Editorial:

Celebrating 50 Years of Grounded Theory: Onward and Forward

Astrid Gynnild, University of Bergen, Norway

Welcome to this very special issue of the Grounded Theory Review. In this issue we celebrate 50 amazing years of grounded theory during which it has become one of the fastest growing methods in the global research world. Five decades after *The Discovery of Grounded Theory* was first published, the seminal work of founders Barney G. Glaser and Anselm Strauss is cited more than 94,000 times on Google Scholar alone.

We celebrate that after 50 years of researching, teaching, defending, explicating and clarifying grounded theory as a principally inductive approach to theorizing, co-founder Barney G. Glaser still produces books on grounded theory at an incredible pace. In the last three years alone, from 2014 to 2017, Dr. Glaser has produced six new books that discuss vital aspects of doing grounded theory.

We also celebrate that the Grounded Theory Review, after two years of scholarly assessment, is accepted into the Emerging Sources Citation Index (ESCI) within the Web of Science. It is a valued endorsement of the quality of the Grounded Theory Review that will improve its visibility within the academic world.

We further celebrate that grounded theorists from all continents have the opportunity to participate in a growing number of troubleshooting seminars. The seminar is a productive arena for bringing emerging theories another step towards publication. While writing this editorial, I find myself once again immersed in the exciting learning space of a troubleshooting seminar led by Dr. Glaser, this time in Mill Valley, California. At the chronological age of 87 Dr. Glaser still runs the troubleshooting seminar with methodological rigor and reversal humor. And he keeps arguing that the discovery of theory from data is a major task confronting researchers today.

Interestingly, when Glaser and Strauss wrote *The Discovery of Grounded Theory* back in 1967, they opened the first chapter in this way:

> Most writing on sociological method has been concerned with how accurate facts can be obtained and how theory can thereby be more rigorously tested. In this book we address ourselves to the equally important enterprise of "how the discovery of theory from data—systematically obtained and analyzed in social research—can be furthered. We believe that the discovery of theory from the data—which we call grounded theory—is a major task confronting sociology today, for, as we shall try to show, such a theory fits empirical situations, and is understandable to sociologists and layman alike. Most important it works—provides us with relevant predictions, explanations, interpretations and applications.

The multitude of theories produced over the last 50 years confirm that Glaser and Strauss were right—GTs do provide us with relevant predictions, explanations, interpretations and applications.

We celebrate these events by publishing a Special Issue of the Grounded Theory Review. In this issue scholars from many disciplines contribute with their ongoing research and reflections on doing grounded theory. These articles demonstrate the breadth of approaches within the global grounded theory community by providing a glimpse into the multifaceted theorizing using the procedures of classic grounded theory. Since grounded theory is a method aimed at conceptualizing patterns of human behavior, examples help us to understand the various steps in doing a grounded theory study. Thus, in this celebratory edition of the journal we follow Glaser's predications on the necessity of exampling, and provide more than 20 papers, short and long, from a great variety of disciplines.

In his latest book, *Grounded Theory: Its origins and growth,* Dr Glaser invites us to share in his matured ideas on the very productive teaching and learning space of grounded theory development. We are happy to publish chapter six of this book, in which he discusses the value of exampling and growth of the grounded theory troubleshooting seminars since the first, held in Paris 15 years ago. Glaser declares that the current grounded theory perspective is well founded (Glaser, 2016) and thus by glorious implication, is not ossified. The productive power of the seminars is exemplified by the fact that nearly all of the contributors to this special issue participated in one or more of his troubleshooting seminars during the course of their PhDs. Each of the papers in this section exemplifies or contributes to the grounded theory perspective.

When I asked Dr. Glaser what kind of articles he would like to see in this issue, he quickly replied "I would like to see more grounded theories!" The two full theories that were selected for publication stem from the health disciplines, and Dr. Glaser was actively involved as a reviewer of both papers. Authors **Lene Bastrup Jorgensen**, **Stine Leegaard Jepsen**, **Bengt Fridlund** and **Judith Holton** have developed what is termed a general substantive theory (GST) on the multidimensional behavioral process of coping with health issues. This theory explains how people who face health issues seek to safeguard and keep intact their integrity as individuals and as members of groups or systems. The theory of intacting integrity thus identifies how this intacting process is executed. **Milka Satinovic** has developed a substantive grounded theory on how to live a life as good as possible with multiple sclerosis (MS). The main concern of the participants is resolved through a process of remodelling the life course through postponing, adjusting, restructuring, and transforming, where transforming means preventing illness from controlling life.

When planning for this issue, I asked Dr. Glaser one more question: What paper would he like to see reprinted, if any? Was there any particular article he had written that he wanted to focus on now after 50 years of exploring and applying the grounded theory method? As a response he sent a copy of the article "The failure of science," which was published in *Science* in 1964. At the time, Dr. Glaser was a young research sociologist of 34 years at the University of California Medical Center in San Francisco. In this article he stated that "Career decisions are perhaps among the most important determinants of a man's fate, and anything which contributes to an understanding of the career in science may help people make these decisions more wisely."

Half a century later, this statement takes on a new meaning. In the paper, Dr. Glaser discussed what he called the feeling of comparative failure among scientists. His

proposition was that scientist communities are filled with ”great men” who serve as acknowledged guiding lights, and

> to take these honored men as models is important for training as well as for a life of research. During training, one learns to think creatively. Emulation of these models results in the internalization of values, beliefs, and norms of the highest standard. This emulation of the great continues and guides the scientist in his research work, however individual in style his work may be.

There might be early signals then, that exampling had a pedagogical grip on Dr. Glaser’s mind from early on. Thus, a main focus of his latest book *The Grounded Theory Perspective: Its Origin and Growth* is, not surprisingly, the role of exampling in the grounded theory learning process. Through his reflections on the fifty years that have passed, Dr. Glaser still inspires his readers to the extent that book reviewer **Olavur Christiansen** suggests the book replace *The Discovery of Grounded Theory* as an early read for novice grounded theorists*.* **Helen Scott,** in her review, says the new book has given her a “a conceptual tool with which to differentiate more concisely the grounded theory method.”

Helen Scott also evaluates and introduces the section of short papers sharing her current understandings of the growth of the grounded theory perspective. She uses this understanding to organize the papers therein.

Judith Holton’s short paper "The discovery power of staying open” exemplifies the grounded theory perspective of emergence. Holton explains how she noticed an emergent main concern while conducting a study of a different methodological design, exposing a tension between participants’ properline data and their burgeoning awareness of their own baseline data. **Barry Chametsky’s** paper also appeals to emergence as he seeks emergent fit for the concept ”affective filter” in his theory, which focuses on a main concern of coping with the anxiety of navigating a stressful and/or unfamiliar situation.

Andy Lowe’s contribution speaks to the perspective of “autonomy.” Lowe shows how autonomy can be fostered and encourages grounded theory novices to develop a robustness to allow them to successfully complete their PhD.

Olavur Christiansen, **Gary L. Evans**, and **Tom Andrews** speak in shared ways to the procedural perspective. Christiansen discusses the opportunity for the grounded theory method in the field of applied economics and elegantly explains the main concern of sustaining employment. He invites collaboration from interested parties to develop a theory of its resolution. Gary L. Evans and Tom Andrews both exemplify the flexibility of the grounded theory method in its use by a team of researchers. Evans discusses how the challenges of collaboration are overcome in the early stages of a new study, while Andrews’ presents a successful international collaboration that produced a grounded theory of “negotiated reorienting”.

Kara Vander Linden, **Anna Sandgren**, and **Vivian Martin** speak to the procedural perspective and are all working towards producing formal grounded theories. Their formal theories speak to the perspective of generality. Vander Linden’s paper “Patterns of theoretical similarity” reviews patterns across two grounded theories and offers ways of moving towards a formal grounded theory. Sandgren meanwhile looks at integrating four of her grounded theories and finds complexity is common to each—a concept which in turn is shared with Vander Linden. Martin’s reflective paper “Formal grounded theory:

knowing when to come out of the rain" describes her path to knowing when to commit to her formal theory of "defensive disattending".

Grounded theory assumes patterns of behavior. The patterns are abstracted from the data, rarely neatly and often one concept at a time. The grounded theory perspective of conceptualisation is exampled by **Hans Thulesius** as he continues his work in the field of dying taboos. In this paper he explores recent memos and introduces the concept of "time framing taboos" as a means of transcending taboos in medical ethics, while **Erica Delaney** and **Evelyn Gordon** offer concepts of imageric power in their paper on "Grappling with the suicidal monster". Theoretical codes organise concepts into a theory of parsimony, which is what **Alvita K. Nathaniel** and **Lisa Hardman** offer in the theory of "Caring with honor".

The section is completed by three papers from Penny Hart & Helen Scott, Odis Simmons and Naomi Elliott, relating to the "neglected option" of applying grounded theory (Glaser, 2014). Hart and Scott present a work in progress in their paper on "Mark maximising in a context of uncertain contribution", whilst in his paper "Grounding anger management" Simmons describes the highly successful application of his theory to a therapeutic program of 25 years standing. In the final paper "Becoming comfortable with MY epilepsy: The How*2*tell study", Elliott explains how her theory is used to inform the design of self-management supports for people with epilepsy.

Last but not least, I want to thank all the grounded theorists who volunteer to ensure the quality and the regular publication of the Grounded Theory Review as a non-profit journal twice a year. In particular I want to thank our editorial assistant **Lee Yarwood-Ross** and our copyeditor **Barry Chametzky** for their consistently patient and helpful attitude and their great capacity for work which enables us to get the journal out in time. I would also like to thank **Helen Scott** for her valued support with finalising the short papers, and a huge thank you to all the grounded theorists who volunteer as reviewers and always provide constructive feedback to submitters. Finally, I offer my grateful thanks to **Jillian Rhine**, who as administrator of the Grounded Theory Review oversees the continued, successful development of the journal and the worldwide dissemination of classic grounded theory.

Final Thoughts on Exampling

Barney G. Glaser, PhD, Hon PhD, USA

This article is reprinted from Glaser, B. (2016). The Grounded Theory Perspective: Its Origin and Growth, chapter 6. Mill Valley, CA: Sociology Press.

The humble purpose of this book is to help novice researchers doing dissertation research to do good GT by emphasizing the learning of GT by example. There is much to learn as GT methods become developed in the literature every year. This book has focused so far on exampling GT from its inception in 1965 to the reader *Methods of GT* in 1994. In this chapter I will discuss exampling GT to 2007 when I put out a reader with Judith Holton of very well formulated GT papers. It was called the *GT Seminar Reader*. Since this reader was published in 2007 to today both method and substantive GT papers have burgeoned following the style and procedure examples given in this reader.

One source of this perfecting of GT methodology was my grounded theory troubleshooting seminar started 14 years ago in Paris. Novices trying GT for a dissertation came from all over the world to get help in doing the PhD dissertation using GT. These seminars are given all over the world by my colleagues. I designed the seminar in 2002 expressly to tend to the myriad of problems that emerge when doing a GT for a dissertation. The rule of the seminar requires participants to be totally open to whatever they think. The participants are also allowed to interrupt at will, to the point of a free for all of emergent possible ideas. There is no such thing as a good question, just whatever emerges as questions leading to possible categories and to perfecting GT procedures. The goal was to get each novice one step further in his GT research and doing this step "right". The seminar unstuck each researcher presenting. Each presentation unstuck by examples of several typical problems that occur when tempting a GT research. Observers learned much as well as the participants. The open talk on troubles and problems was nonstop.

The seminar focuses on exactly where each participant is with the goal of moving him/her one step further in the research. Problem coverage is achieved by listening to the array of problems of eleven or twelve troubleshootees. And after listening engaging in free for all open discussion about the problems and related problems with procedures that will help the participant. I keep the discussion under control as best I can, keeping in mind the helpful benefit of free associations of participants.

The motivation to participate in these seminars besides the 'grab' of discovery is producing an acceptable dissertation that contributes to a field and is rewarded by a PhD.

It must meet the high standards of the academia wherever it is being done. Candidates are committing themselves to this critical career junction at great personal cost of time and money. The value enhancement of going from student to doctor is tremendous. Committing themselves to doing a GT dissertation is a very fateful decision. It is a mystical passage to surrounding laymen, based on the awe-inspiring magic of the GT methodology. It is normal for a candidate to worry if GT research in his hands will pass muster, thus they are highly motivated to get help in doing GT and the GT troubleshooting seminar provides the help they need. They are highly motivated to get on with their lives based on the PhD career rewards. The candidates often go to two or three seminars as their research advances and different problems emerge.

The troubleshooting seminar offerings have proven very successful. Each seminar fills up quite quickly. Novices come from all over the world. They are given all over the world. Novices travel great distances for the promise of help. The seminars are usually given by my advanced students, in their country, but they travel to the USA too. The networking by internet telling of the learning experience and of the dissertation success generates a big demand for holding many seminars.

Many novices come from departments where GT methodology is completely unknown. Supervisors and committees must be convinced that GT research is academically legitimate with great merit. They learn in the seminar how to argue for using GT research for the PhD. The seminar participation has a certifying effect that hopefully gets it accepted at the home department. The anti-GT opinion of academic departments is still strong, but subsiding enough to accommodate many more novices doing dissertations.

The further purpose of the troubleshooting was to inspire all participants to doing GT by the conceptual grab of the concepts that occurred for each participant presenting. Also, to show GT's worldwide use in many disciplines by noting where the participants came from as well as their field in academics. I also noted where other troubleshooting seminars were being given. A major result of the seminar was a codification and clarifying of the GT perception during the few days it was held. Participants discovered in detail a method they had no idea existed. The papers in this GT seminar reader largely came from the seminars generating concepts by constant comparisons.

The troubleshooting seminar over the years has become an important learning tool for GT and thusly a firm feature in the growth of the GT perspective. Researchers network to share their papers through the internet for exampling to each other for comments. The network is largely based on meetings at the seminar. I know of no one who has not participated in at least one troubleshooting seminar as an observer or as a trouble shootee. Most colleagues have been to two or more troubleshooting seminars. The exampling learning is great.

The 24 papers in our reader *The GT Seminar Reader* will show to the reader of this chapter the dissertation successes of the troubleshooting seminar. The title to each paper captures with grab the core problem and sometimes the core variable. They are excellent papers thus good examples, but the reader of this book can be his/her own judge of

these papers using the autonomy afforded by GT methodology. It is my hope that these papers will inspire more GT research by novices, the experienced and senior academics. And I hope they will certify and legitimate by example the use of GT in doubtful academic departments of all disciplines. Many such doubtful departments still exist in spite of the spread of 'ok' for GT. This reader has a strong progressive part in the growth of the GT perspective. It plays a strong part in the history of GT. Since this publication a few more readers and scores of papers have been published which confirm the GT perspective and methodology

So dear reader, enjoy and bear in mind that the papers in this reader are rich in general implications; that they are not bound by the field in which they were researched. The implications can be applied to many areas of social behavior and can also be used to generate formal theory. Also, they were all published in journals, thus peer reviewed by independent researchers.

Bear in mind that the primary purpose of this reader was exampling. There are many benefits from exampling to those who study these papers taken from dissertations. I turn now to give the reader some comments written by Judith Holton my coeditor.

Introduction to Reader by Judith Holton

"As Barney has suggested the primary purpose of the *GT Seminar Reader* is exampling. There are many dimensions to exampling that will benefit those who study the papers in this reader. For the novice, of course, exampling shows the way, inspires their effort to achieve a GT thesis and motivates them to persist through the learning process and applying the GT methodology. For the more experienced grounded theorists exampling offers the delight of reading grounded theories from a diverse range of disciplines and discovering new concepts that capture with imagery and spin with general application beyond the paper at hand. In an earlier Reader (Glaser 1994), Barney spoke of this conceptual power of GT not simply for theorists but for practitioners and participants. I think that this is a primary reason that many of us are drawn to GT. "We are motivated to generate theory that really matters, theory that is vital, relevant and yields high impact main concerns."

Learning GT is an experiential process. Exampling is an important part of the learning process, like the earlier Reader, and serves as a companion to Barney's methodological works and building of a GT perspective. This reader shows how others have used the GT methodology with a high level of ingenuity and grasp, and we see how sensitive they were to the conceptual power of the GT perspective.

The Reader's exampling illustrates the power and scope of classic GT by the ranges of substantive areas under study using GT, the global reach of the GT method and the various levels of methodological maturity of the authors. Here we have the opportunity to study how various grounded theorists have approached their research projects, how they have applied and experienced the methodology, and how they have integrated and modeled their emergent theories to present them to their readers.

Regardless of the reader's level of experience with GT, studying the conceptualization and theoretical construction of this wide range of substantive theories is an important way of experiencing GT methodology. For the novice, such reading guides and supports a high enough level of confidence in taking on a research for a GT dissertation. For the more experienced researchers among us it offers by example important GT method "ah ha's" that clarify, confirm and advance our understanding of GT.

In exampling, this reader provides a rich range of theories that have emerged that have resulted largely from novice efforts at applying GT method procedures. This is an important point to remember. The theories presented here are not intended to indicate an ideal in terms of methodological rendering. They are instead the honest efforts of individuals who have been engaged in learning and using classic GT procedures; they demonstrate clearly that while a novice's effort may not represent perfection it can yield rich GT theory that fits with relevance and works and can be readily modified to accommodate any new data. The theories in this Reader are good examples from which each of us can learn.

We learn by studying these papers for their strengths and areas for further improvement. In approaching each paper begin by skipping and dipping to get an overview of the theory being presented: what is the main concern, how does the core category explain the resolution of this concern, what are the subcategories related to the core process and how has the researcher theoretically sampled in generating the theory, what theoretical code was used to integrate the theory, what are general implications of the core, etc., etc. as a study guide to learning GT methodology.

While the number of academic departments offering training of GT research methodology is limited and widely dispersed there are many individuals who are making the effort to learn and do GT research on their own. We trust that this Reader will prove to be an excellent sourcebook for pursuing study and minus mentor researchers. Those planning to attend a GT troubleshooting seminar will find that studying this Reader in advance is excellent preparation for the analytic exchange that forms the basis of the seminar. It will help overcome the descriptive vs concept struggle. It will help going conceptual. So enjoy your study and memo your thoughts on conceptualizing examples.

I turn now to giving the reader the table of contents of the "*GT Seminar Reader*"

1. Moral Reckoning, by Alvita K Nathaniel
2. Visualizing Worsening Progressions, by Tom Andrews, Heather Waterman
3. Pluralistic Dialoguing, a Theory of Interdisciplinary Team Working, by Antoinette McCallin
4. Keeping My Ways of Being: Middleaged Women Dealing with Passage Through Menopause, by Helen Ekstrom, et al
5. Solutioning, by Maria De Hoyoa
6. Developing a Science of One: The Ongoing Process of Integration, by Cheri Ann Hernandez
7. Rehumanising Knowledge Work through Fluxuating Support Networks, by Judith Holton

8. Stabilising of Life: Families Living with Cancer, by Aino-Liisa Jussila
9. The Temporal Integration of Connected Study into a Stabilized Life, by Helen Scott
10. Beyond the Physical Realm: A Proposed Theory Regarding Consumer's Place Experience, by Mark Rosenbaum
11. Purposive Attending: How People Get the News from the News, by Vivian B Martin
12. Mutual Intacting: A GT of Clinical Judgment in Advanced Nursing, by Naomi Elliot
13. Opportunizing, by Olavur Christiansen
14. Sugar Snacking: Parental Policing Strategies to Regular Between Meal Snacking, by Ruth Freeman, et al.
15. Striving for Emotional Survival in Palliative Cancer Nursing, by Anna Sandgren
16. The Miso Model: A Synthesis and Application of Domestic Violence to Leadership and Organizational Theory, by Jaclyn Gisburne
17. Between Comfort and Cure: Basic Balancing Strategies in Cancer Cure, by Hans Thulesius, et al
18. Veiling Sexuality: A GT in Sexuality and Psychiatry Mental Health Nursing, by Agnes Higgins
19. De-shaming for Believability, by Toke Barford
20. Change Enabling in a Salugenic Place, by Susan Williams
21. Creative Cycling of News Professionals, by Astrid Gynnild
22. Protecting Professional Cool in Multicultural Nursing, by Pernilla Pergert, et al
23. A Simpler Understanding of Classic GT: A Fundementally Different Methodology, by Olavar Christiansen
24. The transition from QDA to Grounded Theory, by Astrid Gynnild

Published by Sociology Press 2007

Intacting Integrity in Coping with Health Issues

Lene Bastrup Jørgensen, University of Aarhus, Denmark, Stine Leegaard Jepsen, University of Aarhus, Denmark, Bengt Fridlund, Jönköping University, Sweden, Judith A. Holton, Mount Allison University, USA

Abstract

The aim of this study was to discover and elaborate a general substantive theory (GST) on the multidimensional behavioral process of coping with health issues. Intacting integrity while coping with health issues emerged as the core category of this GST. People facing health issues strive to safeguard and keep intact their integrity not only on an individual level but also as members of a group or a system. The intacting process is executed by attunement, continuously minimizing the discrepancy between personal values, personal health, self-expectations, and external conditions as health- and culturally-related recommendations and demands. Multifaceted coping strategies are available and used as implements in the attuning process.

Keywords: intacting, health issues, coping strategies, general substantive theory

Background

Creating an overview and a general explanation of how people cope with health challenges is difficult as the literature on the coping process is comprehensive and diverse. This diversity may be due to a profound heterogeneity in literature when it comes to the conceptual structure of coping (Skinner, 2003). Various concepts are used to explain the same complex behavioral coping processes, and no consistent structure-related terminology on coping is available (Skinner, 2003). A fragile theoretical foundation and theoretical rationale for coping-supportive clinical actions may be a consequence of this inconsistency.

Several grand theories (Bandura, 1977, 1995; Lazarus & Folkman, 1984) on coping often lay the theoretical foundation for educating healthcare professionals. The ability and suitability of these grand theories to explain coping processes dealing with health issues has not been challenged in decades. Healthcare professionals are consequently challenged by diversity in the structural understanding of coping and a rigidity in the theoretical understanding. Consequently, the competencies of healthcare professionals in supporting coping behaviors, and thereby the clinical needs of understanding coping, may not be sufficiently met by using these grand theories.

However, according to Glaser and Strauss (1967), moving away from "grand theories" to develop empirically grounded substantive theory gives the theory better fit while sufficiently matching clinical needs. As there is already a plethora of research and substantive theories on coping within the healthcare field, largely differentiated by medical criteria, the aim is to raise the conceptual level by offering a more nuanced explanation and understanding of a variety of substantive areas through development of a general substantive theory of coping in healthcare. Glaser (1978) referred to a general substantive theory as "more general than a substantive theory, but not completely general as a formal theory" (p. 52). Holton and Walsh (2017) referred to this mid-range theory development as "substantive formalization" (p. 22) and proposed that, "The substantive formalization of a substantive theory may be obtained through sampling different substantive groups, contexts, and/or social units within the same setting/substantive area; it increases the scope of a grounded theory" (p. 22). As such, this study of coping with health issues constitutes the first step in the process of generating a formal grounded theory on coping that could, through further theoretical sampling, be extended beyond the health domain.

This general substantive theory (GST) of intacting integrity emerged from two substantive grounded theories: one developed with pulmonary patients dealing with breathlessness (Jørgensen, Pedersen, Dahl, & Lomborg, 2013a; Jørgensen, Lomborg, Dahl, & Pedersen, 2013b) and the second with patients dealing with a fast track total arthroplasty (THA) programme (Jørgensen & Fridlund, 2016). Subsequently, comparing the two theories, almost identical cores were identified: To preserve or restore integrity as a response to an integrity threat. As a main concern, people experiencing threats to their integrity when becoming ill, hospitalized or rehabilitated is a well-known phenomenon (Jacelon, 2004; Morse 1997; Randers Mattiasson, 2000, 2004; Lomborg & Kirkevold, 2005; Damsgaard et al. 2015, 2016; Jørgensen et al., 2013a; Jørgensen et al., 2013b; Jørgensen & Fridlund, 2016). What follows is an overview of our aim in this study, our study design, the emergent theoretical framework that guided our analysis and theoretical elaboration of intacting integrity in coping with health issues.

Aim and method

Our aim in this study was to discover and elaborate a GST explaining the conceptual nature of coping with health issues. By exploring the overarching behavioral process of coping and identifying the pivotal components in its conceptual structure, we have endeavored to synthesize and reduce the heterogeneity of conceptual terminology on coping.

We began by synthesizing the core categories of two substantive grounded theories (GT), both within the health domain: coping with breathlessness in daily life and coping with a fast track surgery programme.

Theory I: COPD patients' coping with breathlessness in daily life

The main concern in coping with breathlessness in daily life is predominantly to preserve the physical and psychosocial dimensions of their integrity (Jørgensen et al., 2013a; Jørgensen et al., 2013b). In trying to preserve their integrity, individuals economize their resources in multiple ways. Economizing means to administer resources in an efficient and suitable manner. The criteria for the efficiency and appropriateness of the economization are coping-type-specific and depend on the focus of each patient's integrity preservation.

Individuals dealing with breathlessness in daily life may adopt one or more of four coping behaviors: overrating, challenging, underrating and leveling capability. Across the four coping behaviors, individuals experience breathlessness as threatening the physical and psychosocial dimensions of their integrity. They fear death related to asphyxiation and loss of worth as social human beings. Consequently, they focus on preserving either the physical and psychosocial dimensions, or only the dimension perceived to be most at risk of being violated by breathlessness. Their choice of preservation focus depends on their predominant type of coping behavior. Coping is a circular process comprising a cascade of physiological, cognitive, affective, and behavioral actions causing either an eroding or restoring effect on integrity due to whether or not they achieve a match or mismatch between experienced capability and actual capability. Across the four coping behaviors, six predominant and interacting strategies for economizing resources emerge: regulating level of activity, justifying existence, normalizing appearance and/ or behavior, curbing feelings and thoughts, diverting attention from the sensations of breathlessness and finally nurturing hope and zest for life.

Theory II: Coping with joining a fast track total hip arthroplasty programme

The main concern among patients coping with total hip replacement in a fast track THA programme is predominantly to restore the physical and psychosocial dimensions of their integrity that have been compromised by a low level of function and mobility in daily life (Jørgensen & Fridlund, 2016). They cope by economizing their mental resources and striving to fulfill the expectations of the fast track programme, which expresses the need for patients to be mentally proactive and physically active. In this way, they aim to regain their habitual level of function and mobility and, subsequently, their social life and self-image as active human beings. Patients adopt one or more of four coping behaviors: exceeding, protecting, challenging and accepting boundaries of capability. These predominant coping types have discriminating purposes and other physiological, cognitive, affective, and psychosocial coping-type-specific features. Coping is a circular process that causes either an eroding or restoring effect on integrity due to whether or not the behavior matches the expectations expressed in the fast track THA programme. Across the four coping behaviors, sharing knowledge with fellow patients and relying on support from relatives are important strategies in the effort to restore patients' physical and psychosocial integrity. For the patients, economizing means administering resources in an efficient and suitable manner, so they will have the strength to restore their integrity by regaining their habitual level of function and self-image.

Substantive formalization

Substantive formalization is the process of raising the conceptual level of a substantive GT to a GST (Holton & Walsh, 2017). To raise the conceptual level, we synthesized the two core categories as intacting integrity and proceeded by following Glaser's (2007) advice on generating a formal grounded theory (FGT) by modifying and saturating the synthesized core through theoretical sampling and constant comparison of empirically grounded literature on coping within the broader substantive area of healthcare. In accordance with classic grounded theory (Glaser & Strauss, 1967; Glaser, 1978, 2007), the process was paced and facilitated by continuously memoing. Synthesizing allowed us to proceed to theoretically sample for both preserving and restoring integrity as subcore categories of the overarching core, intacting integrity, thus continuously challenging the fit of all three concepts and their interrelations through constant comparison and writing of memos.

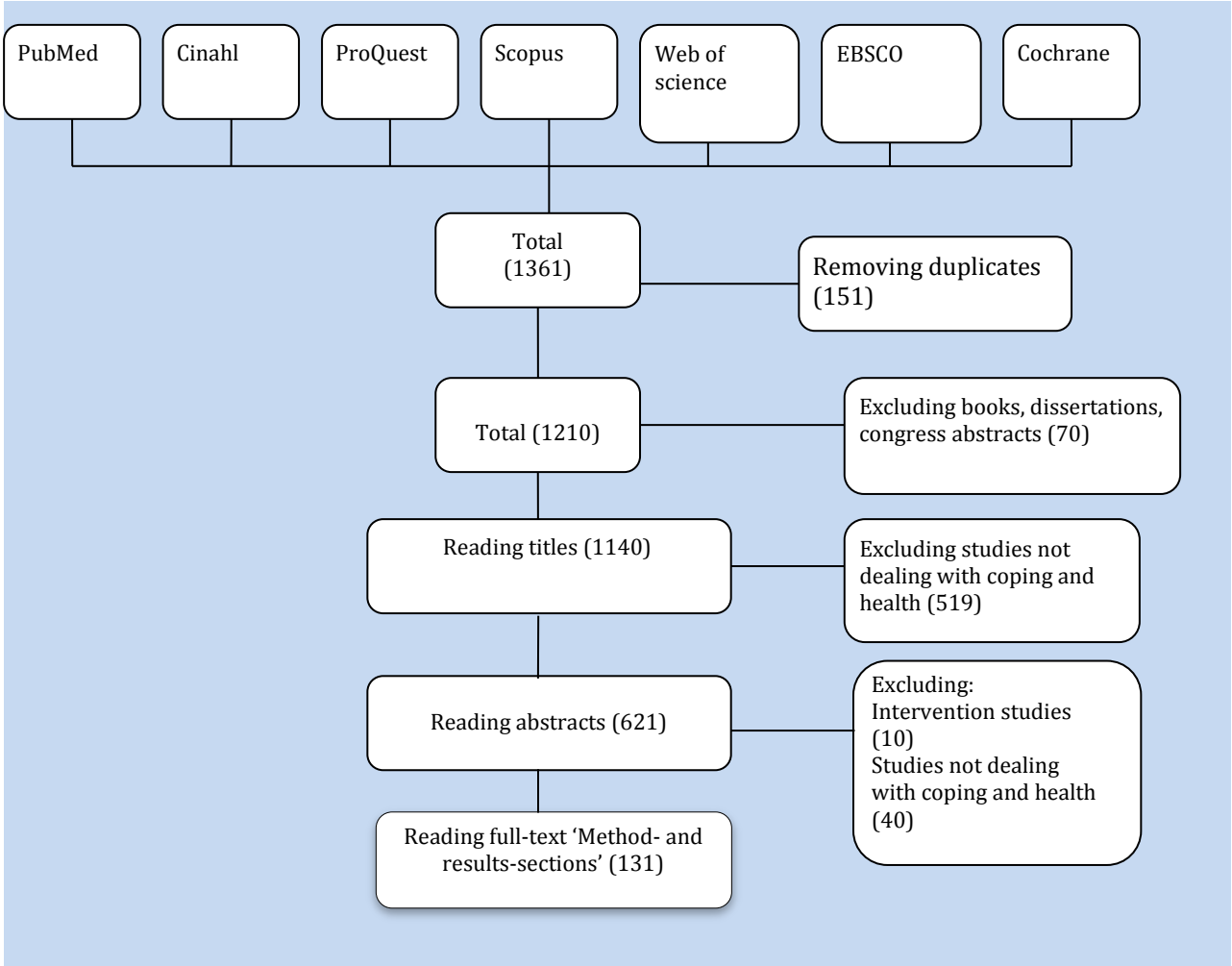
Literature selection

A systematic literature search in selected databases was performed by a research assistant and two research librarians (See Figure 1). In the process of excluding studies not focusing on coping with health, the reference system "Refworks" was used. A variety of criteria of inclusion and exclusion inductively evolved in this review process. Criteria of inclusion were studies dealing with health across age and gender. Furthermore, studies dealing with health focusing on education of healthcare professionals, divorce, and dental health, participants with intellectual disabilities, research methodology, and development of IT solutions were excluded.

As illustrated in Figure 1, a total of 1361 studies were identified. Removing duplicates, this literature search produced 1210 studies. We further excluded 70 references constituting books, dissertations and congress abstracts, leaving a total of 1140 references. Based on the titles not revealing issues of coping in relation to health, 519 studies were excluded. The abstracts of the remaining 621 studies were reviewed and assessed, and consequently further 40 studies were excluded not dealing with coping. Furthermore, 10 intervention studies were excluded due to their focus on evaluating an effect and not exclusively dealing with coping.

Developing a theoretical explanation of the overarching behavioral process of coping was possible after first reading 571 abstracts and subsequently the method and result sections of 131 studies. Health domains dealt with are within the somatic, psychiatric, social, and cultural areas. Throughout the process of reading the abstracts and the results-sections, several new hypotheses on coping emerged including concepts, features, and conditions constituting different hypotheses on the conceptual structure of coping e.g., some studies indicated that coping with cancer held a kind of a transitional process altering values and personal goals relating to integrity. This knowledge generated new memos on questions such as: Does our integrity develop? Do people alter their integrity when facing the risk of health problems? What are the possible trigger points for the alteration, and how do they do it?

Figure 1. Overview of the literature review



A theory of intacting integrity

Intacting integrity, as a GST, clearly constitutes a complex existential and behavioral process. The conceptual structure of coping with health issues is illustrated in Figure 2.

Due to the fear of physical and psychosocial impairment and death, integrity is always at stake when people face health issues. Integrity suggests a sense of being whole with identity based on and changed by personal values, health, self-expectations and external conditions related to health or culture expressed in health demands and recommendations. Integrity is not a steady phenomenon but continuously modified as necessary in meeting health changes. Regardless of health state, people face the risk of their own physical, mental and psychosocial impairment, including death. The main concern in coping with this threat is to safeguard the intactness of integrity, which is a continuous transitioning process. This intacting of integrity is executed by attuning or minimizing the discrepancy between personal values, health and expectations of oneself and external

conditions. Hereby, people preserve, restore, regain, reinforce and reorient their integrity. This attunement is achieved using a variety of coping strategies. Depending on the degree of success with this attunement, people experience either a match or mismatch between personal and external values, expectations and conditions, creating a safe-guarding or eroding effect on integrity. This process is experienced as continuous and circular when an individual is facing health issues.

Figure 2. The conceptual structure of coping with health issues


Main concern
• The integrity is threatened when participating in a health preventive effort, or having health problems themselves or among significant others.
• When integrity is threatened, people face the risk of one's own or significant others' death, physical, mental and psychosocial impairment
Core category
• Intacting Integrity by attunement, continously minimizing the discrepancy between personal values, health and self-expectations and external conditions as health- and cultural-related recomendations and demands.
Coping proces
• Intacting integrity is sought through preserving, restoring, reinforcing, regaining and reorienting integrity by attunement. Reorienting integrity is achieved through either reinterpreting or reframing one's integrity
• Multidimensional coping strategies are used in this intacting process
Consequences of coping
• Integrity-eroding or integrity-intacting effect

A detailed explanation of the emergent theory including the conceptual structure of coping is provided in the following section.

Integrity and its properties in health-related issues

When facing health challenges, intacting integrity sustains a sense of whole and identity based on and changed by personal values, health and self-expectations, and external conditions related to health and culture (e.g., ethnicity, religious, and spiritual orientation). Thus, integrity is also culturally understood, explained, and dealt with when it comes to health. A variety of health challenges exist. Integrity is not a steady phenomenon but is continuously modified in meeting these different health changes, if necessary. As such, integrity is a dynamic phenomenon that changes and transitions at the individual, group, and system levels and poses possible discrepancies between integrities when facing health issues. However, an unaltered integrity is not essential. It is more important to achieve a feeling of match between personal values and external conditions such as recommendations and demands of the society, healthcare system, and health programme etc.

Facing the risk of health issues is integrity-threatening

Facing the risk of acquiring or having health problems constitutes a threat to one's integrity due to the risk of impairment. The impairment may be related to and involve a variety of areas or dimensions including physical, mental, psychosocial, economic status, and spiritual well-being. The predominant threats may include the risk of having a disease or impairment, the degree of disease or impairment, and the treatment as well as a range of impediments including physiological or socio-economic impediments, stigmatization, or environmental impediments.

Physiological impediments are fluctuating phenomena and as such a fluctuating threat. Chronically ill patients' perceptions of their disease, for instance, depend on the fluctuating degree of their disease. The same effect of fluctuation seems to exist when it comes to treatment. Consequently, how aggressively people wish to be treated varies in relation to the perceived severity of the disease. This means that due to the fluctuation of the threat, the ways of intacting integrity (through coping behaviors) fluctuate as well.

Socio-economic impediments, in terms of unequal access to health benefits, may also constitute a threat to integrity. For instance, financial problems can compromise a healthy and well-monitored pregnancy or treatment. The risk of the physical impairment of one's unborn child collides with one's expectation of being a protective mother.

Stigmatization related to ethnicity and class is also a possible cause and threat to integrity in relation to health challenges. This stigmatization may impede necessary help as the stigmatized individual avoids seeking help for fear of sanctions. For instance, obese patients do not dare seek surgery or are denied surgery because of their weight. Despite reasonable recommendations, these individuals experience stigmatization due to their

weight and appearance.

Environmental impediments may also be a threat as a possible stressor among the chronically ill during hospitalization. For instance, the hospital environment does not always encourage patients to be active. This inactivity may reinforce boredom and inactivity, further undermining integrity for children and adults with a natural urge to be active.

Trauma constitutes a health threat due to the risk and purpose of killing and harming people and their loved ones. For example, post-traumatic stress syndrome is a consequence of experiences that took place during a time of war.

Often these threats interrelate through mutual influence. For instance, physical impairment due to arthritis may cause sick leave, dismissal from work and consequently reduced income, which may compromise the possibility for buying the prescribed medication or attending the best rehabilitation programme available. In countries with private health insurance, integrity of individuals, groups, and systems could be more at stake than in countries with equal conditions for the best available health practices. In this way, threats of integrity and the intacting process are also politically grounded and influenced. Furthermore, threats may emerge from health beliefs, health expectations from the healthcare system, former life experiences, prophylactic health interventions (screening, patient education, etc.), risk reducing or risk increasing behavior, and finally religious or spiritual beliefs.

Intacting integrity

Threats of integrity are evidently the prime motivator for intacting integrity in relation to health as a means of avoiding violations to integrity. The intacting process is an existential praxis with possible impact on faith, confidence, and self-efficacy in coping with expectations, demands, and challenges on an individual level. At the group and system level, the integrity of the healthcare system or a patient group may be challenged or supported in the struggle to achieve a match between personal health, values, and external health-related recommendations and demands. For instance, internal values in a group of citizens who choose not to have their children vaccinated against measles may collide with the healthcare system's recommendation on vaccinating all children. As such, intacting the group's integrity forms a threat to the integrity of the healthcare system.

Thus, integrity can be shared and jointly threatened and safe-guarded within a family, between friends, social groups, patient groups, religious-, gender- and age-groups thereby constituting a mutual intentionality. Intacting the integrity of a group or system facing health threats also intacts the integrity of the individuals involved. The integrity and its threat is shared and dealt with by a member of the group, by the group as a whole, or vicariously by others or surrogate decision makers on behalf of the group. Professional groups such as nurses or social workers will fight for protecting the integrity of chronically ill children, adolescents, or prostitutes. Thus, threats to the integrity of others appear to generate empathy and compassion facilitating an urge to contribute to the intacting process

without actually experiencing the integrity threat.

Additionally, the integrity of a system and its recommendations and demands may support an individual's process of intacting integrity, as the person's beliefs in the integrity of the system creates a sense of being safeguarded through information, screening for diseases, treatment, care, and rehabilitation and thereby also reduces a potential or factual health threat on a personal level. As a result of the existence of integrity on an individual, group and system level, intacting integrity involves several agents on several levels. The integrity of the individual may be safe-guarded by the individual, a group, or a system. Likewise, the integrity of a group and a system may be safe-guarded by the group as a whole, an individual member, or a system. In this way, reciprocity exists in the attuning process between the individual, group and system.

There are several trigger points for intacting integrity. The most predominant trigger point is the discrepancy between personal factors such as values, health status and self-expectations and and external factors such as, health-related recommendations and demands. For example, the discrepancy could be between the self-image of being active and participating in life outside the home and personal health conditions such as pulmonary impairment not complying with living on the 4th floor. The physical and psychosocial dimensions of integrity are the dimensions most at stake when facing concrete health problems, or the risk thereof. Those who have the ability to attune their values and needs to their own capability and external conditions appear to be most content with their lives when living with a potential or tangible health problem.

Intacting integrity is executed through different modes depending on how the integrity is compromised or perceived to be at risk. Minimizing discrepancies is accomplished by changing inner values, self-expectations or external conditions as health-related recommendations and demands. People facing health issues try to intact integrity through various modes i.e., preserving, restoring, reinforcing, regaining, and reorienting integrity and/or external conditions with intacting achieved through an attunement process. These modes are used to secure and intact integrity by pursuing a match between personal and external values, expectations and conditions.

Intacting integrity requires either reinterpreting or reframing one's integrity. Reinterpreting and reframing mean to change personal values, bodily, and psychosocial needs attuned to the external conditions. Whether people choose to reinterpret or reframe their integrity by changing personal factors depends on the severity of threat. For instance, patients with cancer seem to be more likely to change inner values and needs by pursuing a match to some external demands as treatments. Threats may also constitute a safe-guarding act. Medical abuse for instance, constitutes a threat to physical and mental health but may also give the individual the courage to join a group and seek acceptance among others in striving to intact their integrity. However, intacting integrity is not always achieved despite attunement. Instead, an integrity-eroding effect may be the result when it is unclear as to which dimensions of integrity most need to be safe-guarded. For instance, abusing drugs to safe-guard the psychosocial dimension of integrity and leaving the individual the courage to participate in life, may threaten the physical and psychosocial dimensions of integrity on a long-term basis. Or, for some chronically ill adolescents with diabetes, fitting

in with peers who do not have a chronic disease is especially important. However, this may have an integrity intacting or eroding effect when the choice later results in neglecting special needs due to the disease and thereby jeopardizes the physiological and psychosocial integrity dimensions creating complications such as blindness, cognitive impairment, and isolation due to a medically non-compliant way of living with their disease. Especially, the chronically ill fight to intact their integrity by regaining their habitual condition as healthy human beings. However, some know they are in a process of transition due to a disease, and that it is inevitable. Whether or not this is a conscious fight varies among persons. Degree of consciousness on what to fight or what to accept, constitutes trigger points for successfully intacting integrity.

Coping strategies

With intacting integrity, people chose, more or less consciously, a variety of coping strategies as implements in the attuning process. The predominant coping strategies may be viewed as tools or resources related to intacting physiological, mental, psychosocial, and cultural dimensions of integrity. The cultural dimension also holds religious, spiritual and ethnicity elements.

These dimensions of integrity interrelate; consequently, the same strategy may be used in intacting different integrity dimensions. Regulating levels of activity and changing life style habits as strategies have an impact on the physiological, mental, psychosocial, and cultural dimensions of integrity. Likewise, predominant strategies such as distraction, curbing feelings and thoughts, gaining knowledge, normalizing appearance and behavior, nurturing hope and zest for life, changing self-image, relying on and using significant others, complying with a group's or system's expectations, and fighting against healthcare professionals and healthcare system for dignity and autonomy are all strategies used to safeguard the intactness of the physiological, mental, psychosocial, and cultural integrity dimensions.

Despite this interrelatedness, coping behavior seems, at the same time, to have corresponding characteristics to the threat in question. For instance, people experiencing threats against a religious or spiritual dimension of integrity seek to eliminate the threat spiritually or through religion with strategies derived from a philosophical/meta-physical tool box. As such, personal beliefs and culture may define the toolbox of coping strategies. For instance, believing in the philosophy of Yin and Yang, a disease is an imbalance in the body and mind, resulting in a wish to restore balance through meditation. Coping strategies may constitute barriers as well as facilitators in striving for attunement. The consequence is that the intacting process may either be integrity-eroding or integrity-intacting. However, despite an eroding or intacting effect on integrity, coping strategies always strive to intact integrity. In this sense, chosen strategies are meaningful and existentially necessary to the individual.

Discussion

This study has first and foremost dealt with discovering the conceptual structure of coping within the substantive area of health. While our GST of intacting integrity is not yet sufficiently developed to offer a detailed explanation and understanding of coping as a formal theory, it does offer two main contributions to knowledge: 1) The discovery of the transitional process of intacting integrity in coping with health issues; 2) The discovery of the conceptual structure of coping. The coping process, its conceptual structure, its implications for healthcare praxis, and its fitness to areas other than health, are the keystones in this discussion.

The process of coping

Our emergent formal substantive theory on coping within the health domain offers a more nuanced understanding of the intrapersonal processes involved in coping. The theory's core category, intacting integrity**,** explains the main concern in coping with health issues. Facing health issues, the individual's integrity is at stake due to the fear of impairment on several levels within a variety of integrity dimensions such as physiology, mental, social behavior and status. This is in line with current knowledge stating that integrity may be threatened as a consequence of becoming ill and hospitalized (Jacelon, 2004; Jørgensen et al., 2013a; Jørgensen, 2013b; Jørgensen & Fridlund 2016; Lomborg & Kirkevold, 2005; Morse, 1997; Randers & Mattiasson, 2000, 2004). While the literature rarely speaks of integrity on behalf of groups and systems, it speaks more often from an individual's perspective when it comes to health challenges; our theory clearly shows how mutual and interdependent the process of intacting integrity is within the individual and between individuals, groups, and systems. This reciprocity constitutes trigger points for pursuing as well as challenging and violating the intactness of integrity.

Integrity is generally understood or described as a sense of whole and as such a static phenomenon. This grounded theory challenges this perspective and broadens the understanding of integrity as a fluctuating phenomenon and attunes personal values with external conditions and expectations. Finding that integrity is a dynamic process that challenges empirical studies inspired by philosophical and theological grand theories (Randers & Mattiasson, 2000, 2004); these authors stated that an individual's sensitivity towards violation of integrity will change concurrently with types of threats such as diseases. This is particularly the case when the person is dependent on help related to the disease (Randers & Mattiasson, 2000, 2004). This sensitivity, especially in relation to disease-based dependency, may well merit a modification of our proposed theory although our theoretical sampling process did not provide the data to support its elaboration as a dimension of our core category.

The conceptual structure of coping

The process of modifying the two substantive theories (on coping with breathlessness and joining a fast track orthopedic program) has revealed new intrapersonal processes and broadened the area of extra-personal circumstances with pivotal influence on the intrapersonal processes. Consequently, a deeper understanding of what is going on when facing different health issues transcends age, gender, ethnicity, culture, and type of health issues or disease.

The overarching conceptual structure in coping with health issues is constituted by four categories: 1) integrity-threat as the main concern, 2) intacting integrity as the core category and the way in which individuals manage their concern in coping with the threat, 3) through attuning internal and external values and conditions to produce, and, 4) an integrity-eroding or integrity-intacting effect.

In nuancing this four-component structure, different subcategories with properties appear to explain the intrapersonal process of coping and its consequences for intacting integrity. Thus, coping with health issues appears to be an existential matter negotiated through a four-component process with one aim: intacting integrity. However, intacting integrity may be achieved through different modes of intacting (preserving, restoring, regaining, reinforcing, and reorienting integrity) by attunement. While our theory does not offer detailed information on the trigger points for choosing between the modes, it most importantly underlines the existential strife of intacting integrity inherent in each coping mode. This intrapersonal process is highly influenced by external factors. Noticeably, the subcategory attunement, with its properties, highlights a contested field between inner values, physiological, mental and psychosocial conditions and values, health expectations and socio-political efforts of the healthcare system.

The theory in practice

Facing the risk of impairment as a consequence of either participating in health prevention efforts, having a health problem, or knowing someone having health problems constitutes a threat against integrity. Intacting integrity makes coping an existential matter (Charmaz, 1983; Jørgensen et al., 2013; Lomborg, 2005; Morse, 1997). This means that healthcare professionals in their efforts to support constructive coping behavior should engage in an ethical, philosophical and psychological praxis in addition to the medical praxis. Furthermore, as integrity comprises physiological, mental and psychosocial dimensions (Jørgensen et al., 2013a; Jørgensen et al., 2013b), clinical praxis calls for a broad scale of necessary competencies accommodating this complex field of coping.

Knowing that values, conditions, and recommendations of a healthcare system have potential influence on the intactness of integrity, healthcare professionals should be aware of how these factors may contribute to an integrity-eroding effect. As representatives of the system, healthcare professionals' theoretical terminology and pre-understanding may have an impact on the person's identity and coping behavior (Telford et al., 2006). In this way, dealing with health issues involves a struggle for keeping the integrity intact, and thereby constitutes an existential challenge. Integrity is philosophical, described as the vulnerable life as a whole (Kemp, 1998) in which physical, mental, and psychosocial dimensions interact (Randers & Mathiasson, 2000). It may be tempting, for instance, in health preventive efforts to persuade and convince persons dealing with health issues to choose a certain health behavior. However, established habits, either integrity-eroding or integrity-intacting, always come across as habits intended as integrity-intacting acts (Jørgensen et al., 2013; Jørgensen & Fridlund, 2016). It seems to be appropriate existential praxis, though, to

support the person's awareness of their choice of coping behavior as well as motivational factors and consequences of the behavior.

Patients who try to keep their integrity intact experience a transitional process in which they may resort to a variety of coping strategies (Jørgensen et al., 2013; Jacelon, 2004; Morse, 1997). Transition seems to be a central component in the altering-process of integrity when striving for the intactness of integrity. According to Meleis et al. (2000), a person may be simultaneously or sequentially engaged in more than one transition with healthy or unhealthy consequences. This transition could support our theory, underlining the continuous attunement of intacting integrity leaving it unchanged (preserved, restored, reinforced, regained) and changed (reoriented through reinterpreting integrity) with potential for positive or less positive intacting effect on integrity.

It is noticeable, however, that despite the consequence of this transitional process, the healthcare professional plays an existential role in the process by representing the social and health system. This calls for an ethical and moral praxis as well. However, it leaves the healthcare professional in a potential conflict of interests that may challenge their integrity as a human being, a member of a group or as a healthcare professional representing a system. Thus, our theory sheds light on the complex reciprocity of intacting different integrities on different levels.

The potential transcendence of the theory beyond the health domain

Modifying two substantive grounded theories on coping by using other studies addressing this topic may form the first step in the process of generating a general substantive theory (Glaser, 1978) on coping by extending data from areas other than the health domain. Even a very cursory literature search reveals that integrity of the individual, group, or system is also at stake within domains as varied as finance, management, education, agriculture, music, acting, architecture, and politics (Cowton, 2002; Cox, 2000; Hagenmeyer, 2007; Kezar, 2004; Steinitz, 1990).

Pursuing a formal grounded theory of coping should therefore include the reciprocity between individuals, groups, and systems. For instance, the integrity of a company, a finance or political system may be threatened by trade-political demands securing the integrity of a working trade group. Or, the integrity of an individual may be threatened by intacting the economic integrity of a company in dismissing the individual. The conciliator or mediator in these situations may come forward as agents of intacting different levels and kinds of integrity, attuning the values, expectations and conditions between parties. Using the concept of integrity in these mediating processes may express and offer an understanding of what is at stake in such processes.

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Remodelling the Life Course: Making the Most of Life with Multiple Sclerosis

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Abstract

The aim of the study was to develop a substantive grounded theory on how to live a life as good as possible with multiple sclerosis (MS). The question of how to improve the quality of life is of key importance when speaking of a chronic illness like MS. We still have little knowledge of this important question from the patients' perspective. Classic grounded theory was used to explore patients' experiences of living with MS. The aim was to identify their main concern and how they process this concern at different phases in their life course. Twenty-one interviews were conducted with 17 participants diagnosed with multiple sclerosis. Participant observation at five courses for people with a multiple sclerosis diagnosis generated field notes. The participants' main concern was how to live a life as good as possible in spite of their deteriorating health. The participants met this challenge through a process of remodelling the life course, in four phases: postponing (keeping up a normal life), adjusting (moving on to a changed life), restructuring (doing the best of it in a changed life), and transforming (preventing illness from controlling life). The remodelling process is influenced by the individual context, like the current health situation, biography, relations, and structural conditions. The process of remodelling helps us understand what facilitates and what hinders patients with MS from living a good life.

Keywords: multiple sclerosis, patient's perspective, quality of life, chronic illness, nursing, grounded theory.

Introduction

Multiple sclerosis (MS) is still an incurable and unpredictable chronic disease that is moderated by medication, and the persons' own lifelong balancing between the illness and life evolvement. MS is challenging for the persons living with MS and the health-care personnel (Maloni, 2013). For the person with MS the challenge is how to handle (manage) the unpredictable and lifelong bodily symptoms and changes, and at the same time try to live a life as good as possible within his or her own life context. For the health care personnel, the challenge is to understand the illness, the persons' own management strategies, rehabilitation, and health promotion in order to support and optimise the persons' potential to live a life as good as possible with MS (Ploughman et al., 2012).

In the study of factors, influencing healthy aging with MS (Ploughman et al., 2012) found resilience to be one of four fundamental factors "relating to the participants' abilities to adapt to changes and disease symptoms, seek out and gain new knowledge, pursue self-

therapy, deal with uncertainty, resolve problems on one's own and cope with and overcome barriers" (p. 29). Thus, understanding the subjective experience of people living as well as possible with multiple sclerosis (MS) is of core importance in nursing, medical treatment, rehabilitation, and health care planning.

Quantitative measurements of quality of life (QOL) have earlier indicated lower quality levels for people with MS diagnoses compared to those with other chronic illnesses (Benito-Leon, Manuel Morales, Rivera-Navarro, & Mitchell, 2003; McCabe & De Judicibus, 2005; Nortvedt & Riise, 2003). In contrast, a study of the relationship between QOL and coping was evaluated by McCabe, Stokes & McDonald, 2009). The study, which extended over a period of two years, revealed that people with MS increase their global quality of life over time. They experience higher psychological QOL, higher level of detachment, and are more focused on the positive coping than the general population. Studies on quality of life in MS using qualitative methods have focused (Dubouloz, King & Paterson2010; Reynolds & Prior 2003; Russel, Mark & White 2006; Somerset, Sharp & Campbell. 2002) on psychosocial processes from the patient's perspective.

Studies by Thorne and Paterson (1998), Thorne and Paterson (2000) and Paterson (2003) showed that shifting between a health and an illness perspective is common when living with a chronic illness. Focusing on people with MS, Somerset, Sharp and Campbell (2003) showed that they experience themselves as reasonably happy when they can have an impact on the illness trajectory. Reynolds and Prior (2003) reported that the central challenge for women living with MS was how to accommodate the illness and maintain an acceptable way of life. Moreover, the patients experienced illness-related changes as an opportunity for growth and development.

Although not related to MS, Dubouloz, King, Paterson, Ashe, Chevrie, and Moldoveanu (2010) described how people with diabetes and HIV go through a process of transformation by embracing the challenge, making adjustments, and integrating a new way of being, thereby generating opportunities for a good life. In this article, I elaborate a substantive grounded theory study on the process by which people with MS try to live a life as good as possible in spite of deterioration of illness.

Design and methodology

Classic grounded theory (Glaser & Strauss 1967; Glaser, 1978)) was applied to develop a substantive grounded theory on how to live a life as good as possible with an MS-diagnosis. The study was carried out in Western Norway, a high-risk area for MS (Author, 2009), in cooperation with the Multiple Sclerosis National Competence Centre.

Participants

The sample selected included a variety of factors: related to type of MS diagnosis, capabilities measured by Expanded Disability Status Scale (EDSS), duration of illness, and gender. The participants were 18 years or older and without a psychiatric diagnosis.

Ethical approval

The Regional Ethical Committee for Medical Research approved the study. All participants were informed that participation was voluntary and they were guaranteed anonymity and confidentiality. Written consent was obtained.

Data collection and analysis

Data collection and data analysis ran parallel during the two main phases. Twenty-one interviews with 17 participants diagnosed with MS were conducted in two phases by the author.

In phase one in 2000-2001, 13 interviews were carried out with 10 participants. As the incidents were coded and compared, they gave rise to new concepts and were renamed if necessary. Memos were written parallel with the coding. The analysis was characterized by constantly comparing, modifying, and renaming—not only the concepts and categories but also what was thought to be a core variable. Two other researchers also took part in the concept-development process in discussing and clarifying the new developed concepts.

Phase two, 2002-2004 in data collection process was guided by theoretical sampling, and took place until data saturation was obtained. It consisted of eight new interviews and participant observations at five courses for MS-patients.

Criteria for evaluation of a developed grounded theory

In this study, the criteria (Glaser, 1978) for fit, relevance and workability have been ensured through data collection and analysis: by constantly comparing incidents to incident and theoretical sampling (fit), by identifying main concern (relevance) and conceptualizing the pattern for handling the main concern (workability). It was further ensured by describing how the pattern of action varies with the life context of the person. With the regard to modifiability, developed concepts were altered in the light of new data through constant comparison.

The substantive grounded theory of remodelling the life course

The participants' main concern was how to live a life as good as possible in spite of the deterioration of their health. The participants met this challenge through a process of remodelling the life course—the core category in this study and explains how they solved their main concern.

Remodelling the life course has four phases: postponing, adjusting, restructuring, and transforming with distinct cutting points. However, a person can move between phases as the life context of the person changes. Four significant conditions were identified: present health situation, biography, relations, and structural conditions.

The process of life course remodelling seems to be a driving force in achieving a good life with MS. When remodelling is difficult or impossible to achieve, suffering and even suicidal thoughts can dominate.

Postponing

In the first phase of the remodelling process, participants tried to achieve a good life by maintaining their previous life course and postponing remodelling process. Their concept of life with MS can be expressed like, "I have MS and I will try to live a normal life for as long as possible". The postponing strategies are concealing, distancing and comparing with others.

Concealing is normally used when the illness is invisible. It is selective and application varies within different contact levels and relations such as family members, employers, neighbours, and society at large. Patients may tell people they are well-aware of the truth and conceal it from the everyone else.

Distancing is expressed in the hope that the diagnosis is not correct by ignoring and not talking about MS, and keeping all MS-related issues at a distance. According to one participant, "When I got the MS diagnosis, those two letters did not count to me. . . . I got a new job . . . and I enjoyed the job". Contacting other persons with MS and attending meetings in MS societies were seen as a threat to their identity as a healthy and active person. Distancing seems to allow patients time to understand life with MS and to move towards the next phase.

The third strategy which helps patients to keep up the previous life course and postpone remodelling is comparing themselves with others, both healthy people and people with serious MS. The fact that life is hard and sometimes full of challenges helps them to endure their one's own fear, and inadequacy. According to one participant, "It's hard to work full time, to have a family and children . . . . Other people complain too." This participant with invisible MS, uses a comparison strategy to hold on to her "normal" life as long as possible. Another participant considered herself lucky, compared to others who experienced worsening in the illness, and who may be suffering from constant pain.

The postponing of the remodelling process may be maintained as long as the illness is invisible to others. Hence, the consequences of postponing strategies are experienced as positive. When the patients' state of health deteriorates, they will be compelled to be open about the illness, and will start to adjust to the fact that MS influences life considerably. A transition to a new phase will take place.

Adjusting

The second phase of the remodelling process is adjusting; it appears if the illness suddenly becomes visible and the person may be forced to disclose the illness. In other situations, the transition to a new phase moves slowly as a person comes to understand that postponing strategies take most of one's energy, and leave little for enjoyment of life. The problem is no longer how to maintain a normal life but what has to be changed in life, how and when it can be done, and what consequences it will have for the enjoyment of life. The strategies that are used to adjust life course are: accepting the need for changes, developing competence to handle MS-related problems and balancing between illness issues and life enjoyment.

Accepting the changes and the fact that the illness is a part of life seems to be crucial to the process of remodelling a person's life course. If the persons cannot accept the illness and MS related changes, they will always long for their earlier life. This position will hinder them in dealing with the illness and establishing a good life in their new circumstances. A chronic illness like MS affects nearly all aspects of life in physical,

psychosocial and existential ways. Some of the complexity of remodelling a life course is evident in one participant's comment: "You lose so much . . ., but you can also gain new values by looking at life in a different way . . . from a different perspective."

Accepting the changes caused by the illness is not enough, however. Relations at home, at work, and in society also affect the process. Friends and workmates may have a problem realizing what it really means to live with MS even though they accept it as a fact. The problem of fatigue can be difficult to grasp and other people's attitudes towards MS can hinder the personal process of acceptance.

Developing one's own competence includes knowledge, attitudes, and skills to cope with various MS-related problems in various life domains. It may, for example, be important to develop skills to administer medication, self-catheterisation and to get a wheelchair or a car. However, at the same time one also has to change his or her attitude towards such activities. The change implies a shift from seeing the wheelchair as the worst scenario to seeing it as a useful means to gain control and be mobile. Competence develops through learning by one's own experience, pieces of advice from health personnel, or from other people with MS. Sources like classes on MS, rehabilitation, and printed material are also important. Furthermore, competence depends on knowledge of one's personal limits and how many activities one can handle. One participant describes the process in this way: "Nobody can take care of your life during the day; it's only you who can do it. You can ask for advice . . . but you have to do it yourself."

Developing competence is a complex and difficult process which takes time and energy and implies a lot of interaction with health-care personnel, relatives, other people with MS, and people in general. These interactions may prohibit and promote the process of acquiring competence.

As the illness becomes accepted as a part of life, and the person's capability to handle MS-related problems improves, the focus changes to a balancing process. To balance between illness issues and life enjoyment is a key challenge. To start using a wheelchair or making a conscious choice concerning work or disablement at the right time—not too early or not too late—is important. The right decision for the individual will vary depending on the illness type and severity, personal values, and life history, on one hand, and on structural conditions and his or her welfare situation on the other. A large number of persons at different community offices, and only limited possibilities to choose between job or disability pension, may make a process of change difficult to achieve in a satisfying way. Taboo about the diagnosis in society in general may also hinder or delay a person in accepting the illness and developing his or her capabilities to tackle illness-related problems and issues.

The consequences of change in the course of life are sometimes positive, negative, and ambiguous. The positive consequences are described as improved relations with a spouse, in the neighbourhood, or at work provided that there is openness, knowledge, and understanding about the illness. Openness can also clear the way for relations with people with invisible MS. During the process of change, people can experience growth and development. The statement "You have been forced to make up your mind on what to get out of your life" describes the positive aspect of change even if one were forced to it. The challenges are no longer experienced only as a threat but also as a possibility. Participants described that they had thought using a wheelchair or doing

self-catheterization were the worst things they could do. After they had started using these devices, they saw them as possibilities to decide when to go to the toilet and expend more energy to do something they liked instead of walking with crutches.

As a person develops competence to manage everyday life with MS, and the MS is in a stable phase, he or she can gradually seem to shift the focus from problems to possibilities.

Restructuring

In this phase, the illness is considered as a normal part of life; it is important to make the best of the situation by restructuring the life course. The concept of life with MS can be described as: "I have MS but I try to get the best possible out of it".

The restructuring is about how to make the best of it and the importance of focusing on life as a whole and not only on the parts of it, related to illness. One of the participants put it like this:

> I am ill. I have always thought I have MS. But I don't go around as a sick person all the time. I am ill when I have a flu or bowel infection . . . I have played down the illness.

Instead of using all energy on illness, one can now use it on life evolvement. Strategies that are applied during this phase are: focusing on values, searching for alternative activities, focusing on community, and using humour.

The strategy of focusing on values is characterized by searching for valuable experience in the past, the presence and the future. Appreciation of the past helps to live in the present. Being a father or having grandchildren will draw attention from illness to more pleasant elements of life.

Life enjoyment is an important value for some people. They can choose between strictly following diet recommendations, or making variations so they could enjoy life, with no bad conscience and fear of deterioration of health. Another participant describes how her energy rose so that she could stand up from the wheelchair at midnight after spending the evening and having fun with her friends in a MS-group. These examples show that doing desired activities generates joy and energy.

To many people, doing sports and outdoor activities is important. Such activities may be impossible to perform because of fatigue, problems with balancing, and spasticity. Therefore, people search to find alternatives that can bring them in contact with nature. "I can't walk that much but I can cycle in the woods" is one example of alternative ways. If one lives on disability pension, it is important not to stay at home all day. Meeting other people for coffee, shopping, going to the cinema or just enjoying nature brings joy to life.

Focusing on possibilities has to do with social activities and doing things with other people. Instead of having focus on their own situation, persons with MS look at community and fellowship. One can be a person who invites neighbours or relatives for a cup of coffee or goes to the theatre. To join an association of interest for people with MS may become a possibility in this phase. In the early phases, one would not take that into consideration. Attending an MS association is now considered as an opportunity to get information about MS, to meet others with MS regularly, to join common vacation trips and so on.

Use of humour is a strategy that can be used to turn negative experiences, feelings, and events into positive ones. Humour seems to be an effective way to create a relaxed atmosphere. Having a memory problem can be turned around to something with a positive aspect also. One participant started to learn a foreign language and had a positive attitude about it, even if she forgot some of it quite soon. She saw it as an opportunity to test her capability and laughed when she did not manage. Not having a job may be seen with a positive or humoristic attitude, for example "You are lucky not having to get up early in the morning and have the opportunity to use your time as you wish".

Restructuring the course of life by focusing on possibilities and making the best of it has a lot of positive consequences described as joy of life, zest of life, and courage. The joy of doing something one wants to do, being active with something meaningful, or just being happy in the company of others are some of the ways participants describe a good life. Sharing memories and pieces of experience with others, being open to support from other people in a situation of distress, or being appreciative of relatives or friends for being there to help, laugh, and joke at different illness related problems can increase joy of life and feelings of fellowship.

Ambiguous consequences of restructuring are sometimes also described as a failure in relational or structural factors. If one has been given the opportunity to work with something meaningful for a while and this activity cannot be continued because of a job shortage, one can be disappointed. If one has met the person with whom one wants to build a future and fails, the trust in other people can be weakened; it takes time to restore *it.*

Negative consequences are experienced when one has come into a vicious circle with health care personnel and feels that the need for help to restructure is not understood. Long waiting hours and shortage of flexibility in different helping instances can result in a feeling of helplessness. As we see, the surroundings can contribute in a positive or negative way when a person with MS tries to make the best of it and live a good life with MS.

Transforming

When the illness gets worse—acutely in a clinical relapse or through a steady progression—the person will again experience a challenge to keep the illness from controlling his or her life, and a shift to the next phase will take place. The transformation strategies have been identified when health worsens and fear of the future increases: Seeking a respite from the illness, being positive, hoping, and not giving in.

There are different ways to seek respite from the illness. One can be occupied with other activities; one can socialize with other people with MS in self-help groups; or one can seek help in different health care institutions like rehabilitation, MS courses, etc.

Participation in a self-help group may function as a type of safety valve for the individual. The group is the place where one can behave in a natural way, forget the illness, and vent frustration. Being at a rehabilitation unit can do "miracles". Staying in a rehabilitation unit can help the person to feel free and give a temporary respite from the illness, and simultaneously help the person start to manage some of the problems

accumulated in the wake of illness. "It was health care personnel who got going the application for the car . . . they push you and guide you how to proceed . . ." Getting free from everyday activities like housework, cooking etc. gives a necessary physical rest. A rehabilitation stay can involve family or other help units in problem solving and engagement. Last but not least, they can all get updated knowledge about the illness, medication, treatment possibilities, etc.

Another strategy used to hinder the illness from controlling life is hoping for the best. Hoping that something will happen that can improve the health situation seems to be central. Some examples may illustrate the use of this strategy. One participant said that she was able to stand the grave deterioration of her health because she always hoped that the good days will return. This was the case even if friends and family imagined that they probably couldn't deal with such a situation themselves. But it's not always easy to keep up hope, and repeated fits of deterioration can challenge even the most optimistic person. When the person succeeds to hinder illness in controlling life, he or she can carry on the fight.

The strategy that can promote hope is being positive. Working on how to tackle difficult situations can help a person develop a positive stance. Such work can be very difficult for persons with a pessimistic point of view or when they are deeply depressed. However, the difficult life situation can also bring a person to an existential decision about what he or she wants to get out of life. Low energy, fatigue, pain, and no signs of progress may lead to a point of no return: to live or die. Even if it's difficult to be optimistic in a situation when life is at stake, this kind of experience may give life a new chance. As one participant told "I decided I want to live. . .". After his decision, he got help to overcome his feeling of helplessness even if he was close to giving up. If one succeeds in keeping the illness from controlling his or her whole life, a shift of focusing on the possibilities may again occur.

Discussion

Remodelling the life course represents a conceptualization of the main concern: how to live a life as good as possible with unpredictable conditions like MS, and patterns for how to manage this concern. Remodelling the life course is a basic psychosocial process used by persons living with different types of MS. It has four phases: postponing, adjusting, restructuring, and transforming with distinct cutting points. However, a person can move between the phases as the life context of the person changes. The process is ongoing but can come to a standstill if the illness is mild and invisible to others. The balancing between MS issues and life evolvement occupies a central position in the remodelling process as long as the illness is stable. As health deteriorates, the transforming phase is used in order to make the most of life with MS.

Four significant conditions that affect remodelling the life course were identified: the present health situation, life history, relations, and structural conditions. These conditions provide an understanding of factors that may prohibit or facilitate remodelling the process. It is important to support the person during the remodelling process and to take into consideration his or her choices and autonomy. Thus, the next of kin, health care personnel, and the society at large can make a difference to promote a life that is as good as possible with MS.

The remodelling process is in line with the shifting perspectives model (Paterson, 2003; Thorne & Paterson, 1998) that describes life with chronic illness as a continually shifting process between a wellness-in-foreground and the illness-in-foreground perspective (Paterson, 2003). In the remodelling process, the illness and the wellness perspective run more or less parallel. MS patients have to take both into consideration in order to live a life as good as possible as they care for the illness issues.

The remodelling process is also in line with the transformation model (Dubouloz et al., 2010), which describes life with chronic illness like HIV and diabetes through three phases: initial response, embracing the challenge, and integrating new ways of being. The remodelling process differs from the transformation model by having four phases, mostly because of an unpredictable and uncertain illness trajectory.

Topcu Buchanan, Aubeeluck & Garip. (2016) have studied the experience of the next of kin of persons with MS and found that formal support from health professionals helped the patients' next of kin care for their loved ones. Some next of kin also report how they struggle to maintain normality in a family with a person with MS (Topcu et al., 2016). Maintaining normality is central for persons with MS as well and is consistent with the findings of Topcu et al. (2016).

Mikula et al. (2013) have studied coping and quality of life in patients with MS and report that strategies on "stopping negative emotions seems to be very adaptive for patients with MS" (p.732) and that the use of these strategies explained the most of the variance of all the coping strategies (Mikula et al., 2013). The part of the remodelling process with its strategies like concealing, distancing, being positive, hoping, and not giving in, is consistent with the findings of Mikula et al.

The need for respite in life with chronic illness has been explored by Årestedt, Benzein, Persson & Rämgård (2016). They found that three places for respite (a place for relief, a place for reflection, and place for recreation) are important for families living with chronic illness. Remodelling the life course also shows that seeking respite is an important strategy for persons with MS as well, and is especially recognizable in the transforming phase.

Audulv (2016) identified four patterns of self-management in life with chronic illnesses over time: consistent (taking medications), episodic (doing exercise), on demand (managing acute episodes), and transitional (adaptation of work and household activities). In the process of remodelling the life course, all of these four patterns are recognizable and support the developed remodelling concept in this study.

The concept remodelling the life course explains how persons with MS handled their main concern: how to live a life as good as possible. Different phases of the process are consistent directly or indirectly with the above studies in the same substantive area.

Limitations of the study

The study has been carried out with persons who more or less have succeeded with their remodelling process. A fewer number of participants did not succeed in the remodelling process. It would therefore be desirable to study the context and the experience of

remodelling the life course in people who do not succeed in living a life as good as possible with MS.

A new data collection would also benefit in order to check out the need for modification of the developed substantive grounded theory. We know that the process of diagnosis and treatment has changed with new technology. A diagnosis can now be established more quickly, and the treatment and the person's remodelling work may profit. It would also be desirable to study the concept of remodelling life course in the context of other chronic illnesses and thus develop a formal grounded theory.

Implications for practice

The concept of remodelling the course of life can be of great help for health care personnel as well as for patients in understanding what's going on in a person's life with MS, which strategies are used, how they vary, and what consequences they can bring for a good life for the individual.

These concepts can be used for screening of persons with MS during a dialog with a nurse in order to get an impression of the phase in which the patient finds himself or herself. Furthermore, they can be used in developing a program for people with MS in order to support, empower, and prepare patients to manage their own health and generate a good life with MS. The theory can further on be explored for applicability to patients with chronic fatigue syndrome.

Acknowledgements

Western Norway University of Applied Sciences, Department of Health and Social sciences, campus Bergen, have funded this study. National Competence Centre of Multiple sclerosis, Haukeland University Hospital, Bergen, funded part of the writing process.

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Comparative Failure in Science

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This article is reprinted from Glaser, B. (1964). Comparative Failure in Science. /Science, 143/(3610), 1012-1012.

A perennial problem for some scientists is their *feeling of comparative failure* as scientists. This problem becomes clearer if we consider two major sources of this feeling that are inherent in the vary nature of scientific work. (i) In science, strong emphasis is placed on the achievement of recognition; (ii) the typical basic scientist works in a community filled with "great men" who have made important and decisive discoveries in their respective fields; they are the acknowledge guiding lights. These esteemed scientists, who have attained honors beyond the reach of most of their colleagues, tend to become models for those who have been trained by them or who have worked under them. As Eiduson has put it in her recent psychological study of basic research scientists "Scientists: are idols-oriented."

To take these honored men as models is important for training as well as for a life of research. During training, one learns to think creatively. Emulation of these models results on the internalization of values, beliefs, and norms of the highest standard. This emulation of the great continues and guides the scientist in his research work, however individual in style his work may be.

But it is precisely here that a feeling of comparative failure may arise. In emulating a great man the scientist tends to compare himself with the model. He estimates how closely he has equaled his model in ability to adhere to high standards of research, to think of relevant problems, to create "elegant" research designs, to devise new methods, to write clearly, to analyze data. In addition, because of the strong emphasis on attaining recognition for research contributions the scientist perhaps will compare his own degree of success with his model's to gauge how he himself is doing. In using the great man's achievements and the recognition accorded him as criteria, the scientist may be motivated to strive continually and unremittingly towards greater heights. On the other hand, he may see himself, over time, as a comparative failure for not having attained a comparable amount of recognition.

Eiduson brings out the dynamics of this problem for scientists:

The model, then, is the ego ideal figure who represents the ultimate position, and in fact, defines what a scientist should do, how he should think, how he should act. *By comparison, everything else is inevitably of lesser worth* [italics mine]. We have seen the way scientists in this group rebuke themselves as they become old, distracted, sit on committees or government advisory boards, or become administrators- and thus move away from the ideal. From this picture it is obvious that the scientist is hard on himself. He has a built-in, clearly marked scalar system, along which attitudes and kinds of performances are measured. When he moves away and deviates from the pattern, he becomes a maverick, or a person who has tossed aside the flaming torch.

Average success

With this basic problem in mind, I recently made a study of the organizational careers of basic research scientists, one purpose of which was to ascertain the consequences, for the scientist's career, of receiving or not receiving an average amount of recognition: At the time of this study, these scientists were employed in a government medical research organization devoted to basic research. This was a high-prestige organization from the standpoint of scientists and was run much as though it were a series of university departments. The study is relevant to this discussion in showing something of the career history of basic research scientists, who are today affiliated with high-prestige organizations devoted to basic research. In these contexts organizational scientific careers are still primarily dependant on professional (not organizational) recognition.

By "average amount of professional recognition" I mean supervisor's favorable evaluation of the quality of the scientist's current research, and proper credit, through publication and through acknowledgement in the publications of others, for his contribution to the cumulative knowledge in his field. This definition gives three major sources of recognition within reach of the typical scientist; references from superordinate colleagues, publication, and publication acknowledgements in the work of others. This "average" degree of professional recognition is attained by most of the country's scientists at any one time and by practically all scientists at one time or another. This degree of recognition is in marked contrast to the highly regarded, and restricted, high-prestige honors (in the form of awards, prizes, grants, lectureships, professorships, and so on) that are part of the professional recognition accorded those scientists who make great and decisive discoveries- the "great men."

Three general aspects of scientists' careers were studied: performance; security in, and advancement of, position; compatibility with others, and satisfaction with one's location in science. With respect to performance, an average degree of recognition was found basic to high performance. That is, recognition maintained high motivation to advance knowledge, and high motivation resulted in the scientist's devoting more of his own time to research; this, in turn, resulted in high-quality scientific performance, as judged by the researcher's closest professional colleagues.

Since, of course, such performance on the part of many individuals is the basis of organizational prestige; it was not surprising to find the organization providing, in return, a stable scientific career for a scientist who received average professional recognition. The scientists accorded this degree of recognition, in contrast to those accorded less, felt more satisfaction in their jobs and salaries. They tended to be more optimistic about their chances of promotion, and their rate of promotion was higher. With respect to the conditions for research – a most important consideration for basic-research scientists – they fared considerably better than scientists not accorded average recognition. They had more freedom to work on their own ideas, had more chance for originality, had more chance to use their current abilities and knowledge as well as to gain new abilities and knowledge, and had generally better research facilities and supplies. In sum, the "average" recognition accorded them was sufficient to give them security and advancement in their scientific careers.

Lastly, with average recognition, the high quality performance and steady advancement could be achieved in a setting that provided personal satisfactions. The scientists accorded average recognition, again in comparison to those accorded less, were more content with their research and nonresearch colleagues. More of them felt intense interest in working with close professional associates. They were more satisfied with their assistants and with the other scientists, the organization leaders, their own supervisors and the directors of their particular institutes. They felt strengthened through belonging to work groups, such as sections and laboratories. They depended more on personal contacts for scientific information, both inside and outside the organization. They participated more in seminars, meetings, and the activities of professional clubs and other small groups.

Closely linked with this compatibility with their associates was a satisfaction with their location in the community of organizations of science. The scientists accorded average recognition, in comparison to those accorded less, felt strongly attached to their respective institutes and organizations. Indeed, they felt more satisfied with the organization's reputation in the scientific world, and more of them felt that a sense of belonging to an organization which had prestige in both the scientific and the general community was of utmost importance. In comparing their own organization (from the standpoint of what job factors they deemed most important) with the "best" universities, hospitals, industrial research organizations, and government research organizations, more of them consistently reported that their organization was generally better. In sum, the context of their careers in science was highly favorable.

Together these findings suggest that an average amount of recognition has a generally stabilizing effect for the careers of the scientists within the high-prestige organization of the study. (Even for individuals who received little or no recognition, the pressure on careers was not so great as to cause an exodus from the organization or from science itself. The great majority of these men thought the lack of recognition was only temporary and planned to continue in the organization, trying to advance knowledge.)

These findings suggest that career stability based on average professional recognition is probably found in other organizations similar in nature to the basic-research organization of this study, and that in organizations of lesser standing even less recognition may assure career stability. In the light of these findings it appears that the feeling of comparative failure that may result when the average scientist judges his lesser success by the considerable success of his "great man" model tends to occur in many instances within the context of a stable, promising career. Further, most scientists can gain, if they do not have it currently, the degree of recognition necessary for a stable career. Comparative failure, then, is an evaluation resulting from a social comparison. It is not to be taken as an absolute failure (loss of position as a scientist). A comparative failure can still be successful; an absolute failure is through.

The scientific career: A carnivorous god?

Comparisons with great men are, however, taken not as comparative but as absolute failure by Kubie in his famous "Some Unsolved Problems of the Scientific Career." Kubie warns future scientists of the perils ahead when devoting themselves to that "carnivorous

god, the scientific career." His criteria in warning of potential failure are absolute (not comparative) judgments, based on the careers of the more notable great men of science. For example, he talks of the "ultimate gamble which the scientist takes when he stakes his all on professional achievement and recognition [italics mine], sacrificing to his scientific career recreation, family, and sometimes even instinctual needs, as well as the practical security and money." Implying again that the scientist whose success falls short of the great man's is an absolute failure, he characterizes the young scientist as having "a self deceiving fantasy: that a life of science well may be tough for everyone else, but that it will not be for him," and as having "ambitious dreams; unspoken hopes of making great scientific discoveries; dreams of solving the great riddles of the universe."

Kubie states that the young scientist "dreams unattainable dreams." More directly relating his judgments to great men, he cautions against choosing science as a career, because of the "many failures it took to make one Pasteur." He states that most young scientists, in using great men as models, unwittingly set themselves up to become failures: "…most young men view the prospect solely by identifying with the most successful chiefs, never stopping to consider how many must fail for each one who reaches this goal." Without making the distinction between absolute and comparative failure, this last statement clearly implies the former.

Admittedly, from this standpoint man must fail and few will attain the stature of their models, but this is hardly a reason for dissuading young men from becoming scientists. The chance is slight that they will equal or surpass their models, but they should be informed that most can gain the fundamental degree of recognition indicated in my study as necessary for a promising career in science. Surely the career to which they commit themselves need not be as Kubie says, "devoid of security of any kind, whether financial or scientific."

Furthermore, these young men should be encouraged to enter science and take great men as their models, for most will be the artisans who do the commendable, but not the earthshattering, research which accumulates to form the foundation for future decisive advances. Kubie himself has recently, although somewhat ambivalently, recognized this, in comparing the typical scientist with the internationally famous scientist. "These little known and unrewarded men are the expendables of science. They are no less essential than are the few who reach their goals. Therefore, until many years had passed it would be hard to weigh which of these two men had had the more profound impact on scientific knowledge."

Perhaps my discussion draws the kind of "implication" from "statistics" that Kubie is looking for in future research when he says in his article on the scientific career: "It is the…duty of scientists and educators to gather such vital statistics on the life struggles of a few generations of scientists and would-be scientists and to make sure that every graduate student of the sciences will be exposed repeatedly to the implications such data may have for his own future." Career decisions are perhaps among the most important determinants of a man's fate, and anything which contributes to an understanding of the career in science may help people make these decisions more wisely.

References and Notes

1. Merton accounts for this in the following manner:"…originality can be said to be a major institutional goal of modern science, at times, the paramount one, and recognition for originality a derived bu toften as heavily emphasized goal" [R.K. Merton, *Am. Sociol. Rev*. **22**, 640 (1957)].
2. B. T. Eiduson, *Scientists: Their Psychological World* (Basic Books, New York, 1962).
3. See O. Klapp, Heroes, Villains and Fools (Prentice-Hall, Englewood, N.J., 1962), pp 18-24 for some functions of role models. I have reference to the function of "providing the individual with self-images and corresponding motivation."
4. In their comprehensive statement on careers, Becker and Strauss note the relative nature of failure: "Of course, failure is a matter of perspective. Many positions represent failure to some but not to others" [H. S.. becker and A. Strauss, *Am. Sociol*. **15**, 257 (1956)] The relative nature of failure can be seen in marked contrast to its absolute nature when a person simply has failed to keep a position. On absoulte failure, see E. Goffman, *Psychiatry* **62**, 451 (1952).
5. B. G. Glaser, *Organizational Scientists: Their Professional Careers* (Bobbs-Merrill, Indianapolis, 1964)
6. C.V. Kidd, *Personell Admin*. 15, No. 1, 16 (1952); W. Kornhauser, Scientists in Industry (Univ. Of California Press, Berkeley, 1962), pp. 131-133.
7. L. S. Kubie, *Am. Scientist* **41**, 596 (1953); Ibid. **42**, 104 (1954) [reprinted in M. R. Stein, A. J. Vidich, D. M. White, *Identity and Anxiety* (Free Press, New York, 1960) and in B. Barber and W. Hirsch, *The Sociology of Science* (Free Press, New York, 1962)]. The remarks by Kubie are base don 30 years' observation. He sees these observations as "random," but their concistently negative character suggests that, by and large, they are observations of his analysands and are random only in that context. My references are to bu tone short section of an excellent article.
8. _____, *Daedaulus **91**,* 304 (1962).

Growing Grounded Theory: Doing my Bit

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In Glaser's recent book, *The Grounded Theory Perspective: Its Origin and Growth* (2016), Glaser writes of how he recorded and explicated the grounded theory perspective and disseminated the perspective as the grounded theory general method of research, over a period of 50 years. During this period he has monitored its use, embracing procedural developments (e.g. Nilsson, 2011; Scott, 2011), whilst vigorously defending and differentiating the grounded theory perspective from adaptions (e.g. Glaser, 1992, 2002). A scholastic endeavour of monumental proportions.

Over the decades, his key tools in achieving the phenomenal worldwide growth of grounded theory[1] are his books and troubleshooting seminars. In this way, he empowers an army of PhD students to spread the use of grounded theory wider still. The result is the continuing diffusion of the grounded theory method geographically and across disciplines including medicine, business, technology, journalism, psychology, international relations, and education and many more substantive areas of interest, including construction, caring professions, careers advice, prison life, de-radicalisation, living on a volcano and so on.

Since learning how to do grounded theory is best achieved by experiencing the method, a key teaching technique used in both books and seminars is "exampling". In his readers, Barney publishes grounded theories that represent the current frontier in grounded theory research. Novices are encouraged to read the theories to develop understandings about how grounded theory studies are conducted and constructed i.e. to identify the theoretical code(s) which model the substantive codes and to experience how the theoretical codes shape the presentation of the theory. In seminars, exampling helps the novice GT researcher envision the trajectory of their own grounded theory by working with other grounded theories at later stages in the development process. Additionally, in hearing of the procedural issues of other participants, novices are able to anticipate or notice their own procedural issues. In discussion, novices also learn how the procedures support the grounded theory perspective and how modifying procedures can, wittingly or unwittingly, compromise the grounded theory perspective.

Encouraged by Glaser, several of his troubleshooting alumni now also publish books (e.g. Gynnild & Martin, 2011; Holton & Walsh 2016) and run seminars: Hans Thulesius and Anna Sandren run troubleshooting seminars in Sweden; Foster Fei runs seminars in China and Tom Andrews and I run seminars in Ireland, the UK, Malta, and Australia.

[1] Year ending 2 June, 2017, www.groundedtheoryonline.com received visitors from 199 countries who made over 150,000 page views, spending on average over 3 minutes on each page. Source: Google Analytics.

One of my problems when learning grounded theory was that coming fresh to grounded theory as a novice PhD student from a department dominated by quantitative methods, much of what I read in Glaser's writings was telling me what grounded theory was not: the issues that were being defended or differentiated were not my issues. I needed to know what grounded theory *is.* This has led me, in my methodological mentoring work to focus on the grounded theory research *process*. This approach works well and has supported my mentees in their development of some truly excellent grounded theories (Krieger, 2014; Stevens, 2015).

My natural style is one of facilitation rather than teaching and I prefer to model grounded theory practices. If a mentee feels a need to compromise a procedure (such as using a structured interview design for collecting data at interview) I take care to explain how that will inhibit development of their grounded theory and example how I would approach the issue. I focus on practical matters of progress.

Previously I have had little patience with what Glaser (1998) terms the "rhetorical wrestle" (p. 35) preferring to focus on the positive. However, reading Glaser's book (2016) has led me to understand that this impatience is not a reason for not engaging with the GT perspective and I now realise that I need to situate my explanations more securely in a discussion on perspective. I need to expand my repertoire.

What I find particularly liberating however, is that I now also have a conceptual tool for differentiating the method, for handling challenges to and questions of the method. Henceforth I shall attempt an approach of assessing and responding to an issue in terms of its impact on the GT perspective, as well as relating the issue to its impact on the progression of a study. Specifically, I shall reassess my understandings of the differences between Strauss and Corbins' and Charmaz and Glaser's works.

But what are the grounded theory perspectives?

As far as I can tell, the grounded theory perspectives include: emergence, researcher autonomy, conceptualisation, procedures, and generality. Corresponding risks to these perspectives include: forcing, compelling and rescuing, description, jargonising and perhaps specificity (unit based explanations). Are there more?

I would also like to understand more about the structure of the grounded theory of grounded theory and how the concepts relate to one another. Perhaps Dr. Glaser, you would write us another book?

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The Discovery Power of Staying Open

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Glaser (1978) emphasized three foundational pillars of GT that must be respected: emergence, constant comparison, and theoretical sampling. While many qualitative researchers who claim to employ GT will assert their use of constant comparison and theoretical sampling, there is much less clarity around claims to respecting GT's emergent nature. Emergence necessitates that the researcher remains open to what is discovered empirically in the data "without first having them filtered through and squared with pre-existing hypotheses and biases" (Glaser, 1978, p. 3) or theoretical frameworks drawn from extant theory. In many qualitative studies, however, emergence is restricted to the analysis phase (e.g., Corley & Gioia, 2004) and with data collection framed through an initial review of the literature (e.g., Partington, 2000), articulation of specific research questions or interview protocols for "consistency" (Xiao, Dahya, & Lin, 2004, p. 43).

Staying open to emergent patterns in data offers surprising and exciting theoretical discoveries—what Glaser has termed the Eureka moment. Even in studies otherwise framed with some level of preconception, as typical of most qualitative research studies, it is possible to remain open to such discoveries. This was the case in a research study conducted in 2010-2011. The focus of this study was a leadership development needs analysis for a health services organization where leadership was aligned with fostering a healthy workplace. The intent of the study was to explore the perspectives of middle managers regarding the overall organizational climate and their leadership development needs. A qualitative approach was adopted with semi-structured interviews to elicit a variety of experiences, directly and indirectly related to leadership development needs. Thirty-two middle managers participated in the interviews. Detailed findings were shared with the organization and also published (Grandy & Holton, 2013a, 2013b).

As a grounded theorist and a co-investigator in this study, what interested me most as the interviews progressed were moments of self-reflection in which verbal confessions and body language revealed a growing discomfort and realization of disconnect between espoused corporate messages about a healthy workplace, their experience of the organizational culture, and their own realized unhealthy work practices. While the organization and we as researchers were focused on identifying key leadership development needs, the grounded theorist in me recognized that this felt disconnect—not leadership development—was the main concern of these middle managers. I wanted to explore this idea further.

Following completion of the initial study, we went back and selectively coded the data to better understand this discovered main concern, subsequently developing the concept *voiced inner dialogue* to explain how managers are able to surface and process the

disconnects they experience between the espoused goals of the organization and their own lived experiences of those goals. We identified and elaborated voiced inner dialogue as a three-stage process:

Reacting, not reflecting

Reacting, not reflecting wherein managers simply react in accordance with organizational norms and espoused values without stopping to reflect on the appropriateness or feasibility of such norms and values, particularly when attempting to demonstrate leadership in a context of constant crisis and "putting out fires" typical of most health care organizations. These "go, go, go" cultures are reactive, not proactive; there is no catching up, no opportunity to be strategic; timelines are short and imposed deadlines unreasonable. In reacting, not reflecting managers assume responsibility for this disconnect by questioning their own competence as effective leaders.

> "I find the more I model this go, go, go, go they [subordinates] pick up on it …. I shouldn't underestimate the barometer that I am because when I'm all wound up they are so I try really hard" [quote].

Noticing cracks in espoused values and lived experiences

Conversational norms in organizations have managers holding to the organization's espoused rhetoric while simultaneously concealing and rationalizing their lived experiences and struggling to balance professional demands with personal well-being. Unhealthy practices are those that consciously or subconsciously blur the lines between work and home: covert catch-ups such as arriving at the office an hour early to check voicemail, email, and sign papers; taking work home each night; heading to the office over the weekend; perpetually checking phones during off-hours; continuing to 'spin' with thoughts of work while being physically present at home; and, waking through the night to check for messages. As managers begin to acknowledge the obvious disconnect between these practices and the organization's espoused values of a healthy workplace, they give voice to an inner dialogue that shifts from self-criticism to critically questioning the appropriateness of organizational expectations and the assumptions that underpin them:

> "So, it's cultural – you are expected to do it… you know I put in many, many hours of overtime. I would describe myself as a workaholic and I realize that my work ethic isn't healthy and I wouldn't condone it on anyone" [quote].

Questioning the implications for leading and living

By giving voice to inner dialogues, managers create space for questioning the implications of dysfunctional organizational expectations and their individual responses to such expectations. Doing so enables reflexive thought and the possibility of realigning their actions in setting priorities and negotiating reasonable timelines; in finding a balance between seemingly endless work pressures, personal wellness and family commitments; and, in finding time to simply reflect and retain some perspective amidst the persistent turmoil.

> "You have to be thinking about whether or not when you go, go, go is it really working for you – is it beneficial. I think it is a hard environment not to overwork" [quote].

General implications of voiced inner dialogue

While voiced inner dialogue emerged in a health care context, hectic work cultures abound in the 21st century where the precarity of work has rendered many employees silent in response to unrealistic organizational demands and expectations. With the increasing value of human capital in knowledge-intensive organizations, unexamined organizational ethos, and expectations have considerable potential to undermine employee effectiveness as well as their health and well-being. As Morrison (2011) suggested, "voice" has important benefits for organizations [and employees] while silence can have significant negative effects. While managers may engage in a high level of voice in general, as is expected in their roles, they may at the same time remain silent on other issues (Morrison, 2011). The unwillingness to speak up stems from a belief that it is inappropriate, wrong or out of place (Detert & Edmondson, 2011) and that raising issues related to their own health and well-being are inappropriate in times of severely constrained resources and increasing demands. Self-sacrificing is the "appropriate" response; the resultant silence perpetuates dysfunctional behaviours that undermine personal wellbeing and organizational productivity.

Our concept of voiced inner dialogue suggests that time for self-reflection triggers an inner dialogue that enables managers who are stuck in the silence of "interpersonal mush" (Bushe, 2009, p. 49) to consider automatically-evoked beliefs and habituated behaviors and to transform their responses to better align personal values with those espoused by their organizations. Listening for voiced inner dialogue is a crucial first step in resolving at least some of the stresses and tensions of leading and managing in today's increasingly complex organizational environments. Once voiced inner dialogue is triggered, the choice to remain silent however becomes a conscious choice (Morrison, 2011); one that merits the attention of any organization espousing the desire to promote a healthy workplace environment.

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Offsetting the Affective Filter

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Abstract

When forced to deal with a stressful, unfamiliar situation, how do people react? People are familiar, in a traditional setting, with sensory overload. But in an online environment, when learners are anxious, they exhibit different behaviors to help mediate their anxiety. Additionally, in an online environment, since visual clues are often lacking, how do these behaviors manifest themselves? People navigate stressful and/or unfamiliar situations by offsetting their affective filter.

Keywords: online foreign language, anxiety, discomfort, affective filter, unfamiliar situations

From 2012 to 2013, I interviewed 15 online foreign language students from various U.S. post-secondary schools. Through the constant comparison of data (Glaser, 1965), I developed a theory, offsetting the affective filter, to explain how learners behave (Glaser & Strauss, 1967) as they try to address their main concern of coping with the anxiety of navigating a stressful and/or unfamiliar situation (i.e., successfully completing their online foreign language course). Since no research exists on situations causing people anxiety—and no substantive theories in foreign language—this theory helps bring foreign language "grand theories" (Glaser, 2002, p. 32) into the 21st century while filling a gap in the literature.

Background

When people step out their comfort zone, anxiety and imbalance exist. In such situations, a realignment is necessary. If a re-balancing does not occur, the tasks cannot successfully be completed. Life is, as one participant said, about balance and deciding "what are you willing to risk, walk away or slug through."

Because online learning is relatively new (Chametzky, 2016), learners studying foreign languages online are often anxious as they do not know the environment, what to expect in the class, or know the target language. This "lack of familiarity" (according to participants) and anxiety lead to an increased affective filter—the invisible psychological barrier that raises or lowers depending on a person's stress level thereby potentially preventing or severely limiting interaction with the task at hand. A clear relationship exists

between the psychological situation (getting out of one's comfort zone), the consequence (high anxiety and limited interaction with the material in question), and any possible "connected variables" (Glaser, 1978, p. 74).

Offsetting the affective filter

To offset an affective filter, participants demonstrated several behaviors: (a) isolating, (b) interacting, (c) motivating, and (d) settling. If none of these behaviors sufficiently helps, then the person quits.

Isolating

In an environment where individuals' senses are overloaded, they tend to isolate themselves as they process the information that overloads them. The proposed cognitive limit of 7 +/- 2 is described in Miller's (1956) cognitive load theory. Yet, in an online environment, cognitive overload happens more easily and quickly because fewer senses are engaged than in a traditional learning environment (Cook, 2012). Participants commented that they are "thrown so much [they] couldn't internalize" it all. Without the skills to navigate the obstacles of a stressful environment like an online foreign language class, and extricate themselves from the quandary caused by a high affective filter, learners isolate themselves.

Interacting

When people are "feeling the strain and stress" (according to a participant), two types of interaction help them overcome an elevated affective filter: (a) verbalizing and venting and (b) peer sharing. Since they form a yin and yang, either or both behaviors may occur.

Sometimes when people are under stress, they cannot verbalize their concerns. They might not be able to process any information cognitively because either the filter is too high or other external or internal issues exist. Such frustration leads to feeling helpless. Putting into words a person's feelings is necessary to offset the affective filter because it "converts" emotions into cognition. By verbalizing and venting their concerns to anyone who will listen, people can expel some of their tension (Thomas, Cassady, & Heller, 2017).

Another way that people relieve anxiety from a high affective filter is through interacting with people who are in the same or similar situation. According to a participant, though peer sharing can result in exchanging ideas, "they could be confusing." Yet, being engaged with peers promotes in-depth learning (Chametzky, 2014) and aids people in connecting with the information on a more personal level. Thus, peer sharing "[pulled] the class together" for participants. Without the "give and take," according to one participant, learners—and people in general—are disadvantaged.

Feeling motivated

Being motivated and focusing on the objective can help decrease stress and anxiety.

Sometimes it is motivation that propels a person to succeed (Yalof & Chametzky, 2016) and "get as much as [he or she can] out of" the situation despite its challenges, as one participant stated. Another participant stated that the "course made me adventurous and interact with others." Being motivated—due to eustress (Iqbal & Kokash, 2011)—allows people to take responsibility for the situation and feel emboldened despite feeling like a "fish out of water."

Additionally, in an online environment, because learners can, in their words, work "at [their] convenience" and at their own pace, they are more easily able to self-direct their learning at a convenient time than in a highly-structured environment. People are motivated, according to participants, when they can "work it [the online class or task]" into their schedules and around the "cracks of [their] life." Thus, an online environment allows people to get "as much as [they] could" provided that they were ambitious.

Settling

When a person realizes that the situation is sub-optimal, the individual settles by plodding through, adapting to, and/or hyper-focusing on the material or task. If everything fails, the individual gives up.

In challenging situations, people need to be adaptable. If something does not work one way, according to participants, it is important to make "the most of it [the situation]," go "with the flow," or try another avenue; it was not "the end of the world" if something was amiss. People can adapt through self-negotiation; as one participant stated, "What am [I] willing to risk?" When the benefits of accomplishing the task outweigh the risks of not doing it, people adapted.

Occasionally, people need to accept the fact that the situation does not meet their expectations. Respondents came to this realization by being myopic and hyper-focusing "on one assignment [or task] at a time" rather than being overwhelmed with the "big picture" or their misguided expectations. Such myopia helps people reduce anxiety and sensory overload.

If a high affective filter cannot be alleviated because of the sub-optimal environment or situation—perhaps because there is "too much to deal with," or the individual does not have "personal drive," the task will be discontinued. For example, when respondents found technology to be insufficient, challenging, or inadequate for their needs (Saba, 2011), they stopped using it. Likewise, if people find that the task or situation does not meet their needs, they quit.

Implications

With online learning being a stable, permanent part of 21st century learning, educators and researchers need to explain why attrition is high and students disengage from their learning. With a greater understanding of why learner disengage—and the anxiety-reducing

manifestation of offsetting the affective filter, remedies can be put into place to help increase retention in post-secondary online courses.

Conclusion

An online course is a microcosm for life: each person's experiences are unique and varied. Additionally, lowering anxiety and the affective filter occur in different fields and walks of life, for example in medicine as students try to succeed in medical school, at job interviews when candidates are insecure, with visitors to a new country, and so on. Offsetting the affective filter is not a one-step, linear process; it requires people to employ different strategies depending on external and internal influences that exist at any given moment. Regardless of the techniques employed, the objective is to reduce the anxiety and vulnerability and regain balance so the person can successfully navigate the situation.

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Intellectual Autonomy of PhD Researchers who use the Grounded Theory Methodology

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Abstract

The decision to choose the grounded theory methodology (GT) for one's PhD research should never be done lightly, as outlined in Glaser (2015). The emergence of a researcher's own intellectual autonomy is often of more importance than the research itself. Intellectual autonomy can be fostered perpetually and spasmodically.

Keywords: intellectual autonomy, grounded theory, perpetual fostering, investigating, negotiating.

Perpetual fostering

Intellectual autonomy can be fostered perpetually in three main ways; discovery of "voice", investigating, and negotiating. Intellectual autonomy involves the discovery of one's own "voice" without arrogance but with humility.

The PhD researcher should never bury missteps in the PhD thesis. Instead write about them and explain how they arose and then the means with which they were dealt. The formal acknowledgement of these errors is always an indicator for the PhD committee that researcher's intellectual autonomy has emerged.

The process of intellectual autonomy begins when the researcher starts understanding, by discovering his own "voice", by critically reading the published works of others. The researcher has to delve beyond the descriptive narrative and begin to tease out the more fundamental deep-seated concepts that underpin the research of others. This approach will also reveal the line of argument being used by various authors. Glaser (1978) emphasized the importance of the GT researcher being able to develop theoretically sensitivity. Put very simply, this means that the researcher has to go directly to the ideas and concepts that underpin the research.

Investigating

Before embarking on any PhD research, it is the researcher's task to demonstrate his intellectual autonomy by using due diligence.

It is the duty and responsibility of the researcher to choose the location where the GT PhD will be registered. This issue is not just administrative; this is because the researcher should be cautious of naively assuming that all research environments are likely to be equally competent and intellectually stimulating.

Find a university that is tolerant of an inductive research design. The dominant research paradigm in academia is the deductive hypothesis approach. Many universities automatically assume that all PhDs will always follow this path. This has the potential to be problematic for the GT PhD researcher because GT research is principally an inductive research method. An online research will reveal the attitude of different universities to inductive research based PhDs. Be wary of universities who compel PhD researchers to use the identical chapter headings and structure regardless of the type of research method being employed. Do remember that what is considered to be the appropriate structure of a PhD is highly variable even at the same university. If a PhD researcher is already signed up to a university with an inflexible system, it still might be possible to do a GT PhD. The workaround is called "the retro fitted PhD". Here the GT PhD researcher faithfully follows the tenets of the authentic GT research method that will result in a robust core variable. Then return to the rigid PhD structure that the university has imposed on the research and repackage the legitimate GT PhD research into the thesis format retrospectively. However, what frequently happens is that when the supervisors read the GT research they often are so impressed by the research that they find ways in accepting the authentic GT PhD structure.

The Conventional full-time PhD

Younger novice researchers may wish to opt for a PhD process that pays the annual registration fee as well as income from teaching at a university. Apart from the obvious financial advantages of this type of PhD process, there are several negative aspects. The problem is that it can be extremely difficult to develop and maintain one's intellectual autonomy if one is being employed by the university to fulfill other tasks. The anonymous (2010) author from The Economist has also cited this as one of the main reasons for dissatisfaction and PhD completion failures.

Conventional part-time PhD

The type of PhD is widely used by researchers who already have their own careers that they do not wish to terminate. There are some negatives in this part-time route. The PhD research is in danger of academic isolation. In Europe and the U.S., a part time PhD registration period can range from 3 to 6 years to complete. In many parts of Asia taking 10 years to complete a PhD is not considered unusual.

Online PhD supplemented by formal training

This system of doing a PhD can work well if the university has a robust support system in place. The Open University in the UK is a good example of how this can work well.

Totally online PhD

This route to the PhD is not recommended because few PhD researchers would be able to develop their own intellectual autonomy in a vacuum.

The investigation of the formal role of the PhD research proposal must be an early priority.

The vast majority of universities have specific requirement that before the researcher is formally enrolled to a PhD degree a formal written research proposal be submitted. The prospective GT PhD researcher should understand the real significance of

this document. It is much more than just a bureaucratic requirement; in certain circumstances it can shield the researcher from ill informed criticism as the research progresses.

Negotiating

The GT PhD researcher should feel comfortable about having frank negotiations with a potential PhD supervisor prior to signing up for the PhD. The PhD researcher should always be the client; the supervisor and university are the service providers. Frequently PhD researchers view things from a reverse perspective, which is not going to enhance their own intellectual autonomy. The GT PhD researcher should begin the process and be prepared to dialogue with potential PhD supervisors *before* committing.

Negotiating the PhD researcher's approach to the final PhD committee

The GT PhDs researchers' opportunity to present their thesis to a committee of experienced academics should be viewed as a being a very positive experience. Once the PhD is completed, there will be no other person in the world that knows as much about the thesis than the PhD researcher.

Spasmodic fostering of the researcher's intellectual autonomy by publishing throughout the PhD process

To spend time and effort carrying out research that is never published is an indulgence. One's intellectual autonomy can only flourish through publication. The act of writing for publication accelerates and clarifies one's thought processes. Most of us only think with clarity once we had externalized our thoughts through writing.

Intellectual autonomy starts with developing theoretical sensitivity, prior to doing the research, and ends with a robust defense of one's own thesis to the PhD committee.

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Rethinking Applied Economics by Classic Grounded Theory: An Invitation to Collaborate

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Introduction

The heading of this paper refers to an issue that so far remains unaddressed by classic grounded theory (CGT) researchers. The aim of this paper is to take a closer look at the accordance between the CGT methodology and the field of applied economics (economic policy-making).

The goal is NOT to present a finished theory; the purpose is to briefly discuss the main concern and to suggest some possible properties of the recurrent solution of the main concern (the core variable) within the field of applied economics.

The paper is based on some open coding of sampled data. These data came from interviews with leading politicians with economic responsibilities, memoirs, and published diaries of leading economic politicians, and a selection of popular books written by leading economists.

The procedure of memo writing has been used to a limited extent, but no sorting of memos has been made. Selective coding has not yet begun. This means that the work is far from finished. It has hardly begun. Thus, it is far from possible to present an entire classic grounded theory. I can only present some initial theory bits that relate to the discovered main concern. This paper is also an invitation to collaborate, see the epilogue.

Two most different methodological approaches

The methodological approach of generating and presenting economic theory by classic grounded theory (CGT) is very different from the conventional economic approach.

Neoclassic and keynesian economics are both normative. These approaches focus on what should be done, and how. Mainstream economics is based on the assumption that the behaviour of economic agents follows the rule of "rational choice" (optimizing), and that the actual behavior of economic agents should follow this rule.

CGT methodology on the other hand is not normative in the same sense. Use of the CGT methodology means that focus will be on actual behavior (what people actually do) and how to explain this actual behavior. No apriori assumptions are made regarding this actual behavior. Discoveries regarding this actual behavior that are grounded in the data may be used at a later stage as a guideline for problemsolving within the field of study (i.e., as "grounded action").

"Schools" of economics

A distinction can be made between present-day mainstream economics (typically neoclassic and neoclassic-keynesian synthesis) and different smaller schools of what we can call "minorstreams economics". These "streams" can typically be identified by the journals, where the respective research is published.

One illustrative example of such a "minorstream" is the approach of Daniel Bromley (2006). Bromley challenges the prevailing economic assumption of "rational choice" of economic agents (optimization), and he offers an alternative evolutionary model of pragmatic human action, where individuals "work out" their desired choices and actions, as they learn what choices are available. Bromley's methodological perspective of "volitional pragmatism" builds on the work of Charles Sanders Peirce and his abductive approach. For Bromley (2006), the most fundamental human need is not eating, drinking or obtaining shelter, but concerns "what to believe" (Ibid). Nevertheless, Bromley's approach just replaces the "rational" choice assumption with the assumption of "volational pragmatism" – i.e. so far, the methodology is not so different from the mainstream.

Methodologies: Better or worse?

Despite this difference of methodological approaches, it would be too brash to claim that the CGT approach is better or worse compared to other approaches. CGT is just different.

From the perspective of a CGT researcher, CGT also becomes justified because it is "different". That it is "different"—and thereby justified—means that it can possibly shed light on some issues that constitute a "blind spot" for other approaches. It can be vice versa, when the neoclassic approach is preferred over the CGT approach.

One main difference between these two approaches is (a) the a posteriori (dependent on grounding in the data) and initially assumption-free approach of CGT, as opposed to (b) the a priori (independent of grounding in the data) and assumption-bounded approach of especially neoclassic economics.

From preconceptions to discoveries – from logical deductions to empirical discoveries

When governments appoint commissions to resolve a particular task (for example, reform issues, a new IT system, digitalization, etc.), these commissions typically follow the neoclassic methodological approach, and the terms of reference (task, mission) typically preconceive "the problem".

An alternative use of the CGT methodology would mean that the first priority should be given to the suspension of preconceptions, and next priority should be given to the discovery of the most important and problematic for those who have a stake in the solving of the task. This latter has to be discovered from a systematic treatment of the data.

The main concern of sustaining employment

Those who have most at stake in the economic policymaking of a country are politicians with special economic responsibilities, the electorate, and professional economists as civil servants. Data have only been collected from these three groups of stateholders. University economists with research responsibilities have not been included[1].

What is at stake is different for these three separate groups of stakeholders. Nevertheless, the main concerns regarding economic policy-making are the same. They are worries about "sustaining employment" mostly in the short term, but also in the long term.

During the periodic business-cycle-dependent waxing and waning of the economy, periods of labour shortages can be just as problematic and relevant as periods of unemployment. Experientially, labour shortages follow periods of unemployment and vice versa. Usually, what is problematic relates to the employment of people (labour), but occasionally there are also concerns about the employment of capital, when this employment is associated to the employment of people.

The impact of employment/unemployment

The importance of work and employment for society, the economy, and the individual can hardly be overstated. In the US, the "king" of economic indicators is the monthly job report. The employment/unemployment number is also the key indicator of the "location" of the economy on the pattern of the business cycle. The importance of employment for the self-worth and self-identity of the individual is obvious.

The balance of governmental finances is highly dependent on the employment/unemployment situation. When people proceed from no work to work, this has a "double effect" on the public finances—governmental expenditures decrease, and govermental taxing incomes increase. It is vice versa, when people lose their jobs. The effects of unemployment on private consumption and private demand is considerable. Geographical areas with high unemployment lose inhabitants, and geopraphical areas with suitable employment attract immigrants. Serious economic crises, such as the recent financial crisis, have affected the quality of sleep of a large proportion of the population; many people had sleepless nights due to fear of losing their job, which impacts the national health.

Influencing employment/unemployment by the standard means of economic policymaking (fiscal policy, monetary policy, income policy, labour market policy, industrial policy, etc.) is problematic. Interventions by these policy means can improve the situation in the short term, but usually at the cost of a worsening in the long term. A delimiting factor will be governmental debt. On the other hand, measures to improve the economic situation and employment situation in the long term are usually not helpful for the short term, and vice versa.

The dependability and undependablity of employment/unemployment

[1] This may be a shortcoming of this study; for all researchers, publishing is also a mean of "sustaining employment".

The numbers of employed and unemployed are highly variable and are highly dependent on other factors of the economy. Simultaneously, most of the other factors of the economy are highly dependent on the trends of employment and unemployment.

One single factor can trigger a change the economy. The change in this factor can affect another factor positively or negatively, which, in turn, effects a third factor of the economy, etc. This is the "domino effect" (a theoretical code). Merged with the "domino effect" (or the inverse domino effect) is another theoretical code of "amplified causal looping" when consequences are becoming causes and vice versa. (In this case, one sees either worsening or improving progressions). These forces make the economy complex, fluctuating and unmanageable, and they reduce the transparency regarding possible causes and effects.

The government finances and the long-term fiscal sustainability of the governmental economy depend on the level of employment. Furthermore, the educational policy, the health policy and the social policy depend on and are dependent upon the employment/unemployment issues. Thus, there seems to be an interdependence between educational policy, health policy, and social policy on the one hand, and the employment/unemployment issue on the other. For example:

(i) Regarding education policy, education is a preparation for employment and can affect job prospects and the quality of employment. This means that there will be a relationship between educational policy and an employment sustaining policy.

(ii) Regarding health policy, one purpose of hospitals and health institutions is to keep people fit for work. It is also common knowledge that unemployed people tend to be less healthy than other citizens.

(iii) regarding social policy, kindergartens and day nurseries for children, as well as home care and nursing homes for the elderly do have an obvious relationship to the employment/unemployment issue.

Relationships between employment, economic growth and productivity growth

The economy (GDP) has an inherent tendency to grow in the long-term. Around its long-term growth trend, there are short-term fluctuations (expansions and contractions) in line with the movements of the business cycle.

This long-term growth tendency of the economy is due to an unstoppable productivity growth that in turn is due to the phenomenon of an unstoppable technological progress.

As long as businesses have to match their competitors in their use of new technology in order to survive, productivity will be boosted and productivity growth will be unstoppable. This becomes a basic social condition.

New technology that sustains productivity growth is usually embedded in investments. The following textbox explains the relationships between changes in employment, changes in productivity, and changes in the size of the economy (GDP):

TEXT BOX

We have: Y=real sum of value added (GDP), L=hours of work, Y/L= Labour productivity, and the identity Y = (Y/L) * L. We use the natural logaritm as approximation to differentiation (can be used when changes are small): Ln Y = ln (Y/L) + ln L. From this we can see that a percentage change in real GDP ≈ a percentage change in labour productivity + a percentage change in employment.

The conclusion from the textbox is thus that a percentage yearly change in real GDP equals a percentage yearly change in labour productivity + a percentage yearly change in employment.

For example, if the yearly growth of GDP is 2% and the yearly growth in labour productivity is 2%, there will be 0% yearly growth in the employment. If the yearly growth in GDP is 0% and the yearly growth i labour productivity is 2%, there will be -2% growth in the employment.

Consumerism and the employment issue

Thus, all else equal, the growth of the economy (GDP) in % has to be higher than the growth in labour productivity in % in order to allow for a positive growth in employment (i.e.,a fall in unemployment).

So far we have looked at the supply side of the economy. It is the demand side that can keep the economic growth higher than labour productivity growth and thus boost the growth of employment.

Productivity growth makes it possible for companies to lower the prices of luxury goods (price elastic and income elastic goods). Such a price cut will boost the revenue from sales. The price cuts will also sustain spending on other goods. Both effects lead to higher demand and higher GDP.

Over time, luxury goods become necessity goods (price inelastic goods). Over time, people become used to these former luxury goods and cannot be without them. A price increase for price inelastic nescessity goods will boost the revenue from sales. This can also lead to higher demand and higher GDP.

Thus, employment depends on the recurrent innovation of new luxury goods (price and income elastic goods) that over time become price-inelastic necessity goods. "Consumerism" (throw away and buy new) thus becomes a precondition (a basic social condition) for sustaining employment.

Technological disruption and the employment issue

It follows from the text box that if the yearly growth of the economy (GDP) in % is less than the yearly growth in % in labour productivity, there will be a negative growth in the employment (i.e. an increase in unemployment).

This is what happens in the case of job-destruction or disruption due to new technology and new innovation that lead to high gains in labour productivity, but without the balancing factor of increased consumerism. The debt burden of government and the private

sector of the economy will be a check on domestic demand of the economy. Globalization and an increase in free trade also have an impact.

During periods of contraction of the economy (busines cycle recessions) jobs are made redundant without the immediate creation of a corresponding number or a higher number of new jobs requiring new job qualifications. According to McKinsey Institute (2011), new job-creation due to technological progress has slowed down during the two recent decennia. Recent elections indicate that such a trend has had a considerable impact on the behavior of the electorate.

The recurrent solving of the main concern of sustaining employment?

The solving of the main concern of "sustaining employment" during the recent financial crisis can be summarised as "sustaining employment apparently". This may be a core variable candidate.

The policy for solving the financial crisis was a monetary policy of quantitative easing (i.e. providing a considerable increase in the money supply) and a policy of keeping interest rates close to zero. It was also a fiscal policy of "stimulus packages". However, interest rates may increase sooner or later, and the money supply has consequently to be normalized. The effects of such interest rate increase and money supply decreases are unknown to leading economists; we do not have any presedents. It was a policy that "looked right" from the perspective of the stakeholders in the context of a serious debt crisis.

Normally, it is not possible to give strong evidence regarding success or failure of economic policy. It is about what "looks right" as a policy in a given context. It is very much about convincing stakeholders by communication. Thus, a preliminary naming of the core variable may be "sustaining employment apparently".

Epilogue

For the core variable to emerge more clearly, more data need to coded selectively, memos have to be written, they have to be sorted at the appropriate time, and theortical coding has to be performed. Someone else is welcome to collaborate or take over and finish this study.

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Grounded Theory: Study of Aboriginal Nations

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Abstract

Recently, Elers (2016) published an article stating the importance of using Classical Grounded Theory (CGT) when researching indigenous populations. This article puts forward CGT as a viable and necessary tool for researching this complex subject as it requires researchers to utilize multiple data sources and, as in this particular project, can be used by multiple disciplinary teams. Canada has much to do to rebuild the trust of the indigenous people of Canada. CGT shows promise as a methodology that gets to the root of the issues and offers one of the best opportunities to develop a theory that can be part of the constructive healing process going forward.

Keywords: Aboriginal, indigenous, TRC, labour readiness, grounded theory, research teams.

Introduction

The project started eight months ago and continues to be a work in progress. This short analysis provides some insights of the challenges and importance of classical grounded theory (CGT) for a critical area of Canadian research. It is not possible to highlight all the findings at this stage therefore the purpose of this paper is to put forward some of the lessons learned. The first and most important lesson to be shared is Glaser's dictate that "All is Data" (Glaser, 2007).

Study outline

The study started with a call from a Canadian research government funded agency looking at pathways to improve education and labour opportunities for Aboriginal youth. The process required interviews and focus groups to be conducted across a region. Concurrently some team members explored literature looking for existing and past insights of specific challenges and opportunities for education and employment. The research team consisted of professors from different universities and backgrounds. The team included Psychology, Anthropology, Education and Business researchers. The literature review material, while being collected concurrently during interviews, was not shared with the research interview teams until after the groups had completed their initial comparative analysis.

One challenge faced by the research team was the diverse level of individual knowledge members had on Aboriginal culture and history. From a researcher's perspective, the flexibility of the CGT methodology was key to researching the job and education

phenomena. Ehigie and Ehigie (2005) highlight that in certain areas of research it is important for team members to have an understanding of the participants they are studying. As put forward by Elers (2016), indigenous research is well suited to CGT and this view is supported by his personal comment received from Barney Glaser "It is all just data with patterns in it" (Elers, 2016, p. 114)

Past quantitative research of education and employment, does not answer the question, why Aboriginal education and employment levels fall far below the national average. During data collection, it became clear the issue was complex and went beyond poor education and labour statistics. CGT provides a framework that supports multiple data sources and allows the data to lead the researcher forward. It was important that all members approach the phenomena with an open mind and willingness to allow the data and process to drive the direction of the study. Classic grounded theory (CGT) researchers need to ask themselves the questions: "What perspective do I represent?" and "How may this perspective influence my reading?" (Deady, 2011, p. 51)

The goal of improving labour and education opportunities was the primary focus, but to understand the phenomena it is necessary to understand the history of Canadian Aboriginal people. Since before confederation the Aboriginal people in Canada faced programs of assimilation and cultural suppression. Aboriginal youth were forcibly removed from their homes and sent to residential schools where they were restricted from practicing their language, culture and in many cases physically and sexually abused. In the 1960s, now known as the 60s scoop, Aboriginal children were put in care of non-aboriginal families removing all ties to their families, language and culture. The last of the residential schools was closed in1996 and the government of Canada in 2016 apologized for the actions of the past including before and after confederation. The Truth and Reconciliation Commission (TRC) was created in 2008 to understand and provide a process to redress past actions. (TRC, 2015). The commission interviewed survivors of residential schools across Canada. The study completed in 2015 put forward a call to action with 94 recommendations, which the government of Canada in 2016 agreed to implement. Broken treaties, racism, illegal seizure of land, human right violations as defined by the United Nations and a multitude of other actions bring us to 2017. The respository of data that we need in order to study and understand the past should include data on what happened and why.

The history books were distorted to hide the true story of the Aboriginal people of Canada. The TRC call to action looks to correct this with a new education process to be implemented for all k-12 schools (TRC, 2015).

The data

The core analysis is based on interview data collected from individual participants and focus groups from specific regions of Canada. Additional data included research reports, statistics, treaties, and government documents.

The challenges

The initial challenge was the size and diversity of the research team. The team members with more Aboriginal knowledge shared required protocols and provided culture awareness without presenting preconceived conclusions. All team members understood the importance of letting the participants fully provide their thoughts and experiences. Cultural awareness is critical for the interview process as it could make the difference between an open or closed communication. It is also necessary for a researcher's "theoretical sensitivity, without which grounded theory analysis is compromised" (Glaser, 1998 p. 123). Memo writing was left to individual team members: one of the advantages of CGT being that it allows each researcher to develop his/her own memo writing and sorting process. (Glaser, 2014).

The data analysis issue of moving from the descriptive to the abstract is a consistent problem for novice researchers. While the narratives were emotionally charged and the similarity between participants from totally different regions was evident it is important to move from the descriptive and to conceptualise (Glaser, 2007).

The researchers continue to engage in constant comparison, comparing incident-to-incident, incident to concept, concept to concept with the ultimate aim of emerging the substantive theory (Glaser, 2007; Holton, 2007). The compelling stories made it difficult for some team members to move to the abstract. Common incidents and concepts were identified in all regions including intergenerational trauma, racism, culture, spirituality, physical, emotional, resilience, celebration, trust and many more. Analysis continues to define the research path forward, the literature set aside for the moment since "more focused reading only occurs when emergent theory is sufficiently developed to allow the literature to be used as additional data" (Heath & Cowley, 2004, p. 143).

This study is unique in the blend of professionals and a strength of CGT is that it permits this diversity. This study is also a testament to the researchers' dedication to let the data guide them to a powerful grounded theory which can be used to support the Aboriginal people.

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Negotiated Re-orienting: A Theory Generated through International Collaborative Research

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Introduction

The theory presented here was generated from a research project that involved researchers in five countries. To our knowledge, this is the first classic grounded theory generated by such an international collaborative effort. This article starts by describing the collaborative process, then the theory is presented.

The project

This research project was co-ordinated by researchers in the United Kingdom (UK). They were quantitative researchers, quite unfamiliar with qualitative research in general, but decided to use grounded theory without any knowledge of the methodology other than being aware that it is effective at generating theory. I was invited to join the project and together with colleagues from Brazil, Germany, Ireland, Palestine, and the UK, we held our first meeting in the UK. It became clear that everyone had a different view as to what GT is. The Brazilians were intent on using constructionist GT, the Germans advocated that situational analysis GT should be used, while the Palestinians and British did not know anything about the methodology. To ensure that we were collecting data and doing data analysis in a similar way, I gave a presentation on classic GT. The quantitative researchers thought of qualitative research as weak and non-scientific. However, following the presentation, they had changed their minds and became even more convinced that classic GT was very suitable to investigate the substantive area of Intensive Care nurses' perception of their role in end-of-life care.

Semi-structured interviews were conducted and included 51 participants in five countries. Although contrary to classic GT, this is a compromise that at least initially had to be made for the sake of the study. Nonetheless, researchers in each country were encouraged to use theoretical sampling by following up on what was said at previous interviews. The project team in each country participated in-person or via Skype in a two-day analysis workshop at the University of Surrey in order to discuss analysis of each country's dataset. It involved a lot of discussion and convincing others that what seemed like differences were in fact not so when the data were conceptualised. This was not surprising given the different ways that researchers were approaching analysis. This proved to be a very effective way of analysing and agreeing on the core and other categories. Memos with supporting quotes and full transcripts of three interviews from each country were prepared and circulated to all team members. Researchers in each country independently read all of the transcripts and coded them separately, looking for patterns.

An additional two meetings took place in the UK, in person or via Skype where the team discussed patterns relating to the core category. Following these two meetings, a template was circulated with sections of memos and interviews from each country in order to reach consensus. At the team meeting in Ireland we finalised the core concept and discussed dissemination of the results.

The theory

Nurses' main concern in Intensive Care end-of-life care is to shift the emphasis from active treatment to palliative care. However, this is problematic given the uncertainty surrounding prognosis. Patients in ICU are often in what Glaser and Strauss (1967) referred to as uncertain death and unknown time when the question will be resolved. This idea is central through negotiated re-orienting. The shift from uncertainty to a greater certainty of impending death implies that activities orientate to curing are now ending and replaced by activities prompted by the dying process. Nurses actively seek to bring this about by facilitating the shift from a narrower to a broader and more holistic practice emphasising comfort and support. This is brought about through negotiated reorienting, where nurses engage in consensus seeking and emotional holding.

Through consensus seeking, nurses coax physicians to realise that further treatment is futile. They encourage physicians to withdraw, de-escalate or limit treatment by directly expressing their views such as detailing the deteriorating condition of the patient. Through information cuing, nurses try to figure out how much relatives know and whether they accept that the patient is not responding to treatment. If successful, nurses then seek to ensure that relatives have a voice in what is happening. Nurses accomplish this task through voice enabling. They create a space and time for relatives to share their understanding as to what is happening and what is likely to happen. Nurses share their observations with relatives so that relatives can more effectively take part in discussions with physicians about treatment options and what is best for the patient.

Through emotional holding, nurses support families by prioritising time spent talking with family members. If families are not aware of the seriousness of the situation, then through creating time-space nurses try to bring about acceptance of what is happening. Nurses try to ensure that families spend as much time as possible at the patient's bedside and they bend rules, such as around visiting times, to ensure that this happens. They also negotiate with physicians and families to delay withdrawal of treatment so that any missing family members can be at the bedside. When death is imminent, they try to create a more peaceful environment around the dying patient. Nurses are concerned that relatives are told in a timely way that their loved one is dying; this is reinforced through bounded communication and the use of religious rituals. In bounded communication, nurses make sure that they only communicate with relatives in a way that has been predetermined by physicians, by reinforcing what physicians have said. In this way, nurses avoid dealing directly with questions that they consider to be within the domain of medicine, such as prognosis. Where nurses perceive the family to be religious, they may appeal to rituals such as references to religious texts in order to convey the seriousness of the situation. Comfort giving is focused on reducing the suffering of patients and their families, and focus on pain relief and other comfort

measures for patients. Comfort giving extends beyond death since nurses are very sensitive to the needs of the recently bereaved family.

Conclusion

Despite approaching this research project using different ideas of grounded theory, we generated a theory because, as a group, we engaged in negotiated re-orienting, whereby we reached consensus through open discussion at meetings and using classic GT as the overall methodology. The theory highlights the important role ICU nurses have in end-of-life care in bringing about consensus as to the patient's prognosis and re-orienting care from an emphasis on cure to one emphasising palliation. The theory demonstrates that nurses have a clearly articulated and complex role in end-of-life care in an area that is medically and technologically dominated.

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Patterns of Theoretical Similarity

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Abstract

Classic grounded theories explicate patterns of behavior used by individuals within a substantive area to address problematic areas that they are working to address. Through the brief examination and explanation of two classic grounded theories conducted by the author, overlapping patterns of theoretical similarity are discussed despite the theories' emergence from different substantive areas. The future development of formal grounded theories from these and other substantive grounded theories is discussed.

Keywords: theoretical similarity, grounded theory, navigating new experiences, surviving the complexity.

Years of conducting classic grounded theory (CGT) research and overseeing CGT research by doctoral students have reinforced Glaser's (1978) statement that "The goal of grounded theory is to generate a theory that accounts for a pattern of human behavior which is relevant and problematic for those involved" (p. 93). Due to the theoretical nature of the patterns of behavior discovered, theories developed using CGT often depict overlapping patterns of behaviors and concepts despite emerging from different substantive areas. This article will exemplify this by examining two CGT studies conducted by the author in two different substantive areas: adult learning experiences and grandparent-headed households. First, a summary of each study will be provided. Then a discussion of areas of theoretical similarity between the two studies will be presented. Finally, next steps in the development of formal grounded theories are presented.

Navigating new experiences

Navigating (Vander Linden, 2005) explains three cyclical stages of going through a new experience and factors that may affect the process. In the mapping stage, people engage in locating (assessing one's location in relation to a goal), surveying (information gathering), and plotting (creating a plan). In the embarking stage, people move through the experience using normalizing (creating a new normal) and strategizing (overcoming obstacles encountered). In the reflecting stage, people reflect on the experience. These stages are affected by properties of the experience (complexity, newness, structure and control, a

catalyst, etc.) and factors that affect the person (emotions, goals, competency, obligations, perception, perspective, modus operandi, etc.).

Surviving the complexity

Surviving the complexity (Tompkins & Vander Linden, 2016) is a survival process of taking on the caregiving role and doing what one can despite multiple factors that make the situation difficult. The theory introduces three types of complexity: situational, relational, and emotional. Throughout the process, the caretaker engages in surviving behaviors to do what he/she can within a complex situation. The process begins with a trigger event (tragic or destabilizing) that leads to the caregiver (parent) abdicating the role to another. Stage 1, rescuing, is engaging in temporary, emergency action (helping-out, stepping-in, and taking-in) to save others from harm. Within rescuing the new caregiver engages in adjusting (figuring out the new role and aspects contributing to the complexity of the situation) and accepting (coming to terms with the situation). Rescuing ends as the new caregiver is faced with the decision to abdicate the role or move to stage 2, taking-on, where the caregiver consciously commits to take-on the caregiver role and the inherent complexity it brings for a longer duration. While taking on, the caregiver engaged is quieting the chaos (bringing order to confusion through stabilizing and normalizing), doing one's best, and problem solving.

Areas of commonality

Both theories identify common patterns of behavior used by individuals resolving problematic aspects within the substantive area and factors that influence these behaviors. Significant concepts that emerged in common between the two theories included: complexity, emotions, power and control, obstacles and problem solving, normalizing, and change.

According to navigating "an experience can be complex due to (1) the number of different components involved; (2) the interactions between the components; and, (3) the impact of the interactions" (Vander Linden, 2005, p. 27). Similarly, surviving explains that complexity results from a "layer of complications created by behavior and beliefs of people within a situation and influenced by community and societal rules, regulations, and expectations" (Tompkins & Vander Linden, 2016, para. 4). Both theories acknowledge that patterns of behavior occur within the context of systems and these systems are complex. Thus, complexity may a condition present in many systems and, as such, a condition within many grounded theories which explain systems.

Surviving identified one specific type of complexity as emotional and navigating also identified the role emotions play as an influencing factor on behavior. Both theories explained that emotional responses guide a person's actions, behaviors, and choices. Thus, emotions are often a common concept in our theories about patterns of behavior.

Concepts relating to power and control also emerged as significant to both theories. "Power is the ability to affect a situation, outcome, or person's behavior and often is tied to a

person's position; whereas, control is exercising some degree of influence over these areas" (Tompkins & Vander Linden, 2016, para. 8). Both perception and utilization of power and control influence when and how people think they can influence a situation or outcome, and thus also influence behavior.

In both theories, people encountered obstacles and used problem solving to address obstacles. In navigating, problem solving was referred to as strategizing; in surviving, it was referred to a quieting the chaos. In both concepts, people identify and develop strategies to deal with factors and conditions to minimize their impact on the situation.

Two final concepts common to both theories are normalizing and change. While not directly identified by either theory, change is a theoretical concept both have in common. Both theories identify a change process occurring in the lives of people within the substantive areas and behaviors used in response to change. In the theories, normalizing was identified as a behavior used in response to change. "A person often experiences an increased sense of disequilibrium as unexpected factors and conditions are encountered" (Vander Linden, 2005, p. 109). The person strategizes about how to address the unexpected factors and conditions encountered and then normalizes to create a new norm and sense of stability. The same idea also appears in surviving within quieting the chaos. Since addressing change is a main concern for people within both settings, it is not surprising that there is commonality with the patterns of behavior used in these theories.

Formal grounded theory

Just as theoretical patterns occur across data in the development of substantive grounded theories (SGT), through the examination of theoretical similarities across SGT the level of generalizability can expand the core category into formal grounded theories (FGT). Glaser and Strauss (1971) defined formal theory as "theory developed for a formal or conceptual area of sociological inquiry" (p. 177) which vary in levels of generality from substantive theory. They further stated, "if the focus of level of generality is on generating formal theory, the comparative analysis is made among different kinds of substantive cases and their theories" (p. 178).

Initially, the theorist may approach the focus on the level of generality in developing a FGT in two ways: looking for new variation and raising the level of abstraction. In looking for new variation, he or she may look at SGT that share similar contexts and/or conditions. When there exist similar contexts or conditions, the theorist may find new conceptual variation of existing concepts that may have emerged from varying substantive areas. For example, in navigating and surviving, problem solving was a behavior used to address obstacles. However, each theory presented different problem-solving strategies and techniques which can be further developed to broaden the generalizability of a FGT. As in developing a SGT, seeking theoretical saturation and accounting for conceptual variation may lead the theorist to gather and analyzed data, this time from varying substantive areas to more broadly expand the generalizability these concepts.

Comparative analysis of SGT and data from varying substantive areas may begin to raise the level of abstraction of the theoretical concepts. Just as the theorist asks, "What is this data a study of?", "What category does this incident indicate?", and "What is actually happening in the data?" (Glaser, 1978, p. 57), asking similar questions of the concepts within the SGT may lead to the discovery of concepts with broader generalizability. For example, as mentioned earlier, change is a concept in common between navigating and surviving however neither theory explicitly identified it. It was through asking "What is happening in theory?" and "How do these core variables relate?" that the concept of change emerged as a more generalizable concept. As the level of abstraction is raised the level of generality increases.

These initial steps in generating a FGT are just that, initial steps. After years of working in CGT research, this researcher is ready to further expand her scope of knowledge and skills to begin generating FGT. Glaser (2007) found that some have cited FGT as a possible area for future research but few have followed through. Hopefully the next 50 years in the history of classic grounded theory will see further development of formal grounded theories.

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Complexities in Palliative Cancer Care: Can Grounded Theories be Useful to Increase Awareness?

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This paper includes first a summary of a grounded theory "Living on hold", which was one of four different grounded theories in my dissertation (Sandgren, 2010). The theory is then explained in relation to the other grounded theories to give an example of how different grounded theories can be integrated, which leads to an increased awareness of what is going on in a research area.

Keywords: palliative cancer care, increase awareness, grounded theories, living on hold.

Living on hold

The aim of this study was to develop a classic grounded theory of palliative cancer patients and their relatives. Interviews and data related to behavior of patients and relatives were analyzed.

Being put on hold emerged as the main concern for palliative cancer patients and their relatives. Being put on hold means that their normal existence is falling apart; normality is breaking down and with it a loss of control. Living on hold consists of three modes of behaviors: the fighting mode, the adjusting mode, and the surrendering mode. Mode being, an individual's current mode, depends on, for example, age, personality, diagnosis and prognosis, social network, earlier experience of crisis, continuity of care, and professional competence. During the disease trajectory, there may be triggers that start a process of reconciliation that can lead to mode shifts, so modes are not fixed. No mode is better than another.

The process of reconciling

Regardless of mode, patients and relatives evaluate not only their lives and their current situation, but also the past and the near future. Mode shifting can happen at anytime during the disease trajectory through the reconciling process. Mode shifting triggers, such as receiving bad news, dependency experience, and feelings of uncertainty, can trigger the reconciling process and lead to a change in behavioral mode. Patients and relatives often evaluate life differently, which may lead to individuals experiencing different behavioral modes within a patient's group. Depending on their different moods, shifting between modes can happen quickly over a short period of time, which could be energy draining for all involved.

Fighting mode

In the fighting mode, patients and relatives are striving to renormalize their lives; no

change to their previous way of life is desired. Through renormalizing, they strive to return to normal, managing themselves, and keeping track as before. Potential powers are discovered and unrealized innate powers may emerge when needed. Rebelling means not only protecting and fighting the whole situation, but also fighting the disease. Through blaming, patients and relatives seek reasons or causes for the disease, and finding something or someone to blame. In the fighting mode, they appreciate foreseeing, since this gives them full control over life, even if it is put on hold. Since individuals are hyper-sensitive, they are scrutinizing everything around them.

Adjusting mode

In the adjusting mode, patients and relatives are adjusting to a new normality and to new routines. Even though they are adjusting, they do not let the disease take over or control their lives. Adjusting to a life on hold involves moment living, which means maintaining a total presence here and now and involves planning for daily life but not for the future. Disease diminishing, which means not letting the disease affect their lives, is achieved through re-routining where new routines are created. Adjusting also involves façading, which means keeping an emotional facade and staying emotionally strong.

Surrendering mode

There are two different ways of being in the surrendering mode: resigning, which means giving up, or accepting, which means submitting their lives to a higher power. In surrendering mode, a life on hold is handled through total trusting. Individuals live in complete trust that everything is going to be alright and they have full trust in others to make decisions. Through releasing control, they let go and surrender control to the health professionals and do not seek any participation in the care.

Feasible mode shifting and possible outcomes

Patients and relatives can be either in the same or in different mode simultaneously; this mode synchronicity may lead to problems within the family and also when in contacts with health professionals (Figure I).

Relative

	Fighting	**Adjusting**	**Surrendering**
Fighting	Ok within the family	Risk for conflicts	Risk for conflicts Vicarious fighting
Adjusting	Risk for conflicts	Ok within the family	Risk for conflicts
Surrendering	Risk for conflicts Vicarious	Risk for conflicts	Ok within the family

Patient		fighting		

Figure I. Possible outcomes of being in different modes for patient and relative

Complexities in palliative care

The situations for health professionals, patients and relatives in palliative care are often complex. To explain some of these complexities, the theory Living on hold will be integrated with the theories Doing good care, Striving for emotional survival, and Deciphering unwritten rules.

The grounded theory Doing good care explains how nurses can have different caring behaviors i.e. anticipatory caring (doing best or even better than necessary through foreseeing trajectories, creating trust, collaborating and prioritizing); momentary caring (doing best momentarily as well as possible in every situation through temporary solutioning and sporadically collaborating); or stagnated caring (doing what is expected of them through avoiding changes and resigning) (Sandgren, Thulesius, Petersson, & Fridlund, 2007). There can be tensions and clashes when professionals have these different caring behaviors and they then meet patients and relatives who are handling their lives being put on hold through the different modes: fighting, adjusting, and surrendering (Sandgren, Thulesius, Petersson, & Fridlund, 2010). For example, if professionals are using anticipatory caring behaviors and the family is in the adjusting mode, displaying facading and moment-living behaviors, the family may not act or behave as if they have understood the information about the seriousness of the situation and the potential for a terminal outcome for the patient. The family lives on as usual, confusing the professionals who give the same information over and over again to try to make the family understand the situation. This leads to frustration for all involved; the professionals may feel that they are not giving the "right care" and are letting the family down. The family, on the other hand, may feel disrespected and trodden on. Professionals' assumptions of what seems to be the best for the patient may actually be in conflict with the patient's wishes. For instance, professionals often perceive patients and relatives in the surrendering mode as positive. The professionals decide what seems to be best for the patients and relatives, without even asking them. They are then seen as good patients and good relatives since they follow all the directives whereas, in fact, patients and relatives who are in the surrendering mode might be the ones who are the most in need of support and encouragement.

In the grounded theory deciphering unwritten rules, the main concern for everyone involved in palliative care is struggling with how to act and behave (Sandgren, 2012). This affects not only how health professionals give care and survive emotionally (Sandgren, Thulesius, Fridlund, & Petersson, 2006), but also how patients and relatives experience the care. For example, nurses engaged in stagnated caring behavior and patients and relatives in the surrendering mode may not have the emotional sensitivity to figure out the unwritten rules of how to act and behave. Instead, they are passing over, which means they are leaving other people around them to figure out the rules, and then copying and following their behavior. However, nurses engaged in anticipatory caring

behavior are on the other hand figuring out the rules in an active way, the same way as patients and relatives in a fighting mode do. When patients and relatives are lacking information and support, they are finding out how to act in order to obtain what they need (Sandgren, 2012).

Methodological notes

In order to explain the complexities in palliative care, four grounded theories were integrated. Analysis was done on earlier written memos and the theories. New conceptual memos were written (Glaser, 1998) about how the theories could be integrated to explain the complexities. Memos were written about how the mode behaviors and strategies in the separate theories related to each other, possible outcomes, and which consequences these outcomes have for nurses, patients and relatives. These memos were then hand-sorted.

Conclusions

This paper demonstrates the complexities in palliative cancer care that are often not recognized by those involved. The grounded theories in this paper can be used to increase awareness and understanding about these complexities, which may positively affect how the care is given and how the care is perceived by the patients and relatives.

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Formal Grounded Theory: Knowing When to Come Out of the Rain

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Getting started on a formal grounded theory is daunting for many grounded theorists, but now, as I tweak a nearly complete one, I find that knowing when to stop, to come in out of the rain, so to speak, can be a challenge, too.

After more than a decade of procrastinating, one of the lessons for me was one I knew but needed reminding of—the implications of the core help shape and delimit the formal grounded theory (Glaser, 2007). Maybe if I had pasted this to my computer and read it each day I could have cut my theory development time considerably. But having a mantra does not clear the path to a theory. A formal grounded theory takes on the world of knowledge far more boldly than does a substantive theory, which is based in one subdiscipline. It is not always simple to clear a path through the competing knowledge claims and epistemologies on the phenomenon one is studying. This was especially true of my theory on *defensive disattending*, which is evident throughout micro and macro level spheres of life.

Defensive disattending explains the processes through which people seek to protect themselves from information, people, and situations they perceive as threats to their sense of self, comfort, autonomy, freedom, power, or belief system. It is evident in areas as diverse as personal relationships (patient-doctor, the spouse swatting away evidence of a cheating mate) to the ways the NFL (National Football League) refused to accept that concussions cause brain damage and created a system to fight the evidence. It became all too clear during the polarizing 2016 Presidential campaign in the US and its aftermath, where fake news and "alternative facts" became substitutes for facts people did not want to face. Through *discounting awareness*, the core of the theory, a range of disattending strategies allow people to distance themselves from discomfort or threat. Typically, the offending phenomenon works its way into the frame of awareness, forcing an encounter that people ignore, marginalize or aggressively resist. Temporality and emotionality are dimensions of the encounters as well.

The various types of disattending strategies do not typically resolve into moments of acceptance. Generally, people continue to fight the fight unless phenomenon from the outside disrupt the cycle—the anti-vaccine parent's child gets really ill, or people's social network changes. In extreme cases, "organizing doubt," becomes a strategy for governments and organizations – tobacco, the NFL, oil companies—that, due to high stakes, wage war on the truth. In many ways, the theory of defensive disattending is a theory about the social interaction of denial.

My substantive theory of *purposive attending,* which focused on how people deal with news media in everyday life, launched my examination of attending and disattending (Martin, 2004, 2008). Despite my focus on the interplay of awareness, the evaluation of relevance and attending, I became more interested in the many ways in which awareness could be snuffed out before it emerged fully. Glaser and Straus's use of discounting awareness (1964, 1965) had intrigued me on many levels. It contained a number of implications in its discussion of the way medical professionals carried on their conversations and routines in front of comatose or mentally disabled people they assumed could not hear or understand them. The sociologist Erving Goffman (1974/1986) had invoked their work in his discussion of how people move situations in and out of frame. I saw possible connection to these understandings in my interviews with people who reported intentionally disattending conversations on controversial news items to avoid uncomfortable encounters with people in their lives. Looking around, the ways in which people erased all manner of discomfort, including the classic look-away when coming across the disabled or homeless on the street, helped launched my journey.

Data for a study such as this abound. I have made use of a variety of government and technical reports where discounting awareness exacerbated problems. Observations, academic and popular literature, and daily events also became data. Numerous theories address pieces of what I was studying, which nipped at my confidence at times. The Third Person Effect scared me a little at first. It holds that people assume how others are more affected by media in a negative way than they are, in effect, discounting the awareness faculties of others. *Selective exposure* holds that people select content in line with their views of the world, and has some connections to *confirmation bias.* I read a whole lot more on these theories than I probably needed to. Their grounding in experimental data restricted how I could use them for theory development; but they were not the real dragons I had to slay.

In short, I had to grapple with denial, which was clearly an element of what I was looking at. Yet denial is a term brandished recklessly in everyday conversation, and not operationalized carefully enough in the scholarly literature. Its place in psychoanalytic theory scared me. Maye I am wasting my time, I thought. Perhaps enough is known about denial. I would be just another voice saying, "I agree with what they said." Several memos helped me reflect on the problem. It wasn't until I started reading the literature on denial that I realized that it is vague, poorly defined, and does not typically account for the interaction and social processes underlying denial. Sociologist Stanley Cohen (2001) has theorized denial processes to better understand why people fail to intervene in human atrocities such as the Holocaust or genocide in Rwanda. Coding his work in the manner I coded many books and articles was useful for understanding how my perspective and focus on processes was closer to his work than some of the literature I examined. And yet it was also different. It took some languishing on my part, but I soon came to accept that the theory of defensive disattending is a theory about the performance of denial in interaction. Because it is processual it speaks more deeply about phenomena that are sometimes merely labeled in other theories dealing with discounting and disattending. The grounded theory methodology allowed me to tell the story, often vaguely implied in a number of the other theories, through the integration of concepts that brought about the theory of defensive disattending.

When I was able to articulate the role of denial in my theory and how it differed from other claims of the concept, I felt satisfied with where my theory begins and ends. Disattending, of course, is necessary in all areas of life; we need distraction-proofing to get through the day. The theory is most concerned with defensive interaction. Yet while it does not predict when people, buoyed by emergent awareness, might intervene to stop evil, it explains the many barriers to breakthroughs, which are often idiosyncratic.

But perhaps I speak too soon. Another factor that has resulted in my procrastination is that, in today's polarized civil society, in the United States and abroad, the patterns explicated in the theory may produce results that transforms situations, and offers new variables for study. In 2016, as I was drafting a working paper on *defensive disattending*, there was growing talk about the growing polarization signified by news bubbles and Internet echo chambers, where people consumed information and interacted with those who share their views, excluding other influences. I was seeing my concepts and their implications elsewhere. Always up for more theoretical sampling, I began looking around for data to analyze in my pursuit of a fully saturated theory.

A grounded theory, however, cannot cover all identified phenomena. Its implications need to provide openings for others to join the conversation. Too many substantive areas start to push the theory toward description. It took a few months of watching and wondering whether there was still work to do. Along the way I learned about new knowledge areas—there's a sociology of ignorance!—and memoed about areas that dovetail with some of what I have done. But ultimately, some of this was work for another day, another theory. It was time to come in out of the rain.

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Transcending Taboos in Medical Ethics

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The following is perhaps what Glaser would call a "theory bit" (1) from a write up of memos inspired by interview data leading up to a grounded theory of De-tabooing Dying Control (2).

This conceptualization of what goes on in medical ethics is the product of the analysis of data from two sources. It is the write-up of memos arising from the secondary analysis of the interview data tht initially led to a grounded theory of De-tabooing Dying Control. It is also the product of the analysis of field notes of talks, chats, and discussions which took place at the Swedish Society of Medicine's medical ethics delegation from 2005 - 2009. Specifically, the data were collected from meetings of physicians engaged in ethical rumination for the purpose of providing statements of opinions on government reports and official documents.

During my years in the Swedish Society of Medicine's medical ethics delegation, I discovered that transcending taboos conceptualized the medical ethics discourse. Taboo is, by Oxford dictionaries, defined as something "prohibited or restricted by social custom" or "designated as sacred and prohibited". To manage taboo topics thus explains what is going on when sensitive issues regarding life, death, and sexuality are managed. The task of the ethics delegation is to scrutinize and vet governmental and other official reports on health issues from a medical ethics perspective. Medical ethics deals with what is acceptable and unacceptable behavior in the medical field, especially for health care professionals: What is right or wrong? What is forbidden or unacceptable is often connected with the big taboo subjects—sex, money, death, and dying.

What is politically correct (PC) may set the agenda for what is taboo and what is not. Political correctness changes over time and so do taboo topics and issues. It seems that political correctness aligns itself with what is taboo—to be politically incorrect could therefore be seen as a property of de-tabooing, i.e. acting or talking in such a manner that a taboo is being challenged or transcended. To be PC regarding medical ethics is a necessity for someone who wants to work in health care and be considered respectable. To go against what is PC is a risky endeavor and therefore transcending the taboo is seldom done in the open.

Transcending dying taboos

Legal abortion is time framed, meaning that it is conditioned primarily by time; it has a time window within which it is sanctioned by law to terminate a pregnancy, in other words eliminate the existence of a future human being to some people and a present human being to others. To terminate the existence of a human being is taboo in most cultures with the exception of the death penalty and situations of self-defense and war.

So, with abortion being another exception to the commandment "Thou shalt not kill" it is connected with the taboo of death and dying and thus one could talk about legal abortion being a time framed death taboo transcendence in the first months of human life. Abortion issues were not commonly discussed in the medical ethics delegation in the 2000s with the exception of sex selective abortions that were somewhat taboo at the time. To decide upon the sex of the fetus within the free abortion time window was not considered a good thing to do—it was indeed not PC to hold this position. Yet, a significant number of people used and still use this opportunity of selective family planning.

Sweden has a generous abortion upper time limit—an 18-week gestational age as compared to 12 weeks in most other European countries. Hence, there was a debate of whether it was morally acceptable for non-Swedes to decide the sex of their future child by going to Sweden for an abortion. By ultrasound it was at the time difficult to establish if the fetus was boy or girl before 12 weeks of gestation. The dysphemism "abortion tourism" was then coined in the press.

When using the widespread technique of ultrasound, it is difficult to establish the sex of a fetus before 12 weeks. A practice arose of other Europeans visiting Sweden to establish the sex of their fetus and sometimes obtaining an abortion as a result of that knowledge. The Swedish press reported the phenomenon as "abortion tourism" prompting a debate of whether it was morally acceptable for non-Swedes to decide the sex of their future child by going to Sweden for an abortion.

Time framed taboo transcendence at the end of life

Time-framed taboo transcendence is not only happening at the beginning of life but is also apparent when life and death is controlled in ways that disrupt normality during the last months of life. Practices of euthanasia and assisted suicide (EAS), withdrawal of active life support (such as turning off ventilators), and palliative sedation (where the dying suffering person is put to sleep by drugs) are examples of how the death taboo is being transcended within the time frame of the last weeks or months of life. Abortion is a legal time-framed death taboo transcendence at an early stage whereas EAS is a time-framed death taboo transcendence that terminates the life of a human being at a late stage in life. EAS is illegal in most countries and jurisdictions but is de-criminalized or de-penalized in some countries (e.g. the BeNeLux, Canada, and Colombia, whilst physician assisted suicide is legal in five states in the United States of America: Montana, New Mexico, Oregon, Vermont, and Washington (3). In 1942, Switzerland de-criminalized the act of assisting someone to commit suicide if not done for selfish reasons. Swiss physicians are not actively involved in assisted suicide apart from prescribing the necessary drugs.

Withdrawing or withholding life support

Withdrawing life support therapy (e.g. ventilator treatment) at the end of life is legal in many countries but illegal in some countries such as Israel, and questionable in many other countries such as Sweden. In Sweden, there have been a few judicial cases of withdrawal of life support where the legality was questioned and physicians accused of malpractice. In consequence, the ethics delegation discussed the option of using delayed response timers to allow a ventilator to be set for a week, or shorter. The ventilator will then stop working when the time is up without human intervention. This practice is tried

in Israel and, if used in Sweden, would bypass laws or legal problems of withdrawing life support since in many cases it is legal to withhold a continuous life support treatment. When the timer need re-setting, a further decision is required of medical staff, often in consultation with relatives, as to whether to withhold or continue the life support ventilator therapy. Not resetting the ventilator will eventually "kill" the patient, but this is then withholding and not withdrawing treatment (4). This circumventing procedure can be seen as an activity to transcend the death and dying taboo.

Palliative sedation – reversible or irreversible?

Palliative sedation means to put a suffering dying person to sleep by the use of sedative drugs. If the sleep is reversible, so that the person can be woken, then the practice of palliative sedation is uncomplicated from a legal and ethical perspective in most countries. It is a medical treatment meant to relieve severe pain and anxiety at the end of life. Indeed, the Roman Catholic concept of "double effect" allows a treatment that may unintentionally hasten death if the purpose is to relieve suffering.

Palliative sedation could however also be achieved by increasing the dose of sedative drugs until the patient's consciousness and breathing capacity is depressed until death arrives. This practice of irreversible palliative sedation is actually euthanasia, except that it is given a nicer name. It is an example of a euphemism, the use of which is not uncommon in the de-tabooing and taboo transcendence discourse. Palliative sedation with this irreversible ending has increased in the Netherlands (where euthanasia is legal if certain procedures are followed) since it reduces the large amount of paper work that comes with the procedures required for traditional euthanasia (5).

To conclude, dying taboos are time contingent since transcending taboos in the field of death and dying depends on timing of death. Abortion is always taboo after a certain gestational age. Euthanasia and withholding life support are taboos in persons with an anticipated significant foreseeable future. Time transcendent death taboos can be seen as a "theory bit" from Detabooing dying control (2).

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Grappling with the Suicidal Monster: A Grounded Theory of how Parents Experience Living with Suicidal Distress

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Background

Suicidal behaviour is a significant public health concern given the strong association between acts of self-injury and death by suicide—particularly among young people where rates of self-injury are steadily increasing (National Suicide Research Foundation, 2017). Furthermore, carers including parents, relatives, and significant others are being allocated increasing responsibility in assisting mental health care services in the early detection and management of family members at risk of suicide (Chiang, Lu, Lin, Lin, & Sun, 2015). Thus, it is essential to understand how this vital role is experienced by parents in order to ensure that sufficient supports are made available to them. However, there is a paucity of literature relating to this phenomenon. This grounded theory (Glaser & Strauss, 1967) study generated a substantive theory about how parents experience living with young adults who are in suicidal distress.

The main concern

The main concern, keeping my child alive, describes the sole focus of the parents throughout the young persons' suicidal distress. Parents' thoughts, fears, and imaginations act as driving forces where they become preoccupied regarding the dangers to which their children may succumb because of their suicidality, rendering a "monster" to be reckoned with for a sustained period in their lives.

The core category/theory: Grappling with the suicidal monster

Grappling with the suicidal monster offers a novel theoretical understanding of the three-staged psychosocial process participating parents undergo to resolve their core concern. It describes how they struggle to understand the suicidal distress that their adult children are experiencing and the various protective actions they take to address this issue. While each progressive stage lessens in intensity and worry for parents, the experience has a profound and prolonged impact on their overall functioning and well-being.

Unmasking the monster

The first stage of grappling with the suicidal monster is unmasking the monster, which describes the processes the parents engage in as they begin to suspect that something might be wrong with their child. They notice changes in their child's behaviour, which lead them to feel increasingly on edge and concerned for their child's welfare, while not

wholly understanding what they are witnessing. They endeavour to communicate with their child about what is happening and become preoccupied with how they might protect them from this new and uninvited intruder into their lives.

Living with the monster

The next phase, living with the monster*,* reflects how the parents, consumed by their need to keep their child safe, enter a prolonged state of heightened fear. Due to this intense focus on their children, daily routines become less important to uphold, with some parents unable to concentrate on tasks, such as working or engaging in activities outside the home. The parents also withhold expressing their own feelings and monitor how they interact with their child for fear of inadvertently making the situation worse. Being continuously on guard results in sleep deprivation and a decline in their own mood. While seeking support for themselves is not a priority, some parents find support in their significant others, specialty programmes, or through creative relaxation exercises.

Surviving the monster

The final phase, surviving the monster, describes how, as the suicidal distress of their child begins to dissipate, the parents struggle to leave this traumatic experience behind and return to life as they had previously known it.

Application of the theory to mental health practice

The substantive theory, grappling with the suicidal monster, offers a theoretical framework for mental health practitioners to understand and respond to parents of young people in suicidal distress, particularly in relation to self-care, stress reduction, emotional support, and trauma recovery work. It can be used as a tool to assist in exploring with parents what stage they are undergoing at a point in time, thereby guiding intervention appropriate to each parents' needs.

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Caring with Honor:
A Grounded Theory of Caring for Veterans within the Veterans Health Administration

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Abstract

Veterans comprise a unique culture. Through their military experience, Veterans become ingrained with shared values, beliefs and attitudes that characterize their everyday existence. Health care providers must take into consideration that culture impacts health care seeking behaviors. The theory of Caring with Honor is emerging through the classic GT method. A team of investigators within the VA health care system gathered data from 19 health care professionals via one-on-one interviews. The emerging theory, Caring with Honor, represents an amplifying process whereby health care professionals engage with Veterans through a process of *enculturating, witnessing, connecting, honoring*, and *caring with purpose*.

Keywords: Veterans, military, grounded theory

The U.S. Department of Veterans Affairs (VA) provides eligible Veterans needed hospital and outpatient health care in one of its more than 1,700 sites (U.S. Department of Veterans Affairs, 2017). This paper provides a glimpse at the emerging theory of Caring with Honor that focuses on those who care for patients within the VA system. The theory provides a powerful look at the psychosocial and social cultural processes within the VA health care system. Following is a background of Veterans' health care and a snapshot of the theory and one of the categories that has emerged from interviews with a variety of Veteran and non-Veteran health care professionals who work within the VA health system.

Background

In fiscal year 2015, 44% of all Veterans used at least one VA benefit or service (U.S. Department of Veterans Affairs & National Center for Veterans Analysis and Statistics, 2015a, 2015b). When caring for Veterans, VA employees must go beyond providing traditional health care required by non-Veteran patients. Veterans' health care must also

address Veteran-specific health care issues such as post-traumatic stress disorder, traumatic brain injury, spinal cord injury, military sexual trauma, readjustment difficulties, and war-related illness and injury.

Veterans comprise a unique cultural group. Through their military experience, Veterans share values, beliefs and attitudes that characterize their everyday existence. Characteristics seen within the cultural group include positive qualities such as a strong sense of duty, honor, loyalty and commitment to fellow soldiers. Other less positive characteristics of Veterans include hesitance to seek health care (Malmin, 2013; Denneson, et al., 2015); debilitating feelings of guilt and shame (Denneson, 2015); feeling of loss of sense of self (Johnson et al.; Demers, 2011); reluctance to report physical and mental health concerns that may bring embarrassment and stigma (Malmin, 2013; Simmons & Yoder, 2013); and feelings of weakness for experiencing mental and physical needs (Malmin, 2013). Health care providers must take into consideration that culture influences health seeking behaviors and that understanding cultural aspects will allow care that effectively meets the unique needs of the Veteran population.

Even though Veterans have a high acuity of complex physical and mental health concerns that could make health care delivery challenging, many VA employees find satisfaction with their work. The Department of Veterans Affairs Federal Employee Viewpoint Survey Results (2015) indicates that 72% of VA employees responding to the survey feel their work gives them a sense of personal accomplishment; 92% are constantly looking for ways to do a better job; 84% identify their work is related to the VA's goals and priorities, and 94% rated that the work they do is important.

The theory of caring with honor

The theory of Caring with Honor is a theory in progress based on the classic grounded theory method as described by Glaser (1965, 1978, 1998). The genesis of the theory began with VA health care professionals discussing unique characteristics of Veterans. In order to pursue the theory, conversations were held with an experienced classic grounded theorist. After discussions and grounded theory training sessions, a team of investigators began gathering data from health care professionals within the VA health care system. Data gathering consisted of one-on-one interviews with 19 Veteran and non-Veteran VA health care professionals including physicians, social workers, chaplains, mental health providers, administrators, and nurses. The unstructured interview started with the spill question "Tell me about being a (nurse, doctor, chaplain, mental health provider, administrator, or social worker) working with Veterans. Does your work with Veterans affect the way you deliver health care?" Following each interview, field notes were recorded after which constant comparison, memoing, and analysis proceeded. Following (in italics) are some of the concepts and categories that emerged from the data.

The theory of Caring with Honor represents an amplifying process whereby health care professionals engage with the Veteran through a process of *enculturating, witnessing, connecting, honoring*, and *caring with purpose*. After being employed by a VA health care

system, professionals quickly begin to differentiate between non-Veteran and Veteran health care experiences, explicitly denoting these as "outside" or "inside." As they learn the complex social-structural processes within the VA, health care workers also observe and accumulate information about the Veterans. Their perceptions evolve over time as they begin to understand and appreciate Veterans' unique needs. They begin to deeply appreciate Veterans and become more and more interested in connecting intimately with them in ways that are unlike patient/provider relationships on the "outside." Recognizing that Veterans, especially combat Veterans, live with lingering wounds of their service—inflicted not only by physical injury, but also by the psychological cost of war and, at times, the violation of their own values—health care professionals begin to perceive Veterans' actions with understanding and begin to feel honored to care for them. Honoring of Veterans is an amplifying process that leads health care professionals to a deep commitment to caring for them with purpose.

Because it is not within the scope of this paper to examine each concept of the theory of Caring with Honor, the following discussion offers a glimpse of the category of *witnessing.* After communicating with, reading about, and observing Veterans over time, health care providers who work in the VA system view Veterans with understanding and compassion. They witness words and behavior that lead them to perceive Veterans as unique, with multitudes of problems, many of which are hidden or repressed. Although most providers deal with the myriad physical problems which plague Veterans, nearly all participant responses in this study focused their responses on moral, mental, and spiritual suffering of Veterans. Thus, providers describe many Veterans as "messed up" or "broken," particularly those with combat experience.

Providers come to understand that many Veterans have experienced "awful things" such as seeing fellow soldiers killed or mutilated, children injured, or the suicide of a fellow soldier. Providers begin to understand that many Veterans were required to commit acts in the line of duty that violated their own previous beliefs and values. Combat Veterans may have killed others, perhaps even children. One provider said, "Can you imagine being told right from wrong all of your life and then having to do what you know is wrong. But, you have to do it or you die or your fellow soldiers die. You lose either way." Having witnessed these outcomes, study participants sensed that the impact is so significant that, once deployed, a combat Veteran never comes home as the same person. According to one provider, "They carry around so many stressors that they cannot get back to normal life." Although Veterans may look strong, many problems are unseen and perhaps will never heal. Witnessing Veterans' behavior and hearing their stories changes providers' views over time. For example, one participation stated, "When I first started working here, I got p****d off at them at how they acted. They were noncompliant. Then I started to see in their charts why they are like they are." Another said, "… no wonder they can't function. I don't get angry now. I don't judge. I am a better person now." Both statements give clues as to how VA providers develop an ethos of care with honor.

Conclusion

Over time, those who deliver care to Veterans become aware of the uniqueness of Veteran patients and their culture. Health care providers gain appreciation and understanding and evolve a sense of honoring those to whom they give care. The theory of Caring with Honor represents an amplifying process whereby health care professionals engage with Veterans through a process of *enculturating, witnessing, connecting, honoring*, and *caring with purpose*. A recognition of this process can enhance VA health care employee orientation and speed the process of caring with honor.

Acknowledgements

This material is the result of work supported with resources and the use of facilities at the Louis A. Johnson VA Medical Center, Clarksburg, WV.

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Authors would also like to acknowledge of the immeasurable contributions of other members of the research team: Denise Boehm and Frank "Jay" Ketterman.

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Grounding Anger Management

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One of the things that drew me to grounded theory from the beginning was Glaser and Strauss' assertion in *The Discovery of Grounded Theory* that it was useful as a "theoretical foothold" for practical applications (p. 268). From this, when I was a Ph.D student studying under Glaser and Strauss in the early 1970s, I devised a GT based approach to action I later came to call "grounded action." In this short paper I'll present a very brief sketch of an anger management program I developed in 1992, using grounded action. I began my research by attending a two-day anger management training workshop designed for training professionals in the most commonly used anger management model. Like other intervention programs I had seen, this model took a psychologizing and pathologizing approach to the issue. Following this, I sat through the full course of an anger management program that used this model, observing the reactions of the participants and the approach of the facilitator. Following each session I conducted open-ended interviews with most of the participants, either individually or in groups of two or three. I had also done previous research in counseling and social work contexts that turned out to be very relevant to an anger management program design.

In analyzing my notes, several things stood out. One was that the conventional anger management approach not only didn't work particularly well, but it was actually counterproductive because it unknowingly replicated the conditions that my observations and interviews revealed as the key anger variables. Almost all of the participants whom I interviewed expressed close versions of what one participant said when I asked for his thoughts about the experience, "I'm more pissed off now than I was when I started!" Some participants stayed mum during the sessions because they were court ordered and feared a negative report about their participation. Several participants reported feigning buy-in. A few, who had not been court ordered, sincerely bought in. And several, attempting to preserve their dignity, took the risk of pushing back. These approaches paralleled those I had seen in other contexts.

Most participants clearly didn't like the program's approach. When I asked them what it was they didn't like about it, their responses revealed their main concerns, which I termed "Rodney Dangerfielding." For those who are not familiar with him, Rodney Dangerfield was a now deceased standup comedian and later comic actor whose catch-phrase was, "I don't get no respect." What I discovered was that from their point of view, the anger that put them in their current situation was a consequence of the paucity of respect and power in their daily lives which led to "things never going my way." Although they were willing to accept what they viewed as their "fair share" of responsibility for anger situations, they resented what they viewed as the "unfairness" of always being the bad guy when others involved were seen as their innocent victims. The interviews indicated that they thought the program was just one more experience of these things. The extent to which their views were or weren't

accurate didn't change the fact that an effective anger management program needed to address these main concerns.

Knowing this, I developed an eight-week program of weekly 2 ½-hour evening sessions that focused on their main concerns. Before the first session, intake materials indicated that all of the initial participants had been through at least one prior anger management program, although not always completing them. This probably accounted for their glum, apprehensive demeanor at the beginning of the session. To immediately neutralize this, I began by saying, "This program is new. I've never done this before. If you were me, how would you do it?" The participants were taken aback by my question. In a disbelieving tone of voice, one of them said, "You really wanna know?" I replied, "If I didn't, I wouldn't have asked." This opened them up, giving me even more useful data. Throughout the session, participants were very engaged, animated and in good spirits. From that point forward, at the beginning of each session existing participants put newcomers at ease, doing the work of atmosphering for me.[1]

Grounding my approach in their main concerns, I devised exercises that were designed to help participants gain a fuller understanding of power and respect, how they were related, and how the participants could engender more of both in their daily lives. For example, for one exercise I proposed to participants that they think about the person in their lives for whom they had the most respect and what it was about them that made them feel this way. As they gave their reasons, I listed them on a chalkboard. I then asked, "How many of these things do you routinely practice in your life?" The usual first response, said with a tinge of ironic humor was "none." This evoked the laughter of uncomfortable insight. I then suggested, "Do you think this might be related to your problems?" That opened up what I always experienced as a wonderfully "honest" conversation, upon which I could build.

This is merely a brief, partial description of the full exercise. And, it is only one of several participatory exercises that I developed to lead participants to insights about themselves and the way they were managing their lives and relationships, and most importantly, how they could improve that. This approach and the atmosphere of the sessions generated open, animated, productive conversations in which participants dropped their defensiveness and began to seriously consider their own role in their anger problems.

Although the agency didn't have the resources to conduct a conventional evaluation study, and I have doubts about the value of such studies, there were many strong informal indicators of how well the program worked, such as consistently positive participant reviews, participants who chose to remain in the program longer than required—several years in some cases, the high level of enthusiasm and engagement of participants evidenced by the difficulty I had getting them to leave at the end of sessions, and so forth. I think the success of the program demonstrates the power of GT, as it was first depicted in *Discovery*. I facilitated the program for eight years, until my workload dictated otherwise. When I handed it over to my replacement, I shared my model with him. The program is still operational—25 years and counting.

[1] I'm borrowing this term from Glaser, as he uses it in his opening remarks at his problem solving seminars.

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Mark Maximising in a Context of Uncertain Contribution: a Grounded Theory in Progress

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Graduates in the United Kingdom are expected to possess professional skills fitting them for a successful transition to paid work. Employers tend to value student attributes such as communication skills, initiative and the ability to work well with others. Assessed group work at university has been seen as a way of promoting these skills and qualities, however it is not always popular with students, who can experience problems when working together.

This practical study is intended to better understand 'what is going on' (Glaser, 1998, p.5) for students in order to inform practice. The substantive population comprises computing students and the substantive area of interest is assessed group work where marks contribute to the classification of the final higher educational award. The analysis to date has produced the shape of a grounded theory but further work is required to understand more about the students' behaviours and we plan to continue the study from October, 2017 to both update and densify the study. A literature review has yet to be conducted, and, as is consistent with the grounded theory method, will be conducted once we are secure in our updated theory.

A study about risk to marks

Glaser states that a grounded theory is a study about a concept (2010): this grounded theory is a study about risk: structural and procedural risk to marks. It emerged from analysis that students are mark driven: the higher the value of marks, the greater the contribution these marks make to a student's final degree class, the greater the student's propensity to contribute effort to the assessment. Students prioritise work according to its value, where the currency is assessed marks.

It further emerged that the main problem facing students undertaking group work is not how hard they work but whether the members of their group will contribute both the time and the mental energy (effort) appropriate to produce the required output. Students are concerned with the uncertainty of contribution and the concomitant risk to their marks and their final degree classification. Our current understanding is that students process this concern using mark maximising behaviours, which mitigate or increase the risk to marks, whilst operating in a context of uncertain contribution, under conditions of assessed group work, where there behaviours are contingent upon group composition. Student behaviours covary according to the perceived risk and the consequence of mark maximising behaviours is a student's final degree classification.

These concepts will be explained in turn. When the theory is better developed, we shall be able to structure the explanation such that the focus is on the patterns of behaviour within constraints: the focus will be more on the relationships between the concepts, rather than by individual concept.

Uncertain contribution

Is this group member going to do the work? On time? To a good standard? If the answer to one or more of these questions is 'I don't know' or 'maybe', the context becomes one of uncertainty.

Students, however, prefer to work in a context of certainty. At the beginning of a course, reputations are unformed and students are unable to answer the 'contribution evaluation questions' above. As the course progresses and reputations are formed, students can be more proactive over achieving a greater certainty of contribution when forming groups and in the performance of the group work.

Group composition

The risk to marks is contingent upon the group composition: there are groups that perform better and groups that perform worse. What impacts on performance is the combined capability of the group, their propensity to contribute effort (time and energy) and their affability.

Students therefore prefer to work with people whose reputations are known to them, where what is known is that person's particular combination of capability, propensity to contribute effort and affability. Where these things are known, contribution can be managed such that uncertainty of contribution and the concomitant risk to marks, is reduced. Where these things are not known, uncertainty of contribution follows and risk to marks is perceived.

Mark maximising

The students' need for marks drives mark maximising behaviours from an early stage. In the hiatus between group work being assigned and groups forming, uncertainty is high: the more valuable the group work the higher the tension. Where students may form their own groups, students aim to create their optimal group using a strategy of quick clustering: in the later years of a course, groups can be formed in seconds on the nod of a head and the wink of an eye. Often, especially early in a course, groups are assigned, membership imposed.

Perceived risk

What varies what students do as they attempt the assignment, is perceived risk to marks (Table 1).

Table 1: Perceived risk

Perceived risk to marks	Certainty of contribution	Mutual trust	Reputations
High	Certain (to be poor)	Low	Known (to be 'poor')
Middling to high	More uncertain	Low	Unknown
Middling to low	Less uncertain	High	Unknown

Table 1: Perceived risk

Perceived risk to marks	Certainty of contribution	Mutual trust	Reputations
Low	Certain (to be optimal)	High	Known (to be 'good')

Where perceived risk to marks is highest, group work is conducted in a context of certainty: group members are confident that the work submitted will be compromised, will be to their collective standard and may be late. Where perceived risk is lowest, groups tend to work well producing work on time to their collective standard.

In this study the prevailing context for most of the people most of the time was uncertainty and the perceived risk to marks was middling or higher.

Performing, rescuing and compensating

The context of some groups changes from more certain to more uncertain as temporal organisation points pass and contributions are unrealised: the non performance of a group member becomes visible and the perceived risk to marks increases.

When non-performance is noticed, group members will contact the non-performing student to encourage and later to exhort the student to contribute. As the assessment deadline approaches, group members will compensate for the work undone by performing it themselves. Sometimes because of the design of the group work, non-performance may only be noticed at a late stage: the heroic may feel the need to go to extreme lengths to compensate perhaps pulling 'all nighters' to finish the work. The tension and anxiety of group members in the period between encouraging and compensating is extremely uncomfortable: they are wracked with indecision about what to do about the non-performing student not wishing to offend or cause ructions. They are cogniscent that relationships have to be maintained beyond this coursework. When group members know that a student has a low propensity to contribute, they can plan to integrate the work earlier in the assessment timeline.

Assessed group work

The main work of the group is the negotiation of ideas and the negotiation of work process: an important aspect of process is temporal. The main dimensions differentiating assessment design relates to the degree of conceptual integration and the degree of temporal integration required. The four main types of assessment design to emerge from this study are colouring-wheel, domino, jigsaw and woven, where design impacts on the timing and the nature of group work rescue.

1. The colouring-wheel design means that the work can be easily segmented and each piece of work is independent of the other temporally and conceptually. There is very little or no negotiation of either ideas or process. The final artefact is assembled by matching the pieces at the edges.

2. The domino design requires sequencing of work and thus each piece of easily segmented work is temporally and conceptually dependent on earlier pieces. There is some negotiation of process and ideas.
3. The jigsaw design has easily segmented pieces of work which are interdependent. The ideas have to be negotiated at the margins and the overall shape and picture has to shared. There is considerable negotiation of process and ideas.
4. The woven design is fully integrated and requires close and continuous negotiation of process and ideas.

For the colouring wheel design, the non-performance can be obscured until the final assembly of the finished physical, digital and/or conceptual artefact. Options to rescue at this point are limited and can result in heroic efforts to compensate for missing work or result in work with missing or compromised segments submitted. Where a group has a student with a poor reputation, (non) performance can be monitored and compensating work integrated more strategically.

For the domino design, timely contribution is critical. Non-performance of an early piece of work on which others rely can create scheduling problems for other group members. The later that group members accept the non-performance and compensate for it, the greater the effort that the remaining group members have to contribute in a shorter timeframe and/or the more the quality of the finished artefact is likely to be compromised. Where a group knows that has a student with a poor reputation, allocating that the student the final piece of work can enable other group members to complete their work and leave time to compensate for non-performance in a slightly less stressful way.

For the jigsaw design, group members performing the work can progress without the non-performing student up to a point. Artefact designs can be shaped and communicated to the non-performing member and the work of the other group members can continue. The sooner that non-performance is noticed, the sooner that the remaining group members can compensate but due to the interlocking nature of the design, the final product is likely to be compromised.

For the woven design, non-performance will be noticed very early in the process. Either the remaining group members have to put in a great deal more effort for the duration of the coursework (potentially to the detriment of other course works) or the work submitted is compromised.

Consequences

The aim of mark maximising behaviours is to reduce the risk to marks whilst the group work is performed and to achieve optimal marks which contribute to the student's final degree classification.

Conclusions

Whilst this theory is incomplete, the practical implications for group work design were evident. Consistent with Glaser's advice (2014) some concepts from the theory were applied to facilitate the performance of group work. We plan to continue with theoretical sampling in October, 2017 to find out more about the effect of the changes made and about what students

do to in different contexts of uncertainty and under different assessment designs. A next step for the grounded theory perspective is encourage the neglected option of applying grounded theory (Glaser, 2014). It is also a planned future step for this theory.

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Becoming Comfortable with MY Epilepsy: The How*2*tell Study

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Introduction

This short paper on Becoming comfortable with MY epilepsy is part of the How*2*tell study on disclosure and epilepsy. The purpose of the study is to explain how people with epilepsy (PWE) disclose information about their condition and, using this knowledge, develop a multi-media educational resource that will support PWE learn how to tell other people about their epilepsy. The inductive approach of grounded theory (Glaser, 1998) allow for a viable means to generate a robust explanation about disclosure—one that was grounded in the realities of PWE everyday life. From a healthcare and policy perspective (England, Liverman, Schultz, & Strawbridge*,* 2012), providing access to relevant and usable knowledge for people with epilepsy that meets their individual needs is important to enable them to participate effectively in self-care management. Grounded theory, therefore, was essential to the How*2*tell study, which was successfully awarded a research grant from the highly competitive Health Research Board and Epilepsy Ireland's research grant programme.

Methods

To gather data on first-hand experiences of disclosure and epilepsy, in-depth interviews were carried out with 49 consenting adult people with epilepsy (18 years and over) in Ireland. In the early stages of concurrent data gathering and analysis, becoming comfortable began to emerge as a tentative category. Later, as data gathering, analysis and theoretical sampling progressed; the category was further developed to becoming comfortable with MY epilepsy.

Becoming comfortable with MY epilepsy

"*I knew about it [epilepsy] to a degree, but not on a personal level . . . not the experience of it."*

A major concern identified by participants in the How*2*tell study related to feeling ready to start talking about their epilepsy with other people. At the time of being newly diagnosed with epilepsy, participants were at the beginning stage of coming to terms with the diagnosis and trying to understand how epilepsy would affect them personally in everyday life. Importantly, participants did not feel ready to talk about their epilepsy with other people until they felt comfortable with the epilepsy diagnosis and, in particular, their type of epilepsy.

Becoming comfortable with epilepsy was a gradual process and developed over time. As part of the process, participants used four main strategies that helped them

reach a point of feeling ready to talk about their epilepsy. The first strategy, becoming knowledgeable with MY epilepsy, involved sourcing information that was relevant to their particular type of epilepsy. Epilepsy is a complex neurological condition and encompasses a broad spectrum of different types of epilepsy and seizures, so that newly diagnosed PWE realize that they need to learn about the complexities of managing their epilepsy. Another strategy that participants use is becoming a member of an epilepsy support group. Although information on epilepsy was readily available from healthcare professionals, information booklets, Internet, and specialty epilepsy websites, participants find that joining a support group where they could meet other people with epilepsy and, importantly, meet people with their type of epilepsy is particularly helpful in becoming comfortable with MY epilepsy. A third strategy PWE use is to confide in a close friend or family member. The first time they tell someone about their epilepsy, they usually choose to tell someone who is close to them and whom they trust. Saying the word epilepsy out loud, getting used to talking to close friends, and dealing with their reactions help PWE to become more comfortable in talking about their epilepsy. The fourth strategy involves practicing telling, which is particularly helpful for disclosure in formal contexts such as a job interview, line-manager at work, or academic course director at a university/college.

"I realized that… if I could accept it, it would be fine."

Conclusion

Becoming comfortable with MY epilepsy is a gradual process and PWE use these strategies to help them to accept their diagnosis and to reach a stage of feeling ready to talk about their epilepsy. The benefit of using Glaser's grounded theory approach is that becoming comfortable with MY epilepsy is grounded in the experiences of people with epilepsy. This is an important part in the design and development of the How*2*tell multi-media educational resource. As a self-management support for PWE, it is hoped that the new How*2*tell smartphone app, website, and booklet will be of benefit to PWE empowering them with practical knowledge about how to tell other people "I have epilepsy". It is also recognized that further research is needed to check if becoming comfortable with my epilepsy patterns out with other PWE in different cultural contexts and outside of Ireland.

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Book Review: Replacing The Discovery of Grounded Theory

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Glaser, B. G. (2016). The Grounded theory perspective: Its origin and growth. Mill Valley, CA: Sociology Press.

This book is Glaser's fourth in Sociology Press' perspective series. The first book in this series was about "conceptualization contrasted with description". The second book was about "description's remodeling of grounded theory methodology"; the third book was about "theoretical coding".

The overriding purpose of all books written by Glaser is to help novice CGT researchers in their dissertation work, often without any mentor involved. In this Glaser's fourth book in the perspective series, the overriding purpose is the same as in the other three books, but special emphasis is on doing good CGT by learning to do CGT by example. People learn better by example. The book facilitates learning by example by providing a listing of earlier CGT works.

Another emphasis in this fourth book is to draw attention to the historical origin and growth of the classic grounded theory perspective. Consequently, the book sums up and links to all the coherent "constituent parts" of the CGT perspective and it gives an overview of and a linking to Glaser's work since the 1960s (the preceding 50 years).

For example, many grounded theories within medical sociology have been published in many different journals. To obtain a copy of all these works is almost impossible and too time consuming for an individual researcher. However, Glaser has done the work. He can provide his readers with access to 59 published articles within medical sociology. This access will facilitate learning CGT by example. A balanced learning by example takes place as (1) reading and comparing of earlier CGT works, (2) supervised (if possible) practical use of the CGT procedures, and (3) a reading of a prioritized selection of CGT methodology books.

The contrast between this fourth book and the first GT book (*Discovery of Grounded Theory* [Glaser & Strauss, 1967]) is enormous. So much has happened in the advancement of CGT during these last 50 years that the" discovery book" in my view is becoming increasingly antiquated as a pedagogical tool. A replacement by *The Grounded Theory Perspective: Its Origin and Growth* (Glaser, 2016) can safely take place. We need a book that goes straight to the most important and problematic element.

On the website of Sociology Press, the publisher suggests the following prioritized reading list for researchers new to classic grounded theory:

1. Start by reading the foundational works (in this order):

a. The Discovery of Grounded Theory (Glaser & Strauss, 1967)
b. Theoretical Sensitivity (Glaser, 1978)
c. Basics of Grounded Theory Analysis (Glaser, 1992)
d. Doing Grounded Theory (Glaser, 1998)

2. Read examples of grounded theories:

a. Try one of the Readers listed in our Index of publications
b. Subscribe to The Grounded Theory Review

3. Next, study the Perspectives Series

a. The Grounded Theory Perspective: Conceptualization contrasted with Description (Glaser, 2001)
b. The Grounded Theory Perspective II: Description's Remodeling of Grounded Theory Methodology (Glaser, 2003)
c. The Grounded Theory Perspective III: Theoretical Coding (Glaser, 2005)

It is remarkable that the "discovery book" is number one on this current list. As mentioned earlier, it could be replaced as number one by *The Grounded Theory Perspective: Its Origin and Growth*. It follows ordinary logic to replace the oldest by the newest.

The understanding of the classic grounded theory (CGT) perspective is, of course, the prerequisite for the use of the CGT methodology. It is also the prerequisite for supervising PhD students in their CGT research, for peer-reviewing CGT research, and for teaching the methodology. Lack of understanding of the CGT perspective will by default lead to a remodeling of CGT.

On the other hand, the understanding of the CGT perspective is not the same as an understanding of the methodology and its practical procedures. The CGT procedures are best learned by practical research efforts (supervised whenever possible), balanced by a systematic reading of the methodology books and of literature that demonstrates CGT by example.

Then, what is the GCT perspective? I can only give my own summary:

The CGT perspective is about a methodology for discovering and generating theory directly from data instead of logically deriving theory from presupposed premises and subsequent testing/verifying of hypotheses. It is about avoiding all preconceived professional interest concern of the researcher (including preconceived ontological and epistemological assumptions that are best replaced by a pragmatic attitude), in favor of the discovery of the substantive interest concerns of those being studied. It is about the discovery of the "main concern" of those being studied and their recurrent solving of their main concern by their actual behavior. It is about what drives and directs the behavior of those being studied; consequently, it will also be the discovery of the most relevant, important and problematic for those being studied and of its recurrent solving. It is about explaining most of the variation in the data (behavior) while accounting for the recurrent solving of the main concern.

CGT is philosophically (almost) neutral. This means that is has nothing or almost nothing to say about ontology and epistemology. Its philosophical stance is limited to the assumption that social life is patterned, and that these patterns can be discovered and explained by the methodological approach of CGT. This methodological approach is also a modifiable classic grounded theory that has "conceptualizing" as its core variable. The (almost) philosophical neutrality of CGT also means that CGT is a perspective and a paradigm as well as a modifiable classic grounded theory of research design and research procedures.

People who know nothing about CGT are usually surprised, when they hear or read about the CGT perspective. Many preconceive it to be something else. For many, the *raison d'être* of CGT becomes obvious. The CGT perspective is not better, it is just different, but it cannot be mixed with other approaches without losing its potential and *raison d'être*.

Book Review: Grounded Theory in Perspective: A Lifetime's Work

Helen Scott, PhD, Grounded Theory Online

Glaser, B.G., (2016). The Grounded Theory Perspective: Its Origin and Growth. Mill Valley, CA: Sociology Press.

The grounded theory general method of research was Glaser and Strauss' response to the problem of "superthink": the generation of hypotheses in the field of sociology without recourse to data. Glaser and Strauss observed that since such hypotheses were of little relevance, pursuing them wasted resources and had fateful impact on young researchers' careers. Glaser and Strauss preferred to ground their hypotheses in data that was from the field and was of relevance to their participants. The resultant development of the grounded theory method to maturity has taken decades of dedicated, scholarly endeavour. Glaser explains and examples how this has been achieved in his new book: *The grounded theory perspective: Its origins and growth*.

Glaser writes that in the early years, the young method was particularly vulnerable to friendly (and not so friendly) appropriation by researchers eager to conduct qualitative research at a time when "qualitative data analysis" (QDA) (p. 117) was also in its infancy; its perspectives and language undefined. His publication list shows us that the assault of QDA on grounded theory has been prolonged and continuous.

Establishing and maintaining the integrity of the grounded theory general research method as conceptual and scientific has therefore been a key concern of Glaser over this period. He has addressed this concern by:

- realising, explicating, and disseminating the grounded theory perspectives; and,
- clarifying, elaborating, and differentiating the grounded theory perspectives from other methodological perspectives.

Glaser's tools are his books and papers, his seminars and the growing library of his students' theories through which he explains and examples the grounded theory method. As he has conducted this effort, the use of the grounded theory method has expanded into many disciplines in many more countries.

This book's proposition is that understanding the GT perspective and its development is needed when doing and explaining GT (p. 1); its aim is to bring "most of the GT perspectives under one cover" (p. 2).

In the first chapter, Glaser gives us a fascinating overview of the growth of the grounded theory method organised by idea rather than chronologically. The second chapter intends to show the growth of grounded theory over 40 years citing theories from the field of medicine. It is intended that students read the theories for examples of the conceptual ideas used as well as how the ideas are structured and presented. The theories themselves are not

published here but can be obtained directly from Glaser. Chapter 3 introduces the technique of exampling and its usefulness as a way of supporting students' learning. The chapter also explains some of Glaser's realisations about the method, which he then codifies as perspectives. The papers referred to but not listed in this chapter example the growth of grounded theory from 1984 to 1994. Chapter 4 lists theories that show successful conceptualisations and demonstrate the use of grounded theory procedures. It also explains further realisations and developments to the grounded theory perspective, some of which are noticed as implications of the selected theories. Chapter 5 lists theories to refocus the grounded theory perspective following the challenges to the grounded method caused by Strauss and Corbin's 1988 publication and Glaser's response in 1992. Chapter 6 lists examples of theories of good quality, produced by seminar alumni.

Readers are collections of papers brought together for a specific purpose for the convenience of the person reading. This book is the 7th reader in the grounded theory reader series (p. 25). The first six were designed to example current use of the grounded theory method. Chapters 3 to 6 of this book uses four earlier readers (1995, 1996, 1994, 2007) as the source material to show the origins and growth of grounded theory: the *examples of the then current state* of grounded theory are used here to *example the growth* of grounded theory. Repurposing materials in this way requires careful integration. Chapter 3 confused me utterly. I needed a clearer indication that pages 34-60 formed the introduction to the 1984-1994 reader; a list of the 48 papers referred to as "the following papers" (p. 25); and since some references were amended and others were not (e.g. p. 52), I needed consistent terminology that either repurposed all of the references to the reader or none of them. Since you are forewarned, my hope is that you will be able to see past this and engage more directly with the ideas.

This book is deceptive. It is very thin but it has captured my attention for far longer than I had scheduled: it has triggered new ideas such that I have found myself referring to the original publications, stared for long periods at the sky, and subsequently updated and rearranged my ideas. It has given me a framework for understanding the publications and, with its overview of the grounded theory perspectives, has given me a conceptual tool with which to differentiate more concisely the grounded theory method. I can't wait to give it a go.

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Barney G. Glaser is the cofounder of grounded theory (1967). He received his PhD from Columbia University in 1961. He then went to University of California San Francisco, where he joined Anselm Strauss in doing the dying in hospitals study and in teaching PhD and DNS students methods and analysis. He published over 20 articles on this research and the dying research. Since then, Glaser has written 14 more books using and about grounded theory and countless articles. In 1998, he received an honorary doctorate from Stockholm University. Email: bglaser@speakeasy.net

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