MEANING MAKING WHILE LIVING AND WORKING WITH A CHRONIC DISEASE: A MULTIPLE CASE STUDY INQUIRY

By

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DECLARATION

I, Loraine Sonia Clur, student number 5934621, declare that "MEANING MAKING WHILE LIVING AND WORKING WITH A CHRONIC DISEASE: A MULTIPLE CASE STUDY INQUIRY" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references. I further declare that I submitted the thesis/dissertation to the appropriate originality detection system which is endorsed by Unisa and that it falls within the accepted requirements for originality. I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

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DEDICATION

I would like to dedicate this thesis to:

- My beloved brother, Christo Cromhout, who passed away in 2021 with terminal cancer, and who influenced countless people in his short time on earth. I miss you more than words can say. Thank you for always believing in me. I look forward to the day we meet again.

- My two sons, Dirk and Heinrich: I love you both so much and I am extremely proud of you. Thank you for your love and continuous support.

- My sisters: Valerie, who is facing the unpredictability of living and working with a chronic disease. I admire your positivity and resilience. Thank you for always being there for me. Cathy, who is currently undergoing treatment for breast cancer. You are in my thoughts and prayers. Sally, who is a breast cancer survivor and battles every day with the side effects of lymphedema. You are an absolute inspiration.

- Everyone living with chronic diseases.

ABSTRACT

The purpose of this hermeneutic phenomenological multiple case study was to explore, describe and explain how people make meaning while living and working with a chronic disease, with a view to developing an organisational support framework centred on meaning making, to facilitate and enhance the wellbeing of employees with chronic diseases. Frankl's meaning-making principles served as the a priori theory and conceptual framework from which the propositions were derived and on which the study was built. The data was gathered through a multi-method approach by using semi-structured interviews, document analysis, diaries, image-based methods and observations. Data analyses were conducted using interpretative phenomenological analysis and pattern matching to replicate and enhance Frankl's theory. The patterns of Frankl's meaning-making principles were confirmed in the data and it was found that central to the meaning making of people with chronic diseases is the reconstruction of a self-identity resulting from self-determination. This process of reconstructing a meaningful self was built on the self-transcendent will to a meaningful self through existential reflection and cognitive reconstruction using Frankl's meaning-making creative, experiential and attitudinal pathways. A framework is proposed to support the reconstruction of a meaningful self, based on a culture of care and psychological safety, adjusted work arrangement policies, individual support programmes like mentoring, coaching and counselling and opportunities to engage in prosocial projects.

KEY WORDS

Chronic disease, cognitive restructuring, Frankl's meaning-making theory, existential reflection, hermeneutic phenomenology, identity work, interpretative phenomenological analysis, meaningful self, qualitative multiple case study, workplace wellbeing

SAMEVATTING

Die doel van hierdie hermeneuties fenomenologiese, veelvuldige gevallestudie was om te ondersoek, te beskryf en te verduidelik hoe mense betekenis skep terwyl hulle met 'n chroniese siekte saamleef en werk, met die doel om 'n organisatoriese ondersteuningsraamwerk te ontwikkel wat op betekenisskepping gevestig is, ter bevordering en versterking van die welstand van werknemers met chroniese siektes. Frankl se betekenisskeppingsbeginsels het as die a priori-teorie en konseptuele raamwerk gedien waaruit die stellings spruit en waarop die studie gebou is. Die data is deur 'n veelmetode benadering versamel deur middel van deels gestruktureerde onderhoude, dokumentontleding, dagboeke, beeldgebaseede metodes en waarnemings. Data-ontledings is gedoen met behulp van verklarende fenomenologiese ontleding en patroonpassing om Frankl se teorie te dupliseer en te versterk. Die patrone van Frankl se betekenisskeppingsbeginsels is in die data bevestig en daar is bevind dat die kern van die betekenisskepping van mense met chroniese siektes die rekonstruksie van 'n self-identiteit vanweë selfbeskikking is. Hierdie rekonstruksieproses van 'n betekenisvolle self berus op die self-transendentale wil tot 'n betekenisvolle self deur eksistensiële oorweging en kognitiewe rekonstruksie met behulp van Frankl se betekenisskeppende kreatiewe, eksperimentele en houdingspaaie. 'n Raamwerk is voorgestel om die rekonstruksie van 'n betekenisvolle self te ondersteun, gebaseer op 'n kultuur van sorg en sielkundige veiligheid, aangepaste werkreëlingsbeleide, individuele ondersteunings-programme soos raadgewing, afrigting en voorligting asook geleenthede om by prososiale projekte betrokke te wees.

SLEUTELWOORDE

Chroniese siekte, kognitiewe herstrukturering, Frankl se betekenisskeppingsteorie, eksistensiële oorweging, hermeneutiese fenomenologie, identiteitswerk, verklarende fenomenologiese ontleding, betekenisvolle self, kwalitatiewe veelvuldige gevalle-studie, welstand in die werkplek

SENAGANWA

Maikemišetšo a nyakišišo ye ya thuto ya mohlala wa bontši ya heremeneuthiki fenomenolotšikhale e be e le go utolla, go hlaloša le go hlatholla ka mokgwa woo batho ba dirago merero ba dutše ba phela le go šoma ka bolwetši bja khoroniki, ka pono ya go godiša foreimeweke ya thekgo ya mokgatlo ye e nepišitšego go dira morero, go nolofatša le go godiša boiketlo bja bašomi ba malwetši a khoroniki. Melawana ya Frankl ya go dira morero e dirišitšwe bjalo ka teori ya priori le foreimeweke ya kgopolo moo elego gore ditšhišinyo di ile tša hwetšwa le moo nyakišišo e ile ya agwa. Datha e kgobokeditšwe ka mokgwa wa go diriša mekgwa e mentši ka go šomiša dipoledišano tše di sego tša rulaganywa gabotse, tshekatsheko ya ditokomane, dipukutšatši, mekgwa ye e theilwego godimo ga diswantšho le dipono. Ditshekatsheko tša datha di dirilwe ka go šomiša tshekatsheko ya fenomenolotšikhale ya tlhathollo le go nyalelanya dipaterone go boeletša le go godiša teori ya Frankl. Dipaterone tša melawana ya Frankl ya go dira tlhalošo di ile tša tiišetšwa ka gare ga datha gomme go hweditšwe gore bogareng bja go dira tlhalošo ya batho bao ba nago le malwetši a khoroniki ke go aga leswa ga boitšhupo bjo bo hlolwago ke go ikemela. Tshepetšo ye ya go aga leswa boithati bjo bo nago le mohola e agilwe godimo ga thato yeo e fetago go boithati bjo bo nago le mohola ka go naganišiša ka go ba gona le go aga lefsa temogo ka go šomiša ditsela tša Frankl tša go dira morero wa boitlhamelo, wa maitemogelo le wa ditsela tša maikutlo. Foreimeweke e šišintšwe go thekga go aga leswa ga boithati bjo bo nago le mohola, bjo bo theilwego godimo ga setlwaedi sa tlhokomelo le polokego ya monagano, dipholisi tša peakanyo ya mošomo ye e fetotšwego, mananeo a thekgo ya motho ka o tee ka o tee a go swana le tlhahlo, tlwaetšo le keletšo le dibaka tša go tsenela diprotšeke tša go thuša leago.

MAREO A BOHLOKWA

Malwetši a khoroniki, peakanyoleswa ya temogo, Teori ya go dira morero ya Frankl, go naganišiša ga go ba gona, heremeneuthiki fenomenolotši, mošomo wa boitšhupo, ditshekatsheko tša fenomenolotšikhale ya tlhathollo, boithati bjo bo nago le mohola, thuto ya mohlala ya boleng bjo bontši, bophelo bjo bobotse bja mošomong

ISIFINGQO

Inhloso yalolu cwaningo-nhlonza oluphindaphindekile lwe hermeneutic phenomenological ukuhlwaya, ukuchaza nokuhumusha ukuthi abantu bayithola kanjani incazelo ngenkathi besebenza ngezifo ezingelapheki, okuyinhloso yokwakha kabusha inhlangano yokweseka incazelo esungulwayo, ukuhola nokukhuthaza inhlalakahle yabasebenzi abanezifo ezingelapheki. Imigomo enikeza incazelo kaFrankl's ithathwa njengenjulalwazi esemqoka nensizakucwaninga okusuka kuyo ukuqanjwa kwezimiso ezakhe lolu cwaningo. Ulwazi luqoqwe ngokusebenzisa izinhlolokhono ezisakuhleleka, ukuhumusha imiqulu, iziggcinalwazi zosuku, ukuhlola nezindlela ezigxile ezithombeni. Ukuhlaziywa kolwazi kwenziwe ngendlela yokuhumusha nokulandela inqubo ehambisana nekhuthaza injulalwazi kaFrankl. Izindlela zikaFrankl zemigomo enikeza incazelo zifakazelwe ulwazi oluzuziwe ngencazelo mayelana nabantu abanezifo ezingelapheki okuwukuthi kugcina kwakheka ukwazi izimo ababhekane nazo bese beyazinikela ekuzinakekeleni. Le nqubo yokwakha incazelo kabusha ibunjwe ngentando yokushintsha kwesimo okuba nomphumela yokubheka emuva ngenhloso yokwakha ikusasa elisha elinokuhluzeka komqondo kusetshenziswa izindlela zikaFrankl zemigomo enikeza incazelo okuyiyona eqambayo, ehlonzayo nesimo somqondo esiya phambili. Le nsizakuhlaziya ineziphakamiso ezeseka ukwakha kabusha incazelo ngaye umuntu ngqo, ehambisana nosikompilo nezokuphepha komqondo, ukuhlelwa kwezinqubo nemithetho yemisebenzi, izinhlelo ezeseka ukucathuliswa, ukwelulekwa, ukuyalwa namathuba okubonisana ngezinhlelo zokunqanda imiphakathi.

AMAGAMA ASEMQOKA

Izifo ezingelapheki, ukwakhiwa kabusha kwengqondo, injulalwazi kaFrankl yemigomo enikeza incazelo, ukubheka emuva kokubakhona, ihermeneutic phenomenology, umsebenzi wokuzazi, ukuhunyushwa kokwenzekayo nokuhlaziywa kwakho, ukuzichaza, ucwaningo-hlonza oluphindaphindekile, inhlalakahle yasemsebenzini

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LIST OF ABBREVIATIONS AND ACRONYMS

The following abbreviations and acronyms are used throughout the thesis:

AA	Alopecia areata
AS	Ankylosing spondylitis
BCEA	Basic Conditions of Employment Act
BP	Blood pressure
CD	Chronic disease
CET	Cognitive evaluation theory
CODIA	Compensation for Occupational Diseases and Injuries Act
COVID-19	Coronavirus
CSR	Corporate social responsibility
EAP	Employee assistance programme
EEA	Employment Equity Act
ECP	European Congress of Psychology
EP	Existential psychology
EPP	Existential positive psychology
HRQoL	Health-related quality of life
HIV	Human immunodeficiency virus
IOP	Industrial and organisational psychology
IPA	Interpretative phenomenological analysis
LRA	Labour Relations Act
MLQ	Meaning in Life Questionnaire
MCC	Multiple chronic conditions
NASA	National Aeronautics and Space Administration
NCD	Noncommunicable diseases
NPO	Nonprofit organisation

PwCD	People with chronic diseases
PWB	Psychological wellbeing
RTW	Return to work
ST	Self-transcendence
STD	Self-determination theory
SOC	Sense of coherence
SCCT	Social cognitive career theory
SWB	Subjective wellbeing
UI Act	Unemployment Insurance Act
USB	Universal serial bus
UNISA	University of South Africa
WHO	World Health Organization

"Man does not simply exist but always decides what his existence will be, what he will become the next moment. By the same token, every human being has the freedom to change at any instant."

VIKTOR FRANKL

CHAPTER 1
SCIENTIFIC ORIENTATION TO THE RESEARCH

1.1   INTRODUCTION

For the meaning of life differs from man to man, from day to day, and from hour to hour. What matters, therefore, is not the meaning of life in general but rather the specific meaning of a person's life at a given moment. (Frankl, 2008, p. 113)*.*

The number of people living with a chronic disease (CD), is on the rise, with nearly half of all Americans suffering from at least one CD (Raghupathi & Raghupathi, 2018). According to Schmidt (2016), chronic diseases (CDs) account globally for two-thirds of the overall disease burden in middle-income countries, directly affecting healthcare budgets as well as employee productivity. Data from Discovery Health suggest that CDs also continue to be more prevalent in South Africa (Hedley, 2018). The number of Discovery Health Medical Scheme members with at least one chronic condition, more than doubled between 2008 and 2017 (Hedley, 2018). Chronic diseases have clearly become a major health-related issue and have been referred to as the great epidemic of our times (Barondess, 2014; Milani & Lavie, 2015), affecting not only individual wellbeing but also social and economic wellbeing (Entwistle et al., 2018; Institute of Medicine, 2012).

Quality of life and daily activities are impacted by CDs (Reynolds, 2005). Individuals are required to adapt to a new reality of normal in their lives (Hoffman et al., 2013; Walder & Molineux, 2017) because living with a CD requires ongoing health-related actions and adjustments on a long-term basis (Reynolds, 2005; Stanton et al., 2001). Because work and health are interrelated in several ways, many people with a CD continue to work while managing their condition (Vijayasingham et al., 2018; Vooijs et al., 2018). However, it is also true that employees with CDs are more likely to discontinue their jobs prematurely, which can affect an individual's socioeconomic outcomes and lead to increased costs for employers and society (Goetzel et al., 2004; Haafkens et al., 2011; Ng et al., 2001).

To facilitate continued productive employment, employers need to enable employees with a CD to find meaning, balance and fulfilment in the workplace (Haafkens et al., 2011; Holbeche & Springett, 2009; Silvaggi et al., 2020), because in order to cope with adverse and challenging circumstances, people require meaning and purpose in life (Martela & Steger, 2016; Seligman, 2011). When people have to live with an illness, especially if their life goals and plans for the future are in jeopardy as result of it, making meaning of the situation becomes imperative for continued optimal living and wellbeing (Roussi & Avdi, 2008; Carver, 2005; Conrad & Barker, 2010; Hartog et al., 2020; Jacobi & MacLeod, 2011; Maes & Karoly, 2005; Martino et al., 2019; Megari, 2013; Winger et al., 2016).

Hence, this study focused on the meaning making of people with chronic diseases (PwCD) as a means of adjusting and improving their wellbeing. Understanding how a person seeks meaning while living and working with a CD provides valuable information, not only for the individual and society, but also for employers to better accommodate and retain these employees.

The purpose of this chapter is to provide a scientific orientation to the study. First the background to and motivation for the study are provided, whereafter the problem statement, research questions and aim of the study and research propositions are presented. This is followed by an explanation of the disciplinary context, and the nature and potential contribution of the study. The chapter concludes with the thesis statement, definition of key terms and the chapter layout.

1.2   BACKGROUND TO AND MOTIVATION FOR THE STUDY

Research has a vital role to play in broadening knowledge of the wellbeing of people living with a chronic illness. From a scientific perspective, research should be directed by previous and current research trends (Bergh & Geldenhuys, 2013). Additionally, as the researcher in this qualitative study, I am the main research instrument (Terre Blanche et al., 2006) – hence I am challenged to motivate my decisions and choices throughout the research process (Fossey et al., 2002). This section therefore provides an explanation of why this study is necessary, by discussing the need to address CD in the work context, the value of work for the employee with a CD, meaning making as a strategy for wellbeing, and lastly, my personal interest in the study.

1.2.1 The need to address chronic disease in the work environment

The number of people living with CDs is increasing worldwide. Approximately one in three of all adults globally suffers from multiple chronic conditions (Adler-Waxman, 2017; Hajat & Stein, 2018; Waterhouse et al., 2017). As mentioned in the introduction, the number of people living with one or more CDs has dramatically increased in recent decades, with inevitable effects on the work sector (Silvaggi et al., 2020; Varekamp & Van Dijk, 2010). According to Suhrcke et al. (2006), a large part of the working-age population is affected by CDs and this impacts all levels of society.

The common features of a CD are that it is a health condition that is permanent, unpredictable over time, varies from day to day and is often invisible (Beatty & Joffe, 2006; Bernell & Howard, 2016; Fuller, 2018). When confronted with an irreversible disease, with a potentially unpredictable course, one's perspective and self-perception change (Charmaz, 1983; Strauss & Corben, 1988), leading to feelings of anxiety, depression (Dekker et al., 2015), anger, guilt or shame about the loss of health and work capacity (Varekamp & Van Dijk, 2010). Besides these psychosocial problems, employees with a CD may experience physical limitations, which influence their overall wellbeing (Bosma et al., 2020, 2021; Clur, 2015; Duijts et al., 2014).

Since CDs include a range of various conditions (Bernell & Howard, 2016; Goldman, 2017; White et al., 2018), the factors related to the disease itself, the number of CDs per person and the impact thereof are unique for every individual and the work situation (Helgeson & Zajdel, 2017; Nazarov et al., 2019). When a person has two or more CDs, the term "multiple chronic conditions (MCC)" is used (Seo et al., 2017). Another commonly used term is "comorbidity", which refers to a condition(s) that coexists with an index disease and may be more useful for the advancement of biomedical knowledge (Harrison et al., 2021). The concept of MCC was deemed more relevant for this qualitative study owing to the emphasis on the individual as a whole and the fact that no condition was prioritised over another (Harrison et al., 2021).

The different effects of CDs could be increased risk of complications, increased economic burden due to healthcare costs, increased functional disabilities, restricted physical activity and loss of productive work time (Seo et al., 2017). These physical or psychological challenges affect emotional, social and occupational functioning (Bosma et al., 2020; Finlayson et al., 2004; McGonagle et al., 2014a; Stanton et al.,

2001; Varekamp et al., 2013) – hence the need for employers to attend to the special needs of an employee with a CD. Consequently, the diversity issue of living with a CD adds to the demands of an ever-changing world, in this instance, one that demands the employer's attention (Beatty & Joffe, 2006).

Besides the impact on employee wellbeing, the reality of employees suffering from CDs also has implications for the employer because it affects work participation (Bosma et al., 2020; McGonagle et al., 2014a; Nazarov et al., 2019). Firstly, work participation for an individual with a CD may be affected by the limitations imposed by the disease (Andersen et al., 2012; Bosma et al., 2020; Hoving et al., 2013; Noordik et al., 2011; Tamminga et al., 2012). Work participation can also be influenced by reduced work productivity and increased absenteeism (Asay et al., 2016; Bosma et al., 2020; 2021; Fouad et al., 2017; Jinnett et al., 2017) because of various factors related to the disease itself. Although work activities and participation can be influenced by CDs, most individuals with CDs can lead productive, fulfilled lives (Bezner, 2015; Nazarov et al., 2019; Varekamp et al., 2009), especially when they are accommodated and supported in the workplace (Silvaggi et al., 2020; Varekamp et al., 2009).

The effect of CDs on labour productivity and labour supply has consequences for individuals, households and thus economic development and growth (Abegunde & Stanciole, 2006; Suhrcke et al., 2006). It is imperative for employers to retain employees with CDs because early work termination can lead to negative health and socioeconomic outcomes for the individual (Bosma et al., 2021; Schuring et al., 2007; Waddell & Burton, 2006) and turnover costs for the employer (Goetzel et al., 2004; Ng et al., 2001; OECD, 2010). When employees leave the organisation, they take with them valuable experience, knowledge and skills (Bosma et al., 2021; Levallet & Chan, 2019; Martins & Martins, 2011; Parise et al., 2006).

The presence of CDs also has implications for the utilisation and costs of healthcare. The economic burden of CDs is enormous at all levels of society, incurring costs for the individual, family, community and the national economy (Sambamoorthi et al., 2015; Suhrcke et al., 2006). Having paid work is considered a typical form of societal participation, and when employees with CDs exit work, it has consequences for their participation in society (Scharn et al., 2019; Van Rijn et al., 2014). Nazarov et al. (2019)

emphasised the significance of the participation of PwCD in the labour market from an economic and social point of view. Economically, huge percentages of health budgets in various nations are spent on CD treatment, and the CD has negative financial and participation impacts on the person, the family and the community.

The importance of attending to PwCD in the workplace is also evident in the finding that interventions in the workplace can lead to positive changes for people with various chronic conditions and increase their quality of life (Bosma et al., 2021; Nazarov et al., 2019; Ntsiea et al., 2015). Addressing PwCD in the workplace not only enhances job retention and work participation (Vooijs et al., 2015), but also reduces the negative impact of CDs on healthcare, state benefits, absenteeism, reduced productivity, disability and the financial security of the families involved (Knoche et al., 2012; Leonardi & Scaratti, 2018; Nazarov et al., 2019; Silvaggi et al., 2020; Vijayasingham et al., 2018).

1.2.2 The value of work for employees with chronic diseases

The value of being employed contributes to a person learning and maintaining skills to help them to continue developing professionally and staying connected to the community (Silvaggi et al., 2020). Work is essential for individuals living with a CD because not only does it provide an income (Beatty, 2012; Saunders & Nedelec, 2014; Leonardi & Scaratti, 2018; Vooijs et al., 2018), but it also helps them to maintain normal life patterns by adhering to a schedule and the structure that work attendance brings (Pinder, 1995). Townsend's (2011) study found that people with CDs wanted to be able to continue with meaningful occupations. Work was deemed fundamental to their identity and sense of self, and particular work roles were regarded as central to their identities and how they defined themselves (Townsend, 2011).

A sense of belonging and self-worth for an individual (Isaksson et al., 2016), social participation (Foitzek et al., 2018; Jones et al., 2017; Leonardi & Scaratti, 2018; Saunders & Nedelec, 2014) and the ability to contribute to society (Vooijs et al., 2018) are key aspects of the significance of work for a person living with a CD. Vassilev et al. (2014) reported that financial independence and participation in meaningful activities are more important to PwCD than power and status in the labour market. Social participation, where PwCD feel valued and useful to other people, is valued by

them (Vassilev et al., 2014). In general, PwCD perceive work as a significant part of everyday life (Johnson et al., 2010; Tiedtke et al., 2010) and participation in work has a positive influence on their wellbeing and quality of life (Bosma et al., 2020; Silvaggi et al., 2020). When PwCD continue working, it minimises the financial impact of CDs, the risk of social exclusion and poverty and contributes to the psychological health and overall wellbeing of individuals and communities (Blustein, 2008; Silvaggi et al., 2020). It is therefore imperative for employers to invest in the wellbeing of employees with CDs to retain their productive and optimal employment.

1.2.3 Meaning making: A strategy for wellbeing

In this section, meaning making as a strategy for wellbeing is discussed by, firstly, highlighting meaning making as an essential component of wellbeing. Secondly, the importance of meaning making in the work context is portrayed in arguing how employees and employers can benefit from this knowledge. Lastly, the benefit for society to know how PwCD make meaning is explained.

1.2.3.1 *Meaning making as an essential component of wellbeing*

The reality of living with a CD implies a lifelong condition (Beatty & Joffe, 2006; Bernell & Howard, 2016; Fuller, 2018), which creates existential challenges relating to the illness (Andersen et al., 2020; Bachhuber, 2011) and leads to existential anxiety (Temple & Gall, 2018). The confrontation with existential anxiety moves one to a process of meaning making (May, 1975; Ownsworth & Nash, 2015) for creative growth (Schneider & Krug, 2010) and leads to an authentic life (May, 1975; Van Deurzen, 2010). According to Frankl (2000), this process of meaning making is the acceptance of taking responsibility for one's existence. Meaning making during a distressing event or circumstance, like living with a CD, is essential for general adjustment and developing the person's wellbeing (Davis et al., 2000).

According to Wong (2016a), existential meaning has to do with the meaning of one's life and human existence as a whole and cannot be simplified in terms of cognitive understanding of life and by having a subjective sense of mattering. Hartog et al. (2020) stated that meaning making cannot be reduced to just another coping process. Human beings engage in meaning making through their efforts to matter and to thrive (Frankl, 2006). Mattering is the feeling that one counts (Prilleltensky, 2014) and

thriving is "the quest for wellbeing" (Prilleltensky, 2014, p. 152). Existential wellbeing is considered to be a balance between the physical, social, psychological and spiritual dimension of human existence (Leijssen, 2014), with purpose and meaning being central to the perspectives of both psychological (Krok, 2015; Ryff, 1989; Ryff & Keyes, 1995) and spiritual wellbeing (Krok, 2015; Park, 2007).

Steger (2018) mentioned three categories in his review of research that assesses relationships between meaning and wellbeing, namely subjective or hedonic wellbeing indicators, psychological or eudaimonic wellbeing indicators and general quality of life indicators. Hedonic wellbeing has to do with affect and the cognitive appraisals of it, defined by pleasurable experience and life satisfaction (Carruthers & Hood, 2004; Diener et al., 2009; Haybron, 2008), whereas eudaimonic wellbeing deals with life purpose and meaningfulness (Ryan & Deci, 2001; Steger et al., 2008a). Living with a CD will in one way or another affect a person's health-related quality of life (HRQoL). The three broad domains of a person's HRQoL are physical, psychological and social functioning, and the assessment thereof includes how the individual experiences the illness (Megari, 2013), in other words, how he or she makes meaning of it.

It was reported that meaning is positively correlated with the indicators of subjective wellbeing (SWB), namely experiencing positive affect and emotions as well as happiness, psychological adjustment and life satisfaction (Steger, 2018). Meaning is positively correlated with the psychological wellbeing (PWB) indicators of self-esteem, self-worth and self-actualisation. Meaning has also been positively correlated to the three needs, according to the Deci and Ryan's (2000) self-determination theory (STD), necessary to flourish, namely autonomy, positive relationships and competence (Steger, 2018). It was found that people who reported having more meaning felt that they were in better health than others and they also lived longer lives (Steger, 2018). Steger (2018, p. 7), concluded that a great deal of research links meaning with wellbeing and justified meaning as a "cornerstone resource for human wellbeing and flourishing".

Meaning making, according to Wong (2014a), is the pursuit of wellbeing, which emphasises meaning and morality not just for oneself, but also for humanity. Wong (2014a), posited that meaning serves to protect (through effective coping) and enhance (through meaning reconstruction and development of psychological

resources) one's wellbeing. Wong's model of wellbeing emphasised the PURE (acronym for the components purpose, understanding, responsible action and enjoyment/evaluation) model (Wong, 2010a, 2011). The PURE model contains these four essential components as well as the eight sources of meaning, namely positive emotion, achievement, relationship, intimacy, religion/spirituality, self-transcendence, self-acceptance and fairness/social justice (Wong, 1998a). Wong (2017a) stated that meaning is at the core of human existence and wellbeing and meaning making are therefore essential to healing and flourishing.

It is evident that there is a strong positive relationship between meaning in life and wellbeing (Bano, 2014; Garcia-Alandete, 2015; Grouden & Jose, 2015; Psarra & Kleftaras, 2013; Ratni & Rastogi, 2007; Santos et al., 2012; Steger, 2012; Steger et al., 2011; Wong, 2017a). Grounded in existential theory, this study relates to the concept of existential wellbeing as it refers to a person's present state of subjective wellbeing across existential domains, such as meaning, purpose, satisfaction in life and feelings of acceptance of adverse circumstances, like living with a CD (Cohen et al., 1996).

1.2.3.2   *The importance of meaning making in the work context*

If individuals connect with deeper meaning within themselves and the deeper meaning of their work, they will be more engaged (Blader & Tyler 2009; Markow & Klenke, 2005; Pattakos & Dundon, 2017a; Popova-Nowak, 2010; Engelbrecht & Schlechter, 2006). Pattakos and Dundon (2017a) proposed that the root of most engagement issues in the workplace is the lack of enlisting employees in meaning. Employers need to heed the importance of meaning in the life of employees and the impact thereof on work engagement (Hoole & Bonnema, 2015; Pattakos & Dundon, 2017a; Van der Walt, 2018). Finding meaning in work can lead to greater wellbeing and job satisfaction (Russo-Netzer et al., 2020; Steger et al., 2012). Research has shown that employees[1] will benefit from knowing how they make meaning and what provides meaning at work so that they can actively participate in work life, and thus be more engaged (Alexander

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[1] Although the research cited here does not explicitly refer to the employee with CD, it is assumed that the term "employee" encompasses all employees, including those with CDs.

& Douthit, 2016; Steger, 2017). Employers, however, will benefit from understanding how employees make meaning and what provides meaning at work to afford them the opportunities and support to make a difference and thus contribute to improving organisational performance (Aguinis & Glavas, 2019; Alexander & Douthit, 2016; De Crom & Rothman, 2018; Sonnentag, 2017).

1.2.3.3   *The importance of meaning making in the societal context*

Living with a CD presents various and multiple challenges that need to be negotiated by developing attitudes and strategies to assist one to integrate the illness into one's life (Liddy et al., 2014; Whittemore & Dixon, 2008). The body image of people with visible CDs is frequently adversely impacted (Cash, 2011; Cash & Szymanski, 1995; Fingeret et al., 2014; Paterson et al., 2016; Pinquart, 2013; Sherman et al., 2019; White, 2000). The former experiences and meanings on which PwCD had built positive self-images are no longer available to them (Charmaz, 1983, 1991, 1995). The individual's sense of self-identity is challenged because of viewing the self through the lens of the illness (Clarke & James 2003; Karnilowicz, 2011; Pierce et al. 2003), and people tend to act according to perceived social stigmatisation (Beatty 2018; Joachim & Acorn, 2000; Leys, 2010; O'Donnell & Habenicht, 2022). Townsend et al. (2006) noted that personal, cultural and social circumstances are involved in the management of an illness. Meanings are formed by culture, perceptions and processes in interpreting information (Matsumoto & Juang, 2004; Ratner, 1997). It is evident that the illness experience is socially constructed on the basis of the concept of reality as a social construction (Conrad & Barker, 2010).

Social or cultural meanings are attributed to certain CDs (e.g. AIDS and cancer), and these meanings have an impact on how PwCD experience, reveal and socially respond to the illness (Conrad & Barker, 2010). People generally want to be accepted, and in the process of meaning making through their relationship with others, they unconsciously attempt to create or maintain accepted identities and social roles (Townsend et al., 2006). An individual with a CD therefore reconstructs a new identity (identities) that incorporates the illness (Charmaz & Rosenfeld, 2016; Clarke & James, 2003; Karnilowicz, 2011; O'Donnell & Habenicht, 2022; Pierce et al., 2003). These attempts may lead to making meaning of their CD through the creation of a new

identity, for example, calling themselves a cancer survivor instead of a person with cancer (Brown et al., 2004; Conrad & Barker, 2010).

Cockerham et al. (2017) suggested that society, in one way or other, can influence one into taking or not taking courses of action. Interaction with others, for example, often includes perceived discrediting or unmet expectations, which may lead someone with a CD to suffer a sense of losing the self (Charmaz, 1983). An example of discrediting would be a person with a CD interpreting others' responses to the illness, such as teasing or laughing at the condition, as an attack upon the person's sense of self (Charmaz, 1983). Unmet expectations could be viewed as discrediting when, for example, one's partner expects one to function as before and shows irritation or impatience if this does not happen (Charmaz, 1983). Society could benefit by gaining knowledge of how PwCD make meaning in the following ways: it could add to current knowledge and awareness about the lived experience of chronic illness; it could increase public awareness and mobilisation; it could lead to change in the social meaning of a condition; and it could encourage support of PwCD to fully integrate into society and maintain their social and work roles (Brown et al., 2004).

1.2.4 My personal interest in the study

Understanding and recognising how I related to this study was an evolving process which demanded critical self-awareness from the very outset and throughout the research process (Probst, 2015). I, therefore, explicated my pre-understanding and knowledge of the phenomenon as well as my relationship with the participants early in this research process in order to enhance the rigour, authenticity and trustworthiness of my study and findings (Dodgson, 2019).

I am an independent consultant with a total of 15 years of experience in offering advice on every aspect of human resources including recruiting, training, developing, performance management, employee relations and employee wellbeing, and eight years of experience in counselling and supporting PwCD. During 2014 to 2016, for my master's study, I researched cancer patients re-entering the work context. This resulted in a phased model of individual adjustment and coping as well as organisational support strategies relating to challenges that cancer survivors experience post-treatment. These support strategies were deemed useful in the

reintegration process for the person with cancer returning to work. Two articles were published on the basis of this study, namely: "Work adjustment of cancer survivors: An organisational support framework" (Clur et al., 2017), and "Returning to work: The cancer survivor's transformational journey of adjustment and coping" (Barnard et al., 2016). I also co-presented the following two papers at the 15th European Congress of Psychology (ECP) 2017 in Amsterdam: "Transitioning the return to work journey: Mapping the cancer survivor's process of adjustment and coping" (Barnard, 2017), and "Returning to work: Exploring the lived experience of the cancer survivor" (Clur, 2015).

On completion of my master's degree, I had an ongoing involvement with PwCD in the form of emotional and practical support. Besides dealing with the symptoms, challenges and self-management of my own CDs, I went through a process of interpretation, attempting to understand and make sense of my life, my relationships and myself, a process known as meaning making (see Gillies et al., 2014; Ignelzi, 2000; Khei, 2019; Yang et al., 2021). During my interaction with PwCD, they raised similar concerns and I discovered that making meaning while living with CDs is a natural, dynamic and ongoing process. Hence my experience as a person confronted with MCC and my ongoing support and consulting with PwCD, led me to further explore the existential issues surrounding the meaning-making process while living with a CD. I was therefore also a member of the population of my study and held an insider position, but in my role as researcher, I also adopted an outsider position (Dwyer & Buckle, 2009). My positionality is further explained in section 2.2.3.

In deciding what would be important for the study, the methods and the analysis of data, I drew upon my experience as a person living with MCC as well as my experience in the field of industrial and organisational psychology, counselling and research. I wanted to know everything about meaning making while living with a CD, and chose an approach that resonated with my experience, world view and the goal of the research (Davis, 2020). As an integral part of the process and final product, I acknowledged that it was not possible or desirable to separate myself from it (Galdas, 2017). I also did not want to claim that this study would reflect objective, opinion-free neutrality, but I committed myself to being transparent by documenting the procedures and processes I followed to collect, analyse and present the data in my multiple case

study (Galdas, 2017). From the outset, I engaged in continuous reflexivity through ongoing listening, thinking, questioning, reading and writing (Spence, 2017) about every phase and aspect of this research project. In this thesis, I attempted to demonstrate critical reflexivity throughout the text, especially in Chapter 2, where I denoted my philosophical stances, and in Chapters 6, 7 and 8, where I indicated my involvement in the analysis and reporting of the data.

1.3   PROBLEM STATEMENT AND RESEARCH QUESTIONS

There is an increasing number of people living and working with CDs (Adler-Waxman, 2017; Hajat & Stein, 2018; Raghupathi & Raghupathi, 2018; Schmidt, 2016; Waterhouse et al., 2017). Living with a CD has implications for the individual's health and wellbeing (Clur, 2015; Duijts et al., 2014). Meaning making is relevant to the psychological wellbeing of individuals confronted with a CD as it serves to protect and enhance their wellbeing (Wong, 2014a). Hartog et al. (2020) reported that there is a wealth of research in psychology and (health) sociology on meaning making and adaptation in the context of stressful life events such as falling ill (e.g. Antonovsky, 1987; Büssing & Fischer, 2009; Folkman & Moskowitz, 2007; Lazarus & Folkman, 1984; Park, 2010, 2013; Park & Folkman, 1997; Park & George, 2013; Ryan & Deci, 2000a; Sales et al., 2013; Tedeschi & Calhoun, 1996; WHOQoL SRPB Group, 2006). However, in general, research relating to the meaning making of individuals with a CD in the organisational and work context is limited (Clur et al., 2017). There appears to be a gap in the literature on meaning making in the context of the employee with a CD. It would be beneficial, not only for individuals with CDs, but also for their society, to know how they make meaning to be able to support them (Cockerham et al., 2017) in staying productively employed.

It is furthermore necessary to know how individuals with CDs make meaning in the work environment as this knowledge should enable employers to support individuals with CDs in maintaining and enhancing their wellbeing (Bosma et al., 2020). Organisational interventions for employees with CDs are mostly directed towards work practices and practical solutions (Esteban et al., 2018; Leonardi & Scaratti, 2018; Nazarov et al., 2019; Vooijs et al., 2017). There is a void in organisational interventions that focus on meaning making to address the psychological and spiritual wellbeing of

employees with CDs. Clur et al. (2017, p. 8) suggested that "adjustment interventions should focus on psychological and spiritual wellbeing". Organisational interventions focusing on the psychological wellbeing of individuals with CDs may reduce or avoid the effect of living with a CD on work performance, absenteeism, negative health outcomes and turnover costs and may increase socioeconomic outcomes (Goetzell et al., 2004; Ng et al., 2001; Schuring et al., 2007; Waddell & Burton, 2006).

Frankl pioneered research on meaning (MacKenzie & Baumeister, 2014) and many studies on meaning focus on the application of Frankl's logotherapy principles in the organisational sphere (e.g. Burger, 2007, 2012; Burger et al., 2008; Burger et al., 2012; De Klerk, 2006; Fillion et al., 2009; Makola, 2013, 2015; Pattakos & Dundon, 2017a; Riethof & Bob, 2019; Van Jaarsveld, 2004; Van der Walt, 2017), and on exploring and explaining the role of spirituality in psychological adjustment (Albaugh, 2003; Arrieira et al., 2018; Britt & Acton, 2022; Laubmeier et al., 2004; Litwinczuk & Groh, 2007; O'Neill & Kenny, 1998). However, no qualitative research relating to exploring or testing Frankl's theory as applied to PwCD in the personal and work context could be found in the literature. This includes South African research as well as research in the international domain.

I explored several research databases, namely Google, Google Scholar, Pubmed, ResearchGate and ScienceDirect, and found predominantly quantitative studies that tested Frankl's logotherapeutic model (e.g. Crumbaugh, 1968; Dyck, 1987; Joshi et al., 2014; Laubmeier et al., 2004; Melton & Schulenberg, 2007; Sappington et al. 1990) and studies applying logotherapy's focus on meaning making to cancer patients in clinical settings (e.g. Bruzzone, 2021; Mohabbat-Bahar et al., 2014). There seems to be a gap in the literature pertaining to the importance of testing Frankl's theory in order to find literal replication, that is, where the theory would predict similar results (Yin, 2009) or provide fresh perspectives on meaning making from an organisational or work psychology perspective. Given the extensive use of Frankl's logotherapy principles, the impact of meaning on the wellbeing of the individual (see Section 1.2.3) and the work outcomes of employees (see Sections 1.2.1 and 1.2.2), it is imperative to test Frankl's theory in the development of knowledge and a better understanding of the individual living with a CD.

Based on the problem statement, the following research questions were formulated:

(1) How do individuals make meaning while living and working with a CD?

(2) What enhances meaning making for individuals living and working with a CD?

1.4   RESEARCH AIM AND PROPOSITIONS

To address the stated research questions, the aim of this study was to explore, describe and explain how people make meaning while living and working with a CD, with a view to developing an organisational support framework centred on meaning making, to facilitate and enhance the wellbeing of employees with CDs.

This study followed a qualitative case study design as explained in Section 1.7 below. The qualitative multiple case study design in theory testing to determine whether empirical evidence supports the theory's propositions (Dul & Hak, 2007) is widely used and recognised (Eisenhardt & Graebner, 2007; Ridder, 2017; Thomas, 2016; Vargas-Bianchi, 2020; Yin, 2009). My approach to theory is elaborated on in Chapter 2, Section 2.5.

In case study research, when testing a theory, at the start of the study, it is necessary to formulate propositions relating to the research aim (Rowley, 2002; Rule & John, 2015; Yin, 1999, 2009, 2018). These propositions serve to determine the direction of the study and the focus of data collection (Baxter & Jack, 2008). In this study, the propositions were derived from the conceptual framework of Frankl's meaning-making principles upon which the study was built. I chose Frankl's meaning-making principles as the theory to guide this study because he is much quoted on the subject of meaning making (e.g. Aldwin, 2007; Beck, 1979; Ellis & Harper, 1975; Lazarus & Folkman, 1984; Rogers, 1969; Wong, 2012b, 2014a, 2014b, 2016b, 2016d, 2017a, 2017c), especially in studies on the role of meaning making in facing life's adversities (e.g. Baumeister & Vohs, 2002; Russo-Netzer & Ameli, 2021; Ryff, 2014; Steger & Park, 2012; Von Devivere, 2018; Wong, 2014b; Wong & Bowers, 2019; Zeligman et al., 2018). The propositions were derived from Frankl's meaning-making theory as a departure point and aimed at testing this theory (Pearse, 2019; Ritchie & Lewis, 2006; Woiceshyn & Daellenbach, 2018).

Frankl is regarded as one of the prominent scholars in the field of meaning, and his theory of meaning is acknowledged and forms the basis for many scholars in modern

health science research on meaning (e.g. Britt & Acton, 2022; De Ridder et al., 2008; Haugan & Dezutter, 2021; Kaplin & Anzaldi, 2015; Kim et al., 2014; La Cour et al., 2009; Lee et al., 2006; Nilsen et al., 2021; Park et al., 2008; Riethof & Bob, 2019; Roussi & Avdi, 2008; Southwick et al., 2021; Starck, 2013; Swinton et al., 2011; Wong, 2014b; Zeligman et al., 2018). Frankl believed that people are motivated by a "will to meaning", which indicates the desire to find meaning in life (Frankl, 2008). He argued that life can have meaning even in difficult circumstances, and that the motivation to live comes from making meaning (Devoe, 2012; Frankl, 2008; Prera, 2020; Wong 2014b). Frankl's thinking was built on values, which establish the meaning structure as well as the meaning-making process in people's lives. Frankl categorised values into three distinct categories that reflect the three different main routes, namely the creative, experiential and attitudinal pathways to discovering meaning (Purjo, 2013). In this sense, values and pathways were used interchangeably in this study. Frankl argued that meaning making involves self-transcendence, moving beyond the self and towards meaning, and purported that meaning making occurs through these pathways (Frankl, 1959, 1966, 2008; Pattakos & Dundon, 2017a; Wong, 2014b, 2016b, 2016d; Worth & Smith, 2021).

The propositions regarding the corresponding research questions were derived from Frankl's meaning-making principles as discussed above and formulated as follows:

- Proposition 1: Individuals living and working with a CD make meaning by following Frankl's meaning-making pathways:

  (1) By using the creative pathway, individuals purposefully move towards adding value to themselves and others.

  (2) By using the experiential pathway, individuals connect meaningfully with someone or something.

  (3) By using the attitudinal pathway, individuals choose an attitude to create a different experience for self.

- Proposition 2: Meaning making for individuals living and working with a CD is enhanced by living out the capacity of self-transcendence.

1.5   DISCIPLINARY BOUNDARIES DEMARCATING THE STUDY

Industrial and organisational psychology (IOP) is the scientific study of human behaviour in the workplace (Cilliers & Flotman, 2016), through the application of psychological theories and principles in organisations, to optimise individual, group and organisational performance (Cummings & Worley, 2015; Van Tonder & Roodt, 2008). This study, within the discipline of IOP, aimed to develop a framework to enhance the wellbeing of employees with CDs to ensure optimal participation in the workplace. The subdisciplines relevant to the study were employee and organisational wellbeing and career psychology and counselling.

According to Bergh and Theron (2009), employee and organisational wellbeing are also referred to as occupational mental health. This field of IOP has to do with optimal wellness for employees and organisations (Schreuder & Coetzee, 2010). Wellness is viewed as the presence of wellbeing and optimal performance (Roncaglia, 2017). Hence maladjustment and impaired work performance are important concerns of employee and organisation wellbeing (Bergh & Theron, 2009). In this study, the focus was on how chronically ill employees make meaning, and how enhanced meaning making enables them to address their wellbeing and ultimately their work performance. This study should contribute to the understanding of meaning making of the employee with a CD and provide vital organisational and management information to guide best practices in developing relevant wellbeing interventions.

Career psychology and counselling are concerned with issues of career development (Barkhuizen et al., 2014), career-related issues and nonwork influencing factors (Schreuder & Coetzee, 2010). The search for purpose and meaning has to do with how one actualises oneself through various life- and work-related roles (Leung, 2008). Existential considerations elucidate the challenges employees face in their current career transition (Maglio et al., 2005). Awareness of existential considerations, as highlighted in this study, is useful in career counselling for employees working and living with a CD. A change in career intervention is required from focusing on "identity rather than personality, adaptability rather than maturity, intentionality rather than decidedness, and stories rather than scores" (Savickas, 2012, p. 14). This indicates a more holistic perspective to assist PwCD as they negotiate career decisions through meaning making and fulfilment (Maglio et al., 2005).

1.6   PARADIGMATIC PERSPECTIVES

The research paradigm defines a researcher's philosophical orientation and provides an indication of how knowledge will be constructed from the data (Kivunja & Kuyini, 2017). I chose the interpretivist paradigm for this study because I wanted to understand and interpret the dynamics of meaning making in the context of the participants working and living with a CD. The key tenet of the interpretivist paradigm is that reality is socially constructed, and as such it is sometimes also called the constructivist paradigm (Locke & Golden-Biddle, 2002; Kivunja & Kuyini, 2017; Ponterotto, 2005). In this study, I used the term "interpretivist paradigm". This paradigm characteristically assumes a subjectivist epistemology, a relativist ontology, a balanced axiology and a naturalist methodology (Kivunja & Kuyini, 2017). Relevant ontological and epistemological deviations have evolved within the interpretivist paradigm (Duncan & Nicol, 2004; Kahlke, 2014; Kelly et al., 2018; Maxwell, 2012; Sandelowski, 2010; Thorne, 2008) to express more pronounced philosophical positions, which I resonate with, such as subtle realism (ontology) and social constructionism (epistemology). Interpretation (hermeneutics) and understanding (*verstehen*) are acknowledged as the key influences in the development of the interpretivist paradigm (Dahlberg et al. 2008). As such, hermeneutic phenomenology, also known as interpretive phenomenology (Van Manen, 1997) was selected as a research approach for this study. These philosophy of science beliefs are explained in more detail as the building blocks of my interpretivist stance, in the methodology chapter that follows.

The psychological paradigms that guided this study were existential psychology, existential positive psychology and cognitive psychology. The notion of meaning making originated in existential philosophies (Evans et al., 2017; Horne, 2019; Yalom, 1980). Because this study relates to the existential experience of living with a CD, it supports the existential perspective that emphasises the importance of facing and accepting the reality of adversity (Gebler & Maercker, 2014). The psychological paradigms will be further elaborated on in the literature review in Chapters 3 and 4 and will be presented as the fundamental psychological paradigms of the meta-theories on meaning making upon which this study was built.

1.7   RESEARCH STRATEGY

A qualitative multiple case study was deemed suitable for this study because I wanted to test Frankl's meaning-making principles as applied to PwCD in the context of working, by exploring the cases' meaning making, while living and working with a CD, and being able to analyse the data both within each case and across the cases (Yin, 2003a,b). The case study provides a form of inquiry that allows for a holistic view of life in its full complexity (Thomas, 2016) and for aligning qualitative inquiry with theory testing (Sprecher et al., 2022; Vargas-Bianchi, 2020). A qualitative multiple case study from the meta-theoretical perspectives of existential and cognitive psychology was therefore deemed appropriate for this study. A qualitative multiple case study, which is descriptive and interpretive in nature, was conducted in a naturalistic context (Patton, 2002), from a hermeneutic phenomenological point of view. The naturalistic context refers to the study of each particular case in its natural setting (Abma & Stake, 2014; Stake, 2006), while the phenomenological point of view relates to the study of the participants' lived experiences from their subjective or first-person perspective (Smith, 2006).

In this study, I used Frankl's principles of meaning making as a conceptual framework for the study and a tool for data analysis (Rule & John, 2015; Yin, 2009). The interpretive hermeneutic phenomenology approach was adopted to interpret and understand the experiences of meaning making (Fuster Guillen, 2019) of PwCD. Three cases were identified to allow me to explore the research questions and propositions in depth (Eisenhardt & Graebner, 2007; Gustafsson, 2017) within each case, and to understand the similarities and the differences between the cases (Baxter & Jack, 2008; Gustafsson, 2017; Stake, 1995). The CDs that the three cases presented were ankylosing spondylitis (AS), asthma, hypertension, breast cancer, psoriasis, depression and alopecia areata (AA).

Case studies are characterised by multiple data collection strategies, such as the use of more than one collection method and/or repeated or prolonged engagement in the fieldwork and with participants (Crowe et al., 2011; Gustafsson, 2017; Rowley, 2002). Data was gathered by means of a multi-method approach (Alexander et al., 2008; McDonnell et al., 2017), with the focus within and across three cases. Interviews, document analysis, diaries, image-based methods and observations constituted the

methods that were used to provide extensive descriptions and explanations of the research phenomenon. As researcher, I engaged with participants in the field over a period of time. During this time, the participants were consulted on multiple occasions to understand the social phenomenon in detail (Rashid et al., 2019). The hermeneutic phenomenology approach to collection and analysis was applied (Laverty, 2003; Sloan & Bowe, 2014; Willig & Billin, 2011). In the analysis of the data, the study adopted a hybrid approach of inductive and deductive thematic analysis (Bendassolli, 2013; Fereday & Muir-Cochrane, 2006; Patton, 1991; Woiceshyn & Daellenbach, 2018). Both the data-driven inductive approach of interpretative phenomenological analysis IPA (Smith, 1996) and the deductive a priori analysis that uses a framework of themes for the coding process (Braun & Clarke, 2006; Pearse, 2019; Spencer et al., 2004) were used. This approach complemented the research questions by allowing the propositions, derived from Frankl's principles, to be integral to the process of deductive thematic analysis, while allowing for themes to emerge directly from the data using inductive coding. Data were analysed within each case and also compared across cases (Yin, 2003a).

From a hermeneutic phenomenological perspective, rigour is predominantly ensured through self-reflective research (Spence, 2017). In this study, a self-reflexive approach was followed, as discussed above in Section 1.2.4 and elaborated on in Section 2.6.4.4. I mainly practised self-reflection by keeping a self-reflective journal. In this journal, I was able to document my observations, thoughts and feelings, and I integrated this information through the research design, data generation, analysis and interpretation process to show how this influenced the research process, and in so doing attempted to enhance the transparency of the research (Annink, 2017; Ortlipp, 2008). In the thesis, I followed a qualitative reporting style that was predominantly of a narrative and thematic nature, using the participants' own words, and told by myself in the first person. Anonymity was used to protect the participants, and real identities were converted to fictitious ones (Yin, 2003a). The interpretation and findings reflect the research questions, propositions and theory that structured the study.

1.8   CONTRIBUTION OF THE STUDY

Case study research plays a key role in advancing the body of knowledge of a phenomenon (Merriam, 2009). Hence, this study should make practical, theoretical and methodological contributions as discussed in this section.

1.8.1   Pragmatic contribution

One of the practical contributions of this study was the detailed insight provided by the three case studies. In this study, strategies for meaning making in the workplace were identified, thereby making a contribution to support the management of employees with CDs in the workplace. The supporting legislation relevant to the management of employees with CDs was illuminated to enhance equality of work access and participation. The study will hopefully result in better outcomes for individuals as well as employers and empower and create a healthy society.

1.8.2   Theoretical contribution

The study should help to build knowledge on the manner in which individuals make meaning while living with a CD. The results generated from these cases may help to make sense of the complex relationships between the effects of living with a chronic disease, meaning making and being productive at work. This should contribute to building knowledge of the career decisions of PwCD. By comparing similarities and differences between the cases, this multiple case study research further tested and built on Frankl's principles of meaning making. The concrete knowledge of meaning making could help to develop future interventions and result in a deeper understanding of how Frankl's theory has value for comprehending and supporting people living with chronic illnesses.

1.8.3   Methodological contribution

In this study, I showed how different qualitative methods and approaches could be uniquely combined to answer the research questions. Qualitative research is predominantly ascribed to and used for explorative and descriptive research (Sprecher et al., 2022). In the qualitative inquiry domain, case study research's distinct traditional contribution has also been regarded as exploration (Ridder, 2017). However, of late, the unique theory-testing capacity of qualitative research has been increasingly

recognised (Sprecher et al., 2022; Vargas-Bianchi, 2020). Qualitative theory-testing research requires the researcher to be directed by existing theory, with the focus on gathering data to prove or reject an existing theory (Creswell, 2014). Similarly, case study research has the potential to create, test and advance theory (Ridder, 2017; Yin, 2009). The study therefore presents a unique qualitative approach to theory testing, which was used to formulate propositions based on Frankl's theory and use pattern matching to compare them with the empirically observed outcomes (Vargas-Bianchi, 2020).

In this study, the assumption was that the richness of experience and the in-depth detail of the data would contribute to testing the theoretical assumption underlying Frankl's meaning-making principles. A multi-method approach was used to collect data, as mentioned in Section 1.7. In interpreting the real-life world experiences (hermeneutic phenomenology) of the individuals (multiple cases) making meaning while living with a CD (phenomenon), I used interpretive phenomenological analysis (IPA) (which has the theoretical underpinnings of phenomenology, hermeneutics and idiography), as mentioned by Tuffour (2017), to allow for themes to emerge directly from the data. Pattern matching (Pearse, 2019) was used to link the data to the propositions because the findings were aimed at improving the scientific applicability of Frankl's theory to the phenomenon being studied (Corley & Gioia, 2011).

1.9   THESIS STATEMENT

Individuals living with a CD make life and work meaningful by following the pathways of creative, experiential and attitudinal values. They enhance meaning making by using the spiritual values of the will to meaning and self-transcendence. Understanding how a person makes meaning while living with a CD provides valuable information for employers to better support and retain these employees.

1.10   DEFINITION OF KEY TERMS

Chronic disease: This is a health condition that is permanent, unpredictable over time, varies from day to day and is often invisible (Beatty & Joffe, 2006; Bernell & Howard, 2016; Fuller, 2018). The World Health Organization (WHO, 2018, p.1) defines noncommunicable diseases (NCDs), also known as chronic diseases "as diseases

that tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behaviours factors". Medical aids in South Africa are required by law to cover treatment for 26 of the most commonly occurring ailments and over 270 other conditions (Businesstech, 2018), which underlines the diversity of the condition.

Comorbidity: This is the presence of additional diseases (Saltman et al., 2005) that relates to an index chronic condition in one person (Nicholson et al., 2019; Valderas et al., 2009). Comorbidity is defined as the "coexistence of disorders in addition to a primary disease of interest" (Feinstein, 1970, p. 455). The index condition is the main condition, while comorbidity is the conditions that exist together with the main condition or developed later but are not a consequence of the index disease (Ording & Sørensen, 2013).

Disease severity: Disease severity refers to the presence and extensiveness of a disease in the body (Finlayson et al., 2004).

Health-related quality of life: This is a multi-dimensional concept that includes physical, psychological, emotional, spiritual and social functioning. It refers to the general wellbeing dimensions of health (Finlayson et al., 2004).

Multiple chronic conditions or multi-morbidity: This explains the co-existence of two or more chronic diseases in an individual (Smith & O'Dowd, 2007). These terms are used interchangeably with the term "comorbidity".

1.11   CHAPTER LAYOUT

Table 1.1 indicates the chapter layout, with a short description of each chapter.

Table 1.1

Chapter layout

CHAPTER 1 Scientific orientation to the study	The introductory chapter provides the background to and motivation for the research problem, research questions, propositions, paradigm perspective and research design applied in the study.
CHAPTER 2 Research Methodology	Chapter 2 provides an explanation of and justification for the research methodology used, explaining how the cases were selected and data collected and analysed.
CHAPTER 3 Meaning making while living with a CD: A conceptual integration	Chapter 3 focuses on relevant literature to contextualise the research within existing theoretical paradigms and emphasises meaning making while living with a CD.
CHAPTER 4 Meaning making of the person with chronic illness in the work context	Chapter 4 continues the literature and research review by focusing on meaning making of PwCD in the context of the workplace.
CHAPTER 5 Case descriptions	In Chapter 5, a general overview of each case is provided by describing the participants' chronic diseases, backgrounds and experiences of living with these illnesses.
CHAPTER 6 Findings	Chapter 6 presents the descriptive findings of the data analysis.
CHAPTER 7 Reconstructing a meaningful self: The essence of meaning making for PwCD	Chapter 7 provides a continued critical reflection using theory and relevant literature, resulting in a critical evolution of the findings.
CHAPTER 8: Conclusions, limitations and recommendations	Chapter 8 contains a discussion of the key findings and outcomes, provides a critical reflection on potential limitations and make recommendations for possible future research.

1.12   CHAPTER SUMMARY

Owing to the increasing number of people living and working with a CD, it is imperative to support their ability and motivation to remain in in employment. The purpose of the study was to explore, describe and explain how people make meaning while living with a CD, in order to develop a support framework to facilitate and enhance the wellbeing of employees with CDs in an organisational context. The aim of this qualitative multiple case study was to study this complex phenomenon of meaning making while living with a CD from many and varied angles in its completeness. This chapter provided a

discussion of the background to and motivation for the study and formulated the problem statement, research questions, research aim and propositions. The nature of the study and its potential contribution were explained, the thesis statement formulated and the key terms defined, and the chapter concluded with the proposed chapter layout. In Chapter 2 focuses on the research methodology.

CHAPTER 2
RESEARCH METHODOLOGY

2.1   INTRODUCTION

This chapter explains in detail the research methodology that established the credibility of the knowledge claims made in this study, which was fundamental to how the study was conducted. Research methodology is the science of understanding how research is to be conducted (Igwenagu, 2016; Schwandt, 2007; Yin, 2012) and incorporates the research paradigm, research design and research methods (Sileyew, 2019). The purpose of the research design is to turn a research problem into data that can be analysed and used to answer the research questions (Creswell, 2014; Hakim, 2000; Merriam, 2009). The design is directed by the research paradigm. Since this study was located in the interpretive paradigm, it directed the qualitative multiple case study design that was followed, and the research design includes the specific qualitative research methods that were used (Makombe, 2017).

This chapter also explains how the goal of the study was attained and how the findings of the research were arrived at. I outline the research techniques that were employed, denoting how the study progressed from the initial research plan to the final data presentation. The philosophical presumptions supporting this study are first explained, along with the congruent research paradigm that defined the study's knowledge-generating claims. I then detail the multiple qualitative case study research design, clarify my theory approach and discuss the research methods employed to conduct the study. Lastly, the ethical considerations and reporting of the findings are explained.

2.2   PHILOSOPHICAL ASSUMPTIONS

The research methodology in qualitative research begins with the researcher expressing the philosophical assumptions (Creswell, 2013a) that reflect the researcher's values and guide the research process (Saunders et al., 2009). The researcher's philosophical assumptions are critical in justifying decisions about the design and methods used to support the rigour of the research (Jackson, 2013; Sikes, 2004). There are usually four types of philosophical assumptions that influence the design and research process (Creswell, 2013a). Saunders et al. (2009) posited that

the philosophical assumptions include assumptions about reality (ontological assumptions), the relationship between the researcher and participants in the discovery of knowledge (epistemological assumptions), and the extent to which and ways in which one's own values influence the research process (axiological assumptions). The ontological, epistemological and axiological assumptions as the building blocks of the research paradigm are discussed next.

2.2.1   Ontological assumption

According to Hudson and Ozanne (1988), ontology describes the nature of reality, and expresses the researcher's view of the world (Marsh & Furlong, 2002). Different paradigms espouse different ontological positions. Two main paradigms to consider are positivism and interpretivism. Moon and Blackman (2017) stated that positivism is underpinned by a realist ontology (which relates to the existence of a single reality), while interpretivism is underpinned by a relativist ontology (expressing the belief that reality is relative according to how individuals experience it). Realists distinguish between the way things actually are and how people choose to understand and interpret them (Ormston et al., 2014). A realistic view assumes that what is reported is a true and faithful interpretation of a knowable and independent reality, and it ignores the way the researcher constructs the interpretations of the findings (Andrews, 2012). The relativist ontological assumptions in qualitative research regard reality as subjective and influenced by the context of the situation (Du Plooy, 2001), the social environment and the interaction between the participant and researcher (Creswell, 2013a; Ponterotto, 2005). Furthermore, a relativist ontological position is based on the belief or assumption that multiple, constructed realities exist rather than a single reality (Guba & Lincoln, 1989; Ponterotto, 2005). Relativism leads to the conclusion that there are multiple realities of which none takes precedence over the other in terms of claims to represent the truth regarding social phenomena, and therefore suggests that nothing can ever be explicitly known (Andrews, 2016). Thus, when defined to include both objectivity and singularity of truth, realism opposes relativism (Baghramian & Carter, 2022). Seale (1999) concluded that relativism does not work in establishing an ultimate truth.

Angen (2000) posited that as researchers we want to be sure that we have done the right thing and have produced the truth. As such, researchers do not want their work

to be considered as merely a relative or subjective opinion (Angen, 2000). When planning my study, I wanted to study something worthwhile and make a significant contribution to a worthy subject. I found myself attuned to the belief in a subjective, multiple view of reality, yet I could not embrace an extreme relativist view, which seemed to me a position in which credible knowledge is always questioned. As such, I continued to seek and build my own style, as Seale (1999) proposed, one that also acknowledges the significance of the researcher's experience and sense making.

According to Cupchik (2001), bridges should be built between different social ontologies through reflection and seeking similarities in the supposed differences. Hammersley (1992) proposed subtle realism as a bridge between relativism and realism. Subtle realism (Blaikie, 2007; Hammersley, 1992) suggests the existence of an external reality that is only made known through human understanding and socially constructed meanings (Ormston et al., 2014), of which the researcher is part (Hammersley, 1992). According to Angen (2000), from the interpretive perspective, reality is socially constructed and, through intersubjective lived experience dialogue, a form of truth is negotiated. Subtle realism thus fits into the interpretivist paradigm and involves subjective perceptions and observations, acknowledging that different methods produce different views of the participants being studied (Duncan & Nicol, 2004). Subtle realism also asserts that the understanding or knowledge that is acquired is because of answers to particular questions about the research phenomena (Hammersley, 1992), thus emphasising the representation of social phenomena instead of the reproduction thereof (Andrews, 2016).

According to subtle realism, any given reality can be represented from the participants' different perspectives, and each of them may be treated as true as they represent reality from the point of view of the different participants (Murphy et al., 1998). The subtle realist approach is increasingly being used in healthcare (Andrews, 2016; Duncan & Nicol, 2004; Murphy et al., 1998), and I felt comfortable with its assumptions and found it to be a suitable basis for how I believed truth, knowledge and reality could be represented in this study.

2.2.2 Epistemological assumption

The epistemological assumption is focused on the study of the nature of the world and how we know what we know (Furlong & Marsh, 2010). As such, epistemology involves the relationship between the researcher and reality, or how this reality is captured or known (Carson et al., 2001; Guba & Lincoln, 1994). The positivist and interpretivist paradigms also espouse different epistemological positions. Positivism is underpinned by an objective epistemology which assumes that reality exists externally or independently of the individual mind. Interpretivism is underpinned by a subjective epistemology that relates to the reality in which people make meaning of the world and interpret it in a way that makes sense to them (Moon & Blackman, 2017). From a subjectivist epistemological perspective, reality is located in the meanings that people attach to their experiences. Multiple sources of knowledge therefore exist and can be used to explore, interpret and make sense of phenomena (Du Plooy 2001; Myers, 2009). Social constructionism is a subjective epistemological stance endorsing the notion that although individuals engage in meaning making, they do it from and within a wider social context (Prasad, 2005).

According to Hammersley (1992), all knowledge is socially constructed and impacted by prior knowledge, which can lead to valuable insights that should be used but also controlled. As such, knowledge, for this study, was acquired through deduction (Blaikie, 2007), where a priori propositions were drawn from Frankl's principles and were tested against evidence or data collected in the empirical part of the study. However, I also applied inductive reasoning in the further interpretation and elucidation of the findings that emerged (Park et al., 2020) in refining or enhancing the existing theory. Hence, a hybrid approach (Swain, 2018; Xu & Zammit, 2020) to knowledge acquisition was applied, which will be further elaborated on in Section 2.6. As noted above, any understanding, or knowledge produced, comprised answers to particular questions about the phenomena (Hammersley, 1992). There were multiple perspectives even though there was one reality of which the researcher was part (Hammersley, 1992). According to Ahrens (2008), interpretive is frequently used to describe a study's broad approach or methodology interchangeably with qualitative, phenomenological and naturalistic approaches. Interpretive gives a broad indication that social reality emerges and is subjectively created, yet through social construction

it is made objective (Ahrens, 2008; Ahrens & Chapman, 2006; Chua, 1986; Tomkins & Groves, 1983).

For this study, epistemologically, in line with the viewpoint of the interpretivist paradigm, I took the position that the knowledge of reality is socially constructed (Burrell & Morgan, 1979; Remenyi et al., 1998). Social constructionism focuses on what emerges because of social interaction. Social constructionism can be either strong or weak. Strong social constructionism argues that all knowledge is socially constructed. Weak social constructionism holds that our perception of reality is formed by the lenses through which we perceive and comprehend it (Amineh & Asl, 2015). Congruent to a weaker form of social constructionism, my epistemological position, in alignment with my subtle realism ontological position, allows for the understanding of the meanings co-constructed in this thesis.

 In adopting this stance I believe that reality was experienced and influenced by the participants' experiences and perceptions, the social environment in which they live and work, my own preconceptions and in the interaction between me and the participants.

2.2.3   Axiological assumption

The axiological assumption refers to the extent and ways one's own values influence the research process (Saunders et al., 2009; Creswell, 2013b). My values, experience and world views influenced the research design and process, and therefore in building on explaining my interest in this study in Chapter 1, I next discuss my positionality in relation to the research (Creswell, 2013b).

The positionality of a researcher within a given study effects how research is conducted as well as the outcomes and results (Rowe, 2014; Savin-Baden & Major, 2013). Berger (2015) stated that positioning refers to how researchers view themselves in relation to the research and the data. To ensure ethical and credible research, it is essential for researchers to reflect and be transparent about methodological issues like their positionality and background, which might have an influence on the generation and interpretation of the data (Savvides et al., 2014). The philosophical position of the researcher reflects the system of beliefs and assumptions about the development of knowledge (Žukauskas et al. 2018). In qualitative research,

the researcher's predetermined or chosen axiological position is referred to as the insider or outsider position (Dwyer & Buckle, 2009; Holmes, 2020; Paechter, 2013).

Insider researchers are those who are members of the researched (Kanuha, 2000; Savvides et al., 2014), while outsiders are deemed non-members (Chhabra, 2020). Hellawell (2006) suggested that researchers can explore and decide to what extent they are insiders or outsiders by thinking about the space in between. The lived experience of illness is intimate, and sharing this experience can expose one's vulnerability (Richards, 2008). As the researcher of this study and a person living with MCC, I could not receive the same protection of anonymity as the participants and would have been left exposed in the sharing of personal and intimate experiences. I decided that I would not participate in this study as a full member but would hold the in-between position of an insider-outsider researcher (Dwyer & Buckle, 2009), also referred to as the hybrid insider/outsider position (Paechter, 2013).

Sharing the experience of living with CDs with participants does not indicate complete sameness (Dwyer & Buckle, 2009). Each CD is a "different country, with different languages and customs, different laws, different international relations with the healthy" (Richards, 2008, p. 1718), meaning that everyone's experience living with a particular CD differs. The insider position gave me access to the participants, the cases that I studied. I was conscious not to assume I understood the full context of living with a CD just because I also share the experience (Doyle, 2019). I was aware that sharing a similar life experience with the participants could evoke personal distress which could inhibit rather than increase my understanding of their emotions (Israelashvili et al., 2020). My training as a counsellor enhanced my self-awareness and knowledge to distance myself when needed to allow the participants to tell and share their stories and experiences. However, I responded to their emotions and offered them support when necessary.

According to Dwyer and Buckle (2009), it is the awareness of being different from others that makes the researcher notice the ways in which there are also similarities, and this is the space in between that allows for both an insider and outsider position. As a person living with MCC, I could not be an outsider to the experience under investigation, but in my role as researcher I did not qualify as a complete insider – hence the fact that I occupied the space in between (Dwyer & Buckle, 2009). As an

insider in the design of the study, I had the advantage of prior knowledge (Brannick & Coghlan, 2007), and this made it easier to empathise with and gain access to the participants and data. This prior knowledge could, however, also have led to sharing too much of my own experience. I had to be aware of this temptation and reminded myself that I had to remain in a neutral position during data gathering because I then occupied the outsider position (Fleming, 2018).

In insider research, however, it is natural for participants to ask the researcher questions because of the shared experience, and then for the researcher to respond to these questions (Fleming, 2018). This was done by answering the question and then guiding the interview back to the participant's experience. It was also possible that the participants would make assumptions that I knew more about their experience than I really did and therefore failed to explain their individual experience fully (Dwyer & Buckle, 2009). A strategy to manage this was to start the interview by explaining to the participants that they needed to discuss the topic as if it was their first time explaining what they felt, thought and had been through, and not to assume I knew anything about their specific lived experiences. I also reminded them that everyone's experience and illnesses are different and unique (Chavez, 2008).

In using IPA, the researcher's position is regarded as an integral part of the research process (Peat et al., 2019; Tuffour, 2017). During the data analyses, I therefore also had to be sensitive to emphasising certain shared experiences and de-emphasising other factors (Dwyer & Buckle, 2009). To balance this dual role I remained aware of my in-between position as well as my own biases and perspectives and used reflection throughout the research process (Dwyer & Buckle, 2009). Fleming (2018) posited that the role as insider researcher challenges one to balance the dual roles of being a researcher as well as a member of the community under investigation. By shifting positions from insider to outsider, it was crucial to engage in critical self-reflexivity, which required me to employ critical self-awareness and skills that would allow for changed perspectives (Shaw, 2013).

I exercised self-reflection throughout the process by keeping a personal journal in which I documented challenges as well as my thoughts and feelings (Berger, 2015; Li, 2018; Ortlipp, 2008; Russell & Kelly, 2002). According to Russell and Kelly (2002), keeping self-reflective journals is a strategy that facilitates reflexivity by closely

examining and questioning one's perspectives and goals and to clarify biases and subjectivities. In using reflexivity, one must be careful not to draw conclusions, but to stay with the information long enough not only to "understand what it says" but also "how it wants to talk with us" (Russel & Kelly, 2002, p. 10). In this thesis, I demonstrated my self-reflexive thinking where relevant in the text, such as in this section. A further part of critical self-reflection was demonstrated in my academic discussions with my supervisor, which engaged me in critically examining my assumptions, deductions and involvement throughout the study.

2.3 RESEARCH PARADIGM AND METHODOLOGICAL APPROACH FRAMING THE STUDY

Guba and Lincoln (1994) defined a paradigm as a basic set of beliefs or worldview that guides one's research actions. A paradigm thus flows naturally from the philosophical assumptions or beliefs discussed above, and provides a framework indicating how meaning will be constructed from the data (Kaushik & Walsh, 2019; Kivunja & Kuyini, 2017). A paradigm defines a researcher's philosophical orientation (Mackenzie & Knipe, 2006), which has significant implications for every decision in the research process (Guba & Lincoln, 1994; Kivunja & Kuyini, 2017). As indicated in the previous section, my research paradigm mainly comprised and was built on the ontological, epistemological and axiological assumptions I hold, and my chosen paradigm guided and upheld the research design I followed.

The two major and popular forms of research are qualitative, which is grounded in the interpretivist paradigm, and quantitative, which is grounded in the positivist paradigm (Antwi & Hamza, 2015; Ataro, 2020). Objectivity and mathematical techniques conventionally imply positivist research (Carson et al., 2001). However, interpretivist research is about understanding and interpreting the meanings of human behaviour and subjective experiences, rather than generalising and predicting causes and effects (Hudson & Ozanne, 1988; Neuman, 2000). Since qualitative research is a form of social inquiry into how individuals interpret and make sense of their experiences and the world they live in, it is mostly interpretive in nature. In interpretive research, the researcher and reality are inseparable (ontology), knowledge is socially constructed (epistemology) and the methods of inquiry can be designed according to case studies, phenomenology, ethnography or ethnomethodology (Bhattacherjee, 2012; Žukauskas

et al., 2018). The findings in interpretive research emerge from the interactions between the researcher and the participants as the research progresses (Creswell, 1998). Subjectivity is acknowledged in that individuals are incapable of total objectivity because reality is constructed through their subjective experiences (Bhattacherjee, 2012). My ontological and epistemological positions were explained in Sections 2.2.1 and 2.2.2, in how these varied slightly from this traditional worldview and building of knowledge in the interpretive literature.

I found the interpretivist paradigm relevant to this study because meanings were interpreted/constructed by individuals in the context of their experience (living with a CD) in their real-life world (Creswell, 2013a; Crotty, 1998). Research located in the interpretivist paradigm that seeks to discover the essence of participants' experiences in context, links the paradigm choice and research approach or methodology (Kivunja & Kuyini, 2017). According to Burrell and Morgan (2017), interpretivism is not a single paradigm but part of a larger family of diverse paradigms. There is a link between the conduct of interpretive research and hermeneutical phenomenology as a research approach (Boland, 1985; Butler, 1998). It is through hermeneutic phenomenology that the lived experiences (phenomenology) of research participants can be interpreted (hermeneutics) and understood (Van Manen, 1990).

Phenomenology is essentially the study of how we perceive the life world which is our lived experience (Langdridge, 2007; Van Manen, 1997). According to Sloan and Bowe (2014), there are two main approaches to phenomenology, namely descriptive (also known as transcendental phenomenology) and interpretive phenomenology (also known as hermeneutic phenomenology). The phenomenological movement has transitioned over the years from being purely descriptive of people's experiences, as prescribed by Husserl, to focusing on the interpretation of such experiences, as suggested by Heidegger (Lopez & Willis 2004; Van Manen 2011).

Descriptive phenomenology's main method is to explore, analyse and describe a phenomenon in richness, breadth and depth (Streubert & Carpenter, 2011), and to use bracketing to set aside existing knowledge about that phenomenon to capture the essence of the phenomenon (Laverty, 2003). Hermeneutic or interpretive phenomenology is attentive to the philosophies underpinning both hermeneutics and phenomenology (Van Manen, 1997). The term "hermeneutics" comes from the Greek

verb *hermeneuein* which means "to interpret" (Fuster Guillen, 2019, p. 220). Hermeneutics is the process of discovering meaning through conversation, written texts, attitudes, actions and any other form of expression (Fuster Guillen, 2019). In hermeneutic phenomenology, existing knowledge is not bracketed as in descriptive phenomenology, but is acknowledged and reflected to show how the researcher's subjectivity is part of the analysis process (Humble & Cross, 2010; Lopez & Willis, 2004; Neubauer et al., 2019).

To summarise, this study was based on an interpretivist paradigm. Hermeneutic phenomenology was thus selected as a suitable methodological approach because paradigmatically it aligns with interpretivism. Phenomenology deals with the experience of individuals and hermeneutics allow for interpretation and analysis of textual information (Goodwin & Compton, 2004). This approach was used to understand the experiences of the meaning making of individuals living with a CD and to interpret and analyse these experiences in light of what they already knew about this phenomenon (Powell et al., 2019).

2.4   RESEARCH DESIGN: QUALITATIVE MULTIPLE CASE STUDY INQUIRY

A holistic and in-depth inquiry using a qualitative multiple case study design allows the researcher to understand living with a CD from the participants' perspectives (Zainal, 2007). When turning to the literature for a description to define case study research, a number of terminologies for case study are presented, such as the following: methodology (Flyvbjerg, 2011; Harrison et al., 2017; Hartley, 2004; Heale & Twycross, 2018; Hughes & McDonagh, 2017; Lucas et al., 2018; Noor, 2008), method (Gustafsson, 2017; Montes-Rodríguez et al., 2019), approach (Crowe et al., 2011; Hardwick, 2016), research design (Ridder, 2017; Tetnowski, 2015), research strategy (Rowley, 2002; Takahashi & Araujo, 2019) and inquiry (Cronin, 2014; Thomas, 2017). Harrison et al. (2017) also emphasised this notion that prominent case study researchers such as Merriam, Stake and Yin, describe case study research in methodological terms as it shapes a specific research design around using multiple data sources and methods. In this study, I referred to the case study as a research design in which the full process of research is included (Creswell & Poth, 2016).

Various types of case study research designs have evolved, and in this section, I explain the details around the case study design that was applied in this inquiry.

2.4.1 A qualitative case study design

Qualitative research is a naturalistic inquiry that is multi-method and interpretative of nature in real-world settings in order to gain insight into the diversity of lived experience (Denzin & Lincoln, 2008; Ritchie & Lewis, 2006). It differs from quantitative research in that it involves words or images rather than numbers to explain outcomes (Bryman, 2008; Denzin & Lincoln, 2008). The socially constructed meaning of individuals' realities as they interact within their world is the focus of qualitative research (Merriam & Grenier, 2019; Sandelowski, 2004). It is a type of social inquiry that favours a flexible and data-driven research design, the use of relatively unstructured data, an emphasis on subjectivity in the research process, the detailed study of a small sample that is purposively selected on the basis of specific criteria and the use of verbal rather than statistical forms of analysis (Fossey et al., 2002; Hammersley, 2013). It is a reflexive approach in which the researcher's role and perspective in the research process are acknowledged. Some researchers use reflexivity to present their personal experiences while conducting research (Ormston et al., 2006). Common modes of data gathering in qualitative research are interviews, focus groups and observation. In the analysis process, data is reviewed, synthesised and interpreted to describe and explain the phenomena being studied (Ormston et al., 2006). The output includes detailed, in-depth descriptions of the phenomena under investigation, which are based on the participants' perspectives and accounts.

Case studies are used in a variety of contexts and disciplines, inter alia, in psychology and social work, political science and organisational studies (Davies, 2007; Mouton, 2001). Irrespective of the discipline in which case studies are applied, their purpose is to provide insight into real-life situations (Merriam, 2009; Pickard, 2013). As such, case study research is primarily described as qualitative inquiry in order to conduct an in-depth analysis of an issue, within its context, to understand it from the participants' perspective (Creswell, 2014; Denzin & Lincoln, 2011; Merriam, 2009; Miles et al., 2014; Simons, 2009; Stake, 2006; Yin, 2014). According to Stake (1995), the case study researcher may be somewhat of a biographer who focuses on a phase or

segment of an individual's life. In this study, the focus was on meaning making in the segment of the work and life of people living with a CD.

2.4.2   The methodological purpose of the case study design

The approach to understanding and sense making in this qualitative multiple case study was congruent with a hermeneutic phenomenological approach (Cohen et al., 2000), which entails a focus on a thick description of lived experience and the interpretation and co-constructed sense making thereof (Sandage, 2010). With the emphasis on knowledge construction, hermeneutic phenomenology enables the researcher to explore the more authentic perspective of participants (Langdridge, 2007). As such, several case study researchers use hermeneutic phenomenology as an interpretive methodology towards promoting knowledge and understanding (Boden & Eatough, 2014; Degand, 2015; Lane, 2018; Nixon et al., 2013; Sandage, 2010; Stewart, 2010).

Yin (2014), proposed three main types of case studies, namely exploratory (looking for patterns), explanatory (explaining how or why of topic), and descriptive (considering theories to frame study and questions). Case studies are primarily exploratory and explanatory in nature in order to gain an understanding of an issue in a real-life setting (Harrison et al., 2017). The type of case study chosen for this study was first exploratory as I wished to conduct an in-depth investigation into the phenomenon of meaning making of individuals living with a CD (Yin, 2014). The study was also descriptive as I described the natural phenomena that occur within the data and started with a descriptive theory to support the description of the phenomenon (meaning making while living with a CD) and how the phenomenon is represented using these theoretical presumptions (Raeburn et al., 2015). The study could also be regarded as explanatory because I explained the phenomena and theory revealed in the data (Raeburn et al., 2015; Zainal, 2007). I therefore deemed this case study research as exploratory, descriptive and explanatory.

2.4.3   Multiple case study design with an ideographic focus

There are also distinctions between single and multiple case studies (Stewart, 2014; Yin, 2014). The multiple case study design was chosen for this study because case studies are flexible, can help to generate new ideas and are often used in

exploratory research (Baxter & Jack, 2008; Ebneyamini & Sadeghi Moghadam, 2018; Harrison et al., 2017; Hartley, 2004; Rowley, 2002). The main advantage of employing a multiple case design was that it allowed for the collection of multiple perspectives from individuals. Multiple case studies are furthermore a useful way of illustrating theories and testing whether theories and models actually work in real life, and they can help show how different aspects of a person's life are interrelated (Harrison et al., 2017; McLeod, 2019).

In this study, I chose three cases (individuals with CDs) to be studied in depth, by exploring differences and similarities within and between the cases (Gustafsson, 2017) to ensure strong and reliable evidence (Baxter & Jack, 2008). Furthermore, Baxter and Jack (2008) suggested that in deciding what the cases should be, one should ask what one wishes to analyse, namely the individual, a programme or a process. In this study, the unit of analysis was the individual and the research phenomenon was meaning making while living and working with CDs. I wanted to analyse individuals in depth and in their natural real-life settings (Crowe et al., 2011; Harrison et al., 2017; Ridder, 2017) and compare the findings (Thomas, 2016), thus emphasising the qualitative aspect thereof.

An advantage of a case study design is that the researcher can focus on specific, relevant and interesting cases (Heale & Twycross, 2018). In adopting an idiographic approach, I focused on the individual case and emphasised the unique personal experience of each case. Case studies are valuable as an idiographic approach because they provide an in-depth insight into an individual or small group (Szostak, 2004). According to Boddy (2016), sample sizes involving only one case in in-depth qualitative research can be highly informative and meaningful, as demonstrated in management and medical research. Small samples are therefore appropriate in a case study inquiry focused on the in-depth exploration of ideographic experience.This was particularly relevant to this study and the three individual cases were studied in great detail from many angles. Personal experiences that were intimate and personal were shared to provide an in-depth insight into the lived world of the individual with a CD. By using multiple case studies, the researcher is thus able to generate rich data for each case and analyse the data both within each case and across cases (Yin, 2003a).

2.4.4 Conventions of data collection and analysis in a case study design

The characteristic techniques, as described by Yin (2014), which apply to case study methodology, include the following: (1) developing theoretical propositions to guide the study; (2) using multiple data sources; (3) establishing a chain of evidence; (4) matching patterns; (5) building explanations; and (6) explaining and addressing differences and using replication logic in multiple case studies. The aim was to compare the cases, and this comparative element is called cross-case analysis, emphasising the comparison between the cases (Schwandt, 2001; Thomas, 2016). Theoretical propositions were developed from Frankl's meaning-making principles and formulated in Chapter 1, Section 1.4. The data sources (Section 2.6.4), and how data was analysed and interpreted (Section 2.6.6), are discussed in this chapter in more detail under the research methods in Section 2.6. Before discussing the research methods, my approach to theory is highlighted because it is fundamental to the whole process and starts with developing propositions in case study research (Yin, 2014).

2.5 APPROACH TO THEORY

According to Yin (2003a, 2014), existing theory is the starting point of case study research and propositions or theories guide the research process. A research proposition is a statement about observable phenomena (concepts) that may be found to be true or false (Cooper & Schindler, 1998). In formulating propositions, the researcher must speculate on the expected findings of the research based on the literature and any other prior evidence (Rowley, 2002). Propositions for this study were derived from the research questions which were formulated on the basis of Frankl's principles. The propositions guided the data collection and discussion, provided direction, reflected the theoretical perspective and guided the research.

According to Rule and John (2015), theory is useful not only during the construction and execution of the case, but also because the study's findings may have theoretical implications. In case study research, a specific theory is applied to one or more cases, sometimes in a different context, as a theoretical lens to understand the phenomenon. (Rule & John, 2015). Hoadley (2006) posited that theory and research have a two-way dialogue, which may lead to further development or refinement of the original theory. Hoadley (2006) began her research with a theory, but during the analysis process, she

encountered findings that could not be accommodated by the chosen theory, prompting her to further theorise. She stated that it was necessary to begin with a solid theory in order to discover that there are possibilities and constraints for further theorising (Hoadly, 2006). Collins and Stockton (2018) supported Hoadly's idea, reminding researchers to be careful that theory does not lead to predetermined results, but that one should look for confirmation as well as negations of existing concepts.

Frankl's principles of meaning making were used as a framework to guide my study and helped me understand and interpret the individuals' perspectives and roles (Daher et al., 2017; Sutton & Austin, 2015) while making meaning living and working with CDs. In case study research, exploration occurs through a variety of lenses in order to reveal multiple facets of the phenomenon (Baxter & Jack, 2008). In acquiring knowledge, there are the two general approaches to reasoning, namely deduction and induction (Åsvoll, 2014; Bertilsson, 2004; Hyde, 2000; Jensen, 2008, Kennedy & Thornberg, 2018; Minnameier, 2010; Thomas, 2010). Deductive reasoning is a theory-testing process to see if a theory applies (Hyde, 2000; Ketokivi & Choi, 2014; Pearse, 2019; Ritchie & Lewis, 2006; Woiceshyn & Daellenbach, 2018). The deductive approach is concerned with deducing conclusions from propositions (Pearse, 2019; Wilson, 2010). Deductive reasoning is commonly associated with the positivist paradigm in scientific research and with quantitative research methods in the social sciences (Guba & Lincoln, 1994; Lee, 1989; Yin, 1981, 2003a). However, it has been found that both quantitative and qualitative researchers use deductive and inductive processes in their research (Hyde 2000; Patton, 1991). Deductive theory testing has been used in only a small percentage of organisational qualitative studies (e.g. Gatignon & Capron, 2023; Langley, 1999; Lee, 1989, Markus, 1983; Sinkovics et al., 2019). Recent qualitative studies, however, are building on promoting the deductive theory testing capacity of qualitative research (Sprecher et al., 2022; Vargas-Bianchi, 2020).

Inductive reasoning is more commonly associated with qualitative research (Bendassolli, 2013; Bitektine, 2008; Nicholls, 2009). Inductive reasoning is a theory-building process (Babbie, 2010; Bradley et al., 2007; Bucher, 2021; Hyde, 2000; Ketokivi & Mantere, 2010; Williams & Moser, 2019). Patton (1991), however, argued that a qualitative study can include both inductive and deductive processes. In this study, I combined deductive and inductive reasoning to create a hybrid approach

(Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006; Rishi et al., 2015; Swain, 2018; Xu & Zammit, 2020). In line with Yin's (2014) assumption that theory drives a case study design, I used the theoretical propositions, derived from Frankl's principles, as a departure point, which were applied to deduce and analyse the results.

The interpretive approach requires the researcher to go further by interpreting the meanings and thus use an inductive approach in order to develop a theory or framework (Fereday & Muir-Cochrane, 2006; Lopez & Willis, 2004; Neubauer et al., 2019). I used a discovery or inductive approach (Patton, 1991) in which I allowed for themes, patterns and categories to emerge from the data (Bendassolli, 2013). By adopting a deductive approach, I focused on verifying the emerging findings against the propositions to see if the theory applied to the meaning making of PwCD. I returned to inductive reasoning in the further interpretation and elucidation of the emerging findings (Park et al., 2020) in refining or enhancing the existing theory.

Yin (2009, p. 38) postulated that when the results from several cases in a multiple case study support the theory, "replication" may be claimed. Similarly, Dul and Hak (2007) proposed that the test of theory, in using qualitative case studies, involves a process to determine whether the empirical evidence supports the theory's propositions. Figure 2.1 below illustrates the use of theory in this multiple case study.

Figure 2.1

The use of theory in this multiple case study
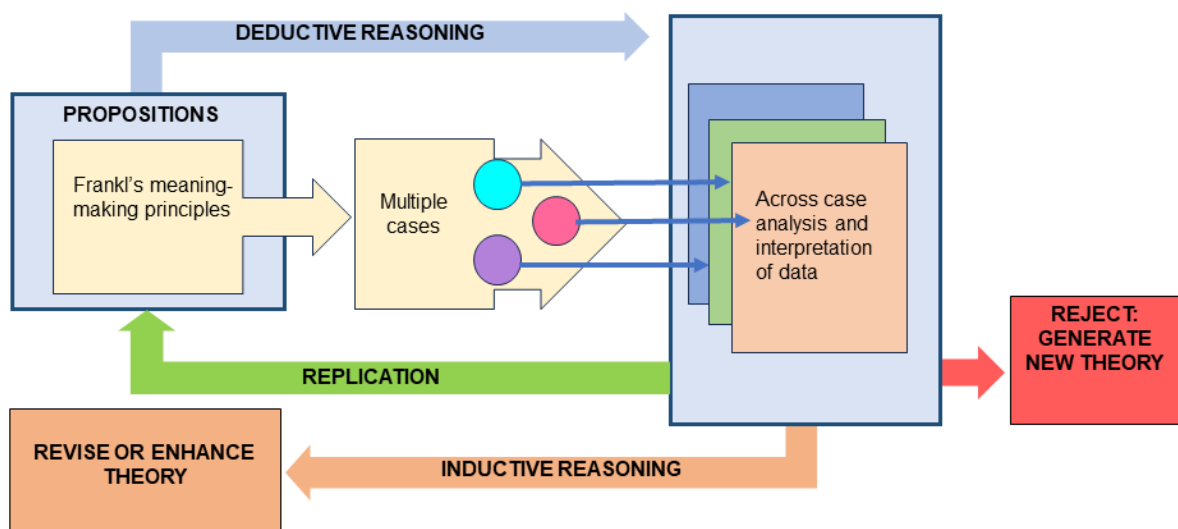
The use of theory in this multiple case study is summarised in Figure 2.1 by showing that the propositions, derived from Frankl's principles, guided the search for relevant evidence by providing direction, thus reflecting the theoretical perspective (Ridder, 2017) in the data analysis and interpretation within and across cases. The aim was to identify relevant evidence that would lead to either replication or rejection of theory, or a revision or enhancement of the existing theory (Ridder, 2017; Rule & John, 2015; Yin, 2014). The multiple case study thus departed from a deductive theory-first approach in which theory was applied to the cases. Thereafter relevant literature and theories were incorporated into the inductive approach of data analysis and interpretation to refine or enhance the existing theory. Hence I combined the deductive and inductive approaches to gain a more in-depth understanding of the phenomenon.

2.6   RESEARCH METHODS

In the context of the qualitative multiple case study design, the research methods section explains the research setting, how access to the participants was obtained, the researcher's role and how the participants were chosen. The boundaries of the case study are explained, followed by a description of the various data collection methods, and data management and analysis.

2.6.1   Research setting, entrée and establishing the researcher's role

I wanted to explore, understand and present the participants' perspectives on meaning making and get close to them in their natural setting (Creswell, 2013a). In this study, the setting encompassed the participants' real-life world. The contextual background and description of each case is provided in Chapter 5. The participants were all from South Africa and live in three different provinces of the country. For confidentiality reasons, the specific locations where these participants work and live, were not revealed.

According to Stake (1995, p. 57), because data gathering is almost always done on someone's "home grounds", permission is required to gain access. The initial approach to recruit participants can be made in one of three ways: face to face (direct), telephonically or via mail (Lakhanpaul et al., 2014). For this study, one participant was

approached during a direct face-to-face meeting, the second was contacted telephonically and the third was contacted via e-mail. During these initial conversations, the study was introduced, explained and outlined, and the individuals' participation requested. After obtaining ethical clearance, the next step was to obtain the participants' written formal consent by ensuring that they understood the nature, aim and implications of the study (Mumford, 2018). To this end, a brief written description of the study was presented to them (Stake, 1995). Confidentiality, other practical issues (e.g., time frame, method of communication, etc.), ethical matters, as well as the COVID-19 guidelines, were also addressed in the informed consent to ensure that the individuals knew what to expect in participating in the study (Dooly et al., 2017; Salmons, 2017). As suggested by Crowe et al. (2011), I considered the ethical implications such as the risk of breaching anonymity or confidentiality. I ensured that all the potential participants were sufficiently informed about the study's risks to allow them to make a decision about their participation.

My aim was to interview the participants in a space that was convenient and accessible to me and them, where we could converse privately, without interruption and where I could make an adequate sound recording of the conversation (Edwards & Holland, 2013). The first participant was initially contacted telephonically and then chose to be interviewed via email. This was a convenient arrangement because the participant and I were geographically separated and she was able to fit it in at a time convenient to her busy schedule. Although this saved time because of a written, produced text, it might have led to a less spontaneous account than might be produced in other interview methods (Edwards & Holland, 2013), because the participant had time to reflect before answering (Saarijärvi & Bratt, 2021). Follow-up questions were addressed telephonically, via email and on multi-platform messaging application, WhatsApp. During my telephonic conversations with the participant I was able to give attention to her tone of voice and reflect on the meaning thereof. I therefore took care to listen to verbal cues such as pauses, hasty responses and tones that would indicate the participant's emotions and feelings (Cachia & Millward, 2011; Carr & Worth, 2001; Chapple, 1999; Farooq & De Villiers, 2017).

The second participant was also geographically separated from me and was initially also contacted telephonically and then interviewed via a virtual meeting. The virtual

meeting was conducted via the platform of Gmail video call. It was arranged during the participant's lunch hour in his work office and I was in my work office. This ensured privacy and no interruptions, as well as giving me a glimpse of him in his working environment. The virtual call enabled me to observe his facial expressions and body language. I ensured privacy by putting a "no-disturb" sign on the door, and the participant arranged the meeting at his convenience by consulting his own schedule and that of his colleagues to ensure he would not be interrupted. Follow-up questions were addressed to him via email and the social media platform, WhatsApp.

The third participant chose to be interviewed face to face in my office where she was assured of convenience, confidentiality, privacy and no interruptions. The face-to-face interview provided the benefit of observing her facial expressions, emotions and body language (Saarijärvi & Bratt, 2021).

Interaction between the participants and me was required to generate data, which indicated my level of connection to and immersion in the field. My emphatic involvement was acknowledged (Ormston et al., 2014; Sutton & Austin, 2015) and reflected upon, as explicated in Chapter 1, Section 1.2.4.

2.6.2   Case selection

According to Thomas (2016), in case study research, sampling is not the correct word to describe the selection of participants. He emphasised the fact that in case study research, the researcher makes a specific case selection to include in the study. This approach to case selection is similar to purposive sampling (Barglowski, 2018). My case selections were made on the basis of the participants' potential to answer my research questions, verify the propositions and reveal a lot about the topic (Kivunja, 2018; Yin, 2003b). The cases were thus instrumental in that they were selected in order to test a theory (Crowe et al., 2011; Rule & John, 2015; Ridder, 2017; Zainal, 2007). According to Patton (1990), there is no consensus in the literature on the number of cases in a multiple case study design. It is, however, widely accepted that when in-depth information is required, which provides much more detailed information (Boyce & Neale, 2006), as was essential in this study, a small number of cases is preferable (Shakir, 2002; Yin, 2003). A multiple case study could be time consuming

and expensive, and any number of cases (more than one) can increase the analytic benefits and generalisability (Yin, 2003a).

The specific case selection, as explained above, relates to purposive sampling, which means the inclusion of cases that will be able to elucidate a specific phenomenon (Barglowski, 2018). I carefully selected the three cases for this study that I perceived to be rich in information (Baxter & Jack, 2008; Crowe et al., 2011; Gustafsson, 2017; Patton, 2002), which would allow for comparison across the cases (Crowe et al., 2011). Information-rich cases are those from which one can learn a great deal about issues of importance to the purpose of the research, namely meaning making while living with a CD – hence the term "purposeful sampling" (Crowe et al., 2011; Patton, 1990). The cases were therefore selected because they served the purpose of this study in that they were interesting, informative, hospitable and could answer the research questions (Baxter & Jack, 2008; Crowe et al., 2011; Ridder, 2017; Stake, 1995).

The sampling was not only purposeful but also convenient. The term "convenience sampling" (also known as haphazard or accidental sampling) refers to a non-random sampling method where individuals of the targeted population who meet certain practical criteria, are included for the purpose of the study (Dörnyei, 2007; Etikan et al., 2016). Convenience sampling is used to select the most productive, accessible sample to answer the research questions (Andrade, 2021). In this study, the participants were selected on the basis of convenience because I had easy access to them, they were available and willing to participate, and I identified them according to predetermined practical inclusion criteria. The main feature of the selected cases was my interest in them and their relevance to the study's objective (Thomas, 2016), research questions, propositions and theoretical context (Rowley, 2002). The practical inclusion criteria were as follows: Having an index CD for more than five years; the fact that the index CD should be interesting and would provide revealing information about living with a CD; being active in the workforce; and being available, easily accessible and willing to participate. Owing to the lapses in the period between identifying the cases and the actual fieldwork, two of the cases had left the workforce and had become self-employed, working for themselves rather for an employer. I acknowledge that the purposeful and convenient selection of the cases did reflect

selection bias and that the sample was not representative of a larger population of people (Farrokhi & Mahmoudi-Hamidabad, 2012; Mackey & Gass, 2005) living with CDs. In using a case study, however, it is about the particular, rather than the general (Thomas, 2016).

To reiterate, the aim of this study was to explore how people make meaning while living with a CD, with the focus on the phenomenon of meaning making and not on the type of CD. It is acknowledged that people differ in terms of their responses to different demands and challenges that different CDs present (Van Houtum et al., 2015), and I therefore admitted that the sample lacked generalisability in terms of the limited variety of CDs presented in this study. However, it was assumed that the typicality of the cases would be sufficient to illustrate what would be typical (Patton, 1990) in meaning making while living with a CD.

The first case was found by chance while reading an article in which a person described in detail her experience living with alopecia areata (AA) for 32 years. AA is a common autoimmune disease that has a huge effect on quality of life and is classified by the extent or pattern of hair loss (Starace et al., 2019). I had contacted this individual, explained the aim of the study, and after it was established that she met the criteria, she agreed to share her meaning-making experience with me.

The second case that met the criteria, is someone I am familiar with. This individual has the MCC of ankylosing spondylitis (AS), asthma and hypertension. AS, the index CD, which he has had for 16 years, is a chronic inflammatory rheumatic disease that affects the spine and the sacroiliac joints (Pelechas et al., 2019). Asthma is a long-term condition that affects the airways (Holgate, 2008). When a person's blood pressure exceeds a predetermined threshold, hypertension is diagnosed (Giles et al., 2005). This participant was contacted telephonically, and after providing him with all the information on the study, he agreed to share his meaning-making experience with me.

I have a working relationship with the third case. This participant also suffers from MCC (breast cancer, psoriasis and depression). Breast cancer, the index CD, which she has lived with for 16 years, starts when cells begin to grow out of control and start in the breast (Laronga et al., 2016). Psoriasis is an autoimmune skin disorder

characterised by patches of abnormal skin (Yang et al., 2017), also seen as a systemic inflammatory disease (Kaushik & Lebwohl, 2019). Depression is a mood disorder that varies (Bernard, 2018; Doktorchik et al., 2019). The symptoms of depression vary but may include sadness, fatigue and loss of interest and appetite (Doktorchik et al., 2019). I discussed my proposed study with this participant face to face and she agreed to participate.

It was assumed that these selected cases, which represented different CDs, would generate relevant rich data to answer the research questions and propositions relating to meaning making while living with a CD.

2.6.3 Bounding the case study

Bounding the case study is necessary to remain focused in collecting, managing and analysing the data (Harrison et al., 2017). It involves specifying the parameters of the case study regarding the participants, context and the time frame for investigating the case (Baxter & Jack, 2008; Harrison et al., 2017; Merriam, 2009; Stake, 2006; Yin, 2014). The boundaries therefore indicate what will be studied within the scope of the research project (Baxter & Jack, 2008).

Suggestions on how to bind a case that will ensure that the study stays within reasonable scope, include binding it by time and place (Creswell, 2003), time and activity (Stake, 1995) and definition and context (Miles & Huberman, 1994). The establishment of these boundaries in a qualitative case study design indicates the breadth and depth of the study and not simply the sample to be included (Baxter & Jack, 2008).

In this study, this was done by:

- selecting only three typical cases;
- setting a theoretical framework (Frankl's meaning-seeking principles) to explore the data;
- setting research questions and propositions to manage the collection and analysis of data accordingly; and

- setting a six-month data collection timeframe, which I believed to be realistic for accomplishing an in-depth comprehension level (Saunders et al., 2018) in order to meet the aims and objectives of my study.

2.6.4   Data collection

Case study research is regarded as a comprehensive method of inquiry because it includes multiple data sources that provide detailed accounts of complex social phenomena in a natural, real-life setting (Morgan et al., 2017). Multiple sources and methods of data collection and analysis are typically used in case study research to provide a more comprehensive view of the issue being studied (Flyvbjerg, 2011; Merriam, 2009; Stake, 2006; Yin, 2014) and could lead to more complete explanations (Morgan et al., 2017). Case study research can employ a wide range of methods to aid in the goal of co-constructing data, including observations, interviews, focus groups, documents and artefact analysis (Merriam, 2009; Simons, 2009; Stake, 1995; 2005; 2006; Stewart, 2014; Yin, 2014).

In this study, research questions, propositions and theory acted as the conceptual framework which guided the design and determined the methods of data collection and analysis (Stake, 2006; Stewart, 2014; Yin, 2014). Thomas (2016) purported that when a researcher looks for evidence and from the outset has a well-defined theory, the data will either support or reject the propositions. For this study, interviews, document analysis, diaries, image-based methods and observations were used to collect data. All three participants were Afrikaans speaking. I am also Afrikaans speaking, so no language difference was experienced in the data collection process. The interviews were recorded and transcribed in Afrikaans (the source language). Thereafter the interviews were translated to English (the target language. The process of back translation was used that involved converting the translation from English back to Afrikaans again to ensure that the same meaning is conveyed from the source language to the target language (Behr, 2017; Qoyyimah, 2023).

Data collection continued until enough data had been collected to answer the research questions and draw the necessary conclusions – in other words, until data saturation had been accomplished (Given, 2016; Saunders et al., 2018). I was dependent upon the participants' willingness not only to take part, but also what and how much they

chose to share about their experiences and thoughts (Karnieli-Miller et al., 2009). Not all of the participants wanted to share information by using all the mentioned means of data collection, and I respected this. However, I still managed to collect sufficient, rich data to answer the research questions through the data collection methods described in more detail below.

2.6.4.1 Semi-structured in-depth interviews and follow-up interviews

Semi-structured in-depth interviews are widely used in qualitative research (DiCicco-Bloom & Crabtree, 2006; De Jonckheere & Vaughn, 2019). Semi-structured interviews involve the development of several key open-ended questions before data collection and are used to define the areas to be explored (De Jonckheere & Vaughn, 2019). Two of the interviews were conducted using semi-structured interviews. One of these interviews was conducted online and the second one face to face.

The online interview was the most convenient way for the participant, who lived in another province, to meet (Salmons, 2017). This interview also ensured adherence to the University of South Africa (Unisa) COVID-19 guidelines (Meyiwa, 2020) in effect at the time of the field work. This interview was conducted via a virtual Gmail video call with follow-up questions using email, the social media platform of WhatsApp and telephone conversations. The second interview was conducted face to face, adhering to strict COVID-19 guidelines, as suggested in Unisa's COVID-19 guidelines (Meyiwa, 2020), with follow-up questions using WhatsApp.

I started the semi-structured interviews with two participants (cases 2 and 3) with the following a context-setting question: "Tell me about your chronic illness(es) and the role it plays in your life", before I moved on to more in-depth questions relating to the aim of the study, such as "How do you make meaning living with a chronic illness(es)?" (as suggested by DeJonckheere & Vaughn, 2019; Jacobi & MacLeod, 2011; Perry 1998). The data for case 1 was gathered by means of information in an article written by her, as well as from follow-up email and telephone conversations, as described in Section 2.6.4.2 below.

It was necessary to obtain specific information to answer the research questions and to be able to make comparisons across the cases (Knox & Burkard, 2009) – hence the development of a shortlist of open-ended questions, possible follow-up and probing

questions to guide the conversation (De Jonckheere & Vaughn, 2019; Jacobi & MacLeod, 2011). The following are examples of follow-up questions: "What does a typical day living with a CD look like?"; "What are your ways of coping with your CD?"; and "What gives meaning to your life?". I then resorted to probing, depending on the participant's responses, by asking for an example: "Can you give me an example?"; for meaning, "What does it mean to you?"; to collect evidence, "What make[sic] you say that?"; and to obtain more detail, "Can you tell me more?".

According to Knox and Burkard (2009), it might be difficult to compare findings across cases if participants have not been afforded the opportunity to respond to the same questions. I remained open and flexible and modified the wording and sequence of questions to best fit the participant (De Jonckheere & Vaughn, 2019), and also probed and followed up where necessary to learn about the individual participants' stories in more depth and detail (DiCicco-Bloom & Crabtree, 2006; Hill et al., 2005).

2.6.4.2 Documentary information

Documents of various types help the researcher make sense of, understand and gain insight into the topic under investigation (Merriam, 1988; Sutton & Austin, 2015). Yin (2009) mentioned the various types of documentation that can be used in case studies, including email correspondence, memos, letters and other personal documents. The variety of documentary information that was gathered for this study included email follow-up correspondence, notes, formal studies or evaluations of the same phenomena that the researcher was studying and an article appearing in the mass media. It was of utmost importance to be critical in interpreting and reviewing documents in order to understand that they had been written for some specific purposes and specific audiences (Yin, 2009).

The major source of data for case 1 was an article written by the participant on her experience with living with a CD, which was then supplemented by telephone conversations and email exchanges. The participant elaborated on her personal experience of living with a CD in this article by sharing her life story. I followed up, via email and telephonically, to clarify and obtain more information by asking her the following questions: "What gives meaning to you in life?"; "What role does work occupy in your life?"; "How did your work role change"?; "What is your advice to people living with AA?"; and finally, "What role does spirituality occupy in your life?".

2.6.4.3 Diaries

The format of maintaining a solicited diary (a requested diary) encourages the participant to focus on daily activities and reflections (Elliott, 1997; Milligan & Bartlett, 2019) that they find relevant to their living with a CD. Through these diaries I could gather information about the participants' daily activities and reflections and then explore those entries during the subsequent interview (Jacelon & Imperio, 2005). Completing a diary involved the participants making a record of living with a chronic disease for a period of at least a week. Only two participants agreed to keep a diary. The third participant mentioned that she has had AA for years and does not experience things on a daily basis, and as such, keeping a diary would be a waste of time.

The participants were asked to write down some key aspects of their lives with CDs and how they approach life and work with it. They were asked to use their own creativity, for example, if they did not feel like writing or typing on a computer, they could draw or paste pictures or anything that would give me an indication of how they live with and manage their chronic illness. They were asked to do this on a daily basis for a period of a week. They were requested to share as much or as little as they wanted to. These diary entries provided valuable information for the follow-up interviews and resulted in me being able to encourage the participants to elaborate on certain aspects during the interview.

2.6.4.4 The researcher's self-reflective journal

I kept a self-reflective journal (Annink, 2017; Boutilier & Mason, 2017; Ortlipp, 2008), which I started at the beginning of the research even before data collection, right to the end of the study. Self-reflection is frequently described as an interpretation of the researcher's engagement and observations with the research and participants, to be used in the data analysis phase (Annink, 2017; Browne, 2013). My self-reflection became reflective data and made me aware of relevant issues that I might have missed (Weiner-Levy & Popper-Giveon, 2013). For example, after I had sent a participant an email to ask if she was prepared to keep a diary, she telephoned me to notify me that she has had the CD for a long time, has adapted to her condition and that it would be difficult for her to keep a diary as she does not experience things on a daily basis. She therefore asked to be excluded from keeping a diary. I made notes in my journal about my interpretation of this conversation in which I had experienced her

as assertive, busy, to the point and somewhat frustrated. This information, together with other telephone conversations with this participant, became part of the data for this particular case. In my journal I also noted thoughts that I had about the cases, opinions, views, emotions, interpretations, observations (Thomas, 2016), the research process and issues that I needed to address or read up on. The journal was a source of reflection that I used throughout the research process to create transparency (as suggested by Annink, 2017; Ortlipp, 2008).

2.6.4.5   Image-based data

In using the creative and art-based method, I asked the participants to create a collage of how they perceive their illness experience and how they deal with it. Collage is the process of gluing pieces of images or materials to a flat surface to represent concepts (Butler-Kisber & Poldma, 2010; Gullion, 2023). Collage is deemed important medium of expression (Davis & Butler-Kisber, 1999; Gullion, 2023), and can also be useful to portray an experience by highlighting different facets in order to gain a better understanding of the experience (Butler-Kisber & Poldma, 2010; Gullion, 2023). I used collage to allow the participants the freedom and creativity to express difficult-to-articulate feelings in order to add, explain or illuminate evidence (Butler-Kisber & Poldma, 2010; Gerstenblatt, 2013). Art-based research is more often used by researchers to evoke a response from participants, in that the researcher creates the art form and uses it as a tool to extract a response. However, I found that by engaging the participants in using art to express themselves, I gained better insight into their real-life experiences and views (Rivera Lopez et al., 2018; Van der Vaart et al., 2018). Other forms of art used in research are pictorial representations of experience (Kirkham et al., 2015; Shinebourne & Smith, 2011) and poetry (Foster & Freeman, 2008; Gregory, 2011; Spiers & Smith, 2016).

Creating a collage, or other art-based expressions, afforded the participants an opportunity to express themselves in their own chosen way and I could use it as a further reference point for clarification. I explained to them what a collage means, but unfortunately only one participant chose to use this method. She did not use a pure form of collage but more one of giving a pictorial representation together with poetry. She made two visuals, in which she captured how she experienced living with CDs. In the one visual, she wrote a form of poetry to interpret an image she had cut from a

magazine, and in the second one, she drew a picture and wrote a sentence. I discussed both of the visuals with her and clarified her interpretation of them, which formed part of my data set.

2.6.4.6   Field Notes

Field notes are part of data collection and analysis because they supplement conventional interview data and are essential for conducting rigorous qualitative research (Creswell, 2013a). Observational field notes prove useful in providing additional information about the phenomena (Morgan et al., 2017; Yin, 2019), and by using them in conjunction with all other data sources, they support and enhance the evidence (Kawulich, 2005; Sutton & Austin, 2015). In taking field notes, observing behaviour involves using all the senses (Preston, 2016; Savage, 2000) to observe what people do rather than what they say they do (Caldwell & Atwal, 2005; Mulhall, 2003; Walshe et al., 2012). For this study, field notes were taken by observing participants' behaviour during my interactions with them, for example, during virtual and face-to-face interviews, telephone conversations, and other communication. During these interactions, I used double notetaking by writing observed behaviour in one column and my reflection of what I observed in the second column (as suggested by Driscoll, 2011). I additionally included methodological notes (information regarding the research process) and comments on my involvement during the process, which, combined with my self-reflective journal, supplied me with valuable insights during the data analysis process.

This use of variety of sources (triangulation) can lead to the credibility of the study's findings (Yin, 2009). I continually practised reflexivity by making notes in my journal and discussing thoughts in a self-reflexive manner with my study supervisor to help me understand the biases I had that might have interfered with my interpretation while collecting and interpreting the data (Kawulich, 2005; Ratner, 2002). I ensured that my understanding of the participants and their experiences within their contexts was expanded through my prolonged involvement in the field (Johnson et al., 2020; Stahl & King, 2020). The following visual representation, Table 2.1, summarises the data collection per case study (please note that pseudonyms are used to refer to the cases):

Table 2.1

Data collection per case

Cases	Data collection method	Follow-up method
Case 1: Fiona	Data from article published in magazine	Follow-up communication via email, WhatsApp and telephone to clarify and address emerging questions
Case 2: Dwayne	Semi-structured interview online; diary; observation	Email, WhatsApp messages and telephone calls to clarify and address new emerging questions
Case 3: Dinah	Face-to-face semi-structured interview; diary; two visual presentations; observation	WhatsApp messages to clarify and address new emerging questions

2.6.5 Data recording and management

The interviews for this study were digitally recorded and then transcribed verbatim. To make the written content intelligible and meaningful, the interviews were transcribed from digital recordings using careful listening, interpretation and representation (Bailey, 2008; McMullin, 2023). Making the text meaningful involved iterative cycles of listening, relistening, interpreting and writing, rereading and rewriting. As early as the transcription phase, I had immersed myself in the data and as such analysis commenced (Bailey, 2008) and the hermeneutic circle of understanding was employed. In so doing, care was taken to accurately transcribe what the participants had said and meant. When something was unclear or uncertain, I clarified with the particular participant (Terre Blanche et al., 2006) to ensure that I understood what was meant. The telephone conversations were not recorded, but after every conversation, notes were made and these were later included in the analysis process. The email and WhatsApp communications were transcribed verbatim and included in the data analysis process.

The integrity of research data is dependent upon having and using a system of data management (Briney et al., 2020). A case study database was created and as such a chain of evidence was maintained (Dul & Hak, 2008; Stake, 1995; Yin, 1993, 2009). This was accomplished by keeping computer files of the case study notes, case study documents and the narratives (as collected and indicated in Table 2.1), and this

ensured that the case study could be followed from initial research questions to the conclusions (Yin, 2009). Together with the aforementioned information and documentation, my personal journal with different information like a calendar, contact information, observation notes, reflections, expenses and all other important matters crucial to the study (Stake, 1995), were also transferred to an electronic file and the relevant data was incorporated in the data analysis. The data are kept on my personal computer, which is password protected. The following steps, as suggested by Kaiser (2009) and O'Toole et al. (2018), were taken to secure the data and protect participants' confidentiality:

- The content of the data was anonymised by removing real names and places.

- The names of participants were replaced with pseudonyms.

- My research journal and other sensitive data were locked in a steel cabinet.

- Backups were made on a universal serial bus (USB) flash drive to ensure that the data would be secure. This USB was also locked in a steel cabinet.

2.6.6   Data analysis

According to Erlingsson and Brysiewicz (2017), because data from lived experiences are complex and imbued with multi-faceted meanings, the complexity of the data should be approached with openness and creativity. The complexity of the data is enhanced when working with multiple case studies, and it is useful to select a rigorous and structured data analysis method that is congruent with the methodological approach of one's inquiry. This multiple case study design was set in a hermeneutical phenomenological approach (Degand, 2015; Hunzicker, 2016). In evaluating the various methods of analysis in hermeneutic phenomenology, I chose IPA (Smith et al., 2009). This method was heavily influenced by Heidegger (Peat et al., 2019) and entails an interpretative process between the researcher and the studied (Smith et al., 2009). It is well suited to analysing multiple case studies and specifically appropriate in health and social sciences to interpret and understand complex and emotionally laden topics such as illness experience (Peat et al., 2019; Smith & Osborn, 2014). In IPA, the aim is to interpret the content and complexity of the meaning that participants convey (Smith & Osborn, 2007, 2008). An approach like IPA is thus useful for analysing

complex, in-depth data (Alase, 2017), and it is done with relatively small sample sizes (Smith et al., 2009).

Generally, in multiple case studies, every case study is individually and separately analysed before making comparisons across cases (Crowe et al., 2011; Gustafsson, 2017; Ridder, 2017). This approach aligns with the IPA process in which the separate (divergence) and the overlap (convergence) of experiences across participants or cases are examined (Allan & Eatough, 2016; Eatough & Smith, 2017; Pietkiewicz & Smith, 2014; Smith, 2011; Smith et al., 2009; Tuffour, 2017). In focusing initially on divergence, I first examined each case independently for themes before seeking convergence by comparing patterns across and between cases (Miller et al., 2018; Tuffour, 2017). There is no right or wrong way to analyse data when using IPA, but the analytic focus should be on finding patterns in participants' experiences, considering how they make meaning of those experiences and interpreting those experiences within social and theoretical contexts (Larkin & Thompson, 2011). Pattern finding is enhanced by applying the principles of the hermeneutic circle, which is a generic tactic in all hermeneutic phenomenological studies and pertinently relevant to IPA as well.

The hermeneutic circle of text interpretation entails moving back and forth between the parts and the whole through a circle of reading, reflection and interpretation towards understanding (Laverty, 2003). This was done for each case through the consistent movement between parts, from words, sentences and paragraphs to the entire transcript (Smith, 2007) within each case. The hermeneutic circle was also applied by moving between individual cases and the data set as whole, and was continued by moving consistently between the data and the propositions, Frankl's principles and the literature review in order to form a holistic account and understanding (Smith, 2007).

Almutairi et al. (2014) applied the hermeneutic movement to the analysis and synthesis of multiple findings from multiple case studies, through a useful pattern-matching technique. In this study, I thus further combined the steps in IPA with a pattern-matching approach, which allows for the interaction of deductive and inductive components, ensuring rigour while allowing for a high degree of flexibility (Bouncken et al., 2021; Vargas-Bianchi, 2020). The whole process of analysis and understanding is described next, first indicating the steps followed in IPA (Alase, 2017; Finlay, 2011;

Pietkiewicz & Smith, 2014; Smith & Osborn, 2008; Volpato et al., 2018) with regard to the in-case analysis, and how they were applied to each of the three cases. The process of pattern matching across the cases is then explained.

2.6.6.1   Steps followed in IPA

The steps proposed in IPA studies (Alase, 2017; Erlingsson & Brysiewicz, 2017; Noon, 2018; Pietkiewicz & Smith, 2014; Smith & Osborn, 2008; Thomas, 2016) were applied to each case in this study as follows:

Step 1: I listened to the audio recording of the first case twice and then transcribed all the data relating to it (the interview, diary, my personal notes, collages, observations, reflections, etc.). I arranged the data systematically by creating and organising files of information (Alase, 2017). I then made an electronic copy of this and now had two copies, the raw data and the working electronic copy.

Step 2: I immersed myself in the data by reading and rereading and highlighting and underlining parts that seemed important (Alase, 2017; Thomas, 2016), and also making notes and observations in the margins. I had two margins – one on the left and one on the right of the transcripts. In the left margin, I documented my initial reactions to the text, such as similarities and differences, reflections, additions and contradictions in what someone was saying (Smith & Osborn, 2008). During this inductive phase, I regarded this part as a brainstorm session and tried to include all the significant ideas, without judgement or analysis (Thomas, 2016), and not just those relating to the theory and propositions. However, I kept the research objective, questions and propositions in mind to retain my focus during the analysis (Erlingsson & Brysiewicz, 2017).

Step 3: I reread the transcript and added ideas to my initial responses, in the left margin, to ensure a detailed and comprehensive interpretation. This was a deeper part of interpretation, where I not only read the responses, but also reflected on them (Noon, 2018) in the context of the study propositions. It is here that the pattern matching described in the Section 2.6.6.2 below started to become a more pronounced part of my analytic approach.

Step 4: I then transformed my notes into emerging themes (Pietkiewicz & Smith, 2014), in the right-hand margin through conceptual notes ascribing meaning to different themes.

Step 5: The next stage was to make connections across emerging themes by identifying common links between them. I thought about these themes, how they connected, what matched with what and any potential contradictions (Thomas, 2016). According to Pietkiewicz and Smith (2014), at this stage, some of the themes are discarded if they do not fit in with the emerging structure of meaning, and a final list of themes and subthemes is compiled.

Step 6: After the primary themes were named, key words and phrases were added to each theme (Smith & Osborn, 2008) with corresponding page numbers, to assist in finding the original responses in the transcripts (Alase, 2017; Pietkiewicz & Smith, 2014).

Two cases were analysed in the same manner following the IPA steps described above. One case was analysed slightly differently, starting from step 2 because there was no audio recording. Each case was analysed separately by starting from scratch, going through the stages and completing separate lists of emerging themes (Smith & Osborn, 2008). They (2008) suggested the options of using the themes derived from the first case as an orientation for the rest of the cases or putting the themes for each case aside and working on the following cases from scratch. I used an integration of both of these options as well as the pattern-matching technique described below. I not only disciplined myself to recognise repeating themes and remained cognisant of the study propositions, but also tried to recognise and acknowledge new pertinently relevant issues (to meaning making) that emerged as I worked through the data (Smith & Osborn, 2008). I engaged in a process of ongoing reflexivity by reflecting on meanings of themes as they came up in each case to maintain the idiographic approach (O'Moore, 2014). This reflexivity in phenomenological research is not only important throughout the data analysis process (Larkin & Thompson, 2011; Smith et al., 2009: Volpato et al., 2018), but also occurs throughout the whole research process, as suggested by Finlay (2011).

2.6.6.2 Pattern matching across cases: Cross-case synthesis

During the IPA analysis of the data I started using a pattern-matching technique (Campbell, 1966; Yin, 2003a, 2009). Yin (2003a) noted that one significant practice during the analysis phase of any case study is to return to the propositions, thus linking the data to the propositions. As noted above, pattern matching became relevant when I started to structure interpretations thematically within each case. The pattern-matching process became more pronounced after all three cases had been separately analysed and I engaged with the cross-case iterative comparison in line with the a priori propositions that directed the study. Finally, applying pattern matching resulted in a cross-case synthesis of themes. Figure 2.2 depicts the pattern-matching process, which involved deriving a set of theoretical patterns from Frankl's principles, forming actual observed patterns of data through the lens of these theoretical patterns, and then comparing these patterns to other theories and literature to enable the emergence of a framework (Bouncken et al., 2021; Trochim, 1989).

Figure 2.2

The pattern-matching process

THEORETICAL PATTERNS	◄PATTERN MATCHING►	OBSERVATIONAL REALM
PROPOSITION 1 Individuals living and working with a CD make meaning by following Frankl's meaning making pathways by using the:		
(1)Creative pathway		Statements regarding "what" and "how" regarding the performing of activities, work, producing or creating things.
(2) Experiential pathway	Pattern matching	Statements about "who" and "what" that indicated interactions with others; relationship with nature, beauty and new things.
(3) Attitudinal pathway		Indications of "how" choices and approaches influenced a meaningful life with a CD.
PROPOSITION 2 Meaning making is enhanced by living out self-transcendence		
Living out the capacity of self-transcendence	Pattern matching	Demonstration of "how" a shift in focus form self to others contributed to meaning making.

Note. Adopted from "Outcome pattern matching and program theory," by W.M.

Trochim, 1989, *Evaluation and Program Planning*, *12*(4), p. 356. https://doi.org/10.1016/0149-7189(89)90052-9

A cross-case synthesis was conducted when comparing and looking for patterns across cases and comparing the emerging themes with the propositions. Pattern matching was then iteratively applied by comparing the propositions with the observed patterns of meaning making and matching these with each other (Trochim, 1989). I used codes for the first proposition to establish the patterns in the data that referred to creative, experiential and attitudinal pathways and tabled these in the corresponding column. Data that referred to meaning making using (1) the creative pathway were labelled with a C in red ink; (2) the experiential pathway with blue ink (labelled E); and (3)) attitudinal pathway in black ink (labelled A). The data that referred to the second proposition relating to self-transcendence experiences was marked with the code ST in green ink and tabled in the corresponding column. Only then were themes finalised by documenting them in a table of themes or thematic framework (Smith & Osborn, 2008; Peat et al., 2019). Certain themes that did not fit in the framework and did not relate to the meaning-making process were discarded (Smith & Osborn, 2008). I composed a first framework with themes that had emerged from the analyses of the individual cases. Following a further analysis between and across cases, allowing for the importation of literature and theory, a final framework and illustration of themes were developed (see Chapter 6).

Analysing the case studies was a difficult and time-consuming exercise. The conceptual framework of Frankl's principles and the identified propositions compelled me to be selective in the data analysis phase and protected me to a great extent from being overwhelmed by information. Relevant meaning-making literature and theory (over and above Frankl's theory) were imported throughout to support the cases and enabled me to translate the themes into a narrative account with verbatim extracts from the transcripts (Alase, 2017; Peat et al., 2019; Smith & Osborn, 2008). The findings reflect a theme structure aligned with the study's propositions as reported on in Chapter 6. In Chapter 7, I present a critical integration and concluding interpretation of the findings based on ongoing critical reflection on enhancing and refining Frankl's principles in the context of meaning making while living and working with CDs.

2.7   ENSURING QUALITY AND ETHICAL RESEARCH

Determining the quality of qualitative research is all about demonstrating transparency (Merriam, 2009; Stewart, 2014; Yin, 2014), accountability and reflexivity throughout each stage of the process (Kalu & Bwalya, 2017). Doing so enables readers of qualitative work to follow the researcher's decision-making processes from the start to the conclusions and thus demonstrate the relevance and quality of the research (Kalu & Bwalya, 2017). Transparency, accountability and reflexivity are demonstrated through the quality criteria suggested by Lincoln and Guba (1985) and Yin's (2003a, 2013, 2014, 2018), whereafter the ethical considerations applicable to this study are discussed.

2.7.1   Quality criteria

Lincoln and Guba (1985) posited that the trustworthiness of a research study is imperative to evaluate its worth. The four criteria widely used to establish trustworthiness in qualitative research are credibility, dependability, confirmability and transferability (Guba & Lincoln, 1994; Lincoln & Guba, 1985). The use of reliability and validity are common in quantitative research and is now also being reconsidered in the qualitative research paradigm (Golafshani, 2003; Mays & Pope, 2020; Winter, 2000). Yin (2003a, 2013, 2014, 2018) suggested that case study research should address validity and reliability. In comparing the quality criteria of Lincoln and Guba (1985), with the criteria suggested for case study research by Yin (2018), it could be said that internal validity refers to credibility, external validity to transferability and reliability to dependability (Ungar, 2006). In this study, construct validity and confirmability were assumed to be the criteria for objectivity. These respective quality criteria of Lincoln and Guba (1985) and Yin (2003a, 2013, 2014, 2018) were applied in this study, as summarised in Table 2.2 below.

Table 2.2

Comparison and application of Lincoln and Guba's Quality Criteria and Yin's Criteria

QUALITY CRITERIA – Lincoln and Guba (1985)	QUALITY CRITERIA – Yin (2003a, 2013, 2014, 2018)
Credibility refers to confidence in the truth value of the findings. Credibility was established by (1) prolonged engagement with the participants until the research questions and propositions had been answered; (2) triangulation (use of multiple data sources like interviewing, documents, articles, etc., using multiple methods to address the research problem like observation plus interviews); and (3) member checking (where participants are afforded the chance to clarify parts of the transcripts). I contacted the participants when I needed to clarify certain meanings and to ensure that my interpretation thereof was correct. This was done through follow-up engagement via WhatsApp messages, email and telephone calls.	*Internal validity* refers to the data analysing phase and is about the logical reasoning approach followed, which should be strong enough to defend the conclusions (Yin, 1994). Internal validity was established by establishing a clear a priori theoretical framework for the study which served as an established pattern against which, during data analysis, empirically observed patterns were matched (Yin, 2018).
Transferability refers to the extent which findings from the data have applicability in other contexts. Transferability can be enhanced by using a purposive sampling method and providing a thick description (Cypress, 2017). The research setting encompassed the participants' real-life world (Section 2.6.1) and the case selection was done to collect rich and insightful data, as explained in Section 2.6.2. Transferability was further demonstrated in Chapters 5 and 6 by grounding interpretations in thick descriptions of the data. Thick description refers to a thorough encounter of the voices, feelings, actions and meanings (Ponterotto, 2006) relating to the research phenomenon so that it can be evaluated for possible applicability to other contexts. Data collection continued until the data were saturated, completed and replicated.	*External validity* refers to the generalisation of the study's findings (Yin, 1994). Generalisation is only applicable if the case study has been informed by theory and can be seen to add to the established theory (Rowley, 2002). The method for generalisation in case studies is analytical generalisation in which a theory is used in the design phase as a template with which the empirical result of the study is compared through cross-case analysis (Yin, 2018). If two or more cases support the theory, replication can be claimed (Rowley, 2002; Yin, 2018).
Dependability refers to the stability of data over time and conditions (Polit & Beck, 2014). One way of assuring dependability is to establish an audit trail which will allow for auditing of materials and documentation. The study can thus be repeated because the research process has been adequately documented and explained (Babbie, 2010). This was done by developing a case study database to organise all the collected data, as explained in Section 2.6.5. The data analysis audit trail discussed in Section 2.6.6 also illustrates that the findings were based on the participants' narratives, and Chapters 5 and 6 provide examples of the coding process.	*Reliability* demonstrates that the operations of the study can be repeated with the same results (Denzin & Lincoln, 2004; Rowley, 2002). During data collection I adhered to the procedures for each case in collecting data (Yin, 2018). I developed a case study database to organise all the collected data and maintained a chain of evidence (Rowley, 2002). Transparency is thus enhanced by careful documentation and clarification of the research procedures.

QUALITY CRITERIA – Lincoln and Guba (1985)	QUALITY CRITERIA – Yin (2003a, 2013, 2014, 2018)
Confirmability refers to the degree of neutrality or the extent to which the findings of a study are shaped by the participants and not researcher bias, motivation or interest. This was achieved by establishing a chain of evidence (audit trail), triangulation and reflexivity. Reflexivity emphasises the awareness of what I brought, my own presence and preconceptions (Annink, 2017), and how this influences the research process. These reflections provided additional information about the context (Reis, 1994) and also created transparency in the research process (Ortlipp, 2008). I used a reflexive attitude within the study by adopting methods such as making notes and keeping a journal (Denzin & Lincoln, 2011; Miles et al., 2014, Stake, 2006; Yin, 2014). I discussed my application of self-reflexivity in Sections 1.2.4, 2.2.3 and 2.6.4.4.	*Construct validity* involves establishing the correct operational measures for the concepts being studied (Rowley, 2002). This was done by establishing a clear chain of evidence to allow readers to follow the research process (Yin, 1994) and also by using triangulation that included multiple sources of evidence in the data collection phase (Yin, 2018). The data collection questions and measures were also linked to research questions and propositions to reduce subjectivity (Rowley, 2002).

By addressing the various components of trustworthiness to evaluate the rigour of the study (Lincoln & Guba, 1985), trust or confidence was confirmed that the findings of this multiple case study research represented the true state of the phenomenon under investigation (Johnson et al., 2020; Korstjens & Moser, 2018).

2.7.2 Ethical considerations

Because ethical dilemmas are linked to specific situations and events, they pose questions about how we should act in relation to the individuals with whom we engage (Brown, 2010). This means establishing a trusting relationship with participants throughout the research process so that their dignity and integrity are respected (Simons, 2009). Vanclay et al. (2013, p. 243) identified ethical principles for research involving humans by categorising the principles according to participation (consent, no harm to participants, respect for privacy, confidentiality), data (protection and security) and the research methodology (appropriateness and full reporting of methods). I applied these guidelines, firstly, by ensuring that participation in the study was voluntary, that the participants were informed by fully disclosing the objective and the nature of the study and also by ensuring the preservation of confidentiality, which will be explained in the next paragraph. Most importantly there was respect for the

participants' private lives by avoiding unnecessary intrusion, and I was therefore sensitive to what was private and personal (as suggested by Vanclay et al., 2013).

The purpose of a confidentiality agreement is to protect the privacy of all parties involved, to foster trust and rapport with study participants, to uphold ethical standards and to ensure the integrity of the research process (Baez, 2002). Confidentiality was maintained by using pseudonyms as well as changing the names of people and places that were revealed in the course of the research. Also, the location where the participants live and work was not revealed. Despite these safeguards, there might still be contextual identifiers in the data linked to people's life experiences (Kaiser, 2009). I thus evaluated whether the particular quotations and scenarios that were presented could lead to participant identification. In the event of this, there were two options. Firstly, the details in the data could be changed. However, changing the data might alter or obliterate its original meaning (Kaiser, 2009). Secondly, certain data that might reveal the participant's identity could be omitted (Wiles et al., 2008). I took responsibility for determining which portions of the acquired data needed to be changed or omitted in order to retain confidentiality while still ensuring the credibility of the interpretations (Parry & Mauthner, 2004; Wiles et al., 2008).

Ethical clearance was formally obtained from the Unisa's CAES Health Research Ethics Committee, reference number 2021/CAES_HREC/015 (attached as Appendix A). Signed consent forms were obtained before commencing the interview process, which contained all the relevant information on the research, the potential risks of participation and how data would be utilised and protected. The participants were also protected from any harm. When their participation caused some emotional distress, they were given the option of terminating the interview (McCosker et al., 2001) and the option for counselling was also available (Orb et al., 2001). None of the participants chose either of these options. The data was used only for the purpose for which it was collected and will be kept secured for an appropriate period of time (Thomas, 2016). The protection and security of data were discussed in Section 2.6.5.

2.8   REPORTING STYLE

In the discussion of findings to follow in Chapters 5 and 6, I provide the reader with enough contextual information to understand the processes that were followed and how conclusions were drawn (Nowell et al., 2017). Minor modifications involving omission of names, places and any identifiable sources, were made without affecting meaning, in order to protect the participants. Care was taken to find the right balance between protecting the identity of subjects and providing enough information for understanding (Kaiser, 2009).

In this study, a qualitative report style was used, based on a hermeneutic phenomenological analysis of a thematic nature in the participants' own words, told in the first person (Schaafsma & Vinz, 2011). The interpretation and findings reflect the research questions, propositions and theory that structured the study at the outset (Merriam & Tisdell, 2016). The way in which interpretations were formed and how reflections influenced the conclusions of the study (Barrett et al., 2020) were clearly communicated in this chapter.

2.9   CHAPTER SUMMARY

In this chapter I presented a comprehensive explanation and description of the qualitative multiple case study that I used to explore and describe the phenomenon of meaning making while living and working with a CD. I started with an elucidation of the philosophical assumptions, paradigms and methodological orientation to the study, followed by the research design, approach to theory and research methods that were adopted. Lastly, the strategies to ensure quality and ethical research as well as the style of reporting the findings were discussed. The next two chapters provide a conceptual discussion of meaning making.

CHAPTER 3
MEANING MAKING WHILE LIVING WITH A CD: A CONCEPTUAL INTEGRATION

3.1 INTRODUCTION

This chapter presents a review of the literature on the concept of meaning making within the existential and cognitive psychology perspectives. Meaning making originates in existential philosophies (Evans et al., 2017; Horne, 2019; Yalom, 1980), and is deemed necessary for healing, resilience, optimism and wellbeing (Eisenbeck et al., 2022; Wong, 2014b), thus supporting the existential perspective that emphasises the importance of facing and accepting the reality of adversity (Gebler & Maercker, 2014). From the cognitive perspective, meaning making is portrayed as a way to process information and understand the world and context in which one lives (Necka, 2018). Frankl's meaning-making principles were emphasised to establish them as the framework for this study. Viktor Frankl laid the foundation for the research on meaning (Ackerman, 2018; MacKenzie & Baumeister, 2014; Starck, 2013) and is also the leading researcher in research and empirical studies on meaning (Von Devivere, 2018; Wong, 2017a). Frankl was instrumental in highlighting the role of meaning making when faced with adversity and trauma (Zeligman et al., 2018), and underscored the human potential for personal growth (Wong, 2017a; Zeligman et al., 2018).

In this chapter, meaning making from the perspectives of existential psychology, existential positive psychology and cognitive psychology will be elaborated on. Meaning making while living with a CD, based on Frankl's meaning-making principles, will then be discussed, followed by a conceptual integration of meaning making.

3.2 MEANING MAKING FROM THE PERSPECTIVE OF EXISTENTIAL PSYCHOLOGY

According to Binder (2022), the existential concerns that accompany illness have an impact on one's spiritual health, physical health, psychological health and social wellbeing. When individuals are faced with the reality of the givens of life (Temple & Gall, 2018), like living with a chronic illness, they experience existential anxiety that evokes a diversity of different existential concerns (Andersen et al., 2020; Frankl,

1982; Larsen et al., 2018) relating to death, hope and meaning (Frankl, 1982; Yalom, 1980). These existential concerns are never entirely processed (Bachhubber, 2011). Individuals with CDs have their own process of reorienting themselves towards existential issues (Whittemore & Dixon, 2008) through experiencing, exploring and meaning making (Kralik et al., 2006; Park, 2010, 2013).

The existential psychology perspective has its roots in existential philosophy. Søren Kierkegaard is widely recognised as the father of existentialism (Du Plock & Tantam, 2019; Swenson, 1983; Wahl, 2019; Westphal, 2014; Wicks, 2019). Nietzsche, Heidegger and Satre are also regarded as prominent existential thinkers (Crowell, 2017; Koole, 2010; Nigesh & Saranya, 2017). These four pioneers, together with other existential philosophers have, inter alia, written about anxiety, dread, the need for meaning in a meaningless world, and the importance of making one's own choices (Koole, 2010). Through their writings and teachings, in the mid-20th century, psychologists, Paul Tillich and Rollo May, followed by Irvin Yalom, brought existential therapy into mainstream psychology (Vallejos, 2016).

Existential psychology focuses on present existence and the central role of suffering (Gantt & Thayne, 2014), death, isolation, freedom, meaning (Yalom 1980) anxiety, sorrow, responsibility and the experiential reflection associated with situations in our lives (Lundin, 1979). Existential psychology thus focuses on the disturbing issues of people's existence, such as guilt, suffering and mortality (Batthyany & Russo-Netzer, 2014). The existential perspective concerns itself with the question of how a person who has an existential need for meaning can find or create it in a seemingly meaningless world (Yalom 1980). Heidegger's most influential concept, and a main characteristic of the existential view, is that an individual is a "being-in-the-world" (Wong, 2006, p. 193; 2017b, p. 1375). According to May and Yalom (1995, p. 265), "being-in-the-world" involves the physical environment, the environment in which relationships are concluded with others, as well as the relationship to oneself. May's concept of "I am", is about the anxiety that results from a sense of self experienced in the world and the awareness of the state of nonbeing or nothingness (Wong, 2006, p. 197). Similarly to Heidegger's concept of being in the world, May (1953; 1959) claimed that integration is being conscious of one's own being in the present, the "I Am," with

the realisation that there is a capacity to change in order to become the best one can be in the situation.

In spite of differences, the existential thinkers generally focus on the conditions of existence of a person and his or her consequent thought processes, emotions, responsibilities and actions (Aich, 2014). According to this thinking, our everyday decision-making process (choices) leads to a search for meaning (Frankl, 1985; Längle et al., 2003; Maddi, 2004). Wong (2017b) also endorsed this role of meaning in the existential perspective by describing it as a means of living and thriving in a meaningless and confusing world. According to existentialism, PwCD can choose how they respond to an illness (Frankl, 2019). When living with a CD, a person is challenged with existential questions and becomes aware of an existential crisis, and this leads to meaning making (Bachhuber, 2011; Bezuidenhout, 2006). Frankl (1986; 2004, 2008, 2019) referred to this existential anxiety as an existential vacuum or a feeling of meaninglessness. Frankl, Yalom and May, further, like other existential psychologists, believed that anxiety could lead to personal growth and meaning (Jones-Smith, 2012).

Existential theory tries to answer many of the questions aimed at helping people find meaning and understanding. The purpose of existential therapy is therefore to assist people in finding meaning and purpose in their lives. The leading figures of the existential psychology movement in the 20th century are Frankl, Yalom and May (Nixon & Solowoniuk, 2006). Frankl's meaning-making principles are expressed in logotherapy, Yalom's existential principles in existential psychotherapy and May's existential psychology theory in support of existential psychotherapy. All three of these existentialists emphasised anxiety and the freedom to choose as pathways to meaning making. The existential theories of Frankl, Yalom and May within their respective therapeutic or psychological views are discussed next.

3.2.1 Frankl's meaning-seeking principles

Frankl is widely acknowledged as a pioneer in the study of meaning (MacKenzie & Baumeister, 2014). He believed that humans are motivated to find meaning in life in what he called a will to meaning (Frankl, 2008, 2019). Even in extremely trying times, life can have meaning, and the motivation for living comes from finding that meaning

(Cuncic, 2019; Frankl, 1985). Frankl (2008) noted that meaning is personal and situational and varies at any given moment. In searching for meaning, one "may rise above" oneself, "may grow beyond" oneself, "and by so doing change" oneself (Frankl, 2008, p. 147). Frankl's will to meaning approach is well recognised and accepted (Adhiya-Shah, 2017; Auhagen, 2000), and also the most referred to in research and empirical studies on meaning (Von Devivere, 2018).

3.2.1.1 Background and history

Victor Frankl was born in Vienna in 1905. He had an interest in learning about human motivations from a young age. In 1925, he first used the word "logotherapy". The Greek word *logos*, translated into English, is meaning or spirit, and it described his approach to psychotherapy. Frankl's first book, which provided the foundation for logotherapy, was first published in German in 1946 as *Ärztliche Seelsorge* and in English as *The doctor and the soul* in 1986 (Frankl, 1946, 1986).Frankl married Tilly Grosser in 1941, and this was the last legal Jewish marriage in Vienna under the Nazis. Under the Nazi regime it was illegal for Jewish people to have children and the Frankl couple was forced to abort their first child.

In 1942, Frankl and his family were arrested and deported to the Theresienstadt concentration camp near Prague where his father died. In 1944, the surviving Frankl family was taken to the Auschwitz concentration camp in Poland where Frankl's mother was exterminated. His wife died later of typhus in the Bergen-Belsen concentration camp in Germany. Frankl spent three years in four different concentration camps. This was an extremely difficult and dark time for Frankl in which he had to deal not only with all the losses in his life, but also with illness and the difficult circumstances in the concentration camps. Frankl, however, was able to find a purpose for living in all his sufferings and thus postulated meaning in one's life as a primary motivational force.

The Nazis confiscated the manuscript of his first book, *The doctor and the soul*, but Frankl managed to reconstruct it on bits of paper. He said that his determination to reconstruct this manuscript (will to meaning), was one of the reasons he survived. During his time in the concentration camps, Frankl attended to the psychological crises and needs experienced by the inmates. He described his own experience and his observations in the concentration camps, and further promoted his theory of

logotherapy. When Frankl was released at the end of World War II, he wrote *Man's search for meaning*, (1959), considered by the Library of Congress to be one of the ten most influential books in America during 1991 (Fein, 1991). In this book, he shares his experiences in the concentration camps with the world and promotes his theory of logotherapy. Thereafter, Frankl further shared his insights on meaning with the world and became an accomplished publisher, speaker, lecturer, and most importantly, the founder of the school of logotherapy. He died in 1997 in Vienna (summary of the details of Frankl's life adopted from Devoe, 2012, pp. 1–3; Kelland, 2015, pp. 196–201; Pattakos & Dundon, 2017a, pp. 13–21).

3.2.1.2 *Frankl's psychotherapy principles*

The search for meaning in life is identified in logotherapy as the primary motivational force in people (Abrami, 2016; Batthyany, n.d; Devoe, 2012; Frankl, 2008; Wong, 2012b), which Frankl termed "the will to meaning" (Frankl, 2008, p. 105). This will to meaning, firstly, involves finding meaning and searching for something that requires one's devotion (Pattakos & Dundon, 2017a; Wong, 2014a & b). Secondly, of importance is the fact that an individual is responsible for realising meaning in life, the "logos of existence" (Frankl, 1961, p. 9). Thirdly, a person can find meaning even when faced with a hopeless situation (Frankl, 1984), and fourthly, there is meaning in every moment and in any situation (Ritchie et al., 2018).

According to Frankl, everyone has the freedom to choose how to respond in a given situation, thus implying decision making (Debats, 1996; Frankl, 2008). Frankl insisted that the primary concern is not to seek pleasure or power but to discover meaning (Ponsaran, 2007). He underscored the need for a shift from focusing on the self to a focus on meaning as the most promising way for individuals to grow, regardless of difficult circumstances and challenging health conditions (Wong, 2014a & b). In so doing, Frankl highlighted self-transcendence, namely serving something or someone other than oneself (Frankl, 1986, 2008). The noetic or spiritual dimension is key to Frankl's logotherapy and captures what is right about people and what is distinct about human beings, thereby emphasising spirituality as an inherent part of human nature (Wong, 2014b). If individuals fail to find meaning, they may experience "existential frustration" (Frankl, 2008, p. 106), implying a feeling of meaninglessness (Bano, 2014; Burger et al., 2013; Debats, 1996). If this experience of meaninglessness continues

over time, it may lead to a condition of boredom and apathy, which Frankl termed "noögenic neurosis" (Frankl, 2008, p. 106). However, when individuals seek meaning, they experience self-transcendence (Debats, 1996; Devoe, 2012; Frankl, 2008).

The assumptions underlying Frankl's logotherapy (Auhagen & Holub, 2006, p. 38, as cited in Farran & Kuhn,1998), are as follows: One's personal values are the basis for meaning in life; meaning can be created through decisions; people are responsible for their actions; and meaning in life can be found by smaller experiences and also by deeper life experiences, which include spiritual experiences. The search for meaning is one of purpose that is oriented towards the future (Frankl, 1985). The three pathways for finding meaning and purpose are to engage with deeper purpose (creative value), connect meaningfully with others (experiential value) and embrace life with attitude (attitudinal value) (Frankl, 2008; Pattakos & Dundon, 2017a, Ritchie et al., 2018; Wong, 2014b).

In brief, Frankl's approach is based on three philosophical and psychological concepts, namely freedom of will, will to meaning and meaning in life (Frankl, 2014; Wong, 2014b). Frankl placed less emphasis on satisfying worldly things and more on the spiritual desire of serving something beyond the self (Wong, 2014b), thereby underscoring the existential idea of self-transcendence in discovering meaning (Frankl, 1966; Osin et al., 2016; Wong, 2014b, 2016b).

3.2.2 Yalom's existential psychotherapy

Yalom is regarded as a noted existential psychotherapist, author and educator and is famous for his psychotherapeutic method (Krug, 2009). Yalom (1980) posited that meaninglessness leads individuals to construct their own meaning. Yalom (2002) defined existential psychotherapy as a therapeutic approach that focuses on existence-related concerns. According to Yalom (1980), the existential therapist's goals are to help individuals find their own truth and meaning and absorb these reflections and discoveries and thereby be more authentic.

3.2.2.1 *Background and history*

Irvin Yalom was born in Washington DC on 13 June 1931. He grew up in a poor ethnic area and spent most of his childhood indoors, immersed in books. After graduating from the Boston University School of Medicine in 1956, he spent several years

completing his residency at John Hopkins Hospital, his internship at Mount Sinai Hospital, and he also enlisted in the military. In 1962, he started working as an instructor at Stanford University's School of Medicine and advanced to professor of psychiatry in 1973. He achieved professor emeritus status on retiring from Stanford in 1994.

Yalom published various books, fiction, nonfiction and textbooks over the years. His first book, published in 1970, was *Theory and practice of group psychotherapy*. This book has been used as a textbook throughout the world. Yalom was awarded the Foundations Fund Award in 1976, and the Oskar Pfister Award in 2001 from the American Psychiatric Association. Through his writing, Yalom explained existentialism and demonstrated its importance in therapy. Yalom's study and practice of group therapy made him a long-time advocate for group therapy from an existential psychology orientation (summary of Yalom's life in Yalom [n.d]).

3.2.2.2 *Yalom's existential psychotherapy*

Existential theory claims that humans choose their own existence and meaning and thereby embrace personal freedom and choice (Holland, 2020). Yalom established the four issues of existential therapy that prevent people from living a fulfilled life (Debats, 1996) – that is, death, meaninglessness, isolation and the freedom or responsibility to make the best choices (Yalom, 1980).

Yalom (1980) deemed meaninglessness to produce existential anxiety, which then again motivates or leads to meaning making. According to Halama (2015), Yalom proposed two ways of making meaning, namely cosmic meaning (e.g. spirituality) and terrestrial meaning, which represents secular values (e.g. commitments, creativity, etc.). Meaning in life, according to Yalom, is considered an individual's creative response to meaninglessness (Debats, 1996). According to Yalom (1980), meaning is created by the self and does not exist outside of individuals. Individuals have to commit themselves to make meaning to avoid the anxiety of nihilism (Debats, 1996). For Yalom, meaning is created by acceptance of the givens of existence and of personal responsibility, intentional choice and increased capacity for intimate relationships (Krug, 2009).

According to Yalom's theory, meaning making leads to stability and a feeling of being secure, whereas a feeling of meaninglessness may result in an overwhelming sense of responsibility and despair (Debats, 1996).

3.2.3   Rolo May's existential psychology theory

Rollo May was the influential founder of existential psychotherapy in the United States (Houe, 2011). He is best known for his work on modern-day human struggles (Abzug, 2021). He believed that in order to navigate life's challenges successfully, one must be able to confront existential issues. According to May, a stronger connection to nature can help people thrive by strengthening their sense of self and finding meaning in their lives (Softas-Nall & Woody, 2017). May advocated confronting life's challenges with meaning and purpose as a means of healing and mental health (Abzug, 2021).

3.2.3.1   *Background and history*

May was Born in Ohio in 1909 and passed away in 1994. He encountered various adverse experiences throughout his life that led to depression. Some of these experiences were his parents' divorce, his sister's major mental breakdown, discontinuing his studies to take care of his family and later his diagnosis with tuberculosis. May was influenced, inter alia, by Adler and Kierkegard (Pitchford, 2009).

On completion of his studies, May went to Greece and acquired a deep philosophical spirit. On his return from Greece, he enrolled in the Union Theological Seminary in New York. There he met Paul Tillich, a German-American theologian and Christian existentialist philosopher, who is regarded as one of the most influential Protestant theologians of the 20th century. Tillich became his mentor and lifelong friend. When May contracted tuberculosis, he temporarily halted his studies and spent three years in a hospital environment. During this period, he theorised about anxiety, which he found to be the underlying cause of nearly every crisis. In 1938, he returned to New York to complete his theology studies, and thereafter changed his focus, resulting in his obtaining a PhD in psychology at Columbia University. He resumed his professional career by continuing to write, serving as a visiting professor at Harvard and Princeton and also giving a series of radio talks on existential psychology (summary of May's life and work from Kelland, 2015, pp. 201–213).

3.2.3.2 May's theory of existential psychology

Most of May's work originated from humanistic psychology, which focuses on the growth and performance ability of humans, and it extended into existential psychology because of his emphasis on the role of anxiety in living an authentic life (May, 1996). May investigated the purpose of anxiety in humans and suggested that anxiety arises as a result of uncertainty in life and impending death. He found that people fear death because of the lack of comprehending their existence (Kelland, 2015). By confronting death anxiety, people can live more creative and authentic lives (Pitchford, 2009).

According to May, anxiety is experienced when a person's existence or a value attached to it is threatened (Wong, 2006). May (1996) suggested that anxiety is a normal part of one's life and the source of all creativity. There are two types of anxieties, namely normal and neurotic anxiety (May, 1999). Normal anxiety is what we all have, and it does not lead to any symptoms. Neurotic anxiety is out of proportion to the objective threat and results in neurotic symptoms (Kelland, 2015). May also argued that guilt can motivate people to make meaning of their experiences associated with guilt (Pitchford, 2009). He proposed that anxiety can be faced by using freedom of choice and the use of will (Pitchford, 2009).

Existence, freedom and will are the central themes of May's existential approach. According to him, freedom is about the power to choose the meaning of existence and direct one's life. He believed that love and will are essential in dealing with life's challenges (Kelland, 2015) and that true religion can help people to find meaning and purpose (May, 1989, 2009). His core belief is that the way people make meaning from something depends on how they relate to it and as result become stronger in the sense of self (Pitchford, 2009).

3.2.4 Summary and critical analysis of Frankl, Yalom and May

Although all three existential thinkers reviewed above share similarities across their theories, there are also several differences between them. For Frankl, meaning can be found in the world, for Yalom it can be found within an individual, and for May, people make meaning within their relationship with the world. Frankl and Yalom emphasised that suffering leads to transformation and growth. They both agreed that meaninglessness produces anxiety. Yalom, however, viewed anxiety as emerging

from the four givens in life of which meaninglessness is only one and death, freedom and responsibility the others. May's main focus of anxiety was that it occurs because of a threat to a one's values and is therefore perceived as a threat to one's existence.

All three scholars articulated the importance of creativity (creating or doing a deed) and self-transcendence in meaning making. While Frankl (2008) posited that meaning can be found in doing a deed or creating work, Yalom (1980) claimed that creating something of beauty adds to meaning in life, and May (1975) suggested that taking charge of one's life requires courage and creativity to form and reform the space one occupies. Frankl valued relationships and love as an important pathway in meaning making, while Yalom proposed that meaning making comes naturally through one's relationships. May emphasised love as a process through which people reach out and influence each other.

For all three scholars, meaning making is in part a relational phenomenon that is constructed naturally and purposefully through relationships and love. All three scholars also concurred that anxiety leads to meaning making and that people have a choice in selecting their response in a given situation. Frankl, Yalom and May postulated that being responsible contains aspects of freedom and will, and is thus an attitudinal choice. Frankl made a distinction between responsibility, which suggests that one chooses to be responsible, and that responsibility implies that one is answerable to others for one's actions. According to Frankl, willpower must be accompanied by responsibility. He claimed that spirituality is linked in the meaning-making process through creative, experiential and attitudinal values. The emphasis is on self-transcendence and meaning of life under all circumstances. Yalom also highlighted spirituality as a way of meaning making, while May proposed that true religion can provide people with meaning and purpose.

 In summary, the main difference between the three existential thinkers is more one of emphasis. Frankl emphasised the will to meaning as the freedom to find meaning through attitudinal, experiential and creative pathways. Yalom focused on the existential themes of freedom, responsibility, meaninglessness and death as one's way of making meaning of being in the world. May posited that psychotherapy should help people to discover meaning in their lives for the better of the society in which they live, and his concern was with the problem of "being" rather than with problem solving.

3.3 MEANING MAKING FROM THE PERSPECTIVE OF EXISTENTIAL POSITIVE PSYCHOLOGY

Existential psychology tends to focus on the more unsettling aspects of human existence (Batthyany & Russo-Netzer, 2014; Solobutina & Miyassarova, 2020; Wong, 2010c), such as suffering, mortality and meaninglessness. By contrast, positive psychology underscores positive experiences and emotions (Fredrickson, 2001; Seligman, 2002; Seligman & Csikszentmihalyi, 2014; Wong, 2010c). The result of combining these two domains of psychology is existential positive psychology (EPP). A major focus of EPP is the search for meaning and purpose (Passmore & Howell, 2014), which highlights the importance of an authentic self-identity (Wong, 2009). The emphasis in EPP is on one's capacity for resilience and positive change (Wong, 2010c), which results in psychological and spiritual growth (Wong, 2009) in the face of adversity. According to Wong (2016a), EPP addresses fundamental questions relating to meaning making and finding a reason for existence through both positive and negative work and life experiences.

One of the characteristics of EPP is the dynamic interaction between dualities. Wong's duality hypothesis states that positives cannot exist without negatives and that authentic happiness results from pain and suffering (Wong, 2016a). In explaining EPP, Wong (2016a) used Yalom's four existential anxieties of death, freedom, isolation and meaninglessness, and added two existential elements, namely identity and happiness. According to EPP, death anxiety is a driving force for personal and spiritual growth and needs to be confronted and embraced in order to live meaningfully (Wong, 2016a). Wong (2009, 2020) posited that human beings have the spiritual dimensions of responsibility and self-transcendence which they apply towards meaning making. Freedom creates anxiety in two ways – on the one hand, too much freedom is overwhelming, and on the other, too little of it can lead to feelings of hopelessness (Wong, 2016a). Because freedom implies responsibility, EPP is concerned with how to maintain a healthy balance between freedom and responsibility (Wong, 2016a).

EPP accepts isolation anxiety as an existential given but emphasises the need to build authentic relationships and to belong to a supportive community (Wong, 2016a). At some point in life the existential question of meaning will arise, and one of the major concerns of EPP is therefore to focus on the search for meaning and purpose (Wong,

2016a, 2020). An identity crisis is necessary in the search for one's true nature and calling that leads to an authentic and meaningful life (Wong, 2010c, 2016a). EPP recognises that the crisis of discontentment is an essential part of human nature and leads to the quest for happiness (Wong, 2016a). He (2016a) proposed that EPP promotes authentic happiness (flows from being authentic), eudaimonic happiness (comes from doing good deeds) and chaironic happiness (stems from one's spiritual nature).

Wong (2014a) postulated that the structure and functions of meaning can be defined as PURE, which stands for purpose, understanding, responsible action and enjoyment. Functionally, these four components cover the psychological processes of motivational (purpose), cognitive (understanding), moral/spiritual (responsibility) and evaluative/affective (enjoyment). These components function together as part of the self-regulation and self-determination process (Baumeister & Vohs, 2004; Carver & Scheier, 2001; Ryan & Deci, 2000a). The main message of EPP is that both the positive and negative aspects of living should be confronted and transformation through meaning making could lead to personal growth as a result of such encounters (Eisenbeck et al., 2022; Wong, 2016a).

3.3.1 Identity work within the existential framework

Identity work encompasses various ways of crafting, revising, sustaining, enhancing or modifying one's meaning of self in order to produce a sense of self-coherence (Alvesson & Willmott, 2002; Sveningsson & Alvesson,2003) and congruence to the ideal self (Jacobs & Barnard, 2022). Self-identity (who I am) is the construction of an individual's self-perception based on their numerous life roles and personal experiences, which include people, relationships, and institutions (Merricks, 2022). Work identity (who I am at work) reflects the individual's roles and behaviour at work (Walsh & Gordon, 2008). Career identity refers to an individual's attitude and performance towards the occupational environment and role in which they work (Feng & Liu, 2023). Self-identity comprises both work and career identities.

On receiving a CD diagnosis, PwCD experience a threat to their identity (Breakwell, 1988), and are confronted with existential issues and experience existential crisis (Bachhuber, 2011; Bezuidenhout, 2006) or existential anxiety, which is described by

Frankl (1986; 2004;2008; 2019) as an existential vacuum or a sense of meaninglessness. People who do not resolve their existential anxiety experience feelings of inauthenticity (Temple & Gall, 2018) and self-detachment or non-being (Wong, 2006; 2012). When challenged with existential anxiety or identity conflict, people strive to cope and reclaim a feeling of authenticity through a process of meaning making (Ownsworth & Nash, 2015). They will attempt to preserve their identities through self-evaluation and self-verification as proof of their continuing self-worth. The existential approach to meaning making includes self-reflection (Wong, 2017), which is linked to negotiating identity continuity through self-concept revision (Baker et al., 2018; Zafran et al., 2012). To make sense of illness experiences, ideal self-identities are created to offer a meaningful future perspective and life purpose (Steger 2012). The ideal self is formed by reflecting on the effects of illness on one's work, relationships, and life orientation, which leads to a revision process and the creation of an ideal self in order to preserve a meaningful sense of self.

3.4 MEANING MAKING FROM THE COGNITIVE PSYCHOLOGY PERSPECTIVE

Cognitive psychology is concerned with our inner mental processes (Farnsworth, 2019), and according to the cognitive perspective, meaning reflects a person's inner mental state (Bering, 2003). According to Park (2010), meaning making is a cognitive process that facilitates understanding and helps individuals to make sense of adversity. Meaning making within the cognitive perspective relates to individuals appraising an event and processing information until meaning is made (Park & Folkman, 1997). Chronic illness leads to change that disrupts a person's normal everyday life, and this emphasises meaning as a component of cognitive adaptation to chronic disease (Walker et al., 2004). Consequently, PwCD are required to redefine their assumed meanings in everyday life (Fife, 1995; Walker et al., 2004). The theories of Baumeister, Antonovsky, Steger and Park are relevant to meaning making within the cognitive perspective and constitute the focus of discussion in this section.

3.4.1 Baumeister's need theory

Baumeister (1991, p. 27) defined meaning as "ideas that connect things together". He (1991; Baumeister & Vohs, 2002) proposed a model based on psychological needs

and the satisfaction of these needs that would lead to a meaningful life. While Frankl (1959, 1985) associated meaning with purpose and emphasised value, Baumeister (1991) added the need for efficacy and self-worth. Baumeister's model suggested four basic needs or patterns of motivation that influence the way in which people make meaning, namely purpose, values, a sense of efficacy and self-worth (Baumeister, 1991, Baumeister & Vohs, 2002). If these needs are satisfied, people will feel that their life has meaning. If not, they will restructure and change their behaviour until all four needs have been satisfied (Sommer et al., 1998).

The explanation of the different needs is as follows: The need for purpose includes meeting one's objectives or goals; the need for value is to view one's actions as having positive value; the need for efficacy is to interpret situations to produce a desired or intended result; and the need for self-worth is the need for self-respect and respect from others (Baumeister, 1991; Vohs et al., 2005). If one need is not met, individuals will search for meaning in that part of their life (Sommer et al., 1998). Living with a CD stimulates the need for meaning in terms of making sense of the disease itself and trying to regain the sense of meaning that is threatened by it (Baumeister, 1991). According to Baumeister, individuals want to feel that their lives are valuable, worthwhile and important (George & Park, 2014). Baumeister and Landau (2018) later also included the concepts of continuity (connection across time) and coherence (forming a logical connection) to further describe existential meaning (meaning of life). Baumeister and Landau (2018) emphasised that people find meaning by connecting with and helping others.

The commonalities between Baumeister and Frankl's theories are that both regarded purpose and value (demonstrated in Frankl's creative value) as part of the meaning-making process. Both of them highlighted the significance of interpersonal relationships. While Frankl underscored the importance of meaningful interaction with others as an experiential value, Baumeister emphasised the need for people to find meaning in their relationships with others and assisting them. In order to discover meaning and confirm their values, and a sense of efficacy and of self-worth, individuals are portrayed from a cognitive perspective as information processors who are influenced by context, social content and social influences.

3.4.2   Antonovsky's salutogenic model

Antonovsky (1979) developed the salutogenic model in which salutogenesis refers to the origins of health. He (1987) introduced the salutogenic model which focuses on promoting health rather disease (Førland et al., 2018; Koelen & Lindström, 2016; Pelikan, 2017). He considered the sense of coherence (SOC) as the key concept in the salutogenic model (Antonovsky, 1979). Meaning in life and SOC both have to do with how one experiences life to be meaningful and comprehensible, but the SOC concept also includes the manageability component (Winger et al., 2016). This concept explains how the meaningfulness, comprehensibility and manageability of a situation or disease can be integrated into a person's meaning making of living with a CD. Comprehensibility represents the sense that a problem is understandable; manageability refers to the belief that one has the necessary resources to respond to demands; and meaningfulness is the belief that life has purpose and is worth living (Førland et al, 2018; Winger et al., 2016). If a person is able to understand (comprehensibility), manage (manageability) and make sense (meaningfulness) of living with a CD, the greater his or her potential will be to successfully cope with the CD (Førland et al, 2018; Winger et al., 2016).

According to Antonovsky (1987), there are four areas of importance in maintaining a healthy SOC, namely emotions, interpersonal relations, the major field of activity (work) and existential questions. Antonovsky's four areas, particularly the last three, are closely related to Frankl's meaning-making pathways, namely meaning is found in what one does, such as work (creative values), what one experiences, such as interpersonal relationships (experiential values), and the attitude one adopts towards existential crises such as unavoidable suffering (attitudinal values).

3.4.3   Steger's meaning in life model

According to Wong (2014b), the most active research on the search for meaning was that of Steger (2012) and his associates (Steger et al., 2005, 2008b, 2009). Steger and associates (Steger et al., 2006) developed the Meaning in Life Questionnaire (MLQ), which has become the standard instrument in meaning research (Wong, 2014b). In this questionnaire, both the presence of and search for meaning are measured. The presence of meaning refers to how one sees the presence of meaning

and purpose in one's life, while the search for meaning relates to how one seeks (the process) meaning and purpose (Steger et al., 2006; Wong, 2014b).

Martela and Steger (2016) posited that meaning is a mentally connecting, reflective approach with the components of coherence, purpose and significance. According to Costin and Vignoles (2020), coherence is about making sense of the experiences in one's life (the cognitive component of meaning in life), while purpose refers to an aim or goal in the future that gives meaning to life (motivational component). Significance is also referred to as existential mattering (an evaluating component), which focuses on the importance of one's life in terms of value and worth (George & Park, 2016). Steger (2018) proposed three facets of meaning in life, which are similar to Frankl's principles in that they contribute towards having a purpose. The three facets are working towards something creatively, comprehending and making meaning of one's experiences, and adopting the attitude of valuing life as being significant.

3.4.4   Park's meaning-making model

According to Park's integrated meaning-making model, individuals have a set of basic global beliefs and goals (worldview), from which they make sense, purpose or meaning in life (Park, 2008, 2010). When people experience stress (e.g., dealing with a CD), they assign meaning to it (appraised meaning), and the extent to which this appraised meaning and global meaning (understanding of self and the world) differ is determined by the level of distress experienced (Park, 2013). This distress leads to meaning-making efforts to try to align the global and appraised meaning and ease the distress (Hartog et al., 2017; Park, 2010). To decrease their distress, people must either adjust their views of the event (situational meaning) or revise their worldview (global meaning) in order to accommodate the new information (Park, 2008, 2010). Park and Folkman (1997) emphasised meaning making as a coping strategy and explained it as a cognitive reappraisal process of the stress experience.

According to Park and Folkman (1997), meaning making is a coping mechanism that involves people reducing disparities between their evaluated meaning of an event and their overall meaning. Frankl (1985) postulated that the will to meaning is the urge to create meaning, and it is discovered rather than created. Park (2013) viewed meaning made as an adjustment to an event by accepting it or changing one's overall meaning

to accommodate it. This shows a shift in a person's perspective (Park, 2013), akin to Frankl's attitudinal pathway, which suggests a more favourable outlook on an experience. Frankl (1985) regarded acceptance as a response, while Park and Folkman (1997) deemed it to be an outcome state. Meaning making, according to Frankl (2008), is a spiritual drive for self-transcendence, which is comparable to Park's (2013, 2014) belief that spirituality gives drive and a sense of purpose.

3.4.5 Cognitive psychology and identity work

The cognitive approach (Berzonsky, 2011) is concerned with processing a life event in order to self-regulate and maintain a coherent sense of self-continuity, which is linked to the concept of identity work. Individuals are considered as information processors who use their social surroundings to construct meaning and reinforce their values, sense of efficacy, and sense of self-identity (Jhangiani & Tarry, 2022). The cognitive approach involves restructuring (Osin et al., 2016). Cognitive restructuring entails a way to see and express oneself in a more positive and meaningful manner. The restructuring of the self, which comprises building, positioning, and maintaining a favourable image of oneself, shows itself in personal branding, which is built on a distinct blend of attributes that communicate a certain self-image via personal narrative and images (Gorbatov et al., 2018). The cognitively branded self is produced by reframing one's life's work, staying connected, and reframing one's life orientation in order to maintain a meaningful sense of self.

3.5 FRANKL'S MEANING-MAKING PRINCIPLES REGARDING LIVING WITH A CHRONIC DISEASE

As mentioned and justified in Section 2.5 in the methodology chapter, this study was guided by Frankl's meaning-making principles, which arise in and from the existential and personal situations of life (Kovacs, 1982). Frankl's meaning-making principles, as discussed in Section 3.2.1.2, regarding living with a CD, are elaborated on next.

The position of Frankl's theory within psychology is a subject of debate. According to Bushkin et al. (2021), Frankl's theory fits the tradition of existential philosophy given his philosophical background in existentialism. His logotherapy, according to Redsand (2006), is a component of both existential and humanistic psychology. De Klerk (2005) referred to logotherapy as a theory of human behaviour, but also noted that the theory

embraced a cognitive perspective that recognises that people interpret events and make decisions about them cognitively. Wong (2014b) claimed that Frankl's principles are part of positive psychology. According to Frankl (1984), people's lived experiences have cognitive psychological and spiritual dimensions. Section 3.6 presents my conceptual integration of how Frankl's theory relates to the various psychological disciplines.

Frankl's work on meaning has connections to fields outside of therapy, such as meaning making in the workplace (e.g. Burger, 2007, 2012; Burger et al., 2008, 2012, 2013; Pattakos & Dundon, 2017a & b). Viktor Frankl's philosophy and methodology are also the foundation of the book by Pattakos and Dundon (2017a) about finding meaning in everyday life and work. They sought to uncover deeper meaning in life, work and society by combining Frankl's ideas with their own study. Pattakos and Dundon (2017a) discovered the following three elements for finding deeper meaning: Connecting meaningfully with others (O); engaging with deeper purpose (P); and embracing life with attitude (A). They named it the OPA formula. The OPA elements correlate with Frankl's principles in the following way:

Table 3.1

Correlation between Frankl's principles and Pattakos and Dundon's OPA elements

FRANKL'S MEANING-MAKING PRINCIPLES (Frankl, 2008, p. 115)	PATTAKOS AND DUNDON'S MEANING-MAKING ELEMENTS (Pattakos & Dundon, 2017a, p. 10)
Experiencing something or encountering someone (experiential value)	Connecting meaningfully with others (O)
Creating a work or doing a deed (creative value)	Engaging with deeper purpose (P)
Attitude towards unavoidable suffering (attitudinal value)	Embracing life with attitude (A)

According to Pattakos and Dundon (2015, p. 17), the Greek word, "OPA!" can be viewed as two sides of the same coin: "One side (ΌΠΑ) refers to the uplifting, enthusiastic expression that is often heard during some kind of celebration. The other side (ΏΠΑ) refers to the human need to remain awake or alert and be on the lookout for any possible dangers, as well as opportunities, in one's life path". They emphasised

that although these two sides of the OPA coin may appear to be two opposites, they are actually interconnected and interdependent in that both are used in the meaning-making process of managing life transitions (Pattakos & Dundon, 2015). The explanation and application of Frankl's principles by Pattakos and Dundon (2017a) are pertinent to and helpful for this study because they offered a practical perspective on it.

Frankl's logotherapy comprises three tenets, namely freedom of will, will to meaning and meaning in life (Devoe, 2012; Frankl, 2008; Wong 2014b). These tenets are interconnected in that people have an intrinsic motivation (will to meaning) and are free to choose (freedom of will) to live a meaningful life (Wong, 2012a, 2014b). Frankl (2008) underscored the will to meaning which involves the spiritual motivation for self-transcendence founded through creative, experiential and attitudinal values.

3.5.1   Self-transcendence

According to Kitson et al. (2020), self-transcendence is explored and conceptualised differently across disciplines. It can be regarded as a human phenomenon (Frankl, 1966); a process of spiritual meaning making (Frankl, 2008; Wong, 2016d); an intrinsic motivation (Wong 2016b); personal transformation (Teixeira, 2008); a personality trait (Cloninger et al., 1993); a development process (Cloninger et al., 1993); a life perspective (Reed, 2018); and also a result of emotions and spirituality (Haidt, 2002; Van Cappellen, 2017;Van Cappellen & Rimé, 2014). Depending on which lens one uses to view self-transcendence, it can be conceptualised as a state, trait, value or process (Kitson et al., 2020).

Individuals living with a CD need to address their physical limitations and the challenges and demands that these constraints impose. The complexity of living with a CD may influence a person's connection to meaning in one way or another (Vos, 2014), but according to Frankl (2008), everyone has a will to meaning in that they aim to create, restore or maintain meaning. The will to meaning stems from one's spiritual nature (Wong, 2014b) and is a motivation to make meaning. The spiritual nature is expressed through self-transcendence when people move beyond themselves (Costello, 2015) and reach further to something, someone other than the self (Devoe, 2012; Frankl, 2008; Wong, 2014b). Frankl (2008) believed that meaning is to be found

in the world, and this direction towards something other than the self is referred to as self-transcendence.

Self-transcendence, according to Frankl (1962), involves reframing one's actions in a broader more meaningful context. Self-transcendence implies intrinsic motivation for personal growth and self-expansion (Wong, 2014b). Frankl (1988, 2000, 2008) postulated that meaning is to be found through the creative, experiential and attitudinal values motivated by one's spiritual nature rather than self-interest. According to him (2008), these different values of meaning making happen in three different ways, namely by creating a work or doing a deed (creative value), experiencing something or encountering someone (experiential value) and the attitude one adopts towards unavoidable suffering (attitudinal value). Eisenbeck et al. (2022) asserted that meaning is found in the appreciation of life as it is (creative value), in one's responsible action towards oneself and others (experiential value) and in an adaptation of an attitude of hope and courage (attitudinal value).

During an interview with ABC news, Hawking[2] (2010), captured these three values by his advice for a meaningful life: "One, remember to look up at the stars and not down at your feet. Two, never give up work. Work gives you meaning, and purpose and life is empty without it. Three, if you are lucky enough to find love, remember it is rare and don't throw it away."

Frankl underscored the spiritual dimension of self-transcendence in meaning making when confronted by existential challenges (Frankl, 2008; Wong, 2014b). One's will to make meaning is another way to say that one has a spiritual need to seek self-transcendence, and it is found through creative, experiential and attitudinal values. Self-transcendence is thus interwoven as a value perspective through all three values, which will be elaborated upon and explained as such in the section below.

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[2] Stephen Hawking (1942–2018), was a British scientist, professor and author who performed ground-breaking work in physics and cosmology. He suffered from a debilitating motor neuron disease, amyotrophic lateral sclerosis (ALS), which ultimately ended his life. This rare disease leads to a gradual decline of the brain's ability to control muscles (Kuo, 2019).

3.5.2 The creative value as the pathway to meaning making

Frankl (1988, 2008) asserted that meaning in life can be discovered through creating a work or doing a deed and as such contribute to life, which he referred to as creative values. Kovacs (1982) posited that one can find meaning in life through activities in the form of performing concrete unique tasks in one's personal life and at work and thus realise creative values. Pattakos and Dundon (2017a, p. 10) refined this creative value of Frankl by calling it "engaging with deeper purpose". Purpose involves the knowledge of self, the commitment to authentic values and goals and service to others (Pattakos & Dundon, 2017b). The creative value entails make meaning by producing or giving something that is to the benefit of the self and others (Wong, in press). Helping others creatively is part of the social process (Forgeard & Mecklenburg, 2013). Yalom (1980) also emphasised creativity as a way to improve and discover not only for oneself but also for others. May (1975) believed that in creatively taking charge of one's life requires courage. May (1975, 1994) asserted that who we are, is partly based on our creativity, that is, the ability to create ourselves. It is usually in work that opinions and unique creativity can be expressed (Pattakos & Dundon, 2017a). This concept of engaging with deeper purpose is also expressed by Csikszentmihalyi (1990, p. 4) in the term "flow", which occurs when a person becomes fully immersed in an activity.

Kaufman (2018) explained meaning making through the past, present and future pathways of creativity. Through the past pathway of creativity, individuals use their imaginations to reflect on events in their lives in order to understand these events (cognitive process) and make sense of the past. Examples of such activities are expressive writing, blogs, personal narratives or memoirs and general creative thinking about life events (Kaufman, 2018). The present pathway of creativity helps people manage their moods, activities and relationships (positive psychology). It is all about the pleasure of being creative, of which Csikszentmihalyi's (1990, 1996) concept of flow (discussed in the previous paragraph) is an apt example.

According to Kaufman (2018), creativity can be a way to engage and connect with people, thus affirming one's self-worth. Examples are to engage in any creativity activity like doing art, drawing and creating something with others (Kaufman, 2018). The future pathway of creativity is about people's desire to be remembered after death by leaving a legacy and thus helping them to handle the inevitability of death

(existential domain). Examples are career narratives, everyday creative activities like sharing stories, drawings, ideas, scrapbooks, videos and inventions (Kaufman, 2018), which can be passed on to family, friends, colleagues, the public or anyone else (Kapoor & Kaufman, 2020). Individuals with CDs realise the creative value of meaning making in a range of activities like work, leisure, volunteering and improving their health (Lim et al., 2017). Beyond the pleasurable act of creating, it can also remind people that they have the potential to help others and that their lives have worth and value (Kaufman, 2018), which is in line with Frankl's view of using the creative value to experience self-transcendence in one's approach to make meaning.

In sum, Kaufman (2018) theorised that individuals use a cognitive process of coherence in the past pathway of creativity; in the present pathway of creativity they use positive psychological methods to increase self-worth; and in the future pathway of creativity, they engage in the existential domain by creating a legacy after death.

3.5.3   The experiential value as the pathway to meaning making

The experiential value could be related to an experience with something such as goodness, truth and beauty, nature or culture or it could be an experience with another human being or higher power (Frankl, 2008; Wong, 2014b). According to Wong (2014b), the experiential value is about how we relate to our daily experiences and it is consistent with mindfulness. A useful example of experiential value is the love we feel towards another (Boeree, 1998), which involves connecting with others and getting to know each person in his or her uniqueness (Hatt, 1965). While in the concentration camp, the mere thought of his loved one was something that gave meaning to Frankl's existence (Frankl, 2008).

The experiential value relating to beauty and nature is expressed in Frankl's (2008, p. 51) work, describing a situation in which he and other fellow prisoners viewed a beautiful sunset and one prisoner said to the other, "How beautiful the world could be!" Frankl (2008, p. 51, 52), also described how his spirit transcended the hopeless, meaningless world when he saw a light shining in a distant farmhouse, which for him symbolised hope – "and the light shineth in the darkness". These examples express the meaning-making value of finding spiritual inspiration in nature by experiencing

connectedness, hope and a sense of belonging (Bethelmy & Corraliza, 2019), even in the midst of death camp experiences.

Thomas (2019), a person living with coronary microvascular disease, also expressed this connectedness with nature in her experience of watching seals. She wrote the following: "during those magical moments, I somehow forgot all about pain or fatigue or the ice pick or anything awful that had been happening that day" (para. 14). She (2019) mentioned that she was "so enthralled by Mother Nature" that she forgot about feeling ill (para. 15). Experiencing nature or kindness from another person can promote a sense of connectedness, meaning (Greenstein & Breitbart, 2000) and gratitude (Wong, 2012b). The feeling of connectedness could be in relation to another person and also towards a transpersonal other such as nature or the divine (Flanagan et al., 2019).

From a spiritual perspective, Frankl maintained that, whether one believes in God or a higher power, all people are equipped with a spiritual nature that longs for beauty, goodness, truth and self-transcendence (Wong, 2014b, 2016b). According to Frankl, transcendence is rooted in our spirituality (Parks, 2011; Wong, 2014b, 2016b). Roger and Hatala (2017) defined spirituality as a dimension of being that gives meaning to life by pursuing personal answers to life's ultimate questions and developing relationships with the sacred or transcendent. Spirituality is often defined in terms of love, meaning, faith (Newshan, 1998) or connectedness to a higher being, oneself and others (De Jager Meezenbroek et al., 2012; Galloway, 2013), and it is this sense of connectedness that inspires and motivates individuals with CDs to achieve their optimal being (Domocmat, 2014). Wong and Bowers (2019) underscored the human capacity to transcend and transform adverse experiences through meaning and faith in enduring adversities and achieve happiness. This is demonstrated by a person living with cancer who asserted the following: "my faith in the grace of Jesus is the thing that made the difference … it gave me calmness" (Clur, 2015, p. 113).

Lysne and Wachholtz (2011, p. 11) cited Bush et al. (1999) by explaining that spiritual meaning-making behaviour affords one the opportunity to draw strength from an unlimited transcendent source and, in doing so, experience positive emotions. Religiosity and spirituality have been associated with prosocial behaviours (Li & Chow, 2015). It was found that, for spiritual people, positive outcomes are often attributed to

intentional acts of God and trigger gratitude in response (Emmons & Crumpler, 2000). Much value is attached to an individual's attitude towards gratitude in Christian, Buddhist, Jewish, Muslim and Hindu thought (McCullough et al., 2001). McCullough et al. (2001) took the idea of gratitude further in suggesting that gratitude has a motivational value that leads to prosocial behaviour.

The lack of authentic connection with others leads to a crisis of meaning (Pattakos & Dundon, 2017a). People are social beings and want to interact and belong with others (Biordi & Nicholson, 2013; Pattakos & Dundon, 2017a). Pattakos and Dundon (2017a) related self-transcendence to the *ubuntu* concept used in South Africa. The full Zulu expression of this concept is *ubuntu ngumunyu ngabantu*, roughly translated as a person is only a person through other persons (Gade, 2011; Van der Merwe, 1996). This implies that by reaching out and connecting to others, we fulfil and learn more about ourselves. *Ubuntu* refers to our interconnectedness and implies that one cannot exist as a human being in isolation (Gade, 2011; Krog, 2008; Van Breda, 2019). Hawkley and Capitanio (2015) underscored this notion of interconnectedness by positing that social interaction is essential to every aspect of our existence.

Living with a CD implies that an individual must manage certain health issues and therefore face a number of challenges in order to remain socially connected (Cornwell & Waite, 2009). It was found that loneliness may be linked to multiple chronic illnesses (Theeke & Mallow, 2013). Social isolation, while living with a CD, may be voluntary or involuntary as imposed by others (Biordi & Nicholson, 2013). There are various reasons why social isolation occurs in a person with a CD. One of the reasons is the sense of being different as part of the ongoing demands of the illness (Biordi & Nicholson, 2013). Another reason might be the stigmatisation of certain CDs and individuals' concern about revealing that they have the illness(es), especially if it might discredit them (Biordi & Nicholson, 2013). The lack of understanding the dynamics of CDs contributes to resigned behaviour that ultimately leads to social isolation (Mellado et al., 2016).

The experiential pathway emphasises meaning making in relation to the experience of isolation and the need for social belonging. Making meaning while living with a CD is a personal and interactional process which involves the social environment such as family, friends, the community and co-workers (Helgeson & Zajdel, 2017; Stanton et

al., 2007). Twos benefit of experiencing social relationships is that they can provide support for the individual in times of need and provide access to group resources (Cockerham et al., 2017; Stanton et al., 2007). The experience of having friends and family can influence a person to manage the CD more effectively and practise a healthier lifestyle (Cacioppo & Hawkley, 2003; Gallant et al., 2007). Social participation is an experiential pathway to meaning making as it helps people to cope with stress, reduce feelings of helplessness and also increase self-esteem and wellbeing (Holmes & Joseph, 2011).

3.5.4 The attitudinal value as the pathway to meaning making

The attitudinal value is to give meaning to one's existence by one's attitude (Frankl, 2008; Hatt, 1965). By adopting a positive attitude, one can confront adversity, grow by transforming an event into an opportunity and overcome suffering through spirituality (Wong, 2014b). Frankl (2008) postulated that when one is not able to change a situation, one is challenged to change oneself. He emphasised that everything can be taken away from a person but the freedom to choose one's attitude (Frankl, 1959, 2008). Freedom is the foundation of people's ability to choose and grow in life (May, 1959). An example of this is Christopher Reeve, an actor who was known for his leading role in the Superman movies, who was thrown from a horse and broke his neck, leaving him a quadriplegic. He exercised his freedom to choose a positive attitude, confront unforeseen changes, survived and thrived and was an inspirational role model to many people during the remainder of his life (Pattakos & Dundon, 2017a).

Pattakos and Dundon (2017a) suggested that it is the ability to recover and adjust to change, thus building resilience, which cultivates attitude. Everyone is responsible for their attitude (Hatt, 1965). Attitudinal values, according to Boeree (1998), include, inter alia, compassion, bravery and a sense of humour. In a study by Kristjansdottir et al. (2018), kindness towards others (compassion) and courage (e.g. a willingness to try out new things) were reported as sources of positive emotions and a sense of meaning. May (1999) promoted the use of one's intentionality (one's will), which is the framework that allows one to search within oneself in order to give meaning to experience. According to Yalom (1998), moving forward is the result of one's will.

Attitudinal values are about the potential to make meaningful choices (Gelman & Gallo, 2009) in situations of unavoidable suffering and adversity (Frankl, 2008). Cultivating a life attitude towards and finding positive meaning in hardship, such as living with a CD, provides individuals with the ability to be resilient and cope better (Dunn, 1994; Frankl, 1966, 1988, 1992a; Psarra & Kleftaras, 2013). Similarly, Frederickson (2001), in her broaden-and-build theory, asserted that positive emotions and affect broaden people's reactions to daily situations, thus building their resources to deal with adversity. Polk's theory of resilience (1997) is also relevant to this study of making meaning while living with a CD. Polk specifically referred to the philosophical pattern that claims that resilience develops in personal beliefs, such as the belief that experiences have positive significance and that life is worthwhile and meaningful and has a purpose.

According to Frankl (1959), human beings are self-determining. Self-determination is an attitudinal value that refers to the ability to provide meaning, acknowledge feelings and make choices in managing one's own life (Seifert et al., 2012) when living with a CD. Self-determination is self-directed behaviour based on the need for autonomy (feeling in charge of one's behaviour), competence (feeling effective) and relatedness (feeling connected) (Deci & Ryan, 2000; Smeets et al., 2019). To cope with specific issues regarding one's health, people can take an active role in satisfying the needs of autonomy, competence and relatedness (Migliorini et al., 2019). When living with a CD, one can self-determine and make changes that may lead to adaptation behaviours (Frankl, 2015).

Frankl (2008) claimed that by choosing attitudinal values, people can handle adversity with courage and dignity and turn it into growth opportunities.

3.6   MEANING MAKING: A CONCEPTUAL INTEGRATION

In the coping literature, meaning making has various conceptual and operational definitions (Clur, 2015; Hartog et al., 2020; Martela & Steger, 2016; Park, 2010; Waters et al., 2013). Meaning making is often described as a separate coping mechanism or strategy, namely meaning-focused coping (Folkman & Moskowitz, 2007; Gruszczyńska & Knoll, 2015; Riley & Park, 2014; Vehling & Philipp, 2018). Some positive psychology constructs (e.g. religion, hope, optimism and humour) are used to describe various ways of meaning making (Clur, 2015), while others focus on the

processes of meaning making. Pakenham (2011), for example, conceptualised benefit finding and sense making in chronic illness as two related meaning-making processes. Meaning making following adversity or a traumatic event has also been conceptualised as post-traumatic growth (Pals & McAdams, 2004; Park, 2010; Tedeschi & Calhoun, 1996, 2004). Park (2013) distinguished between meaning making and meaning made. She postulated that meaning making is a process of searching for a favourable understanding, while meaning made may include the appraisal of a situation as well as changes in one's global meaning (Park, 2013).

According to Martz and Livneh (2016), meaning making involves reinterpreting or reappraising a traumatic event. Meaning making is about reappraising the experience, grieving losses and accepting change (Adelstein et al., 2014). When people have to deal with a stressful experience, like living with a CD, it has been found that positive reappraisal is often used to redefine the situation in a more positive way to be able to find positive meaning in it (Finkelstein-Fox et al., 2020; Lazarus & Folkman, 1984; Ockhuijsen et al., 2014). Meaning making is also referred to as sense making and is related to better adjustment (Martz & Livneh, 2016; Park et al., 2012). Van den Heuvel et al. (2009) described meaning making as a psychological process of interpretation and reflection. Meaning making is deemed important in the process of positive adjustment in living with a CD by means of restructuring or re-evaluating the situation (Barkwell, 1991; Sherman & Simonton, 2012; Yang et al., 2010).

In a study by Clur (2015), it was also found that re-evaluation, in the form of reassessment of values and priorities, was essential in meaning making during the reintegration phase for people with cancer when they return to work. Whereas the coping strategies and processes of meaning making seem to relate closely to the cognitive, processing approach, meaning per se is a key component of coping in the existential framework. When one faces living with a CD, it demands existential courage in confronting the reality and discovering a mature happiness despite suffering (Ehrenreich, 2009). Wong and Bowers (2019) posited that suffering could be overcome by cultivating one's spiritual and existential capability. According to them, meaning making includes self-transcendence, relational wholeness and transformation. It is evident that there is a wide variety of perspectives on the concept of meaning making that can broadly be integrated into existential psychology (EP),

positive and cognitive psychology perspectives. Tables 3.2 and 3.3 constitute the meta-theoretical lens for the data analysis. In the following Table 3.2, the contributions of EP, EPP and cognitive psychology to meaning making and the similarities of these approaches to Frankl's principles are highlighted.

Table 3.2

The contributions of EP, EPP and Cognitive Psychology to meaning making

	Existential psychology (EP)	Existential positive psychology (EPP)	Cognitive psychology
DEFINITION	EP is a branch of psychology that studies how people come to terms with or make meaning of the basic questions and givens of human existence (Koole, 2010).	In EPP, the search for meaning and purpose (Passmore & Howell, 2014) originates from a religious/spiritual perspective (Wong, 2020) integrating negative experiences with positive ones (Wong, 2010c).	Cognitive psychology is about the inner mental processes that facilitate understanding (Kellogg, 2015; Sternberg & Sternberg, 2011).
CONTRIBUTIONS TO MEANING- MAKING	Emphasises the unique, subjective meaning experience, individual choice and responsibility (Jacobsen, 2008). Emphasises meaning making through reflection and self-transcendence (Wong, 2017b) using the creative, experiential and attitudinal pathways.	Emphasises the importance of self-transcendence and authentic self-identity (Wong, 2009) and the building of capacities for resilience and positive change (Fredrickson, 2001; Wong et al., 2021). Wong (2014a) suggested that meaning making can be understood through the concepts of motivation, cognition, spirituality and enjoyment of a meaningful life. Wong thus encompassed the reflecting, evaluating and comprehending components of meaning making.	Meanings are the cognitive categories that make up one's view of reality (Chen, 2001). Meaning is made through reappraisal (Park & Folkman, 1997) and restructuring (Osin et al., 2016).
PROMINENT SCHOLARS IN THIS STUDY	Frankl, Yalom and May	Wong	Baumeister, Antonovsky, Steger and Park
SIMILARITIES AND COMMONALITIES WITH FRANKL'S PRINCIPLES	All three scholars articulated the importance of creativity (Frankl's creative value or pathway) in meaning making. For all three scholars, meaning making is constructed naturally and purposefully through relationships and love, emphasising Frankl's experiential value and	Wong et al (2021) proposes that self-transcendence has become the foundation of existential positive psychology. Similar to Frankl, Wong (2016a, 2020) also emphasised the focus on the search for meaning and purpose.	Baumeister and Frankl both regarded purpose and value as part of the meaning-making process. Baumeister also highlighted the significance of interpersonal relationships, similar to Frankl's experiential value.

	Existential psychology (EP)	Existential positive psychology (EPP)	Cognitive psychology
	self-transcendence. Self-transcendence is relational in that vertically one connects spiritually with a Higher Being, and horizontally one transcends to serve others (Wong, 2014b). All three scholars also agreed that anxiety leads to meaning making and people have a choice about how they respond in a given situation. Frankl, Yalom, and May stated that being responsible contains aspects of freedom and will, thus placing the emphasis on the spiritual and attitudinal value.	In accordance with Frankl, Wong (2014b), also underscored value-driven and situation-specific, responsible action, thereby concurring with Frankl's view on the creative and attitudinal pathways. EPP also emphasises the need for maintaining authentic relationships (Wong, 2016a) in accordance with Frankl's experiential value.	- Antonovsky's four areas, namely emotions, the major field of activity, interpersonal relations and existential questions, are closely related to Frankl's meaning- making pathways. - Steger (2018) proposed the following three facets of meaning in life: working towards something creatively; comprehending and making meaning of one's experiences; and one's attitude of valuing life as being significant. These are similar to Frankl's pathways. - Meaning making, according to Frankl (2008), is a spiritual drive for self-transcendence, which is comparable to Park's (2013, 2014) belief that spirituality gives drive and a sense of purpose.
FRANKL'S CONCEPT RELATING TO EP, EPP and COGNITIVE PSYCHOLOGY	Frankl's two-factor theory of self-transcendence contains a motivational and cognitive factor.		
	Motivational: The importance of self-transcendence in discovering meaning (Osin et al., 2016) is emphasised in EP and EPP. The will to meaning is the motivation to make meaning (Wong, 2016d). Spirituality is seen as the vehicle through which meaning is sought (Cornah, 2006; Frankl, 2008), and Frankl (2008) underscored the spiritual motivation for self-transcendence that is found through the creative, experiential and attitudinal pathways.		Cognitive: - Frankl's attitudinal value of meaning making is linked to the cognitive restructuring of a situation (Osin et al., 2016) and the cognitive component of spirituality is the drive to act towards a sense of purpose (Park, 2013, 2014). - The cognitive factor (of Frankl's two-factor theory) has the adaptive value of making sense of life (Wong et al., 2021).

From Table 3.2, it is evident that despite the variety of views on the concept of meaning making, there are clear similarities in all the perspectives with the basic principles in Frankl's meaning-making theory. To further highlight the similarities between the existential and cognitive theorists' perspectives on meaning making, Table 3.3 below correlates the definitions of the existential and cognitive perspectives that I found to be most aligned with Frankl's theory and the three meaning-making pathways.

Table 3.3

Correlates with Frankl's Meaning-Making Pathways

Frankl's meaning-making pathways	CREATIVE	EXPERIENTIAL	ATTITUDINAL
	By creating a work or doing a deed (creative value)	Experiencing something or encountering someone (experiential value)	Attitude towards unavoidable suffering (attitudinal value)
Existential meaning-making perspectives			
Kaufman (2018)	▪ individuals use a cognitive process of coherence in the past pathway of creativity; ▪ in the present pathway of creativity they use positive psychological methods to increase self-worth; and ▪ in the future pathway of creativity, individuals engage in the existential domain by creating a legacy after death		
Eisenbeck et al. (2022): meaning is found in:	the appreciation of life as it is (creative value)	one's responsible action towards self and others (experiential value);	and an adaptation of an attitude of hope and courage (attitudinal value).
Pattakos & Dundon (2017a): three elements for finding deeper meaning:	engage with deeper purpose (P);	connect meaningfully with others (O);	and embrace life with attitude (A).
Cognitive meaning making			
Martela & Steger (2016)	Purpose component of meaning = having a goal or aim that gives purpose to	Coherence component of meaning = making sense of the experiences in	Significance component of meaning = evaluating whether one's life is

Frankl's meaning-making pathways	CREATIVE	EXPERIENTIAL	ATTITUDINAL
	one's life (motivational component)	one's life (cognitive component)	valuable and worthy (evaluating component)
Antonovsky's (1987) meaningfulness component of SOC	Meaning is found in one's major field of activity (work), that is, what one does	Meaning is found in the interpersonal relationships that one experiences	Meaning is found in resolving existential questions or crises
Baumeister's (1991) need theory	Need for purpose and value creates meaning	Need for interpersonal relationships that support the need for respect from others	The need for efficacy is defined as one's interpretation or perception of situations as producing the desired result.
Self-determination theory (Ryan & Deci, 2000a) = an attitude towards creating self-meaning.	The need for competence	The need for relatedness	The need for autonomy

There is also wide consensus about meaning making being necessary in the individual's adjustment to a stressful event (Frankl, 1985; George & Park, 2017; Gillies & Neimeyer, 2006; Janoff-Bulman, 1989, 1992; Park & George, 2013) such as living with a CD (Clur, 2015; Jacobi & MacLeod, 2011; Sloan et al., 2017). The way in which people make meaning of their disease and other life events influences their wellbeing and quality of life (Affleck et al., 1987; Cohen et al., 1996; Dezutter et al., 2013; Park, 2010; Ryff, 2018; Seligman, 2011; Sprangers, 2015; Van den Heuvel et al., 2009; Van der Spek & Verdonck-de Leeuw, 2017; Wong, 2012a). In the next section, I conclude with an integrative conceptualisation of meaning making.

3.7   MEANING MAKING: AN INTEGRATIVE CONCEPTUALISATION

In this chapter, I grounded meaning making in both the existential and cognitive perspectives (Slattery & Park, 2011; Wong 2017a). According to Wong (2017a), although there is a difference between cognitive and existential meaning, they do in

fact interact. This is evident from the conceptual integration in Table 3.2. From an existential perspective, those experiencing an existential crisis will reflect on existential issues and engage in existential exploration (Wong, 2017a). Meaning, in the existential domain, involves individuals tending to see reason and purpose in their personal experiences (Bering, 2003). The existential approach is concerned with individuals' understanding or interpretation of their existence, which has a personal and social side, in order to make meaning (Gustavsson, 2020). Using their cognitive capacity, individuals mobilise the available abilities and resources to make meaning (Boehmer et al., 2016; Wong, 2017a).

Meaning, according to the cognitive view, entails individuals restructuring a situation (Osin et al., 2016) by means of awareness (Frankl, 2008) and evaluation (Osin et al., 2016). Meaning making always implies decision making (Frankl, 1966) based on cognitive processes such as perception, attention and memory (Prezenski et al., 2017). In summation, meaning making, according to the existential approach, entails reflection (Wong, 2017b), and according to the cognitive view, it involves restructuring (Osin et al., 2016). Both imply that meaning making includes an intrapersonal (internal) and an interpersonal (relational) component, which is conceptualised by emphasising the intrapersonal processual nature (reflection/restructuring) of the phenomenon in an interpersonal context. My synthesis of these dynamics is depicted in Figure 3.1 and presents an integrative conceptualisation of meaning making, which I developed following my literature review of the concept.

Figure 3.1

A process-driven conceptualisation of meaning making based on the integration of existential and cognitive perspectives
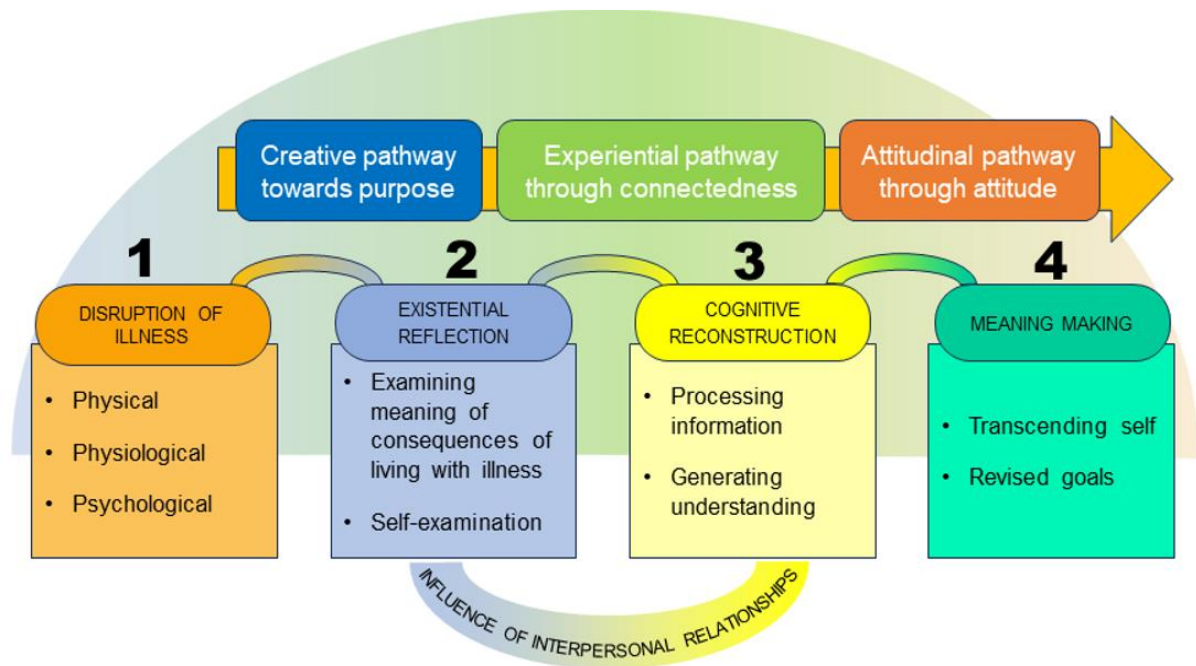
Firstly, Figure 3.1, as noted by Bury (1982), depicts the biological disruption that an illness causes in an individual's life on a physical, physiological and psychological level. Such a life-changing disruption justifies the need to transcend the terrible reality and revise one's life goals – that is, the change is the motivation for a need for meaning making (last block in Figure 3.1). Secondly, as depicted in Figure 3.1, in moving towards meaning making, people engage in existential reflection, because they tend to reflect more deeply on existential concerns, such as the meaning and purpose of their life, when faced with a disruption in life like a diagnosis of a CD (Ownsworth & Nash, 2015; Van Deurzen, 2010). The reflection of individuals' experience and understanding of themselves at the level of being is the main subject of existential viewpoints. People furthermore (third box in Figure 3.1) use cognitive processing to generate their own understanding to make meaning while living with a CD.

At the point of reflection and cognitive restructuring, Figure 3.1 denotes how these two processes of making meaning are relational. One's relational engagement is a crucial component of existential reflection on the uncertainty and existential questions that a CD diagnosis brings. People with chronic illnesses engage in ongoing negotiations with society in order to make sense of their situation (Leys, 2010). Support from a

social network is essential during the reflection stage and is used to strengthen the sense of self and provide emotional and instrumental support (Fernández-Peña et al., 2020). Interpersonal relationships are also vital at the point of cognitive restructuring. People evaluate their perspectives on meaning making through their social connections during the cognitive process of learning and experimenting (Whittemore & Dixon, 2008).

Reflecting on existential challenges and restructuring one's perspectives of the self in relation to the other necessitate utilising the creative, experiential and attitudinal pathways towards transcending the self and revising one's goals. During the existential reflection and constructive reconstruction phases, individuals use the three pathways in various ways, as shown by the use of interpersonal relationships (the experiential pathway) through both the reflective and restructuring phases. The attitudinal pathway is furthermore ever-present in the meaning-making process in the sense that individuals' attitudes in adversity influence how they interact (experiential pathway) and will react, which involves the use of the creative pathway when individuals act towards a purpose.

The themes of reinterpreting, reappraising, adjusting, restructuring, re-evaluating, reassessing and transforming are widely used in the meaning-making literature, indicating that some sort of change has to take place. When confronted with a difficult situation and unable to change it, Frankl (2008) proposed that the challenge is to make changes within oneself, which is consistent with identity continuity (Erikson, 1994), suggesting that individuals will engage in various activities to maintain a personal sense of continuity. Chronically ill people strive to restore or repair the loss of self-identity (Charmaz, 1994, 1995) by mobilising cognitive processes such as acceptance and normalisation (Bury, 1991) in order to maintain meaning in their lives (De Siqueira, 2018). The combination of cognitive processes as well as people's motivational ways can be helpful in understanding how PwCD reconstruct their self-identity (Stets & Burke, 2000). It remains a uniquely challenging process for those living with a CD because chronic illness is in effect an unchangeable part of living, and identity is not something to be achieved or completed; it is a constant process that involves reflecting on one's place in the larger scheme of things (Fereirra & Ferreira, 2019).

3.8   CHAPTER SUMMARY

The purpose of this chapter was to explore meaning making from the perspectives of existential, existential positive and cognitive psychology. Within these paradigms, theories relating to meaning making linked to illness experiences were explored, and Frankl's meaning-making principles highlighted and elaborated on. The chapter concluded, firstly, with a conceptual integration, summarising the different perspectives on the meaning-making concept as visualised in Table 3.2 and 3.3. These visuals constitute the conceptual meta-theoretical lens for the data analysis. The conceptual integration achieved the purpose of aligning different perspectives and theories to Frankl's meaning-making theory and principles, highlighting the latter as a central and foundational understanding of the meaning making concept. Secondly, an integrated conceptualisation of meaning making was presented. This conceptualisation of depicts meaning making as an intrapersonal process dynamic that follows a diagnosis of a CD. The process dynamic in making meaning entails existential reflection and cognitive restructuring in the context of a relational self and through the use of creative, experiential and attitudinal pathways towards transcending the self and revising one's goals in life. The next chapter focuses on meaning making while living with a CD in the work context.

CHAPTER 4
MEANING MAKING OF THE PERSON WITH CHRONIC ILLNESS IN THE WORK CONTEXT

4.1   INTRODUCTION

Meaning making is a psychological process that encompasses a thorough internal exploration of an issue of concern (Van den Heuvel et al., 2009), for example, dealing with changing life circumstances (Linley & Joseph, 2004; Reker et al., 1987; Tedeschi & Calhoun, 1996) such as living with a CD. The workplace is an important environment for meaning making (Steger et al., 2009) because it is a place of engagement (Cameron et al., 2003) where people develop (Steger & Dik, 2009) and spend most of their time (Van Zyl et al., 2010). Meaning making in the work context is related to positive employee outcomes like positive attitudes, motivation, work engagement and enhanced performance (Van den Heuvel et al., 2009). Meaning, engagement and commitment are crucial for optimal workplace functioning and emphasise the role of work as a motivator (Chalofsky & Krishna, 2009). The notion of work, for this study, encompassed both paid and unpaid (e.g. volunteering), as well as entrepreneurial and self-employment efforts (Pattakos & Dundon, 2015).

In this chapter, the meaning making of employees with chronic illness in the workplace is discussed in order to illustrate the impact that various factors in the workplace have on meaning making while living with a CD. Meaning making in the work context is explained by distinguishing between finding meaning in work and meaning making at work. Thereafter, the workplace as a domain of meaning making, the career effects of chronic illnesses, the organisation's role in managing employees with CDs and strategies to improve meaning making at work are discussed. Lastly, an integration of Frankl's principles as applied in the work context, self-determination theory and the OPA meaning-centred formula are explained.

4.2 MEANING MAKING IN THE WORK CONTEXT: MEANING IN WORK VERSUS MEANING AT WORK

In this section, my conceptual understanding of meaning making in a work context is explained, which entails clarifying the concepts of meaning in and meaning at work. According to Martela and Pessi (2018), there has been an increase in research on meaningfulness pertaining to work-related motivation and wellbeing. The above authors (2018) do, however, highlight the fact that many researchers have claimed that the main concept of meaningful work is vague, which may inhibit progress and the direction of research in the field. It is therefore vital that the concept of meaning in relation to one's study is clarified (Tommasi et al., 2020).

According to the aim of this study, meaning making of PwCD is explored through the lens of Frankl's principles and in the context of work and working. Frankl (1970) defined meaning as a unique experience that can be discovered and created in a variety of life situations. Meaning serves a number of key functions in human life. It creates a sense of purpose and self-worth, raises awareness of values and gives one a sense of overall control (Frankl, 1992b). To avoid confusion about how I have approached meaning making in the work context in this study, I have distinguished between the concepts of meaning in work and meaning at work in order to illustrate meaning making in the workplace in the context of Frankl's principles.

4.2.1 Meaning in work

Pratt and Ashforth (2003) posited that striving towards meaningfulness in work has to do with the job itself and relates to Frankl's notion of creative values. The creative values are related to the contribution (Shantall, 2020) and engagement (Mengel, 2021) in creating (Arfian et al., 2020) something meaningful, such as in work activities (Devoe, 2012). According to Burger et al. (2013), except for the creative values, one's attitude (attitudinal values) is crucial in making meaning in work. In this regard, Frankl (2019) asserted that it is the attitude, the manner, in which one engages with work that counts.

Making meaning in work encompasses concepts such as job involvement and flow, which leads to increased work engagement and is therefore associated with motivation and commitment (May et al., 2004; Markow & Klenke, 2005; Pattakos & Dundon,

2017a; Engelbrecht & Schlechter, 2006). Meaningful work, according to Steger (2017), is any work or occupational role, whether paid or unpaid, that people occupy, which for them has meaning, significance or purpose. Work that is deemed significant might contribute to a person's overall sense of meaning (Burger et al., 2013; Martela & Pessi, 2018; Steger et al., 2010; Ünal & Turgut, 2017). Furthermore, finding meaning in work can lead to greater wellbeing and job satisfaction (Russo-Netzer et al., 2020; Steger et al., 2012). When employees find meaning in work, they engage in organisational citizenship behaviours (prosocial behaviours), which include taking on extra roles without remuneration to the benefit of others and the organisation as a whole (Harper, 2015; Mitonga-Monga, 2019; O'Grady, 2018). This may include helping co-workers with work and taking on a mentoring and coaching role for co-workers (Chamisa et al., 2020; Harper, 2015). Finding meaning in work relates to the subjective experience of finding work meaningful and purposeful (Both-Nwabuwe et al., 2017; Martela & Pessi, 2018), and therefore means that one finds meaning in engaging in the work itself.

4.2.2 Meaning at work

Finding meaning at work is dependent on an individual's internal motivation (Pattakos & Dundon, 2017a). While it is drawn from membership in the workplace (Alexander & Douthit, 2016), finding meaning at work relates to how meaning is derived from other factors over and above the work itself. Meaning at work, according to Pratt and Ashforth (2003), is found through Frankl's experiential values, one's sense of belonging, which implies interpersonal relationships, and interactions in the work context. According to Pattakos and Dundon (2017a), people want to be part of the work community. They posited that meaning making at work occurs in the context of how this community interacts each day. It is within this community that individual feels valued. The meaning that PwCD find at work involves, inter alia, being part of the work community (Pattakos & Dundon, 2017a), experiencing social interaction (Saunders & Nedelec, 2014; Vooijs et al., 2018) and being able to make a valued contribution (Vooijs et al., 2018).

Meaning in the work context (in work and at work), according to the existential perspective, can be found through experiencing a sense of completeness and coherence (Lips-Wiersma & Wright, 2012). For the purpose of this study, meaning

making of PwCD in the work context included the terms "meaning in" and "meaning at work" respectively, because together they encompass Frankl's three pathways of meaning making. Meaning making in the work context is elaborated on next, with a specific focus on its importance for PwCD.

4.3   THE WORKPLACE AS A DOMAIN OF MEANING MAKING

Since this study was conducted within the discipline of IOP, studying meaning in the work context was necessary. Many studies have shown that meaning making has a significant value in the workplace (Burger et al., 2012, 2013; David & Iliescu, 2020; Lysova et al., 2019; Park & George, 2013; Van Zyl et al., 2010). In this section, the importance of studying meaning in the work context is highlighted.

The organisation is an open system comprising structures, processes and people, all providing inputs into the system (Amagoh, 2016; Kast & Rosenzweig, 1972; Turner & Baker, 2019). In the continually changing work environments and societies, it is necessary to understand and manage cultural and personal diversity among employees (Bergh & Geldenhuys, 2013). According to Beatty and Joffe (2006), PwCD are a diverse group that experience distinct issues and have specific needs. The increasing number of PwCD leads to a quest for a better understanding of the impact CDs have on individuals' wellbeing, both in their private and work lives. Meaning making has been found to be relevant to the psychological wellbeing of PwCD (Dezutter et al., 2013; Krok, 2015). Hence individuals, organisations and society would benefit from knowing how PwCD make meaning. In this section, meaning making in the work context is discussed by first describing the importance of work participation for PwCD. The role of motivation is then discussed, including a view of significant work-related motivational constructs in meaning making.

4.3.1   The importance of work participation for people living with chronic diseases

Work is more than just making money (Dijkema & Gunderson 2019). It is deemed a source of self-worth (Isaksson et al., 2016), a method to be part of and contribute to society (Andersson, 1992; Peteet, 2000; Vooijs et al., 2018) and a way to address one's own societal needs (Jones et al., 2017; Saunders & Nedelec, 2014). Work can thus be deemed to play an essential role in people's lives, contributing to their sense

of self-worth and overall life satisfaction and happiness (Barnett & Baruch, 1985; Coetzee et al., 2010; Gerstein & Papen-Daniel, 1981; Holahan et al., 1999; Nejad & Nejad, 2022; Peteet, 2000).

People can regard their employment as a job if they focus on the monetary benefits; a career if they concentrate on the rewards; or a calling if they emphasise the spiritual benefits (Bellah et al. 1985; Wrzesniewski et al., 1997). Work is a basic means for people to fulfil themselves (Buchholz, 1978) and how they view and experience their work is crucial to their identity and survival (Bothma et al., 2015). Morse and Weiss (1955) conducted a seminal study on the meaning of work in the 1950s, concluding that work entails having a purpose, accomplishing something and expressing oneself. Bryce (2018) found that work improves eudaimonic wellbeing (a sense of meaning and purpose). Work is a vital component of people's lives because it allows them to stay connected to their community, retain their skills and grow professionally (Peteet, 2000; Silvaggi et al., 2020).

PwCD regard participation in work as an indication of a sense of normalcy and hope (Peteet, 2000) in that their everyday life has been restored (Detaille et al., 2003; Lilliehorn et al., 2013). Work has value for PwCD because of its positive impact on their physical and mental health (Vooijs et al., 2018). Work plays an essential role in people's identities (Christiansen, 1999; Fryers, 2006; Nagy et al., 2017; Walker, 2010) because they find identity in and are identified by their work (Beatty & Joffe, 2006; Gini, 1998; Nagy et al., 2017). Christiansen (1999) posited that a job entails being a specific person and, as such, helps to define and sustain one's identity. Work identity, according to Christiansen (1999), provides the context for meaningful lives. Living with a CD causes an undesired disruption that affects both the individual's physical and psychological wellbeing (Bury, 1982). This has an impact on a person's self-esteem (Charmaz, l983). A working person's professional identity may be shattered as a result of health-related issues (Beatty & McGonagle, 2016). Because one's job identity is intertwined with other aspects of one's identity (Beatty & Joffe, 2006), this disruption necessitates various levels of identity alteration (Asbring, 2001), resulting in positive self-reconstruction (Karnilowicz, 2011; Whitehead, 2006).

In sum, working is beneficial to PwCD because it is restorative in that it aids in the healing process and improves health outcomes (Waddell & Burton, 2006). It supports

social connectedness and the maintenance of skills and professional development (Silvaggi et al., 2020). Having a job encourages independence and helps people to define and sustain their identity (Christiansen, 1999) as such, preserves human dignity (Waddell & Burton, 2006), assist them to be financially self-sufficient (Vooijs et al., 2018) and improve their overall quality of life (Waddell & Burton, 2006). It is evident that work is a vital source of meaning in people's lives and employers should implement strategies for the integration of PwCD into the workplace (Foitzek et al., 2018).

Goldman (2017) recommended that the emphasis should fall on adjustment in the workplace and not on making special arrangements to accommodate the individual with a CD. Meaning making in the work context is essential to employee motivation, performance and wellbeing (Mayfield & Mayfield, 2018). Hence motivation, cognitive evaluation theory and SDT as self-directed behaviour, and lastly, prosocial behaviour in relation to meaning making are also elaborated on in this section.

4.3.2   Motivation and meaning making

Motivation is derived from the Latin term *moveo*, which means to move (McCoach & Flake, 2018). The concept of being moved to action is emphasised in definitions of motivation (McCoach & Flake, 2018) and motivation is guided by meaning (Leontiev, 2012). According to Leontiev (2012), meaning making is linked to needs and values. Motivation is the driving force by which individuals achieve their goals (Mullins, 2002; Seifert et al., 2012), fulfil their needs or uphold their values (Mullins, 2002).

Motivation for PwCD, according to Golay et al. (2007), is more complex than simply meeting current needs (in the present), as they also choose plans to be or do something (in the future) that is value driven, which leads them in a specific direction. People seek meaning because they are spiritual beings, and the will to meaning indicates that individuals have the spiritual drive to pursue self-transcendence (Frankl, 1969; Wong, 2014b). Self-transcendence, according to Frankl, is a main motivation characterised by transformation. This transformation includes a shift in attention from the self to others, a shift in values from extrinsic to intrinsic motivation, a rise in moral concern about doing the right thing and the sensation of wonder that inspires others (Wong, 2017c). The three values, namely creative, experiential and attitudinal, are the

three avenues to fulfil the will to meaning and self-transcendence (Frankl, 2008; Wong, 2014b). According to Frankl, self-actualisation can only be achieved by satisfying the spiritual urge for self-transcendence (Wong, 2014b). Self-actualisation is possible because of self-transcendence (Frankl, 2008; Wong, 2021).

However, Maslow regarded self-actualisation as a motivational level to strive for. For Maslow, people seek fulfilment and change through personal growth (McLeod, 2020). Maslow's hierarchy of needs is arguably the most popular motivation theory (Dye et al., 2005; Gambrel & Cianci, 2003; Koltko-Rivera, 2006; Van den Broeck et al., 2019). Maslow (1943) claimed that when needs at the bottom of the hierarchy are met, the needs higher up the hierarchy are triggered. The motivation to meet these needs grows stronger the longer they are unfulfilled. Frankl found, contrary to Maslow, that although the basic needs of people are not fulfilled, they still search for meaning. Maslow (1987) subsequently emphasised that the order of needs may be flexible, depending on external circumstances or individual characteristics. Maslow (1966), however, agreed with Frankl that the will to meaning is the most powerful drive in people. Maslow's later work (Maslow, 1969a) and private journal entries (Maslow, 1979, 1982), according to Koltko-Rivera (2006), included self-transcendence in his hierarchy of needs, which is a more accurate version of the hierarchy. The principles that urge people to transcend beyond their personal self are known as transcendence needs (McLeod, 2020). Figure 4.1 below is an updated version of Maslow's hierarchy of needs.

Figure 4.1

Revised Maslow's Hierarchy of Needs Model

Physiological needs	Attempts to acquire the basics of life
Safety needs	The need for safety and security
Belongingness and love needs	Interpersonal relationship needs
Esteem needs	The desire for self-esteem and respect from others
Self-actualisation	Seeking self- fulfilment
Self-transcendence	Needs that go beyond the self

Source: Adapted from Koltko-Rivera (2006, p. 303)

The fact that self-transcendence is placed at the top of Maslow's motivational hierarchy of needs emphasises that it is preceded by self-actualisation. Maslow's hierarchy of needs regarding work roles, according to Gyansah and Guantai (2018), begins at the third level of belongingness and love needs, which refer to becoming a member of the work environment and end at the esteem needs level, where one obtains status at work and creates a career. At the level of self-actualisation, one works to realise one's own potential, whereas at the level of self-transcendence, one puts one's own needs aside for the benefit of others, a cause outside of oneself, or a higher

force (Koltko-Rivera, 2006). In Figure 4.2, the link between Frankl's values and Maslow's adapted motivational hierarchy of needs is represented in relation to living with a CD.

Figure 4.2

The linkage of Frankl's values and Maslow's needs in relation to living with a CD
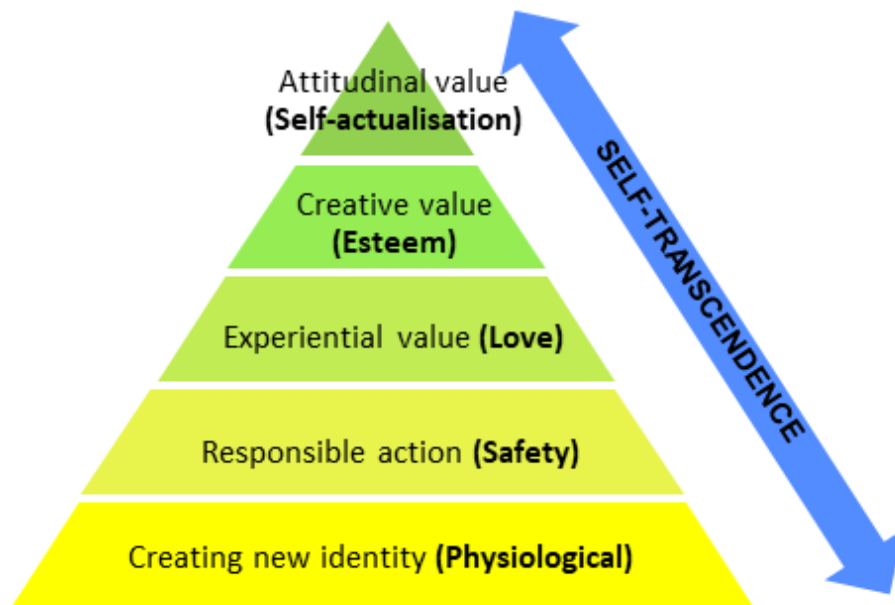
Source: Adapted from Dezelic & Ghanoum (2014)

The overlap between Frankl's values and Maslow's needs hierarchy, which is depicted in Figure 4.2, however, is simply illustrative, because Frankl's values do not fit into a hierarchical format and meaning-making opportunities do not occur in sequential order (Dezelic & Ghanoum, 2014). Maslow's physiological needs are perceived to also coincide with a' person's existential considerations about the new illness identity. The challenges and demands of life that individuals with one or more CDs face are tied to their safety needs. According to Frankl, there are three pathways to meaning making, that is, creative value, which is linked to Maslow's esteem need, experiential value, which is linked to Maslow's need for love and attitudinal value, which is linked to Maslow's idea of self-actualisation. In conclusion, all of Frankl's meaning-making opportunities lead towards the spiritual dimension of self-transcendence, whereas Maslow indicates self-transcendence as a separate level at the top of the motivational hierarchy.

The self-determination hypothesis, however, argues that basic psychological needs are innate – hence its focus on need fulfilment rather than need strength (Van den Broeck et al., 2016). Maslow believed that the strength of one's needs is a predictor of one's happiness and ability to function. Despite adversity, Frankl (1966) contends that people are self-determined to rise above their circumstances through their will to meaning. Self-determination theory (SDT) assumes that all three needs should be met in order to experience good health and wellbeing (Gomez-Baya & Lucia-Casademunt, 2018; Ryan & Deci, 2000a; Visser, 2020). A growing number of studies focus on the application of SDT to health-related behaviour change (Eassey et al., 2020; Karlsen et al., 2018; Koponen et al., 2018; Patrick & Williams, 2012; Ryan & Deci, 2007; Ryan et al., 2008). Hence SDT's applicability to making meaning while living and working with a CD is also relevant to this research. Self-determination theory (Legault, 2017; Patrick & Williams, 2012) is a crucial meta-theory of human motivation that includes various mini-theories that are distinct but conform to the same essential notions (Krettenauer & Curren, 2020; Legault, 2017). Cognitive evaluation theory is addressed next, as one of the mini-theories and antecedents of SDT, coupled with an explanation of SDT in demonstrating how PwCD's motivation is influenced by meaning.

4.3.2.1 *Cognitive evaluation theory*

The contrast between intrinsic and extrinsic motivation is the basis of cognitive evaluation theory (CET), which is a forerunner of SDT (Deci, 1975; Vansteenkiste et al., 2006). CET is a theory of intrinsic motivation that explains how external forces influence internal motivation (Deci & Ryan, 1985). Intrinsic motivation is driven by internal rewards that are naturally satisfying (Deci, 1975) with the tendency to capture a person's interests and abilities and thus to seek and overcome challenges (Deci & Ryan, 1985). People who are intrinsically motivated are motivated simply to perform the activity (Deci et al., 1996). By contrast, extrinsic motivation is driven by external rewards (such as pay) or efforts to avoid punishment (Ryan & Deci, 2000b; Lepper et al., 2005). CET examines how external forces alter internal motivation while focusing on competence and autonomy (Deci & Ryan, 1985). Ryan and Deci (2008) differentiated between autonomous motivation, which comes from internal sources, and controlled motivation, which stems from external regulation (Ryan & Deci, 2008). It is proposed that extrinsic rewards for something that was previously seen as intrinsically rewarding tend to decrease overall motivation (Odendaal & Roodt, 2009).

Self-concordance is an extension of CET, according to Odendaal and Roodt (2009), which implies that people's motivations for pursuing goals are aligned with their interests and basic beliefs. This means that employees opt to accomplish something for reasons other than extrinsic incentives, and companies must offer both intrinsic and extrinsic motivations (Odendaal & Roodt, 2009). Furthermore, according to CET, the social context has a significant impact on intrinsic motivation (Ryan & Deci, 2000a; Fang et al., 2013) because it can help or hinder intrinsic motivation by supporting or obstructing people's basic psychological needs (Ryan & Deci, 2000a).

The needs of competence and autonomy are at the core of CET. According to Deci and Ryan (2000), rewards might have two components: one that regulates people's behaviour and so interferes with their autonomy, and another that increases people's perception of competence. Rewards that are perceived as controlling can undermine intrinsic motivation. However, if the reward supports an individual's feelings of competence, it may maintain or enhance intrinsic motivation (Ryan & Deci, 2000a).

Clur (2015) found that PwCD expressed a need for autonomous motivation in the form of the development of self-efficacy and personal control (autonomy) in the work context. In the work environment, this can be explained by using the example of being asked to mentor someone, which can boost autonomy (personal freedom to decide how to mentor) and a person's self-worth and efficacy (thus a feeling of competence), which all result in self-determination (Kennet & Lomas, 2015).

To summarise, the psychological meaning of an event for an individual determines its impact on motivational processes (Deci & Ryan, 1985; Legault, 2017). One of the numerous ways organisations can provide autonomy support and promote employees' competence is to afford them options and opportunities for self-direction (Slemp et al., 2018), thus helping them to make meaning in the workplace. While CET addresses the social and environmental factors that facilitate versus undermine intrinsic motivation, SDT asserts that the source of intrinsic motivation is an innate pattern of development and assimilation (Ryan & Deci, 2000a), which is the next topic of discussion. While CET focuses on the social and environmental elements that help or hinder intrinsic motivation (Riley, 2016), SDT claims that intrinsic motivation is derived from an inherent pattern of growth and integration (Ryan & Deci, 2000a). SDT will be explored next.

4.3.2.2   Self-determination theory and its role in meaning making

Self-determination explains how the satisfaction of one's needs and intrinsic motives facilitates thriving (Bauer et al., 2019; Ryan & Deci, 2000a). Autonomy (exercising one's free will), competence (a sense of efficacy) and relatedness (interpersonal interactions) are the three basic psychological needs underpinning SDT (Deci & Ryan, 2012; Smeets et al., 2019). In SDT, the emphasis is on the role of these basic psychological needs in self-determined motivation, wellbeing and growth (Deci & Ryan, 2012; Legault, 2017; Ryan & Deci, 2000a, 2017). In other words, it is about a person's orientation and interaction with the social environment (Legault, 2017).

People's senses of autonomy, competence and relatedness are constantly tested psychologically and emotionally (Eassey et al., 2020). Encounters with difficult events such as ill health, may lead to questions about life's meaning (Bauer et al., 2019). To cope with some specific issues regarding one's health, people can take an active role in satisfying the needs of competence, autonomy and relatedness (Migliorini et al., 2019). Workers who are confronted with health decline are likely to be value driven (Briscoe et al., 2006), less likely to be extrinsically motivated and more motivated to act autonomously (Ryff, 1995), thus showing the need for intrinsic motivation.

Smeets et al. (2019) suggested that addressing the three needs could lead to finding meaning in the work context for employees with illnesses and can be demonstrated as follows: The need for autonomy is to feel free to act out of one's own self and could be satisfied by involving employees in self-directing their work process. In other words, it is the need to feel empowered and in charge of one's own life (Eassey et al., 2020), which is illustrated through Frankl's attitudinal values. The need for competence of the employee with a CD could be satisfied by developing new skills and feeling in control of the environment by making adaptations and arrangements in the workplace (Van den Broeck et al., 2016) as emphasised by Frankl's creative values. The need for relatedness or connectedness refers to the emotional dimension of living with a CD (Eassey et al., 2020; Turner & Kelly, 2000). This need may be satisfied when an employee perceives personal and social support from colleagues and other stakeholders in the workplace (Smeets et al., 2019). Bryce (2018) asserted that working conditions that support good relationships with colleagues and stakeholders or facilitate autonomy or personal growth will generate higher experiences of

eudaimonic wellbeing. People with CDs also turn to spirituality for a sense of relatedness in which they feel supported and cared for (Eassey et al., 2020; Büssing & Koenig, 2010). This need for connectedness is demonstrated by means of Frankl's experiential values.

The employee with a CD makes meaning in the internal work environment by means of the creative, experiential and attitudinal pathways towards self-transcendence. The conditions of autonomy, competence and relatedness within self-determination theory (Deci & Ryan, 2000) are instrumental in meaning making. These conditions relate to Frankl's principles (2008), as discussed, and as depicted in Figure 4.3 below.

Figure 4.3

Relationship between SDT and Frankl's Principles
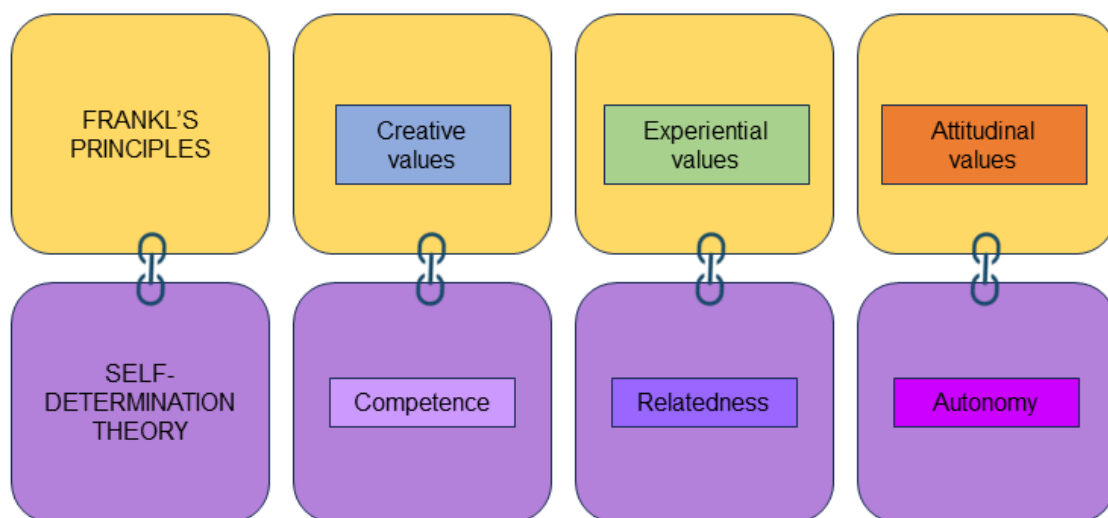
In conclusion, in the work environment, competence means engaging with deeper purpose, using one's creativity at work and finding a link between one's own and organisation's overall purpose, which could help to make meaning for oneself and lead to personal growth. Relatedness means connecting meaningfully with others; it is the experience of encountering someone or something that emphasises how one interacts with others in one's relationships at work that can provide meaning. Autonomy is the freedom of will to choose to embrace life with an attitude that demonstrates the attitudinal value that is the foundation of resilience and one's outlook on life. These principles are integrated in the way in which employees with CDs manage and negotiate their career paths. By embracing a broader perspective and being more

flexible, one can improve one's resilience and recover from setbacks or challenges more effectively (Pattakos & Dundon, 2017a).

It would appear that addressing the three SDT needs contributes to enhanced motivation and improved health outcomes (Ryan & Deci, 2017), and leads to enhancement of eudaimonic wellbeing, which relates back to meaning and self-fulfilment (Ryan & Deci, 2001) in the workplace. In adjusting to living with a CD, one can make meaning and thus find fulfilment through one's creative potential of self-determination (De Siqueira, 2018; Frankl, 2015).

4.4   THE EFFECT OF CHRONIC ILLNESS ON THE INDIVIDUAL'S CAREER

The symptoms of illness lead to physical, psychological and emotional changes that affect the sense of self (Beatty & Joffe, 2006). Living with a CD can cause a reassessment of the self, one's identity and life goals, which is followed by self-transformation (Beatty & Joffe, 2006). Smedema et al. (2009) described this as a psychosocial adaptation process where the illness is integrated into the individual's life, which encompasses his or her identity, body and self-image. In Chapter 3, Section 3.7, the issue of self-image challenges was discussed and, inter alia, how CDs influence people's identities and ways to integrate living with the CDs into their identities. Beatty and Joffe (2006) accentuated the interweaving between aspects of a person's identity and work. It is clear that one's identity is crucial in deciding on a career path and advancing in it (Beatty & Joffe, 2006; Smedema et al., 2009).

4.4.1   Career development for people with chronic illnesses

Chronic disease, according to Beatty and Joffe (2006), impacts one's career path by affecting one's abilities, priorities and long-term outlook. Individuals with a CD do not exist in isolation but are part of a larger social context in which having a CD might result in stigma, which most people want to avoid by concealing their illness. When PwCD accept this devalued status as a result of their condition, they develop a stigmatised identity (Fitzgerald & Patterson, 1995; Idemudia et al., 2018; Millen & Walker, 2001; O'Donnell & Habenicht, 2022; Walker, 2010). People with a CD may be hesitant to report their disease at work for this very reason, and also because complete disclosure may enable others to judge their ability in the job (Beatty, 2018; McGonagle

& Barnes-Farrell, 2014; Walker, 2010). Chronic illnesses vary in their progression; some progress swiftly, while others take longer (Beatty & Joffe, 2006). Some illnesses, such as cancer and heart disease, have sudden diagnoses and symptoms that necessitate an immediate re-evaluation of goals (Beatty & Joffe, 2006). Hence the transition from a healthy to an ill identity might be sudden or gradual (Van Bulck et al., 2019). In cases where a gradual identity shift occurs, the person creates a new self in response to the daily challenges of the illness (Beatty & Joffe, 2006).

Career growth occurs in stages and is influenced by personal and professional issues (Beatty & Joffe, 2006). In his life-stage developmental theory, Super (1957) focused on the development and implementation of one's self-concept in career choice and development. Life-stage models of adult development suggest that each stage of life has psychological issues to be resolved and helps to explain this readjustment process of the individual with a CD (Beatty & Joffe, 2006). Super (1990) proposed a life-stage developmental framework with the stages of growth, exploration, establishment, maintenance (or management) and disengagement. He emphasised that one's commitment to work responsibilities changes over time. Depending on their other commitments, people's investment in work roles will shift as their circumstances, goals, priorities and responsibilities change. People are conscious that their work life in any organisation is not assured, and as a result, they are able to negotiate their work identities in the sense that they may be discarded, changed or new ones acquired (Saayman & Crafford, 2011; Walker, 2010).

Traditionally speaking, a career is about upward mobility and advancement (Burke, 2015). Today a career is about lifelong experiences with upward, lateral and sometimes downward movement, and a career is seen as self-directed (Briscoe & Hall, 2006). Such flexible careers are termed "protean careers" (Hall, 1976; Hall et al., 2013), where individuals have a powerful sense of identity and personal values that direct their career decisions (Cortellazzo et al., 2020). Owing to self-awareness, a protean career orientation is self-directed, self-managed (Briscoe & Hall, 2006; Burke, 2015; Hall, 1976, 2002, 2004; Hall et al., 2018) and driven by personal values (Hall & Moss, 1998).

4.4.1.1 Career barriers experienced by employees with chronic illnesses

The career prospects for PwCD are likely to be affected when they experience some career barriers (Beatty, 2012). People's intentions to continue working, as well as their intentions to stay with their current employer or to pursue alternative employment options, are influenced by career barriers (Beatty, 2012). Anything within individuals or their surroundings that prevents them from progressing in their careers is referred to as a career barrier (Swanson & Woitke, 1997). Career barriers are a notion connected to social cognitive career theory (SCCT) (Lent et al., 1994), which underscores the significance of choice and action in career decision making (Beatty, 2012). SCCT is based on Bandura's (1986) social cognitive theory, which emphasises self-reflection as a means of facilitating motivation and behaviour (Lent et al., 1994). According to SCCT, self-efficacy beliefs, outcome expectations and personal goals determine career aspirations (Lent et al., 1994). Self-efficacy refers to people's belief in their ability to conduct a course of action (Beatty, 2012); outcome expectations are the expected outcomes of specific behaviours (Lent et al., 2000); and people's determination to participate in and shape a specific future outcome is referred to as personal objectives (Bandura, 1986).

Concerns about loss of benefits, work-related health, job skills, discrimination, personal healthcare and workplace accommodation are among the career barriers for PwCD, as highlighted by Martin et al. (2003). Beatty (2012) found that PwCD face challenges because of their illness symptoms and others' reactions to their illness, which lowers their self-efficacy and contributes to overall lower career aspirations. As a result of these barriers, PwCD must choose between staying in their current job and looking for other work opportunities (Beatty, 2012). It is clear that the effects of an illness on a person's identity profoundly influence work life, especially in the career development area (Beatty & Joffe, 2006).

4.4.1.2 Career paths relating to employees with chronic illnesses

When PwCD respond to their illness by remaining in the same line of work, they may follow one of the following career paths: plateauing, redirecting and/or retreating or self-employment (Beatty, 2012). Plateauing occurs when a person remains in a job for such a lengthy period of time that change is unlikely (Beatty, 2012). For the security of health insurance benefits, PwCD are more likely to stay in their current job role (job

lock) (Pelkowski & Berger, 2003) and are thus willing to sacrifice career advancement (Beatty, 2012). Another reason for staying in one's current job is the psychological effort required to explain one's CD and re-establish oneself in a new environment, which demonstrates low self-efficacy and low career success expectations (Beatty, 2012). According to Beatty (2012), redirecting occurs when employees choose a different type of employment. They typically do this as a result of current or potential physical limitations that may hinder them from meeting the physical demands of their current job, prompting them to reconsider their career aspirations (Beatty & McGonagle, 2016). People who are diagnosed with a CD early in their lives may be redirected to a career that is not exactly what they want but satisfies their security criteria (Beatty, 2012).

Beatty (2012) also found that those diagnosed later in their careers rely on prior experience and training and commonly switch to less challenging environments. When people manage their career in a self-directed manner, this redirection may result in a shift in work identity or the acquisition of a new work identity (Nagy et al., 2017). This adaptability may lead to more flexible work opportunities for PwCD, which could help them extend their careers (Nagy et al., 2017). Retreating, however, is a conscious decision to minimise the amount of work effort required. People who choose lower-level or part-time work because they cannot manage the speed or stress of their existing jobs, are lowering their career expectations and demonstrating a lack of self-efficacy. This approach also leads to the redefinition or creation of a new work identity (Beatty, 2012). When individuals choose to work for themselves rather than for a company, they are said to be self-employed. Hence the individual is no longer motivated by a career (Beatty, 2012). Self-employment allows people to lose their prior work identity and develop a new one outside of the workplace. When an illness forces individuals to seek more freedom and autonomy than they cannot find in their current job, self-employment is an option.

Living with a CD can therefore hinder career advancement and lead to unemployment or underemployment, which can have a negative impact on an individual's long-term career goals (Beatty, 2012). Individuals with CDs are challenged to actively reconstruct their personal and work identities (Kirpal et al., 2007). PwCD can still find meaning in and at work, regardless of their career effects or decisions. Although

identity and illness are intertwined, Hill (2019) asserted that PwCD define themselves, make career decisions and find meaning through their work experience rather than through their CDs.

4.4.2   Career as a calling

For many PwCD, career transitions (Beatty & Joffy, 2006) or leaving the formal work sector (Beatty, 2012) are a reality because of the symptoms and effects of the CDs. It was found that CDs are linked to early retirement and as the number of CDs increases, so does the likelihood of being out of the workforce (Yen et al., 2011; Schofield et al., 2008). This affords some PwCD the opportunity to pursue a calling when they are supported by resources to do so (Hall & Chandler, 2005). In pursuing a calling, some choose self-employment, which also offers the benefit of being more autonomous and modifying their working conditions to suit their circumstances (Fleischmann et al., 2018; Prottas & Thompson, 2006; Rietveld et al., 2015).

A calling is regarded as something that gives meaning to one's existence and purpose to one's work (Hall & Chandler, 2005), or a passion that gives meaning to one's existence in the field of work (Dobrow & Tosti-Kharas, 2011). The definition of a calling by Dik and Duffy (2009) contains the dimensions of a summons that originates beyond the self (transcendent), purposeful meaningful work and prosocial orientation. This notion of calling, which is linked to meaning and purpose as well as the betterment of society, is also shared by others (Bellah et al., 1985; Dik et al. 2013; Hardy, 1990; Marsh & Dik, 2021). People who attribute their motivation for meaningful work to an external source such as God, a family legacy or a pressing societal need (Dik et al., 2009), have values and goals that are focused on something other than themselves, and they live out that calling to fulfil those specific goals (Duffy et al., 2017; Hall & Chandler, 2005; Marsh & Dik, 2021). A general sense of calling, according to Wong (2014b), is the desire to devote one's life to serving others and improving oneself in order to reach one's full potential. This concept of self-transcendence, according to Wong (2014b), perceives one's career as a calling to help others. Self-transcendence motivates the discovery of meaning through creative, experiential and attitudinal values (Wong, 2014b). This calling may shift, depending on a person's circumstances, such as stage of growth, life stage and the challenges of each situation (Wong, 2014b).

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4.5 THE ORGANISATION'S ROLE IN MANAGING EMPLOYEES WITH CDS

The organisation's role in managing employees with CDs is to first address the psychological safety of employees. Employees with CDs, according to DeOrsey (2020), must constantly manage stigma in order to meet work expectations. In the workplace, psychological safety for PwCD refers to the ability to disclose one's illness and the freedom to express oneself without fear of repercussions (Kahn, 1990). The psychological safety of PwCD at work must be ensured, since this will lead to job engagement and organisational citizenship behaviour (Kirk-Brown & Van Dijk, 2011). Formal policies (e.g., extended leave or flexible work hours) and informal arrangements to accommodate CDs are two ways to help employees with CDs (e.g., remote work and giving support when needed). The organisational environment and culture can also create flexibility in the management of people with illnesses by empowering managers to change job assignments and schedules to meet individual needs (DeOrsey, 2020). In a workplace where they feel secure to express themselves, PwCD can make meaning and request resources when they need them (Bosma et al., 2020; DeOrsey, 2020; Kirk-Brown & Van Dijk, 2016). In this section, the strategies to assist PwCD in the workplace are addressed, as well as a discussion of South African labour legislation relating to health and wellness, because it is also important to understand the legal obligations of the employer of people with chronic illnesses.

4.5.1 Strategies to assist employees with chronic illnesses to maintain their careers

Supporting employees with CDs can reduce the risk of long-term absence and staff turnover, as well as increase productivity, job retention and employee wellbeing (Bosma et al., 2021; Clur, 2015). Most chronic illnesses do not necessitate time away from work for treatment and recuperation. In fact, most chronic illnesses allow people to go about their daily lives without taking time off work. Six of the seven CDs described in this study (AA, AS, asthma, hypertension, depression and psoriasis) are illnesses that allow a person to continue their daily work and living. Although the concept of return to work (RTW), which refers to a person's return to work following an illness (Nazarov et al., 2019), does not apply to everyone with a CD, all employees with CDs can benefit from some form of organisational support to help them deal with the challenges their illness may bring. Although PwCD can benefit tremendously from

organisational support to adjust and stay at work, some individuals still choose not to disclose their illnesses because of the reasons mentioned above (e.g. denial or stigmatising).

Beatty (2012) proposed the following measures for PwCD to maintain their careers: Firstly, as SCCT suggests, it is critical to assist people in developing realistic self-efficacy and understanding of how their condition may affect their careers (outcome). Secondly, employees' confidence in their coping skills must be developed in order to improve coping efficacy and psychosocial support. Thirdly, measures should be taken as soon as feasible at an organisational level to support people staying at work, such as through accommodations and psychosocial support. Bosma et al. (2019) also suggested that the healthcare sector should play a greater role in preventing work-related issues by addressing the topic of work as soon as treatment commences.

In this section, the following strategies will be explored: flexible working arrangements, adopting a protean career attitude and offering psychosocial support.

Various flexible working arrangements may include part-time employment, job sharing, flexible scheduling and remote work (Bailey & Kurland, 2002; Chung & Van der Horst, 2018; Gascoigne & Kelliher, 2018; Maxwell et al., 2007; Tomlinson et al., 2018). Accommodations such as flexible work hours or remote work have proven beneficial for PwCD (Butler et al., 2009; Detaille et al., 2006; Grzywacz et al., 2008; Hayman, 2009; Madsen et al., 2019) because they have more autonomy and control in the way they achieve their job goals (Casey & Chase, 2004; Madsen et al., 2019; Ray & Pana-Cryan, 2021).

The work environment has changed significantly because of the coronavirus (COVID-19) pandemic, which has resulted in organisations putting the necessary communication technologies in place to ensure flexible work arrangements for many employees who now work remotely (Oakman et al., 2020) and/or engage in hybrid working. Hybrid working is a combination of working from home and working at the office or normal place of work, or other location (Dobbins, 2021). Greater technological connectivity facilitates the flexibility of remote work to the benefit of both employers and employees (Messenger & Gschwind, 2016; Oakman et al., 2020). Besides affording PwCD the opportunity of autonomy (Meyer et al., 2021; Niebuhr et al., 2022)

and scheduling their own time and pace of work, it reduces the number of people travelling to work (Phillips, 2020) and thus reduces their stress levels (Bernstein et al., 2020). Employers further gain from remote work through better productivity, improved retention and lower operating expenses (Felstead & Henseke, 2017; Phillips, 2020). Employees can prevent social isolation by still maintaining workplace relationships through the hybrid working option, which allows for connecting face to face with peers, subordinates, supervisors and customers (Collins et al., 2016). Employees with CDs can benefit from remote or hybrid work because it improves workplace flexibility and contributes to their wellbeing (Bernstein et al., 2020; Felstead & Henseke, 2017; Phillips, 2020).

The protean career, as mentioned in Section 4.4.1, is a career based on self-direction (Hall, 1976, 1986) and means changing one's view of a career being connected to an organisation but connected to and influenced by one's personal life. It can be viewed as a combination of work-related and nonwork-related roles that help to shape one's identity and sense of self (Mirvis & Hall, 1994). Identity development in the form of enhanced self-reflection and self-learning, as well as increased adaptability, are crucial abilities in the protean career that allow for change in behaviour and attitudes (Hall & Mirvis, 1995).

Employers can help PwCD adopt a flexible career attitude by providing ongoing learning opportunities such as chronic illness career counselling and encouragement to gain new skills (Beatty & McGonagle, 2016; Hall & Mirvis, 1995). Mentoring, networking, team building and other relational activities can also be offered to promote growth (Hall & Mirvis, 1995). Because we always learn from one other, one's relationships with other people are a crucial source of continual learning (Hall, 1993; Kram & Hall, 1996).

Coaching to rebuild a work identity could help PwCD to manage and direct their careers in the workplace (Beatty & McGonagle, 2016). Coaching to assist employees with career-related challenges, however, is rarely addressed (Beatty & McGonagle, 2016; Haafkens et al., 2011; Shaw et al., 2014). Coaching in the health field focuses on health and wellness issues most of the time, with self-management as the primary focus (Beatty & McGonagle, 2016; Munir et al., 2007; Wolever et al., 2013). A coach who is familiar with a person's illness can offer practical assistance that is suited to

that person's needs. When an independent consultant coaches an employee, trust and confidentiality are fostered, and the person is not threatened by the possibility of negative career consequences. Employees with CDs may benefit from coaching to help them overcome challenges with self-presentation, better understand their career possibilities and develop retention strategies (Beatty & McGonagle, 2016).

Employers can provide psychosocial support to their employees through an employee assistance programme (EAP), in which counsellors assist employees in identifying issues and finding solutions (Clur, 2015; Crump, 2021; Nunes et al., 2018). These services could be acquired from a third-party provider or offered in-house (Nunes et al., 2018). Counselling can assist employees in maintaining their performance and working relationships (Saju et al., 2019). This can be achieved by improving employees' sense of self, preserving work resources and relationships, as well as meeting the employee's particular situational demands (Nunes et al., 2018). Mayfield and Mayfield (2018) stressed the importance of meaning making at work for employee motivation, performance and wellbeing. Strategies such accommodation at work, adaptation of a protean career attitude and psychosocial support in the form of EAP, should therefore aim to support employees with CDs to make meaning in the workplace and thereby facilitate health, wellbeing and sustainable employment.

To summarise, PwCD should be assisted in developing realistic self-efficacy, coping effectiveness and psychological support, and employers should make early attempts to support them in remaining at work. It is critical to have current knowledge of relevant legislation affecting illness and disability in order to effectively help CDs in terms of motivation, performance and wellbeing, as well as to assist them in remaining at work.

4.5.2   South African labour legislation concerning health and wellness

Work involvement and retention of employees with chronic illnesses are influenced by social processes and systems in both organisational and national contexts. The national context, in this sense, refers to the political environment that influences the business environment through policies, laws and regulations (Foitzek et al., 2018; Mark & Nwaiwu, 2015). According to Bosma et al. (2021), employers often have difficulty supporting employees with CDs because of a lack of understanding of health-related laws and regulations. Silvaggi et al. (2020) underscored the necessity of

effective management practices, such as programmes for CD employees' participation, retention and return to work within organisational guidelines. Close collaboration with all stakeholders involved in organisations, including the consideration of relevant legislation, is necessary to build supportive work environments and prevent employment issues for people with CDs (Bosma et al., 2021; Silvaggi et al., 2020).

In South Africa, the main statutes that affect employees' health and wellness, as mentioned by Sieberhagen et al. (2009), include the following: the Constitution of the Republic of South Africa; the Occupational Health and Safety Act; the Labour Relations Act (LRA); the Basic Conditions of Employment Act (BCEA); the Compensation for Occupational Diseases and Injuries Act (CODIA); the Unemployment Insurance Act (UI Act); the Employment Equity Act (EEA); and the Skills Development Act. The various legislative issues that affect employees with CDs are briefly discussed next.

The South African Constitution is founded on the idea of equality for everyone (Becker et al., 2015), which specifies that everyone must be treated fairly. It refers to the respect, protection and promotion of all people's rights (South African Government, 1996), including the rights of individuals with CDs. According to the Occupational Health and Safety Act, employers must provide and maintain, as far as it is reasonably practicable, a safe and healthy working environment for their employees (Tshoose, 2014). This implies that employers must make reasonable accommodations for PwCD.

According to Grogan (2007), the LRA protects employees from unfair labour practices (e.g. a worker being denied a certain position because of having a CD) and unfair dismissals (e.g. a worker being dismissed because of having a CD). When it comes to terminating a work relationship because of permanent or continuing incapacity caused by illness, there should be a reasonable procedure in place (Burger, 2014; Letlonkane, n.d.). The BCEA establishes basic working standards for all employment relationships and safeguards employees' health and wellbeing by enforcing strict rules that ensure employees receive adequate rest periods, leave and overtime pay (Sieberhagen et al., 2009). The COIDA has an impact on employee health and wellness because it ensures compensation for employees whose health has been affected as a result of their work (Sieberhagen et al., 2009). Mine workers in South

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Africa, for example, are exposed to excessive amounts of dust and asbestos, resulting in asbestosis and silicosis, which are still the main causes of early retirement and death among miners (Tshoose, 2011).

Employees who have lost their jobs because of pregnancy or for other reasons beyond their control are entitled to benefits under the UI Act. This Act only applies to someone who has previously worked and is looking for job or is unable to obtain work because of a confirmed illness (Grogan, 2005). This means that PwCD can apply for illness benefits if they are unable to work because of their condition (South African Government, n.d.).

The EEA strives to make the workplace a more equal and non-discriminatory place (Van der Walt, 2014). According to the Act, no one may discriminate against an employee or job applicant in any employment policy or practice on the basis of the 20 mentioned grounds (which include disability and HIV status), unless the preference or exclusion is based on an inherent requirement of the position (Lebepe, 2010; Ngwena,2004). This Act makes no mention of CDs, although it does describe disability, that also could apply to PwCD, as a long-term or recurring physical or mental impairment that significantly affects occupational opportunities (Western Cape Government, 2014). The Skills Development Act has an impact on employee health and wellness since the workplace serves as an active learning environment for developing and acquiring skills (Sieberhagen et al., 2009). This means that people with disabilities can learn or build the skills they will need when they transfer to new jobs.

Employers must consider the appropriate legislation when providing support to employees with CDs in order to avoid unfairness and, more importantly, to facilitate long-term employment.

4.6 STRATEGIES TO IMPROVE MEANING MAKING AT WORK

Since individuals spend a significant amount of time at work, finding meaning at work should thus be a top priority (Pattakos & Dundon, 2017a). People want to believe that their work is worthwhile and that it is improving their lives, the lives of others and society as a whole (Berg et al., 2013; Martela & Pessi, 2018; Pattakos & Dundon,

2017a). Meaning in the workplace is the reason that an individual has for doing work that makes life more comprehensible, especially when the work is regarded as contributing to others' wellbeing (De Crom & Rothmann, 2018; Isaksen, 2000; Jena et al., 2019). Organisations must recognise the relevance of meaning in employees' lives and the influence it has on job engagement (Hoole & Bonnema, 2015; Pattakos & Dundon, 2017a; Van der Walt, 2018). Working with a meaning mindset, according to Pattakos and Dundon (2017a), is a major driver of engagement, resilience, health, wellness, performance and innovation. The failure to involve employees in meaning making is the root of most engagement concerns (Pattakos & Dundon, 2017a). The simplest task can be seen as having meaning when employees see that their work is meaningful and has a purpose (Steger, 2017).

Carton (2018) cites an example of a NASA study where employees regarded their work as having greater meaning because it contributed to the organisation's long-term goals. In this study, an employee stated that his work is not a short-term activity of just making "electrical circuits," but rather a long-term goal of NASA of placing a man on the moon (Carton, 2018, p. 352). It is self-transcendent because meaningful work makes people feel that they are a part of something bigger than themselves (Bailey & Madden, 2016).

Many studies focus on various interventions for people with different CDs that relate mainly to changes in work and improving work participation (Nazarov et al., 2019; Vooijs et al., 2015). There is, however, a void in knowledge about strategies to facilitate meaning making at work for PwCD (Barnard et al., 2016; Clur et al., 2017), and this is a domain that needs to be explored in IOP. Next, strategies that could assist employees with CDs to make meaning in the work context are elaborated on.

4.6.1 Encouraging prosocial behaviour

According to Clur (2015), the development of self-efficacy, motivation, self-confidence and personal control are all necessary in the meaning-making process of an individual with a CD. These internal sources of motivation that include the need for personal growth and fulfilment are linked to meaning making at work (Bryce, 2018; Steger et al., 2012). Employees find meaning in their work when they help others (Bryce, 2018)

or realise that their work has a positive impact on society (Alexander & Douthit, 2016; Bryce, 2018).

Prosocial behaviour entails those actions that focus on helping others (Batson & Powell, 2003; Thielmann et al., 2020). This behaviour has been linked to improved health and wellbeing (Chancellor et al., 2018; Nelson et al., 2016), as well as life-meaning perceptions (Klein, 2016; Hooker et al., 2018). Prosocial behaviour is also deemed to have therapeutic potential (Miles et al., 2021) because it diverts attention away from stressors while simultaneously promoting a sense of meaning, purpose, self-efficacy (Raposa et al., 2016), social connectivity and cohesion (Holmes et al., 2020). Prosocial behaviours can create a sense of meaning because they are socially motivated (Ding et al., 2018; Miles et al., 2021) and can produce a sense of belonging through positive social interactions (Miles et al., 2021). There are well-known sayings that also refer to this notion of prosocial behaviour providing meaning in life: Emerson is quoted as saying that "the purpose of life is not to be happy … it is to be useful" to others (Brown, 2000); Dickens (1864) stated that "no one is useless in this world who lightens the burden of it for anyone else"; and in the Bible, one finds the following words of Jesus: "It is more blessed to give than to receive" (Acts 20:35b, The Holy Bible, New International Version).

Prosocial behaviour at work, also known as organisational citizenship behaviour (Mitonga-Monga & Cilliers, 2016), refers to an employee's helpful behaviour towards other individuals or the organisation. In general, prosocial behaviour in the workplace can be described as any effort aimed at improving others' needs (Bierhoff, 2005; Vieweg, 2018). Examples of such efforts could include cooperation with colleagues, performing extra tasks, punctuality, helping one's co-workers, using time at work effectively, sharing ideas or representing the organisation positively (Boundenghan et al., 2012). Leaders can facilitate a helping culture in their organisations by encouraging and creating opportunities for prosocial behaviour (Parris & Peachey, 2012).

4.6.2 Corporate social responsibility programmes

Prosocial behaviour refers to individual social responsibility (Bénabou & Tirole, 2010), whereas corporate social responsibility (CSR) relates to an organisation's voluntary activity that contributes to the welfare of society (Kweyama et al., 2015; Thomas &

Nowak, 2006). Being part of a CSR programme may be a way through which employees can make meaning by being part of efforts to benefit society (Alexander & Douthit, 2016) and feeling that they are contributing to the greater good (Rosso et al., 2010). Such a programme should be an external and internal initiative with clear connections to the organisation's purpose (Alexander & Douthit, 2016).

An individual who perceives work to be important to society or the community, thus serving a greater purpose, is likely to experience work as meaningful (Grant, 2008; Wrzesniewski, 2003). An example of such a programme is Pepkor's, "The Ackermans Ububele Schools Programme". The main objective of this programme is to improve the quality of early childhood development by instilling an appreciation of the value of storytelling to promote the development of language and imagination (Kindness and Generosity, n.a., n.d.). The employees have the opportunity to contribute to this programme by offering their time and expertise and are given time off work to personally have an influence on a worthy cause (Pepkor Holdings Limited, n.a., n.d.).

Affording employees the opportunity to be part of a CSR initiative could make them feel part of something bigger and thus facilitate meaning making.

4.6.3   Mentoring relationships

Mentorship is a formal or informal relationship between two people in which one person serves as the mentor and the other as the protégé (Taylor & Curtis, 2018). It can be regarded as an intense interpersonal experience between an experienced colleague (the mentor) and a less experienced colleague (the protégé), during which the mentor provides career-related assistance, direction and feedback to the protégé (Russell & Adams, 1997). It was found that workers want to do tasks where they can build meaningful relationships, have the opportunity to make an impact by helping others and influence the organisation and society so that lasting contributions can be made to benefit future generations (Kooij et al., 2015).

Mentoring relationships can be used to help people find meaning at work. Kennett and Lomas (2015) reported that mentoring enhances a sense of meaning and fosters eudaimonic wellbeing through a combination of self-determination and self-reflection. Being invited to mentor someone can increase individuals' self-worth and efficacy, as well as their social connectedness and autonomy, all of which lead to self-

determination (Kennett & Lomas, 2015). Mentorship entails a bond with the mentee in the form of a close friendship. It includes transcending one's own self in order to help someone other than oneself (Kennett & Lomas, 2015, p. 13). Formal mentoring programmes, according to Kennett and Lomas (2015), may be unproductive compared with informal mentoring. The reason for this is that formal programmes may be more prescriptive and deprive one of autonomy, which is one of the primary aspects of self-determination (Ryan & Deci, 1985). In the interaction of mentoring, meaning making for PwCD is not merely the act of mentoring itself, but also the internal gratification of being able to produce results (Kennett & Lomas, 2015).

4.6.4   Job crafting as a self-determination strategy

People with CDs frequently encounter disparities at work, which leads to unsatisfactory experiences with work tasks, interactions with co-workers and the significance and meaning they ascribe to their careers (Brucker & Sandar, 2020). It is logical to assume that these employees, whose work abilities may have changed, will try to adjust their job characteristics to fit their resources (Kooij et al., 2015). Employees who craft their jobs in a way that fosters job satisfaction, engagement, resilience and thriving at work are known as job crafters (Wrzesniewski & Dutton, 2001). According to Tims and Bakker (2010), job crafting refers to the adjustments that employees make in their workplaces to help them achieve their own goals. It is a bottom-up approach to work redesign that is led by the employee (Brucker & Sundar, 2020), and it could help people maintain their health and manage the stress of their jobs (Tims & Bakker, 2010).

Bakker and Woerkom (2017) posited that job crafting is a self-determination method in which people can build their own work-related flow experiences. This can be accomplished, according to Bakker and Woerkom (2017), by actively modifying one's job in response to changing circumstances, which will satisfy the need for competence while also satisfying the need for autonomy. The need for relatedness will be satisfied by choosing who to interact with and how to interact with them (Tims et al., 2013). Job crafting improves the fit between challenges and skills, as well as the availability of job resources to address these issues (Bakker & Woerkom, 2017). Wrzesniewski and Dutton (2001) identified three incentives for job crafting, namely the need to assert control over one's job, interact with people, and establish and sustain a positive self-

image. Task, relational and cognitive crafting are three types of work crafting that go hand in hand with these needs (Wrzesniewski & Dutton, 2001).

According to Wrzesniewski and Dutton (2001), task crafting allows an employee to change the type or amount of tasks that have to be accomplished. Relational crafting refers to the process of changing one's work relationships, namely with whom and to what extent one wishes to interact. Cognitive crafting is the process of changing the meaning of one's job in order to see it in a more favourable light (Wrzesniewski & Dutton, 2001). Job crafting for PwCD might involve informal alternate methods of accomplishing a task, reasonable adjustments, the use of assistive technology or job redesign (Brucker & Sundar, 2020). Several studies have demonstrated the value of social connectedness in the workplace for CD employees (Banks & Lawrence, 2006; Detaille et al., 2003; Jones et al., 2017; Lacaille et al., 2007; Nilsson et al., 2007; Varekamp & Van Dijk, 2010). Employees with CDs may be meticulous about who they seek out for social support (Breevaart & Tims, 2019; Halbesleben, 2006). Exhausted employees, however, create social resources by actively seeking support, comments and advice (Breevaart & Tims, 2019). Thinking about how one's work adds to life's meaning and purpose, as well as one's own development and wellbeing, is part of cognitive craftsmanship (Devotto et al., 2020).

Lazazzara et al. (2020) identified the following three distinct types of job crafting: approach crafting, in which employees add extra tasks or reframe work roles; avoidance crafting, where workers reduce workplace roles and limit social ties; and crafting in other domains (relating to broader aspects of the job). All of these things can happen in different types of work crafting, such as cognitive, relational and task-related job crafting. The motivation to craft, which may be proactive or reactive, is the first step in job crafting. Reactive motives are tied to the need to cope with misfortune, whereas proactive reasons are related to the desire to do work crafting in order to achieve desired goals (Lazazzara et al., 2020). Job crafting may be a reactive or protective strategy for PwCD to protect their health by reducing job demands (Demerouti & Peeters, 2018).

In my view, job crafting can be an extremely useful strategy for PwCD to help them maintain their health and also enable them to manage the pressures of their jobs. Employers can be more responsive to the needs of PwCD by means of flexibility in the

job that will fit both the employee and employer (Srivastava & Chamberlain, 2005; Varekamp et al., 2006).

4.7   MEANING MAKING AT WORK: AN INTEGRATION

Work participation plays a significant role in people's lives and is a way for them to build a work identity, one in which they create self-worth and a meaningful life (Beatty & Joffe, 2006; Smedema et al., 2009; Walker, 2010). When people have to live with a CD, especially a visible one, it affects them in several ways, including their identity. They now have an illness identity which they have to incorporate into their work identity (Beatty, 2012). The effects of living with CDs on employees not only has implications for their personal health, but also impacts them in the context of the workplace, where they often struggle to maintain their work identity and career (Beatty & McGonagle, 2016; Nagy et al., 2017).

When one is confronted by an event like living with CD, one is motivated to act (Mayfield & Mayfield, 2018). Motivation is broadly divided into two categories, namely extrinsic and intrinsic (Ryan & Deci, 2020). The facilitation of intrinsic motivation for employees with CDs is necessary to enhance self-motivation and health (Beatty, 2012; Bryce, 2018; Golay et al., 2007; Ryan & Deci, 2000a; Seifert et al., 2012; Steger et al., 2012). Beatty (2012) found that intrinsic motivation was associated with an employee's intentions to stay at work. It is therefore vital to facilitate intrinsic motivation by turning to different strategies to improve meaning making at work for PwCD to promote employee retention.

Frankl (1985) suggested three ways of finding meaning, namely giving or contributing something to the world through work (creative value/pathway), experiencing something or encountering someone (experiential value/pathway) and the choice of attitude (attitudinal value/pathway) towards unavoidable suffering (like living with a CD). Frankl (2019) asserted that creative values generally coincide with a person's work life and it is more of a contribution to society than to the actual work self. He emphasised that it is not a job that makes work meaningful, but the manner (attitude) in which one does the work. Csikszentmihalyi (1996) also supported the assumption that creativity is a central source of meaning in life. Wong (n.d.) posited that the creative pathway to meaning emphasises the human being as responsible and

creative and capable of self-regulation, self-determination and goal-striving. According to Pattakos and Dundon (2017b), everyone makes meaning through doing or creating something of value. Finding meaning in work is mainly a function of one's attitudinal values rather than the function of the job itself or its context (Burger et al., 2013). Pattakos and Dundon (2017b) postulated that one's choice of attitude is the foundation of one's resilience and outlook on life. Fredrickson (2001) also underscored the notion that people with a positive outlook (attitudinal value) are more resilient to adversity over time. Confidence in one's own ability (i.e. self-efficacy) is essential in dealing with an event such as chronic illness and one's ability to make meaning of it (Hjärtström et al., 2018). The attitude that one chooses in a given situation will influence the response to and outcome thereof (Pattakos & Dundon, 2017b).

In the workplace, experiential value, which is the experience of something or encountering someone, emphasises the significance of interpersonal relationships and social support (Cartwright & Holmes, 2006). People want to feel meaningfully connected to their co-workers (Pattakos & Dundon, 2017b). The need to belong is a fundamental human motivation (Baumeister & Leary, 1995, 2017). The experiential value also includes other kinds of human encounters and work-related experiences that provide meaning. Human beings are interdependent, and meaning making at work includes spiritual or transcendent experiences (Pattakos & Dundon, 2017b). In the workplace, this connectedness is shaped by the office jargon that is used, the stories that are told, the expectations of how the work is to be done, the leadership styles, the games people play, the office gossip, how promotions and praise are given, how negative behaviour is managed and so on (Pattakos & Dundon, 2017b). This is how the sense of belonging to the work community or village is formed (Pattkos & Dundon, 2017b).The changing nature of work, as mentioned in Section 4.5.1, however, is diminishing this opportunity to socially connect with others. Factors that could reduce social connectedness and cause feelings of isolation include, inter alia, an increase in remote work (Cooper & Kurland, 2002; Golden et al., 2008; Mulki & Jaramillo, 2011), greater reliance on electronic communication and increased work demands and time pressures (Cartwright & Holmes, 2006). Employers need to look into strategies to create belonging among employees, and one possible method could be to schedule a weekly virtual timeslot for a teatime social gathering for all employees to bring the team closer together (Fosslien & West-Duffy, 2019). Pattakos and Dundon (2017b) asserted

that it is more of a challenge to form authentic connections when one does not have face-to-face experiences with others.

Figure 4.4 below is a summative figure that depicts the environment of meaning making of the working employee with a CD in the organisational context.

Figure 4.4

The work environment of the employee with a CD
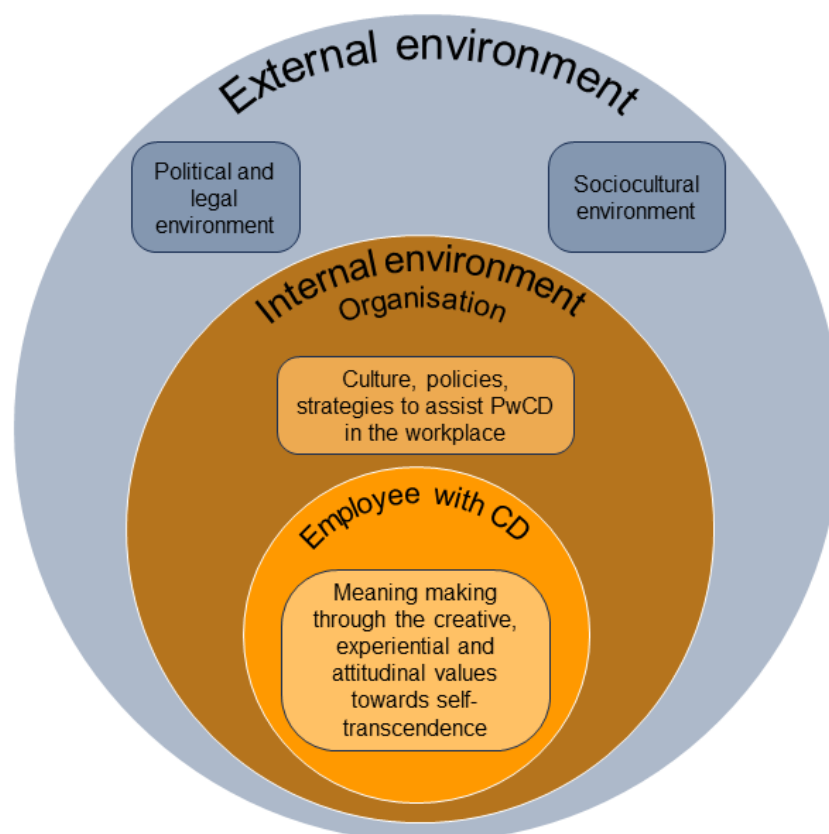
Every organisation operates in an external environment that has an impact on them. Several aspects of the internal and external environments in which businesses operate influence employee management. Government regulations and labour legislation, for example, are part of the political and legal environment and have a direct impact on how people are managed in the workplace (Ikechukwu et al., 2019; Letková, 2018; Swartz, n.d.).

The sociocultural environment explains the values that people in a particular society hold and the behaviours they engage in, and it plays a key role in determining social behaviour (Zakar et al., 2021). Cultural and socioeconomic factors influence people's

opinions of chronic illness, and this will have an impact on whether or not employees with CDs are accepted or socially marginalised (Alves & De Oliveira, 2018). Stigmatising, for example, influence social relationships, psychological and behavioural responses (Hatzenbuehler et al., 2013), and need to be known and interpreted in order to understand (Alves & de Oliveira, 2018) the impact thereof on employees with CDs in the workplace. The internal organisational environment includes the culture and policies that are in place to engage and develop employees in order to enhance their productivity. This can be achieved for formally employed PwCD by the organisation offering a safe space where they can freely express themselves and participate; where pro-social behaviour is encouraged; where opportunities to participate in CSR programmes are created; and where possibilities for mentoring and job crafting are provided.

4.8   CHAPTER SUMMARY

In this chapter, the various aspects of the meaning making of PwCD in the workplace were discussed. Meaning in the work context, the workplace as a domain of meaning making, the effect of CDs on careers, the organisation's role in managing PwCD in the workplace and strategies for meaning making in the work context, were highlighted. In conclusion, an integration of meaning making at work was provided by means of a depiction and discussion of the environment of the meaning making of the employee with a CD. Before presenting the findings in Chapter 6, as illustrated in Figure 6.1, the three cases included in this study are introduced in Chapter 5.

CHAPTER 5
CASE DESCRIPTIONS

The three cases provided an in-depth appreciation of the participants' ways of meaning making while balancing living and working with the unique demands and challenges of their diverse illnesses against the demands of everyday life (Van Houtum et al., 2015). A purposive convenience sampling approach was adopted to select the three cases, and they met the purpose of the study. The rationale for the case selection was discussed in Chapter 2, Section 2.6.2. The case studies represented individuals in the age groups of 41 to 61, all white-collar workers, with a diversity of chronic diseases, each presenting different "clinical and contextual specificities" (Pesantes et al., 2020, p. 372), which had led to unique life and work experiences. The participants were assigned pseudonyms to protect their anonymity.

The aim of this chapter is to provide readers with comprehensive background information on the participants and describe the contexts in which they were researched. Such detailed introductions may support readers' transferability judgements of the study's findings (Baxter & Jack, 2008; Lincoln & Guba, 1985; Meyrick, 2006), and demonstrate that the cases could be used to achieve analytical insight (Thomas, 2021).

5.1   SUMMATIVE INTRODUCTION TO THE CASES

The three cases were selected because they were deemed suitable for this study in that they were diverse in respect of their backgrounds, CDs, age groups and careers. All three cases presented visible CDs (AS, AA and psoriasis) that influenced their self-image and acceptance (Charmaz & Rosenfeld, 2016). Two of the cases also presented with multiple CDs, and have CDs that could escalate into life-threatening diseases, namely asthma (Annesi-Maesano et al., 2008), breast cancer (Akram et al., 2017) and hypertension (Oparil et al., 2018). Two of the cases transitioned, during the course of the study, from formal work to self-employment. The biographical data of the cases is provided in Table 5.1 below.

Table 5.1

Biographical data of the cases

CASE	GENDER	AGE	OCCUPATION	CHRONIC DISEASES	PERIOD LIVING WITH CDs
Case 1: Fiona	Female	61	White-collar worker, Craft artist/self-employed	Alopecia areata (AA)	32 years
Case 2: Dwayne	Male	41	White-collar worker	Ankylosing spondylitis (AS), asthma, hypertension	16 years 8 years 5 years
Case 3: Dinah	Female	51	White-collar worker, Craft artist/self-employed	Breast cancer, psoriasis depression	14 years 5 years Lifelong

Note: Pseudonyms were assigned to the three cases as indicated in Sections 1.7 and 2.7.2.

Information on each case is provided next in order to discuss the participants' relevant background and lived experience.

5.2   CASE 1: FIONA

The first case is "Fiona", who has alopecia areata (AA), which is an autoimmune hair-loss condition (Davey et al., 2019) that can affect the scalp, face and body (Islam et al., 2015). It is estimated that 2% of the population will be affected by AA at some point during their lifetime (Pratt et al., 2017). In some people, it may cause bald spots, while in others, it may be the complete loss of hair on the scalp (alopecia totalis). In extreme cases, hair loss may occur over the entire body (alopecia universalis) (Spano & Donovan, 2015). AA is associated with co-morbidities, which include depression, anxiety and several autoimmune diseases such as thyroid disease, lupus erythematosus, vitiligo, psoriasis, rheumatoid arthritis and inflammatory bowel disease (Pratt et al., 2017). The primary concerns for an AA patient are bald spots on the scalp and visible loss of facial hair, such as brows and eyelashes (Macey et al., 2022).

Hair loss can have adverse effects on women and men because individuals' individuality, and by implication, their identity and self-concept are expressed through hair colour and hairstyles (Saed et al., 2016). AA is associated with impaired social

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functioning because individuals with this condition tend to experience shame and isolate themselves (Aldhouse et al., 2020; Davey et al., 2019). Hair is a central aspect of appearance and self-image. Hence hair loss can have a negative impact on self-esteem, body image, confidence and socialisation (Aldhouse et al., 2020; Davey et al., 2019; Montgomery et al., 2016; Tucker, 2009).

Females experience more loss and invest more in their appearance, according to studies (Aldhouse et al., 2020; Rafique & Hunt, 2015; West, 2010), but men also have negative feelings about their hair loss (Aldhouse et al., 2020; West, 2010). It would appear that AA has an emotional, psychological, psychosocial (Aldhouse et al., 2020; Montgomery et al., 2017; Pratt et al., 2017; Rafique & Hunt, 2015; Tucker, 2009) and overall negative impact on quality of life (Burns et al., 2020). Positive methods that people use to deal with AA are to explore the meanings of hair that shape their experience and develop alternative meanings (Davey et al., 2019), as well as using concealment by wearing a wig or other headwear to manage others' negative reactions (Aldhouse et al., 2020; Montgomery et al., 2016; Pratt et al., 2017).

Fiona is a 61-year-old female who was diagnosed with AA at the age of 29 and has lived most of her adult life with the challenges and demands posed by her illness. Fiona has been a white-collar worker for most of her working life and only recently resigned and became self-employed. She is currently living out her creative talent by selling her arts and crafts online. Fiona did not disclose the nature and extent of her hair loss to me and I respected her privacy in this regard. From the information she provided in her published life story, I deduced that she has total hair loss (alopecia universalis). Fiona is completely unknown to me. Her participation in this study was based on the usefulness of her published life story in the media, for which she gave consent to be used in this study. Follow-up questions were addressed to her via email. I respected her privacy to limit the collection of information to what was essential for this study (as suggested by Kaiser, 2009). I protected her identity by using a pseudonym and also removed any personal identifiers. The contextual identifiers of her life story, as published on a public platform, however, remain (Kaiser, 2009) and as such, could make her identifiable.

When Fiona was diagnosed with AA, she was devastated. The bald spots appeared in mirror image, first on one side and then on the other side. The spots became bigger

and later merged. She, however, was aware of the prognosis of the illness because her brother had already been diagnosed with the same illness at the age of six and she had first-hand experience of the development and progress of this illness. It was a painful experience for her because she had always had long, beautiful hair and it was her pride and joy:

> *My whole life, my hair was my joy and I can honestly say that I never had a bad hair day … A deep pain lodged in my body and believe me, for a long time, I could not look at myself in the mirror without experiencing pain. I would have loved to curl up in a foetal position and withdraw from the world. I felt naked. It was the start of a long mourning process.*

Each month, she began shortening her hair, covering her bald spots with headbands. She said she appeared and felt like a "*tiny baby bird that has fallen out of its nest*". The detrimental impact of hair loss on the emotions, self-esteem and self-confidence of people with AA is exacerbated by the social pressure to be attractive (Aldhouse et al., 2020; Tucker, 2009). In order to hasten the process, Fiona made the following radical choice: "*One morning I shaved my head bald, and that was the start of wigs and then head scarves*". Fiona found that she had to learn to love her new image and develop a new identity:

> *At the age of 29, I had to dig very deep inside myself in search of what makes me more than the person I had known until then, the one with the beautiful hair. I had to learn to fall in love with the new woman in the mirror who greeted me in the mornings. I had to learn to live with loss.*

In developing a new identity, she used her creativity to conceal her baldness and arrange her head scarves in interesting ways to express her individuality: "… *women wanted to know how I arranged my head scarves, and I loved it*". Early in her illness journey, Fiona had to reflect and adapt to her altered image. Her ex-husband had a job which required them to attend many social events. She had also worked in a managerial position for a large part of her working life and as such, was required to attend meetings and other social functions. She had to overcome her self-consciousness and attend these social events: "*I had to put on my stilettos and little black dress and mingle with people over drinks and dinner with my head held high.*"

Although Fiona frequently encounters situations where she has to answer awkward questions about her hair loss, she asserts herself and does not allow stigmatisation. She describes herself as a brave person who is not submissive and who values freedom:

Ek het nie 'n bang haar op my kop nie ["I am brave"].

Anyone who knows me well would attest to the fact that I am not a submissive woman, hair or no hair, scarf or no scarf. I'm too free for that.

I acquired information from Fiona through her online life story of her experiences with AA as well as follow-up interviews via emails, WhatsApp messages and telephone calls.

5.3   CASE 2: DWAYNE

The second case, "Dwayne", has MCC namely, ankylosing spondylitis (AS), asthma and hypertension. According to Pelechas et al. (2019), AS is a chronic autoimmune rheumatic disease that affects the spine and the sacroiliac joints. Physical symptoms including pain, stiffness in the spine and mobility loss, which can make it difficult for individuals to go about their everyday lives (Primholdt et al., 2017). This illness may lead to the fusion of parts of the spine's bones, making the spine less flexible and possibly causing a hunched posture. Breathing deeply may be challenging if the ribs are compromised (Mayo Clinic, n.d.). According to estimates, the prevalence of AS ranges from 0.1% to 1.4% worldwide (Dean et al., 2014). For people living with AS, mobility is restricted because the disease targets the spine (Rouse et al., 2019), and consequently, pain, fatigue, stiffness and disability are challenges they have to face (Brophy et al., 2013; Fongen et al., 2013; Hammer et al., 2018). Many aspects of the everyday life of a person with AS are being challenged because of the experience of slowly losing physical strength and mobility (Mengshoel, 2008; Primholdt et al., 2017; Unver et al., 2017).

During later stages of the disease, it can lead to permanent spinal deformity and postural disorder (Unver et al., 2017). According to a study by Madsen et al. (2015), men with AS were worried about how the condition would affect their capacity to be partners and fathers, as well as how it would affect their social lives and sense of

masculinity. Primholdt et al. (2017) found in their study that males with AS felt that their masculinity was under attack and they also experienced depression and uncertainty about their future and job security. According to studies on men with AS, they want to normalise their lives by changing their daily routines to include movement, modifying their daily tasks to prevent overexertion, learning more about the value of nutrition and creating more conducive work environments so that they can contribute equally and not burden their co-workers (Mengshoel, 2008). Hamilton-West and Quine (2009) asserted that it is essential for individuals with AS to understand the value of training and exercise, to maintain and build new friendships and to modify their pace of living.

Studies indicate that people with AS are at a higher risk of developing asthma (Chang et al., 2016; Shen et al., 2015). Asthma is a long-term condition that affects the airways (Holgate, 2008; Holgate et al., 2015). It is a disease that influences people's daily lives and quality of life (Stanescu et al., 2019), mainly because of the physical effects of asthma symptoms like wheezing, shortness of breath, coughing and chest tightness (Pickles et al., 2018). Because asthma differs in severity, each individual's treatment regime will differ (Pollart & Elward, 2009). People with asthma are more likely to suffer from anxiety and depression (Stanescu et al., 2019; Thomas et al., 2011). Individuals self-manage their asthma condition by taking medication and dealing with unexpected scenarios as learned from health professionals (Daines et al., 2020). Lifestyle changes and activity promotion have also been shown to help manage the illness (Stanescu et al., 2019).

Hypertension (high blood pressure) is a silent disease and is almost without obvious symptoms in its early stages (Dzudie et al., 2017; Stein et al., 2002), but if left untreated, could be a major cause of heart disease and stroke (Dzudie et al., 2017). Hypertension is defined as the blood pressure (BP) level above which treatments have been shown to reduce clinical events in randomised trials, which is accepted as ≥ 140 mmHg systolic and/or ≥ 90 mmHg diastolic BP (Dzudie et al., 2017). The WHO estimated that the number of people affected by hypertension is the highest in Africa, at about 46% of adults aged 25 years and older (Dzudie et al., 2017). It was also found that the most common chronic condition in adults is high blood pressure, which affects one in four people (Goldman, 2017).

Individuals with hypertension may be unconcerned about the long-term complications because of a lack of symptoms (Milne, 1983) or their confidence in their medication to prevent such complications (Stein et al., 2002). Individuals adopting mechanisms to manage living with hypertension reflect lifestyle changes like exercise, healthy eating, cessation of smoking (Lönnberg et al., 2020; Ndejjo et al., 2021; Shamsi et al., 2017), spirituality and using social support from their family (Shamsi et al., 2017). It was found that practising religion or spirituality was associated with lower blood pressure in males (Tartaro et al., 2005; Wyatt et al., 2002).

Dwayne is known to me. He was diagnosed with AS at the age of 25. He has been living with this visible CD for 16 years. Living with AS has a definite influence on Dwayne's mobility and he experiences physical challenges in the form of "*terrible back pain*" as well as stiffness in his hips, which affects the way he moves:

> *AS minimises your mobility and I started to walk funny. To this day, I am still teased by people for the way I walk ...it's like you have adapted by walking in a certain way to try to avoid the pain.*

At the time of his diagnosis with AS, Dwayne's work entailed being stationary for long periods of time and also being exposed to noise and extreme vibration, which worsened his back pain (Apostolopoulos et al., 2010). He only lasted for eight months in this job. The long stationary periods, extreme back pain, which Dwayne described as "*severe ... so much so that my wife had to help me get out of bed*", and the advice of a medical professional to find a job where he "*could be more active*", led to his resignation from this job.

Research has shown that physical activity improves mobility, pain, physical function and disease activity in people with AS (Dagfinrud et al., 2011; O'Dwyer et al., 2014; Rouse et al., 2019). Dwayne redirected his career by returning to a job in which he could be more active because he anticipated future health problems (Beatty, 2012). He re-entered the workforce in the construction sector to pursue a technical position where he could be physically active and thus increase his mobility.

He spent 13 years working in the construction sector. During some of these years, he worked for himself, for a small company and for a family-run enterprise. He did, however, encounter other difficulties that come with working in a family business, such

as family dynamics that affect issues of control, how the firm is operating and family relations, in addition to his career plateauing (Gersick et al., 1999). He left the family business and began working as a white-collar employee for an international organisation, which afforded him the opportunity for education, career advancement and financial security. He stated that his illness identity and the prognosis of his illness did not influence his subsequent career changes. He was able to incorporate his illness into his career because he was diagnosed with AS early in his career life and could therefore set realistic goals to avoid future disappointment (Beatty & Joffe, 2006).

In some CDs, the illness is only apparent to others when a person moves (Hoppe, 2010). Living with a movement-impairing CD like AS could result in comments and jokes being made that could be hurtful, especially if one's movement is hampered. Dwayne stated that because of the "*funny way*" he walks and performs his duties by "*kneeling instead of bending over*", people at work and even close family members occasionally make fun of him. The reason why people react this way is either because they do not know a person has an illness or they do not know how to deal with the illness because they do not understand it (Hoppe, 2010). According to Dwayne, he defends the jokes he has to endure because of his awkward gait by saying that "*it is not meant in a bad way*" and that he is "*thick-skinned*". By rationalising, he lessens the hurt he experiences when people laugh at him. The disease progression and the disabling effects of AS lead to an inferior quality of life and could lead to early withdrawal from gainful employment (Braun & Pincus, 2002). Dwayne is aware of the prognosis of his illness and said that he "*knows immobility awaits*" and he is preparing for it by "*setting*" himself up for it.

Dwayne was diagnosed with asthma when he was 33 and he has lived with this condition for the past eight years. He mentioned that of all his CDs, the asthma is the most bothersome, and he wishes it away so that his "*chest can open up*". He uses an inhaler to relieve the symptoms. He describes his asthma as non-life-threatening and manageable. He was also diagnosed with hypertension (high blood pressure) at the age of 36, while undergoing a routine medical examination at work. He has lived with this condition for the past five years, and described it as "*something that a person can control*", and he said that he "*is going to beat*" the asthma. At the time of the study, he

was not using any medication for this condition and mentioned that he manages it by *"exercising and a good lifestyle".* Despite having to deal with the challenges and barriers of various CDs, Dwayne came across as someone who takes responsibility for the situation by managing it, remaining positive and leading a healthier, more active lifestyle.

5.4   CASE 3: DINAH

The third case, "Dinah", a 52-year-old female, also has MCC, namely breast cancer, depression and psoriasis. Cancer is a disease with long-term consequences for health and quality of life. Breast cancer is the most commonly diagnosed cancer among women worldwide (Irukulla et al., 2016) and starts when cells begin to grow out of control in the breast (Laronga et al., 2016). The general breast cancer survival rate and prognosis are favourable for women who are diagnosed early (Allemani et al., 2015; WHO, 2021; DeSantis et al., 2016). Advances in the diagnosis and treatment of cancer have led to improved survival rates (Martin, 2021). A diagnosis of breast cancer is generally followed by some sort of therapy such as surgery, radiation therapy, chemotherapy, hormonal therapy or any combination of the four (Ward, 2013).

The quality of life of breast cancer survivors is impacted by treatment side effects (Smit et al., 2019). Treatment side effects might cause physical symptoms like lymphedema, arm and shoulder mobility limits, and chronic pain in the affected area. Infertility and early menopause can cause heart disease, osteoporosis and vasomotor symptoms as well as sexual dysfunction (Ewertz & Jensen, 2011). Psychological symptoms include fatigue, insomnia, cognitive impairment (Clur, 2015; Ewertz & Jensen, 2011; Palesh et al., 2018), major depression, fear of recurrence and sexual problems (Ewertz & Jensen, 2011). Cancer treatment may increase the risk of developing other chronic conditions such as obesity, hypertension, diabetes and decreased bone mass (Montazeri et al., 1996). Certain events, such as new onset pain, annual mammograms and check-ups, can trigger distress and anxiety about the possibility of cancer recurrence (Gil et al., 2004). According to Smit et al. (2019), women are never able to fully return to their pre-cancer lives.

It was found that individuals living with breast cancer develop a positive attitude towards taking greater control of their lives and reprioritising their life choices (Gibson

et al., 2015; Hajian et al., 2017; Rajagopal et al., 2019). Among the strategies people might employ to make sense of their breast cancer diagnosis are dietary changes, self-educational growth, social engagement (Rajagopal et al., 2019) and volunteering to assist others (Rajagopal et al., 2019; Schreiber & Edward, 2015). Other studies of the lived experience of breast cancer individuals emphasise the crucial roles of support and spirituality in the meaning-making process (Casellas-Grau et al., 2016; Goyal et al., 2019; Koenig, 2015; Schreiber & Edward, 2015; Williams & Jeanetta, 2016). Several studies focus on the importance of religious/spiritual coping of individuals with breast cancer towards meaning making (e.g. Gall & Bilodeau, 2020; Paredes & Pereira, 2018; Patoo et al., 2018; Post et al., 2020; Swinton et al., 2011). Post et al. (2020) found that spiritual re-evaluation may help people with cancer transform suffering into growth and psychological wellbeing. Frankl asserted that suffering can be transcended by a conscious search for meaning to exceed one's challenges and limitations (Post et al., 2020).

Depression is a mood disorder (Bernard, 2018; Doktorchik et al., 2019) with symptoms such as sadness, fatigue, poor concentration, disturbed sleep patterns, loss of interest and loss of appetite (Doktorchik et al., 2019). Wang et al. (2003) posited that depression is a chronic condition that can impair daily functioning and lead to disability. A number of researchers have reported a strong link between chronic illness and depression (Alderson et al., 2014; Engum, 2007; Engum et al., 2005; Nabi et al., 2010; Liew, 2012). This is why depression is included in the discussion of the studied CDs. Evidence suggests that depression can exaggerate responses to CD symptoms and demotivate people to care for and manage CD symptoms (Kessler et al., 2003).

Alderson et al. (2014) found that PwCD have certain beliefs about depression. They do not understand that their distress might be depression and have fears about stigma and taking medication. Most importantly, depression is perceived as a threat to a person's self-identity, and this may lead to people avoiding the diagnosis of depression (Alderson et al., 2014). Since depression leads to impaired cognitive functioning, it affects an employee's time management and productivity (Backenstrass et al., 2006; Cuijpers et al., 2004; Jain et al., 2013; Stander et al., 2016). By addressing mental health in the workplace, depression can be better identified and addressed (Goetzel et al., 2018) because it affects many areas of a person's life (Kessler et al., 2003;

Stillley et al., 2004). This can be done through programmes that are based on integrated care models and the offering of services such as EAPs, thus reflecting the experiential value.

Skin, nails and joints are all affected by the systemic, immune-mediated, chronic inflammatory disease known as psoriasis (Le Roux & Frow, 2020), which affects a person's quality of life (Higgins, 2017). The clinical signs of psoriasis include distinct pink to red blotches with silvery surface flaking that can range in size from small to large, and these patches may be itchy (Le Roux & Frow, 2020). The elbow, knees and scalp are the most often impacted sites (Kelley, 2015). Itching, burning and pain may be symptoms of psoriasis (Ljosaa et al. 2010). Physical discomfort will increase with the severity of the disease (Owczarek & Jaworski, 2016).

Previous studies have suggested that breast cancer patients may be more susceptible to skin conditions and infections (Brand et al., 2016; Yoshikawa et al., 2014). Yang et al. (2017) supported this idea, suggesting that psoriasis may develop after breast cancer therapy because some medicines can have dermatological adverse effects. The location of the affected area may influence a person's psychosocial functioning. If the skin lesions are visible to others, this has a negative effect on the person's quality of life (Jankowiak et al., 2020).

The appearance of the skin plays a key social role for people with dermatological diseases because appearance is part of the process of identity development (Meneguin et al., 2020). The skin also plays a vital role in establishing contact with another person (Meneguin et al., 2020; Shenefelt & Shenefelt, 2014). People with limited awareness of psoriasis believe it is contagious (Jankowiak et al., 2020). Owing to the appearance and social discrimination of the disease, strategies to avoid public exposure and social circumstances are employed (Khoury et al., 2017, Menequin et al., 2020), like wearing clothes that cover the skin lesions to avoid having to explain them (Menequin et al., 2020), and also limiting social interaction (Dures et al., 2017).

Social discrimination and stigmatisation may contribute to the social isolation of individuals with psoriasis (Jankowiak et al., 2020; Langley et al., 2005). Depression, anxiety (Dalgard et al., 2015; Magin et al., 2009), embarrassment, shame, impaired self-image and low self-esteem are some of the psychological effects of psoriasis

(Magin et al., 2009). These effects of psoriasis differ from person to person, since every individual responds to their illness differently (Jankowiak et al., 2020). According to Chan et al. (2017), individuals with psoriasis may find it easier to embrace the disease and illness experience as a part of their lives by using active coping strategies such participating in social activities, adopting healthy lifestyles and thinking positively.

Dinah described her journey with breast cancer in detail and it was evident that the diagnosis with cancer has been the most pronounced CD for her. She has been living with breast cancer for 14 years. She is in remission but still lives with the fear of recurrence, the side effects of the cancer and the treatment thereof. In her journal she wrote, inter alia, about total fatigue, nausea, headaches, heart palpitations, emotions, anxiety, earache, bladder and bone pain. She spoke of "*loss",* specifically the "*loss of a breast*", "*loss of sexuality*" and health as major concerns. Studies have shown that breast cancer affects various aspects of a woman's sexuality, including changes in sexual function and intimacy (Jeng et al., 2020; Panjari et al., 2011; Raggio et al., 2014; Reese et al., 2020; Rowland et al., 2009) and the perception of femaleness (Wilmoth & Ross, 1997).

Dinah worked for 11 years in a governmental organisation where she developed training material and conducted training. She decided to change careers when she was offered a half-day position, which benefited her by allowing for more time with her children. She entered the private sector and worked in exports and marketing for six years. She described the work as corporate, competitive and a "*harsh world*". Dinah was "*one of the few females there*" and she described it as follows: "*you talked business … the emotional side was totally absent*". It was during this period, that she was diagnosed with breast cancer, which was unexpected as she had been living a healthy life:

> *Deep inside I am a positive human being. At that stage [of cancer diagnosis], I was a relative healthy person ... the question was not why me, but rather where did it come from?*

She approached it from a problem-solving perspective, namely that "*it's something that does not belong in your body. It needs to be removed*". When she underwent surgery, she became highly emotional and could not stop crying, and she jokingly said

that she felt that the hospital had discharged her because of that. The treatment of the breast cancer, especially the chemotherapy, was extremely difficult for Dinah. She described this period of her life in detail and it was evident that it was a challenging experience for her. This was illustrated by her mentioning that the treatment for cancer she received "*drove*" her "*crazy*". She also went on to say that her admission to hospital "*was terrible*" and that she first experienced "*real depression after the cancer*" diagnosis. She explained that she had to "*force*" herself to "*try to do things although it felt*" as if she was "*going to die*". It was an emotional time for her and "*once*" she just "*went to sit in a corner*" and "*cried*".

Dinah described the pain and emotions she experienced during the chemotherapy treatment as excruciating. Studies have shown that chemotherapy is a traumatic experience for some breast cancer patients and that some of them suffer severe physical side effects from the treatment (Liu et al., 2021; Suwankhong & Liamputtong, 2018). At work, things also did not go well for Dinah. She found that "*the corporate world is meaningless*". She resigned, and as things worked out, she and her family moved to another province. Dinah said it was a conscious decision to resign:

> *I decided, I'm not going to stay here any longer. It was a conscious decision to choose a better life. The job no longer made sense; it was extremely stressful. It had been a chase after money.*

She was now at a point where she had to decide what she was going to do with her life. She wanted to make an impact in the world of chronic illness, of which she now was part, and started working at a nonprofit organisation (NPO), where she has remained for 14 years. She described the first years of this new career as terrifying because she had to work with "*extremely ill people*".

Dinah found it a hard learning process to be emphatic and to work with extremely ill people. She took several courses that taught her "*how people's inner beings worked*" and relied on her "*unique instinct*". She mentioned that her work situation caused her to increase her antidepressant medication because she was totally burned out as a result of all the work stress she could not handle. The internal politics were greater than the purpose of the work. During this time, Dinah's father passed away and this was a final breaking point for her. She decided to resign from the NPO:

One day, I was in a counselling session with a patient. When I walked out of there, after the session, I was fine. I then went to Pick n Pay to buy bread and milk, and there I got an unbelievable anxiety attack. And it was then that I decided to put an end to my involvement with death and dying. I have given my all. I am empty. I have nothing more to give.

After her father's death, her mother came to live with her, and Dinah now also had the responsibility of taking care of an ageing parent's needs. Owing to the extreme demands of her work and responsibilities at home, she experienced that she could not "*objectively continue with her work*". She resigned and is now self-employed and creates arts and crafts which she sells online and in person.

Dinah also has depression and this is intertwined with her breast cancer and psoriasis journey. She claimed that although she had always experienced depression and was able to cope with it, the onset of her chemotherapy treatment caused her to experience severe depression that required medication. She claimed that the most recent situation at work had been so demanding that she had been compelled to take more medication. She views her depression as a lifelong illness that will require medication for life because she does not want to be in "*that dark pit*". Dinah feels it is the way that she has been "*programmed inside*" that has caused her illnesses. When we started the interview, Dinah told me that she was "*in a bad spot in her life*". We discussed counselling options as well as the possibility of postponing the interview. She chose to continue with the interview. Dinah is a person I am familiar with, and this contributed to her feeling safe and free to continue or terminate the interview should she experience any distress.

She was diagnosed with psoriasis during the time she worked at the NPO. Psoriasis is regarded as a common disease (Neiman et al., 2006), and it is estimated to affect 2% to 3% of the total population (National Psoriasis Foundation, n.d.). Dinah blames work-related stress for the onset of this disease. It is a visible CD, and Dinah mentions the tendency for flare-ups that happen when she is in a stressful situation or in extremely hot and dry conditions. Red patches appear on her hands, feet, elbows, knees and legs, which she described as, "*itching, burning, and looking terrible*". Dinah mentioned that "*to the next person, it looks very bad*". She covered her patches by wearing "*finely crocheted mittens*" and clothing with longer sleeves to cover the

patches. She said that it is bothersome when she interacts with people who stare at her red patches. That is why she covers them up. Dinah anticipated stigma and remained silent about her psoriasis diagnosis at work. Psoriasis has been found to be cosmetically disfiguring, and consequently leads to social stigmatisation (Chen et al., 2018; Feldman et al., 2014). She mentioned the hurtful comments that people at work made about her red patches and her reaction to it: "*I did not discuss this with people at work. They would say, 'oh you look awful', and I would reply, 'yes, it is because you drive me crazy'!*"

Dinah had considerable training on the effects of CDs on people because her job required her to work with individuals who have a variety of chronic conditions. As a result, she is prepared to understand and manage the demands and challenges of her own chronic conditions.

5.5 CHAPTER SUMMARY

In this chapter, the three cases were introduced by first explaining each participant's different CDs and then providing background information about the participants. It would seem that living with different chronic conditions presents diverse demands and challenges. The effect of living with two or more diseases simultaneously can be profound (Stafford et al., 2018). Scholars have found that the symptoms of MCC can aggravate each other, resulting in a greater negative effect on people's daily lives (Liddy et al., 2014; Lim et al., 2017; Vogeli et al., 2007; Zulman et al., 2014).

The elucidation of the three cases indicated the variety and complexity of the data they provided for understanding the multifaceted phenomenon of living with a CD. It also provided the reader with detailed information on the participants to demonstrate that their cases could be used to achieve analytical insight and that transferability judgements about the study's findings might be made. Chapter 6 focuses on the findings.

CHAPTER 6
FINDINGS

6.1   INTRODUCTION

The aim of this study was to explore, describe and explain how people make meaning while living and working with a CD, in order to develop an organisational support framework to facilitate and enhance the wellbeing of employees with CDs. The research questions focused on how individuals make meaning while living and working with a CD, and what enhances meaning making for them. The purpose of this chapter is to elucidate the essence of the studied phenomenon (Bengtsson, 2016) in response to the research questions and within the defined boundaries (Njie & Asimiran, 2014), as described in Chapter 2, Section 2.6.3. The case study boundaries were as follows: to include only three cases, use Frankl's meaning-making principles as the guiding interpretive framework, utilise research questions and a priori propositions as the basis for data management and adhere to a timeframe of six months to collect data.

The findings of this study are structured thematically in this chapter according to the propositions derived from Frankl's meaning-making principles for each of the cases as illustrated in Figure 6.1. Five overarching themes are presented for each case. The first three themes for each case relate to the first proposition that individuals living and working with a CD make meaning by following Frankl's meaning-making pathways. The three themes thus reflect individuals' respective meaning making by using the creative, experiential and creative pathways. The fourth theme for each case relates to the second proposition, which entails that meaning making for individuals living and working with a CD is enhanced by living out the capacity of self-transcendence. A fifth theme was constructed because the data for each participant was poignantly filled with narratives around identity disruption caused by the CD diagnosis and the participants' response to negotiate identity continuity.

The chapter concludes with the presentation of a thematic framework resulting from the cross-case synthesis, which was described as part of the data analysis process in Section 2.6.6 in Chapter 2. The cross-case synthesis was conducted by using the pattern-matching technique, as illustrated in Figure 2.2 in Chapter 2,   within the conceptual framework of Frankl's principles to identify emerging patterns, compare

them with the propositions for the study, as well as with assertions and claims made by other theories and literary sources. In conclusion, the resulting cross-case synthesis is highlighted as a summative integration of the findings. Figure 6.1 contains a summary of the themes and sub-themes and indicates how the findings are presented in this chapter.

Figure 6.1

Presentation of findings
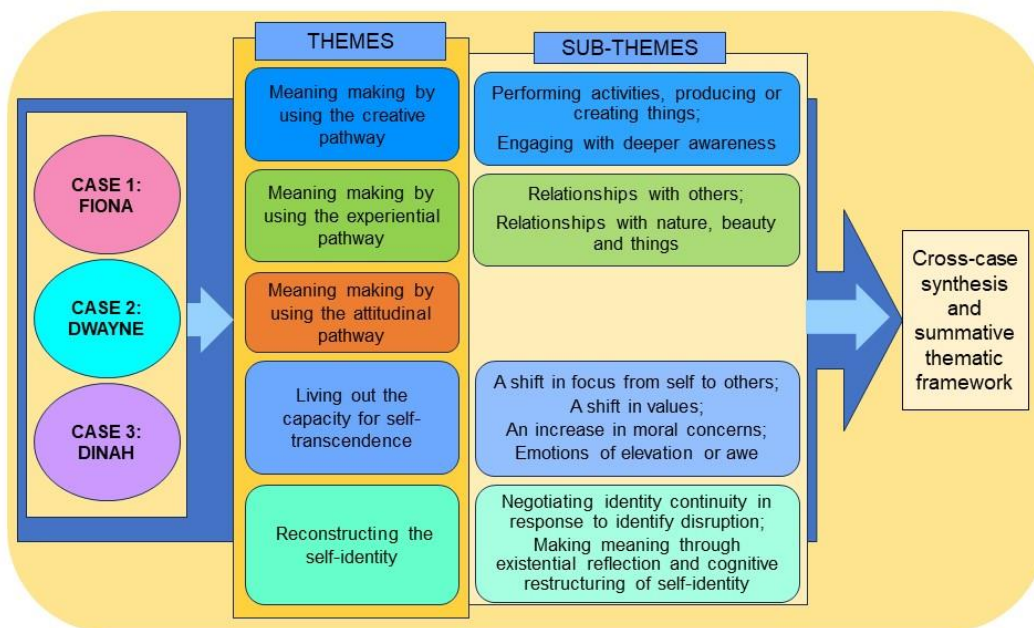
The data from this study was triangulated by analysing data from interviews, document analysis, diaries, image-based methods and observations. My observations, which were recorded as handwritten field notes, incorporated reflections of my own feelings, actions and responses to the situations observed, and are embedded within descriptions of the findings.

6.2   CASE 1: FIONA

The first case, Fiona, has AA, which is a condition of hair loss that can affect the scalp and body (Aldhouse et al., 2020). The impact of AA has a significant psychosocial toll beyond superficial issues, and managing AA is seen as a daily challenge (Aldhouse

et al., 2020; Davey et al., 2019; Mesinkovska et al., 2020; Welsh & Guy, 2009). Davis and Callender (2018) have reported that some of the threats to the identity of a person with AA are feelings of isolation, shame and impaired social functioning, and also that the methods a person uses to conceal hair loss could create a feeling of inauthenticity. At the time of this research, Fiona had had this condition for more than 30 years. She recently left the formal working sector and is now self-employed. The majority of the information was drawn from an article Fiona wrote for a magazine. I first contacted her telephonically and she expressed her preference to be interviewed via email. Follow-up conversations and questions were handled via telephone, email and the multi-platform messaging application WhatsApp.

Fiona was reserved during our interactions, preferring not to share too much information about herself, holding back on her emotions and only sharing information she perceived to be relevant and in line with what she had already mentioned in her article. The reason for her reticence might have been that she did not want to further expose herself to the possibility that she might be identifiable because of her article in a well-known magazine. Other reasons could have been that she is naturally reserved and because of her professional role, was cautious about providing more information than she deemed necessary. During the data collection period, Fiona was faced with challenges such as losing her job and her father suffering a stroke. She asked not to be contacted for a period of time to allow her to process this. After mutual consideration, we decided that further communication would be done via email and WhatsApp. Fiona responded to my follow-up questions concerning clarifications as much as her circumstances allowed, but she ceased communicating after August 2021. Because further communication would have been considered intrusive, I acted ethically and respectfully by being content with her given responses. In her last communication, she mentioned that she had contract work and was therefore still fulfilling a role in the formal work sector.

6.2.1 Making meaning by using the creative pathway

When one creates something of value, one experiences oneself as meaningful (Geldenhuys & Johnson, 2021; Martela & Pessi, 2018). The creative pathway relates to the value people experience from their contributions to life, which involves finding one's true nature and a sense of personal fulfilment (Pattakos & Dundon, 2017a).

According to Wong (2016b), the creative pathway involves people taking advantage of opportunities to maximise their ability to live a life of purpose. Meaning making through the creative pathway will be examined by identifying patterns that indicate the performing of activities, producing or creating things and the participants engaging with a deeper awareness (Frankl, 2008; Pattakos & Dundon, 2017a).

6.2.1.1　Performing activities, producing or creating things

Fiona experienced her work as significant and "*enriching*", which contributed to her overall sense of meaning (Burger et al., 2013; Martela & Pessi, 2018; Steger et al., 2010; Ünal & Turgut, 2017). Her work in the formal working sector afforded her the opportunity to engage with a greater purpose by creating something and being in charge of producing a commercial output that reached and influenced a large number of people. She found meaning in work by engaging in the work itself. Fiona emphasised her competence and creativity, stating that she "*always loved colour and to create something with"* her "*hands",* and thus found her "*official work as an enriching ten years of"* her "*life.*" Working as a self-employed artist, she still enjoys what she "*creates now even more*". Fiona discovered that she could have an impact on others not only through her work, but also through her example of exploring the "*wider world"* and her enjoyment of travel. She has been able to create something lasting, a legacy, by passing this value on to her children (DeAngelis, 2018; Stringer, 2014):

> *My children see the world, and not South Africa, as their home. Clearly this exploration of a wider world is something that I transferred to them. It is nice to be able to travel and to live in other countries, because to remain in one place for the rest of my life would have been ultimately limited.*

Stringer (2014) described travelling as a conscious legacy through which the wonder of living and the hope of a satisfying future can be passed on. Travel is more than just a journey across landscapes and cultures; it is also a journey in which one can experience the world in a new light by exploring those who live, think and behave differently (Salazar, 2015). Fiona believed that she had "*transferred*" this "*exploration*" of other places, cultures, traditions and ways of living to her children. Leaving a legacy is a goal that makes life meaningful (Emmons, 2003) in that there is a belief that life has a purpose and there is a need to leave something positive behind (Hunter & Rowles, 2005).

6.2.1.2 Engaging with a deeper awareness

After Fiona left the formal labour sector and became self-employed, she engaged with a deeper awareness by using her uniqueness and creativity to produce something of value for herself and others:

> *This is now my real work and I enjoy it so much that it does not feel like work. I lose myself in it and can paint for hours on end without getting tired … it gives me energy, calmness and is intensely satisfying.*

Fiona described how she had completely immersed herself in the activity of painting, thus experiencing flow and a state of complete immersion (Csikszentmihalyi, 1990, 1996, 1997). This total participation and interaction in the activity of painting, indicated Fiona's level of engagement and a sense of flow, and thus her experience of meaning making (Doyle, 2017; Osin et al., 2016).

Despite her relief at no "*longer being subject to it*" [negative working conditions], she returned to the workforce as an independent contractor following her "*forced*" retirement. Fiona stated that "*work never defined*" her and that the financial aspect "*does not play an important role at this stage of*" her "*life,*" implying that her motivation for work stems from other things such as the desire to still make a contribution, stay active or connect with others. She used the freedom and autonomy of her self-employed status to create flexible work opportunities that provide meaning and self-fulfilment.

In the discussion of Fiona's use of the creative pathway, it is clear that many of the values explained also have something in common with the experiential and attitudinal pathways. The interaction between the various pathways occurs when the values assigned to one pathway have an effect on the others. Fiona's travel experience, for example, demonstrates not only the creation of a legacy, but also an attitude of opening herself up for exploration and the experience of nature and beauty that provided her with a sense of significance and meaning.

6.2.2 Making meaning by using the experiential pathway

According to Wong (2016d), individuals are driven by love and compassion because they have a longing to connect with one another and with a higher force or the cosmos.

Individuals are able to connect meaningfully with someone or something by employing the experiential pathway – hence the fact that relationships are a component of the experiential pathway. Experiential values represent individuals' relationship with others and natural beauty (Uemura, 2018). Meaning is realised as a result of experiencing beauty, truth and love (Pattakos & Dundon, 2017a; Wong, 2014b). The patterns for using the experiential pathway were matched by looking for examples of relationships with others, life and nature.

6.2.2.1   Relationships with others

Feelings of love from others have been linked to improvements in psychological wellbeing (Oravecz et al., 2020). Martire and Helgeson (2017) stressed the notion of close relationships in fulfilling a vital role in managing life with a CD. Being loved lessens the burden of living with a chronic illness because it makes a person feel cared for and less alone. Fiona expressed the value of the support and love from her husband by saying that her "*hair loss never bothered"* him, and that to him she is *"the most beautiful, cleverest, cutest, sexiest woman on earth".* She had felt her husband's care and continuous support when she *"lost"* her *"hair for the second time around"* and felt that *"loneliness was not part of the process"* because her "*husband always holds"* her hand. Fiona has experienced meaningful relationships with others in that she has *"people to love and who return the love".*

Fiona found meaning at work through her interpersonal relationships and interactions in the work context (Pratt & Ashforth, 2003) by experiencing a meaningful connectedness with her female colleagues at work: "*I worked with a wonderful team of women and it was an ultimate enriching ten years of my life."* Fiona clearly differentiated between her experience of relationships with women and men at work. Fiona expressed her strong dislike for male colleagues by stating that she had been required to work with "*sexist, arrogant men in top management who had warm air for brains*". I did not have the opportunity to question Fiona about her strong feelings towards her male colleagues. I surmised from the criticism she faced as a result of her hair loss and use of head scarves that she felt more at ease interacting with women who were more considerate and thus accepting of her appearance.

6.2.2.2   Relationship with nature, beauty and new things

In the literature, travel is associated with an experience of nature, beauty and new things (Chen & Petrick, 2013; Sonnentag & Fritz 2007). Hence in this study, travelling was also deemed an experiential pathway. Fiona underscored the exploratory experience of travelling by saying that "*it is nice to be able to travel, and also to reside in other countries, because for me to remain in one country for a lifetime, would have been very limited*". She experienced travelling as an "*exploration of a wider world*." Fiona has been receptive to new events, information, experiences and realities that travelling presents (Brown et al., 2007). She used self-determination in drawing distinctions when evaluating the information (Bishop et al., 2004; Frauman & Norman, 2004; Iacob et al., 2021; Langer & Moldoveanu, 2000) gathered when she had "*lived for a period in Greece*" to make a decision that "*to retire to a Greek island and spend our* [her and her partner's] *golden years there*" would be beneficial for her.

Fiona used the experiential pathway to make meaning by focusing on the positive and showing her appreciation for meaningful relationships and love, and the beauty and wonder of experiencing a wider world through travel.

6.2.3   Making meaning by using the attitudinal pathway

According to Frankl, people have the freedom to choose an attitude and create a different experience for themselves (Pattakos & Dundon, 2017a). Attitudinal values are people's attitude towards the limitations in their lives (Frankl, 2019). Meaning making by using the attitudinal pathway will be discussed by illustrating the freedom and manner of recovery and adjustment to change through the use of resources and the way in which meaningful choices to manage living with a CD were made.

According to Kübler-Ross and Kessler (2005), when someone loses something significant, like their hair, they experience sadness, which develops into grief. Fiona admitted that the sense of loss was a huge part of her journey. She experienced a great sense of loss and sadness in losing her hair:

> *It is a loss which is accompanied with great emotional sadness.*

> *... That you have lost something is undeniable.*

> *… I miss the wind blowing through my hair. I miss to go* [sic] *to a hairdresser and walk* [sic] *out with a new hairstyle*

Although Fiona has no hair, she demonstrated positivity expressed through humour in saying that every day for her was a "*good hair day*". Her attitudinal values have changed in that she "*does not take anything for granted, does not compare herself with others, is slower to judge, does not waste energy on false hope and discouragement*". She "*does not stress about stuff that she has no control over*" and "*chooses to laugh rather than to cry*". She has rationalised her condition by saying that given the choice, she "*would choose*" her life again, but at the same time, she expressed her loss and longing to have hair: "*One thing I can tell you, if there is a heaven and I am there before you, the woman with the long, lush red curly hair – that is me.*"

She researched the meaning attached to hair to reflect on her loss and develop an alternative less distressing meaning (Davey et al., 2019). She did so by making use of humour which helped her to maintain a positive perspective (Romero & Cruthirds, 2006):

> *What does hair mean? … in all the cultures hair has symbolism and value. The Amish dictate to woman that they are not allowed to cut their hair … they may only braid it in a certain way. I would have been a problem case for them – the elders would have caucused and prayed about this for a while.*

She also outlined the liberating effects attached to cutting or shaving hair to maintain a positive outlook: "*In the twenties … women decided to cut their hair as part of their liberation. Buddhist monks shave their hair to symbolise the insignificance of materialism and also to be free from vanity.*" Fiona emphasised that "*men who become bald, especially at an early age*" also value hair and "*also have to process a loss*". This indicated that the emotions surrounding hair loss were not only a feminine vanity issue.

Although Fiona could not change the reality of her hair loss, she demonstrated acceptance and that she could choose how to respond to it by exercising her free will because she "*knew that the good in*" her "*life far outweighed the negative*". She addressed the challenge of living with AA by creating a different experience for herself

by being positive and using humour, through an attitude of acceptance and by demonstrating self-determination to exercise her free will.

6.2.4 Living out the capacity of self-transcendence

According to Kitson et al. (as cited in Wong, 2016b), self-transcendence can be viewed as a developmental process, motivation, personality trait, psychological state, value orientation and worldview. The characteristics of self-transcendence for this study were adapted from Wong (2016d) and include the following: a shift in focus from self to others (connection with God, nature or others); a shift in values from extrinsic to intrinsic motivation; an increase in moral concerns; and emotions of elevation or awe. Self-transcendence is the will to meaning and is found through creative, experiential and attitudinal values (Wong, 2014b). Self-transcendence is thus intertwined with all three values (creative, experiential and attitudinal).

6.2.4.1 A shift in focus from the self to others

The shift in focus from herself to others for Fiona happened in the form of her focus on the significant relationships in her life. She emphasised the importance of "*people to love and who love back*". Spirituality in the broadest sense is the focus from the self to a connection with something higher than the self. Fiona experienced a shift in focus with her relationship with God. When faced with a threat to one's wellbeing, a naturally spiritual dilemma may arise which requires some form of attention and processing (Vis & Marie Boynton, 2008). When Fiona was in the negotiating phase of her illness journey, she "*cried out to a Higher Power*" and "*promised various things*" if her hair would just grow back. When this did not happen, it "*led to a great struggle within*" her, and she had *"more questions than answers"*. She had once felt connected, but had now lost this spiritual connection (Agrimson & Taft, 2009; Hayes, 2020; Virant, 2019). Because Fiona was faced with a spiritual dilemma, she needed to reframe her prior view (Vis & Marie Boynton, 2008). She expressed this as follows through a change in her spiritual interest (Büssing et al., 2009):

> Maybe there is something supernatural, but I think it is more of an energy than a divine being. Strange things have happened to me that I cannot explain physically, so am I spiritual? – I do think so, but I am not waiting for a saviour.

The existential crisis that illness creates, affects not only one's self-identity, but also one's spiritual identity (Drutchas & Anandarajah, 2014). Spirituality helps one to assign meaning to the reality of one's circumstances (Mattis, 2002) by providing motivation and goals for living (Park, 2013). Spirituality is the process of determining one's meaning and purpose in life, as well as putting one's sincerely held personal beliefs into practice (Neck & Milliman, 1994). The pursuit of spirituality, which may or may not be expressed through religious forms or institutions, is the search for meaning, purpose and connection with oneself, others, the universe and ultimate reality, in any way that a person chooses to understand it (Sheridan, 2004). According to Frankl (1988), spirituality is the component of a person who is in touch with the universe. Spirituality is not only the presence of religious resources, but can also be found in a profound connection with another person and a delight in the beauty of nature or art (Klimasiński et al., 2022). Fiona expressed this aspect of her spirituality, which had strengthened her identity, through her connection with the people she loves (Bożek et al., 2020), and her appreciation of the beauty of art (Ettun et al., 2014), as described in Section 6.2.1.2, and her experience of travel, as mentioned in Section 6.2.2.2.

6.2.4.2 A shift in values

A shift in values followed Fiona's transition from formal work to self-employment. It involved a shift in emphasis from financial incentive (extrinsic motivation) to benefit for herself (intrinsic motivation). She is now self-employed and can follow her creative calling by doing art and crafts. A calling appears to have the following three components: (1) A person feels called to a specific type of work; (2) It allows for the expression of a sense of purpose; and (3) It allows for self-transcendence by directly or indirectly helping others or advancing the greater good (Duffy et al., 2018). The sense of calling beyond the work context is also related to satisfaction and optimal functioning (Wong, 2014b).

Fiona has been able to express freedom (autonomy) in that she is able to manage her own time and schedule: *"I can do things how and as I pleases [sic]"* and is responsible, workwise, only to herself: *"I do not have to jump through nobody's [sic] hoops"*. She has also experienced a shift in values because living with AA has taught her, inter alia, *"to be slower in judging people"*, *"to laugh rather than to cry"*, she *"like [sic] herself just as is"* and she is no longer *"worried, frustrated or angry"* about her loss.

6.2.4.3 An increase in moral concerns

Fiona's self-transcendence enabled her to take a step back from dealing with issues surrounding her CD and focus on something outside of herself, specifically the outside world (Wong, 2016d). She spoke of an increase in moral concerns in that the sense that issues such as "*global poverty, injustice, war, corruption and violence*" elicited "*anger, frustration and concern*" in her. She realised that her own "*concerns, frustration, or anger*" about her hair loss were no longer an issue, and there was a shift to what was going on in her environment and the wider world. She thereby indicated an increased moral responsibility towards the relational world (Wong, 2016d). There was now a reorientation from an inward (self-centred) focus towards an outward (needs and concerns of a wider world) focus (Wong, 2016d) because of her discovery of being part of a wider world.

6.2.4.4 Emotions of elevation or awe

According to Wong (2016d), emotions of elevation or awe are natural responses to something amazing that moves a person. The experience of elevation or awe includes being immersed (Wong, 2016d), as described by Fiona when she experienced "*energy, calmness and intense satisfaction*" in doing arts and crafts. She expressed awe by being inspired by "*the fact that people exist when you consider how incredibly complex our biological composition is*". This led to a feeling of deep gratefulness for physical health and people in her life. Fiona expressed the experience of awe by finding "*joy*" through her deeper connectedness with "*loved one, children, family*" and "*friends.*" Fiona experienced "*the exploration of a wider world,*" as an expansion of her personal boundaries, which she has *"transferred"* to her children. She has been able to transcend by viewing her travel experiences and insights as contributing to a better future by sharing this deeper meaning with her children.

6.2.5 Reconstructing the self-identity

The fifth theme, reconstructing the self-identity, was added because the data for each participant was filled with narratives around identity disruption caused by the CD diagnosis and the participants' responses to negotiating identity continuity. In order to make meaning in their lives with CDs, it was found that the participants engaged in existential reflection – that is, they reflected on what made their lives meaningful,

mobilised cognitive processes and actively engaged in a variety of activities and relationships (Reynolds & Prior, 2003) to reconstruct their self-identities. Two subthemes emerged from the findings on how the participants reconstructed their self-identities, namely negotiating identity continuity in response to identity disruption and making meaning through existential reflection and cognitive restructuring of the self-identity.

6.2.5.1   Negotiating identity continuity in response to identity disruption

Fiona emphasised that "*hair is seen through the ages as a symbol of femininity, sensuality and beauty but more than that, it gives you an identity".* In saying this, she acknowledged that by losing her hair, she had experienced the loss of a known identity (Davey et al., 2019) and had to create a whole new identity, which in time she had to accept as an integral part of her new normal:

> *I had to dig deep in my inner being to seek for that which made me more than the person which I knew until then, the one with the beautiful hair. I had to learn to love this new woman in the mirror who greeted me in the morning. I had to learn to live with the loss.*

Living with a CD poses a challenge to one's sense of self and the meaning of life (Benkel et al., 2020). Different forms of meaning creation take place through different periods of an event (Fivush et al., 2017; Roussi & Avdi, 2008). A person can still have unresolved issues and seek meaning, which Frankl (1969) referred to as existential frustration. Fiona felt that her dealing with her experience of living with AA was "*part of her life story and had time and time again taught her something about herself and life*". In dealing with her life without hair, she encountered a process of discovering her true nature in which she negotiated identity continuity.

Fiona did this by reconstructing her identity through examining and revising her self-concept (Baker et al., 2018; Zafran et al., 2012), reacting to a change in many elements of herself and her changing future aspirations (Ellis-Hill et al., 2008). As she reconnected with her beliefs and reflected on her relationships with other familial and social roles, she was able to negotiate gaps in identity continuity while facing the difficulties and restrictions of living with AA (Ylvisaker & Feeney, 2000). The self-concept, according to Fielding and Hornsey (2016), comprises a personal and social

identity. Living with a CD necessitates a process of reassessment and identity shifting (Karnilowicz, 2011). The illness(es), sociocultural norms, values and attitudes of PwCD shape their identities (Galliher et al., 2017; Oyserman, 2007, 2015; Oyserman et al., 2012). Identities serve as a guideline and a lens for meaning making (Oyserman, 2007, 2015; Oyserman et al., 2012). The better the construction of the identity, the greater its support of one's wellbeing (Toubassi et al., 2023).

6.2.5.2 *Making meaning through existential reflection and cognitive restructuring of self-identity*

Living with a CD raises issues about how it affects one's existence, prompting PwCD to engage in existential reflection in order to gain a sense of continuity and to better understand themselves and their place in the world (Fang et al., 2023). Existential reflection binds the past, present and future together to create a meaningful life (Levy, 2013). It is through existential reflection that one can understand how past events, present perceptions and future expectations influence reality (Harris, 2015; Kaufman, 2018). In her existential reflection, Fiona experienced disillusionment because her assumptions or beliefs were strongly challenged by her real-life experiences (Maher et al., 2021). She expressed her belief that "*hair … gives you identity*". Fiona's real experience is a life without hair in which this belief is challenged. Because of all the emotions, disillusionment and frustration her condition has caused, Fiona has experienced anger-related feelings.

According to Weiten (2010), people tend to vent or project their anger towards others because they suppress it at the real source. In Fiona's responses about her experiences in the corporate world, she expressed a great deal of frustration and anger directed at "*nasty*" people and the opposite sex in top management positions and viewed them as "*sexists*" and "*arrogant*". Accessing her emotional responses is aligned with existential feelings of loss and attempts to regain a sense of self. One could describe this as a diversion of anger away from her disillusionment of living with AA to a substitute target (Weiten, 2010). Maintaining a positive self-image is a vital part of a positive identity (Dutton et al., 2010).

According to Oyserman et al. (2012), the self and identity are typically derived from what matters to others (social context). A person's appearance is altered by AA, which may be regarded as abnormal because it does not conform to the societal norms of

physical appearance (Hunt & McHale, 2005). Hence when one is confronted by a visible CD such as AA, it inevitably draws attention. Fiona mentioned that people directly asked her "*what is going on under her head scarf?*" together with other assumptions, like asking her "*are you now also Muslim*?" She cited another example of "*a woman in the line at the pharmacy shows [sic] sympathy because you have cancer*" She felt that asking about her physical appearance was a "*very personal question*"," but she had to learn to deal with it.

Fiona used cognitive reconstruction to assist her with the process of integrating her CD into her life context (Whittemore & Dixon, 2008). She did this through reasoning, in an effort to rationalise and understand why people do this: "*The reality is that hair is a so-called natural part of a person's body and anything abnormal will make people inquisitive and not necessarily mean.*" Such rationalisation is akin to a cognitive restructuring of her identity. Fiona attempted to maintain a positive self-image by positively reframing people's reactions to her appearance. She did so by focusing on the encounters she had with people of colour who did not ask why she was wearing a headscarf but actually complimented her: "*the women all want to know how*" she "*fold [sic] it and love it*". The men referred to her wearing head scarves as "*Makhosi*". At first, Fiona thought that "*Makhosi*" meant being submissive. She experienced this reference as unrepresentative of her identity and defended it: "*With or without hair, with or without a head scarf, I am not a submissive woman. For that, I am too free. Luckily, I am living with a man who is possibly more of a feminist than I am.*" Defensive responses are another way to either protect or enhance a person's sense of self (Sherman & Cohen, 2006). However, Fiona researched the meaning of the word "*Makhosi*" and found that it "*is a sign of respect and status,*" which strengthened her self-esteem. By focusing on the respect shown to her by people of colour, Fiona felt valued. Fiona's way of making meaning was to deal with unwanted attention towards her AA by reframing it positively, and as such, reducing the hurtfulness of unwanted attention and comments.

Another example of cognitive reconstruction that Fiona used was to compare herself to celebrities, which helped her cope with her loss by creating a feeling of unity, strengthening her self-identity and reducing the feelings of stigmatisation, loss and isolation (Jenkins et al., 2019; Lotun, 2022). Fiona referred to famous celebrities: "*Two*

famous people who also have Alopecia are Gail Porter and Princess Caroline", who have experienced hair loss. According to Linderberg et al. (2011), when celebrities gain prestige, they become more relevant and special. People who are considered special may challenge the norms more than the general population (Stapel et al., 2010). By using celebrity advocacy, Fiona wanted to remove the stigma associated with AA (Hoffman et al., 2017), thus reconstructing her self-identity in this way.

Owing to her CD, Fiona has had to maintain and build her self-identity as well as deal with her changed status from work professional to retiree. Retirement or leaving the workforce is a significant life event (König et al., 2019; Osborne, 2012), especially when it is forced upon one (Hershey & Henkens, 2014). Retirement removes an aspect of people's lives that may be a significant part of their self-definition (Teuscher, 2010). It is an adaptation process which includes changes in identity where past identities may be maintained, changed or discarded while developing new ones (Ashforth, 2001; Bordia et al., 2020; Kloep & Hendry, 2006; Sargent et al., 2013). When certain aspects of PwCD' identities are challenged, as in Fiona's case, they make meaning by diversifying and focusing on other domains of their identity (Teuscher, 2010).

Identity diversity refers to the number of identity domains that people deem important and necessary for a positive self-concept, particularly when certain aspects of one's identity are challenged (Teuscher, 2010). Examples of this would be Fiona's exploration of the *"wider world"* by travelling and even considering emigrating to a Greek island. While travelling, relationships and experiences in other countries can help to reconfigure oneself (Wilson & Harris, 2006).

Another strategy that Fiona used to minimise the change in identity from formal work to retirement was to promote the benefits of leaving the workforce rather than acknowledge disappointment (Osborne, 2012). When asked what role work plays in her life, she commented as follows: "*I was forced to retire with the closing down of the place where I used to work. Work never defined me as a person – I work to live and do not live to work."* Fiona used rationalisation by emphasising the drawbacks of her working environment and claiming that she "*will never miss it".* When one's professional self-concept is shattered, there is a need to protect one's self-image and build a new one (Rowson & Phillipson, 2020; Van Bavel et al., 2020; Williams & Murphy, 2021). Fiona accomplished this by transforming herself from a formal

employee to an entrepreneur by selling her arts and crafts, thereby maintaining a positive self-concept of still being able to make a contribution.

Fiona's negotiation process for identity continuity was evident in the following statement: "*If there is a heaven and I'm there before you, the woman with the long bush of lush red curly hair – that's me.*" In choosing pseudonyms for the characters, I metaphorically pictured the first participant as the character Fiona with the lush red hair in the animated film *Shrek* (Jenson & Adamson, 2001). Using the animation character from the Shrek film to portray her was clarified with the participant in a WhatsApp discussion and she agreed to it. In the film, *Shrek*, Fiona is a beautiful princess who is cursed to transform into a less attractive ogre at night. Fiona's character struggles with insecurities about her identity and appearance before finally accepting herself. In the fourth sequel to the first film, she becomes adaptable and an empowered warrior and leader. According to Elliott, one of the writers, Fiona's storyline delves into "the actual prevalence of attitudes about appearance in society" (Ryfle & Shewman, 2017). She is shown as a strong-willed individual who can take care of herself. The participant's representation of herself and the character Fiona have similarities in that she, too, struggled with insecurities about her identity and appearance before accepting herself; she also adapted and empowered herself as a strong-willed person capable of taking care of herself in society and at work.

6.3 CASE 2: DWAYNE

Dwayne is living with the MCC of AS, asthma and hypertension. AS is a rare type of arthritis that causes chronic pain and progressive stiffness in the spine (Wenker & Quint, 2022), and Dwayne has had this condition for 16 years. He has had asthma, a disease of the airways (Lambrecht & Hammad, 2015), for eight years, as well as hypertension, a consistent elevation in blood pressure (Grassi et al., 2019), for five years. A video call via Gmail was used to conduct the interview with Dwayne. He received follow-up inquiries via email and on the social media platform WhatsApp. I have known Dwayne for many years, and before we began the formal interview, we shared some amusing incidents that had happened to us during virtual meetings. This put him at ease, and we were able to begin the interview with him feeling at ease and relaxed. We also discussed the interview format and agreed that we would conduct it

in such a way that he should assume I know nothing about him, his situation or CDs. I also assured him that he could end the interview at any time if he became emotional, uncomfortable or upset. I also stated that if that happened and he desired it, I would make arrangements for counselling. I did not notice any emotional issues during the interview. After the interview, I repeated the offer of counselling, which he declined, as he stated that discussing his illnesses was not an issue for him.

This was a difficult interview because I know Dwayne well and did not want to impose or assume any opinion, idea or perception about him. It was difficult for me to maintain objectivity. During the interview, I concentrated on holding back and listening, affording Dwayne the opportunity to narrate. Other methods that I used to maintain objectivity were to compare data from the interview with my personal notes as well as with his journal entries, and to follow up to ensure that I understood Dwayne's meaning making. At times, I had the impression that he only provided information that he thought would be adequate for the study rather than raw, honest information. He was reserved and specifically downplayed the emotional aspects of his CDs in order to maintain an image of health and autonomy (Clarke et al., 2008).

6.3.1 Making meaning while using the creative pathway

According to Frankl (2008), meaning can be discovered by creating a work or doing a deed. This is a way to achieve or accomplish something (Frankl, 2008). The creative pathway consists of achieving tasks (Devoe, 2012) in performing activities, producing or creating things and engaging with a deeper awareness.

6.3.1.1 *Performing activities, producing or creating things*

Dwayne engaged purposefully in his job and experienced his work as enjoyable and challenging. When, for example, he had returned to work from vacation, he said that "*there were many challenges waiting at work, but I enjoyed it*". Dwayne felt valued and appreciated at work: *"I frequently receive praise from the manager for promptly completed work as well as for my problem solving abilities."* He mentioned that "*co-workers have nominated me for a certificate because of my prompt handling of administrative problems".* Individuals with a CD have to adapt to the new situation and continue to adapt as they encounter new challenges and restrictions (Charmaz, 1995; Whittemore & Dixon, 2008). Dwayne accomplished this by performing and adapt in

his work to overcome the limitations of his CDs. Dwayne adapted to his life with AS by using job crafting to expand his activities in the workplace to include observation by walking around, which serves to provide him with unfiltered, real-time information and at the same time satisfy his desire for exercise in order to maintain his mobility. He expressed pride by sharing the positive feedback he received at work, which increased his feelings of competence, self-worth and self-esteem (Bedrov & Bulaj, 2018; Cast & Burke, 2002; Peifer et al., 2020). According to Fryers (2006), personal identity and self-esteem are closely intertwined and arise from a sense of personal value and worth. Besides the work context, Dwayne participates in and excels at physical activity, which increases his personal value and worth, as indicated in the following remarks:

> *… I was really motivated during workouts.*

> *… I had a good workout session last night at CrossFit.*

> *… I find that I am in another head space with CrossFit.*

Because Dwayne has had to face a threat to his mobility and general health, he focuses on his achievements in other areas, such as being a skilled worker and a weightlifter, to demonstrate that he matters and can make a difference (Sherman & Cohen, 2006).

The expression of creativity is often used to create a legacy (Kaufman, 2018; Kapoor & Kaufman, 2020), especially when it is socially valued and recognised (Sligte et al., 2013). Dwayne's desire to be recognised as a role model and for having made a positive impact on others served as an example of his need to leave a legacy: "*It is important for me to be a positive role model",* and *"I think I'm destined for more than what I'm experiencing right now. I believe I still have something to contribute to people's lives*". A legacy can also be established through the creative output of one's work or through the mentoring of others (Kapoor & Kaufman, 2020), which Dwayne wishes to do by setting an example to co-workers, as indicated in the previous paragraph.

Owing to his physical condition, Dwayne encountered a challenge relating to his workspace, but instead of complaining, he made an inexpensive adjustment to his office space to accommodate his chronic back pain. He did this by *"packing boxes on*

the desk to adjust the height" of his *"workstation"* and *"provided a raised chair to easier alternate between sitting and standing".* This not only benefited him, but it also aligned with his personal goal of independence (autonomy): *"I believe they* [my co-workers] *would say that I do not want to be given special treatment; I can take care of myself. I don't need anyone's sympathy or assistance".* He created meaning by accepting responsibility for his own wellbeing, and in doing so, hoped to demonstrate to others that he was self-sufficient, and thus set an example for them.

Dwayne also "*likes"* to be creative by "*doing small projects around the house"* and gardening. According to Kaufmann (2018), when one engages in creating something positive, like doing projects or creating something beautiful such as gardening, it makes one aware that life is worthwhile and valuable and that one has the potential to help others (Kaufman, 2018).

6.3.1.2   Engaging with a deeper awareness

Dwayne considered his formal work purposeful and, as a result, engaged with a deeper awareness by stating that he "*enjoyed work"* and the "*challenges"* it offers. According to Vanderweele (2017), most people tend to thrive and feel that life is worth living if they have a sense of fulfilment, such as engaging in meaningful activities and work. Dwayne gained a deeper awareness, as well as "*enjoyment"*, in his engagement with "*teaching young people at church"*. His volunteering to teach children in his free time is an example of a calling stemming from his desire to be a role model and a positive influence in others' lives. This is an example of a creative activity that contributes to the feeling of creating and giving something to others, and it adds meaning to one's life (Van der Walt, 2017). Dwayne further engaged with deeper awareness in his exercise regime to accomplish his objective of enhancing his fitness and body. Engaging with a deeper awareness is linked to a positive attitude (see attitudinal pathway below), which Dwayne demonstrated by highlighting the areas in which, as a result, he experienced positive feedback.

6.3.2   Making meaning through experiential values

Meaning can be found in the interaction with others (Pattakos & Dundon, 2017a) as well as in experiencing something positive or pleasant (Längle, 2001). According to Längle (2001), when one truly encounters another person or engages in something

valuable, such as enjoying music or nature, one realises meaning. Dwayne realised meaning through experiencing things that were valuable to him.

6.3.2.1   Relationships with others

Dwayne demonstrated the experiential value that also enhanced his sense of self through his connectedness. He experienced a feeling of belonging, relatedness (Eassey et al., 2020), connectedness and value through some of his relationships (Kristjansdottir et al., 2018; Sloan et al., 2017). He values his family and loves to spend time at home and with them: "*I had some leave and spent it at home doing fun things with the kids." "There is no better place*" than *"home."* This underscores the significance of having a loving family and a place where he can rest and be himself without pretending to be well when his body tells him otherwise.

Connecting with children at church, resulted in an experience of prosocial behaviour, which Dwayne regarded as purposeful: "*It* [teaching children at church] *gives me meaning and balance, as well as an opportunity to be charitable".* Dwayne experienced social connectedness in his interactions with people at the work, gym and church. At work, Dwayne thrived on feedback from co-workers. For example, "*if you want something done, ask 'Dwayne'",* indicating the value he placed on being respected and regarded as a productive worker. He also mentioned that his "*colleagues trust*" him "*because they do not hesitate to ask*" his *"advice or to seek"* his *"counselling"*, indicating a connectedness of trust and friendship in the workplace that boosted his feelings of purposefulness and self-esteem. Dwayne stated that he felt grateful when receiving positive comments about his physique at the gym where he worked out because it boosted his self-esteem. Dwayne's need to belong was evident in his participation in social groups such as at church and the gym. As a result of his unity with others, he discovered that he could form satisfying relationships and thus experience connectedness, acceptance and appreciation.

At work Dwayne did not disclose his CDs to his employer because he did not perceive them to "*influence"* his work. This indicated his fear of losing his work identity (Markle et al., 2015), which would have undermined his professional role, or that there might be a lack of understanding on the part of others (Ganesh & Lazar, 2021). By concealing his MCC it was difficult to attain the needed workplace accommodations and support needed (Beatty & McGonagle, 2016; Earnshaw et al., 2012). He therefore

had to arrange his workplace and equipment by using his own limited resources, as mentioned in Section 6.3.1.1. Relationships are influenced when there are concealments which may cause anxiety, frustration and anger, as demonstrated by Dwayne.

Dwayne expressed feelings of anger and frustration, which led to diminishing relationships. He mentioned that he "*often gets angry when people disrespect or second-guess*" him. The action he took on such occasions was "*to keep quiet*", which later led to "*an outburst*". His anger stemmed from his belief that he had been treated disrespectfully, prompting his desire to re-establish that respect and thus maintain his self-image (Smedslund, 1993). His anger-related behaviour always had "*negative consequences*", which resulted in him "*apologising*". It is clear that authentic connections were more difficult to form as a result of Dwayne's selective disclosure of his CDs and the consequences thereof, as well as his anger-related behaviour.

6.3.2.2   Relationship with nature, beauty and new things

Dwayne experienced the value of being in nature by gardening: "*Saturdays I do gardening*"; by enjoying music: "*Sunday I went to church and enjoyed gospel music*"; and enjoying the sea: "*We took a break to the coast where we recharged a little by dipping our feet in the seawater*". Being in nature, outside the working environment, gave Dwayne an outlet in that he did not have to pretend and could just be himself. Dwayne valued his leisure time and found it to be a time where he could relax and enjoy his connectedness with nature and beauty, focusing on something other than his life with chronic illnesses.

Dwayne asserted that he "*is more aware of trying new things*" than the "*normal person*". A case in point is his experimenting with various methods to improve his health. For example, he tried new technology to trace his movement frequency: "*I started to use a smartwatch*", and his willingness to experiment with various exercise regimes like "*cardio*", "*weightlifting*" and "*CrossFit*" to improve his wellbeing. Living with MCC compels people to make certain changes in their lives, seek new meanings and reassess things. For Dwayne, the prognosis of AS has the potential to affect his mobility and, as such, this would have life-changing effects on him and his family. He therefore found himself more receptive to new things to increase his wellbeing.

6.3.3 Making meaning by using the attitudinal pathway

Attitudinal values have to do with one's basic outlook on life (Längle, 2001). According to Pattakos and Dundon (2017a), Frankl has taught us that everyone has the freedom to choose an attitude towards whatever is happening in one's life. They suggest that letting go of a negative attitude releases energy that could be used to connect meaningfully with others.

Dwayne adopted a positive attitude of *"keep on moving"*. He also mentioned his acceptance of the outcome of his AS and the fact that he cannot change it. It was evident that he had come to terms with the reality of the situation and demonstrated an attitude of acceptance: "*I have taken an attitude of it is what it is, so much so that if someone does not remind me of it, I even forget about it."* Dwayne's way of dealing with his CDs has been to not ask the hypothetical question, "W*hy me?*" He has experienced his CDs as a challenge and he wants to confront them: "*I want to be the first guy to beat AS or who can exercise himself out of a blood pressure problem."* Dwayne used self-determination by exercising because he valued the health benefits.

It is evident that Dwayne did not want to be pitied or have any special treatment because of his CDs. He wished to be treated like any other person and he has actively tried to shape his life around his MCC. This indicates another way of trying to restore a sense of normality: "*Does not need anyone's sympathy or help to do things".* He believed he is "*destined for more*" and has the ability to make a difference in other people's lives. He also gave the following advice to other people with similar CDs, expressing the importance of acceptance in his attitude to life:

> *We all have something. Your something is this. Accept it, research it, comprehend it, and try to discover solutions to manage it. Accept it and move forward. Nobody will sympathise with you or give you any special attention. Remember, the weak are banished for extradition in the animal realm. So make up for it* [the CD] *by remaining strong.*

Despite his struggles with three different MCC, Dwayne exemplified self-determination by accepting what he could not change, setting goals for himself, engaging in problem solving and giving his life meaning by focusing on the positive aspects of it, such as

being seen as a role model by others and striving to maintain his health and self-identity.

6.3.4 Living out the capacity of self-transcendence

The practice of focusing on someone or something other than oneself is known as self-transcendence. To effectively help others, one must go beyond one's own needs (Pattakos & Dundon, 2017a), and this entails a shift in focus from the self to others; a shift in values from extrinsic to intrinsic motivation; an increase in moral concerns; and emotions of elevation or awe.

6.3.4.1 A shift in focus from self to others

Dwayne transcended himself by shifting his focus to help others. He did this by interacting with children at church, where he could impart knowledge and help to intentionally influence young minds. He shifted the focus from himself by spending some of his leisure time preparing for and attending these classes. In the shift of focus from himself, he saw a way to focus on how he might influence others. He experienced exercising at the gym as a way to encourage people: "*An elderly lady at the gym commented that I motivate her because she sees I have issues with movement, but in spite of that, I always work the hardest".* Additionally, he found that he could be helpful to his co-workers by setting an example to them: "*I frequently hear comments like 'If you want something done, ask* [Dwayne]*'."* By helping others, Dwayne went above and beyond his duties at work. In so doing, he also developed his self-worth and self-esteem: "*I think that my colleagues trust me since they do not hesitate to ask my advice or seek my counselling",* he said. Being a supportive colleague can be useful in improving relations and also aiding in the development of others. Dwayne maintained focus on himself as the supportive teacher, motivator and colleague, but in doing so, at the same time helped others and felt good about himself.

6.3.4.2 A shift in values

When illness becomes a part of one's life, a person starts to concentrate on what is important in life. Dwayne had to re-evaluate his work situation because of the symptoms of AS and the specialist's recommendation to "*get a job"* in which he could be more "*active"* and where the work would not further damage his health. He changed careers to prevent further damage to his health and sought a job where he "*could be*

more active". Whenever he changed jobs, he kept the importance of mobility and health in mind: "*I know immobility waits ahead, so I am busy setting myself up*". Dwayne's focus changed from financial gain (extrinsic motivation) to caring for and preparing for his long-term health prognosis (intrinsic motivation).

His relationship with his family has become more crucial to him. He would spend time "*doing fun stuff with the kids*"'. When once asked to "*teach kids at church*", at first he had hesitated, but he then took on the task and experienced it as *"meaningful"* because *"it gives purpose and creates a balance"* and affords him "*an opportunity to be benevolent"*. Dwayne's view of building a relationship and being a positive role model for youngsters can be regarded as a form of positive reappraisal that has increased his personal worth and meaning in life (Park, 2013).

6.3.4.3   An increase in moral concerns

On many occasions, Dwayne stated that he wanted to *"do the right thing".* It became essential for him to be a positive example to others and it was a significant value that enhanced meaning making for him. The increase in moral concerns and the shift in values and focus from the self to others are interrelated in that Dwayne enhanced meaning through self-transcendence by focusing on others, doing the right thing and trying to make a difference in others' lives. Dwayne indicated that he had participated more in religious activities, which indicates that there was an increase in his moral concerns. He mentioned that when attending a religious meeting, he would often *"reflect on the meaning of it for his life".* He reported that this generated positive emotions and had a beneficial effect on his life because when he encountered challenges, he would strive to do the *"right thing".*

6.3.4.4   Emotions of elevation or awe

Dwayne's participation in religious activities led to an elevation in awareness of God, himself, nature and others. During our conversations, Dwayne frequently mentioned sermons that had had a profound impact on him, such as one sermon in which he stated that he believed *"God addresses our attitude"* and that it became clear to him in the sermon that *"we are placed in this world to make an impact on others".* It became clear to me that he has a spiritual elevation, which causes him to focus on doing what is right.

In his journal, he concentrated on his "*gym sessions*", which he kept a weekly summary of for three months, and this put him "*in another head space*", indicating the elevation of his emotion of awe. He could see and experience "*sweet results*" in his physical appearance. Dwayne had feelings of elevation when reaping the benefits of being a "*positive role model*" and "*doing the right thing*", and he asserted that "*striving for contentment*" is what gives meaning to his life. When he spent time in nature and enjoyed its beauty, he expressed feelings of awe. Examples of this were enjoying a "*breakaway to the coast*", "*gardening*", taking his "*dogs for a walk*" and "*listening* [sic] *to music*".

6.3.5   Reconstructing the self-identity

Dwayne experienced an identity disruption caused by living with the visible CD of AS and the additional diagnoses of asthma and hypertension. In this section, the reconstruction of self-identity is expanded upon by demonstrating how Dwayne negotiated his identity continuity in response to identity disruption, as well as how he proceeded to make meaning through existential reflection and cognitive restructuring of his self-identity.

6.3.5.1   Negotiating identity continuity in response to identity disruption

The diagnosis and challenges of daily living with AS are an undeniable reality for Dwayne. According to Maurer (2020), AS is a visible debilitating illness that causes stiffness and damage in the joints affecting a person's flexibility and mobility. Hence living with the condition of AS may influence a person's self-identity because of the visible symptoms of the disease. Dwayne confirmed this by mentioning that he would "*get mocked by people*" because of his awkward gait. Dwayne anticipated stigmatisation in the way that people would see him as not fitting in. He acknowledged that he wanted to be accepted and he took action to achieve this by working on his physique: "*I worked really hard because I wanted to appear like a weightlifter. I feared that people would think I didn't look the part*". He wanted to achieve a sense of normalcy despite his CDs (Joachim & Acorn, 2000; Synnes et al., 2020) by focusing on building his body to maintain his health and posture.

Positive self-esteem is strongly linked to meaning making (Kralik et al., 2010). Dwayne's identity was influenced by his MCC, and negotiating his identity and self-

image was difficult (Charmaz, 1994). The stigma associated with chronic illness is a real issue (Taft & Keefer, 2016). When individuals experience stigmatisation, they may respond in a variety of ways (Stangl et al., 2019) to negotiate identity continuity. Dwayne covered up his chronic conditions and kept them hidden from people whom he perceived to have an impact on his career. He acknowledged that he only disclosed his CDs to "*work colleagues, who I will call my friends*". Dwayne sought to retain self-esteem while negotiating his identity continuity by improving his health and posture, and not disclosing his CDs to individuals he did not feel comfortable with.

6.3.5.2   *Making meaning through existential reflection and cognitive restructuring of self-identity*

Dwayne experienced many challenges in juggling all three of his CDs and living a meaningful life. While accepting the diagnosis of one CD (AS), he struggled to come to terms with the diagnoses of the other two CDs, namely hypertension and asthma. He stated that he did not "*fully accept*" his diagnosis of asthma and hypertension. This refusal to accept the additional CDs could be the result of his existential reflection, in which he perceived them as an additional threat to his self-identity (Van Bulck et al., 2018; 2019). As he struggled to accept his body's betrayal (Charmaz, 1995), from being a healthy person in the past to living with the severe symptoms of AS, he simply could not deal with the additional serious illnesses of asthma and hypertension. Dwayne indicated that he wanted to maintain and build his self-image and self-worth when faced with his health problems. To restructure his self-identity, he consequently cognitively focused on other areas in which he did have any influence, such as improving his physical appearance: "*I so desperately wanted to look the part as a weightlifter that I pushed myself very hard ... I was rather scared that someone might think I did not look the part.*" He further cognitively restructured his self-identity by emphasising that he *"frequently receives praise",* thereby establishing himself as a valued worker.

I asked Dwayne to send me a WhatsApp of an image that he identified with. He indicated that he identified with the character Buzz Lightyear from the animation film *Toy Story* (Lasseter et al., 1995). In the film, Buzz Lightyear is an archetypal hero. According to Goethals and Allison (2012), seeing oneself as an archetypal hero is to be admired or idealised for one's courage in overcoming obstacles to achieve one's

objectives. In the above film (Lasseter et al., 1995), Buzz Lightyear gradually discovers that he is a toy, not a spaceman destined to save the universe. Buzz Lightyear is forced to accept himself for who he is, transcending his self-importance to become a lesser but, in fact, greater type of hero as he becomes other-focused and contributes to others' wellbeing in different ways (Placido, n.d.).

Dwayne stated that "*It is important for me to be a positive role model",* and that his co-workers and manager at work often "*praised*" and acknowledged him as a skilled worker, thereby strengthening the perception of being a hero to others. In the negotiation of an identity continuity, Dwayne experienced that transcending the self and focusing on others (youngsters at church) created a meaningful self-identity in that he could influence and contribute to others' wellbeing. Dwayne's fear of stigmatisation, as well as his desire to be perceived as a positive role model, necessitated reconstruction (Scambler, 2009) and negotiation of his self-identity as an active process of self-discovery and self-development (Charmaz, 1983).

6.4   CASE 3: DINAH

Dinah is a self-employed woman who has been dealing with breast cancer for 14 years, psoriasis for five years and depression her entire life. Dinah transitioned, during the course of the study, from formal work to self-employment. Dinah was interviewed face to face and follow-up questions were addressed to her via the multiplatform messaging application WhatsApp. Dinah and I know each other, and we first had a general conversation in my office before the interview, during which we exchanged pleasantries. She demonstrated her sense of humour by telling me some amusing stories during this exchange. Dinah is the only participant who visualised her experience while living with her various conditions. She accomplished this by keeping a journal, combining poetry with a pictorial representation of her experience (Figure 6.2), and drawing a picture (Figure 6.3).

Figure 6.2

Dinah's Illustration of her illness experience
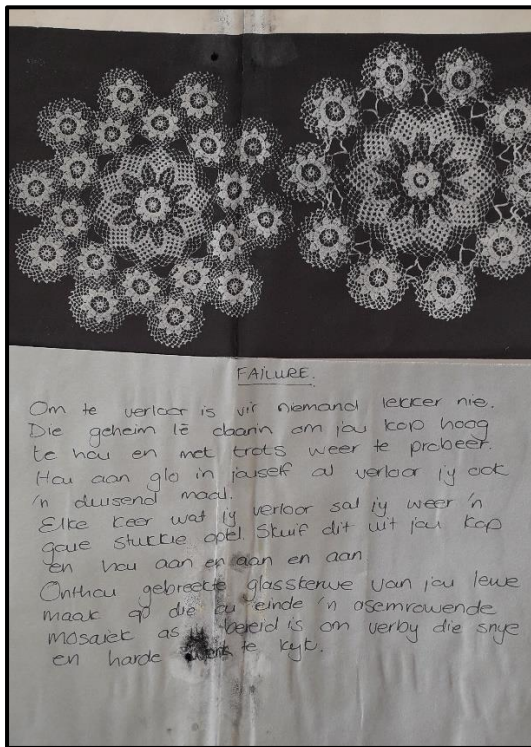
The following is a direct translation of what she wrote:

FAILURE

> *Nobody likes to lose. The key is to keep your head up and try again. Maintain your faith in yourself, even if you fail a thousand times. Put it behind you and move on. You will be given another piece of gold for each loss. Remember that if you are willing to look past the cuts and hard work, the broken glass shards of your life will eventually form an awesome mosaic.*

I asked Dinah what this image represented and meant to her, and she explained it to me. She said that she has had to deal with a lot of issues in her life because of her CDs. She handles this by using positive self-talk to lift her spirits and she continues to move forward, putting all of her losses behind her. She emphasised the importance of finding the positive in every situation. She concluded by saying that "*although life is full of challenges and sad events, if you put all of the brokenness together, thus making meaning of it, you will be able to see the benefits and beauty of life*". In addition, she also made a small drawing, as depicted in Figure 6.3:

Figure 6.3

Dinah's picture of a Storm

She labelled her picture "*Storm.*" Above the drawing she doodled lose fragments and wrote the words, "*fragmented, broken horizon, known in part*" (direct translation from Afrikaans). She explained it as follows (direct translation from Afrikaans):

> *It's just a representation of one's own brokenness, whether it's illness, work, or death, which you don't always understand. The incomplete understanding of it, or its brokenness, is depicted as a whirlpool, a whirlwind, whether you're up in your life, which is heaven, or down on earth. Perhaps I should just add that a lack of comprehension frequently leads to anger.*

In the drawing, which she explained to me, it was also evident that she was struggling with a lot of unanswered questions. Her life felt like a "*whirlwind",* which is something that involves various fast-changing events or feelings (Meriam Webster, n.d.). The drawing describes her changing emotions, her ups (heaven) and downs (earth), and because she only partly understands what is happening to her, this often causes frustration and anger.

Dinah's visual efforts initially disappointed me because I expected more from her as an artist. I admit that I am deeply ashamed of these unkind thoughts because, as I reflected on this, I remembered Dinah saying that she had been in a *"bad spot"* at that

stage. At that point, I realised she had not been making art but rather expressing her feelings. Her visuals were authentic in that they depicted her feelings at the time and how she was experiencing living with MCC. Dinah has a difficult time living with her CDs, and these images for me speak as loudly as anything she said during the interview.

After we had completed the formal interview, I asked Dinah if there were any emotional issues that she wished to discuss further, and she replied as follows:

It was nice to speak to someone about this stuff. Someone who will not say "shame" but who is on the same level and makes one feel it is okay to say things. It was very "lekker" [nice] and I think that is what one needs.

In conclusion, I offered Dinah counselling and further support should she need it.

6.4.1 Making meaning by using the creative pathway

Using the creative pathway to make meaning implies doing, achieving or creating something (Boeree, 2006). Hence one makes meaning through creatively contributing towards something (Shantall, 2020). Meaning making using the creative pathway will be discussed by identifying the patterns that indicate how Dinah would perform activities, produce or create things and engage with deeper awareness (Frankl, 2008; Pattakos & Dundon, 2017a).

6.4.1.1 Performing activities, producing or creating things

Dinah stated that creating something is vital for her, and her desire is to make a contribution. She wants "*to really make an impact or a difference*". She creates something by doing things that others find valuable: "*I helped to train people ... I developed all that learning material*". She has found that doing something meaningful excites her: *"I'm always looking for something to get me excited about. It's not good for me if it doesn't excite me. That is why my work was meaningful to me ... it excited me and gave me purpose"*. Working allows one to engage in deeper purpose (Pattakos & Dundon, 2017a), which results in a sense of value and meaning. Work gives people hope as well as a renewed sense of identity and purpose (Hill, 2019). Dinah discovered that staying busy and working has helped her maintain balance: *"I continue to work like a maniac. Forcing my mind to focus on work appears to help me maintain my*

balance". When she retired from formal work, she started creating things by doing art and crafts: *"I'm going back to my art, painting and designing, and re-discovering this incredibly creative period in my life"*. She experiences value and happiness when she sells something, which indicates that others also find beauty and value in her work: *"I sold a painting and have another one on order. I am happy."* Dinah asked herself what gives meaning, and then she answered her own question as follow: *"What makes your world go round? To mean something to another human being."*

Legacy building is taking advantage of the opportunity and responsibility to serve others while also benefiting from it (Llopis, 2014). Dinah enhanced her legacy building through her mission in life (Wong, 2007) and an attitude (Vestal, 2014) of serving others. Wong (2014b) underscored the significance of the opportunity to be an example to and to be valued by others. Dinah accomplished this by pursuing a career in which she could care for, influence and make a difference in the lives of others.

6.4.1.2 Engaging with a deeper awareness

Working towards an end goal has been significant for Dinah because it has led to a sense of deeper purpose (Griffith & Graham, 2004; Park & Folkman, 1997): *"I got a stall at the local craft market to sell my wares. I am extremely pleased. Working toward an end goal is critical for me. Making something and hoping it goes somewhere doesn't work for me."* Dinah demonstrated that the value of wanting to achieve something and engaging with a deeper awareness towards a purpose has created a sense of meaning in her life. She has empowered herself by *"reading extensively"* and enrolling in *"a variety of courses such as counselling, gestalt and colour therapy",* to enable her to engage with a deeper awareness when rendering a service to her clients. In this context, engaging with a deeper awareness means broadening her knowledge in order to understand her clients' needs and address them constructively.

Dinah *"started volunteering"* and experienced it as *"nice to see some patients."* The value she has added to the lives of others in giving her time by volunteering has given her satisfaction and added meaning: *"I arranged a sponsorship for a cancer patient that enabled the person to pay for chemo medications that the state does not provide".* The value that she experienced in volunteer work was that she had the opportunity to share her knowledge and experience and, at the same time, felt connected to others.

Dinah demonstrated how wanting to achieve something and engaging with a deeper awareness towards a purpose has benefited her and given her life meaning.

6.4.2 Making meaning by using the experiential pathway

According to Frankl (2008), when one truly connects with others, meaning is realised. The patterns for using the experiential pathway were matched by looking for examples of Dinah's relationships with others, life and nature.

6.4.2.1 Relationships with others

Throughout her treatment, Dinah valued the support of a friend. She emphasised this by recalling an incident in which she had felt alone in the hospital and received support from a friend: "*I once sat in a corner and cried because the loneliness was unbearable. I then called a friend, who arrived at the hospital and bathed me.*" Goto et al. (2018) stressed the benefits of bathing for stress relief, refreshment and relaxation. Dinah remembered this incident because she had valued her friend's consideration and support, who had recognised the benefits of bathing and its calming effect. This is an example of how small acts of kindness often have the greatest impact on a person's wellbeing (Pfaff et al., 2021).

A number of scholars have emphasised the value of social support for people living with a CD (Brown, 2018; Curtis et al., 2004; Helgeson & Cohen, 1996; Maguire et al., 2021; Mallinckrodt et al., 2012). Dinah had been overwhelmed by the cancer treatment and had not wanted to return for her final chemotherapy session: "*When I had only one chemo left, I said, 'Listen, I am done'.*" The oncologist was very upset and asked me to give it a chance.*" After initially rejecting the recommended treatment, she had reconsidered and decided to proceed with it. Premature discontinuation of chemotherapy is known to be associated with a high rate of relapse and death (Dhotre et al., 2016). Dinah realised the risk, and it was under protest that she decided to continue with the last treatment: "*I thought about it for two weeks ... and phoned my friend. I told her she must take me for my last chemo, but I knew I was going to retreat and walk away, so I asked her to remain persistent".* She had felt frustration and anger, and had directed it towards her friend: "*She came to fetch me, but that morning I was very angry. I was 'de moer in' [furious] with her. She said, 'Come, get in the car'." I was so angry, but she remained stubborn. She said, 'You are going to do it'.*" Dinah

experienced valuable support, love and tenacity during a time when she needed it the most, even though she knew it had an emotional impact on the friend: "*It was a wonderful gesture on her part. However, I later discovered that it was very difficult for her to be persistent and that it had a significant emotional impact on her.*" Dinah had displayed an intimate connection with her friend in that she had been able to project her anger and frustration on to her friend, and in spite of that, her friend had still supported her. The intimate connection with her friend is also evident through the experience of having been nurtured (when she had bathed her) and cared for. In experiencing this intimate connectedness in her friend's gesture of care and love, Dinah had realised meaning (Frankl, 2008, 2019).

Dinah found pleasure and value in interacting with people – her family, friends, her clients and her co-workers. The career paths that Dinah followed indicated that she had found working and interacting with people meaningful. In Section 6.4.5.1, I indicated Dinah's social isolation as a result of her depression, which had led to a decline in her social interactions. During this period, however, she had paid a visit to her ex-colleagues and found solace in their reaction towards her. They had confided in her about the situation at work that might jeopardise their positions, and she valued the support she could give them in return: *"Everyone was overjoyed to see me, and I was overjoyed to see them. It felt like a family reunion. They greatly needed a serious outlet ...".* In this instance, the support she had been able to provide was a valuable and enjoyable experience for her.

Dinah discovered that she missed "*interaction with a lot of people"* after resigning. She missed the caring aspect of "*giving support"* the most. This demonstrates the value she experienced by not only receiving, but also giving in return (Algoe, 2005; Inagaki & Orehek, 2017). Dinah felt extremely emotional and that she "*just mean* [sic] *nothing to anyone* [tears in her eyes]" and she *miss* [sic] *so much to be able to give to someone, other than family*". It made her feel meaningless, indicating that being able to offer support to others was a crucial value for her. It is evident that she experienced what Viktor Frankl (2008) termed the "existential vacuum", which occurs when one becomes aware of the lack of content in one's life. She filled the void by volunteering and reconnecting with others, and by doing so, she benefited herself.

6.4.2.2 Relationship with nature, beauty and new things

Value can also be gained in experiencing something of beauty, like art or nature (Frankl, 2019). Dinah experienced meaningful moments when she "*paints and has absolute quietness around*" her, and stated that "*it makes*" her "*happy, it gives meaning*". She also experienced meaning in the beauty of nature and enjoyed walking on the beach and "*being at the sea*". Dinah noted that "*bird song and silence*" were preferable to "*man-made noise*". She indicated that silence and nature sounds had affective and renewal effects on her in that they calmed her and made her happy. According to Frankl (2019), when one experiences the splendour of nature, one's life cannot be seen as meaningless.

Dinah was open to new experiences in her life, as evidenced by her career transition from the formal business sector to working for a nonprofit in the health sector, and then to self-employment because of her health conditions. Change is unavoidable when dealing with MCC, and Dinah had to adopt an enterprising attitude to address these changes: "*The psoriasis is a cosmetic eye sore for the next person*". People express their personalities through the clothes they wear (Efremov et al., 2021). Dinah had to modify her wardrobe to make it more functional. She wanted to conceal the rash and scaly patches caused by psoriasis because, as she put it, "*it looks very bad to people*", and "*during counselling sessions, I noticed that my clients' eyes were focused on it* [the scales]". She had to compromise and changed her appearance by starting to wear "*mittens*" and "*longer sleeves*" to cover up the rash and scaly patches. However, she still found a way to express her personality through her clothing, for instance, by wearing interesting mittens. This indicates her self-determination to address the challenge, act on it and then experience meaningfulness.

6.4.3 Making meaning by using the attitudinal pathway

Attitudinal values are about a person's attitude when facing adversity (Frankl, 2019). When faced with adversity, such as living with various CDs like Dinah, one's outlook on life is critical to making meaning of it (Frankl, 2008). The attitude Dinah adopted is evident when she suggested the following: "*our minds determine who we become*", implying that positivity is crucial. She also stated that "*you make plans to survive somehow*", thereby emphasising the problem-solving aspect of dealing with CDs, as

also indicated in Section 6.4.1.2. According to Pattakos and Dundon (2017a), in facing life's transitions, we create opportunities for growth and meaning.

An attitude of gratitude was evident when Dinah completed her treatment and felt "*healthy*" again. Gratitude is a positive attitude towards life that provides strength (Emmons & Crumpler, 2000). Syropoulos and Markowitz (2021) also described gratitude as an attitudinal response. Dinah (as the receiver) expressed her gratitude towards God (whom she perceived as the giver): "*I conversed with the Lord*" and said, '*thank You*'." In these words of gratitude, Dinah's attitude of acceptance shone through.

During the interview, Dinah used a lot of third-person self-talk to psychologically distance herself from her emotions (Moser et al., 2017). This helped her to compose herself and enabled her to talk about her life with the various CDs. Dinah depicted her attitude in Figure 6.2, where she indicated that although she had had to face adversity, she had kept "*faith*" in herself and her abilities and had demonstrated that she always "*found a way*" to manage her CDs. She had put the things she could not change "*behind*" her and "*moved on*" by finding and using the pieces of "*gold*", that is, the positive things, to build an "*awesome mosaic*", indicating that life, despite the challenges and restrictions of MCC, could be "*awesome*".

Dinah demonstrated her determination by adopting a problem-solving attitude in her life, especially when confronted by her CDs. Examples of how she planned and took action to set herself up before her cancer treatment included "*finding out as much as possible about chemotherapy, how you do it, the side-effects*". She had also acted proactively by making sure her children were taken care of by "*filling the fridge with frozen foods*", arranging for her "*parents to come and stay to assist with the kids*". She also "*organised a child psychologist*" for her children to assist them with the emotional distress they might experience as a result of her serious illness. Dinah showed determination in dealing actively with the challenges her CDs presented. This was demonstrated in her journal where she wrote about how to deal with serious depression and labelled it "*How to up your game after serious depression*". The advice she gave herself included "*grounding; making a vision board; exercising; watching 'The Earthling' movie; keeping moving; planning; quieting your thoughts; interaction*

with people; keeping a low profile; making conscious decisions; having a good cry; speaking to someone outside your situation".

6.4.4 Living out the capacity of self-transcendence

Self-transcendence involves devoting oneself to a mission greater than the self, like serving someone else (Wong, 2016b). According to Wong (2014b), one can relate to suffering in different ways, and one of these is an attitude of overcoming suffering by developing spirituality. The patterns of living out the capacity of self-transcendence were matched by a shift in focus from self to others (connection with God, nature or others); a shift in values from extrinsic to intrinsic motivation; an increase in moral concerns; and experiencing emotions of elevation or awe.

6.4.4.1 A shift in focus from self to others

Dinah focused on God by thanking Him for "*carrying*" her "*through*" and, in return, promised to "*give*" something "*back*". The way that Dinah gave back was by providing support, something valuable to others. She accomplished this through prosocial behaviour:

> *My act of gratitude was to visit the chemo room, which I detested because of the smell! I still want to run away when I smell it, but I pushed myself. So I would often go sit with the patients and just talk, or I would bring a rose for each one.*

Dinah retired from formal work and followed her calling of creating arts and crafts. Although she found it satisfying, she also experienced emotions of emptiness and longed for the feeling of giving something of value to others:

> *I so miss it to give something to someone and it must not be my mother, it must not be my child, it must not be my husband, because you must remember when you give, you also put on a mask, but it helps you to be sane sometimes.*

Dinah explained that when giving to others, she could hide behind a mask. By that, she meant that her own suffering could be hidden and put aside by transcending her own personal concerns to tend to others. She mentioned that after her retirement, a NPO had contacted her to ask her to volunteer her services by providing practical and emotional support to chronically ill people. She accepted this and said that she enjoyed

"occasionally seeing people" for whom she could still mean something. Volunteering is also regarded as a calling (Faletehan et al., 2021), a form of prosocial behaviour that has many benefits such as encouraging social interaction, reducing feelings of loneliness and ultimately providing purpose and meaning (Chambré & Einolf, 2008; Maier et al., 2021).

6.4.4.2 A shift in values

After Dinah's cancer diagnosis, she experienced a shift in values in that she no longer wanted to remain in a career where "*you have to talk business*" and "*emotions had to be set aside*". It became "*senseless*," and she resigned. She then wanted to focus on "*making an impact or difference*" in other people's lives. She switched to a career at an NPO, where she dedicated her time to supporting people emotionally and practically. Dinah was now intrinsically motivated by "*meaning something to someone*". When the emotional burden of this job became too much for Dinah, she found that she "*can't give 100%*" and that "*somewhere someone is going to suffer because of it*". She therefore resigned and shifted her focus to her health, which she believed would benefit the people she had to serve because she was no longer able to give them the attention they deserved. Dinah became self-employed doing arts and crafts, which she said made her "*happy*".

6.4.4.3 An increase in moral concerns

Dinah's increase in moral concerns is evident in her actions. She changed her business-oriented career to selfless service to others in need. She continuously mentioned her need to "*give something*" to others that would make an impact on their lives. Dinah expressed her moral reasoning in her illustration of her illness experience, as represented in Figure 6.2, and stated the following: "*The key is to keep your head up and try again. Maintain your faith in yourself, even if you fail a thousand times*". In her moral reasoning, she shared her attitude towards living with MCC, and this is reflected in her concerns and actions towards "*making a difference*" for other people.

6.4.4.4 Emotions of elevation or awe

Dinah expressed emotions of elevation in her encounters with God, in that He had "*carried*" her "*through and healed*" her. This feeling of being part of something larger than herself (Wong, 2016d) triggered a desire in her to want to "*give something back*".

She experienced awe in being able to help others in different ways. Dinah expressed awe in "*painting and sitting in absolute silence*," being able to walk on the beach ("*we live at a beautiful place; at the sea*") and enjoy nature. When in nature, one becomes aware of the beauty, wonder and peace of one's surroundings. According to O'Malley (2020), the awe of nature's experience connects one to something greater than oneself.

6.4.5 Reconstructing the self-identity

Dinah experienced an identity disruption caused by living with MCC. In the subsections below, the reconstruction of self-identity is expanded upon by demonstrating how Dinah negotiated her identity continuity in response to identity disruption, as well as how she proceeded to make meaning through existential reflection and cognitive restructuring of her self-identity.

6.4.5.1   Negotiating identity continuity in response to identity disruption

Dinah maintained her self-image by trying to maintain a sense of normalcy (Roger et al., 2014) through her diagnosis and treatment of cancer by remaining in formal employment. When Dinah was diagnosed with psoriasis, a visible CD, she concealed it by wearing gloves and long-sleeve clothes. Psoriasis has been found to be stigmatising, which has a great influence on self-identity (Donigan et al., 2015; Jankowiak et al., 2020). Dinah experienced this by having to deal with people's reaction to the rashes on her hands or arms. People at work would say she "*looks terrible*", and she would use humour to deal with it by replying "*it is because you drive me crazy*". She thus maintained her self-image by concealing and using humour to deal with this particular CD.

Dinah stated that, for her, depression is a "*lifelong condition*", and she is on chronic medication to assist her with it. In her drawing of the storm (Figure 6.3), Dinah expressed the "*stormy*" feelings she experienced in negotiating identity continuity. She explained that sometimes her emotions were "*up*" and sometimes "*down*", and that because she did not always "*understand*" everything, "*it often leads to anger*". According to Cast and Welch (2015), depression has a negative impact on people's self-image in that it causes them to reassess themselves in ways that are consistent with the negative emotions they are experiencing. Vis et al. (2019) asserted that PwCD

are more likely to be depressed, which may lead to social isolation. Hawthorne (2008), however, reported that people who have feelings of social isolation are likely to also suffer from depression.

Social isolation is related to living with MCC (Cantarero-Prieto et al., 2018; Van Wilder et al., 2021). When a person has few social relationships and participates in few social activities, these feelings of social isolation lead to social disconnectedness (Cornwell & Waite, 2009; Klussman et al., 2020). Dinah wrote in her journal that her depression had led to feelings of loneliness and keeping a "*low profile in interacting with people*". Dinah described her path in negotiating an identity as one of "*extreme loneliness*". However, she relied on a "*close friendship*" for solace and support and thereby negotiated identity continuity in a safe space where she could experience a sense of belonging and connection. According to Singer (2018), people are social species and need interaction with other humans. When people have a CD, they need to feel as if they belong and to be socially connected even more (Hatchcock, 2012).

6.4.5.2 *Making meaning through existential reflection and cognitive restructuring of one's self-identity*

The lives of PwCD are constructed and made coherent by reflections that allow them to integrate the past, present and expected future into a meaningful whole (Ricoeur, 1980). Identity, according to Savickas (2002), develops and unfolds in response to a person's life experiences. Before and when Dinah was diagnosed with cancer, she had been employed in a highly stressful job, as evinced in her words, "*It was extremely stressful*". She found that her job was no longer meaningful after her cancer diagnosis: "*After the cancer, the corporate world was meaningless ... It did not make any sense anymore*". According to Lee (2008) and Van der Spek et al. (2013), when confronted with a life-threatening disease such as cancer, existential distress such as experiencing things as meaningless, may emerge. Dinah decided she "*was going to quit*". She said that she *"could not continue with what was happening"* in her life. She described this time of her life as highly challenging: "*It was terrible, I hated it*". Living with cancer usually entails creating new identities in order to integrate the experience into one's self-concept (Park et al., 2009; Zebrack, 2000). Dinah wrote in her journal that "*there is no control in a cancer diagnosis*", underlining the uncertainty in the experience of living with cancer (Bury, 1982) and the need to negotiate a self-identity.

Dinah used art to convey the meaning of her out-of-control emotions, as can be seen in her drawing in Figure 6.3, which depicts the feeling of being out of control by using the storm to echo these feelings.

Dinah's cancer disrupted her pre-existing identity and compelled her to reconsider her career plans (Beatty, 2012). After her cancer diagnosis and treatment, the corporate world had lost its meaning for her. She now considered herself a member of a social group comprising people living with cancer. By seeking to work with cancer patients, she hoped to incorporate a work identity based on her social identity as a person with cancer (Walsh & Gordon, 2008). She thus became involved in cancer-related activities like advocacy and emotional support. Meaningful work, whether paid or unpaid, provides individuals with a sense of inherent value and of social connection and belonging (Doherty, 2009; Taylor, 2004, 2015).

Women with breast cancer wish to be seen as women and workers (Trusson et al., 2021). Dinah underscored this by stating that it was important for her to try to "*make a difference and impact*" in the "*cancer world*". Self-reflection and interaction with others are used to build a new identity (Hecht, 1993; Palmer-Wackerly et al., 2018). Dinah negotiated a new identity through her interaction and being part of the cancer community (Hecht, 1993). Identity in the communal sense gives people a sense of belonging to a group of people with whom they can best relate and communicate and who understand their cancer experience (Stephens & Thorne, 2022). Social interaction is a key part of how people with CDs navigate and construct new identities (Dewji, 2022; Whittemore & Dixon, 2008).

Dinah described her last paid jobs as stressful, harmful to her health and the reason for her worsening depression, resulting in *"total burnout"* and the reason for her resignation. She indicated that she "*always seeks things that excite her*". She thus had to reconstruct her work-identity by becoming self-employed and giving herself time to use her creativity within her own time frame and limits. Working from home, however, tends to further isolate her from social connections, especially when she does sales online. She discovered that she now "*misses the interaction with people,*" thereby indicating she missed the part of her that identified with the cancer community. She wrote in her journal that "*to mean something to another human being*" gives meaning, and she missed this. In her subsequent cognitive restructuring, Dinah began to

volunteer to provide practical and emotional support for women with breast cancer, thus negotiating a self-identity as a cancer advocate. Dinah appears to have an ongoing cognitive restructuring process in which she tries to incorporate her MCC into her self-identity.

I asked Dinah to send me a WhatsApp with an image of a character she identified with, and she chose Lisa from the animated television series, *The Simpsons* (Groening, 1989). Lisa's character is intelligent, kind and passionate about the planet and all living things, an advocate for various causes, and she is considered a bit of a loner and social outcast. Lisa is also illustrated as a strong liberal and activist for peace, equality and the environment ("Lisa Simpson," n.d.). Dinah strived to create a meaningful self in her negotiation process of identity continuation in that, while she experienced being a loner and social outcast because of her psoriasis symptoms, she could reconstruct her identity as one who cares for others and is an advocate for the marginalised.

6.5   CROSS-CASE SYNTHESIS AND THEMATIC FRAMEWORK

The three participants' narration of their lived experiences with their various illnesses included all their life experiences, including their emotional, intellectual, psychological and social understandings. The cross-case synthesis allowed for the assessment of similarities and differences in events, actions and processes between these three cases through the lens of Frankl's principles and relevant literature (Cruzes et al., 2015). The findings support the study's propositions on meaning making. Firstly, the findings support the proposition that individuals living and working with a CD make meaning by following Frankl's three meaning-making pathways in the following ways: by using the creative pathway, individuals purposefully move towards adding value to themselves and others; by utilising the experiential pathway, individuals connect meaningfully with someone or something; and by following the attitudinal pathway, individuals choose an attitude to create a different experience for self. The second proposition was also confirmed in that meaning making for PwCD is enhanced by living out the capacity of self-transcendence, in the following ways: by shifting from being self-focused to other-focused (selflessness); from a shift in values of being extrinsically to intrinsically motivated; increasing their moral concerns; and in emotions of elevation or awe in a deepening of their connectedness.

From the theory it is evident that self-transcendence is the will to meaning – in other words, people's capacity for self-transcendence motivates them to consistently strive towards making meaning. While self-transcendence motivates PwCD to make meaning, meaning making is found through Frankl's three pathways. From the data it was clear that not one of the pathways could be prioritised or considered in isolation, and that self-transcendence needs were intertwined in each of the pathways. Experiences overlapped to demonstrate how the participants made meaning in the different pathways. The three pathways worked together to create a unity with varying emphasis and space for every meaningful human thought, endeavour, action, feeling and suffering (Lukas, 1986).

As the participants purposefully sought goals, the domain of work was stressed in the subthemes of the creative pathway through performance, producing and engaging with a deeper awareness in the meaning-making process. The subthemes of relatedness with others and with nature, beauty and discovering new things emphasised the experiential pathway to meaning making. From the attitudinal pathway, it is evident that acceptance, positivity and self-determination played a vital role in the meaning-making process for all three cases. The attitudinal pathway, in particular the attitude of self-determination, revealed a meaning-making orientation, which in turn continued to initiate further engagement in making meaning through the creative, experiential and attitudinal pathways.

It is proposed that self-determination acts as an orientation that maintains PwCD engagement in meaning making, and this was demonstrated by the participants in fulfilment of their needs for competence, relatedness and autonomy (Deci & Ryan, 2000). Competence relates to the creative pathway, relatedness to the experiential pathway and autonomy to the attitudinal pathway. Meaning while living with CDs was thus discovered through the creative, experiential and attitudinal pathways, which were motivated and enhanced by the capacity for self-transcendence (ST) and maintained by the need for self-determination.

Two themes that emerged to be contextually relevant to understanding the meaning making of PwCD, in addition to the directing propositions, were self-determination and identity reconstruction. As explained above, in all three cases, the participants demonstrated self-determination in the way they engaged purposefully by using the

creative pathway, through their experiences with others and things and with an attitude of acceptance and positivity towards meaning making. The CD diagnosis led to an identity disruption, which all three participants described pertinently, confirming the discussion in the literature review in Chapter 3 (see Figure 3.1). In response to their identity disruption they engaged in various activities that reflected their need to negotiate a continuation of their identity, which resulted in a continuous reconstruction thereof.

I could therefore not ignore the pertinent issue of identity work in my understanding of how the participants engaged in the meaning-making process. The reconstruction of identities involved a process of comparison between who the participants were before their illnesses (past), who they are now (present) and who they wish to be (future). This process illuminated the identity disruption they experienced and their continued pursuits to ensure identity continuity. Identity construction can be seen as a meaning-making process in itself, entailing a continuous process of existential reflection and cognitive restructuring through self-determination towards identity integration, diversification and transition in their social and work lives to restore and find new ways of fulfilment. Looking back at their identities prior to their illnesses, they faced existential concerns about loss of freedom, isolation and meaninglessness. Their illness(s) indicated change and elicited deep reflection on who they are now and who they aim to become, leading to cognitive restructuring to meaningfully integrate the illness(es) into their self-identity and thereby reposition their definition of a meaningful self.

The outcome of the cross-case synthesis is presented in Figure 6.4, which is a summative thematic framework illustrating meaning making while living and working with a CD.

Figure 6.4

Cross-case synthesis: Meaning making of people with chronic illnesses
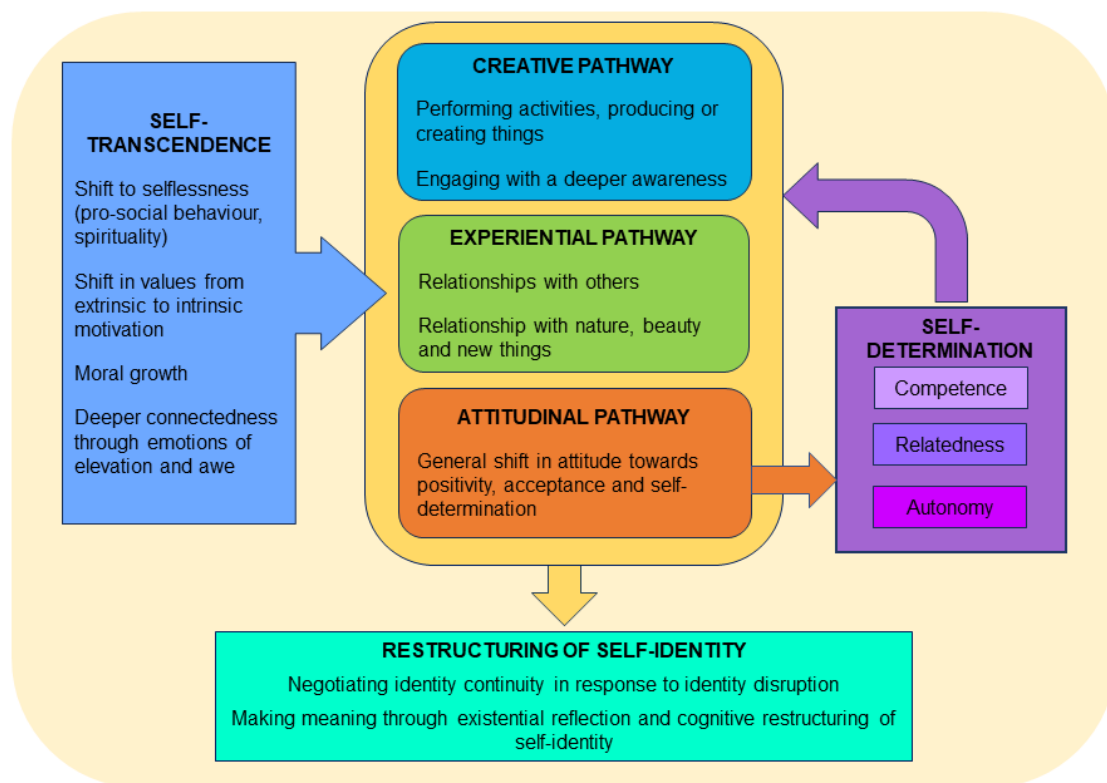
It would appear that the process of meaning making while living and working with a CD was situated in the participants' construction of new identities motivated and maintained by self-transcendence and self-determination by using the creative, experiential and attitudinal pathways.

6.6   CHAPTER SUMMARY

In this chapter, important concepts, recurring patterns and themes relating to Frankl's theory and the research questions were identified in the data. From the data analysis, a thematic framework emerged that integrated the results of the study as they were represented through a synthesis of the three cases. The further hermeneutic reflection and theoretical integration of these initial interpretations led to a critical evolution of the themes, which forms the basis of the discussion in Chapter 7.

CHAPTER 7
RECONSTRUCTING A MEANINGFUL SELF: THE ESSENCE OF MEANING MAKING FOR PWCD

7.1 INTRODUCTION

According to Frankl (1992a, 2008), the meaning of one's life may change, but the need for meaning remains constant. This is especially true of PwCD, for whom meaning making while living with CDs is crucial in adjustment and the development of their wellbeing (Davis et al., 2000). The disruption that diagnosis of a CD brings requires individuals to make meaning by integrating their illness into the context of their life. Meaning making, whether at work or in everyday life, is crucial to people's self-identity and how they define themselves (Townsend, 2011). Since many PwCD continue working (Goldman, 2017), the workplace is an important environment for meaning making. Through various accommodations and interventions, the organisation can assist PwCD in the workplace in leading productive, meaningful lives (Nazarov et al., 2019).

This chapter presents the culmination of the findings in response to the research aim of the study. The purpose of this chapter is to present a hermeneutic phenomenological integration of the findings to describe and explain the essence of meaning making for PwCD, and on the basis of this, to construct a support framework that could be applied in an industrial and organisational psychology context. Hence the chapter is divided into two main parts. The first part deals with the essence of meaning making for PwCD, which is encapsulated in the notion of constructing a meaningful self, and incorporates the central themes that conceptualise their meaning-making process, based on Frankl's meaning-making principles and existential and cognitive meaning-making meta-theory. In the second part, a support framework is constructed and presented for use in an IOP context. The purpose of the organisational framework is to promote an understanding of employees with CDs and to suggest avenues of support for the organisation in the facilitation of meaning making in the workplace.

7.2 THE ESSENCE OF MEANING MAKING: CONSTRUCTING A MEANINGFUL SELF

The essence of meaning making for PwCD is derived from an integration of the findings. This integration was driven by hermeneutically reflecting on the meta-theoretical conceptualisation of meaning making (in Chapters 3 and 4), the narrative context of the cases (in Chapter 5) and the data-driven findings presented thematically according to the study propositions (in Chapter 6).

In Chapter 3, I established a process-driven conceptualisation of meaning making. This was depicted in Figure 3.1 and provided a systematic basis for my hermeneutic reflection, which I used as a guide to structure my thinking on presenting the essence of meaning making. In the continued reflection, theoretical integration and interplay of inductive and deductive reasoning, it was confirmed that because living with a CD is an evolving adjustment process, meaning making is an ongoing process in the participants' social and work lives. This realisation emanated from an integration of the theory with the data and gave me a slightly different sense of the elements that I had initially included in the process-driven conceptualisation of meaning making in Chapter 3. I therefore present a slightly revised version of Figure 3.1 below as Figure 7.1 in order to highlight the main process elements that elicited and maintained the meaning-making process for PwCD. These process elements form the essence of conceptualising meaning making, as presented in this first part of this chapter. In the conceptualisation of meaning making, the self, or the notion of identity, is at the heart of the process elements as the main concern in the meaning-making process of PwCD.

Figure 7.1

Process elements in the meaning-making process of PwCD
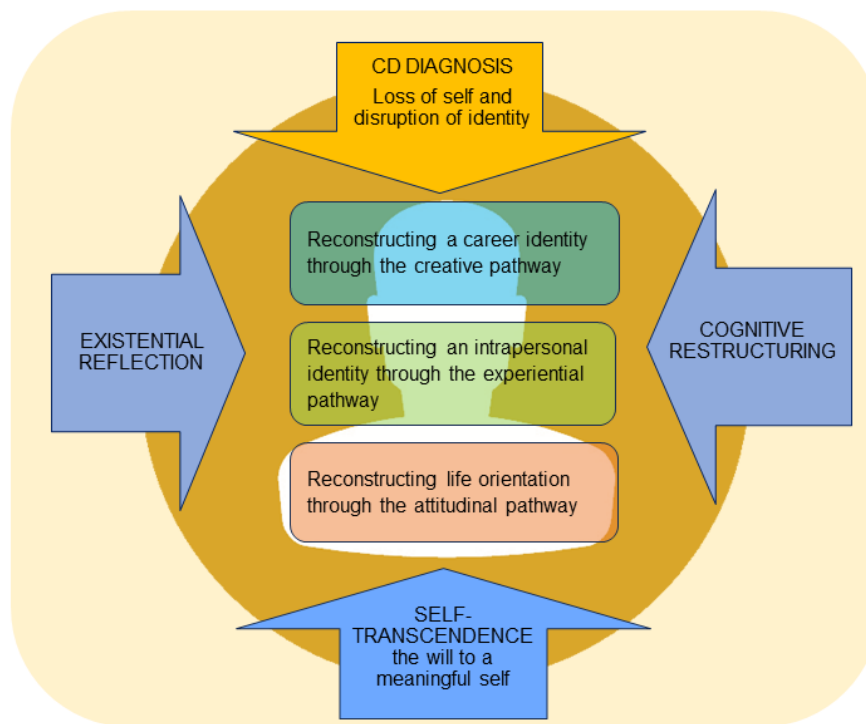
The process elements that revolve around the self will next be highlighted by explaining (1) the loss of self and disruption of identity that follows a CD diagnosis (see Figure 3.1, element 1 "Disruption of illness"); (2) seeking and constructing a meaningful identity through existential reflection and cognitive restructuring (see Figure 3.1, element 2 "Existential reflection" and element 3 "Cognitive reconstruction"); (3) reconstructing a self-identity through Frankl's meaning-making pathways (see Figure 3.1, element 4 "Meaning making" as well as the indication of the use of the three pathways throughout the process in the arrow above the elements); and (4) self-transcendence as the motivational drive or the will to reconstruct a meaningful self (see Figure 3.1 element 4 "Meaning making" that encompasses transcending self as motivation towards meaning making). This section concludes with the conceptualisation of the essence of meaning making for PwCD as constructing a meaningful self.

7.2.1 CD Diagnosis: Loss of self and disruption of identity

The essence of meaning making for PwCD cannot be understood without comprehending the impact of the CD diagnosis as the encompassing context for

participants' meaning-making process. It is the consequences of the CD diagnosis that immediately place the self at the core of the process. This was clear in the participants' narratives, and confirms that living with a CD inevitably changes one's perspective and self-perception (Charmaz, 1983; Strauss & Corbin, 1988). Bury (1982, 1991) used the concept of biographical disruption to refer to the impact of a chronic illness which drastically alters a person's current and future self-narrative. When individuals with a CD have to deal with the disruption of the previous experiences and meanings around which they have constructed their self-identities, which are no longer available to them, they experience a loss of self (Charmaz, 1983). According to Binder (022), the existential concerns that accompany CD influence one's physical, psychological, spiritual and social wellbeing (Binder, 2022). The participants described physical, emotional, psychological and spiritual symptoms that had a detrimental impact on their self-identity and social functioning as a result of the loss of self, which was caused by the disruption of the CD diagnosis.

The loss of physical health was experienced through altered physical appearances and physical symptoms caused by the diseases. Fiona's life was disrupted by her AA in that she had an appearance-changing hair loss condition. Owing to AS, Dwayne experienced stiffness and pain in his spine, which caused his abnormal gait. His other CDs, hypertension and asthma symptoms, led to physiological symptoms that were bothersome and had to be self-managed to prevent further complications. For Dwayne, living with the physical symptoms of MCC was complicated, and his debilitating symptoms of AS made him downplay the CDs of hypertension and asthma in order to maintain his self-esteem. Dinah experienced a loss of health and self-esteem as a result of the significant disruption of her physical symptoms following her breast cancer treatment. She mentioned "*total fatigue, nausea, headache, heart palpitations, earache, bladder and bone pain*", and the red patches caused by psoriasis, which she described as "*itching, burning, and look* [sic] *terrible*". Dinah's symptoms while living with MCC were further exacerbated by the fact that physical pain and depression have a deeper biological connection in that pain is often the presenting symptom of depression (Trivedi, 2004). Living with the CD of depression further contributed to her loss of self in the experience of the debilitating effects thereof on her as a person.

The emotional and psychological effects of living with CDs further contributed to the participants' sense of loss of self because these effects impacted their social wellbeing. Fiona, Dwayne and Dinah all mentioned the stigmatisation of living with visible diseases, which evoked feelings of shame and isolation, thereby further diminishing their sense of self. The influence of the social support system, namely family, friends, colleagues and society, influenced the participants in the way that they perceived and acted on the expectations, pity, stigmatisation and ignorance of others. When one has to deal with the comments and actions of others that have an influence on one's self-image, one experiences psychological vulnerability and a loss of personal power (Karnilowicz, 2011).

Fiona underscored the fact that the loss of self in living with AA meant that she had to learn to love herself again, thus indicating that her altered physical image was unlovable. According to her, her life with AA was a long psychological process of dealing with her loss. Experiences of embarrassment in dealing with stigmatisation, loss and isolation were emphasised by Fiona's comment that she *"would have loved to curl up in a foetal position and withdraw from the world"*.

Dwayne's work life was initially affected by AS symptoms, and he therefore had to seek alternative employment in which he could manage his AS symptoms. This was a major disruption and not easy, and he worked in various jobs and was even employed in a family business for a while before finding a sustainable job that would not exacerbate his symptoms. Dwayne's despondency is clear in his question, "*What am I going to do now?"* as a result of the disruption of having to leave the security of his current job and face the difficulty of finding a new job that might fit his needs. His self-concept and perceived social position were further disrupted as a result of stigmatisation because of his altered gait and stiff movements.

Dinah found that work in the corporate world was senseless after her diagnosis of cancer, and she expressed "*emotions and anxiety",* was "*in that dark pit"* and felt out of control. Stigmatisation was also experienced in her dealings with the visible scarring of psoriasis. Dinah's depression further contributed to self-doubt and low self-esteem, resulting in her leaving her job.

The existential crisis that the disruption of an illness creates affects both self-identity and the spiritual identity (Drutchas & Anandarajah, 2014). In the same vein, the loss of self for the participants related to an altered spiritual identity. Fiona expressed disappointment in the fact that her call for healing went unanswered and this led to a change in her spiritual identity. She still acknowledged a higher power, but no longer believed in a Saviour, thereby indicating a change in her spiritual orientation. She lost her spiritual connection to a Saviour and refocused it on the people she loves, her appreciation of nature and the aesthetic. Dwayne and Dinah both demonstrated an intensification of their spiritual nature through religion. Dinah expressed gratitude towards God for guiding her through her cancer journey and experienced meaning in acts of beneficence. Dwayne similarly experienced meaning by performing acts of beneficence and in his connection with God through churchgoing, prayer and music.

In summary, the loss of self because of the CD diagnosis, implies a loss of making sense of what PwCD found meaningful in defining the self. The loss of what defined the self as physically, emotionally, socially and spiritually meaningful is suddenly no longer true for the PwCD. Inadvertently, PwCD respond by seeking meaning and wanting to reconstruct a meaningful self. This response is described by the natural tendency of PwCD to engage in questions of an existential nature and by cognitively revising aspects of the self from which they can derive new meaning.

7.2.2 Existential reflection and cognitive restructuring to sustain a meaningful self

In order to sustain meaning in life, PwCD constantly strive to restore or repair the loss of self-identity (Charmaz, 1994, 1995). Similarly, to sustain a meaningful self, the participants' efforts to restore or repair the loss of self were demonstrated in the way in which they negotiated identity continuity through mobilising existential reflection and cognitive reconstruction. As explained above, the diagnosis of a CD initially disrupts the body, social roles and social surroundings, whereafter it causes a disruption in self-identity that requires an existential reflection of the individual's biography and self-concepts (Charmaz, 1983, 1994, 1995, 2002). The intrapersonal process of existential reflection is accompanied by cognitive reconstruction, through which people then deploy resources to deal with the disruption (Bury, 1982), and revise or reconstruct their sense of self. In essence, the revision of self is motivated by the need to sustain

continuity in one's identity or one's experience of self as being meaningful. In this section, the two processes of existential reflection and cognitive reconstruction are discussed as PwCD's response to the loss of self and through which they seek identity continuity by reconstructing a meaningful self.

7.2.2.1 Existential reflection

The existential perspective is concerned with one's "being-in-the-world" or existential need for meaning (May & Yalom, 1995). The distress caused by the loss of one's sense of self in a meaningless world led to the creation of May's concept "I am" (Wong, 2006), where individuals create their own reality and the manner in which they intend to make meaning of their own experience (De Castro, 2009). A disruption and loss of self-identity necessitates an existential evaluation of one's value and worth (Steger, 2018) and of one's true nature and calling so that one can revert to leading an authentic and meaningful life (Wong, 2010c, 2016a). The disruptions of a CD-affected life, namely the loss of self, leads to existential reflexivity, in which the participants attempted to revert back to a sense of a meaningful self by creating a cohesive and stable sense of the self "living in the world" (Giddens, 1991, p. 187).

The participants engaged in identity work, which, according to Sveningsson and Alvesson (2003), is the process of constructing, reconstructing, sustaining, enhancing, or modifying one's identity in order to produce a sense of coherence and difference. In their existential reflection to re-establish their meaningful self, the participants continuously compared themselves to where they were, where they are and where they want to be. The reflective process is about negotiating an identity continuity by reconstructing the identity through examining and revising the self-concept (Baker et al., 2018; Zafran et al., 2012).

This process entails a reconciliation between the past (their lives free of chronic disease), the present (living with chronic disease), and setting goals for the future. In their existential reflection, the question, "Who am I?" seems central, and in reflecting on this question, the participants created positive versions of how they would like to be perceived. This future sense of self, which I termed "the ideal self", represents the participants' endeavours to re-establish their worth, value and meaning. The need to find meaning in the past, present and future towards self-continuity is also evident in

Kaufman's (2018) theory. According to him (2018), people creatively make meaning in three ways: in the past to help people reflect on and understand the events of their lives; in the present to help people manage their moods, activities and relationships; and in the future to fulfil their purpose, in which the creation of a legacy is emphasised (Kaufman, 2018).

Fiona indicated that her coherent sense of living in the world should be seen as individualistic and something to be respected, which to her was a vital aspect of a meaningful self. Dwayne's reflection of a meaningful self was to "*be a positive role model*", while Dinah wanted "*to mean something*" to others. The ideal self serves as motivation, urging one to reconstruct themselves in order to align with the ideal self (Rogers, 1959). Figure 7.2 depicts the participants' impersonations of their ideal selves.

Figure 7.2
Impersonations of the self
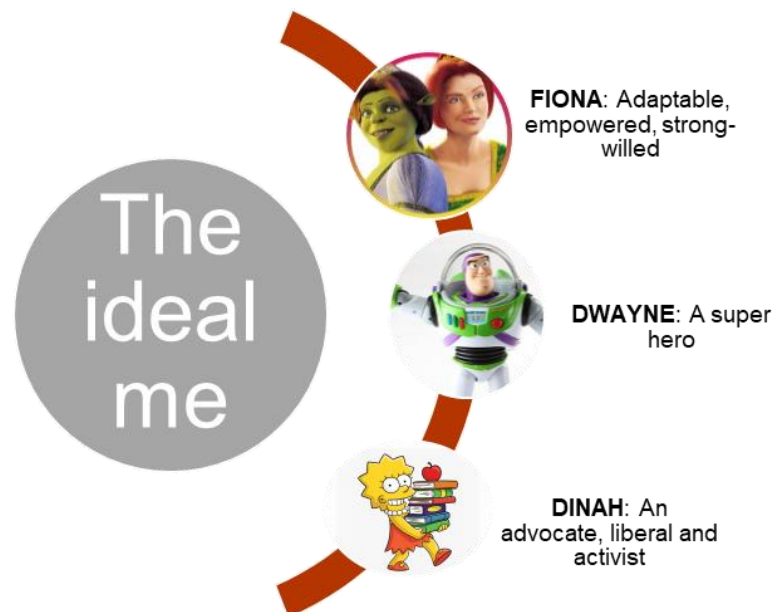
As indicated in Chapter 6, Section 6.2.5.2, the character, Fiona, in the film, *Shrek* (Jenson & Adamson, 2001), was chosen to portray the first participant as an adaptable, empowered and strong-willed individual. Fiona admitted that she "*had to dig deep into her inner self to seek that which made her more as the person with the beautiful hair*". She indicated that she had questioned her worth, reflecting on her value

and meaning in living in the world as a person experiencing the loss of hair and self. She envisioned herself in the larger scheme of things which she expressed by emphasising the importance of *"exploring a wider world"*. By affirming herself as a person who is open to exposure and new experiences, she positioned herself in the *"wider world"*.

As mentioned in Chapter 6, Section 6.3.5.2, in his reflection of himself, Dwayne likened himself to the character, Buzz Lightyear, from the animated film, *Toy Story* (Lasseter et al., 1995). Dwayne's reflection on his life with MCC led him to the conclusion that acceptance allowed him to anticipate everyday challenges and plan for better outcomes in the future. He thus envisioned himself as a hero who could overcome his CDs and be applauded and admired for his hard work and physique. The acceptance and validation of others were shown to be essential to his identity.

Dinah's reflection on her life with MCC was to focus her thoughts on work, which helped her maintain balance. Her guiding principle was *"that our thought processes shape who we become"*. In her reflection of herself (Section 6.4.5.2), Dinah compared herself to the character, Lisa, from the animated television series, *The Simpsons* (Groening, 1989). Dinah wanted to be seen as an advocate, liberal and activist, someone who can stand up for the rights of others, liberal in her thinking and actively engaging in issues concerning others' wellbeing. It is evident that the participants presented an ideal self, because the ideal self represents an identity continuity after the CD diagnosis.

An ideal self reflects an identity which the participants could continue to experience as meaningful and valued. Through the construction of an ideal self, the participants wanted to make meaning of their illness experiences, have clarity on their self-identity and have a future prospect and purpose in life (Steger, 2012). In their existential reflection, the participants engaged in a process of reconciliating their lives free of CDs (past), living with CDs (present) and creating a sense of an ideal, valued, meaningful self to rectify their life's direction, thereby creating a purpose in life. The participants' existential reflection coincided with cognitive restructuring, to enact sustaining an identity continuity by reconstructing a meaningful self.

7.2.2.2 Cognitive reconstructing

The cognitive perspective on meaning making indicates that individuals are impacted by context, social content and social influences to reinforce their values, sense of efficacy and sense of self (Baumeister, 1991). Because it is about reinforcing the self, I deduced that the cognitive reconstructing process in this study was also about negotiating identity continuity. People with CDs engage in ongoing negotiations with society in order to make sense of their situation (Harrison & Tronick, 2022; Leys, 2010) and to ensure self-coherence and identity continuity (Erikson, 1994) by making changes within themselves (Frankl, 2008). Identities emerge in the social arena, where perceptions and ideas are created in response to social interactions, attitudes and ideas, as well as the impact of the larger systems in which people interact (Von Wrede-Jarvis, 2021). In this section, I reflect on how the participants reconstructed a positive and valued identity by reframing their experience of how others perceive them, by integrating the CD into their self-identity and by reconstructing a new identity to mask the deficiencies of their CD. The reconstruction of a positive and valued identity manifests in a rebranding of the PwCD identity.

People asked Fiona *"timely and untimely what was going on under the headscarf"*. In her reflection, she revised the situation in the relational context, cognitively integrated it and concluded that "*anything abnormal makes people curious and not necessarily mean*". In living with AA, covering her baldness, her otherness, with scarves became a method to mask her humiliation. In Dinah's case, psoriasis is a cosmetic problem because it appears as a red, dry and flaky patch of skin, which is extremely noticeable. She perceived that when she did counselling, people's "*eyes caught it"*, and some colleagues at work commented, "*Oh, you look bad!",* which she found "*disturbing".* Dinah concealed her psoriasis and used humour in an effort to make others feel more at ease and, at the same time, build a sense of belonging (Joachim & Acorn, 2000). She used various ways to conceal it, like wearing longer sleeves and "*finely crochet* [sic] *mittens.*" Clothing can help people to discover and shape of their identity, because people express themselves through what they wear (Boomsma, 2020). Fiona and Dinah therefore employed accessories like scarves and mittens as instruments to construct a bohemian style, which gave their self-identities a new free-spirited, individualistic and eclectic aspect (Boomsma, 2020). Park et al. (2018) reported that above and beyond its cosmetic benefits, wearing a wig improves psychosocial

elements in people with severe AA. By contrast, Fiona, chose not to wear a wig, but rather asserted her individuality by distinguishing herself by wearing scarves, thereby embracing and incorporating her CD into her self-identity.

Dwayne's AS symptoms have resulted in chronic pain and stiffness in his back and hips, which give him an awkward gait, resulting in *"the guys making fun"* of him. He, like Dinah, made light of it in order to mask his discomfort. This teasing, however, had an effect on his self-concept and he cognitively reframed his image from that of a disabled person to that of a weightlifter, and began training seriously. This improved not only his health, but also his idealised view of himself as a weightlifter: "*I pushed myself very hard because I desperately wanted to look the part as a weightlifter*". Living with a visible CD, particularly when stigmatisation is experienced through others' comments, resulted in the creation of recategorising tactics. Dwayne appeared to have substituted the socially given crippled otherness with a different type of positive physical otherness, that of a weightlifter.

Fiona and Dinah did the same by substituting their physical otherness of baldness and scarring with the otherness of imitating an individualistic bohemian attire. They all still underlined their otherness, but in a more positive light, and in this way, experienced inclusion and belongingness through association with particular communities. In so doing, the participants emphasised positive and valued identities while minimising stigmatised identities.

The participants further used personal branding to reconstruct their self-identities in the context of making meaning while living with a CD. Branding is usually associated with marketing, but the role of personal branding in the formation of self-identity is not a new concept. Gorbatov et al. (2018) posited that scholars such as Erikson (1968), Ibarra (1999), Mead (1934) and Turner and Oakes (1986) had introduced this concept several decades earlier. Personal branding is defined as the strategic process of establishing, positioning and sustaining a positive image of oneself based on a unique blend of distinctive qualities that communicate a specific promise to the target audience through personalised narrative and imagery (Gorbatov et al., 2018). In this sense, personal branding can be seen as the equivalent of cognitive reframing where people endeavour to see and present themselves more positively. The participants

employed personal branding to cognitively reconstruct a meaningful self, as depicted in Figure 7.3.

Figure 7.3

Using personal branding to cognitively create a meaningful self
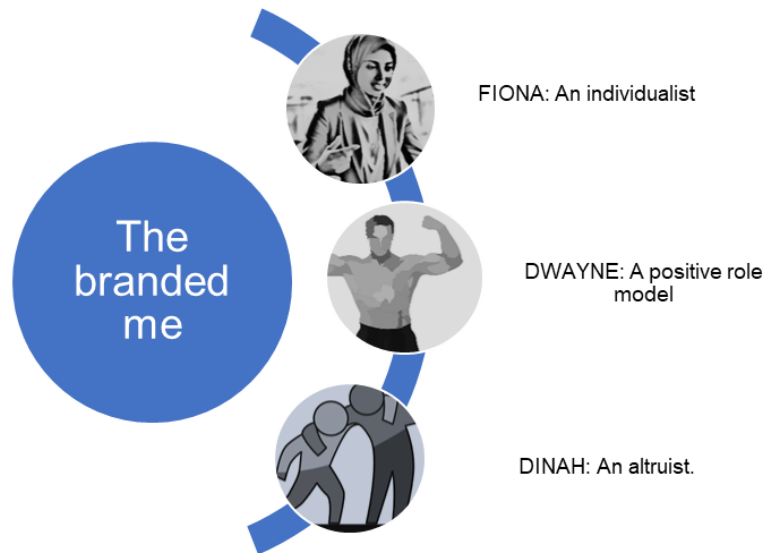
Fiona used personal branding to help her reconstruct a meaningful self-identity by portraying herself as an individualist, someone who is unique and original in her appearance and actions. Dwayne built a meaningful self through branding by establishing himself as a positive role model for youngsters at church and co-workers, and in the social environment. Dinah branded herself meaningfully as an altruist, a person who shows concern for the welfare of others.

Through existential reflection and cognitive restructuring, PwCD respond to the loss of self and endeavour to negotiate identity continuity. Through existential reflection, the participants reflected on their lives before CDs and their current lives with CDs, and by creating an ideal identity, they rectified their future life's direction. Through cognitive reconstruction, they found alignment with the ideal identity by constructing a branded identity in which they presented themselves positively. Cognitive restructuring served as a channel through which the participants set themselves in the positive frame of a meaningful self. To facilitate the necessary change and growth aligned to the branded-self, the participants continued the reconstruction of a meaningful self through Frankl's meaning-making pathways.

7.2.3 Constructing a meaningful self: Applying Frankl's meaning-making pathways towards self-determination

Self-determination theory identifies three universal needs that must be satisfied for a person to achieve wellbeing, namely competence, relatedness and autonomy. The study data indicated that the participants satisfied these needs by reconstructing a meaningful self through the creative, experiential and attitudinal pathways. Through the creative pathway, the need for competence is satisfied by a sense of efficacy in using creative ways to engage with deeper purpose and thus finding new ways of fulfilment. The need for relatedness is addressed by using the experiential pathway of supplementing oneself through interactions and connecting meaningfully with others, nature, beauty and new things. The need for autonomy is satisfied through the attitudinal pathway of redirecting one's orientation to life through freedom of will, spirituality and responsibility. The connection between Deci and Ryan's (1985, 2000, 2012) self-determination theory and Frankl's meaning-making principles was theoretically addressed in Chapter 4, Section 4.3.2.2.

Motivation for PwCD is more complex than simply meeting current needs. Their motivation is value driven, and they purposefully follow a specific direction (Golay et al., 2007). According to Frankl (2008), people are ultimately self-determining, and such self-determination was evident in the data in all three cases in this study. On the one hand, self-determination was evident in the way the participants intentionally sought meaning and purpose through each of Frankl's meaning-making pathways, and on the other, how they became self-determined through the pathways. Hence being self-determined not only enhanced their construction of a meaningful self, but also represented a meaningful self. Through each of the three pathways they sought meaning and purpose in reconstructing a meaningful self. The participants found meaning by (1) reconstructing their sense of competence and career identity; (2) rebuilding their sense of connectedness and intrapersonal identity through experiencing interactions and connections; and (3) redirecting their orientation to life.

In the following sections, I explicate how the participants (1) reconstructed their career identities through the creative pathway; (2) reconstructed their intrapersonal identities through the experiential pathway; and (3) reconstructed their life orientation through

the attitudinal pathway, to ultimately construct a meaningful self, which is also reflected in self-determination.

7.2.3.1   Reconstructing career identity through the creative pathway

The participants' creative reconstruction of a career identity by performing activities, producing or making things and engaging with a deeper awareness, led to feelings of competence in their dealings with the work environment. Their career identities were reconstructed within their self-identities, and they felt more competent in their ability to perform activities and thus produce things.

Career identity is related to people's self-image and the work they do (Chen & Reay, 2021). Through reflection and cognitive responses to the challenging realities of living with CDs, PwCD reconstruct their career identity by establishing meaningful connections between their own needs, motivations, interests, talents and suitable career roles (Meijers & Lengelle, 2012). When confronted with challenges, such as living with CDs, people tend to opt for the security of the already known in their decision-making processes about careers (Meijers & Lengelle, 2012) and engage in personal legacy projects to create a better version of themselves (Harrison & Tronick, 2022).

Fiona reconstructed her career identity by choosing a flexible, safe environment in which she could incorporate her self-identity by expressing her individuality and creativity by wearing head scarves and doing a job that was familiar to her. When she faced forced retirement because of the closure of the business, she became self-employed, losing her prior career identity and reconstructing a new one outside of the workplace. In following her calling, in her role as entrepreneur and doing arts and crafts, she maintained her self-image by creating a career identity outside the formal sector, where she experienced a deeper awareness of competence, claiming that doing arts and crafts "*is now*" her "*real work*", and she "*enjoys it so much that it does not feel like work*". She subsequently added freelance consultant remote work to her entrepreneurial agenda, and was able to incorporate her self-identity into the protean career identity of self-directedness and self-management within the safe confinement of her home, where she did not have to conceal her AA. Fiona's vision of creating a legacy towards a better version of herself was found through the value experienced in her formal work in producing something of value for many people, and she further

claimed to be a role model for her children in that she had "*transferred"* her sense of "*exploration of a wider world"* to them. Using her arts and crafts talents in her formal job role and in entrepreneurial role reflected her reversion to what was known to her. In the creation of a legacy, she envisioned herself as a role model, and in conjunction with her freelance activities, arts and crafts contributed to her feelings of fulfilment and competence.

Dwayne reconstructed his career identity to meet his needs by reverting to a safe space, integrating his self-identity and need for competence and self-esteem, and simultaneously managing his health. When Dwayne was first diagnosed with AS, on a medical practitioner's advice, he had to revise his career identity. He reverted back to the known safe space of his previous career identity within the security of a family business, where he had more flexibility to manage his health. In the midst of a mid-career life phase, Dwayne felt that he was "*destined for mor*e" – hence his re-entry into the formal working environment and choice of a career with the flexibility of a structure where he was not office bound and could integrate his self-identity with his career identity and still manage his health. Dwayne experienced competence and fulfilment in being seen and appreciated for his "*problem-solving abilities"* and as a good worker and colleague. According to Soomro and Shah (2019), for workers in an organisation, meaning making occurs in the ordinary course of business within a structure of job delineation and performance assessment.

Within the structure of job delineation and performance assessment, Dwayne reconstructed a career identity that enabled him to experience meaning making through the deeper awareness of competence in the feedback of task execution from management and colleagues to the satisfaction of his self-esteem. He further used job crafting to expand his activities in the workplace by including observation by walking around to further his feelings of competence and simultaneously meet his need for exercise in order to maintain his mobility. Dwayne created a legacy by conveying his intention to "*be a positive role model"* and confirming this improved version of himself through positive feedback received at work. He reconstructed his career identity by including his self-identity, values and needs in making meaning after the disruption of the diagnosis with his CDs and the concomitant loss of health through creative ways of performing activities and experiencing competence through feedback.

Dinah reconstructed her career identity by following a calling, namely her desire to devote her life to serving others, thereby integrating her self-identity into her career identity. Dinah merged her career and illness identity, thereby reconstructing a self-identity in an area in which she felt related, safe and understood. She was no longer motivated by the extrinsic motivator of having a paid career after her cancer diagnosis – she was now internally motivated to find fulfilment by responding to others' needs. For Dinah, there was a shift in values in that she felt that "*after the cancer, the corporate world was meaningless ... It did not make any sense anymore*". She experienced an existential meaninglessness in which she felt driven towards making meaning in her life context. Her existential reflection of wanting to extend beyond herself by making a difference in others' lives led to a cognitive restructuring in her career decision-making process.

Dinah demonstrated that by embracing her cancer and using this experience to shift her goal from working in the corporate world to supporting people living with cancer, she engaged in legacy creation with a deeper awareness and gained self-worth, value and feelings of competence. Her meaning making arose from the internal satisfaction and integration of her self-identity and career identity towards her contribution to others' wellbeing – hence her entry into career with an NPO where she could experience competence by performing activities that she could relate to and at the same time fulfil her need for prosociality. After Dinah left the formal employment sector to pursue another kind of calling, namely arts and crafts, she found fulfilment in her ability to be creative in the safe space of her home, reducing the concealment concerns linked to her psoriasis that she had had to deal with at work. However, she experienced a void in her need for benevolence and returned to volunteering and freelance work in the cancer support arena. Freelance paid work supports the protean approach of autonomy and self-management, self-direction, and emphasises Dinah's self-driven intrinsic motivation to "*mean something to someone*". Dinah experienced feelings of competence and meaningfulness in the self-directedness of creative freelance activities and arts and crafts within a self-determined safety space.

It was clear that the participants used their self-identities to reconstruct their career identities by reverting to safe known spaces, incorporating their personal values and

needs, creatively finding ways to do their activities and produce things that led to a deeper awareness of competence and meaningfulness.

7.2.3.2 *Reconstructing intrapersonal identity through the experiential pathway*

The reconstruction of an intrapersonal identity can be accomplished through the experiential pathway of experiencing relationships with others and nature, beauty and new things. The participants' sense of self was supplemented through the experiential pathway of maintaining relationships, fostering a sense of belonging and interacting with nature, beauty and things. They could reconstruct their self-identities through experiences of being loved, forming part of social groups, receiving support (being cared for) and interacting with nature, beauty and new things.

The relational concept of *Ubuntu* (Ewuoso & Hall, 2019; Pattakos & Dundon, 2017a) is applicable in the context of meaning making through the experiential pathway. The philosophy of *Ubuntu* has been translated in a variety of ways, but for this study, "a person is a person through other persons" was deemed appropriate (Ewuoso & Hall, 2019, p. 96; Gade, 2012; Pattakos & Dundon, 2017a). The participants' perceptions and intentions in reconstructing their self-identities were influenced by their different experiences in their various relationships. True identity is formed via interactions with others in which one is impacted and inspired (Pattakos & Dundon, 2017a). The impact of others on the self was explicated in Section 7.2.1 in relation to the role of stigma in the loss of self-identity. The participants engaged in strategies to disguise defects in their physical attributes produced by their CDs, thereby reconstructing their self-identities in an effort to be acceptable to society. Fiona, for example, wore head scarves to hide her baldness; Dwayne exercised to modify his physical appearance as a person with AS; and Dinah covered her psoriasis. They therefore reconstructed their self-identities to align with perceived socially acceptable identities.

Meaning through relatedness was found in interactions with others, like giving and receiving love and feeling safe to be themselves, expressing sadness and venting their anger and frustration. Fiona experienced her relatedness with her family as a loving, safe space in which she could be herself. She expressed her positive relationships in the workplace as meaningful in that she *"worked with the most amazing team of women".* Dwayne indicated that "*home*" was the best place where he could experience love from his family and could just be himself without any pretence. He supplemented

himself through his interactions at work, thriving on positive feedback from colleagues and management, and experienced belongingness in joining social groups at the gym and church. Dinah found that in the safe space of her friendship with a close friend, she could vent her frustration and anger without being judged and shunned. She also discovered a strong sense of belonging and value, not only by receiving but also by rendering support to others through her formal work and acting as a catalyst by listening to the challenges of her former colleagues and giving advice. It is through relatedness, the social connections one employs, that people with CDs make sense of their lives in the context of others, through offering love, sharing good and unpleasant experiences, and receiving and processing feedback.

Two of the cases in this study revealed that their spiritual relationship with God was helpful in reconstructing their self-identities, offering moral principles and emotional consolation (Thune-Boyle et al., 2006). Religion provides one with a sense of security (Frankl, 2019) and helps one cope with the stressors accompanied by living with a CD (Koenig, 2012), thereby strengthening one's self-identity, which is grounded in God (Park et al., 2006). Dwayne stated that he "*spends time on his knees in prayer*" and is inspired to strive for the value of doing what is morally right, implying that his relationship with God strengthens his self-identity. Dinah expressed gratitude to God for helping her through her cancer journey and healing her, indicating that she found comfort and support in her relationship with God in coping with her diagnosis and treatment of breast cancer. Her intimate relationship with and love for God enabled her to reconstruct her self-identity and as such, according to Frankl (2019), she enriched herself through her prosocial behaviour.

The experiential pathway extended to the participants further meaning making through their aesthetic experiences of their unique connections and interactions (Peacocke, 2023) by means of the following: positive evaluation of an object or its creator (enjoying nature and beauty); enjoyment of the activity of being creatively involved (arts and crafts); relief from certain stressors (feeling relaxed when on vacation, travelling and gardening); and pleasure in gaining knowledge and understanding of something (exploration through travelling). Connecting with nature made the participants feel happy and reduced their physical and psychological stress, thereby increasing their sense of wellbeing. Feeling connected to nature is a sensory experience that involves

seeing, hearing, smelling, touching and sometimes tasting (Bratman et al., 2019). Connecting with nature can happen in various ways. One way is to do so while expressing one's inner creativity through drawing or painting, as shown by Dinah and Fiona. Another way, as mentioned by Dwayne, is the happiness, restfulness and peace he experienced while on vacation at the coast where he "*recharged a little by dipping*" his "*feet in the seawater*". Being close to water or sitting and watching the waves roll over the sand benefits one's mental health while experiencing happy emotions (Bratman et al., 2019).

The participants reflected on and responded to the influences, guidance and support experienced in their spiritual relations and their relationships with friends, colleagues, family and society, and as such reconstructed their intrapersonal identities. In their connectedness with nature, they further regenerated their selves by valuing these experiences, and at the same time felt less stress, improved their moods and had more energy to face their lives with CDs.

7.2.3.3   Reconstructing life orientation through the attitudinal pathway

Frankl (2008) posited that people are self-determining and self-determination is an attitudinal value that refers to the ability to make meaning. According to Pattakos and Dundon (2017a), in choosing an attitude, individuals assume the role and responsibility of a cocreator of their reality, thus embracing life with attitude. The three cases displayed a continuous process of acceptance and assimilation of the symptoms and effects of their reality of living with CDs into their self-identities via the attitudinal pathway. The result was a self-determined attitude that promoted a more positive outlook on life (Whittemore & Dixon, 2008).

According to Frankl (2008), freedom of will is associated with one's choice of attitude in the face of adversity, such as living with CDs. In the attitudinal redirection of their orientation to life, all three participants wanted to accept and gain control, with the determination, as Dwayne put it, "*to own it and move on*". The participants embraced the challenges and limitations of living with CDs with a self-determined attitude of acceptance and positivity. Fiona demonstrated an attitude of acceptance by stating that she had "*learned to love*" her "*new*" self and had reoriented herself to be "*happy without hair*". Dinah illustrated positive attitude taking in her written narrative, which she called "*Failure*". In this narrative, she indicated that, for her, living with CDs

represented a form of failure, but she still emphasised positivity and growth in that "*if you are willing to look past the cuts and hard work, the broken glass shards of your life will eventually form an awesome mosaic*".

The idea of taking responsibility and control over the disease is an unconscious attempt to maintain autonomy through one's identity and social role (Townsend et al., 2006). Dinah and Fiona demonstrated the preservation of their identity and social role in their pursuit of autonomy and freedom by embarking on self-employment in selling arts and crafts, while also freelancing in their prior field of work. It gave them the flexibility to continue working in the formal sector, while also allowing them to schedule work around the symptoms of their CDs.

Living with a CD entails disruptions that necessitate various levels of identity alteration, not only in one's personal life, but also in one's work life, resulting in positive self-reconstruction. One's work and personal lives are often separated, but in reality, they are intertwined. It was found that the reconstruction of the self-identity in private and work life is intertwined through the creative, experiential and attitudinal pathways. Self-determination was particularly evident in how the need for competence, relatedness and autonomy compelled the participants to intentionally seek meaning and purpose through each of Frankl's meaning-making pathways. However, self-determination also became reflective of the meaningful self. Hence the reconstructed career and intrapersonal identities and reframed life orientation fulfil the competence, relatedness and autonomy needs, which drive the construction of a meaningful self, and become reflective of the meaningful self. The interaction dynamic between self-determination needs as fulfilled through the three meaning-making pathways in constructing a meaningful self who is self-determined, is represented in Figure 7.4.

Figure 7.4

The reconstructed career and intrapersonal identities and reframed life orientation as a reflection of the meaningful self
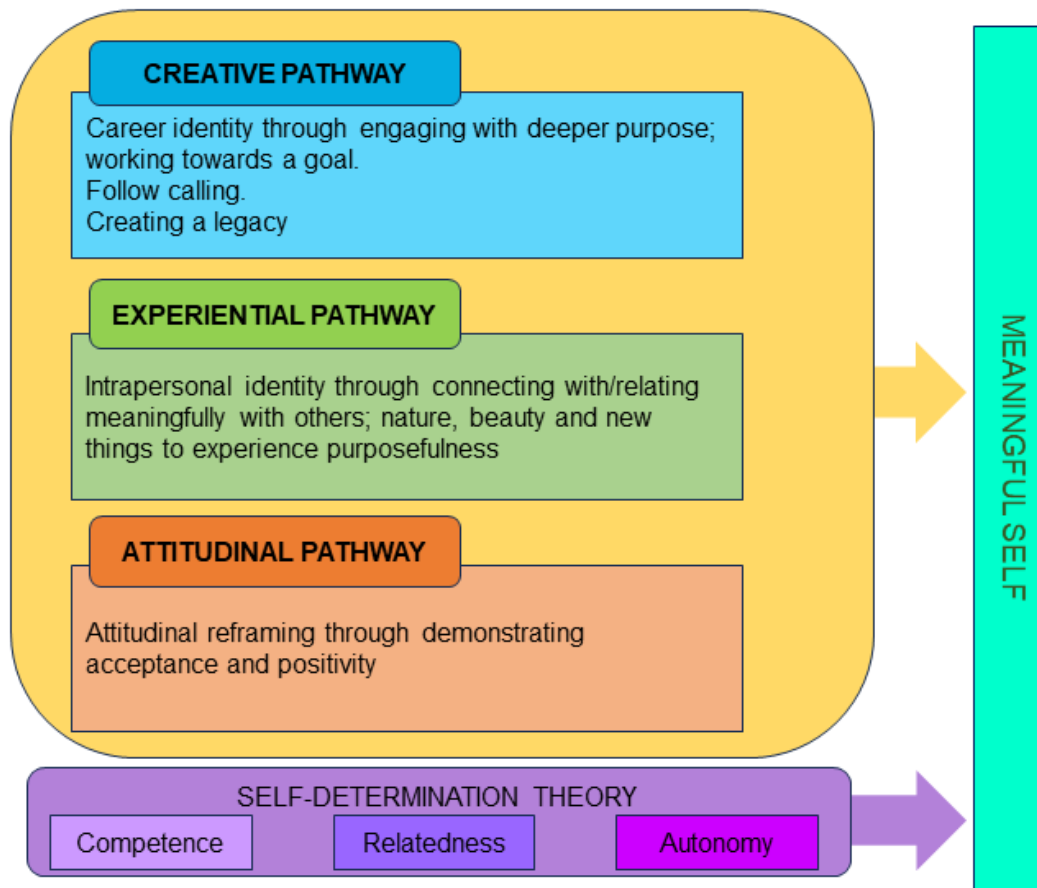
The participants reflected and responded in a self-determined way by constructing a meaningful self through the three pathways. Through the creative pathway, they reconstructed their career identities by engaging with deeper purpose in performing activities and making things, following a calling and creating a living legacy, and as such gained a sense of competence. In their experiences of relatedness through their meaningful interactions with others, nature, beauty and new things, they reconstructed an intrapersonal identity; and through the attitudinal pathway, they demonstrated a redirection of their life orientation through acceptance and positivity through freedom of will, thereby satisfying the need for autonomy. A meaningful self can thus be conceptualised as being self-determined – feeling competent as a result of having a sense of purpose and legacy; feeling purposefully related to others; and feeling autonomous through attitudes of acceptance and positivity.

7.2.4 Self-transcendence as a facilitator and enhancer in reconstructing a meaningful self

According to Frankl (2008), true meaning is found not in but outside the self, in the world, when one forgets the self (to transcend) and directs oneself towards a cause or serves others. The other-centredness of self-transcendence enhanced the participants' meaning making. This was evident in the way their will to reconstruct a meaningful self was motivated by self-transcendence in the sense that they experienced a shift or change in their orientation to be other-focused, as well as in their altered perceptions and thinking.

According to Wong (2016d), the will to meaning is a motivational factor of self-transcendence relating to the adaptive value of making meaning in adversity. This motivational will to meaning was demonstrated by the participants through their need to make meaning and find purpose in their lives. They focused on others, in the form of family, friends and co-workers in order to find value in these relationships and enhance meaning in the new, different roles that the illnesses imposed upon them. In this way, the participants' relationships and social connectedness were enhanced and their sense of purpose and control in life was restored. They revealed a shift from being self-focused to being other-focused, which created positive outcomes for them.

Fiona stated that her experience with AA had taught her to discover joy in other areas such as her social relationships, her "*loved one, children, family, and friends",* and moral concerns such as "*worldwide poverty"* and "*war".* Dwayne felt that spending his free time to focus on others by teaching youngsters at church gave him "*purpose, created balance, and an opportunity to be benevolent".* He also discovered that "*colleagues sought"* his "*advice or counselling*", and by focusing on them, he created purpose. Dwayne believed that he was "*destined for more*" and had the ability to make a difference in others' lives. Focusing on others revealed other aspects of his identity, such as being a mentor and counsellor, which helped him to develop a sense of worth and find purpose outside of his CDs. Dinah devoted her life to fulfilling a calling in serving others. For her, "*to mean something to someone*", by helping others experiencing similar struggles or dedicating her time to volunteering for causes she cared about, created purpose in her life. Stepping away from self-interest, according to Wong (2016b), helps individuals to be more aware of their experiences, as well as

the opportunity to access moral values such as conscience, compassion, will to meaning and responsibility.

The participants looked at their lives with CDs through a spiritual lens. They expressed a spiritual connectedness (Reed, 1991), which included the elevation of emotions of gratitude and awe that occurred in the context of their lives with CDs (Fredrickson, 2001, 2003, 2006; Pizarro et al., 2021). Fiona expressed the positive emotion of gratitude in the awe she found in her "*beloved husband, children, family, friends*" in respect of her "*physical abilities*" and her ability to "*work, travel and live*". She demonstrated increased interest in morality by shifting her focus from her individual loss to concern for global moral issues, and expressed this as follow: "*global poverty, inequities, war ... all elicit rage, frustration, and concern in me*". Dwayne experienced a deepening of his spiritual nature when he described how he "*spent lots of time kneeling in prayer*", and reported that it evoked positive emotions, which led to reflection and morally making "*the right decisions*", which helped him to overcome difficulties and resolve problems. Dinah expressed gratitude towards God for "*carrying her through*" (her cancer treatment) and that she "*is healed*"". Dinah's gratitude resulted in her promising that she "*would return*" the favour, which she did by working with cancer patients.

Gratitude is one of the positive emotions associated with self-transcendence, which has a moral and prosocial nature (Chen et al., 2022) and has effects via the enhancement of positive affect. Dinah's resolve to do what is morally right drove her to devote her life to people in need when she explained that "*after cancer, the corporate world was meaningless*" and she wanted "*to make an impact or difference*" in the lives of cancer patients. The self-transcendence elevation in emotions and morality resulted in her revising her strategies for self-fulfilment.

As indicated, living with a CD, caused the participants to make meaning in the sense that they sought to clarify their relationship between living with CDs (being in the world) and self (Längle, 2001). According to Reed (1991), the core of self-transcendence is relatedness (Reed, 1991), which was evident in the participants' expansion of personal boundaries in their experiences of interpersonal and spiritual connectedness in order to sustain their intrapersonal wellbeing.

7.2.5 The essence of meaning making for PwCD: Reconstructing a meaningful self

The essence of meaning making for PwCD is conceptualised in Figure 7.5 by integrating the process elements into a conceptual whole revolving around a meaningful self and reconstructing a meaningful self in response to the CD.

Figure 7.5

The fulfilment of the self and enhanced meaning making of PwCD
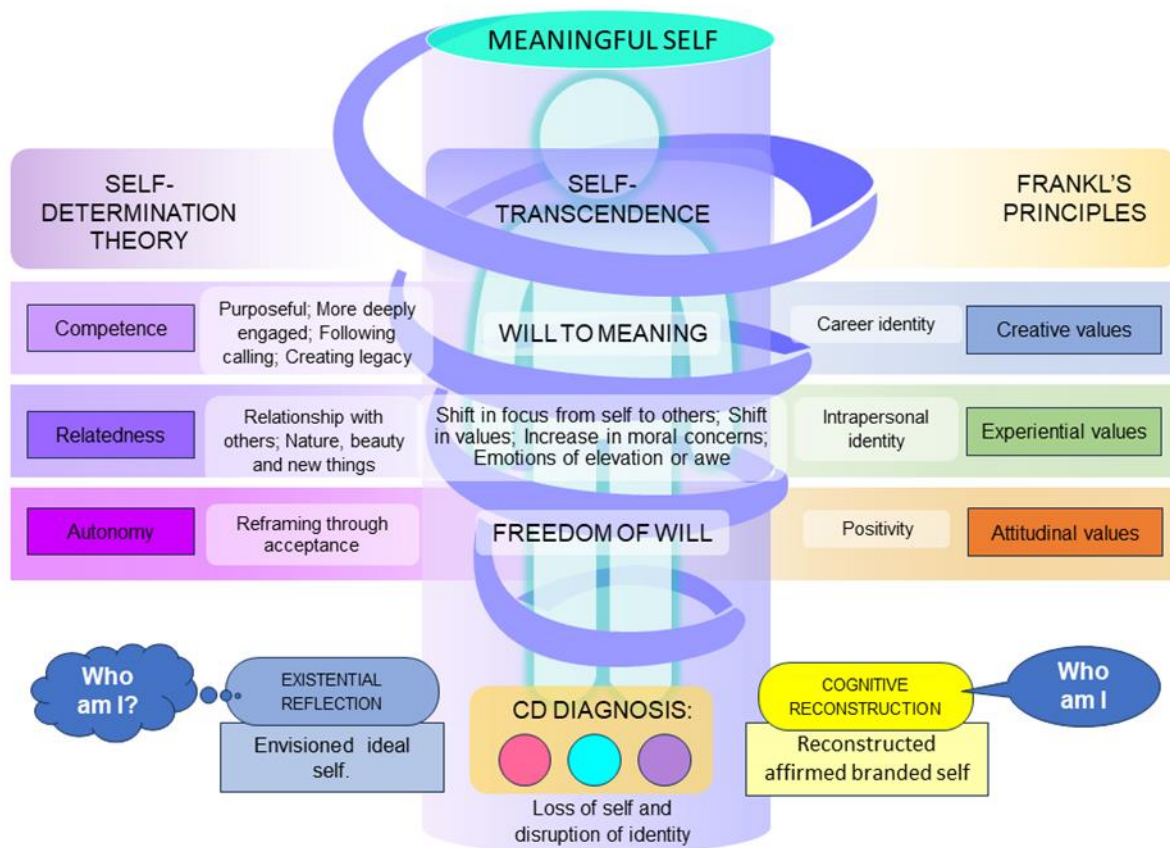
Firstly, the self is placed in the centre in the experience of loss of self, because when diagnosed with a CD, the participants' lives were disrupted. The disruption was caused by physical symptoms, threats to their physical appearance, and their autonomy and identity, all of which elicited a range of emotions that culminated in an overall sense of identity loss. One can describe it as a feeling of "I am not who I was".

Secondly, the participants naturally responded to their experience of the loss of self with the need to negotiate identity continuity. This was negotiated through the

concurrent intra- and interpersonal processes of existential reflection and cognitive restructuring. Through existential reflection, the participants were concerned with the question of "Who am I?", and in attempting to sustain the self (identity continuity), they envisioned an ideal self to reposition themselves meaningfully in living in the world (Giddens, 1991). Through cognitive restructuring they constructed a branded self to reframe aspects of the self in relation to others, resulting in affirming "who I am".

It was clear that the participants viewed themselves on the basis of cues received from the social environment in which they participated, and cognitively restructured their self-identities accordingly. Hence, the ideal self (through existential reflection), in a sense, is "attained" or "realised" in the branded self (through cognitive construction). The ideal self is represented by characteristics of who the participants wished to be and what they believed made their self-identity meaningful. The branded self is a reflection of characteristics that the participants ascribed to themselves to affirm their meaningful self. PwCD's notion of the ideal and the branded self were continuing to interact in the existential reflection-cognitive reconstruction dynamic, thus reflecting how PwCD continued to work on reconstructing a meaningful self.

Reconstructing a meaningful self-identity is an inter- and intrapersonal process in that the participants' constructions were driven by existential reflection and cognitive reconstruction (two intrapersonal processes), but these processes manifested in a social context in which the participants' meaning making was consistently influenced by the social constructions. They therefore constructed and co-constructed the meaningful self to make sense of their lives with CDs and their identities within their interpersonal, social context (see Haste, 2004). In establishing a meaningful self in the context of their lives with CDs, they envisioned an ideal self and cognitively reconstructed their identity by using personal branding in reframing and presenting themselves in a way that they deemed purposeful and meaningful.

Thirdly, consequent to their existential reflection and cognitive reconstruction of what they regarded as a meaningful self, the participants were self-determined to reconstruct a meaningful self through the three meaning-making pathways. Their self-determination needs for competence, relatedness and autonomy compelled the participants to make meaning through Frankl's three meaning-making pathways. Through these pathways they realised these needs and thus constructed a meaningful

self as reflected in them feeling competent, related and autonomous, that is, being self-determined. Through each meaning-making pathway, they reconstructed the meaningful self. Through the creative pathway, they reconstructed a meaningful career identity, determined by their need for competence. A meaningful career identity was characteristically defined by engaging with purpose and leaving a legacy. Living with the effects of a CD caused a shift in values from extrinsic to intrinsic gratification, finding gratification in positive feedback and engaging with a deeper purpose. Creating and living a legacy proved to be the means to incorporate their ideal and branded self into their career-identity. Through the experiential pathway, the participants conceptualised a meaningful self as one who experiences value and self-worth through their relational experiences of receiving and giving support.

In their interaction with and appreciation of beauty and nature, another kind of connectedness was formed, which inspired calmness and a feeling of being part of something bigger than the self. Through the attitudinal pathway, the participants demonstrated self-determination by pursuing autonomy in reconstructing a more meaningful life orientation. A meaningful self, through the attitudinal pathway, entails integrating self-determined attitudes of acceptance and positivity. Overall, reconstructing the meaningful self is a process that is attained through the intra- and interpersonal processes of existential reflection and cognitive restructuring and reflects the "ideal self and branded self" dynamic. More specifically, reconstructing the meaningful self is driven by self-determination needs, and a meaningful self is reflected in fulfilling one's self-determination needs through the meaning-making pathways. The meaningful self is thus incumbent upon integrating into the self a reconstructed career identity, interpersonal identity and life orientation.

Lastly, meaning making was enhanced by self-transcendence in using freedom of will and motivated by the will to meaning through the four defining characteristics of self-transcendence (Wong, 2016d). All four characteristics of self-transcendence were shown to have a mutual effect or be intertwined. The participants experienced a sense of connectedness in the shift from self to focusing on others in their interrelationships as well as by following a calling in serving others, and as such, developed a sense of worth and purpose outside of their lives with CDs. Through spiritual connectedness, they expressed the positive emotion of gratitude in the awe they experienced in

interaction with others and their own physical abilities, through a deepening of their spiritual nature and gratitude. This deepening triggered the need to do what is morally right, thereby increasing their moral concerns. The shift in values and increase in moral concerns were intertwined in such a way that one led to the other. A further increase in moral concerns was demonstrated by a shift from the focus on individual loss to a concern for global moral issues. The participants enhanced meaning making in their self-transcendence experiences of interpersonal and spiritual connectedness in order to sustain their intrapersonal wellbeing (as suggested by Reed, 1991).

In conclusion, the essence of meaning for PwCD as constructed in this study, has suggested that a meaningful self is motivated by self-determined freedom of will, enhanced by the will to self-transcendence, driven through existential cognitive processes and operationalised through the three pathways to reconstruct career identity, intrapersonal identity and individuals' overall life orientation in congruence with their ideal and branded selves. A meaningful self is self-determined and reflects a sense of competence, relatedness and autonomy. Reconstructing a meaningful self encapsulates the meaning-making process of the PwCD in response to loss of self as a result of their CD diagnosis and its consequences. Hence this meaning-making process is driven through the processes of existential reflection and cognitive restructuring.

7.3   A SUPPORT FRAMEWORK TO FACILITATE MEANING MAKING FOR PWCD

The purpose of this second section of the chapter was to develop a support framework that could be applied in the work context to support work-related wellbeing, coping and adjustment of PwCD. The framework was based on the understanding of the essence of PwCD's meaning making, namely the reconstructed self, a meaningful self that reflects competence, belonging, autonomy (i.e. self-determination) and a self-transcended connectedness in work life.

According to Lee (2021), when individuals experience respect and dignity in the workplace, it promotes a positive self-identity. It was evident in this study that the participants experienced a sense of psychological safety in the work environment that allowed them to express their individuality as PwCD. For example, Fiona, felt safe

wearing head gear to disguise her AA, Dwayne was able to apply job crafting to improve his symptoms of AS and Dinah felt comfortable dressing in an unconventional way to disguise her psoriasis. The support in creating a safe psychological environment, helped them to reconstruct their self-identity in that they experienced respect and dignity. Figure 7.6 illustrates the further discussion in this section of the organisational support in facilitating and enhancing meaning making of PwCD in the workplace.

Figure 7.6

Organisational support framework to facilitate and enhance meaning making of PwCD in the workplace
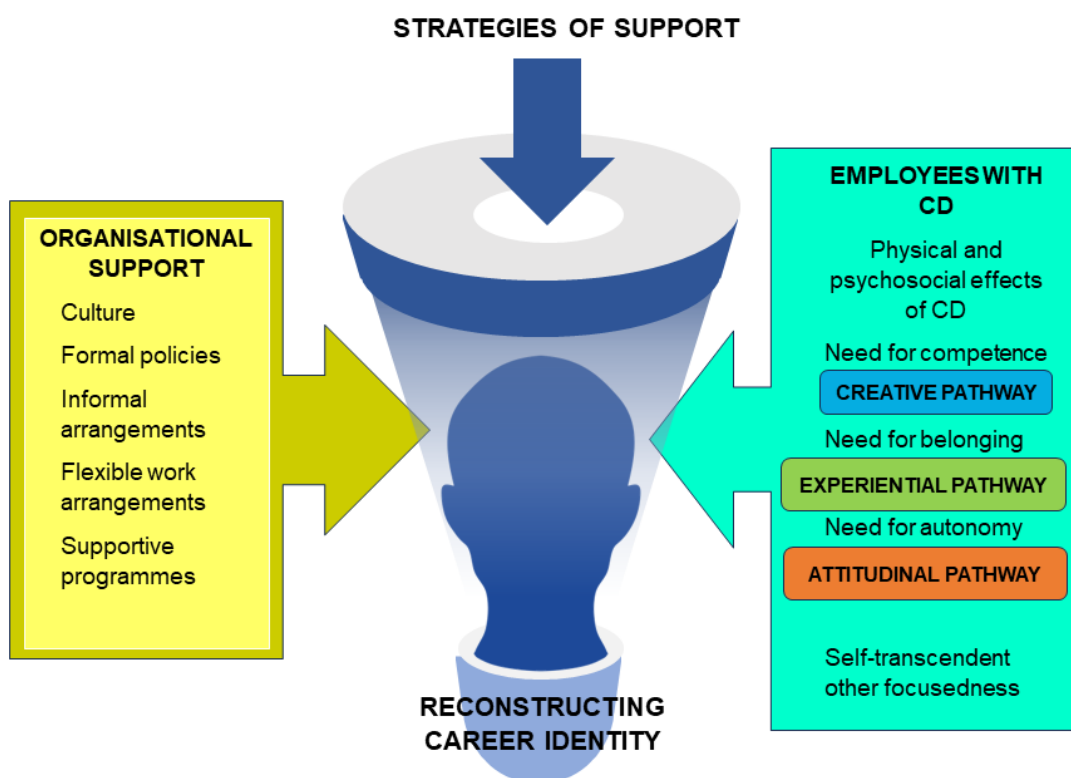
The framework was built on an understanding of the essence of PwCD meaning making, namely the reconstructed meaningful self. The meaningful self reflects the need for competence, belonging, autonomy (i.e. self-determination) and self-transcendent experiences of connectedness in one's work life. These needs can be addressed in the organisation by establishing a supportive organisational culture, which is informed by formal and informal policies as well as strategies and related supportive programmes. The organisation facilitates meaning making for employees

with CD through strategies of support in the areas mentioned, and the employee with CD, in the process, reconstructs his or her career identity to reflect a self that has integrated the illness into the self-identity.

According to Coe et al. (2019), organisational culture refers to the shared beliefs and values that influence workplace and employee behaviour. The organisational environment and culture can create flexibility in the management of PwCD by empowering managers to change job assignments and schedules to meet individual needs (DeOrsey, 2020). A supportive culture is characterised by an atmosphere of respect, understanding and compassion that values work-life balance and wellbeing for PwCD. Such a culture could be promoted in support of employees with CDs by providing training for managers and designing interventions to reduce stigmatisation. Employees feel a sense of belonging and fulfilment when their organisation demonstrates a culture of care and reacts to their intrinsic needs (Lee, 2021; Lee & Chui, 2019).

The participants indicated that they experienced feeling psychologically safe to express themselves through their revised strategies for self-fulfilment, such as job crafting, following a calling and finding ways to engage in value-added contributions to themselves and others, which led to feelings of competence in dealing with the work environment. Organisational culture is informed by and drives both the formal and informal policies and strategies employed in an organisation to manage talent. If an organisational culture that fosters psychological safety for PwCD is built, it could incorporate policies and strategies aimed at supporting PwCD's self-determination needs in the ways discussed below.

Formal policies that regulate leave, flexible work hours and job tasks would be beneficial in directing support for PwCD. Although formal policies usually direct managers to support employees with CDs, these policies should include flexibility to also use informal arrangements. This could include actions such as assigning colleagues to assist the employee in task-sharing where possible, and granting them reasonable time off when needed for medical reasons. Flexible working arrangements that include part-time working, job sharing, flexible scheduling and remote working could be beneficial for the employee with a CD.

To address the need for relatedness, supportive programmes like mentoring, coaching and counselling are valuable in enhancing meaning for employees with CDs. The relatedness in the workplace provides a way for PwCD to learn from and focus on others, feel a sense of belonging and self-worth, and as such, construct a meaningful identity. The participants emphasised the value and self-worth they had experienced through their interrelationships at work by experiencing group cohesiveness and feedback that built their self-esteem. Mentoring at work offers career-related and psychosocial support (Gill et al., 2018). Through mentoring, a sense of being a positive role model (for the mentor) and the building of self-confidence (for both the mentor and mentee) as well as positive social interactions can be accomplished (Gill et al., 2018). For the employee with a CD, being mentored or fulfilling the role of a mentor for others can be experienced as meaningful. Coaching to rebuild a meaningful career identity could help PwCD manage and direct their careers in the workplace (Beatty & McGonagle, 2016). Employers could provide psychosocial support by ensuring access to counselling services for their employees through an employee assistance programme (EAP) to further aid in the reconstruction of a meaningful self.

Another way to enhance meaning making for PwCD would be to encourage and create self-transcendent opportunities for prosocial behaviour where employees could participate in efforts directed at meeting the needs of others (Bierhoff, 2005; Vieweg, 2018). Examples of such activities are cooperation with and assistance to co-workers, completing extra jobs, exchanging ideas or positively representing the organisation (Boundenghan et al., 2012). Prosociality could be further encouraged through an organisation's corporate social responsibility (CSR) programme as a way through which employees could make meaning by being part of something bigger by giving their time and expertise in efforts to benefit society (Alexander & Douthit, 2016).

The disruption of the physical and psychosocial effects of the participants' CDs and the concomitant experience of loss reflected the need for competence, relatedness, autonomy and self-transcendent other-focusedness. For people with CDs, the essence of meaning making is encapsulated in the concept of constructing a meaningful self. Employers could support employees with CDs through collaboration and providing supportive work environments involving support policies, strategies and programmes to aid PwCD in the reconstruction of a meaningful self. All the support

initiatives mentioned can be consolidated into a CD toolkit for the use of all the stakeholders in the workplace. Such a training tool and toolkit can facilitate employees' wellbeing, health, and work ability; prevent the development of chronic diseases; and assist persons with ongoing CD issues to continue working (e.g. CHRODIS+ Training tool and toolkit[3]). All the help and support for people with chronic illnesses can be further captured in a smartphone application (App) that facilitates accessibility (see Smith et al., 2017).

In this chapter, a framework for organisational support was developed as a guideline on the facilitation of meaning making for PwCD in reconstructing a career identity and, as such, could lead to positive wellbeing, coping and adjustment in the workplace.

7.4   CHAPTER SUMMARY

In this chapter, a hermeneutic reflection and integration of data with the literature resulted in a critical evolution of the findings. The participants, motivated by self-transcendence, moved beyond the loss of self and identity disruption to meaning through existential reflection and cognitive reconstruction. This was achieved by reconstructing a career identity via the creative pathway, an intrapersonal identity via the experiential pathway and a life orientation via the attitudinal pathway. Making meaning while living with a CD entailed integrating the illness into their self-identities through Frankl's pathways, enhanced through self-transcendence. The evidence suggested that the essence of meaning making for the participants was the reconstruction of a meaningful self. In conclusion, an organisational framework was developed to facilitate and enhance the wellbeing of employees. Chapter 8 deals with conclusions, limitations and recommendations.

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[3] The CHRODIS PLUS Toolkit for Workplaces is available at http://chrodis.eu/chrodis-plus-training-tool-and-toolkit/ and offers 127 evidence-based, concrete means to promote health, prevent chronic health problems, and foster work participation of individuals with chronic diseases.

CHAPTER 8
CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

This final chapter is a conclusion and reflection of my research journey in conducting this study. While the outcome was crucial in this journey, the research and writing process were life-changing. I concur with Mackenzie and Ling (2009) that it was indeed a lonely journey, but also a fulfilling one. In this chapter, I will illuminate the findings, explain why they are valuable and how they could be applied, and discuss possible future research on this topic. I will summarise and discuss the important research findings and their contribution and significance in relation to the research objectives and questions, reviewing the strengths and limitations of the study, and making recommendations based on the findings. Lastly, further opportunities for future research will be proposed, and the chapter concludes with my reflections on the research journey.

8.1 SUMMATIVE REFLECTION OF THE MAJOR FINDINGS AND CONCLUSIONS

In Chapter 1, the first research question addressed how individuals make meaning while living and working with a CD, and it was proposed they make meaning by following Frankl's meaning-making pathways in the following ways: by using the creative pathway, individuals purposefully move towards adding value to themselves and others; by utilising the experiential pathway individuals connect meaningfully with someone or something; and by employing the attitudinal pathway individuals choose an attitude to create a different experience for self. The second research question addressed what enhances meaning making for individuals living and working with a CD, and the proposition was formulated that meaning making for them is enhanced by living out the capacity of self-transcendence. In Chapter 6, the findings were shown to support the study's propositions on meaning making while living and working with CDs. Meaning making was discovered through Frankl's creative, experiential and attitudinal pathways, which were motivated and enhanced by the capacity for self-transcendence and maintained by the need for self-determination. Two themes that emerged to be contextually relevant to understanding meaning making of PwCD, in addition to the directing propositions, were self-determination and identity reconstruction. The

evolved theorising in Chapter 7 led to the finding that existential reflection coincided with cognitive restructuring to enact sustaining identity continuity by reconstructing a meaningful self, which was the essence of meaning making for PwCD. It was concluded that the meaningful self was constructed by integrating the CDs into the participants' self-identities by means of Frankl's three pathways, enhanced by self-transcendence.

The multiple case study provided a rich context for understanding the phenomenon investigated in this study, namely how individuals living with CDs make meaning. A literal and a theoretical replication strategy were used through deductive and inductive reasoning to identify consistent patterns of behaviour and uncover new themes. Literal replication was achieved by obtaining similar results in all three cases. Theoretical replication confirmed the patterns derived from Frankl's theory. The data were found to corroborate the research questions and propositions, with an emphasis on the reconstruction of a self-identity that was evident throughout the meaning-making process. The main findings are further elucidated in the sections below.

8.1.1 Making meaning while living and working with a CD by means of Frankl's pathways

By analysing the lived experiences of three cases, this research showed how Frankl's pathways shaped meaning making while living and working with a CD. It was found that all three cases engaged in a process of existential reflection and cognitive restructuring to position themselves meaningfully within their social and work lives. From the individuals' perspective, meaning making involved self-determination to incorporate their illnesses into their lives through establishing competence in the creative pathway; by experiencing relatedness through the experiential pathway; and by maintaining a sense of autonomy through the attitudinal pathway.

The results indicated that in all three cases, the participants followed three primary strategies through the creative pathway to establish competence, namely, to perform activities, produce or create things, and engage with a deeper awareness. Through the experiential pathway, meaning making was experienced in showing relatedness in relationships with others and with nature, beauty and new things. It was shown that the attitudinal pathway was intertwined with the creative and experiential pathways in that the positive redirection in their lives with CDs was demonstrated through these

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pathways in their acceptance of the diagnosis of their CDs, and a choice of a positive, self-determined attitude to create a different experience for themselves.

8.1.2 Enhancing meaning making through self-transcendence in reconstructing the self-identity

Self-transcendence, according to Frankl, is a main motivation characterised by transformation, as indicated in this study. Self-transcendence is a primary motivation characterised by (1) a shift in focus from the self to others; (2) a shift in values from extrinsic to intrinsic motivation; (3) an increase in moral concerns of doing what is right; and (4) the elevation of emotions or awe (Wong, 2016d). In this study, self-transcendence was shown to have contributed to reconstructing the self and making an impression in others' lives. Through self-determination and the three pathways, self-transcendence shaped the participants' meaning making in their lives with a CD.

The disruption of the CDs in the participants' lives led to a sense of loss and a desire to reconstruct their self-identity. In the context of health, self-transcendence is compared with reconstructing oneself, which entails the construction of a revised and enhanced sense of self following the loss of one's former identity (Eldershaw & Morse, 2016). The participants moved beyond their illnesses, and in so doing self-transcended, expanding their self-boundaries and orientation towards broadening their life perspectives (Reed, 2008) in order to reconstruct their self-identity. The participants showed the need for a socially validated self-identity to conform to expectations and gain the approval of others (Hewitt, 2001). The notion of creating a socially favourable self-identity was evident in the participants' reconstruction of their self-identity through the creation of an ideal self and branding themselves as such in order to be accepted and to participate positively in society. The reconstruction of the self-identity was thus shown to be co-constructed, leading to the end result being beneficial to the self and society. Self-transcendence was therefore shown to have improved meaning making in the process of reconstructing the participants' self-identities in order to go beyond themselves and provide something of significance to others.

8.1.3   Organisational support centred on meaning making

A large part of the life of working people is consumed by the time they spend at work. In terms of time and place, this entails numerous challenges and limitations that PwCD experience in making meaning of their lives when dealing with chronic illness in the workplace. The participants reconstructed their self-identities in the area of work through the value they placed on feedback from others, by rediscovering values and goals and through a deeper engagement at work.

In this study, the self-directed strategies of job crafting, following a calling, choosing a career and workplace that ensured psychological safety were evident in contributing to meaning at work. The supportive role of the organisation in facilitating the meaning-making process is deemed crucial in enhancing the wellbeing of employees with CDs. According to Lee (2021), employees value autonomy, trust and empathy. Facilitating meaning making was shown by the employers through a supportive culture in creating a safe psychological environment for the participants, where they could follow a calling and feel safe in expressing their individuality, thereby experiencing autonomy and trust. In the proposed organisational framework provided in Chapter 7, Figure 7.5, the essence of meaning making for individual with a CD is depicted as the reconstruction of the self as reflected in the need for competence, belonging and autonomy (i.e. self-determination) in their work lives. These needs can be addressed by the organisation in the form of policies and procedures, flexible work arrangements and supportive programmes like mentoring, coaching, networking, psychosocial support, team building and other relational activities to assist individuals in integrating their CDs into their work lives.

The experience of living with chronic illness revealed a complex process and interaction between the participants' internal worlds of existential, cognitive and emotional experiences and value struggles within the domains of their external worlds of relationships, work and the broader culture of society and work. Experiences of living with CD created an intricate sense of self in relation to others, where the participants expressed self-determination through the three pathways in the formation of identities to incorporate the illness into their lives. The essence of meaning making for PwCD is thus to construct a meaningful self. A meaningful self is one in which the need for autonomy, relatedness and competence (self-determination) is pursued and

satisfied. The meaningful self is enhanced by self-transcendence, namely when one feels connected beyond the self in the four ways of other-focusedness, shift in values, an increase in moral concerns and the elevation of emotions and awe. The reconstruction of a meaningful self is a process maintained by the intrapersonal processes of existential reflection and cognitive reconstruction.

Although living with CDs may be disruptive in that it presents challenges and limitations, it also provides pathways to reconstruct the self and ways of living and being. The participants reconstructed their identities and overcame their challenges throughout the meaning-making process. Experiencing a life with CD through the eyes of these participants created insight into how meaning making and a way of living in the world are presented. Individuals with CDs, employers, counsellors and other role players may gain a better understanding of the unique experiences individuals with CDs face, as revealed in this study, in order to facilitate the meaning-making process in constructing a meaningful self.

8.2   STRENGTHS OF THE STUDY

This qualitative multiple case study method was grounded in and applicable to the real-life meaning making of PwCD and provided in-depth relevant data. The study's strengths will be evaluated in this section by first explaining my role in the research process, discussing the practical, theoretical and methodological contributions, demonstrating internal, external and construct validity and the reliability of the findings, and finally comparing this study with other studies.

I am also a person living with MCC, which enabled the participants to share their experiences freely with the assurance that they were being heard and understood. My biases and assumptions, from the insider's perspective, were reflexively integrated and essential to the interpretive process, thus enhancing the authenticity of the findings. I constantly engaged in personal reflections to question myself and keep perspective. My self-reflexive thinking was demonstrated when relevant in the text. Further critical self-reflection was demonstrated in my academic discussions with my supervisor, who challenged me to critically examine my assumptions, deductions and involvement throughout the study.

The study illustrated further strength through the pragmatic, theoretical and methodological contribution it provided. The practical contributions of this study were evident in the detailed and in-depth insight into meaning making while living with a CD and in the identification of strategies to support employees with CDs in the workplace to ensure a meaningful work life, thereby contributing to a healthier society. The concrete knowledge of meaning making could help to develop future practical interventions in understanding and supporting people living with CDs.

The study further contributed theoretically by applying and testing Frankl's meaning-making principles through the comparison of the three cases to build knowledge of the reconstruction of self-identity in the meaning-making process of PwCD, thereby promoting an understanding of the complex relationships between the effects of living with a CD, meaning making and productivity at work.

The methodological contribution in this qualitative multiple case study was evident in the interpretive hermeneutic phenomenological methodology that was used, which allowed me to compare individual cases with a variety of qualities, allowing for a more in-depth understanding of the phenomenon under investigation without losing the individuality of the single cases. The study was based on the existing theory of Frankl's meaning-making principles in formulating propositions, and pattern matching was applied to compare, prove or reject the theory and further build on it. A multimethod approach was used to collect data, and IPA, with the underpinnings of phenomenology, hermeneutics and idiography, was conducted to derive themes from the data and using pattern matching to link the data to the propositions of Frankl's theory in order to prove the scientific applicability of his theory to the phenomenon being studied.

The findings of this multiple case study research represent the true state of the phenomenon under investigation and reliability was established on the basis of internal, external and construct validity. The internal validity was established by using Frankl's a priori theoretical framework, which served as an established pattern in pattern matching, to empirically match observed patterns in the data. External validity was evident because all three cases confirmed Frankl's theory, which was used as a template in the design phase to compare the empirical results of the study through cross-case analysis. The contexts of the three cases were explained in Chapter 5.

The research setting encompassed the participants' real-life world, and the purpose of case selection was to gain rich and insightful data that was deemed appropriate to answer the research questions. Construct validity was achieved through data triangulation by using a variety of sources, including interviews, documents, diaries, my self-reflective journal, image-based data and observations, as well as follow-up telephonic calls, emails and WhatsApp messages in the data collection process. It was through prolonged engagement with the participants that sufficient data was collected to answer the research questions and propositions. I used reflexivity throughout the research process and integrated it in the findings to emphasise the awareness of what I brought, my own presence and preconceptions, and how these influenced the research process. Construct validity was further established by clarifying and explaining the research procedures and leaving a chain of evidence (an audit trail) in Chapter 2, which would allow readers to follow the research process and enable auditing of materials and documentation, as illustrated in Figure 8.1.

Figure 8.1

Illustration of chain of evidence
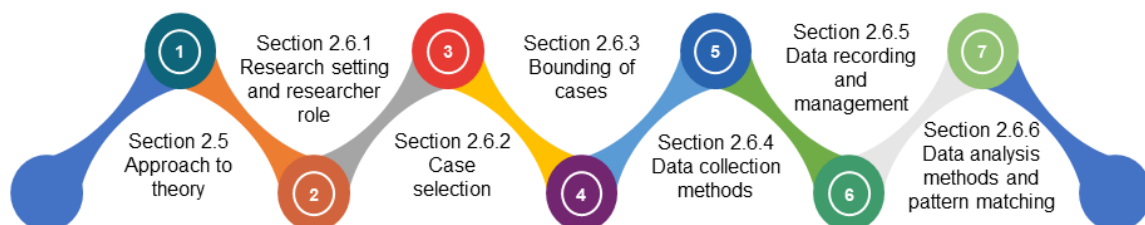
In Section 2.5, the approach to using Frankl's theory was explained. In Section 2.6, the following research methods as applied in the study were discussed in detail: the research setting and researcher role; the process of selecting the cases; the bounding of the cases; the data collection process; data recording and management; and the method of data analysis and pattern matching. Reliability was demonstrated during data collection, where I adhered to procedures for each case in collecting data and developing a case study database to organise all the collected data and maintain a chain of evidence. Hence transparency was enhanced through careful documentation and clarification of the research procedures. In Chapters 5 and 6, contextual information was provided to further transparency in how the processes were followed and how conclusions were drawn.

The findings of this study are consistent with studies of people living with CDs (e.g. Charmaz, 1991; Fang et al., 2023; Walder & Molineux, 2017; Whittemore & Dixon, 2008), which also reported that CDs influence people's identities in various ways. This study, however, expands on previous research in a number of ways. Firstly, the study adds a much-needed detailed description of the influence in the workplace and the connection to theory to help explain the lived experience of living and working with CDs, thereby contributing to the support of the management of employees with CDs in the workplace. Secondly, the findings highlight meaning making through self-determination in using Frankl's three pathways to reconstruct a meaningful self-identity in chronic illness. Thirdly, the emphasis on the need for belongingness and connectedness in negotiating their identities serves as a direction for social support for PwCD.

Although only three cases were used in this multiple case study, they presented with diverse CDs and life and work experiences, and the data gathered from them were rich and descriptive enough to enable me to answer the research questions and propositions, and it is likely that the findings are transferable to other PwCD.

8.3   LIMITATIONS OF THE STUDY

As in most research studies, the design of this study had a few limitations, namely the use of only three cases, limited demographic characteristics and possible researcher bias.

While one of the merits of qualitative methodology is its ability to unearth depth of material (Patton, 2002), this study was limited because only three cases were involved. Where qualitative research seeks to promote a detailed descriptive understanding of the phenomenon in question, it neither predicts outcomes nor generalises to a larger population. It was evident, however, that the three cases supplied sufficient, rich data to enable the researcher to answer all the research questions and propositions.

 The sample could have been enhanced by including a broader variety of demographic characteristics. There were two women and one male in the study between the ages of 40 and 60. While there was diversity in gender, the racial distribution was one-sided

because the participants were predominantly white South Africans. Despite efforts to include other ethnically diverse individuals, it was difficult to find participants willing to share their lived experiences on such an intimate topic. Another demographic variable that might have enhanced the present study would have been the inclusion of variety in the age group by including younger participants because this might have provided fruitful data on the world of work of individuals in the early career phases. Because living with a CD is an intimate and personal event, PwCD are reserved in sharing their experiences, and as such, it was difficult to approach and recruit participants. Two of the participants were well known to the researcher, which made them feel at ease in talking about their experiences. This, however, may also have caused the respondents to be discouraged from providing information they thought might undermine them or make the researcher pity them.

I was the primary instrument in the gathering and analysis of the data. I admitted being a member of the population of my study and held an insider position, but in my role as researcher, I held an outsider position. I was an integral part of the process and final product, and acknowledged that it was not possible or desirable to separate myself from it. To minimise the possibility of researcher bias, I used reflexivity and transparency throughout the process. The findings were presented to my supervisor, which led to further reflection, and ultimately enhanced the richness and rigour thereof. I enhanced the study by making essential data, theory and the research method transparent. I fulfilled my ethical responsibility in protecting the participants by keeping everything that could identify them anonymous, changing or omitting data that could identify them and keeping most of the source material confidential.

8.4   RECOMMENDATIONS

Meaning making during a distressing event or circumstance, like living with a CD, is essential for the general adjustment and development of the individual's wellbeing (Davis et al., 2000). In order to facilitate and enhance meaning making in the wellbeing of employees with CDs in the workplace, the following recommendations were formulated:

- Employers should be aware of the consequences of CDs for the organisation and foster a culture and climate of creating a safe psychological space by using the

proposed phase model as a guideline for facilitation and support in the wellbeing of PwCD in the workplace.

- Employers should adhere to the necessary legislation on PwCD and incorporate it into the organisation's relevant policies and procedures.

- Training should be provided for leaders to communicate emphatically and effectively with PwCD to support and strengthen meaning making through various avenues in ensuring that the work goals are congruent with their personal goals.

- More emphasis should be placed on career development and counselling in the workplace by including alternative career paths, promoting protean careers, investigating flexible work arrangements such as remote or hybrid work, and retraining where necessary in order to promote autonomy and retain PwCD.

- Employers could demonstrate community leadership and initiate CSR programmes as a means for not only PwCD, but also other employees, to practise prosociality and find meaning through self-transcendence by participating in efforts to benefit society.

- More tailored support, like job crafting and opportunities to mentor, should be made available because every worker with a CD has specific needs.

- Individuals with CD need to accept their illness and develop strategies for incorporating both the uncertainty and physical limitations of their illness into their work and personal lives.

- Employers should make supportive programmes, like counselling and coaching, available to demonstrate empathy and help empower workers with CDs to navigate their challenges and facilitate the identity work needed towards a meaningful self-identity, reflective of competence, relatedness and autonomy.

- Employers could develop a CD training tool and toolkit for the use of all the stakeholders in the workplace.

- A smartphone application (App) can be developed to further accessibility to support and assistance for PwCD in the workplace.

Recommendations for future research:

- This study could form a conceptual basis for the development of an organisational intervention programme for PwCD that could be evaluated in future research.

- Employer support for PwCD in the workplace could be investigated through research.

- Further research could explore the effectiveness of the use of CSR programmes to enhance meaning making for PwCD.

- Research could include diverse age and ethnic groups to inform the career decisions of PwCD.

- More research is needed on self-employed workers with CDs.

- Future studies could combine interventions with other organisational efforts, such as supervisor training, to measure the effect thereof on the wellbeing of PwCD.

8.5   CONCLUDING REFLECTIONS OF THE RESEARCHER

As a person who also lives with MCC, I could relate to the participants. As such, I was an insider, sharing many of the things they experienced. However, I also had to fulfil the role of an outsider, a researcher, which meant that I had to remain as impartial as possible. This was extremely difficult for me, especially because I knew two of the participants well. I am aware that my perceptions, attitude, thoughts and emotions influenced my interpretation and application of the data and theory. However, I used the same methods that I apply in counselling, namely reflection, self-awareness, honesty, congruence, knowledge and ethical integrity, to ensure that I remained as true as possible to the participants' lived experiences. I guided and directed my search for relevant evidence by using and comparing data to an existing theory (Frankl's principles), which was used as a theoretical framework to formulate research questions and propositions and substantiate the findings through pattern matching. I further kept a journal and specifically noted the instances where I knew I could not be totally impartial. I referred back to these notes many times throughout the analysis phase to ensure the quality of my study.

Imaginatively and purposefully creating a meaningful self and feelings of competence is a reason for my existence. From my own internal, self-reflective stance, I am able to resonate with the importance of relationships in making meaning while living and working with a CD. It is through my spiritual relationship with God, my relationships with my family and others that I can reconstruct myself and understand my place in

the world and experience support and resonance with my own value system. It is through these relationships that I can reflect who I am and who I wish to be – hence my self-identity is co-constructed through my relationships. My spiritual connectedness with God influences my relationships with others and motivates me towards prosociality. My relationship with my family gives me a sense of belongingness and security, which influence my disposition and orientation. In my relationships with others (not family), I can influence and contribute to others' wellbeing, and at the same time receive feedback, which, although at times painful, contributes to my learning and development, and the formation of my self-identity.

I see my life with MCC as a one of learning and development. Everything that has happened to me has taught me something about myself. I have learned that I can survive and thrive despite the many challenges I have had to face, both physically and emotionally. I am continuously busy incorporating my illnesses and the effects thereof into my identity by changing some parts of my known identity and by diversifying into other areas towards a meaningful self. Some of these elements or effects are voluntary and others are forced because of the diseases or circumstances resulting from them. Those are the ones that are extremely difficult to incorporate, and this can be seen as an ongoing process. I make meaning by engaging with a greater purpose, for example, starting and completing my doctoral studies. I also make meaning through my connectedness with God, my family, friends and others. Finally, I find meaning in a self-determined attitude of transcending adversity and focusing on being positively and actively part of life.

8.6   A LAST THOUGHT

I hope that the readers of this thesis will give it meaning and that it will lead to reflection and action for those who engage with it. The contributions emanated from a variety of sources that were consolidated in this study, and I hope you, the readers, will be enriched by it as much as I was.

I wish to conclude with the following quotation by Theresa Akerley (2022):

"In the isolation of the chrysalis of your" chronic illness*, "there is an opportunity to believe and trust that this process"* of meaning making *"is an opportunity to transform*

into something different and more beautiful and gain the ability to move in your world in new, more powerful ways". Believe that you *"will emerge with wings and learn how to use them to fly to places"* you have only imagined.

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APPENDIX A
ETHICAL CLEARANCE CERTIFICATE

UNISA | university of south africa

UNISA-CAES HEALTH RESEARCH ETHICS COMMITTEE

Date: 15/02/2021

Dear Ms Clur

| NHREC Registration # : REC-170616-051 |
| REC Reference # : 2021/CAES_HREC/015 |
| Name : Ms LS Clur |
| Student #: 5934621 |

Decision: Ethics Approval from 11/02/2021 to 31/01/2022

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Researcher(s): Ms LS Clur
loraine.clur@hotmail.com

Supervisor (s): Prof HA Barnard
barnaha@unisa.ac.za; 012-429-4712

Working title of research:

Making meaning while living and working with a chronic disease: A multiple case study inquiry

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Qualification: PhD Psychology

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Thank you for the application for research ethics clearance by the Unisa-CAES Health Research Ethics Committee for the above mentioned research. Ethics approval is granted for one year, **subject to further clarification** , and renewable on a yearly basis until the completion of the project, **subject to submission of yearly progress reports . Failure to submit the progress report will lead to withdrawal of the ethics clearance until the report has been submitted.**

The researcher is cautioned to adhere to the Unisa protocols for research during Covid-19.

Due date for progress report: 31 January 2022

Please note the point below for further action:

1. The researcher must indicate how the risk of Covid-19 will be mitigated, as two of the three subjects' underlying conditions put them in the high-risk category for the virus.

What measures will be put in place to mitigate this risk?

*The high **risk application** was **reviewed** by the UNISA-CAES Health Research Ethics Committee on 11 February 2021 in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.*

The proposed research may now commence with the provisions that:

1. The researcher will ensure that the research project adheres to the relevant guidelines set out in the Unisa Covid-19 position statement on research ethics attached.

2. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.

3. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the Committee.

4. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.

5. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

6. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.

7. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.

8. No field work activities may continue after the expiry date. Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

APPENDIX B
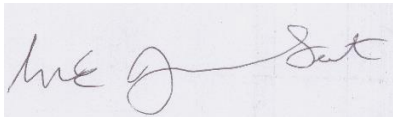
DECLARATION OF PROFESSIONAL EDIT

TO WHOM IT MAY CONCERN

This is to confirm that in my capacity as a professional language practitioner (retired), I completed a thorough language edit of a doctoral thesis for Ms Loraine Clur.

Title: "Meaning making while living and working with a chronic disease: A multiple case study inquiry"

Supervisor: Professor H. A. Barnard

Yours sincerely

Moya Eileen Joubert

30 September 2023