

**A GROUNDED THEORY APPROACH TO PHYSICAL ACTIVITY AND
ADVANCED CANCER: A QUALITATIVE STUDY PROTOCOL**

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Abstract

Background: Physical activity has demonstrated benefits on cancer-related fatigue and physical functioning in early stage cancer patients, however the role of physical activity at the end stage of cancer has not been established. To challenge positivist-empiricist assumptions, I am seeking to develop a new theoretical framework that is grounded in the advanced cancer patient's experience of activity. **Aim:** To gain an in-depth understanding of the experience of activity and quality of life in advanced cancer patients. **Objectives:** 1) To explore the meaning of activity for advanced cancer patients in the context of their day-to-day life, 2) To elicit advanced cancer patients' perceptions of activity with respect to their quality of life, and 3) To elicit advanced cancer patients' views of barriers and facilitators to activity in the context of their day-to-day life. **Study Design:** A two-phase, cross-sectional, qualitative study will be conducted through the post-positivist lens of subtle realism, and informed by the principles of grounded theory methods.

Study Methods: Advanced cancer patients will be recruited through the outpatient department of a tertiary cancer centre. For Phase One, participants will wear an activPAL™ activity monitor and fill out a daily record sheet for seven days duration. For Phase Two, the activity monitor output and daily record sheets will be

used as qualitative probes for face-to-face, semi-structured interviews. Concurrent coding, constant comparative analysis and theoretical sampling will continue with the aim of achieving as close as possible to theoretical saturation. **Ethics and Discussion:** Ethical and scientific approval will be obtained by all local Institutional Review Boards (IRBs) prior to study commencement. The findings will generate new mid-level theory about the experience of activity and quality of life in advanced cancer patients, and aid in the development of a new theoretical framework for designing interventions for this population.

Keywords: Grounded theory, physical activity, palliative care, cancer, quality of life

Author's Note: This study protocol will be conducted in partial fulfilment of the first author's PhD in Palliative Care degree at Lancaster University, under the supervision of the last author (80%) and the second author (20%), and under the local sponsorship of the third author. The first author will independently conduct all aspects of the study protocol, as indicated by the use of the first pronoun therein, unless otherwise specified.

Background And Study Justification

Quality Of Life In Advanced Cancer Patients

The World Health Organization (2013) defines palliative care as an interdisciplinary approach towards the relief of suffering caused by physical and psychosocial problems in patients facing life-threatening illness. The primary aim of palliative care is to optimise quality of life, which is a subjective, multidimensional construct encompassing several aspects of physical and psychosocial wellbeing (Cella, 1994). Physical symptoms, such as weakness and fatigue, and psychosocial symptoms, such as depression and anxiety, contribute to significant deterioration in quality of life in advanced cancer patients (Gilbertson-White et al., 2011), that is those with progressive, incurable and locally recurrent or metastatic disease. Palliative care therefore seeks interventions which could ameliorate these distressing symptoms, in order to improve patient well-being and enhance overall quality of life.

In a cross-sectional survey of 3,030 patients from European palliative care centres, two of the most prevalent symptoms were generalized weakness (50%) and fatigue (48%) (Laugsand et al., 2009). Fatigue, which is defined as “a subjective feeling of tiredness, weakness or lack of energy” (Radbruch et al., 2008,

p.15), is amongst the most distressing symptoms in cancer patients (Stone et al., 2000). Mallinson et al. (2006) demonstrated a negative correlation between self-report fatigue scores and physical functioning scores in cancer patients receiving chemotherapy. Fatigue impairs an individual's ability to perform activities of daily living, including basic self-care (BADLs) such as bathing and transferring positions, and instrumental self-care (IADLs) such as housework and preparing meals (Struck and Ross, 2006). An individual's perceived loss of physical function therefore has a detrimental impact on the quality of life of advanced cancer patients.

Physical Activity As A Behavioural Intervention In Cancer Patients

Given the negative impact of fatigue and loss of physical function on quality of life in cancer patients, recent attention has been given to behavioural interventions to try to improve these outcomes (McMillan and Newhouse, 2011). Physical activity is one such behavioural intervention which has been found to improve fatigue and physical functioning outcomes in healthy adult populations (Ferreira et al., 2012, Reiner et al., 2013, Warburton et al., 2010). Physical activity is defined as any bodily movement produced by the skeletal muscles that results in a substantial increase in energy expenditure over resting levels. In contrast, exercise is any

form of physical activity undertaken by an individual during leisure time and performed repeatedly over an extended period with the goal of improving fitness or health (Bouchard and Shephard, 1994). The positive effects of physical activity in healthy adults has fuelled interest in determining whether and how these interventions can be applied to cancer patients.

Multiple systematic reviews highlight a growing consensus that moderate- to vigorous-intensity physical activity can improve several aspects of physical and psychological well-being that contribute to quality of life in early stage cancer patients (Speck et al., 2010, Fong et al., 2012, Mishra et al., 2012b). The American Cancer Society's most recent guidelines recommend regular exercise to cancer patients both during and after treatment, for improved quality of life (Rock et al., 2012). These conclusions, however, are drawn from an evidence base that is largely restricted to early stage cancer patients who are able to participate in moderate- to vigorous-intensity exercise interventions.

Physical Activity As A Behavioural Intervention In Advanced Cancer Patients

Given that disease progression is associated with worsened fatigue, loss of physical functioning and deterioration in overall quality of life (Giesinger et al., 2011), there is a lack of clarity about whether physical activity can positively

impact these outcomes in advanced cancer patients. The first author conducted a systematic review that showed preliminary evidence that at least some palliative care cancer patients were able to tolerate physical activity interventions, with some demonstrating improvement in quality of life outcomes post-intervention (Lowe, 2009a). A subsequent review concluded that there was insufficient evidence to support efficacy of exercise as an intervention in patients with metastatic cancer, although it was acknowledged that not all studies with palliative or end stage cancer were included (Beaton et al., 2009). Another review identified preliminary studies supporting the feasibility of physical activity interventions in advanced cancer patients (defined as post-diagnosis and post-treatment but before disease recurrence or death) (Albrecht and Taylor, 2012). Given the limited evidence base, any claims related to the role of physical activity in the advanced cancer population are premature.

Following the first author's systematic review, a pilot survey was conducted wherein 50 advanced cancer patients were recruited from an outpatient palliative care clinic and palliative home care, with a median survival of 104 days from time of survey to time of death (Lowe, 2009b). Walking was the most common reported physical activity. There was a positive association between patients who reported

walking 30 minutes or more per day, and higher existential, support and total quality of life scores on the McGill Quality of Life Questionnaire. Using the Theory of Planned Behaviour, affective attitude, self-efficacy and intention were the strongest correlates of total physical activity levels in this sample (Lowe, 2012). The majority of participants indicated that they would be interested in and felt able to participate in a physical activity program, with a majority preference for walking and home-based programs (Lowe, 2010).

Using the same recruitment strategy, the first author conducted a pilot uncontrolled pre- to post- intervention trial in a sample of advanced cancer patients with a median survival of 92 days (Lowe, 2013). Informed by the results from the pilot survey (Lowe, 2009b), a six-week home-based intervention was developed and involved a daily walking program with supervised strength training component three times per week. There was, however, low recruitment and high attrition, with only three of nine recruited participants completing the intervention (Lowe, 2013). Declared interest to participate in a physical activity program (Lowe, 2010), and a positive association between patient-reported physical activity and quality of life (Lowe, 2009b), did not translate into the feasibility of a theoretically-informed physical activity intervention in this advanced cancer sample (Lowe, 2013).

Reflexivity And My Role As A Positioned Subject

As the lead author and researcher of this study, the remainder of this paper reflects upon my epistemological-ontological paradigm shift, and how challenging my previous positivist-empiricist assumptions informed the study methodology. Denzin and Lincoln (2011) assert that “research is an interactive process shaped by one’s personal history, biography, gender, social class, race and ethnicity” (p.5). My clinical training and practice has been conducted within the paradigm of evidence-based medicine (EBM), which is defined as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (p.71) (Sackett et al., 1996). Goldenberg (2006) argues that EBM is fundamentally positivist in its “elimination of culture, contexts and the subjects of knowledge production from consideration” (p.2622). In keeping with the positivist-empiricist paradigm, EBM assumes that any claim must stand or fall in light of evidence as objective and value-free `facts` about the world. My clinical education and training prioritized quantitative methodology, with randomized controlled trials being considered the gold standard in the hierarchy of evidence (Kaptchuk, 2001).

Personal reflexivity refers to personal reflection upon the ways in which the researcher's own experiences, values, beliefs, interests and social identities have influenced the research (Willig, 2008). In conjunction with my professional background, my personal experiences have likewise influenced my research interests. I have both seen and experienced the benefits of physical activity on quality of life through teaching adults to be more physically active, and being physically active myself. Each of these anecdotal experiences has informed my core assumption that physical activity is fundamentally good.

Epistemological reflexivity is defined as reflection upon the assumptions about the nature of the world and the nature of knowledge, and the implications of these assumptions for the research and its results Willig (2008). Upon reflection of its underlying assumptions, physical activity research is predominantly positivist-empiricist in approach (Wheeler, 1998). The "predominantly positive face" of physical activity (p.242) (Wheeler, 1998) is substantiated by a large body of quantitative, rational-empirical evidence (Ferreira et al., 2012, Reiner et al., 2013, Warburton et al., 2010). Moreover, there is a growing body of quantitative evidence supporting the benefits of physical activity in the quality of life of cancer survivors and cancer patients undergoing active treatment (Mishra et al., 2012a,

Mishra et al., 2012b). Thus, this quantitative focus, and the positivist-empiricist assumptions underlying physical activity research, would suggest that physical activity may be beneficial at all stages of the cancer trajectory, including for advanced cancer patients.

Reflexivity encompasses the researcher's continuous, active reflection throughout all stages of the research process, which is influenced by the researcher's own values and beliefs (Carter and Henderson, 2005). Both my personal experience and professional training have contributed to my research interest in physical activity and palliative care. Given that palliative care aims to maximise quality of life (WHO, 2013), and that physical activity improves the quality of life in diverse populations (Ferreira et al., 2012, Reiner et al., 2013, Warburton et al., 2010), my core assumption is that what is beneficial for healthy adults and early stage cancer patients, should also be good for advanced cancer patients.

A Fundamental Paradigm Shift

According to the updated Medical Research Council guidance, failure of implementation of a complex intervention necessitates thorough evaluation of the processes and underlying assumptions at the development stage (Craig et al., 2008). My previous research demonstrates a fundamental gap between the high

level of interest expressed by advanced cancer patients in undertaking a physical activity intervention, and the low level of actual participation of the intervention that resulted. My use of extant theory (i.e., the Theory of Planned Behaviour (Ajzen, 1991)) within a positivist-empiricist approach, and my positive assumptions regarding physical activity, did not enable me to bridge this gap. The findings from my previous research highlight tension between the *etic* (outsider) perspective regarding the “predominantly positive face” of physical activity (Wheeler, 1998, p.242), and the *emic* (insider) perspective of advanced cancer patients on the actual experience of physical activity.

Reflecting upon my previous research, I recognize that my positivist-empiricist approach and my assumption of the inherently positive nature of physical activity became the perceptual lenses through which I addressed this research problem. The very research questions that I formulated, and the methodological approach which I used to address these questions, may themselves have been the barriers which prevented me from understanding the meaning of physical activity for advanced cancer patients. Had I continued to follow my previous positivist assumptions then the resulting research would be “merely the production of bricks

rather than a systematic approach to building knowledge based on sound theoretical modelling” (p.243) (Wheeler, 1998).

As a result I have opened myself up to an epistemic-ontological paradigm shift. My previous research demonstrates that extant theoretical frameworks about physical activity in cancer cannot be applied as if “one size fits all”. Indeed, as these were not developed from research in the advanced cancer population, they are not likely to be applicable. I seek to challenge my previous positivist-empiricist assumptions, and to develop new theoretical frameworks that are both grounded in and applicable to the advanced cancer patient’s experience.

Ultimately, I seek to understand the meaning of physical activity to advanced cancer patients within the context of their day-to-day lives. To date, it is not known what are the meaning and perceptions of, and barriers and facilitators to, activity from the perspective of advanced cancer patients. My primary research aim is to gain an in-depth understanding of the experience of activity and quality of life in advanced cancer patients. The specific objectives of the study are:

1. To explore the meaning of activity for advanced cancer patients in the context of their day-to-day life;

2. To elicit advanced cancer patients' perceptions of activity with respect to their quality of life; and
3. To elicit advanced cancer patients' views of barriers and facilitators to activity in the context of their day-to-day life.

Justification Of Method

Theoretical Paradigm: An Argument For Subtle Realism

Rather than borrowing extant concepts and replicating studies within the positivist paradigm, I accept the fallibility of my previous assumptions: physical activity may not be fundamentally good for all patients, and what is beneficial for healthy patients and early stage cancer patients, may not be for those patients with advanced cancer. I recognize the need to develop an approach to inquiry that is grounded in the participant's experience, in order to generate theoretical frameworks that are relevant and have utility for advanced cancer patients.

Historically, the advent of the mid-20th century heralded a "reflexive turn" (p.731) in the form of post-positivism. This allowed for subjective interpretations of what was acceptable as truth, and argued for plausibility by searching for evidence to establish credibility of claims (Madill, 2008). Realism is the post-positivist philosophy, which unites ontological realism with epistemological relativism. In

particular it endorses that : 1) there is more than one way to understand reality, 2) all understanding is relative to a particular perspective or world view, and 3) all knowledge is “partial, incomplete and fallible” (p.1) (Maxwell and Mittapalli, 2007).

Although distinctions between middle-ground realist positions exist, Seale (1999) contends that “subtle realism provides a pragmatic philosophical rationale for researchers locating their practice within a constructively self-critical research community” (p.30). Subtle realism endorses naïve realist ontology in that an independent reality is seen to exist, but differs in its belief that this reality can only be accessed indirectly. Subtle realism endorses naïve realist epistemology in that reality is knowable, but differs in its belief that this knowledge relies on cultural assumptions and is merely one representation of “many possible valid accounts” (p.733) (Madill, 2008). Given that direct apprehension of reality is not possible in subtle realism, knowledge of reality can never be absolutely certain. The criteria adopted by subtle realists include: 1) plausibility with respect to extant knowledge, 2) credibility given what would be reasonably expected under the conditions, and 3) relevance to issues of concern (Madill, 2008).

Subtle realism fits with my belief that activity is a tangible entity that exists independently of my view or others’ views of it, although it may not be possible to

directly access that reality. Subtle realists do not refer to dual realities; rather, there is a distinction between mental and physical perspectives that both refer to a single reality seen from different conceptual stances (Putnam, 1990). Subtle realists view causality as inherently local, and thus seek to understand site-specific causal explanations rather than generate universal laws. Subtle realism fits with my belief that examining these situational contingencies may further illuminate the gap between expressed interest in activity, participation in activity, and quality of life in advanced cancer patients.

Qualitative Methodology: An Argument For Classic Grounded Theory

In keeping with the subtle realist approach, I looked towards a qualitative methodology in order to explore the contextual nature of this phenomenon, and to develop a theoretical framework that is indigenous to the advanced cancer patient experience. Glaser and Strauss (1967) originated grounded theory methodology as the concurrent collection, coding and analysis of social research data for the primary purpose of generating new theory, in response to the positivist paradigm and quantitative methodologies that prioritised verification of theory in the mid-1960s (Willig, 2008). *The Discovery of Grounded Theory* (1967) described a

systematic process of discovering conceptual categories, properties and related hypotheses which are induced from the data (Glaser and Strauss, 1967).

Grounded theory methodology requires: 1) constant comparative analysis wherein similarities and differences are compared between any groups that indicate the same conceptual categories and properties, and across multiple theoretically-sampled cases, 2) theoretical sampling wherein the emerging theory determines where and what data to collect next, and 3) theoretical saturation wherein recurrence of similar instances with no other additional data contributing to the properties of the core conceptual category (Glaser and Strauss, 1967). To be truly grounded, theory must both *fit* and *work*: fit refers to being indicated by or applicable to the data, whereas the work refers to being able to explain or be relevant to the data (Glaser and Strauss, 1967). Because extant theory did not enable me to bridge the knowledge gap identified by my previous research, the *fitness* and *workability* of grounded theory appeals to my desire to generate a theoretical framework that is relevant to and useful for advanced cancer patients.

The aim of classic grounded theory is to ensure that generated theory will closely correspond to the “real world” (p.42) (Glaser and Strauss, 1967), reflecting an objectivist stance (Engward, 2013). Whilst not endorsing a *tabula rasa*

perspective, Glaser and Strauss (1967) advocate that the researcher should approach data without any preconceived theory that predetermines what concepts or hypotheses might be relevant. I believe this is particularly salient for my study given my previous research in physical activity and advanced cancer. Fitness and workability can never be forced, but are properties that emerge from the data under study. As such, my stance aligns with the classic view that comparisons with extant literature and theory should be conducted after the core conceptual categories have emerged, in order to facilitate integration (Walls, Parahoo & Fleming, 2010).

Following a period of renewed interest in interactionism and the role of the researcher as an active participant in the research process (Willig, 2008), Strauss and Corbin (1990) diverged from classic grounded theory by emphasizing the processual and purposeful nature of action/interaction being present in all phenomena. This predicated their use of explicit coding procedures, such as axial coding, as the “operations by which data are broken down, conceptualized, and put back together in new ways” (p.57) (Strauss and Corbin, 1990). Although Strauss and Corbin’s (1990) emphasis on conditions may share similarities to a subtle realist perspective on situational contingencies, Glaser (1992) argues that

the use of axial coding and conditional matrix may force data to conform to preconceived categories. In view of challenging my previous assumptions regarding physical activity in advanced cancer patients, my stance therefore aligns with the classic grounded theory model of analysis, which is less prescriptive and more open to what emerges from the data (Glaser and Strauss, 1967).

Study Methods: A Two-Phase Cross-Sectional Study

A classic grounded theory approach will be undertaken. This will be a two-phase, cross-sectional study, wherein an objective activity monitor and daily record sheets are used as a qualitative probe to gain in-depth understanding of the experience of activity in advanced cancer patients (see Figure 1):

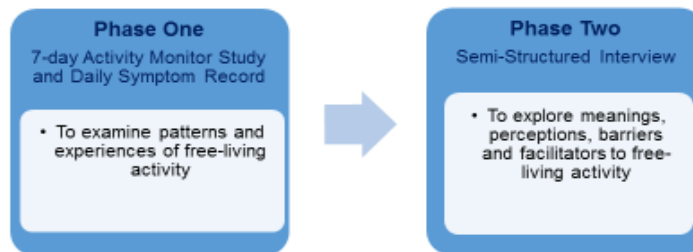


Figure 1. Flow Chart of Study Phases

Study Design: Setting and Participant Selection

Ethical approval will be obtained by all local institutional and Lancaster University review boards prior to study commencement. The setting for this study will be participant's homes, and participants will be advanced cancer patients who are recruited through an outpatient palliative care department at a tertiary cancer centre. Inclusion criteria will be: 1) 18 years of age or older; 2) ability to understand, provide written informed consent in, and speak English; 3) diagnosis

of advanced cancer, which is defined as progressive, incurable, and locally recurrent or metastatic disease; 4) clinician-estimated life expectancy of less than 12 months; 5) cognitively intact, which is defined as a Mini-Mental State examination score at or above the level expected for patient's age and education level (Crum et al., 1993); and 6) approval of attending physician. Exclusion criteria will be: 1) Palliative Performance Scale level of 30% or less (Anderson et al., 1996); and 2) any patient who, in the opinion of the treating physician, is within the last days to hours of life

Study Design: Research Team

Interdisciplinary team members from the outpatient palliative care department will screen all outpatient referrals for eligibility criteria for the study. When approaching patients for their verbal permission to contact them regarding the study, interdisciplinary team members will provide my name to interested participants, but will not disclose my clinical background. Once the patient gives verbal permission for me to contact them regarding the study, I will telephone each potential participant and introduce myself as the researcher. Once I speak to the patient on the telephone, and they have agreed to participate in the study, I will fax a letter to the patient's attending physician for their written approval for the patient to

participate in the study. After I receive the attending physician's written approval, I will then meet face-to-face with each participant in order to obtain written informed consent.

Study Design: Phase One

For Phase One, participants will wear an *activPAL*TM activity monitor (Grant et al., 2006) to record free-living activity for seven days duration. The *activPAL*TM activity monitor is a 20 gram, 35 x 53 x 7 millimeter unit that is secured to the participant's anterior mid-thigh using an adherent hydrogel PALstickieTM (Grant et al., 2006). The *activPAL*TM system records triaxial movement and time spent supine, sitting, standing and stepping, including volume and intensity, on a second-by-second basis. The activity monitor has been validated in a number of clinical populations (Skipworth et al., 2011), and most recently has been tested in a sample of 84 patients with thoracic cancer (Maddocks and Wilcock, 2012). From a positivist-empiricist perspective, objective activity monitors, are considered the gold standard of quantitative measurement of physical activity in older adults (Gorman et al., 2014); from the subtle realist lens it will contribute one of multiple means by which I hope to better understand the independent, tangible entity of activity in advanced cancer patients.

At the face-to-face meeting to obtain written informed consent, I will explain in detail the method of attachment and use of the *activPAL*[™] activity monitor, and directly demonstrate this. Once the activity monitor is placed and secured, I will give the participant a one-week supply of PALstickie[™], waterproof Tegaderm[™] dressings for application over top the activity monitor, and daily symptom record sheets for each day of the one-week period. I will ask participants to remove the units when bathing or showering, and replace once the underlying skin is dried.

At the end of each day, participants will fill out a single record sheet to document their symptoms, how they felt, and general impressions of daily events (see Appendix A). The daily record sheet will include the revised Edmonton Symptom Assessment System (ESAS-r). The ESAS covers 9 items, including physical, psychological and well-being subscales, and has been also widely tested and validated in palliative care populations (Nekolaichuk et al., 2008). I will meet with the participant at the end of the one-week period to collect the activity monitor and daily symptom record sheets.

Study Design: Phase Two

Within one week of completing Phase One, I will conduct a face-to-face in-depth interviews, of up to 90 minutes duration, with each participant. The activity monitor

output and daily record sheets from Phase One are unique for each participant, and will be used to inform and individualize interview questions to glean insight into what is relevant and significant from the participant's perspective (Payne, 2007). This semi-structured topic guide will be supplemented with primary questions to cover the following topics: 1) participant's perceptions of activity, 2) participant's experiences of activity, and its meaning within the context of overall quality of life, and 3) participant's views on barriers and facilitators to activity.

All interviews will be recorded using a digital audio recorder. During each interview, I will write field notes in the margins of the printed activity monitor output; immediately after the interview, I will also write field notes regarding my initial impressions and observations. Upon the participant's request, caregivers will be allowed to be present during the interview, however I will not be specifically eliciting caregiver views. I will not be soliciting participant feedback on the interview transcripts, due to the limited life expectancy of participants. The activity monitor output will be shared with the participants, and they will be given the option to keep the printed activity monitor output at the conclusion of the interview.

Study Design: A Classic Grounded Theory Approach

Using a classic grounded theory approach (Glaser, 1978), this study aims to develop new mid-level range theory through the triumvirate of constant comparative analysis using theoretical memos, theoretical sampling, and theoretical saturation (Coyne, 1997) (see Figure 2):

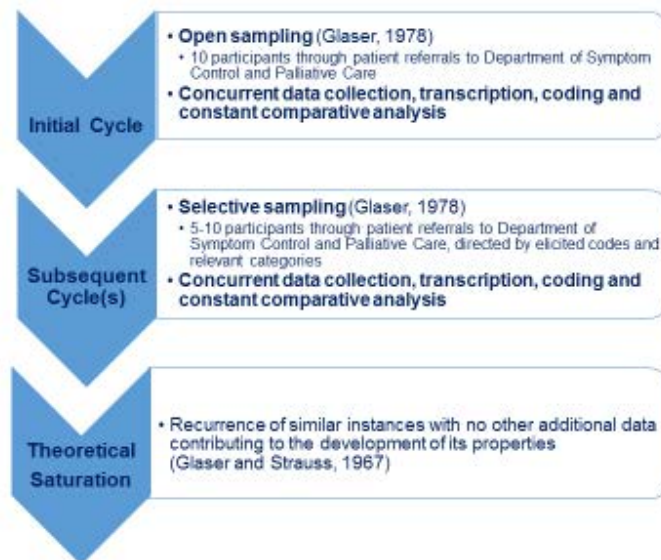


Figure 2. Flow Chart of Theoretical Sampling for Study

I will use constant comparative analysis in order to generate conceptual categories, properties and hypotheses that are directly relevant to the data that I

collect (Engward, 2013). A conceptual category and its properties can emerge from a single case, which is one of multiple possible indicators for the generated concept; similarities and differences can be compared between any groups that indicate the same conceptual categories, and their properties can then become significant qualifying conditions under which the categories exist and vary (Glaser and Strauss, 1967). In keeping with classic grounded theory, I will write theoretical memos throughout coding and analysis, in order to elaborate conceptual categories, their properties and inter-relationships, as well as to identify gaps. This ultimately leads to verification of generated hypotheses, delimitation of a theory's applicability, broadening a theory's generality, and increasing its predictive and explanatory potential, all of which result in a "rich, complex and dense" theory (p.32) (Glaser and Strauss, 1967). The core conceptual categories will thus guide my data collection and analysis in order to seek out the fullest diversity of categories, their properties and interrelationships (Engward, 2013).

I will employ theoretical sampling as the purposeful process wherein the emerging theory determines where and what data to collect next for my study (Bartlett and Payne, 1997). In keeping with classic grounded theory methods (Glaser, 1978), my initial cycle of open sampling will be guided only by a general understanding on

where activity, the phenomenon of interest, resides (see Figure 2). This initial cycle of open sampling benefits from full coverage of the advanced cancer patient group as conceptual categories begin to emerge. As concurrent data collection, coding and analysis proceeds, the emerging theory will direct me to what groups or subgroups I should turn to next, in the subsequent cycles of selective sampling (Glaser, 1978). Thus as theoretical sampling proceeds, it entails “only collecting data on categories, for the generation of properties and hypotheses”, thus becoming more focused (p.69) (Glaser and Strauss, 1967).

Study Methods: Data Handling And Analyses

I will transcribe the digital audio recordings within four weeks of conducting the interview. I will maintain participant anonymity and confidentiality by removing all identifying information and using pseudonyms where required. After transcription is completed and verified, the original digital audio recording will be deleted. All data will be stored on a password-protected, encrypted USB key. Study records will be kept for 25 years as per federal regulation, after which they will be anonymized and shredded. Study records are stored in a locked cabinet in a secure office at the tertiary cancer centre, with security features including monitored security system, smoke detectors and fire extinguishers.

As per classic grounded theory methods (Glaser, 1978), I will be performing line-by-line, open codification on each interview transcript, with integrated reference to my interview field notes, the participant's activity monitor output and daily symptom record. I will use ATLAS.ti™ qualitative data analysis software (ATLAS.ti™ Inc., Berlin, Germany). Preliminary codes will be developed to group data together and encapsulate the main concepts emerging from the data. Selective coding will follow wherein only those factors that relate to the emerging core category are analysed (Glaser, 1978). Constant comparison analysis will be conducted concurrently, wherein emergent themes and codes from early stages of data analysis will inform subsequent data collection (Coyne, 1997). Theoretical memoing (Glaser and Strauss, 1967) will commence with open coding, and will proceed throughout data analysis

Theoretical saturation is the criteria by which I will decide to stop sampling different groups that are relevant to the core categories of the emerging theory, and which typically occurs at the end of concurrent data collection, coding and analysis (Glaser and Strauss, 1967). According to classic grounded theory, theoretical saturation may be achieved for a conceptual category if: a) diversity and range of data is maximized relevant to the conceptual category, b) any gaps

within that category have been filled, and c) there is recurrence of similar instances with no other additional data contributing to the development of its properties (Glaser, 1978). Comparison of different slices of data will shed new perspectives from which I hope to increase my theoretical understanding of a conceptual category, its properties and conditions.

Study Rigour

In keeping with classic grounded theory methods (Glaser, 1978), I will be following four main criteria for evaluating my grounded theory, including: a) fit, b) understanding, c) generality, and d) context. Fitness of theory pertains to its fidelity to the day-to-day reality of the substantive area under study, and incorporating slices of data as diverse as possible through my use of theoretical sampling.

Understanding pertains to the ability of both research participants and practitioners to make sense of the theory as it relates to the phenomenon of interest. Generality pertains to the theory being conceptually abstract and broad enough in scope to be applicable to a wide range of contexts related to the phenomenon of interest.

Control pertains to the theory being dense in explication of conceptual categories, properties and interrelationships such that its conditions would be applicable to a specific situation.

Implications for Research And Dissemination

This study will provide new mid-level theory from which future research directions can be proposed. The findings from this study will be disseminated by scientific peer-reviewed publication and conference presentations.

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Appendix A - Daily Symptom Record Sheet

APPENDIX 1 – Daily Record Sheet

Wednesday May 21, 2014
How would you describe your day today?

Good Neutral Bad

Please explain why: _____

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety

Not drowsy 0 1 2 3 4 5 6 7 8 9 10 Worst possible drowsiness

Best appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible appetite

Best feeling of wellbeing 0 1 2 3 4 5 6 7 8 9 10 Worst possible feeling of wellbeing

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

Other problem 0 1 2 3 4 5 6 7 8 9 10

Examples of Activities	Rating of Perceived Exertion (RPE)
01 - Walking	0 Nothing at all
03 - Housework (making meals, doing laundry, cleaning)	0.5 Very, very light
04 - Lawn & Garden (picking flowers, watering lawn or garden)	1 Very light
05 - Lying (reading, sleeping)	2 Light
06 - Sitting (reading, watching television)	3 Moderate
06 - Sitting (reading, watching television)	4 Somewhat hard
07 - Self Care (bathing, dressing, eating)	5 Hard
07 - Self Care (bathing, dressing, eating)	6
08 - Transportation (riding in a car or bus, driving)	7 Very hard
08 - Transportation (riding in a car or bus, driving)	8
08 - Transportation (riding in a car or bus, driving)	9
09 - Other	10 Very, very hard

Time of Day	Activity	Duration (minutes)	RPE (0-10)	Comments
Morning				
Afternoon				
Evening				