all 30 available, the coercive speed-bump, Foucault and the Panopticon for prisoner self surveillance.

These procedural observations yield insights much closer to the actual practice. For example: the telecare webcam allows for much more frequent contacts between the nurse and the patient; the technology makes a simple modification to the parameter of "frequency of contact". What we end up getting in practice is that the nurses develop new routines in dealing with the patient that are not passive, reactive to the patients concern as they were previously voiced in the quarterly face to face meetings between them. The frequency shift allowed the nurses to engage the patients in a preventative, active manner of caring. Much more incremental and procedural the nurses had much more opportunities to give practical advice about care measures, check their upkeep and monitor the unstable patients attitudes and conditions over time; making the nurses intimately more familiar with the particulars - allowing the tailoring of care measures; the ethnographic observation being: by adjusting the practice (frequency of contact) new routines emerge (preventative instead of reactive care) which manifest some values presumed better/more practically aligned for the underlying the engagement, modifying their practical efficiency (nurse providing good care, on terms of their own ethical enframing, to the patient following palliative and care ethics).

By observing practice changes first, as they happen/play out, we reach a more precise image of the value adjustments in practice, caused by the technologies introduction into the existing care situation. Nursing as a medical discipline is, for Pols, in a unique situation as having always to engage in a "practical rationality"²⁵⁸ of an intertwined medical knowledge and application of interventions. Relating between patients and doctors they differentiate the life-changing, medical dimensions and the benign, everyday activities/disciplines as the [ideally] seamless integration of all stakeholders interests and capacities into an actual daily grind of practices caring²⁵⁹. This seems oddly reminiscent of, say it with me, Saunderian concepts - compare chapter 2 [no surprise really, seeing as Saunders started as a nurse]. Pols summarizes her approach in the well named concept of "uncontrolled field study"²⁶⁰ - a direct hint as towards the stance she takes with regards to the quantitative measures and methodologies of statistical significance. She realizes that the current methodology, the dialectics of quality and efficiency as she calls it are still going strong and that true fitting in her qualitative sense has yet to emerge.

Key part in the Dutch context of her research is that the quantitative discourse is also enframed in a market situation of provisioning, with policy makers taking a very hands off approach to the issue, assuming the market regulates and develops on its own; with the consumer (presumed stable, again...) taking over political action by choosing, and "quality" emerging as an accidental quality. The problem with this perspective for once is that it turns the results of a scientific investigation into a trade secret, a commodity of value in the fiscal sense, rather than into public knowledge as it should be [or is promoted as "pure science anyway"]. The problem of the market commodification of the TCT research is that it did not magically shift towards quality and resolved its issues but ground to a halt with the stakeholders in a standstill; TCT projects rarely survive the trial phase when shifting to a model of self-sustaining activity. The discourse investigated by Pols is stuck in marketing and promotional activities, stakeholders interlocked [first mover disadvantage], the full effect of hope/doom narratives - what Pols also calls the "soapbox". So, solving this Pols maps out the methodology of uncontrolled field studies. The observation of practices is the key to proper,

258 J. Pols (2012) pg. 85

259 J. Pols (2012) pg. 95

260 J. Pols (2012) pg. 143f

qualitative research data and results in the long run - as Pols puts it: *"I reflect on a different sort of research that actually delivers useful knowledge on novel telecare practices, that engages the parties concerned and their practical knowledge while granting more space to the actual telecare users - patients and professionals."*²⁶¹.

Observing the innovative practice of the actual end users without prescribing factors and variables is the central object of research, thus fundamentally changing the type of science really being conducted. (1) Pols changes the way problems are articulated, away from data like say patients weight over time, Pols specifically engages the indistinct worries a patient might have, (2) This means also that the way problems are addressed has to change, actively involving the patient in his or her care trajectory, embedding direct practices and experiences (for example COPD patients distributed their experiences between them via webcam), (3) From practice to values, what makes "good" care hinges on values that are incompatible with the quantitative method; the increase in frequency of the previous example shifted the assessment of what quality the care has to the degree of preventative efforts the nurse could engage in. Active participation down to the patients own team building between them shifts the generation of "good" care to local communal efforts, away from professional interventions [and thus away from professional power structures]. This type of research data would be considered part of the subjective experience within the methodological framework of the quantitative research, making it inherently not part of the data looked for and gathered, too microscopic in the scale of fixed variables and statistical significant cohort sizes.

These modifications of research conduct - compared to chapter 4 and the quantitative methodology - outlined above does not occur in empty space though, running along the chaotic and seemingly random fitting of end users and technology is the second task of integrating the conventional care efforts into the changing system. The fitting process is inherently complementary to existing structures, but with the unstable end users and changing attitudes and practical dispositions the process is much less recognizable as it is say in the quantitative discourse - it contradicts both narrations of replacement styled efficiency and self-management as well as the nightmare of the alienated patient dying alone and forgotten. The end results of uncontrolled field studies that Pols proposes are suggestions and possibilities of user's innovative care practices and fitting processes of contingent nature; rather than directives and probabilities that come out of quantitative research efforts. The gathering of these make them local, rather than universal facts/data points; meaning that in order to get "proper" results the methodology needs several rounds of application and refinement to develop into a full-fledged research and scientific concept. [It also hinges very much on the researchers self-conception, regarding how much and what kind of "theoretically informed observer" on will, and can be.]

261 J. Pols (2012) pg. 136

6. Conclusion of the Thesis

Conclusion General

Now, for the conclusion of this thesis let us return to the initial research question and the very reason for this thesis existence: How does the introduction of TCT into the palliative care context modify the ethical values and attitudes of the relevant stakeholders involved - or does it at all to begin with ?

Answering this question required a thorough research of relevant literature, delineating projects that involved multiple stakeholders as to attempt to get a satisfactory picture of the situation at hand. As palliative care literature is scarce in comparison to medical literature on pain therapies and analgesic composition, researching literature on TCT experimentation in a palliative care context was at times like a walk in the desert. Notable from the start was that the research projects investigated were all highly prototypical & experimental in setup, conduct and overall structure. In addition there was/is very few contact between those researchers, despite continued efforts of institutions like St. Christopher's to bundle up more and more scientific inquiries relating to palliative care. My initial pursuit of the main research question led me to the historical development of palliative care as a starting point for the thesis (see Chapter 2). As the historical context is not only to satisfy academic requirements of the thesis proper, but also serves to delineate exactly what the difference between palliative care and medical care approaches is. As their respective ethics refer to the same set of baseline values in a somewhat contingent combination of deontological and utilitarian elements, it made the historical and ethical delineations necessary to have clear cut terms to refer to in the thesis - as well as to provide a comprehensive primer for the reader that engaged this thesis.

With these necessary preconditions and central research question at hand I engaged the initial observational hypothesis, facing it off against the relevant research literature. The hypothesis was, that from the very long dealings with the dying patients and Death in the cultural contexts, palliative care ethics was to have had an impact on the attached values & realizations of TCT in modern palliative care and the stakeholder attitudes. With the strong histories of faith-based palliative caring, the development of palliative care ethics as a distinct set of values, the emergence as a medical discipline and the focus on academic, empirical research since the 1960's, etc. I presumed that palliative care ethics was to play a decisive part in the TCT care practices. A rich ethical context, deeply rooted in a discipline and its professionals facing off against modern digitization efforts in a highly sensitive context.

This hypothesis has been falsified over the course of the thesis research, as it emerged that medical ethics are very much entrenched in & defining of the current iterations of TCT usage patterns. The value realizations take place within this single ethical frame, with the medical doctors at the top of the stakeholder lineup with regards to their values actually being respected and realized - trumping even over the patients in this regard due to their privileged access to specialist knowledge. Secondary to the doctors are the nurses as specialist-knowledge equipped but dependent from the doctors decisions - in terms of ethical value realization degrees of freedom/opportunity. Even less impact in values and the respect for their respective composition is given to the informal carers as they are too diverse & vestigial to be properly considered in the first place. The same applies once even stronger, more pointedly to the set of mostly accidental/backdrop enframed tertiary stakeholders.

Aside from this very strong dualistic primary care relationship dominating in the trajectories, the quantitative papers contain no hint as towards any inroads of palliative care ethics discernible when it comes to TCT usage conceptualization. An expectation of mine was that if palliative care ethics would have made any progress into TCT mediated palliative care trajectories, it would be notable in the researched literature. The total absence of any element of palliative care ethics highlights again the very strong position of medical ethics which TCT apparently embeds in the discourse structure, and is at least indicative of an unrealized/unresolved value engagement conflict between the two ethical sets. The core values themselves are not in question, but the way they are engaged and are achieved via stakeholder differentiation between medical and palliative care ethics is where the conflict divide should run along. Hence the focus of the sub-research questions - and the next section of the conclusion below - being geared towards the varying stakeholder constitutions and inter-actional value realizations unto themselves and between each other. The contrasting between the stakeholders of the quantitative approach with that of the qualitative methodology reveals the extant shortcomings of the former, still the hypothesis is falsified regarding palliative care ethics, yet the reframed stakeholders indicate a potential opening for the palliative ethics set, as well as the impact a proper look at the practices can have towards the realistic handling of TCT in palliative care and palliative care in general. The qualitative approach highlights the methodological necessary shortcuts of the quantitative discourse in TCT palliative usage as too severe as to be getting a realistic model at least out of it, leading us up to the meta-level normative criticism and reflections at the end of this conclusion.

Conclusion Stakeholder Specifics

Now, lets look at the stakeholder specific results as to how they are affected by TCT in their ethics and value realizations, answering the sub-research questions to the main RQ of this thesis. But beforehand some general remarks about the stakeholder analysis. The first step is to distinguish the stakeholder baseline conceptions between the quantitative and the qualitative approach. In order for the quantitative method to work, the researchers had to make some simplifying assumptions related to the stakeholders. That is not to say the qualitative approach does not make simplifying assumptions about the stakeholders, it does, but they are more precise and tailored to the practices of the care trajectory - specific articulation of the nurses over the doctors for example - at hand rather than to make its claims more valid in terms of conforming to scientific methodology only. For the important primary care interactions they map out the attitudes of doctors and patients very precisely, but position each as stable, unchanging stakeholders over the course of the care trajectory - important as to have usable before-after or with-without TCT data-sets to work from. Especially the contingent attitudes of the patients have to be simplified for the methodology to work, the abstract concept of Quality-of-Life is an easy to use shorthand for the idiosyncrasies. The improvement or detriment of the patients QoL being expressed in the quantifiable numbers of 1-10²⁶²²⁶³, pain questionnaires, anxiety score lists over time, and codified semi-structured interview responses. The doctor as stakeholder codification was simpler due to more unified standards of the profession as a group, simply tying the assessments to professional feedback under the fixed medical ethics standards. With regards to secondary or even tertiary stakeholders the simplifications were farther reaching and done in a broad stroke fashion, giving them the nature of background embedding - in some cases justifiably so, for example the policy makers and state institution are so large and hard to move, that for one experiment its reasonable to stick to official research

262also: "happy to frown face" scale - works surprisingly good, even though its is a more low-key practical tool, having issues with altered pain perceptions for example in autistic patients who have trouble ordering the smiley-frown face scale due to their difficulty of properly interpreting human emotional reactions

263<http://www.theatlantic.com/health/archive/2015/01/beyond-the-smiley-face-pain-scale/384049/>

guidelines, the political formulation of public health care and call it quits in terms of depth and precision for this stakeholder group - same as with the designers, whose consumer electronics are (ab-)used in an accidental fit fashion. With regards to the informal carers on the other hand, the simplifications sometimes appear as to rough/imprecise - they are even more of a mess to grasp than the patients idiosyncrasies and their relation and ethical/therapeutic value to the care trajectory ends at "they do informal, beneficial stuff for the patient due to their pre-existing relationships. Now, on to the detailed conclusions about who the relevant stakeholders are, how their reactions to TCT in palliative care are enframed (and differ) in the academic narratives, and most importantly how their value constitution and realization is achieved, blocked or ignored. As for brevity each stakeholders conclusion contains both narrative approaches and set of sub-research questions intertwined in a neat package - excruciating details are to be found in re-reading Chapters 4 & 5 respectively.

The shared primary stakeholder between the quantitative and the qualitative method - the patient is infuriatingly hard to grasp, due to the circumstance that by contracting the "right" disease about just everyone can become a relevant stakeholder. Most diverse biographical backgrounds and attitudes make this group nigh impossible to target with standard research methodology when it comes to their ethical enframing, wishes and values - hence the relevant papers engaged in the aforementioned simplification of the patient group. As the most central stakeholder in the palliative care and TCT arrangements, the patient autonomy as a moral value and ethical imperative is respected by all other stakeholders, the medical professionals especially. This prominence makes the patient the second set of stakeholders whose values are actually realized - and as fully as can be - save for the medical doctors values being number one for reasons to follow below. The patients usual late adopter status of technology contributes to the group taking over existing techno-social enframings of the TCT devices by the time they reach the palliative field. The devices have existed for considerable time at this point and the process of large scale societal adaptation is as good as done - though of course disconnects between young and old patients persist in terms of technology utilization and attitudes.

Despite the societal usage patterns attached to the devices, the patients in the quantitative experiments mapped out intuitively the usage patterns that researchers had presumed: contacting loved ones, alleviating social isolation due to disease effects, and of course TCT contacting and counseling via their doctors. Aside from technological breakdowns in the devices, the patients voiced almost no concerns, issues like privacy, regulations of data access, etc. do not come up in the papers researched. As for the relation between patients and the medical professionals; the patients are depending on the information given in order to realize their personal value sets. Which in turn empowers the doctors in terms of what information at what time the patient has access to - after passing the relevant information through the specialist palliative care team. There is a perceivable contingency within the doctor's idiosyncratic makeup and relation to the specific patient - whose degree of exercised patient-centered, fundamental rights rests on the doctor's personal and professional attitudes towards for example palliative TCT devices and perceived usefulness thereof. Organizational disconnects in team communication on the professional side can lead to massive spikes in anxiety scores on the patient's side, and if persistent to long term deterioration of value realizations over the trajectory if not addressed swiftly and competently. With the doctor's sticking to the medical ethics, the expression of the baseline values is in the myriad of interactions between doctor and patient - the primary care relationship - which boils down to degrees of decisional freedom contingent on professional attitudes. Harking back to the thesis hypothesis, I expected a conflict between patient and doctor, brought on by the increased degrees of information freedom that TCT devices bring on, coupled to the flattening of hierarchies. Within the quantitative papers the expected conflict/negotiations are curiously absent - instead the device designed to further open communication is actually cementing and reinvigorating the hierarchical structures of the classic

medicine, the doctors as crucial stakeholders influencing TCT research design and adaptation. The absence of any conflict surrounding the introduction of a new technology in this decidedly low-tech founded field is indicative of an unrealized, hidden power distribution issue between the primary and the other stakeholders, regarding TCT control and aspects of idiosyncratic value realizations.

To contrast, in Pol's work the patients are part of a second primary relationship - between them and the nurses, complementary to the patient-doctor relationship outlined above. The focus of Pols is on the practical dimension of the nurses work as an under-researched and neglected grouping crucial to care. In practice the proper attunement of the patients to the TCT device helps to realize the benefit of pro-active care interventions for the nurses, with the respect for the patient's autonomy and personal desires regarding care frequency and intensity. Juxtaposing the patient with the nurse as a companion, both facing the doctor's overall care trajectory planning, the TCT in Pols research necessitates an increase in patients capacity/capabilities to align the technology with their own values. The issue persists that TCT usage requires significant mental acuity from the patient which is not always a given in the palliative care context. If alignment/fitting can be reached though, Pols observed that the TCT's frequency allows the patient to address the disease in smaller, less taxing steps. Also the nurse gets a better care oversight and after TCT contacts are done the patient frees the rest of their time from the disease. Changes in the disease can be addressed faster and more frequently - means flattening the amplitude of the inevitable deterioration leaps over time, leading to overall better quality of life and idiosyncratic value realization for the patient as their capacities are cared/protected better. One final caveat that was indicated by Pols' investigation of the practical dimension is that patients can grow overly reliant on the device, with the potential for negative/too complacent/passive patient's behaviors emerging due to TCT usage²⁶⁴.

Now for the the medical doctors, in the quantitative papers of TCT palliative care adaptation they do regain a power/control position that they did not possess to that extent for a long period of time. Again, the doctors are also the most coveted target group of the researchers when planning and organizing TCT trials, since they play such a crucial role in the primary care relationship. They are explicitly mentioned as gatekeepers for the promotion of the TCT tech and are enframed as champions for the cause if the researchers manage to convince them of the benefit TCT offers, banking on their endorsement on professional assessment grounds. The care team negotiations are a structural contributing factor to this - barring professional disagreements in the sessions - the doctors and specialists engage the patient as a unified front with a distinct care plan recommendation/TCT usage patterns at hand, which usually if presented as the ideal information available is accepted by the vast majority of the patients (for example a lot of patients would accept TCT in their home if asked by their physician to do so²⁶⁵). This overarching decisional authority of the doctors re-inforces medical ethics into the TCT adaptation from even before experiments are conducted. Infused with functions like the clinical eye the TCT researchers tailor their experimental setups to the gatekeeper at hand. To give it once more a comprehensive citation: *"It was discussed there was a need for an individual approach when planning any intervention or interaction; control of the relationship between clinicians and families was guided by needs of the family but it was the actions of the clinicians that determined how needs were met."*²⁶⁶

In Pols work we find a still intact primary care interaction between doctor and patient as it has been described above. However in the white box and the webcam experiment Pols investigated, the medical doctors were involved only in terms of weekly or monthly checkups on the patients. Pols' focus was very much set on the second primary relationship she observed in situ between the patient

264 see: 5.3.2.2.

265 A. Stern et.al.

266 Bradford et.al. (2014) pg 4

and the nurses. As such medical doctors are present but muted, and are framed as part of the system backdrop for the ethnographic investigation. Ethical-value wise their realization of medical ethics standards and influence on the general direction of the care trajectory remained unaltered as positioned in the quantitative papers explicated above, the specific daily care interactions of the nurse responsibilities - dependent from the general care trajectory they design.

On to the third main stakeholder group embedded in the direct palliative care and TCT usage, the nurses in the quantitative research results. Initial reactions of the nurses towards TCT were split as the decision of utilization was not directly in their hands. Early experiments recorded reservations regarding loss of work-hours, influence, and most crucial that nurses would literally lose touch with the patients. This last aspect though was quickly addressed with the rejection of the replacement model of TCT and supplanting it with the complementary model of TCT that is used until today in the quantitative research model. Despite the inclusion of practical concerns, the nurses value sets of nursing, care, and palliative care ethics variety are lacking in representation within quantitative TCT research. They do not possess the authority of the doctor stakeholder group and are subsequently only enframed as a secondary stakeholder group - adjuncts to the medical doctors. Not addressing their value sets, the researchers tend to frame them as the executing group of the doctors orders, foot soldiers of the classic, medical ethics driven medicine bound by the doctors authority. Some papers even go so far as to subsume the practical impact of nurses as being the same as the doctors, juxtaposing a simple duality of clinicians (doctors + nurses) vs. patients - despite practical indications of nurses being (idealistic) mediators for the patients, their position much more in-between chairs than mere adherents of medical ethics procedures and hierarchies. Even when differentiated, the differentiation is done in the context of specialist care team composition, not recording their specific sub-set of ethical inputs, which is then again subsumed under medical professionals coordinated facing the patient in order to present a unified front in terms of trajectory designs - given the organizational effect that the two staged communication model achieved. Lastly, the simple duality of clinicians versus patients of course also helps in terms of simplification of any questionnaire/interview-driven codified research approach to this situation. Subsuming the specific team stakeholder as above, this simplification makes it easier to align empiric presuppositions with the realistic limitations of quantitative experimental conduct and claim statistical significance & veracity. The practical interactions of the day to day activities that happen between nurses and patients are largely not recorded within the quantitative methods and their ethical engagement of TCT with the patient together seems to generate such context-bound and idiosyncratic data that they cannot possibly fit the empirical, RCT-styled research designs of the investigated papers.

In a reversal of emphasis, the nurses switch places with the doctors within the quality approach of Pols "uncontrolled field study" prototypes. They engage in a second primary care relationship²⁶⁷ with the patient, the distinct field of expertise of the nurses being the focal point of the investigation - practices and routines in good care delivery, to which TCT as a technique is added. Still depending on the doctor's care designs and the classic medical system, the investigation of the practical care delivery dimension exposes degrees of freedom in terms of caring on the nurse's side for the provision of warm, human care engagements, generation and utilization of "phronesis"²⁶⁸, and the depiction of realistic value realizations. The introduction of TCT into the practical dimension of the nurse's work triggers a very crucial reframing of the entire care engagement that improves value realization as laid out in the medical ethics' and palliative care ethics' shared foundation. The care delivery before TCT was very much only reactive; whereas with TCT the contact frequency goes up, a seemingly simple practical adjustment in Pols results. What TCT enables is the redesign of

267 A different way of framing it would be that doctors, nurses, and patients for a care "triangle" and different axis are emphasized.

268 The nurse as a competent companion to the patient.

care routines into pro-active practices. Operating in economic constraints of a hospital/hospice and under the doctors authority, the nurses were able to claim more control over the patient's issues due to the multiplication of interactional loci in the care trajectory. Instead of trying to manage a lot of issues at once, the nurses were able to address each of them as they came up, nigh-immediate care adjustments and deeper connection to the patients were enabled due to TCT utilization - leading to an overall improvement of the care trajectory and better patient's dispositions and attitudes, and eventually value realization in the practices.

On to the secondary stakeholders, beginning with the most prominent set - the informal caregivers in quantitative research enframings. As an even more colorful and varied group in terms of values and attitudes than the patient it is impossible for the quantitative methodology to trace all the relevant ethical issues that might persist in this group in relation to TCT usage. Other than most general statements of favorable baseline attitudes towards the design, as related to the social interactions with the patient, nothing could be asserted. Any further effect this group has on the care trajectory is filed under informal care, as is evident in their name, an unspecified impact on patients QoL, their specific ethics and values are removed from the research data (they do not enter to begin with, as no one attempted to design a research setup for them past a general questionnaire). Their practical value is that they can be the extended hands for the telenurse if properly taught, providing help and lowering their inherent anxiety in dealing with a palliative relative/friend, aligning them with overall care goals. To truly access this stakeholder group there would have to be an extensive sociological study run in parallel with a TCT experiment quantitative assessment. I could not find any, and as the patient's idiosyncratic attitudes are already more than enough for the researchers to contend with in the primary care interactions, it is only logical that the even more diverse informal carers are neglected. The informal carers are nigh impossible to target, their data of subjective context bound nature is almost unusable by the statistical methods - if it were to be collected & collated to begin with. For the quantitative approach general assumptions about them are good enough - and occasional questionnaires of "are you worried " allows to focus on the minimum empirical data relevant for the patient situation.

In Pols' work, we have the same situation as in the quantitative research, a myriad of combined stakeholder ethical backgrounds and enframings, coupled with desires & concerns dependent on the patient's constitution in conjunction with the overall care trajectory. In short, it is a bloody mess and as the group is of no central research interest to Pols, her focus remains on the nurse-patient care interaction in practice. Thus in practice their role is under-researched in the qualitative attempt as well. They do play a role in the daily care delivery, more so than in the quantitative research, but in essence Pols remains with the informals at the stage of "remote hands" and "they do informal (hopefully positive) stuff for the patient QoL", full stop.

Hospital admins & managers in the quantitative research are concerned with the financial costs and organization of the TCT research in their institutions, making their value alignment chiefly concern distributive justice as an ethical issue. They used to be further up in terms of importance during the early days of TCT research, as the gatekeepers for uncertain TCT devices, tightening cost management and were the very first stakeholder group for prototypical TCT researchers to convince - this champion spot now occupied by the doctors. As market forces have diminished the overall costs for TCT devices, so diminished the role of the managers & admins, though resource allocation will always remain an issue within hospitals. Thus this stakeholder group retains importance in properly addressing distributive justice of TCT on a meso-scale, in conjunction with the public health managers & state institution's macro health care policies. Their reasoning also being based on quantitative data, further research of that type, even if primarily aimed at doctors on the medical side of things, is easily adapted into ethic-economical considerations - especially important in

getting an embedded research program off the ground as they control the hospice staff - degrees of cooperation of personnel and material so to speak.

This stakeholder group enters Pols' analysis in the same fashion as in the quantitative papers, they engage in the distributive justice value realization in terms of budgets, planning, and organizational setup for TCT to function and benefit the most patients - in terms of Pols' focus on the nurses, the admin & managers determine nurse duty rosters for example. There is a modification though, in that initially the managers & admins assumed the TCT to be just another tool in the arsenal of the nurses to deliver care as it has been, not accounting for the eventual shift to pro-active care practices and the necessary restructuring of care organization on their end. There was a need for nurses and managers to renegotiate the care approach due to the TCT modifications as to reform the distributive justice underlying aspects of allocating proper work spaces and organization as the end to which the devices are a means had changed.

Second to last tertiary stakeholders, the designers & manufacturers. Their ethical alignment with proper palliative TCT is accidental at best within the quantitative discourse. Their designs of consumer goods, especially the tablet/pad systems, are an accidental good fit for the technological, practical and ethical requirements of the TCT usage within a palliative care context. This adaptation of their commercial products into the medical context at large constitutes a creative use event/process to which it is questionable as to what degree exactly the designers are responsible for eventual negative effects as their developed product is engaged by a population's communication tool usage and use patterns. At most their interest regarding the value modification of TCT in palliative care are of economical nature, aligning their product's layout for the monetary valorization.

Again as a tertiary stakeholder group the setup/engagement via Pols of the designers is largely identical to the quantitative research literature, with the only difference being that one device that was utilized - the "white box" - was not an off the shelf consumer good adaptation but a purposeful development for palliative and therapeutic care. Thus in terms of designer responsibility and access to material modifications if necessary, the designers were much closer tied to the nurses and other professional stakeholders desiring the device to work in accordance with their values. This circumstance also means that the designers of the white box are to a degree much more responsible for their design, e.g. questionnaire design of the white box - and any shortcomings in practice than say the designers of the tablet/pad systems that were never precisely intended to work in a palliative context.

The final tertiary stakeholder, the policy makers and state institutions are very much the backdrop of macro-scale societal context - decision makers regarding the allocation of public health care resources (basically what to do with the tax allotment). As for the research, it is an important stakeholder in financing research efforts via grant money, the relevant decisions based on quantitative data of medical or financial authorities tied to legally codified ethics & morals (e.g. no financing of dubious research proposals). As a group, these stakeholders rely heavily/exclusively on the type of data quantitative research produces as to be able to draft public health care provisions - macro-scaled distributive justice. Other than that, this stakeholder does not enter the TCT research, though on occasion researchers exhibit promotional attitudes as to make their work relevant for societal digitization drives.

Last of the tertiary stakeholders, and again the same as in the quantitative enframing, this stakeholder group is the backdrop of larger societal enframings against which Pols positions her research - with her research being operated on an actual state grant which was part of a larger

investigation into the digitization of the Dutch health care system. Despite that, the actual research approach of Pols - the uncontrolled field - runs exact counter in producing micro-type data sets to the type of data this stakeholder group relies on as to draft/organize macro-scaled health care provisions. Thus making the qualitative data sets wholly unusable in their current form to the societal distribution of medical goods in accordance with classical medical ethics.

For the final paragraph let us return to contemplate the main research question, what do we get out of this stakeholder lineup above, what does this stakeholder-focused perspective yield us to get main research questions answered? Varying degrees of actual value realization in the researched projects as the most obvious effect. Within a TCT palliative care trajectory the stakeholder to whom more importance is attributed by consent of the others - or affirmation by the researchers due to presumed/real importance - have their respective value sets as well as their individual idiosyncrasies respected and implemented into care trajectories. This holds true for both methodologies juxtaposed, with differences in emphasis on the shared stakeholders being manifest for their respectively different observational hypothesis. As for the assumed impact of the palliative care ethics of my hypothesis, both discourses show no immediate sign of having been impacted by palliative care ethics proper.

The more overarching issue that this discourse analysis exposed is that the research/observational theories predicate and premeditate the stakeholder conception beforehand, with the qualitative approach of Pols being closer geared towards the practices at the cost of scientific veracity. There is a certain circumstantial necessity tied into this situation, budget constraints and researching an exploratory corner of palliative care just being the tip of the iceberg. The situation is exacerbated by the ethical approval barriers and high attrition rates in palliative care research plaguing both methods - forcing a scientific "making ends meet" situation onto the researchers from the start, which is especially noticeable regarding statistical significance claims in the quantitative approach.

So to what extent is the quantitative approach towards the stakeholders capable of depicting what is asked in the central research question. Well, if the researched literature is any indication the ethical issues are far removed from any given central research interest, as the researchers are struggling to build basic statistical significance for very initial efficiency and efficacy claims. Hence the meta-level criticism that is explicated below emerged during the research of the discourse as it is manifest in the stakeholder conceptions. The qualitative approach is better in yielding a more realistic - or at least practice focused - stakeholder composition for ethical investigations, yet Pols' approach is far from an accepted methodology, unable to lay claim to the requirements for "proper" science as the method explicitly & consciously foregoes them. Making claims within the qualitative framing difficult without a lot of repeated qualitative systematic investigations that eventually could build up to a context-bound, quantifiable data pile.

Conclusion Meta Analysis

Final paragraph of the thesis and conclusion, in which I want to address the meta-level issue that became more and more apparent in researching this issue as exhaustively depicted above. It has to do with the type of baseline research methodology that is being used to get at TCT usage within palliative care. The further I immersed into the empirical, objective, fact driven, RCT-styled research methods results, the more it became apparent that the results were not realistic in terms of my then presumed ethical conflict between medicine and palliative care ethics, nor in terms of practical results of the research papers. To be fair no empirical research is a fully realistic, proper depiction of the matter it investigates, assumptions are made and presuppositions are tested & done

away with, and simplifications when deemed adequate are streamlining the research process as a whole. Yet with the quantitative results of the investigated papers there are such deeper disconnects with the values and attitudes of relevant stakeholders not occupying a gatekeeper functions - for example; assuming a stable stakeholder over time in a care trajectory is discounting a severe element to the ethical complications and complexities that a care trajectory for the dying entails. Fragmented and isolated research programs forego a precise assessment of patient QoL as inherently unquantifiable - the abstraction of very subjective experiences (like pain) into empiric-targetable numbers, scales and codified responses loses too much in terms of resolution and fidelity to the source of the data when statistical optimization simplifications and streamlined calculations are made to make it fit the methodology. Another prominent issue is too small a set of research participants (due to attrition and approval barriers) who still are supposed to be statistically relevant for society at large - even though on the quantitative methodology's own rules and merit the sample size is too small/insignificant. Further the catering of researchers to the presumed needs of gatekeeper stakeholder is problematic, yet I am also very clear that promotional effects and desires in research will not be going anywhere soon, it is still an issue that in combination with sub-par utilization of a misfitting research methodology it severely skews the results and scientific accuracy of the whole undertaking in favor of promotion and digitization for its own sake.

An alternative to this dissatisfying state is sketched in the work of Pols, the explicit renouncement of the conditions on which quantitative studies operate - quantifiable data-sets. Before diving into it, the issue which is to be faced immediately is that the relevant stakeholders of the scientific community and the medical deciders all only ever accept RCT-styled, objective data as relevant science, proper science to begin with - even when attempting the analysis of personal, moral-ethical issues pertaining to the most subjective thing a human can do - that is to die. In rejecting the admission criteria for research into the scientific community Pols frees up the possibility to tailor her approach much more to the idiosyncratic and manifold events of care practice. Her so aptly named concept of an "uncontrolled field study" enables us to get non-RCT results, bound in a specific context rather than generalized abstraction. As crucial as it is to rework the approach to research in this regard it is also important to be realistic in terms of facing the established research community and to promote and sell this particular research approach as something that at least in a complementary setup to empirical methodologies adds something of value to Science. Just as palliative care and care ethics address the ethical-foundation shortcomings of the classic medical ethics in the engagement between the relevant stakeholders, the qualitative approach of Pols' methodology addresses fundamental-systematic-functional/performatory shortcomings of the scientific methodology set and assessment of the relevant stakeholders in something as concrete as TCT adoption processes into palliative and therapeutic care scenarios.

In this aspect of meta level assessment of research methodologies, this master thesis ceases to be a pure descriptive piece of work as set out initially. The normative claims of mine - as in the preference for more qualitative approach elements in palliative care research methodology - I endorse are limited in certain ways. As a final remark I want to clarify this particular aspect. First, this aspect truly concerns the meta-level of methodology choice only - the underlying shared values between the methodologies are not in question here - with the indications derived purely from the contrast of the qualitative workings of Pols to the quantitative approach. The normative exultation is also only negative - I can surely say that the quantitative method has certain methodological issues which makes it insufficient to account for a realistic depiction of the palliative TCT situation, though the qualitative approach of Pols surely has academic shortcomings too (no general pull, context bound results, smaller scales, etc.). One has to explicate and accept that in foregoing the empirical requirements of quantifiable scientific methodologies the way we conduct the TCT palliative research changes. We can only leave with the hint that a quantified qualitative attempt

hybrid might be the way forward for TCT in palliative care and maybe even in any technology-focused research attempt in palliative care in general. In collecting enough context bound, weaker claimant-typed qualitative research results we might be able to give context specific quantitative results - eventually. Adjusted of course for temporal context and the respective country/society in which they were conducted. A combination of both methodology's best aspects would enable a hybrid-meso level analysis of the technology, something useful maybe even past the focus on TCT but to embrace the statistical anomalies in palliation for example. This is harking back to Interlude 4, as the statistical methodology eliminates aberrant values as to smooth the reliability over. Thing is, every error is a human death, ergo you should not statistically smooth them over. A horrible/perfect palliation is a treasure trove of data as to what went wrong/right respectively. And if you already fucked it up - there is no second try for the dead patient - might as well dissect them for the specifics as to not repeat the mistakes in the future. This is the practical focus of the qualitative approach. It might impair on large scale reliability in statistics but improve care provisions as well as the design of care procedures overall for better long term results in palliative TCT technological integration.

Chapter 7 - Source Material

D. Clark: *“From margins to centre: a review of the history of palliative care in cancer”* in D. Collingridge (ed.): *“The Lancet Oncology”* Vol. 8 No. 5 Philadelphia, Elsevier (2007)

H. Wansbrough (trsl.): *“New Jerusalem Bible – Standard Edition”* New York, Doubleday Religion (1999)

J. Kerr: *“Monastic Hospitality – The Benedictines in England, c. 1070 – c1250”* Woodbridge, The Boydell Press (2007)

D. Nicolle: *“Knights of Jerusalem – The Crusading Order of Hospitallers 1100 – 1565”* Oxford, Osprey Publishing (2008)

E. Duffy: *“The Stripping of the Altars: Traditional Religion in England, 1400 – 1580”* New Haven, Yale University Press (1992)

G. W. Bernard: *“The Dissolution of the Monasteries”* in E. Griffin (ed.): *“History”* Vol. 96 No. 324 Oxford, Blackwell Publishing (2011)

R. G. Asch: *“The Thirty Years War: The Holy Roman Empire and Europe, 1618 – 1648”* London, St. Martin's Press (1997)

<http://www.jeanne-garnier.org/dames-du-calvaire/histoire/> (retrieved: 18.10.2014)

<http://www.calvaryhospital.org/site/pp.asp?c=ktJUI9MPIsE&b=3266481> (retrieved: 18.10.2014)

C. Saunders, D. Clark (ed.): *“Selected Writings 1958 – 2004”* Oxford, Oxford University Press (2006)

<http://www.stjh.org.uk/Resources/StJosephsHospice/Documents/Other/The%20History%20of%20St%20Josephs%20Hospice%20Hackney.pdf> (online source | retrieved: 10.10.2014)

M. Bailey: *“A survey of the social needs of patients with incurable lung cancer”* in *“The Almoner”* London, Institute of Almoners Vol. 11 (1959)

R. Paterson & J. Aitken-Swan: *“Public opinion on cancer: a survey among women in the Manchester area”* in R. Horton (ed.): *“The Lancet”* Vol. 264 No. 6843 Amsterdam, Elsevier (1954)

J. E. Finesinger et. al.: *“Managing the Emotional Problems of the Cancer Patient”* in O. Webb-Brawley (ed.): *“A Cancer Journal for Clinicians”* Vol. 3 No. 1 New York, Wiley (1953)

E. Wilkes: *“Cancer outside hospital”* in R. Horton (ed.): *“The Lancet”* Vol. 283 No. 7347 Amsterdam, Elsevier (1964)

E. Wilkes: *“Terminal care at home”* in R. Horton (ed.): *“The Lancet”* Vol. 285 No. 7389 Amsterdam, Elsevier (1965)

J. M. Hinton: *“Problems in the care of the dying”* in R. R. Gaiser (ed.): *“Journal of Chronic Diseases”* Amsterdam, Elsevier Vol. 17 No. 3 (1964)

- B. G. Glaser & A. L. Strauss: *“Awareness of Dying”* New Jersey, Aldine Transaction (1965)
- A. Cartwright et. al.: *“Life before Death”* London, Routledge (1973)
- C. Saunders: *“The Management of Terminal Illness”* in J. Tinker (ed.): *“British Journal of Hospital Medicine”* Vol. 35 No. 1 London, Hospital Medicine Publications Ltd. (1967)
- E. Kübler-Ross: *“On Death and Dying”* New York, Scribner (1997)
- M. B. Sporn: *“The war on cancer”* in R. Horton (ed.): *“The Lancet”* Vol. 347 No. 9012 Amsterdam, Elsevier (1996)
- D. Santoro: *“Development of the concept of pain in history”* in G. Gamvbaro (ed.): *“Journal of Nephrology”* Vol. 24 Suppl. 17 (2011)
- H. Merskey & N. Bogduk (eds.): *“Classification of Chronic Pain – Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms”* Seattle, IASP Press (1994)
- A. Harrison: *“Arabic Pain Words”* in F. J. Keefe (ed.): *“Pain”* Vol. 32 No. 2 Philadelphia, Lippincott Williams & Wilkins (1988)
- E. Astyrakai et. al.: *“References to anesthesia, pain, and analgesia in the Hippocratic Collection”* in S. L. Shafer (ed.): *“Anesthesia & Analgesia”* Vol. 110 No. 1 Philadelphia, Lippincott Williams & Wilkins (2010)
- Seneca, R.M. Gummere (trns.): *“Ad Lucilium Epistulae Morales”* Vol. II London, Harvard University Press (1920)
- L. J. Elders: *“The Metaphysics of Being of St. Thomas Aquinas in a Historical Perspective”* Leiden, Brill Academic Publishers (1993)
- M. L. Colish: *“The Stoic Tradition From Antiquity To The Early Middle Ages”* Leiden, Brill Academic Publishers (1985)
- B. Pascal, A. Levi (ed.): *“Pensées and Other Writings”* New York, Oxford University Press (2008)
- G. W. F. Hegel: *“The Science of Logic”* Cambridge, Cambridge University Press (2010)
- M. Scheler: *“The Nature of Sympathy”* New Haven, Yale University Press (1954)
- R. Descartes, T. Steele-Hall (trns.): *“Treatise of Man”* Amherst, Prometheus Books (2003)
- H. O. Handwerker: *“Von Descartes bis zur fMRI”* in L. Radbruch (pub.): *“Der Schmerz”* Vol. 21 No. 4 Berlin, Springer (2007)
- P. D. Wall, R. Melzack: *“Pain Mechanisms: A New Theory”* in D. Wolffe (ed.): *“Science”* Vol. 150 No. 3699 Washington D.C., AAAS (1965)
- G. Vargas-Schaffer: *“Is the WHO analgesic ladder still valid ?”* (online publication: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2902929/#!po=25.0000> | retrieved 01.11.2014)

C. Saunders: "Dying of Cancer" in "St. Thomas's Hospital Gazette" Vol. 56 No. 2 London, St. Thomas Hospital (1958)

R. Twycross: "The Brompton Cocktail" in J. J. Bonica, V. Ventafridda (eds.): "Advances in Pain Research and Therapy" Vol. 2 New York, Raven Press (1979)

M. Tonato et. al.: "Antiemetics in cancer chemotherapy: historical perspective and current state of the art" in F. Ashbury (ed.): "Supportive Care in Cancer" Vol. 2 No. 3 Berlin, Springer (1994)

I. J. Higginson et. al.: "Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?" in R. K. Portenoy (ed.): "Journal of Pain and Symptom Management" Vol. 23 No. 2 Amsterdam, Elsevier (2002)

"Clinical Practice Guidelines for Quality Palliative Care – Third Edition" pg. 6 (online resource: http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf retrieved 03.11.2014)

Recommendation 1418: <http://assembly.coe.int/main.asplink=/Documents/AdoptedText/ta99/EREC1418.htm>

Recommendation Rec (2003) 24: <http://www.eapcnet.eu/LinkClick.aspxfileticket=3KJ5U3BQLVY%3d&tabid=1709>

S. Mercadante, F. Fulfaro: "Alternatives to Oral Opioids for Cancer Pain" in J. O. Armitage (ed.): "ONCOLOGY" Vol. 13 No. 2 London, UBM (1999)

D. Clark et. al.: "The Syringe Driver and the Subcutaneous Route in Palliative Care: The Inventor, the History and the Implications" in R. K. Portenoy (ed.): "Journal of Pain and Symptom Management" Vol. 29 No. 1 Philadelphia, Elsevier (2005)

H. Ruben & H. M. Mohelsky: "A Simple Automatic Syringe" in S. M. Yentis (ed.): "Anaesthesia" Vol. 9 No. 1 Hoboken, Wiley-Blackwell (1954)

Department of Health and Social Security: "Health Circular" No. 9 (1976)

R. D. Propper et. al.: "Continuous Subcutaneous Administration of Deferoxamine in Patients with Iron Overload" in A. S. Relman (ed.): "The New England Journal of Medicine" Vol. 297 No. 8 Waltham, Massachusetts Medical Society (1977)

P. S. Russell: "Analgesia in terminal malignant disease" in F. Godlee (ed.): "British Medical Journal" Vol. 1 No. 6177 London, British Medical Association (1979)

R. Melzack et. al.: "The Brompton mixture versus morphine solution given orally: effects on pain" in J. Fletcher (ed.): "Canadian Medical Association Journal" Vol. 120 No. 4 Ottawa, Canadian Medical Association (1979)

P. C. Milner et. al.: "Ownership, availability, and use of portable syringe drivers among hospices and home-care services" in P. Mackie & F. Sim (eds.): "Public Health" Vol. 103 No. 5 Amsterdam, Elsevier (1989)

"Hazard Notice – HAZ(SC)96/01" from 21.02.1996 (www.hfs.scot.nhs.uk/publications/PHAZ9601.pdf)

retrieved 05.11.14)

R. S. Murphy & S. J. Wilcox: “*A New Approach in the Design of High-Risk Infusion Technology*” in M. Chyu (ed.): “*Journal of Healthcare Engineering*” Vol. 1 No. 2 Hockley, Multi-Science Publishing (2010)

“*Rapid Response Report NPSA/2010/RRR019: Safer ambulatory syringe drivers*” pg. 5ff (online source: <http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=92961&type=full&servicetype> | retrieved: 07.11.2014)

W. M. O'Neill: “*Subcutaneous infusions – a medical last rite*” in C. Walshe (ed.): “*Palliative Medicine*” Vol. 8 No. 2 London, Sage UK (1994)

A. Dickman et. al.: “*The Syringe Driver – Continuous subcutaneous infusions in palliative care*” Oxford, Oxford University Press (2002)

J. F. Seely & M. M. Balfour: “*Palliative medicine and modern technology*” in J. Fletcher (ed.): “*Journal of the Canadian Medical Association*” Vol. 161 No. 9 Ottawa, Canadian Medical Association (1999) pg. 1120

R. G. Twycross: “*Palliative Care: An International Necessity*” in A. G. Lipman (ed.) “*Journal of Pain & Palliative Care Pharmacotherapy*” Vol. 16 No. 1 New York, Informa Healthcare (2002) pg. 63 and 67

D. Hoegler: “*Radiotherapy for palliation of symptoms in incurable cancer*” in K. P. MacMullen (ed.): “*Current Problems in Cancer*” Vol. 21 No. 3 Amsterdam, Elsevier (1997) pg. 129ff

K. Mannix et. al.: “*Using bisphosphonates to control the pain of bone metastases: evidence-based guidelines for palliative care*” in C. Walshe (ed.): “*Palliative Medicine*” Vol. 14 No. 6 London, Sage UK (2000) pg. 455ff

S. Mercadante: “*The role of octreotide in palliative care*” in R. K. Portenoy (ed.): “*Journal of Pain and Symptom Management*” Vol. 9 No. 6 Amsterdam, Elsevier (1994) pg. 406ff

T. L. Beauchamp, J. F. Childress: “*Principles of Biomedical Ethics*” New York, Oxford University Press (1979)

J. L. Bernat: “*Ethical Issues in Neurology*” Philadelphia, Lippincott Williams & Williams (2008)

H. T. Engelhart: “*Bioethics and secular humanism: the search for common morality*” London, SCM Press (1991)

R. M. Veatch: “*Hippocratic, Religious, and Secular Medical Ethics: The Points of Conflict*” Washington D.C., Georgetown University Press (2012)

R. E. Ashcroft et. al. (eds.): “*Principles of Health Care Ethics*” New York, John Wiley & Sons (2007)

J. Bentham, J. S. Mill, A. Ryan (ed.): “*Utilitarianism and Other Essays*” London, Penguin Books (1987, 2004)

- G. Mooney: *"Economics, Medicine and Health Care"* Harlow, Pearson Education Ltd. (2003)
- I. Kant: *"Groundwork of the Metaphysics of Morals"* Cambridge, Cambridge University Press (1997)
- M. Huemer: *"Ethical Intuitionism"* Basingstoke, Palgrave MacMillan (2008)
- L. Sandman: *"A Good Death – On the Value of Death and Dying"* New York, Open University Press (2005)
- L. Edelstein: *"The Hippocratic oath, text, translation and interpretation"* in E. L. Minar Jr. (ed.): *"The American Journal of Philology"* Vol. 66 No. 1, Baltimore, Johns Hopkins University Press (1945)
- Thomas Aquinas: *"Summa Theologica"* Notre Dame, Ave Maria Press (2000)
- Thomas Aquinas: *"On Law, Morality, and Politics"* Indianapolis, Hackett Publishing (2003)
- J. F. Childress: *"Who Should Decide?: Paternalism in Health Care"* Oxford, Oxford University Press (1982)
- G. B. Weiss: *"Paternalism modernised"* in J. Savulescu (ed.): *"Journal of Medical Ethics"* Vol 11 No. 4 London, British Medical Journal (1985)
- J. J. Chin: *"Doctor-Patient Relationship: From Medical Paternalism to Enhanced Autonomy"* in T.E. Kiong (ed.): *"Singapore Medical Journal"* Vol. 23 No. 3 Singapore, Singapore Medical Association (2002)
- C. E. Schneider: *"The Practice of Autonomy: Patients, Doctors and Medical Decisions"* New York, Oxford University Press (1998)
- N. Kohut et. al.: *"Stability of treatment preference"* in E. G. Howe (ed.): *"The Journal of Clinical Ethics"* Vol. 8 No. 2 Hagerstown, The Journal of Clinical Ethics (1998)
- R. M. Gready et. al.: *"Actual and Perceived Stability of Preferences for Life-Sustaining Treatment"* in E. G. Howe (ed.): *"The Journal of Clinical Ethics"* Vol. 11 No. 4 Hagerstown, The Journal of Clinical Ethics (2000)
- P. H. Ditto et. al.: *"Stability of Older Adults' Preferences for Life-Sustaining Medical Treatment"* in A. E. Kazak: *"Health Psychology"* Vol. 22 No. 6 Washington D.C., American Psychological Association (2003)
- J. M. Breslin: *"Autonomy and the role of the family in making decisions at the end of life"* in E. G. Howe (ed.): *"The Journal of Clinical Ethics"* Vol. 16 No. 1 Hagerstown, The Journal of Clinical Ethics (2005)
- G. Garbutt, P. Davies: *"Should the practice of medicine be a deontological or utilitarian enterprise?"* in F. Godlee (ed.): *"Journal of Medical Ethics"* Vol. 37 No. 5 London, BMJ (2010)
- F. Randall and R. S. Downie: *"Palliative Care Ethics – A Good Companion"* Oxford, Oxford

Medical Publications (1996)

F. Randall and R.S.Downie: *"The Philosophy of Palliative Care – Critique and Reconstruction"* New York, Oxford University Press (2006)

A. W. Frank: *"Asking the right Question about Pain: Narrative and Phronesis"* in R. Charon, M. Spiegel (eds.): *"Literature and Medicine"* Vol. 23 No. 2 Baltimore, Johns Hopkins University Press (2004)

D. Thomasma: *"Aristotle, Phronesis, and Postmodern Bioethics"* in M. G. Kuczewski, R. Polansky (eds.): *"Bioethics: Ancient Themes in Contemporary Issues"* Massachusetts, MIT Press (2002)

W.T. Carpenter et. al.: *"Decisional Capacity for Informed Consent in Schizophrenia Research"* in J. T. Coyle(ed.): *"Archives of General Psychiatry"* Vol. 57 No. 6 Chicago, American Medical Association (2000)

P. S. Appelbaum & T. Grisso: *"The MacArthur Treatment Competence Study I: Mental Illness and Competence to Consent to Treatment"* in M Bull Kovera: *"Law and Human Behavior"* Vol. 19 No. 2 Washington D. C., American Psychological Association (1995)

W.T. Carpenter et. al.: *"Decisional Capacity for Informed Consent in Schizophrenia Research"* in J. T. Coyle(ed.): *"Archives of General Psychiatry"* Vol. 57 No. 6 Chicago, American Medical Association (2000)

C. W. van Staden, C. Krüger: *"Incapacity to give informed consent owing to mental disorder"* in F. Godlee (ed.): *"Journal of Medical Ethics"* Vol. 29 No. 1 London, BMJ (2003)

S. Vanheule: *"Diagnosis and DSM: A Critical Review"* Basingstoke, Palgrave Macmillan (2014)

D.R. Park: *"The usability of videophones for seniors and hospice providers: a brief report on two studies"* in E. Ciaccio (ed.): *"Computers in Biology and Medicine"* Vol.35 No. 9 Amsterdam, Elsevier (2005) pg. 782 - 790

A. Stern et.al.: *"Use of home telehealth in palliative cancer care: a case study"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 18 No. 5 New York, Sage Publications (2012) pg. 297 - 300

L. Kidd et.al.: *"Telehealth in palliative care in the UK: a review of the evidence"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 16 No. 1 New York, Sage Publications (2010) pg. 1 - 9 http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303 (retrieved 21.06.2015)

R. Becker: *"Online courses for nurses working in palliative care"* in J. Riley (ed.): *"European Journal of Palliative Care"* Vol. 16 No. 2 Newmarket, Hayward Medical Communications (2009) pg. 94 - 97

S.V. Browning et.al.: *"Telehealth: Is Your Staff Ready To Implement ?"* in M. Anthony (ed.): *"Home Healthcare Nurse"* Vol. 27 No. 4 Alphen aan de Rijn, Wolters Kluwer (2009) pg. 242 - 248

N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic*

review" in I. Pala (ed.): *"BMC Palliative Care"* Vol. 12 Article No. 4 Berlin, Springer (2013)

R. Gaikwad & J. Warren: *"The role of home-based information and communications technology interventions in chronic disease management: a systematic literature review"* in R. Procter (ed.): *"Health Informatics Journal"* Vol. 15 No. 2 New York, Sage Publications (2009) pg. 122 - 146

D.P. Oliver et.al.: *"A systematic review of the evidence base for telehospice"* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine and e-Health"* Vol. 18 No. 1 Larchmont, Mary Ann Liebert (2012) pg. 38 - 47

G. Morgan et.al.: *"Home videoconferencing for patients with severe congenital heart disease following discharge"* in D.S. Moodie (ed.): *"Congenital Heart Disease"* Vol. 3 No. 5 Hoboken, Wiley Periodicals Inc. (2008) pg. 317 - 324

N.L. Young et.al.: *"An examination of quality of life of children and parents during their Tele-Homecare experience"* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine and e-Health"* Vol. 12 No. 6 Larchmont, Mary Ann Liebert (2006) pg. 663 - 671

N.L. Young et.al.: *"Taking the call-bell home: a qualitative evaluation of Tele-HomeCare for children"* in K. Luker (ed.): *"Health & Social Care in the Community"* Vol. 14 No. 3 Hoboken, Wiley Periodicals Inc. (2006) pg. 231 - 241

M.A. Hebert et.al.: *"Potential and readiness for video-visits in rural palliative homecare: results of a multi-method study in Canada"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 12 No. 3 New York, Sage Publications (2006) pg. 43 - 45

G.C. Dolittle et.al.: *"An empirical chart analysis of the suitability of telemedicine for hospice visits"* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine and e-Health"* Vol. 11 No. 1 Larchmont, Mary Ann Liebert (2005) pg. 90 - 97

M.A. Hebert et.al.: *"Analysis of the suitability of 'video-visits' for palliative home care: implications for practice"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol 13 No. 1 New York, Sage Publications (2007) pg. 74 - 78

G. Demiris et.al.: *"Hospice staff attitudes towards telehospice"* in R.E. Enck (ed.): *"American Journal of Hospice & Palliative Care"* Vol. 21 No. 5 New York, Sage Publications pg. 343 - 347

G. Demiris et.al.: *"Ethical considerations for the utilization of tele-health technologies in home and hospice care by the nursing profession"* in K.D. Sandford (ed.): *"Nursing Administration Quarterly"* Vol. 30 No. 1 Alphen aan den Rijn, Wolters Kluwer (2006) pg. 56 - 66

Dolittle et.al.: *"A cost measurement study for a home-based telehospice service."* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol 13 Suppl. 1 New York, Sage Publications (2000) pg. 193 - 195

P. Whitten et.al.: *"Telehospice: reasons for slow adoption in home hospice care"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 15 No. 4 New York, Sage Publications (2009) pg. 187 - 190

P. Whitten et.al.: *"Addressing telehealth's foremost barrier: provider as initial gatekeeper"* in M.

Mäkelä (ed.): *"International Journal of Technology Assessment in Health Care"* Vol. 21 No. 4 Cambridge, Cambridge University Press (2005) pg. 517 - 521

P. Whitten et.al.: *"Providers' acceptance of telehospice"* in C.F. van Gunten (ed.): *"Journal of Palliative Medicine"* Vol. 8 No. 4 Larchmont, Mary Ann Liebert (2005) pg. 730 - 735

P. Whitten et.al.: *"An analysis of provider perceptions for telehospice"* in R.E. Enck (ed.): *"American Journal of Hospice & Palliative Care"* Vol. 15 No. 5 Thousand Oaks, SAGE (1998) pg. 267 - 274

G. Demiris et.al.: *"Telehospice tools for caregivers - a pilot study"* in D.E. Gallagher-Thompson & L.W. Thompson (eds.): *"Clinical Gerontologist"* Vol. 31 No. 1 Abingdon, Taylor & Francis (2007) pg. 43 - 57

D.P. Oliver et.al.: *"A systematic review of the evidence base for telehospice."* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine and e-Health"* Vol. 18 No. 1 Larchmont, Mary Ann Liebert (2012) pg. 38 - 47

N. Bradford et.al.: *"Home telemedicine for paediatric palliative care"* in A.C. Smith & A.J. Maeder (eds.): *"Studies in Health Technology and Informatics"* Issue 161 Amsterdam, IOS Press (2010) pg. 10 - 19

N. Coyle et.al.: *"Audio-Visual Communication and Its Use in Palliative Care"* in R.K. Portenoy (ed.): *"Journal of Pain and Symptom Management"* Vol. 23 No. 2 Amsterdam, Elsevier (2002) pg. 171 - 175

M. Bensink et.al.: *"Paediatric palliative care with Internet-based video-phones: lessons learnt"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 10 Suppl. 1 Thousand Oaks, SAGE (2004) pg. 10 - 13

D.R. Oliver et.al.: *"Telehospice support for elder caregivers of hospice patients: two case studies"* in C.F. van Gunten (ed.): *"Journal of Palliative Medicine"* Vol. 9 No. 2 Larchmont, Mary Ann Liebert (2006) pg. 264 - 267

I. Olver.: *"The use of videophones to enhance palliative care outreach nursing in remote areas"* in M. Davis (ed.): *"Progress in Palliative Care"* Vol. 13 No. 5 London, Maney Publishing (2005) pg. 263 - 267

G.C. Dolittle et.al.: *"Hospice care using home-based telemedicine systems"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 4 Suppl. 1 New York, SAGE (1998) pg. 58 - 59

K.T. Washington et.al.: *"Telehospice acceptance among providers: a multidisciplinary comparison"* in R.E. Enck (ed.): *"American Journal of Hospice and Palliative Medicine"* Vol. 25 No. 6 New York, SAGE (2008) pg. 452 - 457

K.L. Schmidt et.al.: *"Demonstration of Facial Communication of Emotion Through Telehospice Videophone Contact"* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine Journal and e-Health"* Vol. 17 No. 5 Larchmont, Mary Ann Liebert (2011) pg. 399 - 401

D.J. Cook et.al.: *"Administrator and provider perceptions of the factors relating to programme"*

- effectiveness in implementing telemedicine to provide end-of-life care* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 7 Suppl. 2 New York, SAGE (2001) pg. 17 - 19
- M.E. Bensink et.al.: *"Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 23 No. 3 New York, SAGE (2009) pg. 228 - 237
- M.A. Hebert et.al.: *"Potential and readiness for video-visits in rural palliative homecare: results of a multi-method study in Canada"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 12 Suppl. 3 New York, SAGE (2006) pg. 43 - 45
- M.A. Hebert et.al.: *"Successes and challenges in a field-based, multi-method study of home telehealth"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 10 Suppl. 1 New York, SAGE (2004) pg. 41 - 44
- R. Cohen et.al.: *"QOLTTI-F: measuring family carer quality of life"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 20 No. 8 New York, SAGE Publications (2006) pg. 755 - 767
- M.-P. Gagnon et.al.: *"Telehomecare for vulnerable populations: the evaluation of a new model of care"* in R.C. Merrell & C.R. Doarn (eds.): *"Telemedicine Journal and e-Health"* Vol. 12 No. 3 Larchmont, Mary Ann Liebert (2006) pg. 324 - 331
- G.J. Morgan et.al.: *"Home videoconferencing for Patients with Severe Congenital Heart Disease Following Discharge"* in D.S. Moodie (ed.): *"Congenital Heart Disease"* Vol. 3 No 5 Hoboken, Wiley 2008) pg. 317 - 324
- N.L. Young et.al.: *"Taking the call-bell home: a qualitative evaluation of Tele-HomeCare for children"* in K. Luker (ed.): *"Health & Social Care in the Community"* Vol. 14 No. 3 Hoboken, Wiley (2006) pg. 231 - 241
- M. Bensink et.al. (2004); G. Demiris et.al.: *"Telehospice Tools for Caregivers"* in D.E. Gallagher-Thompson & L.W. Thompson (eds.): *"Clinical Gerontology"* Vol. 31 No. 1 Abingdon, Taylor & Francis (2007) pg. 43 - 57
- B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 - 161
- A. Reis et.al.: *"Information and Communication Technologies in Long-term and Palliative Care"* in M.M. Cruz-Cunha et.al. (eds.): *"Procedia Technology"* Vol. 9 Amsterdam, Elsevier (2013) pg. 1303 - 1312
- S. Hall et.al.: *"Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient, carer and professional perspectives"* in V. Neale (ed.): *"Family Practice"* Vol. 29 No. 5 Oxford, Oxford Journals (2012) pg. 576 - 585
- B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 - 161

- S. Levy et.al.: *"End-of-Life and Living Technologies, The role of Telemedicine in palliative care of children and young people"* presented at Pervasive Health, Dublin, Ireland (2011)
- N. Bradford et.al.: *"Home telehealth and paediatric palliative care: clinician perceptions of what is stopping us ?"* in J. Mockridge (ed.): *"BMC Palliative Care"* Vol. 13 Art. 29 Berlin, Springer (2014)
- J. van Gorp et.al.: *"How audiovisual teleconsultations between hospital-based palliative care specialists and outpatients challenge interdisciplinary collaborations between primary and tertiary care providers"* presented at the EAPC World Research Congress 2014, 5- 7 June, Lleida, Spain
- Primer for discourse analysis methodologies, by J.R. Ruiz: <http://www.qualitative-research.net/index.php/fqs/article/view/1298/2883>
- N. Fairclough: *"Language and Power"* Harlow, Addison Wesley Longman Ltd. (1989)
- M.W. Rabow et.al.: *"The comprehensive care team: a controlled trial of outpatient palliative medicine consultation"* in R.F. Redberg (ed.): *"Archive of Internal Medicine"* Vol. 164 No. 1 Chicago, American Medical Association (2004) pg. 83 - 91
- D. Marshall et.al.: *"Enhancing family physician capacity to deliver quality palliative home care"* in N. Pimlott (ed.): *"Canadian Family Physician"* Vol. 54 No. 12 Mississauga, College of Family Physicians of Canada (2008) pg. 1703 - 1703e7
- D. Howell et.al.: *"A shared care model pilot for palliative home care in a rural area: Impact on symptoms, distress, and place of death"* in R.K. Portenoy (ed.): *"Journal of Pain and Symptom Management"* Vol. 42 No. 1 Amsterdam, Elsevier (2011) pg. 60 - 75
- M. Desmedt & H. Michel: *"Palliative home care: improving co-operation between the specialist team and the family doctor"* in F. Ashbury (ed.): *"Supportive Care in Cancer"* Vol. 10 No. 4 Berlin, Springer (2002) pg. 343 - 348
- J. van Gorp et.al.: *"How outpatient palliative care teleconsultation facilitates empathetic patient-professional relationships: a qualitative study"* in "PLoS One" Vol. 10 No. 4 (2015) (online publication)
- K. Kroenke et.al.: *"Effect of Telecare Management on Pain and Depression in Patients with Cancer"* in C. DeAngelis (ed.): *"JAMA"* Vol. 304 No. 2 Chicago, American Medical Association (2010) pg. 163 - 171
- J. Pols: *"Care at a Distance - On the Closeness of Technology"* Amsterdam, Amsterdam University Press (2012) Chp. 3

7.1. Appendix A

D.R. Park et.al.: *"The usability of videophones for seniors and hospice providers: a brief report on two studies"* in E. Ciaccio (ed.): *"Computers in Biology and Medicine"* Vol.35 No. 9 Amsterdam, Elsevier (2005) pg. 782 – 790

A. Stern et.al.: *"Use of home telehealth in palliative cancer care: a case study"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 18 No. 5 New York, Sage Publications (2012) pg. 297 – 300

A. Reis et.al.: *"Information and Communication Technologies in Long-term and Palliative Care"* in M.M. Cruz-Cunha et.al. (eds.): *"Procedia Technology"* Vol. 9 Amsterdam, Elsevier (2013) pg. 1303 – 1312

B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 – 161

J. van Gorp et.al.: *"How audiovisual teleconsultations between hospital-based palliative care specialists and outpatients challenge interdisciplinary collaborations between primary and tertiary care providers"* presented at the EAPC World Research Congress 2014, 5- 7 June, Lleida, Spain

J. van Gorp: *"How outpatient palliative care teleconsultations allows for empathetic and intimate care relationships"* in *"PloS One"* Vol. 10 No. 4 (2015) (online publication)

R. Gaikwad & J. Warren: *"The role of home-based information and communications technology interventions in chronic disease management: a systematic literature review"* in R. Procter (ed.): *"Health Informatics Journal"* Vol. 15 No. 2 New York, Sage Publications (2009) pg. 122 – 146

N. Bradford et.al.: *"The case for home based telehealth in paediatric palliative care: a systematic review"* in I. Pala (ed.): *"BMC Palliative Care"* Vol. 12 Article No. 4 Berlin, Springer (2013)

N. Bradford et.al.: *"Home telemedicine for paediatric palliative care"* in A.C. Smith & A.J. Maeder (eds.): *"Studies in Health Technology and Informatics"* Issue 161 Amsterdam, IOS Press (2010) pg. 10 – 19

S. Levy et.al.: *"End-of-Life and Living Technologies, The role of Telemedicine in palliative care of children and young people"* presented at Pervasive Health, Dublin, Ireland (2011)

N. Bradford et.al.: *"Home telehealth and paediatric palliative care: clinician perceptions of what is stopping us ?"* in J. Mockridge (ed.): *"BMC Palliative Care"* Vol. 13 Art. 29 Berlin, Springer (2014)

B. Johnston et.al.: *"An evaluation of the use of Telehealth within palliative care settings across Scotland"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 26 No. 2 New York, SAGE (2012) pg. 152 – 161

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4115303

S. Hall et.al.: *"Introducing an electronic Palliative Care Summary (ePCS) in Scotland: patient,*

carer and professional perspectives" in V. Neale (ed.): *"Family Practice"* Vol. 29 No. 5 Oxford, Oxford Journals (2012) pg. 576 – 585
http://www.scottishneurological.org.uk/content/res/quality_strategy.pdf pg. 27ff

N. Coyle et.al.: *"Audio-Visual Communication and Its Use in Palliative Care"* in R.K. Portenoy (ed.): *"Journal of Pain and Symptom Management"* Vol. 23 No. 2 Amsterdam, Elsevier (2002) pg. 171 – 175

G.C. Dolittle et.al.: *"Hospice care using home-based telemedicine systems"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 4 Suppl. 1 New York, SAGE (1998) pg. 58 – 59

M. Bensink et.al.: *"Paediatric palliative care with Internet-based video-phones: lessons learnt"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 10 Suppl. 1 Thousand Oaks, SAGE (2004) pg. 10 – 13

N.L. Young et.al.: *"Taking the call-bell home: a qualitative evaluation of Tele-HomeCare for children"* in K. Luker (ed.): *"Health & Social Care in the Community"* Vol. 14 No. 3 Hoboken, Wiley (2006) pg. 231 – 241

M.E. Bensink et.al.: *"Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study"* in C. Walshe (ed.): *"Palliative Medicine"* Vol. 23 No. 3 New York, SAGE (2009) pg. 228 – 237

P. Whitten et.al.: *"Addressing telehealth's foremost barrier: provider as initial gatekeeper"* in M. Mäkelä (ed.): *"International Journal of Technology Assessment in Health Care"* Vol. 21 No. 4 Cambridge, Cambridge University Press (2005) pg. 517 – 521

P. Whitten et.al.: *"Providers' acceptance of telehospice"* in C.F. van Gunten (ed.): *"Journal of Palliative Medicine"* Vol. 8 No. 4 Larchmont, Mary Ann Liebert (2005) pg. 730 – 735

P. Whitten et.al.: *"An analysis of provider perceptions for telehospice"* in R.E. Enck (ed.): *"American Journal of Hospice & Palliative Care"* Vol. 15 No. 5 Thousand Oaks, SAGE (1998) pg. 267 - 274

G. Demiris et.al.: *"Telehospice tools for caregivers - a pilot study"* in D.E. Gallagher-Thompson & L.W. Thompson (eds.): *"Clinical Gerontologist"* Vol. 31 No. 1 Abingdon, Taylor & Francis (2007) pg. 43 – 57

S.V. Browning et.al.: *"Telehealth: Is Your Staff Ready To Implement ?"* in M. Anthony (ed.): *"Home Healthcare Nurse"* Vol. 27 No. 4 Alphen aan de Rijn, Wolters Kluwer (2009) pg. 242 – 248

G. Demiris et.al.: *"Hospice staff attitudes towards telehospice"* in R.E. Enck (ed.): *"American Journal of Hospice & Palliative Care"* Vol. 21 No. 5 New York, Sage Publications pg. 343 – 347

G. Demiris et.al.: *"Ethical considerations for the utilization of tele-health technologies in home and hospice care by the nursing profession"* in K.D. Sandford (ed.): *"Nursing Administration Quarterly"* Vol. 30 No. 1 Alphen aan den Rijn, Wolters Kluwer (2006) pg. 56 – 66

G. C. Dolittle et.al.: *"A cost measurement study for a home-based telehospice service."* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 13 Suppl. 1 New York, Sage Publications (2000)

pg. 193 – 195

D.J. Cook et.al.: *"Administrator and provider perceptions of the factors relating to programme effectiveness in implementing telemedicine to provide end-of-life care"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 7 Suppl. 2 New York, SAGE (2001) pg. 17 – 19

P. Whitten et.al.: *"Telehospice: reasons for slow adoption in home hospice care"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 15 No. 4 New York, Sage Publications (2009) pg. 187 – 190

M.A. Hebert et.al.: *"Potential and readiness for video-visits in rural palliative homecare: results of a multi-method study in Canada"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 12 Suppl. 3 New York, SAGE (2006) pg. 43 – 45

M. A. Hebert et.al.: *"Successes and challenges in a field-based, multi-method study of home telehealth"* in V. Wade (ed.): *"Journal of Telemedicine and Telecare"* Vol. 10 Suppl. 1 New York, SAGE (2004) pg. 41 - 44