An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis

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Abstract

Background:

Evidence suggests that teenagers and young adults (TYA) present with a unique challenge for healthcare, in that they require services specific to their needs that do not fit with paediatric or adult services. They are at a key developmental stage for their cognitive, social, psychological, and emotional development which impacts on what they need, particularly when approaching end of life. TYAs live in a 'computer-mediated society', which is seen as a place where people construct themselves and others. The 'internet' use continues to increase and in 2020 72% reported an increase in their social media consumption and this is becoming intrinsically embedded in the lives of TYAs who are considered 'social media natives. TYAs share their experiences of their cancer journey online, with the purpose of sharing information, seeking support, and leaving a legacy.

Aim:

This study aims to explore the life stories of young people who are dying of cancer before diagnosis and after diagnosis in order to further understand the impact of their diagnosis and treatment on their social well-being from the perspective of the young person experiencing it.

Methodology:

Social constructionism refers to illness as a social construct and is based on how people experience, understand, and live with illness. Stories are used to create meaningful constructs of the events that take place, and these can be shared on social media by TYAs. These stories or narratives can be analysed to support understanding of illness experiences from the perspective of those living with it.

Methods:

YouTube vlogs were used as data source and 6 participants identified from the UK that were eligible for this study. Narrative analysis was used to explore what was told, how I was told and what was the result of it being told. The analysis was based on Riessman and Franks approach of dialogical and performative narrative analysis, with a focus on the purpose of the narratives.

Findings:

The findings of this study outlined that TYAs' narratives differ depending on their life experience and their current family and social dynamics. The complexities of supporting TYAs does appear unique to their age group; therefore, providing effective end of life care remain a challenge for services.

The themes that were present in the data highlighted the importance of the sense of self which develops throughout the illness trajectory and changes between a sense of hope and hopelessness and the overwhelming desire to feel 'normal'. TYAs appear to seek their self worth from their peers and through posting online. TYAs reported the significance of relationships with their family, friends, and partners to support them following diagnosis but also the value placed on their audience on social media that would comment on their posts, leading to the development of electronic intimacy between them and their followers and for some a dragonfly effect. Within the data there was imagery used in the forms of metaphors, with TYAs feeling that they should be 'brave' and 'fight' in line with social and cultural expectations and constructs placed on TYAs.

Conclusions:

This study highlighted how TYAs use social media to cope with their illness, seek relationship support and leave a legacy. This could be harnessed by health care professionals to develop interventions for TYAs that engage them through social media. In addition, this study has emphasised the potential of the role of Speech and Language Therapy working with TYAs at end of life, which requires further evidence base, guidance, and training to develop.

To support with future studies utilising social media as a data source policy and procedures need to be developed for researchers to support them to navigate the ethics, practicalities, and analysis.

Keywords:

Cancer, Palliative, Teenager and Young Adult (TYA), social media, Internet, Vlogs

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Abbreviations

AHP	Allied Health Professional
BPS	British Psychological Society
DPIA	Data Protection Impact Assessment
DNA	Deoxyribonucleic Acid
DoH	Department of Health
EORTC	European organization for research and treatment of cancer
GP	General Practitioner
HCP	Health Care Professional
HRQoL	Health-related quality of life
HRA	Health Research Authority
IRAS	Integrated Research Application System
IMR	Internet Mediated Research
MDT	Multi-disciplinary team
MMU	Manchester Metropolitan University
NICE	National Institute of Clinical Excellence
NHS	National Health Service
PROM	Patient reported outcome measure.
RCSLT	Royal College of Speech and Language Therapists
TYA	Teenage and Young Adult
Vlog	Video log

Chapter 1 Introduction

1.1 Introduction

In this chapter I will explore in more detail my chosen topic, the rationale for my choice and the journey I have taken prior to undertaking this work. I will outline the background and context of the study, including national guidance specific to cancer care and in particular palliative care. Firstly, I will outline key definitions to provide a shared understanding of concepts, this includes Teenagers and Young Adults (TYAs), chronic illness, survivorship, and end of life care, how these impact on quality of life, the use of the internet and social media in young people and how these fit into this research project. The chapter then describes the background and study context, which provides cancer statistics and explores why this group requires further research. I will further identify my research aims and questions, including why I have chosen them. I will conclude with a summary of the structure of this thesis. The basis of the study is to establish the current narratives impacting on the identified population (TYAs) and using narrative genres to support the storytelling of young people's lives.

1.2 Key Definitions

1.2.1 Teenagers and Young Adults (TYAs)

Research broadly defines TYA as aged 13 to 39 years (Nicklin et al., 2021), with most of the research considering TYAs to be aged between 16 years and 24 years; particularly in UK based research and statistics (Barr, 2011; Herbert et al., 2018; Marshall et al., 2018; Taylor et al., 2020a). This age range is important as it is the developmental period in which the individual begins to take on the responsibilities associated with being an adult (Erikson, 1950; Whitbourne & Whitbourne, 2010). The term ‘young adult’ was first used as a distinct phrase in healthcare until approximately 2005 (Judd, 2014).

Within the TYA developmental periods there are individual differences in decision-making, risk taking and speed of development (Shad et al., 2011). Choice selection is a key component in decision making (Ernst & Paulus, 2005) and this develops uniquely to each person based on their life experience. For TYAs faced with physical health issues, their ability to make treatment decisions will vary based on their behaviour and experience rather than necessarily their cognition and chronological age. For most individual’s, maturation of social cognition, impulsiveness, risk taking, and cognitive control improve with age, however this may temporarily worsen due to maturation (strengthening some pre-existing connections and reshaping others) in the brain (Barber et al., 2013). These changes in the brain have intra-individual variability which further adds complexity to neurophysiological development (Bodmer et al., 2018). Deductive and inductive reasoning, along with decision-making develop during this time, and understanding of consequences of the decisions they’ve made are realised over time (Case, 1992), meaning they develop the skills to reflect on the decisions they have made and start to learn from them (Klaczynski et al., 2001). Throughout the adolescent period the ability to use another’s perspective to support and guide the decision-making process develops (Dumontheil et al., 2010). This may impact significantly on a TYAs ability to make important decisions and function as a stable adult. It is often felt that during a period of disequilibria, an individual may regress to earlier identity modes (Marcia, 2002) and therefore increase their reliance on support networks.

Emotional maturity, which includes the ability to regulate intense emotions and self-soothe independently, is still in a phase of development and therefore TYAs can find managing their own emotions overwhelming (Saarni, 1999). They start to distinguish feelings from facts to avoid reasoning based purely on emotion (Saarni, 1999). They are starting to develop intimate relationships, vocational capability, and financial independence (Christie & Viner, 2005). The adolescent period of development is a transition period from dependence to independence. TYAs are on “the cusp of autonomy, starting to gain success at independent decision-making, when the diagnosis of cancer renders them ‘out of control’ and throws them back to a dependent role with their guardians” (Albritton & Bleyer, 2003).

In addition, it needs to be considered that the impact childhood stressors have on an individual’s ability to cope in adult life will impact on the TYA population (Luecken et al., 2013). The family structure and development of autonomy, expectations and world conceptions goes hand in hand (Sessa & Steinberg, 1991; Jackson & Goossens, 2006). A sense of feeling loved and valued by their families gives them a sense of stability and is required for them to transition effectively into adulthood (Gordon & Grant, 1997).

Transitioning during life can be stressful and for some individuals puts them at a higher risk of experiencing mental health difficulties, which in turn, impact on daily functioning, relationships with others, academic learning, and reduced life expectancy (Wei et al., 2021). Transitioning from childhood to adulthood includes identity exploration, instability, and the feeling of not being an adult or a child (Marion et al., 2017). Furthermore, those with chronic illness can find transitioning between paediatric services and adult services challenging if not planned and well-supported (Chu et al., 2015). Factors that can influence a TYAs ability to manage the transition from childhood to adulthood include negative life events, cognitive vulnerability (making TYAs more susceptible to depression, anxiety, and other mental health conditions), and opportunities for development. During periods of transition the need for support and guidance from adults is crucial for a successful transition (Marion et al., 2017).

For those with a diagnosis of cancer the transition issues that should be considered vary from growth and development, symptom management, fertility preservation, sexuality, cognitive functioning, mental health, and social competence (relationships, employment) (Nathan et al., 2011). If these areas are impacted on due to treatments and periods of being unwell it can lead to a developmental delay in any of these key areas, which for cancer survivors needs to be addressed (Freyer, 2010).

TYAs are often considered to be able to deal with challenges and have increased resilience due to a positive strong social support system (Woodgate, 2006), which has been recognised in cancer literature for years (Wortman, 1984). However, alongside this social support there is a desire to be independent. The sociocultural processing with TYAs moves towards “achievement of relative self-sufficiency” (Blakemore & Mills, 2014). TYAs are affected by the requirement to manage the social complexities of their communities, whether that be as a dependent or independent member.

The key issues for TYAs who are experiencing palliative care are age specific services (Albritton & Bleyer, 2003), the uniqueness of the TYA developmental period (Dyson et al., 2012), what they consider important (Otis-Green et al., 2014) and how these fit in with policy and guidance (NICE, 2005). The age range I have selected for this thesis is 16 years-24 years, as this is the age range outlined as requiring age specific services (NICE, 2005). In England the TYA Principal Treatment Centres are for patients are aged 16-24 years, which would support potential recruitment. Some studies have shown that a desire for a ‘normal life’ plays a part in not only identifying the correct services and treatment compliance but also the overall quality of life of TYAs with cancer (Carr et al., 2021). TYAs consider a ‘normal life’ to include socialising with their friends and attending education as examples. For services to support them to experience a ‘normal life’ they need to have spaces for TYAs to socialise, support them to access social activities and to offer access to education. This highlights the importance of TYAs being actively involved in their care, decision-making and communication (Gibson et al., 2021) as often their priorities can differ from the adult population (Grinyer, 2009). TYAs are potentially in the process of transitioning from being children whose parents lead on decision-making to moving to the foreground of decision-making, whilst their parents transition into a supportive background role (Gibson et al., 2010). This can be challenging even without the complexity of a cancer diagnosis and can take time for those involved to adjust to the new dynamic. Those individuals with a strong support network are felt to adapt to having cancer much better than those without (Trask et al., 2003) as their support network increases their ability to cope with their diagnosis and prognosis. The limited TYA specific services can impact on treatment, support, and sense of belonging (Barling et al., 2012). All these issues lead to this being an interesting and significant topic which will be further explored within this thesis.

In conclusion, TYAs are experiencing a unique personalised developmental period which makes the chronological age of a TYA (although to some degree indicative of maturation) not a clear indicator of factors such as coping mechanisms, decision making abilities, and level of self-sufficiency. They are in the process of developing their own identity and a vision for their future (Sodergren et al., 2018a; Erikson, 1963).

1.2.2 Chronic Illness

Defining chronic illness is complex both in terms of a medical definition and psychosocial definition (Wideman-Johnson, 2011). From a medical perspective it is a condition that lasts longer than 3 months (Duggan et al., 2004), however this does not capture the complexities associated with individuals experiencing chronic illness. Others define chronic illness as “diseases that endure over time and have the potential to profoundly impact on people’s day-to-day lives” (Moss-Morris, 2013:681). Some organisations (e.g., Centers for Disease Control) include diseases such as cancer, diabetes, hypertension, stroke, heart disease, pulmonary conditions, and mental illness (Bernell & Howard, 2016) and others (e.g., Centers for Medicare) may also include COPD, HIV, and dementia.

Broadly speaking chronic illness is defined as long-term conditions requiring on-going management and care (Zheng et al., 2021). Generally, all definitions include the core components of occurring for at least 3 months and have a significant impact on the individual’s ability to function and quality of life.

A long-term condition is defined as a condition for which there is currently no cure and is therefore managed by other treatments and medications, e.g., diabetes, chronic obstructive pulmonary disease, arthritis, and hypertension (Kings Fund, 2022). About 15 million people in England are thought to have a long-term condition. In addition, a life-limiting condition is progressive and fatal in which the progress cannot be reversed by treatment (Haven House, 2022). Cancer can be positioned as both a long-term condition but also, an imminent life limiting condition depending on the type, stage, and treatment profile for the cancer. Cancer survivors may end up with long term disabilities which impact on their functioning and quality of life and may require ongoing long-term support (Phillips & Currow, 2010) however, some

TYA’s may either not go into remission or have recurrence leading to end-of-life care. The uncertainty of prognosis can make it difficult for individuals to make informed treatment decisions (Richardson et al., 2015), impact on their quality of life (Halkett et al., 2010) and their relationships with others (Beach and Good, 2004).

In addition, individuals with cancer are likely to experience life-limiting symptoms as part of their disease progression, particularly those with advanced cancer or that are considered palliative.

There is limited literature on TYAs with cancer as a chronic illness, however as numbers of TYAs with cystic fibrosis is much higher more research exists. Research indicates TYAs with chronic illness engage in less risky behaviours than that of their peers (e.g., smoking, sexual intercourse, drunk driving) (Britto et al., 1998). In addition, chronic illness can have a significant impact on TYAs in relation to body image, mental health, independence, and end of life care (Withers 2012). These findings are likely to be applicable to TYAs with cancer.

1.2.3 Survivorship

Survivorship of cancer has increased between 1975-1977 approximately 50% had a 5-year survival rate, however in 1999-2005 this increased to 68% (Hong et al., 2012). The definition of survivorship remains a working definition and can be considered both in the context of the individual with cancer surviving their primary treatment and the family members who survive once the family member has died (Feuerstein, 2007). The National Cancer Institute’s definition of a cancer survivor is “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted and included in this definition” (National Cancer Institute, 2022).

There needs to be consideration of the impact of cancer on those that survive as Hall et al. (2012) reported that young adult survivors have lower levels of social functioning, increased levels of financial difficulties and sexuality needs compared to their older counter parts. Casillas et al. (2010) reported that we need to be mindful of the continued emotional trauma of childhood cancer experiences that are carried into adulthood. Barnett et al. (2016) reported that information about the long-term implications of cancer survivorship is lacking for TYAs. Some of these traumas may include issues with infertility (Zebrack et al., 2004), self-esteem related issues (Bellizzi et al., 2012), difficulties in establishing relationships (Quinn et al., 2014) and other aspects of functioning (Quinn et al., 2015)

D'Agostino et al. (2011) reported that TYA’s need to be able to participate in as much ‘normal’ activities as possible with minimal disruption to their lives to maximise their health-related quality of life. This enables developmental opportunities not to be missed and promotes a sense of ‘normalcy’. This ‘normalcy’ and development supports to reduce the impact of cancer on the survivors.

For some individuals they may initially have cancer types that are curable and/ or treatable and therefore would be in the survivorship category, however prognosis can quickly change, and individuals can find themselves considered palliative due to a range of contributory factors such as poor response to treatment, further spread of the disease and other complications. Illness uncertainty is considered a significant cause of psychological stress among cancer patients (Jabloo 2017) and quality of life (Sammarco 2001). The uncertainty can also extend to their family and friends (Guan et al., 2021).

1.2.4 Palliative / End of Life Care

This study will focus on TYA patients who are dying of cancer, the terms ‘end-of-life’ and ‘palliative’ are used within the literature; within this study I will be using ‘palliative’. In 2002 the WHO defined Palliative Care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (WHO, 2020). ‘Together for short lives’ (2013) defines children’s palliative care as promoting quality of life for every child and their families and emphasizes the importance of giving choices. The ‘Together for short lives’ charter outlines building packages of care around the unique needs of the individual, MDT working to support the individual in all elements of their care, supporting families’ choices of place of care and those wishes discussed and planned for well in advance. Their guide to children’s palliative care (2018) provides further information to support commissioning, standards for care and workforce requirements.

However, the WHO definition was criticised for the lack of acknowledgement of the wider implications of palliative care, for example, the burden for those living with severe and multiple chronic conditions who may fall outside of this ‘palliative care’ definition. (Murray et al., 2017; Radbruch et al., 2020). To add to this argument, the ‘International Children’s Palliative Care Network’ (2021) refer to ‘life-limiting’ and ‘life-threatening’ conditions within their vision and mission statements. In addition, the term ‘impeccable care’ has been used in relation to palliative care and some have doubted as to whether this is a valid marker for assessment and treatment as it lacks clear definition in relation to what should be provided (Radbruch et al., 2020). It is also thought that this definition does not account for different models of care delivery (e.g., face-to-face, virtual, Health Care Practitioners, support groups/peer support) and the organisations that are part of this (Radbruch et al., 2020). A review of the various definitions of palliative care revealed that there was significant variance in both how and when palliative care would be implemented or considered (Pastrana et al., 2008). Whilst there were significant variances, common themes identified included prevention and relief of suffering and improvement of quality of life (Pastrana et al., 2008). Following the Lancet Commission (Knaul et al., 2018) it was recommended that the WHO definition be revised to encompass all levels of the health care system and factors which influence palliative care (Radbruch et al., 2020).

The definition of palliative care is the ‘active total care of patients whose disease is not responsive to curative treatments’; with the aim of this care being to improve and /or maintain quality of life for the patient and their family. The Center to Advance Palliative Care defines palliative care (2021) as ‘specialised medical care for people living with serious illnesses’ within their palliative care programs and toolkits.

The National Cancer Institute defines ‘supportive care’ as “care given to improve quality of life of patients who have serious illness or life-threatening disease” (National Cancer Institute, 2020) and refrains from using ‘end of life’ care where possible. The terms palliative care and supportive care can be defined in different ways, however, as the National Cancer Institute and other associated institutes use these terms interchangeably (Bruera & Hui, 2012) within this research they will also be used interchangeably within this study. Whilst these terms are often used interchangeably, end of life is felt to be specific to those whose are likely to die within the next 12 months, including patients whose death is imminent and those with advanced, progressive, or incurable conditions (National Palliative and End of Life Care Partnership, 2021). Whereas palliative refers to the care they receive as part of their condition. Usually those people considered ‘end of life’ can be in the last year, months, weeks, or days of their life (Gomes et al., 2013). Therefore, a definition of ‘palliative care’ should incorporate both the recognition of the condition itself but also the implications this has on quality of life.

It is worth noting that TYAs’ illness trajectory is depending on their individual stage of development and the cancer type that they have (Taylor et al., 2020a). Therefore, unlike adult cancers where information on illness progression can be discussed, this is much more difficult for TYAs. This is due to the time in their life when their illness occurs as they are typically experiencing changes to their sense of self, settling into adulthood and have significant life events, e.g., getting married, moving out of their parents’ house, having a child, finishing school, or going to university. Not being able to experience these things can leave a TYA with a sense of loss and grief, which will be explored later within the thesis.

1.2.5 Quality of Life

The definition of quality of life is subjective and difficult to define (Jocham et al., 2006). The term is subjective and dynamic (Taylor et al., 2020a) and unique to each person dependent on their stage of development and illness trajectory. (Ahmedzai et al., 2004) reports that it is an individual’s perceptions of their position in life within the context of their culture and values; along with their goals, standards, and concerns. Whereas Ferrans (1990), goes into more specific detail and feels that there are five categories outlining quality of life: ability to live a normal life, happiness / satisfaction, achievement of personal goals, ability to lead a socially useful life, and physical and/or mental capabilities (actual or potential). Quality of life is often found to be judged against whether the person feels that they have achieved the goals they set out for themselves, which may often be a struggle to achieve for those who have significant ill-health they often struggle to achieve these (Taylor et al., 2008).

Whilst there is not an agreed definition of ‘quality of life’ within the general population, factors impeding this enhance when this is applied to adolescence. This lack of clear conceptualisation of what is defined as ‘quality of life’ impedes both research and health care. This is due to a neglect of specific issues which are deemed important to young people and how this develops and changes throughout adolescence and early adulthood (Taylor et al., 2008). However, as outlined above quality of life as a definition is very multi-dimensional and can be as broad as to include economic welfare, characteristics of environment (air and water quality), and health status (Patrick & Erikson, 1993).

Empowerment has been linked with Health-Related Quality of Life (HRQoL) and has become a very topical issue in recent years (Kaal et al., 2017; Van den Berg et al., 2013), particularly in relation to TYAs. Definitions of empowerment start as early as 1984 when Rappapon (1984) defined it as ‘a mechanism for which people, organisations and communities gain mastery over their lives’. More recently empowerment has been defined as a process in which the power transforms between individuals (Maiorano et al., 2021). However, within health research it often lacks clarity of definition (Castro et al., 2016). Zimmerman (1995) refers to a ‘feeling of control’ which includes how people think about themselves, their perceived competence and how they relate to their social environment (Kaal et al., 2017; Eskildsen et al., 2017).

It can be difficult to quantify in health research, and therefore a more circumscribed concept is HRQoL is required, and this is generally defined as opportunities a persons' health status affords, constraints it places upon a person, and the value that person places on their health status (Feeny et al., 1999). HRQoL includes both negative and positive subjective evaluations from the individual (Centers for Disease Control and Prevention, 2014). Sodergren et al. (2017) interprets the WHO's definition of HRQoL as a construct which is shaped by a range of factors including physical health, psychological wellbeing, dependence levels, relationships, and individual beliefs. It is pertinent to TYAs due to the complex developmental challenges in which they encounter (Sansom-Daly & Wakefield, 2013; Bleyer, 2005; Thomas et al., 2010). HRQoL studies refer to TYAs which encompass age ranges from 15-39 years; however, the UK based studies follow the definition of 16-24 years (Desandes & Stark, 2016).

In addition to using HRQoL as a measurement, clinically and within academic studies, Patient Reported Outcome Measures (PROMs) are used. Wilson (2018) strongly advocates for the use of both within cancer research to enable to a fuller understanding of quality of life and patient experience. Wilson (1998) noted that the tools used to measure HRQoL are often not specific to TYAs and therefore omit domains such as sexuality and spirituality (Klassen, 2017). It is also acknowledged that TYAs are not a homogenous entity, and therefore will differ in terms of HRQoL concerns (Sodergren et al., 2017; Treadgold & Kuperberg, 2010). Younger TYAs often report concerns with independence from their parents, educational achievements, and peer relationships, whereas older TYAs will often cite career choice, financial independence and establishing intimate relationships as their main concerns (Sodergren et al., 2017). HRQoL measures used within clinical practice have been found to enhance communication between TYAs and services, increased overall patient satisfaction and overall patient outcomes (Santana & Feeny, 2014; Basch et al., 2015) and increased empowerment in TYAs, which is noted as significant (Kaal et al., 2017).

TYAs are at such a unique (Arnett, 2000; Morgan et al., 2010), vulnerable time in their lives (Dyson et al., 2012; O'Leary et al., 2008) which already poses significant challenges for TYAs (Barnett et al., 2016; Wicks & Mitchell, 2010) and this is heightened when given a diagnosis of cancer. This can cause significant tension in what is described as their ‘natural lifecycle’ (Graetz et al., 2019), and they are required to face their mortality whilst only at the start of their journey to adulthood. The physical, emotional, and social challenges are unique and especially difficult for both families and healthcare providers alike (Albritton & Bleyer, 2003).

Dyson et al., (2012) states that TYAs are considered to be in the most complex, vulnerable, and critical stages of development because each individual develops at a unique pace. When working with TYAs, services need to convey the dynamic nature of TYA development rather than focusing on chronological age as this does not always correspond with their level of cognitive and social development. Services need to acknowledge the impact of ill-health on biological, psychological, social, and vocational developments of this age group (Farre et al., 2016).

1.2.6 The ‘Internet’ and Social Media

The internet was originally developed in the 1970s with the purpose of connecting computers to each other and was mainly used for military purposes (Hine, 2008). Gradually, use of the internet increased to include universities and more commercial organisations yet was still very limited until the late 1980s when internet providers became more common, and from the 1990s, internet use became a more widespread social phenomenon (Hine, 2017). In the 2000s, the internet posed new ways of communicating via the ‘World Wide Web’ and social networking sites such as Facebook, Twitter and YouTube came into being. The internet moved from being a specialised medium to a mainstream service across society and this re-defined what the term ‘internet’ now means. The internet was no longer only a place for gaining information or watching videos but the ability to share things became a reality (Biel & Gatica-Perez, 2011). It increased the ability to develop peer relationships (Sangeorzan et al., 2019), allowed access to a wider range of materials and people (Berger et al., 2005), and embraced the lack of geographical boundaries (Stephens-Reicher et al., 2011).

The internet is defined by many as a “tool for retrieving or transmitting information and connecting with others” (Markham & Buchanan, 2012). Over the past few decades there has been a shift from thinking about the internet as a place, to start to think of it as a tool (Seale & Abbott, 2007); particularly a way to explore in a ‘computer-mediated society’ how people construct themselves and others (Markham & Buchanan, 2012). With internet use increasing and becoming part of people’s day-to-day lives, it is only natural that social researchers have started to think about ways to utilise the internet as a data source (Hine, 2017). However, alongside the apparent benefits of using the internet and the possibilities of exploring the social phenomena it presents, there is also the need for consideration of the ethics of online research (Hine, 2017), and with this comes the requirement for researchers to develop new skills in how to use the internet meaningfully and appropriately.

It needs to be considered within this research the significant digital divide that continues to exist not only between richer and poorer countries but even within countries. The recent COVID-19 pandemic has further highlighted the digital deprivation within the world (Beaunoyer et al., 2020), and specifically within the UK; impacting on access to technology and support (Greenhow et al., 2020). Therefore, all social researchers using the internet as a data source need to be mindful of their study limitations and acknowledge this within their discussion and this will be outlined within the thesis. Pagoto (2019) reported that social media comes with potential benefits but also potential harm, and that there is little public guidance on how to use these platforms effectively to maximise benefits to health and well-being and whilst avoiding harm. Research is rapidly increasing in this field but there is no robust regulation to support this (Pagoto et al., 2019), with national guidelines not always accounting for the ethical challenges associated with research within social media (BPS, 2017). Internet based research has benefits which include potentially faster and cheaper ways of recruiting participants via social media platforms such as Facebook (Whitaker et al., 2017), it can improve the reach of recruitment (Bender et al., 2017), and provides the potential for the research to engage with a wider audience (Hassan et al., 2021).

Social media platforms including Myspace, Facebook, Instagram, Twitter, YouTube, Snapchat, TikTok and many others are continually emerging. Each of the social media platforms attract different types of users and they in turn post differently depending on which platform they are using at the time. The use of social media platforms continues to rise and within 2020 72% of people reported an increase in their social media consumption (primarily due to the COVID-19 pandemic) (Gismondi, 2021). During 2020, Facebook was the most used social media platform with over 2.7 billion monthly active users (Davis, 2021); however, it has been acknowledged in the media that younger generations are starting to shy away from using Facebook and opting for platforms such as Instagram or TikTok. YouTube whilst falling fifth in the ratings for social media users, is the second largest search engine behind Google (Davis, 2021). YouTube receives more than 2 billion logged-in users per month and feeds over 1 billion hours of videos each day (Davies, 2021). Burgess & Green (2018) outline YouTube as a high-volume website and social network, which reaches 61 countries and is in 61 languages.

Social media has been intrinsically embedded within people's lives and TYAs are considered 'social media natives' (Pagoto et al., 2019). TYAs place a high value on what social media sites bring to their lives and are reluctant to disconnect from them. Research relating to social media platforms often focuses on harm that has occurred through its use (Woods & Scott, 2016; Hunt et al., 2018), and headlines in mainstream media focus on the negative elements of social media (Rounsefell et al., 2020; Marino et al., 2018). Many researchers agree that both no social media or too much social media promotes harmful behaviours and therefore needs to be considered in moderation for TYAs (Cole et al., 2019; Martinez-Pecino & Garcia-Gavilán, 2019). However, further research is needed to review what people are using social media for and how this impacts on their health and well-being (Pagoto et al., 2019).

1.3 Background

My clinical background is as a Speech and Language Therapist working with young people and adults. I had always had a keen interest in research and evidence-based practice, but it was not until I started working within the palliative care field that I felt compelled to conduct research of my own. This was due to the difficulties in accessing therapy services within palliative care and particularly for those who are young adults. One of the challenges I noted of working in the palliative care field, particularly with TYAs, is the lack of age specific services and this is supported by the literature (Albritton & Bleyer, 2003; Kaluarachchi et al., 2020; Benedetti et al., 2013).

Whilst existing studies have highlighted a focus on TYAs on coming to terms with dying, studies have recommended that further research in examining the needs of TYAs and their carers facing end of life care is needed (Gibson et al., 2016). It has been reported that often research is not often conducted in end of life as it is commonly thought people may not want to spend their remaining time involved in research, research can be seen as exploitive within this clinical area, and participants do not stand to gain anything through their involvement (Koffman et al., 2009; Addington-Hall, 2002). However, if consideration is given to their level of vulnerability, ability to communicate their opinions, and researchers' flexibility to respond to situations in the context of data collection (Koffman et al., 2009), then this group could provide valuable and insightful perspectives within end-of-life care.

Within this thesis I have used the acronym TYA for Teenagers and Young Adults, this is in line with charities such as 'Teenage Cancer Trust', the NHS England guidelines (NHS: Cancer Services for Teenagers & Young Adults, 2015) and organisations such as the European Society of Paediatric Oncology. In addition to this, young people refer to themselves as TYAs and it is important that young people's voices are heard and empowered within the literature. The use of the acronym has been further reinforced within social media, particularly on sites such as Twitter which up until recently had a 140-character limit for all tweets (this has now been increased to 280). The use of a hashtag (#) allows individuals to search on social media for key terms which enable them to have access to data and information about a specific topic, join a community, contribute to discussions, and develop relationships (Katz, 2019), e.g., #ayacsm (adolescent and young adult cancer social media). Blogs have been seen as a form of self-expression for individuals with a chronic illness such as cancer; with the things posted being part of that person's identity and acceptance of themselves as being unwell (Nesby & Salamonsen, 2016; Tembeck, 2016). Stüwe and Wegner (2020) found that TYA's social media posts were 15% illness specific and 8% uploads to Instagram, all using TYA in their hashtags.

1.4 Study Context

According to the Improving Outcomes: Strategy for Cancer (January 2011), it has been estimated that more than 1 in 3 people will develop cancer each year and 1 in 4 people will die of the disease; Cancer Research UK state it is 1 in 2 people for those born after 1960 (Cancer Research UK, 2021). Public Health England published figures in January 2020 (taken from 2018 data), which appear to indicate a rise in the last few years in the number of people diagnosed with cancer (316,680) and people that die of the disease (270 deaths per 100,000; 2017, Office for National Statistics, 2017) with approximately £6.5 billion spent on cancer services each year. This expenditure highlights the importance of providing the right cancer services to the right people to ensure cost effectiveness.

Incidence of cancer in TYAs in England has increased from 233.1 per million in 2001 to 299.7 per million in 2015 (Teenage Cancer Trust, 2018) and the greatest increase in cancer mortality rates since the early 1970s has been in people within this age bracket (Cancer Research UK, 2021). As the mortality rates continue to increase for this age bracket, further research is required to determine the rationale for this but also to ensure that services provided to these individuals is effective, supportive and aims to support their quality of life. Cancer is the fourth most common cause of death in young men aged 15-24 in the UK, accounting for 9% of overall male deaths. For young women aged 15-24, cancer is the most common cause of death overall, accounting for 15% of overall female deaths. For both men and women within this age range, cancer is the most common cause of death from disease (Cancer Research UK, 2021).

The incidence of cancer in TYAs is less than 1% of all cancer cases, which is considered rare, and this has led to it being an under researched area, which is why I wanted to focus this study on this age bracket. Cancer rates in this age group in the UK are highest in those aged 20-24 years (Cancer Research UK, 2021). TYA cancer mortality rates are less than 1% of all cancer deaths and make up for around 270 deaths in TYAs. Approximately 1/4 of deaths in the TYA population are cancer related (Taylor et al., 2015). However, evidence suggests that this will continue to increase (Pesola et al., 2017) and services should be equipped to provide adequate and effective care which is deemed age appropriate.

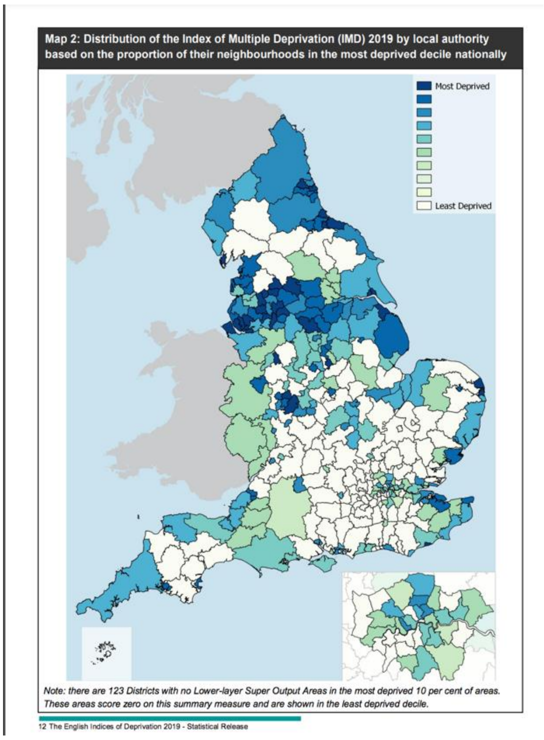
Globally it has been reported that approximately 35% of childhood cancers (aged 0-19 years) are leukaemia's and 18% brain or nervous system cancers; however, significant variability exists across nations (Force et al., 2019). The types of cancer usually seen in the TYA population are late paediatric cancer types, e.g., Wilms tumours, neuroblastomas; early onset adult cancer types, e.g., Melanoma, thyroid cancer and nasopharyngeal cancers and peak incidence within TYA population cancer types, e.g., osteosarcoma, Ewing's sarcoma and soft tissue bone sarcoma, gonadal germ cell tumours and Hodgkin's lymphoma (Pearce, 2009; Whelan, 2003; Kelly & Gibson, 2008). Lymphomas, carcinomas, and germ cell tumours make up one-third of those diagnosed in the TYA population (Cancer Research UK, 2021). In addition, research indicates that often the cancer diagnosis is more aggressive within TYAs (Bleyer et al., 2006). As the cancer is often more aggressive it is important to consider symptom burden, treatment options and the impact that this has on an individual (and their family's) quality of life.

Overall, the prevalence of TYA cancer in the wider context of cancer is relatively low; however, within the TYA population it accounts for 11% of deaths (compared to 30% in the adult population) (NDRS, 2021) meaning that services need to be equipped to support TYAs both in survivorship and end of life care. The area is under researched and warrants further attention to ensure that services are age appropriate and support quality of life for those individuals.

1.4.1 Socio-economic Status

Cancer is the leading cause of disease-related death for TYAs in high income countries (Herbert et al., 2018; Barr, 2011). Those considered as TYAs have benefited less than almost any age group in relation to increased survival over the last 30 years (Bleyer, 2002), with lack of age specific care a significant contributory factor (Palmer et al., 2007; Thomas et al., 2006) as individuals have either been treated in paediatric or adult services dependent on their age or type of cancer. Given the uniqueness of this age group and the lack of specific services for them, I felt that this research would have meaning and the potential to lead to improvements in services.

The World Health Organisation (WHO) is working towards a sustainable developmental goal of developing palliative care policies to cover 40 million people who require palliative care globally (including 20 million carers) (WHO, 2021). Their strategy focuses on supporting low and middle-income countries to receive adequate and effective palliative care. In addition, Public Health England has developed Palliative and End of Life Care Profiles, a theme within these is inequalities within the UK for those receiving end of life / palliative care (Care Quality Commission, 2016; Macmillan, 2018). The Office for National Statistics (ONS) (2020) outlines that socioeconomic deprivation is a major determinant of where, when, and how people die (See Figure 1 for Indices of Deprivation), with deaths registered in 2020 being almost triple in highly deprived areas compared to the least deprived areas across both males and females (ONS, 2020). Lloyd-Williams et al., (2021) reported that socio-economic factors influence delay in presentation and diagnosis of cancer, with some reporting up to a 3 month or more in a delay in presentation (Forbes et al., 2014). A Canadian study found that patients living in the most deprived areas were significantly less likely to seek support from an oncologist or receive radiotherapy or chemotherapy (Davis et al., 2020). Previously research relating to socio-economic status and inequalities has tended to focus on access to care (Davies et al., 2019), rather than on symptom burden. The National UK Survey of Bereaved People (ONS, 2014) shows that those living in the most deprived areas have similar access to community-based services but are less likely to die at home (Macfarlane & Carduff, 2018), with a later survey in 2015 showing that people in more deprived areas rated quality of care at end of life as fair to poor compared to those in less deprived areas (ONS, 2016). Lloyd-Williams et al., (2021) conducted a study of patients with advanced cancer accessing hospice day services within 20 hospices in the Northwest of England, which included areas of significant socio-economic deprivation. Their study found that moderate to severe depression had a significant association with socio-economic disadvantage, and individuals from a low socio-economic status were more likely to report pain. This supports other studies where socio-economic deprivation and treatment-resistant depression were predictive of poor improvement in cancer pain (Wang et al., 2012). Overall, there is felt to be a significantly higher global symptom burden score reported by patients who live in more socio-economically deprived areas (Lloyd-Williams et al., 2021). This is worth considering as this study is focusing on social media use and those with low socio-economic status will potentially have digital deprivation and may be unable to share their narratives in this way. This will be discussed further in Chapter 5.



Map 2: Distribution of the Index of Multiple Deprivation (IMD) 2019 by local authority based on the proportion of their neighbourhoods in the most deprived decile nationally

Note: there are 123 Districts with no Lower-layer Super Output Areas in the most deprived 10 per cent of areas. These areas score zero on this summary measure and are shown in the least deprived decile.

12 The English Indices of Deprivation 2019 - Statistical Release

Figure 1: Distribution of deprivation in the UK

(Ministry of Housing, Communities & Local Government: The English Indices of Deprivation, 2019).

1.5 Cancer Care

The Calman-Hine Cancer Report (CHCR) (1995) was one of the first strategic documents to focus on improvement of cancer care, with an emphasis on measuring quality of life and the role of the Multi-disciplinary Team (MDT). Following this was the National Cancer Reform Strategy (2007), National Cancer Intelligence Network launch (2008) and Improving Outcomes: A Strategy for Cancer (2011); which all aim to develop cancer services. The National Cancer Reform Strategy (2007) laid out actions to improve cancer care, which included reducing cancer inequalities, delivering care in the most appropriate settings, and stronger commissioning for services. This references that the majority (34%) of TYAs reported visiting their General Practitioner (GP) over 5 times before their diagnosis; a plan for improving access to diagnostics at a primary care level is included.

The National Health Service (NHS) Long Term Plan (2019) has a strong focus on improving access to diagnostics and treatment, and determines all people diagnosed with cancer should have personalised plans. In relation to infants, children, and young people, there is a priority within the NHS Long Term Plan (2019) placed on improving physical health, mental health, and well-being, along with a better skilled workforce to respond to their needs. The plan aims to move towards a 0-25-year service model with age-appropriate care and an integrated transition into adult services based on clinical need not age. This is important for TYAs as it is often reported that they fall in between service gaps and age-appropriate services are lacking or are difficult to access (Martins et al., 2021). In addition, the NHS Long Term Plan (2019) lays out its aims to prevent and tackle health inequalities, which as we know can lead to a significant impact on those diagnosed with cancer (Lloyd-Williams et al., 2021). With specific relation to cancer and young people the plan aims to improve outcomes, and simplify pathways and transitions between services, with a focus on ensuring every patient has access to specialist expertise. It states that the NHS will actively support the involvement of young people in clinical trials and introduce more personalised, wider ranging treatments (reducing the need to travel abroad to receive these). In addition, they are developing the use of digital technology to support young people with a range of apps to support specific health conditions and increased access to technology to enable improved delivery of services. These will initially focus on supporting people with anxiety and depression and build on the diabetes prevention programmes that already exist virtually.

The NHS Long Term Plan (2019) refers to a clear vision for health and care system improvement and the NHS have also committed to improving end of life care. Such improvements aim to increase the identification of people at the end of their life to enable the provision of personalised care and increase service integration and collaborative working to improve overall care delivery (National Palliative and End of Life Care Partnership, 2021). In 2008 the national strategy for end-of-life care (Department of Health and Social Care, 2008) in England stated that we needed to do more, as people did not die in their place of choice, preparation is needed to support larger numbers of people dying, and that not everyone received a high quality of care. Previously, the Liverpool Care Pathway (Marie Curie Palliative Care Institute, 2009) was used to support end of life care, however this was criticised within the Independent Review of the Liverpool Care Pathway (Neuberger et al., 2013) and was replaced with new government guidance which focused on advanced care planning, sensitive communication and that the wishes of the dying person (and those close to them) are actively listened to. The care is individualised and compassionate towards the dying person (New Approach to Care for Dying, 2014). In addition, the Review (Neuberger et al., 2013) highlighted the requirement for more research in the field of palliative care to support improvements to service delivery. Since this publication there has been numerous strategies aiming to build on these aims and significant investment to support this (National Palliative and End of Life Care Partnership, 2015). The ambitions set out in the National Palliative and End of Life Care Partnership (2015) support person-centred care and the need to support personalisation for all that are approaching end of life, whilst also promoting the recognition of distress (both physically and mentally) and skilled symptom management (National Palliative and End of Life Care Partnership, 2021).

1.5.1 TYA, Cancer, and Service Provision

Due to the limited number of people within the TYA population getting cancer, evidence suggests limited access to clinical trials, delays in diagnosis, lack of specialist support and overall poorer outcomes compared to the children and adult populations (Pearce, 2009; Taylor et al., 2011). This may be due to the distinct impact cancer has on their physical and mental health, development domains (Smith et al., 2013a), and inequalities in accessing the care they require (Albritton & Eden, 2008) since age specific services are not easily accessible in all areas of the UK. In 2005, the NHS were mandated by the National Institute for Health and Care Excellence (NICE) to provide age specific services for young people, as their needs were poorly met in adult or children services as they were often not working collaboratively (Taylor et al., 2020a; Stark et al., 2016). However, the predicted improvement in outcomes has yet to be well defined (Rae et al., 2020). Often young people will spend time researching where they want to access the best treatments (Lea et al., 2018b). There must also be consideration to be given to the environment of where the care is given (Lea et al., 2018a), the workforce to delivering the care (Taylor et al., 2016) and the individualistic nature of the young people receiving the care (Fern et al., 2013; Taylor et al., 2011; Gibson et al., 2012).

Within this population over the last decade there has been numerous organisations (e.g., Teenage Cancer Trust) that have ignited a catalyst for change, including the services and information provided. The implementation of NICE guidelines has significantly improved outcomes for children and young people (Pearce, 2009). There were ten key recommendations, which included increased opportunity to participate in research, meeting the needs of this age group effectively and offering age-appropriate treatments, and ensuring cancer networks employ specialist, skilled staff (NICE, 2005; Aldiss, 2019). Changes in medical treatment and support have emerged; however, furthering this to improve more effective quality of life care and person-centred care is emergent.

In 2005, there were thirteen identified trusts which would host age-specific TYA services, and these were chosen based on factors such as geography, existing established services, and other cancer services available in the area (Taylor et al., 2011). The current NICE guidance (NICE, 2005) reported those aged between 16-18 years old should be treated in specific TYA Principal Treatment Centres, and those 19-24 years old could choose their preferred placement. By 2010, approximately 2/3 of those 15-18 years old and 1/3 of those 19-24 years old had received contact with a TYA Principal Treatment Centre (O’Hara et al., 2013).

Whilst there is acknowledgement of significant improvements in available services for TYAs, improvements in survival in this population still lag behind both children and older adults (Herbert et al., 2018; Smith et al., 2010). Fern et al., (2021) found that there was no difference in survival rates dependent on whether the person was treated in a TYA specialist cancer centre or other placement; however, quality of life was improved for those in the specialist cancer centres. There have been some considerable improvements in TYA survival rates made since the early 1990s and this has come as a consequence of learning more about treatment recommendations, for example, using paediatric treatment plans instead of adult treatment plans has increased the success rate of this treatment for acute lymphoblastic leukaemia (Boissel et al., 2003). A factor impacting on survival rates is the low participation in clinical trials which impedes the development of optimal therapies for this age group (O'Hara et al., 2015; Fern et al., 2008; Whelan & Fern, 2008). The Teenage Cancer Trust is supporting TYAs to have more opportunities to be involved in clinical trials (Teenage Cancer Trust, 2014), as a way of improving outcomes for TYAs and to create more flexibility in their movement between children's and adult services. In addition, the Teenage Cancer Trust lead an agenda on communication about trials, policies, and treatments with TYAs to ensure they are able to make informed choices about their cancer journey.

1.5.2 End-of life / hospice care for TYAs

For some individuals they fall through the gap in terms of not fitting into either a paediatric or adult service. It has been reported that TYAs experience challenges of not feeling like they belong in both paediatric hospice or palliative care settings and their adult equivalents (Taylor et al., 2020b), meaning they require something more bespoke to meet their individual needs. Current evidence suggests that children and young people with cancer who are in receipt of specialist palliative care are cared for differently across settings (Taylor et al., 2020b). For example, some have access to TYA specific care whilst others are cared for in adult or paediatric settings, some services include members of the MDT such as psychologists and Speech and Language Therapists whilst other MDTs are more limited. However, there are only a small number of individuals requiring palliative care within this age range which has led to services not necessarily being invested in and it is has been difficult to achieve across all geographical areas for organisations. Some of the unique challenges for TYAs is developmentally they are likely to move between acceptance and denial of their prognosis (Wiener et al., 2015; Wein et al., 2010) and therefore may not engage in advance care planning and consideration of specialist services. This challenge is more unique in TYAs as dying in this age group is rare and acceptance of this can be very difficult for the individual and their families (Montel et al., 2009; Wiener et al., 2015). In addition, it has been reported that TYAs and their families can find the term ‘palliative’ negative (Boldt et al., 2006) which can make advance care planning for health care professionals difficult. It can be difficult for HCPs to discuss palliative care treatments, services, and support without acknowledgement of the term ‘palliative’ or suitable alternatives. Without these discussions advance care planning cannot take place. This will be discussed further in Chapter 2.

Higginson and Thompson (2003) published an epidemiological study of 3,197 children and young people with cancer, which indicated that there were a relatively high proportion of home deaths compared to hospital deaths. However, Montel et al. (2009) found that of the 21 TYA’s 19 died in hospital and 2 at home. Their families shared that they did not feel actively engaged with the choice of the place of death, but had they been, they would have chosen the hospital. They reported difficulties in having conversations about place of death as families reported that this might give the impression that they were no longer “fighting” the disease, and this might be demoralising to the child. They also reported that the conversations just seemed too difficult to have with their child. Families reported that they would have chosen the place of death as the hospital as if the child had died at home, they feared that the image of their dead child at home would be more present and persistent. Grinyer and Barbarachild (2011) found that TYAs die in a variety of settings including at home, in a Teenage Cancer Trust unit, in A&E, in intensive care and in hospital. Taylor et al. (2020b) found that the majority of children and young people continue to have high-intensity treatments towards the end of life (Kassam et al., 2017; Corkum et al., 2019) with nearly half of them dying in the acute setting (Gao et al., 2016) despite preferences typically being to die at home (Bluebond-Langner et al., 2013; Ngwenya et al., 2017). The contributory factors leading to this were challenges such as rapid decline in physical health and home environments, for example, not yet set up with the right equipment to care for the person at home (Taylor et al., 2020b).

Some of the challenges identified with supporting TYAs at the end of their lives include adult hospice care being inappropriate and not age-specific, dying at home was frightening for the TYA and community-based teams were traumatised by the death of a TYA with cancer which increased pressure on the family (Grinyer & Barbarachild, 2011). The way in which choices are offered to the individual and their family are based on the clinical staff members' previous experiences and therefore the trauma of this may be reflected in their communication style. This can be further exacerbated by challenges in communication between services and for 16–18-year-olds 'falling through the gap' of services. The knowledge of available services is consistently reported problematic by TYAs (Zebrack et al., 2007). Mallon et al (2021) found that TYAs in the UK lacked knowledge of what palliative care is therefore there is a need for public health organisations to develop this information to inform young people. This is linked to the social phenomenon of 'death denial', in which scholars have reported that Western society continues to be afraid of death and seek to deny it (Leming & Dickinson, 2007; Tradii & Robert, 2019) and experience it 'behind closed doors' (Wood & Williamson, 2003). Macdonald (2019) reflects on social discourses of grief and how grief frameworks reinforce the grief taboo and stigmatisation.

1.5.3 Impact of COVID on cancer care

Whilst it is difficult to understand the full extent of the impact of the COVID-19 pandemic on cancer services and outcomes; initial data indicates a substantial decrease in cancer screenings, visits, therapy, and surgeries in March-July 2020 compared to March-July 2019 (Patt et al., 2020; Cancino et al., 2020). Some modelling studies have predicted a substantial increase in the number of avoidable deaths in England are to be expected as a direct consequence of the delays in diagnostic assessments (Maringe et al., 2021; Gheorghe et al., 2021).

The pandemic also led to a reduction in the offer of hospital-based care, treatment, and psychosocial support (Hulbert-Williams et al., 2021). Hulbert-Williams et al (2021) found that over half of the respondents (144 participants total) reported unexpected changes to treatment and confusion about longer-term consequences.

In addition to the impact on cancer services, the COVID-19 pandemic had a significant impact on an individual’s wellbeing and psychosocial health. The pandemic came at a time when there was already a focus on the rising stress levels experienced by children and young people (Cowie & Meyers, 2021) in combination of high expectations from peer groups which played out on social media (McLoughlin et al., 2018). Some studies such as Imran et al. (2020) noted that young people had an increased feeling of anxiety during the pandemic and were at heightened risk of bullying due to excessive social media use. A study by Košir et al. (2020) indicated that of the 177 individuals surveyed about the impact of COVID-19 on their cancer care, a third of respondents indicated increased levels of psychological distress and more than 50% wanted information tailored to them as young patients with cancer.

1.6 Research Aims

Based on the review of the background and context of the clinical and research area, I have devised three key aims for my research, which are:

1. To explore the online stories of young people who are dying of cancer and the impact of their diagnosis and treatment on their social well-being from the perspective of the young person (TYA) experiencing it.
2. To ascertain views of current palliative care from the perspective of the young people (TYAs) from information shared within their stories.

The outcome of this research is to provide rich meaningful data that will identify the key elements of the individuals' experience of the palliative care journey, and collectively embedded within this will be key themes to extrapolate to answer the primary aims. The primary outcome is to produce a thesis and additional publications.

1.7 Structure of the Thesis

This thesis reports on the narrative approach using the work of Frank (Frank, 1994, 1995, 1997, 2012, 2013) and Riessman (Riessman, 1993, 2008) to explore TYAs with a diagnosis of cancer who are considered palliative. The report has been structured to commence with an introduction to the rationale for undertaking the research, key definitions, and the aims of the thesis (Chapter 1). This is followed by a detailed literature review supporting the research (Chapter 2). The literature review analyses existing literature on TYA's with cancer including diagnosis and their decision-making ability. It reviews literature on the impact of cancer on TYAs including quality of life, spirituality and wellbeing, grief and loss, illness trajectories, symptom burden and services available. The chapter also includes background to the method of data collection and analyses in detail the use of technology for education and intervention, peer support and blogs / vlogs. Chapter 3 outlines the methodology used along with my epistemological and ontological framework. Within this research there have been numerous ethical challenges which are outlined in detail within this chapter. There will be a clear focus on internet mediated research and the specific challenges faced when using this approach. Chapter 4 (Method) details the narrative approach of data collection and analysis, transcription processes, and the reflexivity needed when undertaking this type of research. The analysis and findings of the data are discussed in Chapter 5, with a holistic narrative analysis taken initially followed by the identification of recurrent themes. Chapter 6 examines the themes and the implications of these within the national context of TYA cancer and considerations of developments within the clinical field. Chapter 7 concludes the thesis with outlining the study limitations and implications for future research.

1.8 Summary

This chapter has summarised and outlined the structure of the thesis, the focus of the research and the context and rationale for my choice of research topic. The following chapter examines the literature supporting the research into TYAs in the context of cancer and palliative care. It acknowledges that everyone’s experiences are unique and attempts to look at end of life from the perspective of those experiencing it (The National Council for Palliative Care, 2015).

Chapter 2 Literature Review

2.1 Introduction

A literature review allows for a review of the research that has already been conducted and to identify any gaps (Hart, 2018). Initially, the literature review followed a clear structure, however, this evolved along with the research aims. The literature review used a systematised approach, linked directly to the research questions, and was broken down into the relevant key areas (Booth et al., 2016). There was no formal quality appraisal conducted within the literature review as the aim was to summarise the extent of the wider literature related to the key topics and not to produce a meta-analysis or synthesis of this. Therefore, this was a scoping literature review. The literature review was conducted from 2016-2021; including research that had been conducted and/or published throughout the duration of the thesis. The literature review included citations from within the identified journals.

The inclusion criteria were articles from 1990-2021 that included cancer in the title and those cited within the highlighted articles. All articles were written in English or translated into English. Articles that focused on the needs of those at end of life, the developmental period of TYAs and the impact that cancer had on TYAs and people's experiences of living with cancer were selected. As the research on TYAs is limited compared to literature focused on older adults and children, relevant literature from those fields is included within this study. I used search terms that would elicit information to support a wider literature review on this topic (Table 2.1: Search Terms), and this is based on the scoping literature review aim of: 'To explore the experiences of TYAs with cancer'. To elicit literature that would answer this question the Search Terms used were TYA (and alternatives) and Cancer. These are outlined in Table 2.1.

Table 2.1: Search Terms

Databases searched: Medline/PubMed, Science Direct, Wiley

Search Terms:

Cancer AND TYA OR AYA OR Young people OR Adolescents OR Teen* OR Older Children

TYA AND end of life OR palliative OR dying

In addition, the literature review used Boolean operators such as truncation using * to add to words to enable a wider search, e.g., teenage*; which would then include teenage, teenager.

A summary of the included studies can be found in Table 2.2, studies primarily include literature reviews and questionnaires/surveys, although there are some interviews and randomised control trials. The main themes that occurred within the literature review were, the impact that cancer has on TYAs and the existing services for TYAs at end of life. These will be further outlined below.

Figure 2: Literature Search

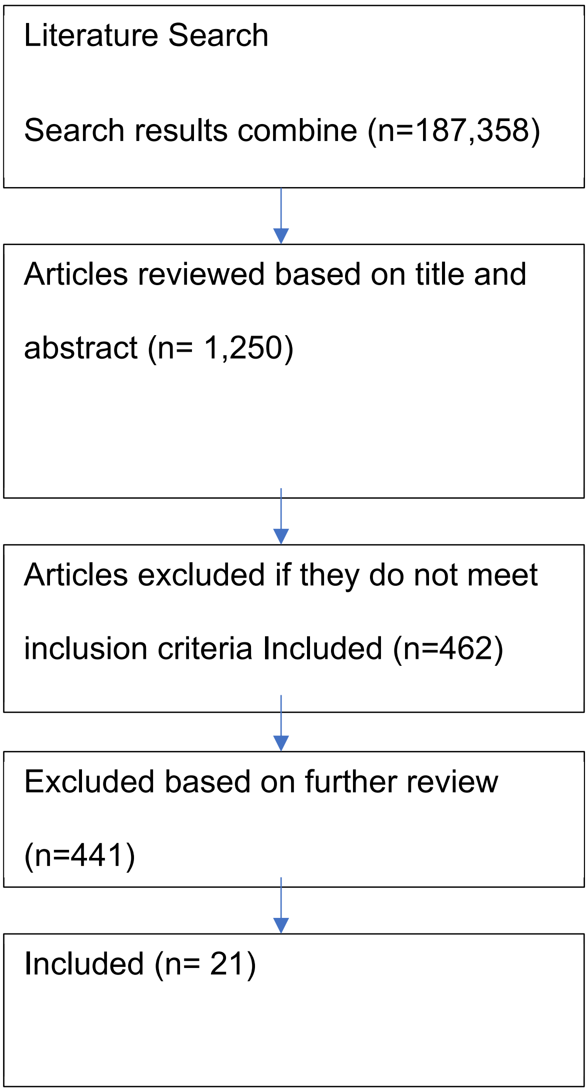


Table 2.2: Summary of literature review

Authors	**Title**	**Methodology/ Method**	**Participants**	**Country**
Barnett et al. (2016)	Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review	Systematic literature review	38 studies	Worldwide
Lang, David & Giese-Davis (Lang et al.)	The age conundrum: a scoping review of younger age or adolescent and young adult as a risk factor for clinical distress, depression, or anxiety in cancer	Scoping Review	24 studies	Worldwide
Taylor et al. (2016)	Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer	e-Delphi survey	179 Professionals working in TYA care	Worldwide

Warner et al. (2016)	Social well-being among adolescents and young adults with cancer: A systematic review	Systematic review of literature from 2000-2014 including patients and survivors diagnosed between 15-39 years.	26 articles reviewed	USA
Sodergren et al. (2017)	Systematic review of the health-related quality of life issues facing adolescents and young adults with cancer	Literature review	AYA literature review	UK
Kaal et al. (2017)	Empowerment in adolescents and young adults with cancer: relationship with health-related quality of life	Questionnaire	83 AYA (aged 18-35 years)	Netherlands

Jibb et al. (2017)	Implementation and preliminary effectiveness of a real-time pain management smartphone app for adolescents with cancer: A multicenter pilot clinical study	Questionnaires	40 adolescents	Canada
Ang et al. (2018)	Experiences of adolescents living with cancer: A descriptive qualitative study	Semi-structured interviews	10 adolescents (aged 10-18 years)	Singapore
Sodergren et al. (2018a)	Does age matter? A comparison of health-related quality of life issues of adolescents and young adults with cancer	Questionnaire with rating scale	22 AYA (aged 14-25 years) and 25 older adults (aged 26-60 years)	Europe

Sodergren et al. (2018b)	A life put on pause: an exploration of the health-related quality of life issues relevant to adolescents and young adults with cancer.	Semi-structured interviews	45 AYA (14-25)	Across 6 countries
Herbert et al. (2018)	Diagnostic timelines in adolescents and young adults with cancer: a cross-sectional analysis of the BRIGHTLIGHT cohort.	Cross-sectional analysis (interviews)	830 AYAs (aged 12-24 years)	UK
Force et al. (2019)	The global burden of childhood and adolescent cancer in 2017: an analysis of the Global Burden of Disease Study 2017	Global data review	0-19 years data used globally	Worldwide

Mack et al. (2019)	Adolescent and young adult cancer patients' experiences with treatment decision-making	Survey	203 AYA with cancer (aged 15-19 years)	USA
Barr & Feeney (2019)	Health-related quality of life in adolescents and young adults with cancer–Including a focus on economic evaluation.	Literature Review	HRQL with AYAs	Canada
Graetz et al. (2019)	Things that matter: Adolescent and young adult patients' priorities during cancer care	Survey	203 cancer patients (aged 15-29 years)	USA

Aldiss et al. (2019)	Research priorities for young people with cancer: a UK priority setting partnership with the James Lind Alliance	UK-wide survey of young people (13-24) who have experienced cancer, carers, and professionals.	292 respondents	UK
Osborn et al. (2019)	Models of care for adolescent and young adult cancer programs	Review of clinical models	Professionals' experience of clinical models	UK, USA & Australia
Duran et al. (2020)	Quality of life and pain experienced by children and adolescents with cancer at home following discharge from the hospital.	Exploratory study	33 participants	USA

Friebert et al. (2020)	Congruence gaps between adolescents with cancer and their families regarding values, goals, and beliefs about end-of-life care	Cross-sectional study	80 adolescent family dyads	USA
Kaluarachchi et al. (2020)	Being a teenager and cancer patient: What do adolescents and young adults with cancer find valuable and challenging with their friends and cancer peers?	Semi-structured interviews	12 AYA	Australia
Gibson et al. (2021)	Reporting the whole story: Analysis of the 'out-of-scope' questions from the James Lind Alliance Teenage and Young Adult Cancer Priority Setting Partnership Survey	Survey	Young people (aged 13-24 years)	UK

To complement the academic literature review, a search of grey literature sources such as online forums was performed, particularly to gain an increased knowledge into the statistics relating to TYAs and cancer/end of life. For statistics relating to the use of the internet or social media, the information was gained from sources to enhance the academic literature.

As the thesis evolved further, consideration was needed to include blogs, vlogs, autobiographies, newspaper articles and magazines within the literature review to gain the perspective of what people were putting in the media about their cancer journeys. The search for these included using the same reference terms above and searching within ‘Google’; however, allowing the dates to be more flexible to allow for articles with rich data to be utilised.

The literature review consists of three key areas, teenagers and young adults, end of life and the importance of technology within this age range. To expand on the identified themes, supplementary literature has been included.

2.2 Teenagers and Young Adults (TYA)

2.2.1 Diagnosis of Cancer within the TYA population

Alongside physical health issues and services available, a diagnosis of cancer is likely to significantly negatively influence social well-being (Warner et al., 2016). Warner et al. (2016) reviewed 26 articles relating to patients and survivors aged 15 to 39 years and these highlighted domains of social wellbeing that are understudied amongst TYAs with cancer, which include, educational attainment, employment, social relationships, and supportive care. The Teenage and Young Adult with Cancer James Lind Alliance priority setting partnership identified 10 research priorities for young people with cancer through steering groups, questionnaires, and workshops with young people (aged 13-24 years) with a current or previous cancer diagnosis, their families, partners, friends, and professionals working with this population (Aldiss et al., 2019) (Table 2.3).

Highlighted within these research priorities is how to improve psychological well-being, social functioning, and mental health, along with supporting those with incurable cancer; these are further explored within this chapter.

Table 2.3: Top 10 research priorities for teenage and young adults' cancer (Aldiss et al., 2019).

1. What psychological support package improves psychological well-being, social functioning, and mental health during and after treatment?
2. What interventions, including self-care, can reduce or reverse adverse short-term and long-term effects of cancer treatment?
3. What are the best strategies to improve access to clinical trials?
4. What General Practitioner or young person strategies, such as awareness campaigns and education, improve early diagnosis for young people with suspected cancer?
5. What are the best ways of supporting a young person who has incurable cancer?
6. What are the most effective strategies to ensure that young people who are treated outside of a young person's principal treatment centre receive appropriate practical and emotional support?
7. What interventions are most effective in supporting young people when returning to education or work?
8. How can parents/carers/siblings/partners be best supported following the death of a young person with cancer?

9. What is the best method of follow-up and timing which causes the least psychological and physical harm, while ensuring relapse/ complications are detected early?

10. What targeted treatments are effective and have fewer short-term and long-term side-effects?

2.2.2 Decision-making for TYAs

The capacity of TYAs to make decisions about their treatment and their understanding of end of life has been found to be no less mature than their adult counterparts (Friebert et al., 2020), which reflects previous studies such as, Hinds et al. (2005). In addition, most studies assume that families will accurately represent the preferences of the TYA in relation to goals and treatments (Friebert et al., 2020). However, supporting literature suggests when tested (Jacobs et al., 2015), this was not found to be the case (although the study was a small-scale study on a single site).

Mack et al. (2019) surveyed 203 TYAs (15-29 years old) (response rate 74%) in Boston, Massachusetts (USA) and asked them to report on their decision-making preferences. A reported 58% wanted to share the decision-making responsibility with their oncologist/medical team and 51% preferred limited involvement from their parents. They also reported that 24% experienced regret about their initial cancer treatment decisions at baseline. Therefore, demonstrating that some TYAs want support whilst others want to be independent, or have limited support in decision-making.

Supplementary literature suggests, TYAs experiencing cancer, are required to make decisions about their treatment that may challenge their perception of what path their life was on, for example, the impact on them establishing their independence and making career plans (Hedström et al., 2004). This coupled with their evolving understanding of their diagnosis and prognosis this may be very difficult. Dunsmore and Quine (1995) found that 2/3 of 12-24-year-old cancer patients wanted more information about the long-term effects, fertility, and side effects of treatments to support decision-making. Kelly et al. (2017) found that children and adolescents would often default to thinking that parents and medical staff 'will do what's best', and therefore wanted to be involved in the decision-making but not necessarily be the decision-maker. However, the participants for this study were 9-17 years old, and therefore have more dependency on their parents than TYAs.

Sodergren et al. (2018b) suggests a diagnosis of cancer during their period of critical development will disrupt the negotiation of the challenges that occur within this developmental period (Sansom-Daly & Wakefield, 2013; Zebrack, 2011). In addition, disruption to their developmental milestones can lead to reduced quality of life (Nolan et al., 2014; Quinn et al., 2015), with older TYAs noting distress relating to family planning, romantic relationships, and financial burden (Zebrack et al., 2014), which will be discussed in more detail within this chapter.

2.3 Impact of Cancer on TYAs

2.3.1 Quality of Life

Quality of life is increasingly used within literature and publications embedded in the title of academic articles along with TYAs with cancer (Barr & Feeny, 2019). In 1998, there was less than 500 publications relating to TYAs with cancer and quality of life, compared to over 1,000 in 2008 and peaking at 2,000 in 2016 (Barr & Feeny, 2019). Quality of Life is usually measured for those with chronic conditions and is frequently found to be impaired or measured as poor (Megari, 2013). It has been found that the co-morbidities can also have a strong negative effect on HRQoL (Heyworth et al., 2009).

Kaal et al. (2017) conducted a study of 18–35-year-olds in the Netherlands (age of TYA in line with their national guidance), in which several HRQoL tools were used alongside the Cancer Empowerment Questionnaire. The results of this outlined that if the TYA was treated within a specialist care centre, then they had increased levels of empowerment. The factors most influencing empowerment were autonomy, gender, and social support. They found males were more likely to have increased empowerment, increased autonomy and increased social support compared to their female counterparts based on questionnaire results. They also reported that health-related information delivered appropriate to the TYAs age improved their feeling of being empowered. They also found the needs of TYAs in relation to empowerment and overall quality of life intensify if they transition to end of life within their illness trajectory (Kaal et al., 2017), this is related to factors such as palliative treatments negative association with quality of life. Warner et al. (2016) found that HRQoL was also linked to financial burden and financial independence, in which TYAs with lower socioeconomic status at the time of their diagnosis were reported to be linked with lower HRQoL outcomes. In addition, TYAs who had moved to reliance on their parents for financial support reported feelings of loss of control and therefore lower HRQoL outcomes.

The European Organisation for Research and Treatment of Cancer (Sodergren et al. 2017) quality of life group interviewed 45 TYAs aged 14-25 years (Sodergren et al., 2018a) who reported issues relating to health-related quality of life. These included symptoms, activity limitations, disrupted life plans, adverse social impact, emotional comorbidity, changes in body image, positive self-appraisals, outlook on life, restrictions in lifestyle, treatment related sequelae, fertility, and financial concerns. Of the issues raised several would not typically appear in HRQoL measures. However, it is acknowledged that as the age range of TYAs and individual differences that present within are vast, it would be difficult to develop something that would cover all areas impacting on HRQoL (Sodergren et al., 2017; Clinton-McHarg et al., 2010; Quinn et al., 2015).

Sodergren et al. (2018a) conducted research specifically looking at health-related quality of life measures in TYAs within Europe and asked them to complete a rating scale. The issues they identified were: interruption to education (86% 14-18 year olds and 100% of 19-25 year olds), increased maturity (86% of 14-18 year olds and 68% of 19-25 year olds), access to age appropriate information particularly relating to psychosocial concerns, e.g. fertility, older TYAs reported changes of living situations, e.g. having to move back in with their parents, boredom frequently recognised (86%), and disconnected social networks, e.g. friends do not know how to help them or feel uncomfortable around them. The significant changes to social networks have also been found in several other studies (Ang et al., 2018; Kaluarachchi et al., 2020; Graetz et al., 2019). Ang et al. (2018) interviewed ten participants aged 10-16 years, the themes emerging demonstrated the significant changes to their relationships with family and friends, with a particular focus on the difficulties of people visiting them during treatments, due to their immune system weaknesses. However, some report positive changes to social functioning with an increased drive to achieve and increased opportunities to make new friends (Sodergren et al., 2018b). Graetz et al. (2019) found that TYAs reported having supportive people around them was ‘extremely’ or ‘very’ important to them (94% of participants), with being with family, returning to school, maintaining relationships with friends, and feeling as normal as possible all-important factors to supporting their quality of life.

2.3.2 Spirituality and wellbeing

Spirituality can be described as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred,”(Puchalski et al., 2014:643). It has been found that cancer patients can experience high levels of high burden of spirituality needs (Merath et al., 2020) and Merath et al. (2020) found that 50% of respondents (199 participants with diagnosis of cancer living in the USA) reported that cancer influenced them to “lean into” their spiritual beliefs (p.1938). Some participants stated that they had negative thoughts about spirituality and described feeling an anger towards God (Merath et al., 2020). Spirituality can lead to improvements in quality of life and reduce the burden of anxiety and depression in cancer patients (Chaar et al., 2019). Feng et al. (2021) defines spirituality as the way “individuals seek and express meaning and purpose in life” (p.2), they found that patients with a higher level of spirituality had a lower death anxiety. This is due to factors such as reduced impact of fatigue and increased sense of meaning-making (Chaar et al., 2019).

2.3.3 Grief and Loss

Humans are wired to create attachments even in the world of impermanence (Neimeyer et al.2014), in which loss is inevitable. When people experience a loss, they are in a state of bereavement (Rando, 2012) and grief is the emotional and cognitive response to the bereavement (Kutner, 2002). Bereaved experiences vary on an individual basis (Nelson et al., 2022), however they often include a sense of numbness in response to sadness, feelings of helplessness or feeling stunned (Attig, 2011; Kutner, 2002). Death and loss are universal (Neimeyer et al., 2014) and grief is a universal experience where “the story of the death itself and our changed relationship to the deceased are personally narrated and socially shared” (Neimeyer et al., 2014:486). Grieving can be described as all-encompassing and experienced at all levels including biological, personal, interpersonal and at social levels of discourse (Stroebe et al., 2008). Thematic analysis of grief narratives has demonstrated those who felt death was ‘Gods will’ or ended the person’s suffering had less distressing grief symptomatology (Lichtenthal et al., 2010).

For parents it can be difficult to accept the impending death or actual death of their child as it is not considered the natural order of things (Cooke & Randall, 2021). It has been reported that there is a difference in losing a child to other types of bereavement, which results in increased risk for development of complicated grief and negative impact on coping strategies (Rosetto, 2015). Lannen et al. (2008) reported that parents can often experience ‘unresolved grief’ if they have lost their child to cancer, and this has negative implications for their psychological and physical health over time. In addition, it can be difficult for the child themselves to understand the concept of death as it has been calculated that by the time a child reaches 16 years old only 4-7% will have experienced death of a relative (Talwar et al., 2011) and therefore they do not have the experience to draw upon to support their development of the concept of death.

The social constructionist model of grief in western cultures appears to be primarily a private and intrapsychic process, however Neimeyer et al. (2014) argues that grief is not primarily an interior process but one that is intricately social and understood through narratives. We are asked to reconstruct the world of meaning even though it has been challenged by loss (Neimeyer, 2001). A narrative perspective can support in understanding the processes in which loved ones construct a sense of resilience following a shared loss (Hooghe & Neimeyer, 2012).

Grieving and mourning in both private and public moments draw heavily on narrative processes (Neimeyer, 2006; Neimeyer et al., 2014). There is a strong urge in human nature to create stories which aim to organise experiences in “terms of plot structures with meaningful beginnings, middles and ends” (Neimeyer et al., 2014:487). These are related to neurophysiology in the brain processing episodic memories, consolidating them into autobiographical memories of which these are subject to reconstruction over time (Rubin & Greenberg, 2003). Anticipatory grief is the term given to those who express grief when the loss of someone is inevitable and is felt by a person prior to death (Coelho & Barbosa, 2017). As part of this grief process disruption can occur at several levels including family structure, relationship changes within the family and awareness that everyone’s life will inevitably change (Gunnarsson & Öhlén, 2006; Beng et al., 2013). Anticipatory grief can leave people feeling separation anxiety (Saldinger & Cain, 2004; Coelho & Barbosa, 2017) and concerns about the future (Gunnarsson & Öhlén, 2006; Beng et al., 2013). In addition, there can be a fear of painful death and a fear of what the reaction will be to the death, which can impact on the grieving process (Gunnarsson & Öhlén, 2006). Caregivers can experience helplessness and compassion fatigue during the period of anticipatory grief (Beng et al., 2013).

Grief therapy often utilises narrative frames to make sense and understand the individual’s experiences and those of their loved ones to process grief in a meaningful way (Neimeyer et al., 2014). Narrative therapies use a social constructionist approach putting the individual in the centre of their story to support meaning-making (Neimeyer, 1999). For some, narration of loss serves a purpose of social agenda in which it aims to promote a greater understanding of things such as cancer awareness (Neimeyer et al., 2014). Stories can be used to help make loss more comprehensible and “compensated by the life learning it entails” (Neimeyer et al., 2014, p.488), and increases the adaptability of the person grieving. The life learning can support people to ‘sense-make’ through their grief and reflect on the “preciousness of life” in appreciation (Neimeyer et al., 2014). For those people who experience traumatic or premature loss in their loved ones the intensity in their search for meaning can increase the intensity in their grief symptomatology (Currier et al., 2006). The experience of profound loss can challenge the individual’s self-narrative (Neimeyer, 2004). By creating narratives this can support people to help make sense of their trauma (Pennebaker & Chung, 2007). There is an opportunity to externalise emotions and reframe their grief (Rafealy & Goldberg, 2020). With this externalisation comes better understanding of trauma (Nelson et al., 2022) and to reconstruct components of their emotions to include hope, empowerment, and growth, which enables the individual to accept and reintegrate into daily life in a meaningful way (Hedtke, 2014).

2.3.4 Illness Trajectory

For individuals living with a chronic illness, their illness evolves over time and is generally thought to have several key milestones within the illness trajectory (Sannon et al., 2019). The process of illness trajectory is considered a social process due to the significant meaning people assign to how they are viewed by other people. The diagnosis of cancer is likely to lead to an immediate and/or long-term impact on their personal goals and this is most prevalent in TYAs due to the developmental period in which they are at in their lives (Sodergren et al., 2018b). Ang et al. (2018) found that reductions in seeing family and friends due to treatments were a significant factor in their psychological wellbeing and as their illness progressed became more prevalent. The participants reported spending more time with their parents, but that they did not like being treated like a child. They had reduced time spent with their friends and peers, and friends were more cautious around them.

Warner et al. (2016) reported that there were significant impacts on education and employment linked with the illness trajectory however, these were related to cancer survivors. Warner et al. (2016) found approximately 25% of TYAs reported cancer negatively impacted on their relationships with their spouse/significant other, and in addition, their views on relationships, marriage and parenthood continually changed throughout their illness trajectory, and treatment.

Further literature supports that the process of illness trajectory changes the impact the cancer has on the TYA. The milestones include acceptance of the illness, changes to the concept of ‘self’ and evolving identities (Lonardi, 2007). When discussing their cancer journey with others, TYAs will often refer to milestones reached by their peers, e.g., starting college, and learning to drive (Hinds et al., 2004) and feel that they have been left behind.

The onset of cancer can negatively change relationships with others which by definition will increase anxiety and tension within support networks. In order to adapt TYAs developmental abilities whilst managing their cancer diagnosis, the process is thought to include establishment of new self-image (both intellectually and sexually), development of abstract and future orientated decision-making skills, renegotiation of relationships with parents and loved ones, and formation of new committed and complex relationships with peers (Albritton & Bleyer, 2003). Kaluarachchi et al.

(2020) found that TYAs report strained friendships with some friends feeling sorry for them or avoiding them altogether (Miedema et al., 2007; Decker, 2007). Some TYAs noted feelings of guilt for not being able reciprocate support for their friends (Zebrack et al., 2010). Yet TYAs also reported finding positive relationships with their peers (TYAs with cancer) as they had similar experiences and this promoted a sense of identity (Warner et al., 2016; D'Agostino et al., 2011). This peer group was a safe space to address concerns about things such as levels of dependence and body image (Zebrack, 2011; Kaluarachchi et al., 2020). Previous studies concluded that for TYAs friends and family were less important than peers (in this study peers refers to other TYAs with cancer); however, more recent findings do not support this (Kaluarachchi et al., 2020) as friends allow for some level of normalcy (Miedema et al., 2007). Therefore, the increased need and reliance on health care services for support is a challenge (Kyngas et al., 2000).

Adolescents with chronic illness constantly struggle with independence (Kyngas et al., 2000), and this is caused by a range of contributing factors relating to their illness trajectory, symptoms, and treatment. Adolescence is when individuals carve out their personalities and the restrictions placed on them relating to their diagnosis can prevent them from becoming ‘adults’. The achievement of typical developmental processes are significantly affected within the TYA population following a cancer diagnosis (Hedström et al., 2004). This is because the management of normative developmental tasks is disrupted by coping with the challenges of their cancer diagnosis (Rosenberg-Yunger et al., 2013). People diagnosed with cancer in their 20s and 30s are thought to have a high level of unmet needs (Giese-Davis et al., 2012; Keegan et al., 2012), lower functioning, higher levels of financial difficulty, and report needs for sexuality, relationships, and health systems navigation to be part of the support offered (Hall et al., 2012). Within the ages of 16-24 years, people will go through periods of social development, identity formation (Marcia, 2002), body image worries, educational aspirations, and family dynamic changes; however, this is heightened for the TYA population who have a diagnosis of cancer (Dyson et al., 2012). The uncertainty about their diagnosis, future, physical changes, relationship changes, lifestyle changes and family stressors all contribute to their overall psychological distress (Woodgate, 2005; Woodgate, 2006). Chiang et al. (2009) found that TYAs' future life plans were compromised due to changes to their education, difficulties engaging in activities and the impact this had on their talent realisation. This led to overall increased distress and reduced HRQoL (Sodergren et al., 2018a; Sansom-Daly & Wakefield, 2013; Thompson et al., 2009).

The emotional impact of cancer is widely reported within the TYA population (Sodergren et al., 2018b) and further literature suggests this is felt to be more significant than in other age groups, with increased anxiety, distress, and depression the main factors (Burgoyne et al., 2015; Lang et al., 2015; Park & Rosenstein, 2015). Anxiety related to their appearance changing and increased feelings of isolation (Hedström et al., 2003). TYAs report decreased psychological well-being and self-esteem because of their diagnosis and/or treatment (Enskär & Von Essen, 2007). Stinson et al. (2015) interviewed TYAs who reported feeling less attractive, which then led to changes in their self-esteem and confidence particularly relating to romantic relationships This significantly impacted on their overall quality of life. This can be variable within the TYA population; often dependent on their support from others (Hymovich, 1990; Wong et al., 2017; Zebrack et al., 2010) and ability to cope, e.g., have intact cognition (Hymovich & Hagopian, 1992; Sodergren et al., 2018a) and the opportunity for psychosocial development. Bellizzi et al. (2012) found that

TYA survivors can show signs of posttraumatic growth, and therefore are prone to maladjustments and on-going psychological distress.

Their perception of their symptoms can significantly vary but some common themes are symptom burden, cognitive dysfunction, and concerns about body image, sexuality, and fertility (Avis et al., 2005), which are often manifested as unmet needs. Collie et al. (2016) reported that individuals aged within their 20s or 30s at the point of diagnosis have high levels of unmet needs and often present with lower social functioning. Relationship difficulties are described as complex and lacking (Hall et al., 2012). It has been reported that TYAs suffer from changes to emotional unbalance (Enskär et al., 1997) symptom distress, and life situations (Sodergren et al., 2018a; Wong et al., 2017), and changes to their sex lives (Kyngas et al., 2000). An individual’s ability to cope will continue to change and needs to be seen as a dynamic process.

In addition to managing the physical and psychological symptoms, there is additional symptom burden such as the financial impact (Enskär et al., 1997; Chaturvedi et al., 1996), which is reported to be at a higher level for TYAs with cancer comparative to their adult counterparts (Hall et al., 2012). This poorer social functioning and increase in financial difficulties are commonly reported in HRQoL measures and are particularly prevalent in younger patients (Quinten et al., 2015). There is a common distress, anxiety and concern relating to financial, physical, and social tolls that are placed on carers/family members whilst the TYA is undergoing treatments (Otis-Green et al., 2014).

Some TYAs will state that the ‘disease made them more mature than their friends’ (Stark et al., 2016); however, they felt their freedom was more restricted due to the number of hospital appointments and admissions they had. Many have noted that without good support networks. TYAs are less likely to adjust well to their diagnosis and treatment (Enskär et al., 1997; Suzuki & Kato, 2003; Trask et al., 2003). Wong et al. (2020) found that strong support networks help TYAs to cope, and TYAs reported their involvement in ‘typical’ TYA tasks minimises the impact of their cancer and improves their quality of life (Zebrack et al., 2010).

2.3.5 Symptom Burden / Physiological Impact

Duran et al. (2020) had conducted an exploratory study to understand quality of life and pain in children and adolescents with cancer. There were 33 participants aged 8 to 17 years who had been discharged from hospital, of those 33, 51% experienced pain at home, with 18% categorised as moderate to severe. Jibb et al. (2017) found pain in TYAs with cancer is common, with negative implications on HRQoL. Kaluarachchi et al. (2020) reported that TYAs felt there was a detrimental impact on friendships because of side effects such as, increased fatigue reducing the ability to participate in normative tasks and maintain good communication.

Literature suggests when receiving treatments for cancer types, common side effects include fatigue, hair loss, reduced appetite, or ability to eat, nausea, vomiting, pain, fever, and mucositis as examples (Collins et al., 2000; Hedström et al., 2003). Insomnia is often reported in patients with cancer (Savard et al., 2015), leading to reduced energy levels. Additionally, to this managing medication schedules and hospital appointments can lead to increased planning of each day and reduced ability to engage in ‘usual’ activities. This is due to limited energy reserves to attend appointments and therefore not then being able to engage in social activities following appointments. Not engaging in social activities has led to a significant decrease in life being ‘satisfying’ (Enskär & Von Essen, 2007) and poor HRQoL as reported in outcome measures (Sodergren et al., 2017). According to Collins et al. (2000) one in three TYAs report feeling sad, nervous, irritable, or anxious during or following their treatment, which appears heightened compared to their peer group of the same age without cancer (Hedström et al., 2005). Side effects such as increased fatigue reportedly prevented TYAs from being able to participate in normative tasks (everyday tasks that help them to feel normal) and fully communicate with their friends (Kaluarachchi et al., 2020), which has significantly impacted on their self-reported quality of life.

Pain in TYAs is common (studies indicated between 49-95%) (Baggott et al., 2010; Stinson et al., 2015b; Wolfe et al., 2015) and is usually self-reported on an intensity scale as moderate to severe (Sung et al., 2009). This significantly negatively impacts on HRQoL (Jibb et al., 2017), and contributes to their overall levels of distress. Treatment advances have meant that pain management can now be better supported in the home environment (Fortier et al., 2011; Duran et al., 2020).

To cope with the symptom burden and symptoms (physical and emotional) associated with the diagnosis, treatment, and symptoms, effective social support networks have been found to be the best solution (Aymanns et al., 1995; Nichols, 1995). These help individuals to share thoughts, experiences, and feelings to support them to deal with their illness (Grahn & Danielson, 1996). For all cancer survivors, it has been identified that they will often engage in risk behaviours as part of their coping mechanisms, e.g., smoking, increased alcohol intake and unprotected sex, and this is much more common comparative to the general population (Klosky et al., 2012; Hollen & Hobbie, 1996). Therefore, further consideration is needed for the long-term impacts of cancer on quality of life for TYAs.

2.4 Available Services for TYAs

The number of TYA specialist cancer centres has increased over the last ten years and further research into the specific needs of TYAs (Aldiss et al., 2019; Gibson et al., 2021). In addition, improvements are being made in relation to diagnostic timelines in TYAs (Herbert et al., 2018).

Within the UK, there has been pioneering work implemented to provide adolescent specific services which are able to offer age-specific nursing care, recreational therapy, and peer companionship (Albritton & Bleyer, 2003). It has been acknowledged that the interface between adult and paediatric services can lead to increased clinical service development (Vassal et al., 2014; Marris et al., 2011).

Studies that have recruited health and social care professionals working with TYAs have shown a much higher level of nurses and doctors participating in the wider multi-disciplinary team as opposed to allied health professionals (Force et al., 2020). Taylor et al. (2016) conducted questionnaires with health professionals nationally, and of the participants, 35% were nurses and 39% were medical doctors, meaning the remaining health professionals (psychology, social worker, allied health professionals and ‘other’) made up 26% of respondents. In addition, on review of five randomly selected Teenage Cancer Trust Centres, they specifically employed nurses and youth workers (43% and 57% of workforce) (Teenage Cancer Trust, 2021).

In order to provide person-centred care a multidisciplinary team is required and this supports more holistic care (Anghelescu et al., 2006); however most cancer-based services compromise exclusively of doctor and nurse dyads (Otis-Green et al., 2014) TYA specific units aim to have the skills of a multi-disciplinary team with a lead clinician or nurse and referrals made to specialist allied health professionals, which include psychology, social work, youth workers, dietitians and others as appropriate (Carr et al., 2013).

"High-functioning interprofessional teams that include psychosocial professionals are needed to effectively provide the level of nuanced, culturally congruent, and 'person-centred' care necessary…" (Institute of Medicine, 2013, p.433).

In terms of health care delivery, it has become apparent that TYA patients tend to occupy a sort of no-man's land, being at home in neither of the two different worlds of paediatric or adult oncology (Ferrari et al., 2010). There are a lack of appropriately resourced services and recognition of the specialist needs of the TYA population (Whelan, 2003) with different goals and philosophies between adult and children services (Barling et al., 2014). As TYAs occupy such a unique place within cancer care (Bleyer et al., 2008), it poses a challenge for services as they need specialist attention, care, and resources (Barnett et al., 2016; Kaluarachchi et al., 2020).

The thought of 'who should provide the care?' has been heavily debated, with adult oncologists verbalising they have inadequate knowledge of the support systems utilised within the TYA population, e.g., education systems, and paediatric oncologists reporting their reduced experience in working with the cancer type (Albritton & Bleyer, 2003). It is thought that service provision should reflect the evolving epidemiology of the cancer types being displayed within the TYA population (Stevens, 2006). The difficulties often lie with the variety of cancer types, and the unpredictability of the impact this has on the TYA is complex (Albritton & Bleyer, 2003). The benefits of having age-specific care are not only the access to specialist medical care to improve treatment outcomes but to be able to encourage peer support for TYAs (Whelan et al., 2007; Pearce, 2009; Smith et al., 2011; Fern et al., 2021).

When asked what is important to them in relation to care, TYAs reported that they wanted health professionals who were able to facilitate communication through their ‘ability to listen, genuine concern, expertise and honesty’ (Hedström et al., 2004, p.7; Gibson et al., 2021). TYAs commented on expected qualities such as clinical competence and continuity of staff but reported flexible working (to facilitate as normal a life as possible) and respect for integrity as additional qualities that are preferable. Whilst other studies have found that the emotional support provided to the TYA is a determinant of the psychosocial response to the experience of having cancer (Ritchie, 2001; Taylor et al., 2011). TYAs have also reported their frustrations with needing to repeat conversations about cancer to various health professionals and services (Fern et al., 2013).

Between the ages of 16-24 years as outlined previously, there are varying levels of maturity, independence, and coping mechanisms in situ, this makes it difficult to indicate definitively whether adult or paediatric services should provide care. There has been found to be less access to age-appropriate professional psychological support for this group than for children and older adults (Zebrack, 2012). As the psychosocial impact is unique (Hall et al., 2012), there is often unmet physical, psychological, and social needs within the models of provision that exist (Palmer et al., 2007; Gibson et al., 2021). Therefore, services need to be specific to TYAs to address their specialist and unique needs. It has been identified that young cancer patients have an increased desire to be treated as a partner and integral team member within their treatment (Morgan, 2009), and therefore an individualised approach should be adopted allowing the TYA to choose which service they feel best suits their needs.

It is often considered difficult to navigate the health care system as a whole and accessing local services and community-based services in a timely basis (Liao et al., 2011). The benefits of local and outpatient services have been well documented within the research (Rabow et al., 2015; Rabow et al., 2013; Zimmermann et al., 2014). Outpatient care allows patients with cancer to be seen early in the course of their illness (Scibetta et al., 2015), and this can lead to benefits such as aggressive management of symptoms, longitudinal psychosocial support for patients and their family, effective conversations to support understanding of illness, prognostic factors, and transitions of care (Rabow et al., 2015). Utilising technology and the delivery of online groups, support and consultations and has improved the effectiveness of services (McAlpine et al., 2015).

In addition to the complexities of identifying specific TYA care, it has been reported that despite advanced cancer having detrimental effects on the quality of life for the individual patients and for their families, there are few interventions have been developed to support their quality of life and focus on elements of psychosocial wellbeing (Northouse et al., 2012; Hagedoorn et al., 2008). However, interventions focusing on improvement of quality of life are in constant development (Aldiss et al., 2019). Cancer support groups for TYAs have become increasingly popular and aim to facilitate emotional expression and promote social connectedness through a range of therapy types (Collie et al., 2016). These include complementary self-care therapies, art and music therapy, and services closer to home (Taylor et al., 2011).

There is no unitary definition of family-centred care, but essentially, it is a commitment to involving the family in care of the individual with the aim of supporting the individual's treatment, recovery and reduce emotional trauma (Uniacke et al., 2018). Family-centred care is a model where the care is planned around the whole family not just the individual (Al-Motlaq & Shields, 2017). The model recognises the importance of the family, particularly in care delivery (Uniacke et al., 2018; Foster & Shields, 2020). Family-centred care enables the whole family to participate in decision-making and make relationships with the health care professionals which aims to improve the care offered (Hill et al., 2018). It aims to meet the needs to patients and families who are experiencing palliative care and maintain this into bereavement (Kissane, 1999).

Family-centred care has been found to strengthen the coping mechanism for the individual and their family (Gabriel et al., 2021) and improve the wellbeing of the whole family (Franklin et al., 2018) for those with cancer and other long-term conditions. There is research in support of offering family therapy for those with children experiencing cancer and some studies for young adults with conditions such as cerebral palsy (McDowell et al., 2015); however, there is little evidence of the use of this with TYA's with cancer and therefore further research could be done to support the development of this approach. This would support professionals in developing therapeutic care for TYAs utilising family-centred approaches.

2.5 Dying/Supportive Care and End of Life

Gibson et al. (2021) conducted a UK-wide survey with the aim of identifying research priorities for TYAs with cancer. This offered insights into the views of TYAs, parents and professionals about end-of-life care. Participants suggested that communication about choices and information about illness progression were vital in supportive care

(Gibson et al., 2021). They reported they wanted professionals to have experience in supporting TYAs at end of life and embrace a holistic approach to care (Gibson et al., 2021), alongside ensuring staff have the skills to support these honest and sensitive discussions (Osborn et al., 2019). These discussions may address issues such as advanced care planning, memory-making, fulfilling goals, and how to support family and friends after the person has died. This often requires collaboration between the TYA specific cancer services and the palliative care teams to ensure joint working, avoiding duplication of appointments/plans, and supporting the individual effectively. In addition, TYA specific teams will rarely experience an end-of-life patient, and palliative care teams will rarely experience a TYA, so they need to share their skills to provide effective care (Gibson et al., 2021).

Within the wider literature, the importance of considering a multifaceted and holistic approach to a dying person, including the physical, emotional, and spiritual aspects of care has been found (Tait et al., 2011; Maguire et al., 2013). Looking at care from a person-centred approach is vital within palliative care (Maguire et al., 2013). Ensuring that TYAs manage their own end of life care planning is very important (Wiener et al., 2012). Whilst advances have been made in the management at end of life from a physical symptom’s perspective, such as pain management, there remains fewer studies to evaluate and develop therapeutic interventions for psychological and spiritual concerns (Xing et al., 2018; Cheng et al., 2019). The management of pain has improved utilising technology (Jibb et al., 2017), improvement of the ability of clinicians to assess pain (Scarborough & Smith, 2018), recommendations/guidelines supporting pain management (Vargas-Schaffer, 2010), early introduction of pain management within disease progression (Scarborough & Smith, 2018), and the increased use of non-pharmacological interventions in cancer care (Oei et al., 2021; Duncan et al., 2017). Palliative care is in place with the aim of enhancing quality of life and should do this by addressing the physical, psychological, social, and spiritual needs of individuals and their families (Saunder, 1998).

Once it has been identified that a person has a cancer type that will at some stage become palliative, palliative care professionals should become involved and offer support through the entire cancer journey not just at the end (Ahmedzai &Walsh, 2000). This is to get to know the individual, provide them with all relevant and age-specific information, and support them in their decision-making effectively (Gibson et al., 2021). It is important to align patient care with the individual's preferences as this will prevent unwanted, burdensome, and potentially ineffectual oncology treatments at end of life (Hui et al., 2014). Evidence suggests that having the choice of supportive care at home can reduce symptom burden. This has been found to be the case particularly for those with advanced cancer (Gomes et al., 2013), yet despite this evidence, end of life/advanced care planning remains neglected (Higginson et al., 2013). This is also true for the TYA population and may be due to the rareness of this occurring. However, studies are beginning to demonstrate the effectiveness of this (Sellar, 2015). There is also a fine balance between 'natural' and 'peaceful' and using medical technological advances to support 'comfort' or reduce pain; as it is about the individual's own perception of suffering and how to support that (Boston et al., 2011).

There has been some thought that palliative care should be integrated within routine oncology care to improve overall clinical quality (Hui et al., 2014), however, with no clear consensus about how to implement this further work is required (Rabow et al., 2015). It is important to utilise the skills of the TYA specialist care centres alongside both palliative care teams and general oncology services (paediatric and adult as appropriate) (Gibson et al., 2021). The benefit of this is that the patient gains from the experience of both specialist teams and it leads to improved outcomes for the patient. Dying well is described as “facilitated by people being involved in discussion about the transitions to palliative care early in the dying journey” (Barling et al., 2012:4). Dying well is the overall objective in palliative care, and some definitions of this include ensuring that practitioners aim to prevent suffering on a physical level and aim for the person to be pain-free (Vanderveken et al., 2019). Rainsford et al. (2018) describe dying well as maintaining one’s identity, autonomy and control over decisions related to care and not being overwhelmed by the physical management of the dying process. Practitioners need to consider a range of factors which can contribute to an individual’s view on a ‘dying well’ which include culture, values and attitudes of the person, time (preferences are likely to change with illness progression) (Bovero et al., 2019; Yun et al., 2018; Gibson et al., 2008) their life history and their personal relationship with death (Bovero et al., 2019; Thoresen, 2003). Some studies mention the patient-carer dyad being at the centre of the care to be important (Frambes et al., 2018; Holdsworth, 2015).

When interviewing family care givers and HCPs caring for those with cancer, Bovero et al. (2019) found that there were 9 common themes threaded through the responses which included symptom and pain control, no over treatment, respect of individuals will to treatment and with regards to death, presence of loved ones, good communication with HCPs, space for sharing emotions and inner peace. They reported additional comments which they found to be not a necessity but still important. These were mental clarity at the end, patients’ awareness of their upcoming death and patients being able to attribute meaning to their death.

’Dying well’ has mainly been looked at from the perspective of adults experiencing it or their loved ones and HCPs, and the outcome of this research is what forms the foundation of end-of-life care (Taylor et al., 2020; Steinhauser et al., 2000a; Steinhauser et al., 2000b; Emanuel & Emanuel, 2013). Studies are comparatively fewer for children and young people, but research is emerging (Webb & Tucker, 2009; Lyon et al., 2013; Hinds et al., 2005; Wiener et al., 2012; Pritchard et al., 2011). Taylor et al. (2020) interviewed HCPs who were caring for TYAs’ with cancer and the themes reported included: transparent communication, symptom management, acceptance (parental acceptance), honouring patient and families’ preferences, expectation/anticipation of death (to be able to plan and prepare), support from family and MDT and having a sense of control. These are all similar to those found in adult studies; however, it is worth acknowledging how these can be achieved effectively for TYAs is still in development.

In summary the key themes from the literature that describe ‘dying well’ for a TYA with cancer include pain management and management of symptoms, presence of loved ones and respecting the will of the patient (Bovero et al., 2019, Kehl, 2006; Yun et al., 2018). The challenges of supporting TYAs to have a positive experience when dying remain for HCPs as they continue to understand and navigate how to deliver services for this unique population.

2.5.1 Sense of Injustice

Cancer is an unsettling reminder of the unpredictability and injustice in the world (Kleinman, 1988). There is an underlying ‘sense of injustice’ in that people feel they are too young to die or that the people they are leaving behind are too young to be going through this.

There is an underlying sense of injustice felt within society by the death of a young person (Chasteen & Madey, 2003), with a belief felt that if we lived in a just world that is meaningful, then it is an injustice when a young person dies versus an old person dying (Chasteen & Madey, 2003; Ianoff-Bulman, 1992). An act of injustice such as a young person dying, can be disturbing for people to understand as they feel that the person didn’t deserve what has happened. This is due to the social construct that an older person has had more years to contribute to society (Jecker & Schneiderman, 1994) and has lived a fuller life. Whilst death is always considered sad, it is more accepted when the person is elderly and is deemed ‘unfair’ if the person is young (Jecker, 2011). When people were shown literature about different deaths, they perceived young deaths as more tragic and hypothesised that the grief associated with this would be more difficult to accept (Chasteen & Madey, 2003). Research has also indicated that the age of a person can significantly impact on people’s judgements about whether they should access certain treatments or be eligible for transplants, with younger people being looked on more favourably. With age-related stereotypes impacting healthcare professionals’ views on treatment compliance (Madey & Chasteen, 2004). However, this research is very limited and requires more in-depth analysis to be able to draw accurate conclusions (Chasteen & Madey, 2003). More recently, in relation to the COVID-19 pandemic healthcare professionals and the media have reinforced the homogenous view that older people are vulnerable (Swift & Chasteen, 2021; Ayalon, 2020) and this has been embedded with negative terminology and stereotypes (Cohn-Schwartz & Ayalon, 2021; Swift & Chasteen, 2021). This is the opposite of how young people are considered, which is fit and healthy, with a lot of positive stereotypes; this social construct enhances the sense of injustice when a young person gets cancer and dies.

They are in a generation where there is an increased focus on aspirations of things such as travelling, buying a house, and getting a good job. They will often hypothesize about the future and what could have been (Kroger, 2007); literature has shown that those with less or no regrets will fear death less (Tomer & Eliason, 2005). A sense of regret is not only for past-related things, for example, I should have, but for future related regrets, for example, In the future I wanted to get married and have children. This fits into Erikson's (1982) theory of development, with ego integrity versus despair (a person's perception of whether they have lived a meaningful life) a part of TYA cognitive-emotional development. Whether life is meaningful is a social construct, and death anxiety can be affected by self-belief and beliefs about the world (Tomer & Eliason, 2005).

2.5.2 Legacy

Legacy can be defined in several ways, however for the purpose of this literature review legacy is considered the process of leaving something behind (Hunter, 2008) and within palliative care legacy building refers to creating a legacy or making meaning from their experiences (Sisk et al., 2012). Legacy building can include journals, photo albums, handprints, writing letters or sharing stories (Boles & Jones, 2021). The most long-standing legacy intervention appears to be Dignity Therapy, which was developed as a way in which to produce a sense of meaning and purpose with the aim of reducing suffering at end of life (Chochinov et al., 2012). Dignity therapy is thought to be one way in which people can enhance a sense of legacy and have their emotional needs met (Montross-Thomas et al., 2015). Dignity therapy supports people to share their memories, accomplishments and hopes for others, to aim to bring about a sense of purpose and meaning at end of life (Watts et al., 2020). Until recently there has been limited research undertaken relating to the use of dignity therapy in young people (Rodriguez, Smith & McDermid, 2018). ‘Legacy artwork’ such as handprints, digital storytelling and photography appeared more frequent in paediatric studies as opposed to ‘Life stories’ which were more prominent in adult studies particularly those of individuals with Dementia (Schaefer et al., 2019; Johnston & Narayanasamy, 2016).

Studies have shown that individuals that have participated in a form of ‘legacy making’ have had reported improvements in emotional wellbeing (Boles & Jones, 2021; Piderman, et al., 2017a; Piderman et al, 2017b; Piderman et al., 2015) and in some cases more prepared for end of life (Keall, Steinhauser & Clayton, 2013). Individuals reported they felt that legacy interventions enabled them to leave a story for their loved ones (Boles & Jones, 2021), which was beneficial for them (Keall, Steinhauser & Clayton, 2013) and for their loved ones (Akard et al., 2018; Akard et al., 2020). Watts et al., (2019) reviewed the main two themes from a twitter chat led by MAGICYL (Meaning making and Generativity in Children and Young people), valuing the individual and being remembered. Valuing the individual referred to the extent to which young people felt their voice was heard and their perceptions of the value of their lives; being remembered referring to the level of control they felt they had on choosing what to share with others and how they would like to be remembered. This demonstrates what is potentially important to young people and how this can influence professions to support with legacy making.

2.5.3 Services

A further review was conducted to gather a baseline for what services are currently on offer within cancer care. In order for health and social care staff to support a person considered to be at the end of their life, it is thought that they need to be better equipped both with physical resources and the emotional resilience to respond to the person’s emotional well-being and understanding/acceptance of their situation. Health and social care staff need to have the skills to be able to facilitate a conversation about end of life and take into consideration relevant cultural and contextual factors (LeRoy et al., 2020; Blank, 2011; Balaban, 2000; Lea et al., 2018b).

Palliative care is ever expanding, and to support the increased clinical scope of roles, further training has been introduced for all clinical professionals (Mathison et al, 2010). The complexity of physical health presentations, including respiratory issues, swallowing difficulties and communication impairments (Gooden et al., 2005). and person-centred approaches to care planning (Parker-Oliver et al., 2005) have increased the requirement for a Speech and Language Therapist to sit within the MDT based on clinical reflection and experience. This is important, as my clinical role as a Speech and Language Therapist working within this field ultimately sparked my interest in this research.

The role of the Speech and Language Therapist in palliative hospice care is relatively new, and therefore the evidence base for their involvement limited (RCLST, 2021). However, it is known that people with palliative needs may often experience communication impairments or difficulties with eating, drinking, and swallowing. A communication impairment can impair a person’s ability to make decisions, impact on social closeness with their family and reduce their overall quality of life (Pollens, 2004; Grayson et al., 2021). The primary role of a Speech and Language Therapist working with TYA would be:

a) Consultation: in relation to communication, cognition, and swallowing function
b) Developing strategies: to support with communication, decision-making, social relationships, and quality of life.

c) Optimising function: to increase quality of life.
d) Support other members of the MDT.

Within the last 20 years, the process of providing information to patients about their treatments to support decision-making has significantly improved (National Cancer Institute, 2018), with easy-read information available, online forums and opportunities to speak to peers.

Palliative services describe providing symptom management, emotional support, and supporting the individual to interpret the oncologist (Back et al., 2014). It is noted that there are significant rewards felt by staff members working within end-of-life care (Dix et al., 2012). These rewards came in the form of feeling like they've 'made a difference', which motivated staff even through periods of great stress (Taylor & Aldridge, 2017). However, along with the reward comes increased stress due to a multitude of factors such as increased complexity of patients care, heightened expectations from patient and family members and the on-going burdens of managing end of life care (Taylor & Aldridge, 2017; Kracen et al., 2020). Within cancer nursing evidence suggests the relationship between work stressors and support provided can lead to burnout (Barnard et al., 2006). Those providing palliative care in general settings experience more burnout than those in specialist palliative care settings; however, the range of burnout amongst health professionals working in palliative care significantly varies (Dijxhoorn et al., 2021).

Mindfulness-based interventions can be used as a psychosocial support in cancer care and are often used to support patients with complex emotions and difficulties in processing their cancer experiences (Rieger et al., 2021). These approaches have been found to have positive impacts on individuals' quality of life (Monti et al., 2006;

Monti et al., 2013; Jang et al., 2016) and can be used to support hidden experiences become seen, heard, and transformed (McNiff, 2013).

If comprehensive and holistic psychosocial interventions are provided to individuals with cancer it has been found that this can reduce the cost of medical services (Bultz & Carlson, 2005; Beyers et al., 2017).

2.5.4 Advance Care Planning

Before HCPs consider advanced care planning, they first need to break the bad news to the individual and their families about their diagnosis and prognosis. Bad news is considered any news that will negatively affect the patients' view of the future, which is challenging for the patient to hear (Buckman, 1992; Cassim et al., 2021). Often cancer as a term can cause fear, uncertainty, and anxiety (Clarke & Everest, 2006). If the person interprets the news negatively it can then lead to a negative impact on the treatment process and their physical health (Hobenu & Naab, 2022; Monden, et al., 2016).

Parker et al. (2001) found from a sample of 351 patients with cancer that the important themes when breaking bad news are: Content (what and how much information), facilitation (setting and context variables) and support (emotional support during the interaction of breaking the news), which is echoed in Munoz-Sastre et al. (2011) who reported the quality of information and emotional supportiveness are the most important factors. In addition, HCPs need to have the right communication skills to communicate effectively and be knowledgeable about the subject matter (Goebel & Medhorn, 2018). Some HCPs use the SPIKES[1] model

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[1] SPIKES model – S, Setting up (environment of discussion), I, Invitation (what do they want to know about the illness), P, Perception (how much do they already know about the disease), K, Knowledge (use simple and understandable terms to describe illness), E, Emotion (express empathy and

to support breaking bad conversations as research indicates that this has a positive impact on patients' acceptance (Von Blanckenburg, 2020; Bai et al., 2019) and having a clear protocol increased confidence and comfort levels for HCP (Ferreira da Silveira et al., 2017). However, challenges with using the SPIKES model include it lacks cultural sensitivity to all countries/cultures (Holmes & Illing, 2021), HCPs can overdo the empathy or have excessive physical contact which makes it appear ingenuine (Matthews et al., 2019), unsympathetic nature of some of the HCP (Brown et al., 2014), HCPs not skilled enough in the use of the protocol (Mostafavian & Shayne, 2018) and younger people have been found to need more attention and different approaches than older people (Marschollek et al., 2019) although this has not always been found to be the case (Nabi et al., 2022). Any decision making should be guided with the aim of maintaining or improving a good quality of life balancing treatment risks/harm with benefits (Engelhardt et al., 2018).

Shared decision-making entails the HCPs explaining treatment options including the benefits and risks, the patient and their care givers explaining their preferences and values (Belanger et al., 2011; Hajizadeh et al., 2016) leading to an optimal decision being made together (Charles et al., 1997; Baik et al., 2019). Shared decision-making is an important part of person-centred care as it is thought to support empowerment of the individual and their families (Baik et al., 2019) and is included within family centred care (Dunst et al., 2007; Kuo et al., 2012). This empowerment may enable them to make informed and optimal decisions for end-of-life care which are rooted in their own attitudes, values, beliefs, and preferences (Baik et al., 2018).

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understanding of patients feelings), S, Strategy and Summary (summarise discussion, agreed strategy/next steps and prognosis) (Meitar & Karnieli-Miller, 2021).

To ensure that end of life care is effective and respectful it is imperative that HCPs understand the patient's wishes, this has also been found to reduce the stress for family members particularly if they need to make those difficult decisions on behalf of their loved one (Detering et al., 2010). In order to understand the person's wishes HCPs, need to engage in talking about end of life as the first step in advanced care planning (Garrett et al., 2008).

Individuals have been found to want to engage in advance care planning, however they will wait for the HCPs to initiate this (Davison, 2006; Heyland et al., 2013; Tobler et al., 2012). Advance care planning is the process of discussing life-sustaining treatments and establishing long-term goals with an individual who is considered terminal, palliative or end of life (Tsai, 2008). Due to the difficulties in predicting progression of diseases it can be important to have these discussions early to ensure maintained quality of life and that this is balanced with prolongation of life treatments (Tsai, 2008).

Liberman et al. (2014) found that 2/3 of parents of children with chronic conditions have never heard of advance care planning. In addition, despite having advance care plans in place, a study in Canada and the US with adults found that there was only 30% agreement between stated wishes and what was documented in their medical records (Heyland et al., 2013; Wenger et al., 2008). Research indicates that there are barriers to HCPs having these conversations which can relate to parental readiness, unrealistic expectations and differences between parent and HCPs understanding of the prognosis (Bogetz et al., 2015; Dyrall, 2012; Edwards et al., 2012). Therefore, to ensure the effectiveness of advance care planning HCPs need to be experienced and skilled in having the right conversations (Ho et al., 2016), including being pro-active in their communication (Basslet et al., 2015). Discussions should include quality of life, benefits/values and hopes/goals (Orkin et al., 2020).

There is limited research on TYAs and advanced care planning, however Obsorn et al. (2019) indicates that TYAs reported the conversations need to include practical issues (wills, advanced care planning, symptom control), emotional or existential concerns (fulfilling life goals/ambitions, memory-making, relationships) and who will support their loved ones after their death. Osborn et al. (2019) also discussed the importance of having the TYA age-appropriate services linking in with palliative care teams to ensure that the TYA is offered bespoke support from knowledgeable HCPs.

2.6 Summary of Literature and Themes

Although a diagnosis of cancer remains rare in TYAs the impact of a diagnosis of their lives and the lives of their loved ones is significant. As outlined above a diagnosis can impact on their physical, emotional, and psychosocial development and their overall quality of life. Whilst services are in place to support TYAs these remain limited and complexities with them providing end of life care remain. In order to support end of life care in the best possible way services need to engage in shared decision-making and advanced care planning, as this supports empowerment of the individual and their families, improves quality of life and reduces stress. It is important to consider the loss and grief experienced by the person themselves who is dying and those that have been left behind, as this is a factor that TYAs have described as imperative for 'dying well'. The literature has given some consideration to the views of young people on their care and what 'dying well' means to them, which include pain management and management of symptoms, presence of loved ones and respecting the will of the patient (Bovero et al., 2019, Kehl, 2006; Yun et al., 2018). Therefore, the aims of this study will enable further exploration of these key themes.

2.7 Background to Method of Data Collection

As the method of data collection is innovative in this clinical area, I have reviewed the background literature supporting this. There are many functions of technology in relation to health care; from information sharing to development of peer networks, and use of social media. Individuals will engage with social media platforms based on their own goals, e.g., information sharing and seeking support, with their use of social media often changing as their illness progresses and changes (Sannon et al., 2019). In addition, there are considerations made within the broader social media ecology (Zhao et al., 2016), and consideration of privacy boundaries (Farnham & Churchill, 2011). Online spaces introduce new and different contexts for interaction with others and these interactions are thought of as more flexible, with people having more control over the way in which they are able to present themselves and their illness (Merolli et al., 2013). Sannon et al.'s (2019) study showed that individuals would choose the social media platform based on what they wanted to achieve. Semi-structured interviews were conducted with 19 people ranging from ages 18 to 55 years. They found that 89% of people shared content via Instagram which was noted to be mainly related to seeking emotional support, and 84% used Facebook mainly to seek information out about their condition and consisted mainly of posts in closed groups (Sannon et al., 2019). Only 16% shared content via YouTube; however, those that did share, they did this as a way of documenting their journey in a journal style, and to provide reminiscence for themselves and those around them (Sannon et al., 2019). It is worth noting that the study was limited to those with chronic conditions and did not have any participants at end of life, in addition, of the

19 participants only 6 fall into the definition of TYA. Networking online has been found to be a critical part of their ability to connect with peers in the same situation (Hokkanen et al., 2004) and social media is their preferred mode for information gathering about their diagnosis (Treadgold & Kuperberg, 2010; Chou et al., 2011; Lea et al., 2018a; Domínguez & Sapiña, 2017).

Therefore, in terms of research, there is a large platform from which to select data from (Pace, 2008). However, the limitations of that are the reliance on the way in which a video is uploaded to YouTube in terms of title, key words and how YouTube itself categorises it (Gehl, 2009). This can make for a challenge for researchers searching using key words (Gibson, 2016), and requires additional manual screening to ensure a comprehensive data set (Sangeorzan et al., 2019). Research in the field of social media has focused on text-based platforms such as Facebook or Twitter, with YouTube remaining relatively understudied (Sangeorzan et al., 2019).

2.7.1 Education and Interventions

Technology can be used to provide patient education and support, alongside their clinical teams (Rabow et al., 2015; Perales et al., 2016). Websites, social media, and applications can assist patients and families with symptom assessment, advanced care planning, and patient/family support (Attai et al., 2015; Batenburg & Das, 2014; Bender et al., 2013; Hong et al., 2012). Skinner et al. (2003) reported that health questions are amongst the most common reasons for searching the internet, with TYAs' lives in a constant intertwine with technology. Significant research has been undertaken within the mental ill-health population, and it was consistently found that people turn to social media platforms to connect and get more information about their health (Birnbaum et al., 2017). More recently, social media has been used as part of organisational media campaigns, e.g., American Blood Centers and the

American Red Cross used Facebook to show people where they could go to give blood (Budaraju, 2019). Facebook, Instagram, Pinterest, and Twitter all have suicide hotline information for those users who have used suicide related search terms on their platforms (Pagoto et al., 2019). Social media platforms have also been working hard to remove ‘fake news’, and have removed misinformation about vaccines (Bickert, 2019) and adverts on antivaccine (YouTube Help, 2019).

Vloggers can share their experience of treatment, and this has been found to reduce stigma associated with diseases such as cancer, HIV, and diabetes (Sangeorzan et al., 2019), and support a level of catharsis for the vlogger (Nardi et al., 2004).

Different stakeholders will generate health-related content and post this on social media platforms, such as YouTube (Lau et al., 2011). In addition, video healthcare can be used to provide care for those not able to travel to specialist facilities (Rabow et al., 2015; Ekeland et al., 2010). Interventions which utilise technology may be very appealing to TYAs, given the amount of time they spend engaging in online activities (Badawy et al., 2016). Smartphone based interventions are being used to support patients to self-manage their symptoms, e.g., pain management (Smith et al., 2015; Limke et al., 2015), with specific cancer applications for TYAs/children in development (Fortier et al., 2016).

2.7.2 Peer Support

Online peer support communities have been set up effectively (Pagoto et al., 2019), and have been found to be not just beneficial from a support perspective, but in allowing individuals to share their experiences (Haldar et al., 2020). These online communities have been formed on nearly all social media platforms, and generally show positive trends in engagement with cancer services, talking about cancer, and accessing peer networks (Attai et al., 2015). Attai et al. (2015) identified that when using Twitter people had an 89% increase in a range of disease knowledge, 66% learnt of trial opportunities, 31% were inspired to increase their advocacy efforts, and 67% had decreased levels of anxiety. Haldar et al. (2020) found that even for those who did not actively contribute, they still experienced benefits from reading peer advice and others' comments (Haldar et al., 2020). 'Health Unlocked' is the largest online social network for health (Health Unlocked, 2021), and they found that there was a significant reduction in accident and emergency hospital visits due to utilising online platforms for information and support (Pagoto et al., 2019).

As TYAs typically spend approximately one-third of their waking day with peers, it is not surprising that they would turn to peers for advice and emotional support (Brown & Klute, 2003), as opposed to health professionals. They choose to use this social media as a space to share their lived experiences about their illness (Syed-Abdul et al., 2013; Gowen et al., 2012); however, little is known about the impact of sharing experiences for those both sharing and observing (Huh et al., 2014). Within mental ill-health, some consider the use of social media to exacerbate their symptoms and increase their dependency (Takahashi et al., 2009), whereas others feel that it creates an intimacy between strangers which can be therapeutic and help to avoid feelings of loneliness (Valentine, 2006; Cornwell & Waite, 2009).

One of the challenges of peer support networks on social media, is that despite growing numbers of people having access to technology in the form of computers or mobile phones, there remains digital deprivation amongst certain groups, such as those with mental ill-health compared to the general population (Black et al., 2013; Ben-Zeev et al., 2013). There is no specific data available for young people with cancer and their access to technology, yet this needs to be considered in terms of the groups of people not represented on social media. Blogs, vlogs, message boards, and specific health related hashtags are used to create online networks for people, e.g., #ayacsm (Katz et al., 2015).

2.7.3 Blogs / Vlogs

People with chronic illness often use social media to integrate their illness into their lives and feel a sense of being ‘normal’ by socialising with others outside of their usual social circles (Liu et al., 2015). They can reframe their illness using humour, e.g., chronic illness memes on Tumblr (Gonzalez-Polledo, 2016) and elicit empathy from others (Gonzalez-Polledo & Tarr, 2016); for both of these studies the focus has been on pain management rather than end of life. In addition, blogs have been evidenced to be therapeutic to those posting them as they are able to share and reflect on their experiences (Ressler et al., 2012). Vlogs in the context of this research refers to blogs created in video form rather than textual (Molyneaux et al., 2008; Maity & Racat, 2018), or a series of videos on a video sharing site (Freeman & Chapman, 2007). The purpose of sharing videos is for self-expression and to share content that people find interesting (Kruitbosch & Nack, 2008).

Pereira et al. (2017) reported that people with cancer who engage in expressive writing can reduce psychological distress and medical side effects, along with reducing depression and increasing quality of life (Craft et al., 2013). The ability to reconstruct a story in a meaningful way can give hope for the future and lead to more positive outcomes for the person writing it (McAdams, 2005). With the emergence of technology, this has expanded to video making (Chou et al., 2011) and videos have been found to promote self-reflection, which can lead to improved coping mechanisms and enhanced social relationships (Pereira et al., 2017; Gardano, 1994; Robb et al., 2014). TYAs writing blogs have been found to feel more empowered and have improved their peer relationships and improved their psychological wellbeing (Boniel-Nissim & Barak, 2013). In addition, Chung & Kim (2008) found that those who write blogs generally have less concern for social judgement, improved peer relationships, good self-expression and enhanced ability for problem solving. TYAs often participate in testimonial videos which aim to share their stories in a creative way (Pereira et al., 2017; Chou et al., 2011; Tosone et al., 2005). With some research indicating that posting videos can create a sense of community for TYAs (Chou et al., 2011; Song et al., 2012).

Most of the research based on blogs as vlogging is still a relatively new phenomena, and therefore literature relating to this is still emerging (Sangeorzan et al., 2019). Marwick (2013) notes that sharing personal information with an audience and documenting everyday life has become normalised (particularly through livestreaming). Often, there is what appears to be a barrage of ‘happy’ and ‘beautiful’ people appearing on social media feeds (Smith et al., 2013b), and this is generally displayed in visual forms (Berryman & Kavka, 2018), with Instagram being significantly associated with ‘lifestyle envy’ (Prickett, 2013). YouTube vloggers often post vlogs that are designed to be inspirational (Berryman & Kavka, 2018). However, as there is an increase in what would have previously been deemed a ‘private interaction’ being made public, there has been more focus on posts that include what are considered ‘negative feelings. Hjorth and Lim (2012) report the increased use of “intimate publics” via social media platforms, which Dobson et al. (2018) defines as digital intimate spaces where public and private intermingle, with the potential for oversharing and unpredictable interactions. Social media platforms globalise the possibility of intimacies between strangers (Valentine, 2006) and allow for relationships to be sustained via ‘electronic intimacy’ (Gibson, 2016). This is often found in vlogs and blogs as the person posting can create a narrative of their life and subscribers can follow this (Carr & Rosengarten, 2021). Gibson et al. (2018) reports that vlogs are often an on-going process of self-disclosure and vloggers actively engage with their subscribers leading to electronic forms of intimacy (Rosen, 2012). It has been reported that the anonymity of the internet allows a more instantaneous intimacy to develop between strangers (Gibson, 2016). Zapatero (2013) conducted a survey of young people in Spain and found that 80% of their online interactions were with strangers; whilst there has not been an updated study to provide further insight into this, many researchers have anecdotally concluded similar findings (Gibson, 2016; Berryman & Kavka, 2018). Due to the visuals present within vlogging, it allows the vlogger to share emotions and develop connections with their 'audience' as it allows for them to emulate face-to-face interactions (including non-verbal communication) (Sangeorzan et al., 2019). Therefore, the research appears to indicate that social media continues to challenge the boundaries of what is considered public and private, and the definitions of these are continually being re-written as digital technology develops.

There can be noticeable tension on social media platforms between "a developed persona that is aligned with the attention economy and a 'bare' face" (Berryman & Kavka, 2018, p86). This is when a person puts on a persona based on what they feel their audience would prefer, therefore purposefully looking a certain way whether that is a true representation of the person or not. There is known to be both ethical and psychological impacts of the pretence of being happy online and the acknowledgement that this is seen as 'fake', and therefore, not desirable to audiences (PewDiePie, 2017). Negative emotions are becoming more commonplace in vlogs, for example, when talking about depression (Dobson et al., 2018), eating disorders (Pereira et al., 2016) and grief or bereavement (Gibson, 2016). This has led to the development of what is known as ‘crying vlogs’, which is a confessional address to the camera of the person’s state of emotion and a description of the causes that have led to them to feel this way (Berryman & Kavka, 2018); this may be described a tight focused narrative. These are not to be mistaken with ‘anxiety vlogs’ as these usually have the desired outcome of becoming an educational tool for people in which a person outlines their individual struggles and coping strategies for others to learn from (Berryman & Kavka, 2018).

Research indicates that young people seek self-worth through the ability to share and organise their emotions into a narrative which can be described as ‘self-transformational’ which is then posted to a social media platform (Silva, 2013). This is because they use the experience of creating the social media post as a reflective and therapeutic tool. With some using blogs and vlogs as a diary or way to communicate and connect socially with others (Raun, 2012).

2.8 Summary of the Chapter

A review of recommendations for TYAs and cancer care posited by Pearce (2009), highlights 4 central themes that would be considered important, these are also similar to the themes reflected within the literature review. The central themes are place of care, the multi-disciplinary team, improving clinical outcomes, and psychosocial and supportive care. These are reflected in the literature and have been found to be important to TYAs. The themes are further outlined in the table below.

These themes are echoed in the more recent publication of the ‘Top Ten research priorities for TYAs’ (Table 2.3) (Aldiss et al., 2019). The ideal place of care for TYAs was reported to be somewhere where they could feel like a ‘normal teenager’ and talk about everyday things, rather than the focus always being on the cancer (Kaluarachchi et al., 2020). The importance of recognising patients’ views and experiences in determining future care and influencing policy has been noted (Marris et al., 2011).

Table 2.4: TYA and cancer care themes (Pearce, 2009)

Place of care	With the recommendation that 16-18-year-olds should be offered a principal treatment centre for TYA, and those aged 18 years and over should be offered the principal treatment centre or an adult treatment centre.
Multi-disciplinary Team (MDT)	Is vital for providing support for all elements of treatment required.
Improving Clinical Outcomes	Specifically addressing the diagnostic delays within TYAs.
Psychosocial and supportive care	looking at supporting development of normative tasks for the TYA population to support with overall coping mechanisms.

In summary, TYAs with cancer are more likely to have a ‘worse’ quality of life compared to the general population, regardless of demographic factors (Geue et al., 2014; Smith et al., 2013a). Within HRQoL measures, TYAs report both positive and negative aspects of their care and information received (Smith et al., 2013b; Zebrack et al., 2014; Dyson et al., 2012; Quinn et al., 2015; Zebrack et al., 2010). TYAs report many anxieties and fears relating to their cancer diagnosis and the perceived stigma associated with cancer (Bellizzi et al., 2012; Casillas et al., 2010); this intensifies for those at end of life (Quinn et al., 2015; Cohen-Gogo et al., 2011). Overall, the issues they face are similar to other age groups, yet they appear more pronounced for TYAs (Sansom-Daly & Wakefield, 2013; Sodergren et al., 2018a). Within my research, I consider quality of life aligned to the psychological perspective in which quality of life is measured on the individual's appraisal of their own life, and their ability to fulfil the goals which they set themselves (Eiser & Morse, 2001).

Therefore, the literature review above and wider literature included supports understanding of the literature review question 'to explore the experiences of TYAs with cancer'.

Chapter 3 Methodology

3.1 Introduction

This is a narrative study focusing on the life experiences of Teenagers and Young Adults (TYAs) who have a diagnosis of cancer and are at the end of their life. In this chapter I will outline the rationale for the study and the overall research aims. I will discuss the theoretical framework which underpins the study and the external influences that have informed the design and implementation of this project. The narrative analysis will be theoretically discussed in preparation for Chapter 4 in which this is applied.

The literature review indicates that whilst there appears to be a wealth of information starting to form in relation to TYAs with cancer; this remains an under-researched area. The cognitive and psychosocial development of the TYA population is unique and complex to understand with increased variability between individuals. This makes it difficult to develop services that are considered appropriate for TYAs, particularly for those with cancer who are considered palliative as this remains rare. Based on this, my study will focus on TYAs at the end of their life telling their stories online, and I will use this to draw some conclusions in order to meet my research aims. The first aim is to explore online stories of young people with cancer, which will be achieved by reviewing vlogs that they have posted. The data from those vlogs will inform the other aims of exploring the views of young people about palliative care and what they feel constitutes a positive experience whilst dying.

3.2 Epistemological Position

Epistemology refers to “what we regard as knowledge or evidence of things in the social world” (Mason, 2002, p.16), essentially your theory of knowledge and how social phenomena is known (Mason, 2018). There is a broad range of epistemological frameworks that researchers can consider (O’Reilly & Kiyimba, 2015). Qualitative methodologies span a variety of epistemological positions (Crotty, 1998), in which philosophically my stance stands within a social constructionist paradigm. Social constructionism is a collection of a range of approaches (Burr, 2015).

I interpret social constructionism as meaning generated by our culture and the development of phenomena in relation to social contexts, therefore providing sociological constructs (Fuller, 2010). It is the meanings that people bring to their life experience and identities that we construct for ourselves (Stephens & Breheny, 2013). By telling stories individuals are reporting how something is seen and reacted to; therefore, meaningfully constructed. The construction of this is dependent on the community, and to a certain extent the culture; even if the story is their own, the voice of the community will be apparent in what is said (Crotty, 1998). Individuals devise stories around themes and content that they deem appropriate for the listener (Riessman, 1993). Human experience is not predetermined but is mediated through linguistic, cultural, and historical constructs (O’Reilly & Kiyimba, 2015).

Within socially constructed realities, there needs to be an acknowledgement that these are sustained by observations of social rules that are conducted by social interactions, therefore providing a shared meaning to these experiences (Greenwood & Greenwood, 1994). Individuals live their lives through the ever-changing narratives they develop alongside others through conversation (McNamee & Gergen, 1992). A socially constructed reality is seen as on-going and dynamic, which is reproduced by people acting on their interpretations and knowledge of the world (Fuller, 2010).

Gergen (1973) argued that ‘all knowledge is historically and culturally specific’ and that knowledge is sustained by a social process (Gergen, 2009). The interpretation of actions and events is dependent on our culture, and from this, our perceived thoughts and emotions can be socially constructed (Harré, 1986; Fuller, 2010). The meaning behind our actions comes from our construction of the world we live in, and the engagement of our experiences within that social world (Crotty, 1998; Lock & Strong, 2010). To have an informed view we also need an understanding of psychology and society, in which we must seek to discover the social, political, and economic realms to discover (Burr, 2003), This process of ‘sensemaking’ allows us to expand our world and support decision-making (Galbin, 2021).

When identifying ‘social problems’, they are thought about in terms of how they are perceived and managed by within cultures and historically significant constituencies (Weinberg, 2015), and there is a reliance on people in ‘authoritative’ positions to construct events (Chermak, 1997). For example, reporters will rely on political and criminal justice officials as sources for their narratives (Chermak, 1997). Social researchers examine the social processes through which they are constituted as public rather than private problems, which therefore may indicate that the remedies are socially produced too (Weinberg, 2015). The social world created within the media, and more recently social media, has been known to accelerate understandings and shape perceptions of other people’s social and political attitudes (Standlee, 2019); and in turn is used to create social constructs.

Within health care and particularly mental health services, treatments often are not objective, but constructions created by social, political, and practical considerations (Page et al., 2013; Lester & O'Reilly, 2015; Georgaca, 2014; Walker, 2006). Analysis of social interactions can help us to understand the meaning of human activity (Lock

& Strong, 2010), and in the case of my research is allowing access to participants who are ‘hard to reach’.

Gergen (2001) identified the importance of recognising the cultural and historical context of the research, and any political or ideological vested interests within the research should be acknowledged. In order to counterbalance, these suggestions of reflectiveness within the social constructionist approach are considered best practice. It has been argued that illnesses are socially constructed, and this is based on how people understand and learn to live with their illness (Conrad & Barker, 2010). Weinberg (2015) reports that constructionist studies promote ways of thinking about improvements to the world we live in; and whilst I acknowledge the growth and development of services for TYAs occurring over the last ten years, there is always worth in further reflection and improvement.

As a Speech and Language Therapist, I analyse interactions between individuals, the way in which they communicate, and the impact that I have on that interaction. When people interact with each other they form a political, ethical, and social world (Shotter, 2005). We have some shared expectations and some different expectations based on life experiences and our own individual social constructs that our experiences have led us to create. A person’s reaction and responses in situations are interesting to examine since they appear spontaneous but are developed, often subconsciously, from our underlying social constructs and social practices (Payne, 2020). Social constructs are developed over time through interactions, and life events can happen over a lifespan that will interfere with these, for example the social construct of family identities can change over time (Leeds-Hurwitz et al., 2006); events such as illness can significantly impact on this. Being able to communicate effectively is for most people a critical part of their identity and helps determine the role within the family and their social networks. Language is also really important to help people create their reality (Walker, 2006). As a clinician, I aim to improve or maintain communicative skills in individuals with impairments; this plays a huge role in redefining identities and social constructs (Shadden & Agan, 2004). An example of a common social construct is Autism, which is seen as a ‘devastating neurodevelopmental disorder’ (Goodley & Runswick-Cole, 2012, p58), Townsend et al., (2018) found that this social construct is embedded in practice and in conjunction with lack of experience, manifested in a ‘fear of the unknown’ for coaches working with Autistic people. In clinical practice I work towards raising awareness of and redefining people’s social constructs of those with an illness or disability to enable improved social interaction and relationships (RCSLT, 2021b).

A ‘networked narrative’ is one in which individuals will come together to construct shared stories (Georgakopoulou, 2007), and as part of this interaction will co-construct social identities (Page et al., 2013). These ‘networked narratives’ often occur in social media and online and are not limited to conversational exchanges but can also include semi-automated interactions such as tagging, liking, sharing videos or links, and enacting an identity within a community, e.g., following a TV show fan page (Page et al., 2013). Page et al., (2013) found that Facebook was a place in which ‘networked narratives’ flourished in the form of status updates. The updates to the functionality of Facebook such as tagging other people in updates, linking information across multiple online platforms, adding multimodal resources, e.g., videos and photos and how posts can be shared, e.g., public, friends only, and private, has led to examples of more complex narratives and interactions.

Therefore, with social constructionism narratives are used to share individuals’ views of the world and their experiences but these are founded within the social constructs and norms that exist in their cultures. The social constructs are also influenced by the responses that they receive from others when sharing this narrative, which in an online forum (e.g., Facebook, YouTube) comes in the form of comments, likes and sharing the post.

3.3 Choice of Methodology

I have chosen a qualitative research paradigm as it allows for a detailed analysis of people's stories, social interactions, and links to social constructionism. Denscombe (2014) outlines the five main approaches that are used within qualitative analysis, which are: content analysis, discourse analysis, conversation analysis and narrative analysis. The main forms of qualitative analysis used to analyse stories are thematic analysis, conversational analysis, content analysis, and narrative analysis (Robson, 2011).

For this research I will use narrative analysis as the main form of analysis; however, I will take influences from conversational analysis. Conversational analysis focuses on how things get done through the language used (Denscombe, 2014.), with a focus on the displayed meaning rather than the implied meaning. This is in keeping with social constructionism as ontological and epistemological approaches. As a Speech and Language Therapist, I have a keen interest in language analysis and therefore naturally elements of analysing the language used will come into my overall data analysis. However, narrative analysis focuses on the 'how' and 'why' things are the way they are and therefore goes beyond the surface unlike other approaches such as thematic analysis (Riessman, 2008). It looks for implied meanings within the data to find symbolic significance within the story (Denscombe, 2014). Narratives are socially constructed (Joyce, 2015) and therefore this methodology falls in line with the underlying epistemology of social constructionism.

3.3.1 Introduction to Narrative Analysis

Narrative analysis itself is not thought of as a method, but rather a theoretical approach to interpreting ‘people’s talk’ (Stephens & Breheny, 2013). Narratives can be viewed as a set of social constructs that represent particular locations and environments, and are determined or moulded by specific political, cultural, or social experiences, places and events (Carey, 2012). Narrative is a rendition of how life is perceived by the self and others rather than something that is objective (Webster & Mertova, 2007).

Some researchers make a distinction between ‘narrative’ and ‘story’; however, for the purpose of this research, these terms will be used interchangeably in line with other narrative researchers (Ferrari et al., 2010; Riessman, 2008). This is to allow for a wider literature review and remain in line with other researchers.

Narratives or telling stories are a way in which individuals share their experience of an event in relation to how it was seen, felt, and reacted to; this is ‘meaningfully constructed, within a given community’ (Crotty, 1998). Storytelling captures personal experiences, and the context in which these are set impacts the understanding of the story (Petty, 2017). The connections between stories and narrative can be viewed theoretically as social constructs. Bruner (1991) argues that story making is vital in creating an understanding of the world. Gergen (1989) reported that the primary motive for interaction is to gain a voice, and that we tell stories of our lives, and these become our autobiographical narratives (Bruner, 2004; Munhall, 2012).

Narratives are representations of how people want themselves to be perceived and they allow a reflection/analysis from the person on a particular event; often referred to as ‘storied accounts’ or ‘interpretive devices’ (Lawler, 2002). Narrative analysis describes and analyses the phenomena of development and transition in people's lives (Josselson & Lieblich, 1993). Narrative is not an objective reconstruction of life but a rendition of how life is perceived (Webster & Mertova, 2007).

It has been found that in an attempt to represent ourselves in the ways we believe to be positive, we may present the narrative in a certain way, and the acceptance of this narrative is completely dependent on the willingness of the others featured within the narrative (Burr, 2003). Narrative analysis will be used as it serves as a basis for better understanding the experiences of individuals. The individual seeks to construct an identity which refers to the uniqueness of their circumstances (Smith & Sparkes, 2008). The narratives themselves are previous life stories and the cumulative situations of their lived autobiography (Barling et al., 2014; Davies & Harre, 1990). Narrative analysis allows researchers to tie together individual experiences and use them to create a context to understand meaning (McCance et al., 2001). It also goes beyond individuals as it examines the cultural narratives that shape individuals' lives.

3.3.2 Narrative in the Context of Social Media

The ability to tell stories on digital platforms has led to developments in concepts of narrative theory, including what constitutes a narrative itself (Marie-Laure, 2006). Initially, narratives in a digital space derived from video gaming or role-playing situations, but as technological advances were made the 21st century gave rise to stories of personal experience being shared in blogs, discussion forums, and across social networking sites (Page, 2010).

The rise of the internet and the post-millennial social media revolution has transformed the social experience (Chambers, 2001; Davis, 2013), particularly for young people. Social media in relation to academic research has already been used for projects such as examining Facebook updates for narrative structure (Page, 2010), and narratively organised online gaming environments (Ryan, 2004). Page (2010) viewed Facebook status updates as an ongoing narrative which documents the user's life experiences; and Georgakopoulou's (2007) work is interested in the immediacy in which the story is told, as Facebook updates are often done in the moment of the event and as it is unfolding. This significantly differs from traditional narrative analysis where the narrative is often in past tense and requires a more complex literary analysis (Page, 2010).

3.3.3. Purpose of Narrative

The focus of narrative analysis is the people who tell the stories, and the stories themselves are merely a way to better understand them (Hollway & Jefferson, 2000). Narrative analysis will be used as it serves as a basis for better understanding the experiences of individuals. The field of study relating to illness has increased in its complexity and therefore lends itself to methods of narrative and discursive inquiry (Hyden & Brockmeier, 2008). This is because narrative methods have the ability to look beyond quantitative data and analyse the deeper meanings behind how people behave, feel, and respond to illness. Within health and social care, there has been an increasing interest in the use of narratives, this arises from recognising the importance and role stories have in health, as ways through which we understand illness set within the context of our lives (Green & Thorogood, 2014).

Within the field of palliative care, narrative analysis has been a powerful tool to gain access to a world of participants (Holloway & Wheeler, 1996), and holds specific potentials to unfold the sometimes unconscious and often hard to express thoughts, and experiences, and concerns of patients and their informal caregivers towards the end of life (Müller-Mundt et al., 2013). Narratives have been greatly influential in developing the hospice movement (Gunaratnam & Oliviere, 2009), and narratives have been a good method for research in the palliative care field (Bury, 2001). Within the 21st century, there has been a plethora of television documentaries and films which tell stories and provide narratives on end-of-life care and the person experiencing it (Hakola, 2021). Such narratives have then gone on to influence end of life care as they have raised the profile of this field within mainstream media and services. Frank (2013) reported that stories of suffering are known to facilitate healing, as the person shares their lived experience (Barling et al., 2012).

Narratives can often be a way in which people shape and give voice to their suffering (Kleinman, 1988). Brockneier (2008) notes that this allows the sufferer to cope with the intrusion that having an illness can bring, and it does this by situating the illness in the context of on-going biographical narratives. Chronic illness can be viewed as a ‘biological disruption’ to usual lives (Green & Thorogood, 2014); and therefore, narrative analysis for end-of-life care is able to contextualise this experience within a coherent frame. Hydén (1997) reported that illness narratives can be used to understand illness experience and social/cultural underpinnings of those experiences. Hydén (1997) defines there to be multiple functions of illness narratives, including construction of the illness experience, re-construction of the life history, making illness understandable, and collectivising the illness experience.

Frank (2013) states that stories can be used to repair the damage that an illness has done to the sense of self, and to inform others of what is happening in their illness. It does this by giving a public voice to a private experience and situating the illness in the context of the person’s whole life (Frank, 1994), which when applying this principle to my research, supports the purpose of the individual posting the vlogs.

In addition, it can be seen to bring to the forefront issues that may have been neglected in more traditional forms of research (Webster & Mertova, 2007). Bingley et al. (2008) highlighted the importance of narratives to support improving our understanding of an individual's needs but also to further inform and shape policy development and improved practice. Therefore, in essence, the researcher is seeking to understand the ways in which the participants experience, perceive, and feel about their life experiences, which then will be evaluated in line with the research aims.

This study aims to use stories to allow researchers and those reading it to reflect on the narratives and develop ideas to support action for progressive social change (Riessman, 2008). It allows us as researchers to understand what the experience is like for the people experiencing it (Webster & Mertova, 2007). People in late adolescence and young adulthood often put their lives together in stories (McAdams, 2005) as this helps them develop their sense of self.

3.3.4 Narrative and Illness

It has been reported that research has increasingly sought the views of children and TYAs (Weller, 2012; Balen et al., 2006). When taking their perspectives in research into account and 'giving them voice', positive themes such as empowerment have arisen from the research (Gibson, 2014; Gibson et al., 2010), with research using adult proxies coming under increasing criticism (Gibson, 2014; Gibson et al., 2010). To enable children and TYAs to participate in research and invest in them expressing themselves methodologies to facilitate this have been developed (Weller, 2012) which have included creative approaches to research (Weller, 2012).

Bingley et al. (2008) reports that there has been a significant increase in narrative accounts of illness. The increase in narrative accounts has not only been found in academia, but also in magazines, television, radio, and the internet. Hydén (2008) states that illness narratives can be used to understand the illness experience, but also the social and cultural underpinnings of illness.

People have wanted to share their illness journeys and narratives for decades and the media has given them a way to do this. Newspapers and magazines articles that document individual's illness narratives, such as Hosie (2016), who writes in the Independent a summary of Magill's (2016) blog 'Terminally Fabulous' in which she talks about "the good, the bad and the ugly side of all things cancer". Vlogs have been used in other clinical areas, such as patients post stroke wanting to have their stories heard and sharing their rehabilitation experience with others (Chen et al., 2018).

The internet has allowed for anyone to be able to share their experiences. Anna Swabey (2016) posted a blog and vlog that documented her brain tumour experience from diagnosis to end of life. She wanted to share this with people as a way of documenting her story, but also raising money for a brain tumour research campaign.

3.3.5 Types of Narrative

It is often thought that 'narrative' is an umbrella term within which there are several types of narrative analysis. These are often referred to as genres or typologies. It can be complex to clarify an exact definition of each genre, and there is often considerable overlap between genres (Van De Mieroop, 2020). From a constructionist perspective it is considered that storytellers/narrators continuously creatively construct and negotiate narrative genres. Therefore, the options for genres can be considered endless. So, genres in this sense are thought of as an analytical reference point (Van De Mieroop, 2020). Some of the genres include:

- Thematic narrative analysis
- Rhetorical narrative analysis
- Structural narrative analysis
- Interactional narrative analysis
- Personal narrative analysis
- Visual narrative analysis
- Performance narrative analysis
- Dialogical narrative analysis

I will outline these genres in more detail below, with a specific focus on those I have chosen to support the analysis of my data.

Thematic narrative analysis

The focus is on the content within the whole story and the themes that surface within this (Smith, 2016), which will be further explored below.

Rhetorical narrative analysis

Identifying what oppositions and enthymemes are in stories (Smith, 2016).

Structural narrative analysis

The focus is on the 'telling' of the stories and how they are put together (Smith, 2016), looking at narratives being understood through discourse and structure. This includes examining linguistic structures (Bold, 2012; Labov & Waletzky, 1997).

The main critique of this approach is that it is an inflexible tool that is difficult to apply to any narrative that does not comply with the outlined structure (Bold, 2012). It also assumes temporality of narratives, which does not always fit with experience (Ochs & Capps, 2009). It takes the context into account in a limited way and focuses more on the referential features of the narrative. Within the context of this research, the context of the narrative is equally as important as it allows insight into the intention behind sharing the story, and the expectations placed on the viewer of the story as part of the data analysis. This method is also difficult to apply to narratives that are not whole, by which I mean the nature of vlogs and interviews means that the person may not report a story in its entirety, or they may segment their stories across several vlogs.

Interactional narrative analysis

The focus here is how stories are constructed through interactions, either those that occur within day-to-day life or within a researcher-created context (Smith, 2016). The narrative is treated as an event and there are underlying assumptions made about the purpose of the narrative.

Personal narrative analysis

This focuses on the evolving life stories of individuals (Linde, 1993). This includes personal opinions, which can be built often from contradictory and fragmented experiences (Wetherell, 2005). Personal narratives are usually organised around a particular event or consequential events, and therefore researchers should work to maintain the narrative as a whole when they conduct their analysis (Riessman, 1993). This is not a search for any truths but an acknowledgement of a personal experience (Bochner, 2001).

Visual narrative analysis

This is based on images, including how and when they were created and who created it. This also looks at individuals’ responses to the images (Smith, 2016).

Performance narrative analysis

This incorporates elements of structural and thematic analysis (Riessman, 2008), and considers how talk is dialogically produced and performed within the context of the narrative. This includes consideration of the setting of the narrative, the influence of the researcher, the social circumstances of the narrative, and the overall interpretation of the narrative. In order to understand these elements, the researcher needs to ask themselves; who is the narrative’s audience, and when, why and for what purpose have they shared the narrative? The narrator is thought to give a ‘performance’ of personal experience (Goffman, 1981) with an attempt to influence the audience in some way (Cortazzi, 1993). The narrative is designed to trigger a reaction and evaluation from the audience (Cortazzi, 1993). Therefore, the narrative is treated as a performance (Riessman, 2008), and when we perform, we show our identities. Mishler’s (1995) framework for understanding these different approaches is based on the principle that there are three different functions of language: meaning, structure, and interactional context. Firstly, the focus is on the content of the narrative and the actual events and experiences that are recounted by the teller. Secondly, the narrative’s structure and the way the story is constructed by the teller. Thirdly, the narrative’s performance and the interactional and institutional context of how the narratives is produced by the teller.

For performance narrative, we must also consider the role of the audience; a story is told with the expectation of a response (Cortazzi, 1993). The narrator performs using gestures, facial expression, body position and intonation patterns/emphasis to draw in the audience (Cortazzi, 1993). Feedback is also vital to the narrator, as without an audience, there is no performance (Goffman, 1981). Some would consider the researcher to not constitute an audience (Cortazzi, 1993); however, this research does not solely rely on the researcher. For vlogs, the audience is considered the followers of the YouTube channel or the people who watch the vlog and they have opportunities to make comments on the post (Maity & Racat, 2018). It is thought that the narrative features of the vlog impact on the likelihood of supportive and positive comments from the audience (Huh et al., 2014).

Boenisch-Brednich (2002) outline that key narratives arise as a result of the narrator re-telling them, which allows for them to become well-structured and more polished. In line with this research, it is important to consider that the vlogs may have been filmed multiple times, with the version that has been posted being polished and perhaps even edited.

Dialogical narrative analysis

The focus on dialogical narrative analysis is what is told in the story, how it is told (Gubrium, 2006), and what happens as a result of the story being told (Smith, 2016). This is the narrative I have chosen to use for this study. Stories are told within dialogues and in response to others (whether physically present or imagined), and within this dialogue the teller anticipates future responses which shape their narrative (Frank, 2012). Both Frank (2010) and Riessman (2008) discuss the performative nature of stories, which is used as a way of communicating the story to the audience and shape the story in anticipation of the audience's response. Specific narratives are designed for particular audiences, and this is demonstrated through the chosen context of that narrative (Riessman, 2008).

Dialogical narrative analysis “understands stories as artful representations of lives; stories reshape the past and imaginatively project the future” (Frank, 2012:33). According to Frank dialogical narrative analysis asks four fundamental questions.

1	What multiple voices can be heard in any single speaker’s voice; how do these voices merge, and when do they contest each other?
2	What makes stories distinct from other forms of narrative; what count as a story, and what does not?
3	Why is someone choosing to tell a story, among other expressive possibilities? What particular capacities of stories does the storyteller seek to utilize?
4	What stakes does the storyteller have riding on telling this story, at this time to these listeners?

Table 3: Dialogical Narrative Analysis Frank (2012:33).

Question 1: Dialogical narrative analysis requires the researcher to hold a healthy tension between the dialogue and the analysis (Frank, 2012). Bakhtin (1984) recognises that any individual voice is a dialogue between voices, as “two voices is the minimum for life” (Bakhtin, 1984:252) and therefore dialogical narrative analysis is interested in hearing how multiple voices find expression within any single voice (Frank, 2012). Stories whilst told by a storyteller, consist of fragments of stories from others or previous stories which are arranged into the narrative they present with.

Bakhtin (1984) uses two conceptual terms to describe this: polyphony and heteroglossia.

For illness narratives polyphonic refers to a narrative being made up of voices such as medical professionals with explanations of the disease along with treatment effects, loved ones and friends describing their hope and expectations and their ‘ill’ peers who they may meet in waiting rooms, support groups or online forums (Frank, 1995; Frank, 2004; Frank, 2012). For illness narratives heteroglossia is when people speak in different codes based on appropriacy for a given situation, e.g., codes of professional jargon, codes of emotional expression, codes of reflecting expectations of plot progression (Frank, 1995; Frank, 2004; Frank, 2012).

Question 2: The narrative analyst has the privilege of hearing multiple stories from multiple tellers, gathering all the different voices together and when they are heard collectively this gives them a more evocative force (Frank,1995; Frank, 2012). This enables voices to be heard alongside other voices that have experienced something similar, and this collectively shapes the dialogue.

Question 3: We live in a world where stories are part of everything that we do and to tell these stories is part of our nature as human beings. Humans need to tell stories to represent their experiences, and without telling their stories their experiences become inchoate (Frank, 2000). Humans develop part of their sense of selfhood by the stories that they tell and those told about people like them (Nelson, 2001).

Question 4: Stories are told and re-told to allow people to revise their self-understanding and therefore on some level there is no ending. However, for analysts to be able to draw conclusions and produce reports the stories need to have an ending from a practical perspective (Frank, 2012). What is interesting is that for stories told in videos and shared online there is a reduced capacity for the storyteller to re-tell the story and to revise it to support their self-development. Therefore, unlike traditional storytelling the use of posting online challenges this concept.

The summary of dialogical narrative analysis does not aim to summarise findings but instead increase “people’s possibilities for hearing themselves and others” (Frank, 2012:37) and people’s responsibility for what they have heard and how they might respond.

Dialogical narrative analysis involves consideration of ‘who tells the story to whom?’, which in the case of analysing online vlogs includes how the story is framed to the intended audience. Analysis considers ‘how does the story teach people who they are.’ (Frank, 2012:45), which includes narrative identity (Bruner, 1986; Frank, 2010). And finally, consideration for what the storyteller has riding on telling this story to these listeners. In order to structure narrative analyses Frank (1995) suggests there are three core narratives that exist. Restitution narratives have a plot consisting of someone getting unwell, they are treated and eventually they get better. Within a chaos narrative a person presents with multiple problems (not usually limited to their illness), one bad thing has led to another and “life is collapsing around that person” (Frank, 2012:47). Quest narratives are based on a journey metaphor in which the main character experiences obstacles and gains wisdom for overcoming these.

Chosen Narrative Approach

The pressure is on the researcher to analyse the data in such a way that it gives meaning to the participants data and stories (McCance et al., 2001). Therefore, the chosen methodology was a combination of dialogical narrative analysis and dialogical performance analysis. I have outlined the initial analysis process in which reviews of each narrative were initially conducted to support the theory of analysis being at its best when the stories are considered whole. I have then used Franks (2010) approach of quest narratives as an interpretative technique to support the process of structuring the individual analysis of the narrative data. The analysis was then concluded with a cross-narrative analysis in which recurrent themes within the individuals' narrative analysis are further discussed.

Within this research, I will use a combination of the dialogical narrative analysis and dialogical performance narrative to fully understand the purpose and meaning of the narratives. This is supported by my clinical experience in linguistics and social communication, which will enhance the analysis when using these approaches. There will be little analysis on the structure of the narrative, but the focus will be on the content, meaning and performance of the narrative. There will be an acknowledgement that narratives when re-told follow a tidier version than how they occurred in real life; this is usually because the narrator has had the opportunity to reflect on it and re-tell it in a more logical way to enhance the meaning and purpose (Sikes, 2000). In addition, narratives usually involve interaction with the person listening to the story; however, the vlogs analysed are "self-narratives" as there is no input from the listener at the time of the story being told (the comments on the vlogs made after it has been posted will not be analysed within this research).

3.4 Positionality

Within the field of end-of-life care Speech and Language Therapy involvement in care is a relatively new field and the role is evolving (RCSLT, 2024). Kelly et al., 2016) reports an expansion in the provision of assessment and intervention for Speech and Language Therapists working in end-of-life care. However, this has primarily focused on Dysphagia management and communication strategies rather than considering the role within supporting relationships for people. My clinical role has focused on listening to people's stories and experiences, supporting them to think about what is important to them and then developing bespoke interventions to support them to achieve their goals. This has included supporting a TYA with technology for dictation so that he can continue to post Facebook status updates even after he had lost his eyesight, making a video of treasured memories and experiences as a legacy and pre-recording statements so that someone could keep talking to their dog even after they had lost their voice. These goals are focused on maintaining relationships, which we know is one of the key contributing factors in quality of life. These goals are developed through listening to people's stories and giving them the time to think about what is really important to them. This inspired me to consider researching this clinical area so that I could drive the development in this clinical field and make a difference not only to my patients but to others' patients and the profession.

The area of End-of-Life care and the role of Speech and Language Therapy is under researched, has no specific guidance to support clinicians in their role and therefore is not always included in services clinical offer to those at end-of-life. I see my role as promoting the importance and value of these types of clinical interventions and developing evidence to support the role of Speech and Language Therapy in this clinical field. As part of this research and my role on the Professional Practice and Policy Committee for the Royal College of Speech and Language Therapists I am supporting to develop further guidance, toolkits and training to increase the knowledge of the potential role of Speech and Language Therapy in End-of-Life Care.

3.5 Summary of Chapter

In this chapter I have explored social constructionism and narrative analysis. Individuals will tell stories about their lives and the content of these is meaningfully constructed based on their experiences and factors such as community and culture. The social constructs develop over time and are influenced by events that occur in individuals' lives. As a Speech and Language Therapist understanding communication and people's experiences is vital to support them to develop their identities and social constructs following a change in their lives, e.g., a diagnosis of cancer. A narrative is a story told of how the person perceives their life and this is made up of social constructs. Illness narratives are used for individuals to describe their illness and share with others what they are experiencing and feeling. Using narrative analysis supports us to understand more about people's experiences and there are many ways to conduct narrative analysis. For this study I have chosen to use dialogical narrative analysis to explore the vlogs. The performance of individuals telling their story and the way the individual perceives the audience's reaction influencing their delivery provides an enhanced insight into their experiences.

Chapter 4 Methods

4.1 Introduction

The previous chapter sets out the methodological considerations for this research project and outlined the analytical approach as a combination of dialogical narrative analysis and performance analysis set within the epistemology of social constructionism. This chapter sets out the way in which the research project was achieved, outlining the method of data collection, the sample, inclusion/exclusion criteria and transcription. A detailed description of internet mediated research is included, along with exploration of the ethical challenges, consent and managing reflexivity.

For individuals with chronic illness and those approaching end of life they often experience symptoms as a direct or indirect consequence of their illness or treatment. These may include pain, breathlessness, nausea/vomiting, fatigue, and impacts (Henson et al., 2020) and also refer to emotional wellbeing (Davis et al., 2017) These can lead to acute hospital admissions (Henson et al., 2020), inability to carry out activities of daily living such as bathing and dressing (Lage et al., 2020) and these can influence their ability to cope (Davis et al., 2017). These symptoms and the burdens associated with them are likely to influence an individual's ability to record and post vlogs, which may mean that they are short in length, unpredictably posted and often unedited.

However, a story must have a purpose and engage the listener, whether to explain oneself, encourage others to join a cause or to entertain (Holstein & Gubrium, 2012; Frank 2012). The format of this story can be in the form of conversation or written memoir, blog, or vlog. A good narrative requires an accurate representation and evocation of what happened (or is happening)(Goodall Jr, 2018). Page (2018) comments that shared stories are a form of interaction, mediate, and are mediated. Stories mediate between the people who “produce, consume and reproduce them” (p3). Shared stories are mediated by technologies like YouTube in the context of production and reception. “Mediated discourse as a form of analysis moves from examining concrete interactions to consider the constitutive role that these interactions might have in their social and cultural context. Shared stories move from the detailed analysis of a particular textual mediated forms of shared stories to question what these stories do and how they are mediated by their various socio-cultural contexts” (p3). Page (2018) draws on human agency and the social implications of the shared story. Therefore, the length of the vlog becomes of secondary importance. For vlogs even of a short nature, they include the main elements that make up a story (the ‘how’ and the ‘why’ and therefore have meaning and value (Georgakopolou, 2011). The length of the vlog does not diminish the significance or story that the narrative is intending to deliver to the listener.

Self-stories are a recognisable part of popular culture (Frank, 2013), and are thought to be part of the act of reclaiming or ‘finding one’s voice’ (Frank, 2013, p.71). A vlog unlike written blogs provides a personal and immersive experience for viewers as they enable them to see and hear the vlogger, their environment and make comments. Vlogs on YouTube vary in length from a minute to 10 minutes upto over an hour, however vlogging ‘how to guides’ indicate that a vlog of 1-3 minutes is the ideal length. This is because they take less time to make and engage people more as they are within their maximum attention span (which is approx. 76 seconds in young adults, Simon et al., 2023). TYAs communicate and interact with each other electronically through instant messaging and social network sites. This includes written messages, sounds bites/ voice notes and videos. This can be seen as a more accepted, mediated cultural frame, in which stories are delivered and received for Generation z and will continue to advance for Generation Alpha. Therefore, as this is the main mode of communication and interaction for young people to share their stories and experiences and if this is how they are presenting themselves then as researchers we should be developing methodological approaches to better capture ad analyse narrative and story creation.

4.2 Method of Data Collection

The social media platform ‘YouTube’ was used to identify appropriate vlogs matching the participant criteria. YouTube is a search engine similar to Google; however, it is limited to the search terms that you use and will not necessarily search for similar vlogs/videos. The way in which vlogs/videos are saved by the person uploading them will significantly impact the way in which they are accessed, as key words need to be in the title of the vlog/video for it to come up in a search and they need to have made the vlog/video publicly available. The search terms used were:

- Cancer / End of life / Dying / Palliative
- UK / England
- Teenager / Adolescent / TYA / Young Person
- Narrative / Story / Life

These search terms were used in a variety of combinations with the aim of finding the most appropriate vlogs to use as data. If the vlog is part of a series, I have considered whether to analyse the series of vlogs to ensure adequate analysis of the data can be achieved or chosen to analyse a particular vlog. The evidence supporting this decision making is included in the thesis.

Once a vlog had been identified as meeting the eligibility criteria, I attempted to ascertain whether the person in the vlog was still alive, in line with the ethical approval documentation. If the person was found to be alive, they were to be contacted using a specific format via email or posting a comment on their vlog to seek consent. In the case of the six identified vlogs, it was clear that they were all deceased and therefore consent was not sought in line with the ‘Data Protection Impact Assessment’ (DPIA, Appendix 2).

YouTube was selected as it has an advantage over other sites such as Facebook and Twitter. Twitter is limited to a selected number of characters and does not allow for photos, videos, and other links to be easily shared; a disadvantage when looking at narratives. An image or video accompanying text can provide the required context which is vital when analysing narratives. For example, Page et al. (2013) analysed Facebook status updates and had a participant post “Born at 8:45am, Millie is a drunken lush by 12.45. I give her until 2 before she’s collapsed completely”. This is a very ambiguous statement and could be interpreted in a variety of ways; however, the text is accompanied by a photograph of a snowman which adds the context to support interpretation which is crucial in this case. In addition, Facebook is often used to share status updates, photographs and videos with friends and family, which for the purpose of this research would not have been readily accessible, whereas those videos posted on YouTube are readily accessible to the public (if the video has been posted on a public setting).

4.3 Sample

Guetterman (2015) found that no specific sample size is recommended for narrative inquiry. Researchers have asked for the past five decades, how many qualitative interviews are enough (Guest et al., 2020). The concept of ‘data saturation’ was initially introduced in the 1960s; however, related specifically to Grounded theory, it has developed over time in a broader sense to describe the “point in data collection and analysis when new incoming data produced little or no new information to address the research question" (Guest et al., 2020, p2). Researchers such as Morgan et al. (2011) found that the first five to six interviews produced most of the information in the dataset, with little new information gained from the subsequent fourteen interviews. Similarly, Guest et al. (2020) found that the 70% of the identified themes arose from the first 6 interviews and subsequent studies echoed the similar results (Guest et al., 2020).

In order to maintain the integrity of the research, there needs to be transparency in the deconstruction and interpretation of the narrative (Elliott, 2005) to ensure that there is a sensitivity and ethical obligation to those telling the stories. Within the development and experience of a Speech and Language Therapist, there is emphasis on understanding narratives, particularly with a focus on the linguistic elements and the purpose of the narrative or story. Narrative therapies are often delivered by Speech and Language therapists to support with language development in children and in adults who have had a brain injury/developed aphasia (Mack et al., 2021). Therefore, based on my experience in working clinically as a Speech and Language Therapist I have developed skills to observe narratives, and this has supported my data selection process along with the analysis of these.

The research utilises YouTube vlogs as the data source and due to this, the specific geographical location of the participants is hard to pinpoint. The advantage of this is that it has made the participants more accessible (Haigh & Jones, 2005). There were vlogs that were difficult to tell the participants age and did not explicitly state it; therefore, these were excluded. There were others where the person's accent did not appear to be native to the UK, and therefore these were excluded. The data was collected within the time frames indicated within the eligibility criteria; however, there was an underlying assumption that they were filmed around a similar time to being posted. For some of the vlogs, date stamps are present, or the individual overtly states the date, but for others it was judged by the date marked as when it was posted.

A virtual environment has been used to create networks to communicate about experiences and share common knowledge (Ohno-Machado, 2012); there is a removal of barriers such as geography, language and cultural barriers which makes it so prevalent for posting videos on. YouTube was chosen as it is considered a valuable resource for personal stories about health and illness (Gabarron et al., 2013; Chou et al., 2011).

4.4 Inclusion, Exclusion and Withdrawal Criteria

Inclusion Criteria for Vlogs

- Participants are aged 18-24 years and have received their diagnosis between the ages of 16-24 years.
- Vlogs dated from 2018-2021 from YouTube only.
- Participants who live in the UK
- Participants have a poor prognosis for their diagnosis.
- Participants have a diagnosis of Cancer (specific type not required)

Exclusion Criteria for Vlogs

- Participants are not within the age range of 18-24 years or have had their diagnosis prior to aged 16 years.
- Participants live outside of the UK.
- Participants have a good prognosis for their diagnosis or are considered curative.
- Participants do not have a diagnosis of Cancer.
- Vlogs dated pre-2018.

**Dates were chosen in line with the PhD study being undertaken*

Withdrawal Criteria for Vlogs

- The information is within the public domain and the individuals within the vlogs will not have the opportunity to withdraw. Due to the nature of the material and it being available in the public domain there is no way to withdraw from the study (Herbert et al., 2018).

The videos were then filtered to identify the ones that match the eligibility criteria.

The age range was chosen because this is in line with research age categories, as typically research groups are deemed to be children, TYAs or adults. This is also supportive of the age of consent in the UK and ability to make decisions independently.

No specific cancer type was chosen because the total number of individuals considered eligible for this study was already limited and it was felt that this would be a further challenge to data collection. In addition, the type of cancer has not been shown in previous studies to shape the journey of the person in any unique way, and therefore all cancer types were included (Fern, 2021).

4.5 Consent to Participate

All information collated via YouTube and other social media platforms is in the public domain, and therefore participants will have provided consent for their information to be made available in the public domain by agreeing to the terms and conditions where they have posted the information. In addition, see Appendix 14 for decision-making support for consent for participants for vlogs.

For those participants where there is no clear evidence that they have deceased, attempts would have been made to contact them via YouTube. If the person required contact, then their profile would have been reviewed for a way to contact them personally and they would have been sent an email (see Appendix 10 for exact wording). If personal contact information was not available, then a comment would have been left under the video (See Appendix 10 for exact wording). If the person did not get in touch following contact being made the vlog would not have been used within the research.

The evidence that was considered to clarify if the person is deceased was:

- Within the vlog itself there is reference to the person dying either from another person or written in text within the vlog
- Within the comments underneath the vlog, it has been made clear that the person has died (must be multiple examples of the comments for them to be considered)
- Further vlogs from the same individual or part of the series indicates that the person has died (vlogs by family members have been posted to inform viewers of the individuals passing)
- The vlog is part of a wider documentary series and within this it has been made clear that the person has died.

4.6 Ethical Process

The study required full Health Regulatory Authority ethical approval by the Research Ethics Committee (Nardi et al., 2004) prior to commencing participant recruitment due to the nature of recruitment initially using face-to-face interviews. An application was submitted using the Integrated Research Application System. As part of the application the documents included the study procedure (Appendix 1), letter of introduction (Appendix 3), Participant Information sheet (Appendix 4), Participant Information Sheet for those present in their interview (Appendix 5), Consent forms

(Appendix 7 and 9), and example interview questions (Appendix 11). Ethical approval for this application was granted on 19/03/2018 (See Appendix 12).

As participants meeting the eligibility criteria are few in number and have on-going emotional, psychological, and physical health changes, recruitment to the study was difficult. In combination with the COVID-19 pandemic and the limitations this placed on accessing participants via participant recruitment centres, a review of the recruitment process was undertaken. Consequently, the analysis of vlogs from YouTube using individuals who met the outlined participant criteria was introduced as a recruitment method. Therefore, as there had been a methodological amendment which constitutes as a substantial amendment to the original approval, further approval was sought. In addition, as the research involved online data, and subsequent further approval was required as part of the DPIA (See Appendix 2) in line with GDPR/UK Data Protection Act (2018). A substantial amendment and additional documents were submitted, which included the Participant Information Sheet for vlogs (Appendix 6), decision-making tool (Appendix 7), Consent form (Appendix 8), and email to seek consent (Appendix 10). Ethical approval was received from the HRA on the 29/09/2021 (Appendix 13).

The main ethical issues provoked by this study were confidentiality and anonymity, participant burden/risk, and risk to the researcher's emotional wellbeing. These identified issues required some reflection and negotiation for adequate solutions and will be detailed within this chapter.

Throughout the ethical process, reflexivity was used to support understanding of the nature of ethics in relation to this qualitative research project, but also the practical steps of how ethical practice can be achieved (Guillemin & Gillam, 2004).

4.6.1 Ethical Issues

The data is considered ‘non-reactive’ as it is collected from individuals unobtrusively from secondary sources (BPS, 2021), in this case, through analysis of social media postings. This comes with ethical challenges which are considered below; alongside consideration of vlogs content and internet mediated research (IMR).

The stories told in these vlogs can almost be considered echoes from the past, narratives for posteriority, and legacy videos left for loved ones. The vlogs cover sensitive and possible distressing interview topics, which may provoke a number of ethical issues. Although there are many governing bodies issuing guidance on research ethics, no general consensus exists that defines what is considered good social media research ethics (Ryan, 2007). Difficulties also exist in adapting current ethical guidance to fit qualitative research (Boser, 2007), especially for those considered ‘vulnerable’. Vulnerable in this sense refers to individuals who are unable to give consent, e.g., children and those who lack capacity; yet it also accounts for those more psychologically susceptible to social influence, particularly negative social influence (Bruning et al., 2020). However, many of the existing guidance includes informed consent (including avoidance of deception) and harm/exploitation (Wiles et al., 2006), which can be used to support ethical decision-making in relation to using the data or not.

Given the nature of the research, there have been challenges throughout the research process that merit further discussion, these are participant’s distress, anonymity, risks/burdens and benefits, and reflexivity within the research.

It was also worth considering whether the people talking within the vlogs would be considered ‘vulnerable’, as the essence of vulnerability is what the individual’s perception of themselves is, and therefore could in itself be considered a social construct (Liamputtong, 2007). Defining vulnerability is a complex process and one that cannot be explored within this thesis due to the level of analysis required. However, it should be acknowledged that participants' perceptions of their own vulnerability will be considered within the analysis of the data.

4.6.2 Technology

Digitalisation has made it possible for the users of social media platforms to access an infinitude of works (Erickson et al., 2015), with some scholars describing the 'public domain' as a negative space due to the lack of formal intellectual property rights (Landes & Posner, 2003). Other academics discuss the activities made possible by users without the need for permission (Erickson et al., 2015). For users of the internet, and in particular social media platforms, the first interaction a person has with the platform and the username they choose sets the tone for how they want to use the platform to communicate (Van der Nagel, 2017), and how they want to be perceived. It can be thought that choosing a username to a certain extent is providing individuals with a sense of anonymity (Farrimond, 2013).

The debate relating to anonymity versus non-anonymity arose as a consequence of the increase in people 'telling their stories' using online profiles, with only superficial consideration given to anonymity. With 96% of households in Great Britain having internet access in 2020 (ONS, 2020), the use of this for networking and information gathering has significantly increased.

Therefore, TYAs have an increased online presence and thus more likely to already have a profile that reflects a variety of personal aspects of their lives. There are thought to be (data from 2019) 3.484 billion active social media users around the world, with 98% of internet users having visited or used a social network or messaging service in the last month (Avocado Social, 2019). There are thought to be approximately 45 million social media users in the UK, with 97% of 16-24 years olds stating they have their own social network profile (Statista, 2021). The UK safer Internet Centre (2017) states that 1 in 6 young people (as defined here as 8-17-year-olds) had shared a photo in the last hour and 1 in 8 shared a selfie in the last day. The research participants have an age range of 16-24years, and it has been noted that 82% (of 15-25year olds) of this population said they used the video-sharing platform YouTube in 2020; making the site the most-used social media site in the UK (when compared to Facebook, WhatsApp, and Instagram) (Statista, 2021).

4.7 Internet Mediated Research (IMR)

The definition of IMR is considered to be any "research involving the remote acquisition of data from or about human participants using the internet and its associated technologies" (BPS, 2017, p.3). In the context of IMR, the term 'public' is defined as 'readily accessible by anyone' (BPS, 2017). IMR research is taking data from 'public forums' potentially, and therefore there is greater visibility, traceability and permeance (BPS, 2021), which are factors in establishing if the research is considered ethically acceptable. The ethics procedures and safeguards implemented need to consider the proportionality of the level of risk and potential harm to participants (BPS, 2021), and that GDPR/UK Data Protection Act (2018) are included within research considerations.

The British Psychological Society (2017; 2021) outline 4 key guidelines for research which are taken from the 'Code of Human Research Ethics' (2009; 2021); which are summarised in Table 4.1.

Table 4.1 Summary of the main ethics issues of IMR research (BPS, 2021, p.7).

Principle	Considerations
Respect for Autonomy, privacy and dignity of individuals and communities	• Public/ Private distinction • Valid Consent • Confidentiality • Anonymity • Deception • Withdrawal • Copyright
Scientific integrity	• Levels of control – How reduced levels of control may impact on the scientific value of a study, and how best to maximise levels of control where appropriate.
Social responsibility	• Disruption of social structures – the extent to which proposed research study procedures and dissemination practices might disrupt / harm social groups.
Maximising benefits and minimizing harm	• Maximising benefits to participants • Minimising harm to participants • Minimising harm to researchers

I have considered each of these in relation specifically to IMR.

4.7.1 Respect for Autonomy, Privacy and Dignity of Individuals and Communities

It is important to differentiate between privacy, confidentiality, and anonymity, in order to provide clarity on the reflections within this research. The traditional definition of privacy states “the claim of individuals, groups of institutions to determine for themselves when, how and to what extent information about them is communicated to others” (Westin, 1967). However, the more updated definition refers to the extent of control you have over how much access other people have to your private life, thoughts, and feelings (Farrimond, 2013). The reflections relating more specifically to privacy can be found within the discussions of the role of online profiles.

Confidentiality refers to the sharing of information within the agreed limits, therefore within this research, this refers to sharing the data within the confines of the supervisory team and not with external agencies. However, the analysis of the data can be shared within the public domain, as agreed within the consent form (Appendix 7, 8 and 9). Anonymity refers to removal or disguise of the identity of a person, in this case the participant within research.

Anonymity has been considered a standard and 'default' research practice for many years. It is underpinned within legislation and is endorsed by a number of regulatory bodies, including the Association of Social Anthropologists, British Psychological Society, British Sociological Society, and the National Research Ethics service for the NHS, but to name a few. The evidence supporting this is that anonymity ensures the privacy of the participant and the confidentiality of the data, reduces the potential harm that identification of the participant might have, and protects the participant and researcher in a legal context from any disclosures within the interview (Farrimond, 2013).

4.7.2 Unachievable Anonymity

There is a misconception that 'anonymity' provides protection for the participant (Kelly, 2009) and anonymity is achievable, particularly if context information is included in the data inadvertently or without conscious effort from the researcher. Some would argue that true anonymity cannot be achieved within the field of social qualitative research (Van Den Hoonaard, 2003), and describe anonymity as a mere 'illusion' (Stein, 2010). It is described as an 'illusion' on the premise that if an individual had the desire to ‘uncover’ the identity of a participant, that given the right tools, they would be able to dissect the data set and use this to identify the participant (Kelly, 2009).

The research process undertaken within qualitative research can make it difficult to achieve anonymity (Shaw, 2003); this is usually relating to the number of data fields that are required to be anonymised before true anonymity can be achieved (e.g., name, places, religious/cultural beliefs, occupation, family relationships) (Saunders et al., 2015). Within certain research groups, participants may be highly recognisable, particularly to other participants who are within the same group or to professionals/researchers who work commonly within those research groups (Farrimond, 2013). So rather than abandoning the concept of anonymity altogether, researchers need to be transparent about what is achievable in relation to offering anonymity, and the impact of their identity being known. The participant can then make an informed choice based on their full understanding of the research and dissemination of this. All efforts to mitigate any risk have been detailed in the DPIA (See Appendix 2). In the context of IMR, the term ‘public’ is defined as ‘readily accessible by anyone’ (BPS, 2017).

It is worth acknowledging that in relation to the internet, technological improvements and changes occur rapidly and so there is a constant need to review the salient considerations in relation to IMR (BPS, 2017). The guidelines that support ethical decision making in research are not always aligned to IMR, and therefore require careful consideration and application to IMR research. The Code of Human Research Ethics (2009) states that observation of public behaviour for research purposes can only take place in public situations where those would be expected to be observed. Other researchers have felt that Internet postings by individuals onto forums which can be viewed by the public does not constitute ‘Human subjects research’, and therefore does not require additional ethical considerations (Rodriquez, 2013), and in some cases can be considered secondary textural analysis (Bradley & Carter, 2012). However, can an online space such as YouTube be perceived as public? Often, a video posted onto a social media space is posted to be intentionally ‘public’, and therefore should be perceived as within the public domain and usable for research purposes. However, some would argue that if the video is made in their home environment, the video should be considered private. Yet, posting this video in an ‘open forum’ then converts the video to being considered public. An open forum has been defined by some researchers as websites that do not require registration or posts by anonymous authors (Fleischmann & Miller, 2013; Marcus et al., 2012), whilst others argue that even websites requiring registration can be viewed as a public space if the right level of consent from the website is sought (Schotanus-Dijkstra et al., 2014). In ‘open forums’, data is publicly visible, has traceability to the source and a level of permanence; therefore, the question is, does this make it ethically acceptable to use the data freely for research purposes? To support answering this question it is worth referencing the web service users licence agreements; these would typically require the person posting the ‘data’ to agree that this is public, grant other users of the service permission to reproduce, distribute, and modify the data and provide clear guidelines for removal of the data should they wish to do so (YouTube, 2020). Whilst it may be impractical or unnecessary to gain explicit permission from the data owners, this needs to be balanced alongside the social responsibility of what the data will be used for (BPS, 2017). The responsibility for understanding the potential distribution of the video goes beyond the academic and social network (including regulatory bodies) and includes all those that use the video streaming site (Ess, 2013). The ethical obligation of choosing to use a video or not falls within the research in the form of a gatekeeper, and the process for this decision-making is outlined within this chapter.

Within IMR, consideration needs to be further given to the argument of anonymity for participants, particularly as any published quotes within the research may compromise any anonymity or confidentiality for the participant (BPS, 2017), and there is increased ‘traceability’ associated with those quotes (Beaulieu & Estalella, 2012; Roberts, 2015). Some researchers would state that it is almost impossible to preserve confidentiality and anonymity with the sophistication of search engines that are widely available (Mann, 2002). Consideration has been given to the impact of this on this research, and processes such as paraphrasing or combining quotes could be used as a compensatory strategy, if required. However, as the person is appearing in the video themselves and identifying themselves within the video using their real names, participant anonymity proves difficult. This also supports the understanding that within IMR and within research of specific clinical groups, true anonymity is difficult to achieve. However, in an effort to protect individuals and organisations who may have been mentioned within the video but not have consented to being involved in the video, they have been anonymised within the data.

4.7.3 Scientific Integrity

It is important that a research project meets the criteria of ‘quality, integrity and contribution’ (Code of Human Ethics, 2021). The lack of physical proximity between the researcher and participant may impact on the integrity of the data because it does not take into account the interaction exchange between people and the opportunity to provide consolation and encouragement (Atanasova et al., 2018). The researcher holds little or no control over the research procedures and this impacts the research as the researcher has limited knowledge of the participants behaviour and characteristics. Depending on the material analysed, there is likely to be variance in the context, participant, and procedural aspects of the way in which the vlogger has posted their vlog. However, within qualitative research and narrative analysis, the research integrity is less susceptible to these variables as the analysis does not specifically rely on a process to be followed to enable to the data to be considered trustworthy. In addition, the person presenting the narrative in the video is presenting a ‘representation’ of what they want to share with the world (Zimmer & Kinder-Kurlanda, 2017), and therefore will potentially be retreating from elements of the narrative they would not want to share. This in turn will shade the data available for the research, and the narrative will be shaped by what has been shared, not necessarily the whole picture. This is the case for all narratives and stories as they are performed in a way in which they are fractured and have a bias in what is shared or omitted. Whereas others would state that social networking by a digital means is not a social retreat and instead is a ‘referential expressiveness’ of the individual (Zimmer & Kinder-Kurlanda, 2017). The basis of autonomy is affected by this shift, and Stadler (2011) states that social networking is a place to pursue individual goals, and connect with people and resources, and as a consequence, people will share personal information generously and with little worry of privacy or individual autonomy.

Therefore, consideration needs to be given for the impact of this on the integrity of research, the research findings, and the conclusions that are drawn from the research (BPS, 2017, 2021). The researcher does not want to disseminate inaccurate or misleading information following data collection, therefore, the limitations of data collection via IMR should be acknowledged and clearly communicated. This will be further discussed in Chapter 6.

The researcher's emotional reaction can compromise the validity and reliability of the research data (Lee Ellington et al., 2013). This is more apparent in interviews with participants rather than with vlogs; however, researchers when watching vlogs can become emotionally attached and this can impact on how they view the data. Processes such as keeping reflexive diaries, debrief sessions with supervisor's post interview, and the experience of the researcher were in place to reduce the impact of this on the data. As the overall aim of the research is to produce detailed rich data rather than generalisable data (Elliott, 2005), issues relating to validity are not appropriate for this study.

4.7.4 Social Responsibility and Maximising Benefits and Minimizing Potential Harm and Participant Harm

Posting on social media can be seen as a therapeutic method to support patients who are dying, to express their stories and provide empowerment of their situation (Tait et al., 2011). It is felt that analysis of their stories can enable the researcher opportunities to treat both the data and participants with respect and portray an honest reflection and representation of the research topic. This also provides an opportunity to be involved in research specific to their age group, which they may otherwise have not been involved in.

The person is given an opportunity to discuss their experiences with someone who is actively listening and seek feedback via comments online from those listeners. This is often to discuss how they are feeling, the impact the diagnosis or treatment is having on their lives, and to seek support for themselves. This is not often to discuss specifics about their healthcare and some researchers would argue that due to their reliance on health care workers to provide care, they will not criticise the care received in research (Addington-Hall, 2002) or in the vlogs that they post. However, several studies have found that participants will comment on the healthcare they receive in both positive and negative ways, particularly if they feel that their comments may be used to offer improved services for others. For example, Pask et al. (2018) interviewed 65 participants, 10 of which were patients and family carers. They found reports of dissonance between patients, families, and health professionals are a pertinent theme, particularly around how they should manage their care, and that challenges were experienced when these beliefs differed. In addition, Chambers et al. (2019) completed a qualitative evidence synthesis and reviewed 93 records, some of the main themes highlighted barriers relating to effective relationships and communication between patients/carers and health professionals.

A consideration for social media posts is that they give the people reading or viewing the post the option to comment on it. These comments can evoke positive and negative emotions to the person posting, and this in turn will influence what they are likely to say within the post, whether they will post again, and whether the aim of their post was achieved or not. I will further explore this within Chapter 5.

The research participants are talking about their lives at a time in which they are experiencing palliative care, which may but not always lead to the possibility of the participant experiencing temporary distress. The research is guided by a combination of the researcher’s clinical experience in working within the clinical field of palliative care, alongside the use of the ‘Advisory Distress Strategy’ for qualitative data collection (Appendix 5).

It is important to remember that distress itself is not always a negative feeling, and in some cases, being able to openly discuss topics of this nature may provide a level of reassurance to the participant, and in some cases be considered therapeutic for some (Hollway & Jefferson, 2000). Telling stories can be a way of empowerment for the person and help them to think about their experience (Viney & Bousfield, 1991; Perales et al., 2016).

In brief, the role of the researcher is to have good ‘emotional literacy’ to view the vlogs several times, and specifically when participants become distressed (Farrimond, 2013; Sangeorzan et al., 2019). In relation to vlogs, this is about the maintenance of good emotional wellbeing for the researcher, which should be considered explicitly (Moncur, 2013) as this supports the interpretation of the research. This has been achieved through reflexivity and de-briefing sessions with the supervisory team; in addition, I have clinical experience in palliative care and therefore would consider myself resilient in these potentially distressing situations.

For the analysis of vlogs, it would be considered non-reactive data which has been obtained unobtrusively. However, the implications of this are that the ‘participant’s’ ability to control, monitor, consent or withdraw from the study is not only limited but, in some cases, is not present (BPS, 2017), and the ubiquity of this requires further consideration. Essentially, observations of videos are an analysis of the “inner workings of private worlds” (Zimmer & Kinder-Kurlanda, 2017), and there is a level of responsibility that comes along with this that must be carefully considered. Vlogs may also be recorded multiple times, and the individual has had time to plan what they might want to share or edit out. Therefore, the distress is likely to have also been managed off camera and the observer has no part in their emotional or psychological interaction. When analysing the vlogs, this is an interesting point to consider as the vlogger had the emotional leverage to highlight the points they want to and edit out anything they do not want to share.

Although the definition of ‘public’ clearly states it will be readily accessible to anyone, individuals posting on websites may not anticipate the reach of their vlog when they post this or anticipate the comments this may lead to. Therefore, when they provide consent and agree to the terms and conditions, they may not fully appreciate the magnitude of what they are consenting to. Comments made can be highly supportive, cathartic, and have a positive impact on the person; however, they can also be harmful, slanderous, and have damaging impacts on the person.

When considering the participant criteria, which in this case is 16-24-year-olds, it can be difficult to ensure that what the person states in the video is an accurate reflection of how they are feeling or whether it is a performance of what they think people want to see. Social media “affords selective, self-presentation, and this allow for self-expression that may be inconsistent with the true self” (Luo & Hancock, 2020, p.112). If the researcher feels that the inclusion of the video within the data set would increase distress to, potentially harm (the vlogger or individuals/organisations mentioned in the video) or not provide any benefit to the research that would outweigh this, then that particular video should not be included within the data set. Any comments of a hurtful or slanderous nature that may have been written in response to a video will be analysed if it is deemed to enhance the data within the vlog; however, those posting the comments will be anonymised within any analysis.

Some research may put the individual into a position where they would be publicly dealing with a private issue. For my research, they have chosen to talk about their private issue and chosen deliberately not to mask their identifies, therefore the research itself would not be leading to any additional exposure of the issues discussed, but rather framing them in a narrative to support development in this clinical field.

Research reflexivity is central to ensure that the researcher is respectful to any participants in social media research. The application of reflexive ethical thinking will allow an in-depth review of ethical roles and social media systems, negotiate any procedural aspects of the study, and update the practices based on the outcome of this ethical thinking process (Zimmer & Kinder-Kurlanda, 2017). This has been achieved by conducting a thorough literature review, discussions with subject matter experts, and in-depth discussions with thesis supervisors. For all decisions made about the use of specific videos, quotations and analyses drawn, I conducted a thorough process of reflexivity and discussion alongside my supervisors and took issues to IMR and qualitative research forums for further discussion and opinion. This then informed the processes employed within this research and amendments made as indicated, along with clear justifications and rationale for these amendments, which will be outlined as they arise in the data analysis chapter.

The use of social media can allow access to participants that would otherwise be considered ‘hard to reach’ (Zimmer & Kinder-Kurlanda, 2017), and it could be argued that analysis of social media versus face-to-face interviews leads to less burden and distress for the participant. The difficulty with assessing potential harm for IMR is that there is a lack of empirical frameworks which accurately assess the magnitude of potential harm (Zimmer & Kinder-Kurlanda, 2017; Buchanan & Ess, 2009). We therefore need to use strategies to mitigate the risks based on the researcher's own knowledge and experience. The clinical knowledge and experience of working within this client group has supported the development of my analytic and ethical decision-making for research, which I will utilise to support decisions made, including clear rationale for these on a case-by-case basis. The decision-making process is outlined in Appendix 14. This process allowed for my review of each vlog, my reflection on the ethical and moral issues relating to them, in-depth analysis of participant risk, and benefit and integrity of the data. Only after this careful decision-making process was a vlog included within the data set.

4.8 Summary of Internet Mediated Research (IMR)

The balancing act between protecting the participant/vlogger whilst maintaining the integrity of the data is a constant challenge for researchers (Saunders et al., 2015). Based on the above literature review and the ethical approval requirements, further consideration into consent and ethics within the context of internet-based research has been considered further in this chapter.

In summary, IMR evokes ethical considerations for researchers and there is "more than one ethically defensible response" (AoIR, 2019, p.6). As there lacks a clear and singular response to the ethical dilemma of whether it is ethically responsible to use videos from a social media website, it is the role of the researcher to outline the rationale for their decision. Ethical decision-making needs to be supported by a framework of agreed expectations, values and practices that lead to moral good ends and support and promote positive actions (Zimmer & Kinder-Kurlanda, 2017). This includes utilising national guidance (BPS, 2017; BPS, 2021; Code of Human Ethics, 2021), my professional and personal experience as a Speech and Language

Therapist and reflecting on my role as a researcher to support the decision-making process.

In relation to this study, the aims are to improve understanding of the impact of their diagnosis and treatment on social well-being, identify ‘best practice’ methods to support palliative care, and ascertain the viewpoint of a young person on what is a ‘dying well’, using narrative analysis to draw this information from the videos. Therefore, within the data, focus will be on the positives outlined by the person, examples from their specific life in relation to palliative care and the support they have received; all taken from what they have chosen to share in a public forum. The social media platform has user guides to outline who has access to the video and how to communicate when making a video, this on some level constitutes ethical facilitation and demonstrates consent (Zimmer & Kinder-Kurlanda, 2017).

Recommendations for this research are provided based on contextual flexibility of ethical decision-making using rights-based principles (Zimmer & Kinder-Kurlanda, 2017) and consideration of the factors for IMR. These include the right to rectification (right of people to amend data held by the researcher) and right to erasure (right of people to remove their person data as outlined within GDPR Article 17) (Fjeld et al., 2020), which within this study were compounded due to the nature of the participants and data collection. For this research, the videos selected will be in line with the participant criteria, the content of each video individually reviewed by the researcher to ensure that the benefits outweigh any potential risks, and that the process of anonymity for certain aspects of the videos is implemented as appropriate.

4.9 Transcription

The data has been transcribed verbatim and included within the transcriptions there has been consideration of the context of the interview (Lindseth & Norberg, 2004). It was important to have a consistent transcription approach in order to support the overall quality of the transcriptions (Poland, 1995). The transcription had some focus on the characteristic flows within the conversation, including intonation patterns and style of speech. Hollway and Jefferson (2000) looked at ‘reading between the lines’ for hidden meanings within narratives, and meanings that might not even be known to the person telling the narrative. Suggestions regarding transcription procedures will be adapted from Norrick (2000), which includes commenting on the use of pause, pitch changes and the use of laughter, throat clearing, sobbing. The transcription includes separation into key segments within each interview, whilst maintaining the importance of the whole story (Silverman, 2011). Riessman (1993) states that transcription and analysis cannot be separated and therefore must be conducted by the researcher. The transcriptions were transcribed by the researcher.

The increase in the use of interpretative research strategies has increased the acceptance of the qualitative paradigm as a viable social sciences research method; including researchers working hard to ensure credibility of this qualitative analysis (Bailey, 1996). This had led to more systematic ways in which to analyse data (Denscombe, 2014). It has been suggested that there is a reconceptualization of the concept of validity into the process of validation (Bailey, 1996). The ways to support the process of validation and authenticity include ensuring that the research process is visible to allow for systemic scrutiny, and to present the data in full to allow for discussions with others. For this study, the chief investigator was the sole interpreter of the data; however, advice was sought from the supervisory panel who have considerable experience in using this approach. There is also a consideration for the importance of reflexive practice throughout the process, particularly within the clinical field of palliative practice.

4.10 Initial Analysis Process

The chosen analysis approach is a combination of dialogical narrative analysis and performance narrative analysis. The initial analysis of the narrative was done using six steps (Crossley, 2000):

1. Reading and familiarising
2. Identifying important concepts
3. Identifying 'narrative tone'
4. Identifying narrative themes and images
5. Weaving all this together in a coherent story
6. Writing up research report

The following questions were considered as part of the analysis of the data:

1. What is the content of the story you are examining?
2. Who are the principal agents?
3. How is the story told (structure and sequence)?
4. What purposes does the story serve (functions)?
5. In what place or setting is the story told (context)?

(Riessman, 2008)

This uses Riessman's (2008) method of narrative analysis by asking the five questions outlined above. Riessman's (2008) approach to narrative analysis asks for the narrative to be treated as a social construct and that this needs to be explicit within the analysis of this (Hill & Burrows, 2017). Narratives contain events and actions which are organised into sequences which depict certain meanings, in the context of end-of-life narratives, this is particularly poignant as it evaluates why the person chose to include specific events and perhaps omit others. This then can be used to think about how the selection of what to include is reflected in their individual social constructs.

Each vlog was watched once to review content and eligibility against the inclusion criteria. Once selected for the study, the video was watched twice to allow for the researcher to summarise each vlog. It was then watched twice again to complete transcriptions and informal analysis and finally it was watched at least twice more to analyse the non-verbal communication elements and the intention or purpose of the vlog. Once analysis had been completed, it was re-watched to ensure there were no elements missed and that the analysis was reflective of the content and context of the vlog.

4.10.1 Content

The initial content of the stories reflects the interpretations and values of the individual. For all the stories selected for this study, there is an 'intrinsic' critical event. The 'intrinsic' critical event has a significant impact on the storyteller (Webster & Mertova, 2007), which in this case is the participants illness. The events are unplanned, unanticipated, and uncontrolled (Webster & Mertova, 2007). The stories all start with an outline of their illness, symptoms, and when this was discovered. They then move on to outline the impact that this has had on them, their lives, and the people around them, and they conclude with a level of acceptance of their journey.

4.10.2 Principal Agents

In all the narratives they are ‘auto-biographical narratives’, and therefore the person themselves is talking about their own journey. In some vlogs there are appearances from their close family members for example, mum, dad, and partner. The impact this has on the narrative has been further discussed within each individual analysis. For others, they have chosen to remain on their own and merely reference their loved ones within their narratives.

Within all the narratives, there is a sense of the audience being a principal agent; particularly for those that have tens of vlogs posted. They will reference back to previous comments made by people underneath the vlog they have posted and thank people for their comments and support. It is important to consider here the role of the audience as a principal agent, as some feel that there is no performance without an audience (Cortazzi, 1993) and that the audience plays a central role within a narrative (Michael Murray, 2003). Narratives generally occur when someone is telling someone else a story; therefore, without the audience it would be a monologue rather than a story which holds a different purpose. In addition, people post vlogs with the intent of getting a response from the audience and so how the audience view their vlog is important as it impacts how the vlog is developed.

4.10.3 Structure and Sequence

The vlogs analysed do follow a sequence of events, they all start with the news of diagnosis, move onto the things that are important to them and the impact that the diagnosis is having on their lives; however, the ending or conclusion is where the sequence does not logically follow. For each individual, they are not aware at the time of filming or posting their vlog that this will be the last one they have the opportunity to post; therefore, the stories in terms of the narrative they present do not have a clear ending. The ending of the narrative can appear abrupt and unfinished; however, that is the nature of their prognosis and of this research. I have used Campbell (2015) three stages of narrative analysis; the departure, the initiation, and the return to analyse the individual narratives. The *‘departure’ phase* within an illness narrative is considered the ‘symptom’ or sign that the body has changed or is not like it was before, e.g., noticing a lump, feeling increasingly tired. Often, this phase includes a period of ‘denial’ or ‘refusal’ in which the individual rejects the thoughts of something being wrong, and it can take some time for them to accept this (Frank, 2013). For some individuals, it can take something significant such as a hospitalisation or surgery for them to move into acceptance. Moving into acceptance is considered crossing the first threshold and is the sign that the person is moving into the *‘initiation’ phase* of their illness narrative (Frank, 2013). The *‘initiation’ phase* is the “road of trials” (Frank, 2013. P.118) and is the story of all the various sufferings that have been felt within the illness journey including physical, social, and emotional sufferings. Within the ‘*initiation’ phase* this can include stages such as ‘atonement’ and ‘temptation’ (Frank, 2013). For most people during the ‘*initiation’ phase,* they will go through a subconscious transformation where the storyteller has been transformed by what they have been through, and that from this they have gained something, e.g., insight to pass to others. The final stage is the ‘*return’ phase* which is when the person is no longer ill but remains ‘marked’ by the illness in some way (Frank, 2013). For the individuals within this study, they will not necessarily experience the *‘return’ phase* as they will not recover from their illness, but they may still experience a feeling of insight to pass on to others.

4.10.4 Purpose of the Story

To understand more about the purpose of the story, I have broken this down into four levels by which elements can be analysed further. The personal, interpersonal, positional, and ideological levels.

The ‘personal level’ is understanding people’s accounts of their own experiences. Williams (1982) used this approach in relation to chronic illness and Somers (1994) used an ‘ontological’ approach to make sense of our own lives and define our identity. The vlogs within this study demonstrate 6 individuals who are trying to make sense of their diagnosis and lay out who they want to be. *“The old saying when life gives you lemons, make lemonade, but what do you do when life gives you cancer?”* (Participant – Harry). They are exploratory in nature for the individuals as they are figuring out their new life in the wake of their diagnosis and prognosis. Most of the participants appeared at times to be having a ‘breakdown’; they appeared to be trying to make sense of these through their stories (Crossley, 2000; Lyons & Coyle, 2007), examples of which will be provided within the data analysis. By ‘breakdown’ I am referring to their ability to regulate their emotions, which is often done by adolescents by posting and talking about themselves with others on social media (Vermeulen et al., 2018; Rimé, 2009; Bazarova et al., 2015).

The ‘interpersonal level’ is understood from a dialogical perspective as a joint enterprise, or conversation which produces narratives based in socially and historically available discourses. There needs to be consideration taken for the way in which the interviewer interprets the narratives, accounting for the representation of the broader social world in which the narrative is placed. For the analysis of vlogs, there has not been a ‘conversation’ between the narrator and the researcher; however, the narrator acknowledges the audience and there does appear to be an active conversation. The narrator often acknowledges the audience in their later vlogs; thanks, them for their support and comments or opens the vlog with *“I wanted to give you all an update on how I am doing”* (Participant – Gemma). There is some active conversation occurring between the narrator/vlogger and the audience as they are able to post comments after the video has been posted in the public forum; most of the comments are related to being empathetic towards the narrator and what they are going through. The conversation and comments written after the vlog has been posted have not been analysed as part of this research. The interpretation of the vlog is being carried out in an attempt to appreciate and understand the perspective of the individual posting the video, in line with the research questions for this study.

The ‘positional level’ is the broader social context and social/moral functions of narrative. Williams (1982) uses narratives to demonstrate how the storyteller views themselves in society rather than focus on chronic illness.

The ‘ideological level’ is the direct attention to broader social systems of shared beliefs and representations in which narratives are embedded. Garro (1994) outlines how storytellers position narratives in context of broader cultural narratives. Often, public narratives are drawn upon to provide stand points for the speakers within their social and cultural network. These positions are considered fluid and can change as the narratives and illness itself evolves.

There are varying types of narratives which frame the purpose of a common narrative type. With illness narratives, it a quest narrative; often described as a narrative that meets “suffering head on” (Frank, 2013), the person appears to accept their suffering/illness and seeks to use it for a particular purpose. The illness is defined by the person’s perception that there is something to be gained from the experience. The quest narrative gives the narrator the voice for their own story, with the most published illness stories being that of quest narratives (Frank, 2013). Quest narratives occur in three facets; a memoir (telling the illness story and other events in their lives), manifestos (prophetic in nature and can be used to demand social change by using the illness/suffering to move others into action), and auto mythology ('reinventing self from the ashes' following a trauma). Within the context of this research, the quest stories appear to be 'memoirs' as they are autobiographical descriptions of the person's life and significant events; however, some could also be considered 'manifestos' as they seek to use their suffering to inspire others into action.

4.10.5 Place / Setting

The narratives are all posted to YouTube with public permissions granted; therefore, accessible to all users. The place in which the filming of the narratives occur take place in a variety of settings and these contribute to the purpose of the narrative and give viewers further glimpses into the lives of the people posting them. It has been found that the setting of a vlog can significantly impact whether the vlog is seen as positive by it is audience, and for those that are filmed within a residential setting, audience members have reported this increases the level of positivity felt towards the vlog (Folkvord et al., 2019).

Whether the video is 'realistic' with no-editing or has been edited has been found to directly link with the popularity of the vlog (Christian, 2009). Stein et al. (2020) found when asking 14 participants to rate their viewing experience on elements such as enjoyment, that the professional edited vlogs came out significantly more favourably across all elements than more realistic non-edited videos. This does not appear to be reflected in the number of views of the vlogs included in this data set. Adam's video has been edited and appears professional in it is overall production and has had approxiamtely 154,000 views (as of 16th November 2021); whereas David's video is a monologue and 'mobile' combination with no edits at all and has had 9.7 million and 1.5 million views for the two videos analysed (as of the 16th November 2021). There is some evidence that the participants recorded their videos multiple times in order to ensure that what they were posting met with their expectations, *"this is my 3rd time filming this video, so hopefully 3rd time lucky" (*Participant Gemma).

A vlog is generally a single person who is facing the camera directly and addressing the audience most of the time (Biel & Gatica-Perez, 2010), which does have some similarities to videoconferencing. However, vlogs are generally considered asynchronous in that the people commenting on them who are 'interacting' would not be doing so at the time in which the vlog has been filmed, but would be doing this after it had been posted. A close up-direct address has been theorised to create empathy for the audience (Rizzolatti & Sinigaglia, 2008) and is used to persuade audiences towards something (Christian, 2009), particularly when it comes to using vlogs as a means of influencing or advertising. The use of recording in a bedroom space allows vloggers to share a sense of sociality and intimacy with their audience, and this supports the audience in their perception of authenticity of the vlogger (Ashton & Patel, 2018).

4.11 Individual Narrative Analysis

The narratives of individuals are reviewed using narrative smoothing (a way in which to select that which is pertinent to the development of the analysis), and then narrative configuration is conducted (the bringing together of the elements into a meaningful and coherent analysis) (Hatch & Wisniewski, 1995).

4.12 Reflexivity and Narrative Analysis

It is thought that rather than the interpretations reflecting reality, interpretations instead construct reality (Finlay & Gough, 2008). Reflexive practice constructs the researcher and immerses them within the phenomena they are researching (Finlay & Gough, 2008). The researcher considers how they construct themselves socially whilst also constructing others (Alvesson & Sköldberg, 2017), as after all people, construct their social reality and this applies to the researcher and the participant.

Narrative represents the unstructured whole account of a person's experience; the story is then the recreated narrative which aims to have a structure and chronology (Petty, 2017). For the analysis of the vlogs, the narrative may not be in its raw and unstructured form, as by the nature of social media things can be recorded multiple times with the later versions being posted and those containing things that the person does not want to share being removed. Therefore the 'performance' of the vlogger is refined. The researcher must engage in research reflexivity to acknowledge how their own experiences and contexts inform their understanding of the narrative (Etherington, 2004).

4.13 Managing Reflexivity

Woolgar (1988) uses a continuum of reflexivity to describe the range from radical constitutive reflexivity ("reflexivity as both a constitute organisation of everyday life and a practical organisation that is available for study and description" (Macbeth, 2001, p.48), usually framed in ethnomethodology) to benign introspection (reflection). For those of us working in a qualitative interpretivist paradigm, where the focus is on interactions between us as humans and our world, reflexivity should be embedded solidly within our research (Shaw, 2010). By definition, reflection can be thought of as a general set of thoughts whose main concern is that of process and a goal of supporting accuracy of people's accounts (Woolgar, 1988). Whereas reflexivity involves turning your gaze back to the self and considering the co-constitution of meaning within a socially orientated scenario (Shaw, 2010). This includes concentrating on how experiences are understood within the context in which they happen (e.g., our interaction with the social world), the ways we make sense of these experiences (Shaw, 2010), and how we as researchers have influence over the interpretation of this (e.g., how our own experiences impact on the interpretation we have of the world and our perspective development).

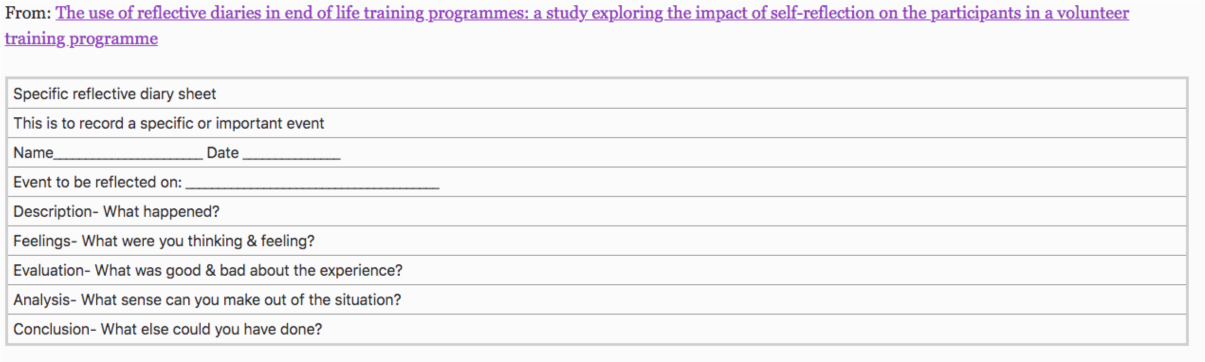
Reflexivity is vital in qualitative research in ensuring that transparency in the construction and interpretation of the narratives is clear within the research process (Smith, 2015; Finlay & Gough, 2008). It can also be used to critique theory and support the researcher in drawing conclusions (Ashmore, 1989). Some researchers feel that there should be greater reporting of reflexivity and transparency within qualitative research (Newton et al., 2012), and Shaw (2010) argues researchers have a responsibility to assess the impact they have on the data and be transparent about this (Alvesson & Sköldberg, 2017). This level of transparency is felt to enhance the quality of qualitative research by the research community and participants of research.

Within the context of social media, interpretation of data is influenced by the problems of virtuality and lack of context (Pousti et al., 2020) and often no active reflection on the impact of the setting. Branthwaite and Patterson (2011) highlight how social media presents challenges, such as the lack of ability to develop a conversation with the participant, which for my research is made even more complex due to the nature of the participant's condition. In addition, there can be challenges related to methodological approaches (McKenna et al., 2017) due to limited guidance available to support researchers in this developing and emergent research field. McKenna et al. (2017), outlines the challenges that exist within IMR often deter qualitative researchers from using social media platforms as data sources, they refer to the sheer volume of data being overwhelming for researchers to create a data set, for example, there are 2.3 billion users of YouTube worldwide (Oberlo, 2021), and 500 hours of videos are uploaded every minute worldwide (Tubefilter, 2019); it would take 82 years to watch the amount of videos uploaded in one hour. McKenna et al. (2017) also reports difficulties in the analysis of the data due to digital texts containing further information, such as images, links, emoji and conversation threads, the lack of visual cues given by the person posting (if analysing digital text only), the understanding of new online behaviours such as 'lurking' (passively listening, observing but not participating) and how these impact on the data. McKenna et al. (2017) also reports the complexities involved in accessibility of data, e.g., you may need additional permission to enter certain chat rooms and see certain posts, the authenticity of the data, and the ethics involved in using the data. Reflexivity within this field requires further consideration in line with more traditional approaches (Pousti et al., 2020). In this context, reflexivity enables researchers to be critically engaged and maintain a level of self-awareness throughout the study, which leads to a richer and more 'connected' knowledge of the data (Gilgun, 2008). This is because it allows the researcher time to reflect on the data and be more objective in their interpretation whilst also connecting with the participants as they get to know them through watching their vlogs.

Chan et al. (2015) found that healthcare professionals had a tendency to become overwhelmed by emotions and suffering of their patients, leading to increased stress (Ellington et al., 2012; Dickson-Swift et al., 2008), which within this study would be a distinct possibility. The research indicated that professionals needed to acquire a competence to face the impact of death on themselves within their work (Taylor et al., 2016). Therefore, the risk to the researcher is ‘emotional burden’. Back et al. (2016) highlights the importance of building resilience skills to stop the burnout of a clinician or researcher using reflective skills and a framework of training and support.

Reflective practice has been evidenced to improve clinical competency and support an individual to identify independently their learning needs (Miller & Moyers, 2006). There has been an emphasis that structured reflection enhances clinical learning, which then enriches clinical performance (Mamede et al., 2014). Throughout this research, I have used ‘reflective portfolios’ to provide opportunities to channel my reflections, provide a heightened awareness of my learning experience, and as a reference for future self-directed learning (Tsingos et al., 2014). These have been completed following the initial watch of the vlog and then as often as required. The reflective portfolio is based on the work of Germain et al. (2016).

Table 4.2 Example of reflective portfolio



From: The use of reflective diaries in end of life training programmes: a study exploring the impact of self-reflection on the participants in a volunteer training programme

Specific reflective diary sheet
This is to record a specific or important event
Name__________________ Date ____________
Event to be reflected on: _______________________________
Description- What happened?
Feelings- What were you thinking & feeling?
Evaluation- What was good & bad about the experience?
Analysis- What sense can you make out of the situation?
Conclusion- What else could you have done?

I conducted the observations of the vlog and transcriptions at home, and therefore there were considerations of the risks of lone working. Specifically thinking about the psychological and emotional risk I faced in having to analyse the potentially upsetting or distressing data. To manage these risks effectively, I have clinical experience within the field of palliative care, which supports resilience, I utilised the reflective portfolios and accessed regular supervisions to support and de-brief in relation to any issues and observations made. Alongside reflexive practice, I required strong support from mentors and peers to reduce any emotive burden experienced (Penner et al., 2016).

It has been known for researchers to suffer from the cumulative effects of repeated exposure to conversations focusing on death and dying (Ellington et al., 2013). The interviews within this research are at vulnerable times in the individual's life, and they post their vlogs "in the hopes that their experience will ultimately benefit others" (Ellington et al., 2013, p.128). In order to honour their participation, I have reflected and appreciate how the observation of the vlog has affected them.

The researcher cannot always fully detach from the interview due to the emotive nature of the topics within, and this will then shape the interpretation of the data (Hollway & Jefferson, 2000). It is likely that the vlogger knew from the content of their vlog that it would evoke an emotional reaction in those observing it; however, it was clear from the vlogs that they did not want the observer to 'feel sorry' for them but instead wanted them to have empathy for them and to use this emotion to further support this clinical area, e.g., donating to one of the cancer related charities. Researchers can have strong emotional reactions within the interviews, transcription, or interpretation, and often this is done whilst lone working. Therefore, it is important to utilise mentors and peers (Penner et al., 2016). I was given the opportunity within my supervision sessions to acknowledge and validate my emotions and then channel the emotions evoked from the vlogs into the analysis of them as data. I utilised the reflective logs to structure my thoughts and feelings to aid these discussions within the supervision sessions.

Within the field of social science research there are a number of methods used to counterbalance any attachments. Initially, there is a requirement within to embody self-scrutiny (Berg, 1988) and a strong encouragement to have mindful and reflective practice. Evidence suggests that mindfulness encourages moral reflexivity and self-transformation, which in turn can contribute to new ways of management learning (Vu & Burton, 2020). Researchers exposed repeatedly to death and dying conversations are encouraged to practice mindfulness (Dickson-Swift et al., 2008) and reflective practice. Orellana-Rios et al. (2018) conducted a study in a palliative care setting using interventions consisting of group meditation, 1:1 meditation session, mindfulness breaks, posters in the staff rooms, and at home meditation CDs. They found a significant reduction in anxiety and burnout of staff and 85% achieved their personal goals, which included improved self-care. However, the interventions were very intensive and therefore if done with less intensity, may not have the same significant impact.

4.14 Summary of Chapter

This chapter has examined the typologies of narrative analysis and the rationale for the selection of dialogical narrative analysis and dialogical performance analysis; to be utilised for the individual narratives. A cross-narrative approach has been used to analyse similarities within the narratives to identify themes. I have articulated the methods used to gather the data in the form of vlogs. I have provided a very detailed examination of the ethical considerations of working with TYAs who are at the end of life, anonymity as a concept, and the complexities of IMR. I have evaluated the importance of transcription within this method and the aspects of speech and interaction I will be analysing. In the next chapter, I will explore the findings of the data.

Chapter 5: Findings

5.1 Introduction

This chapter will outline the sample for the study and the transcription coding used to transcribe the selected data. It is first thought that the researcher needs to imagine the shape in which the findings will be discussed (Clandinin & Connelly, 2000). For this chapter, the shape of the analysis is a summary of the data, the individual analyses, and then the cross-analysis of the narratives.

5.2 Sample

For some individuals selected for the research there were tens and hundreds of vlogs posted by that person, which made it difficult to sift through the material to find the most appropriate ones to include in the research. For those individuals, I have opted to choose the first video they posted, along with the last video that they posted and then if appropriate, ones in between that held some specific information that was pertinent to the overall narrative, for example when they received an update about their medical health or their prognosis changed, or if they were experiencing a significant life event, e.g., getting married. For those individuals, the narratives do appear linear as they follow a logical sequence of when they were diagnosed and follow their journeys as the disease progresses. For others who only posted one vlog, their narrative can at times be constructed in a non-linear way and this is reflected in the analysis of these.

Within the data sample, there are 6 individuals whose ages range from 15 years to 23 years at the point of diagnosis, and 19-24 years at the time of death. It has not been possible within the data collection to identify their ethnicity and nationality as this is not explicitly mentioned within their vlogs; however, they all appear White British with English or Welsh accents. They include individuals living at home with their parents and studying, and individuals who are living independently with their partners; one participant had a baby. They were all at very different places in their lives at the point of their diagnosis and when they posted their vlogs. Therefore, the sample does include a range of important demographics. The demographics of the 6 participants are outlined in Table 5.1; it states the gender of the participants, of which 4 are male and 3 are female. They all had cancer for at least 12 months before they died and were all over the age of 19 years at the time of death.

Table 5.1: Study Demographics

Name given to participant	Gender	Age at diagnosis	Age at death	Vlog Times	Total Vlog Time
Adam	M	23 years	24 years	4:06	4.06
Billy	M	22 years	24 years	3:32	3.32
David	M	22 years	22 years	9:10, 1:24, 5:12, 7:15, 6:40; 8:56, 8:00, 5:42, 3:36, 1:42, 2:43, 0:58, 17:16, 4:44, 9:41	89.79
Francesca	F	22 years	23 years	5:10, 5:54, 9:56, 5:29, 4:53, 6:09, 10:31, 5:30, 16:29, 6:33, 7:02, 6:10, 9:24, 10:53, 4:47, 9:09, 9:57, 4:43, 8:56, 7:48,	197.34

				10:16, 11:13, 8:13, 7:06, 10:03	
Gemma	F	16 years	19 years	4:41, 3:13, 2:48, 3:36, 1:36, 2:43, 0:43, 6:52, 12:52, 4:42, 8:05, 1:31, 0:27, 0:36, 0:24, 0:44, 7:54, 1:04, 1:08, 7:51, 6:14, 9:36, 9:16, 8:42, 7:35, 15:11, 10:55, 13:28, 13:56, 7:08, 6:56, 14:18, 17:43, 18:09, 7:39	232.56
Harry	M	15 years	20 years	9:19	9.19
				Total Time	**536.26 minutes (8.9 hours)**

5.3 Transcription coding

For the transcription of the vlogs, a specific code was used to allow for consistency and replicability. The code used was based on Norrick (2000) and aims to capture both what is said but also how it was said, so that the reader can build a mental image of the vlog including the feelings behind what has been said.

Table 5.2: Transcription Coding

Code	Meaning
(Insert number); e.g. (1.2)	Timed pause of >1 second
Single hyphen (-) directly after a letter / word	Abrupt cut off
A period / full stop e.g..	Falling intonation
A comma e.g.,	Continuing intonation
Underlined	Specifically, emphasised syllables, e.g., higher pitch, greater volume, prolongation of vowel
{insert words}	Laughter
‘Insert word’	Crying
[insert words]	Interruption from another person / overlapping speech
((insert word / action))	Non-verbal communication
Hyphen with a space, a – a	A short pause

?	Raise of intonation (not necessarily a question)
H	Audible breathing / significant exhalation (the more ‘h’ the longer this is for)
Asterisk e.g., *insert word*	Words spoken very softly / gently
Parentheses e.g., “insert word”	To represent unclear speech and the approximations of the transcriptions

Taken from (Norrick, 2000; Ochs and Taylor 1992; Drew, 2015)

This section contains the individual analysis of the six vlogs that were chosen to be included in this study. Each analysis will begin with a brief introduction to the participant and a summary of their vlog (c*ontent*), and the people that are mentioned within the vlogs (*principal agents*). Each narrative is then organised into the important narrative elements of the vlog (*structure and sequence*) analysed in line with Campbell’s (2015) elements of *departure, initiation, and return*. The purpose of the narrative is outlined (*purpose*) and the place/setting where it occurs (*place*).

5.4 Analysis

5.4.1 Content

Within the dialogical narrative approach there is consideration for what makes a story (question 2, Table 3), in this report there is a collection of voices that share similar experiences that all tell their stories differently. The content of those stories reflects their shared experiences. For each of the participants the intrinsic critical event that has led them to create these narratives is their diagnosis of cancer. For those participants with a single vlog, they start by outlining how they received their diagnosis, the symptoms they had and the current status of their treatment; and for those with multiple vlogs there is a vlog specifically posted that introduces this.

For five out of the six participants, have other individuals feature in their vlogs in relation to sharing their views and emotions and adding to the narrative. For Gemma she features on her own in the vlogs except for her final vlog in which she features visually but her mum speaks the words Gemma has written due to the progression of her illness.

For five out of the six participants talk within each of their vlogs about the symptoms that they are currently experiencing and the impact that this has on their lives and the lives of those around them.

Adam states, “slowed down a little bit” (referring to his physical health and ability to keep up with his previous lifestyle of socialising) and how these impacts on his ability to play sports which is a passion of his. Frankie goes through “losing hair, losing function of things”, “shattered” and “dizzy” which prevents her from participating in the things she describes as normal, e.g., going out for lunch with her family; but then in between treatments she feels “stronger” and can go to the gym which is something she describes as her “way to cope”. Billy describes episodes of “collapsing on the floor and shaking (1.6) and some days I couldn’t’ move”; he uses this to demonstrate the support he has received from his wife “what she’s done for me”. The long pauses in his speech suggest reminiscence and reflection on the support she has given him and the love she feels for him. David does not talk in his earlier videos about his symptoms, and this is suggestive that he follows a restitutive narrative which aims to show his audience he is a fighter, and that the cancer has a limited impact on his life. However, in his later videos when he is approaching the end of life he describes “I can’t get on top of the pain, sickness or symptoms, and I am very unwell” which is indicative of him moving towards the acceptance of his illness and the realisation that he is unwell and unlikely to recover. Charlotte clearly documents the progression of her illness within her vlogs and is candidly honest about her symptoms but also articulates that she feels that these are temporary and will get better. For example, “if I try to smile (smile attempted) you notice this cheek goes up instead of smile (smile attempted) but this one, this side isn’t responding and isn’t doing anything…I need to do sort of mouth exercises” and “my voice still very funny….in the morning my voice sounds better”. Harry does not talk about his symptoms at all, he spends his vlogs talking positively about the things he is getting to do, the opportunities he has and how life with cancer “doesn’t have to be about suffering”, this means that it is difficult to understand the true impact of cancer on his life and what he is experiencing in his real life (off camera).

5.4.2 Principal Agents

Within the vlogs the main principal agents are the participants themselves, family members that appear in the vlogs and the audience. The dialogical narrative approach focuses on the different voices that can be heard in stories (question 3, table 3), which is discussed in this case as participants.

5.4.2.1 Participants

The vlogs are all depicted in autobiographical narratives, which involve the participant themselves talking directly at the camera, talking about themselves and at times including others in their vlogs. There are six participants and I have described each of them below using information obtained from within their narratives and their own voices. Whilst most of the vlogs are monologue in nature, they can still be considered dialogues. As previously discussed in Bakhtin’s (1984) work there are two voices as a minimum per life, the dialogue that exists between the individual experiences and the socio-cultural discourses (Vitanova, 2013). There is a polyphonic nature in all the vlogs which is apparent in how they describe the impact that others have had on them and how this influences how they represent themselves. There is a heteroglossia nature covertly present in the vlogs and this is reflected in their choice to post them online and consideration needs to be given for the impact that this has on how they represent their emotional codes as an example.

Adam was 23 years old when he received his diagnosis, and 24 years old when he died. Adam reported “being told at the age of 24 you probably won’t see 30 that’s a moment you’ll never forget”. Adam was a young aspiring athlete and lived with his parents. Adam described the brain tumour as “ended my career” and reported the impact on him and his family as “the worst nightmare”. Adam has posted one YouTube video outlining his cancer journey.

Billy was 22 years old when he received his diagnosis and 24 years old when he died. Billy attempted all the treatment offered to him as he wanted to say that he had done everything, he referenced that he owed it to his wife because she “stuck to her vows, in sickness and health”. When Billy found out that he had cancer his wife was heavily pregnant. Whilst Billy only posted one vlog, this had small clips in from the point of diagnosis to the end of his life, so within one of the clips he was with his new baby and in these specific clips his whole demeanour changes to smiling, happy and positive “I’m glad we had her when we did otherwise, I might never have had the chance to have a baby”.

David was 22 years old when he received his diagnosis and 22 years old when he died. He lived at home with his mum and dad. David had been documenting his cancer journey from the point of diagnosis through videos that he posted online; there are tens of videos. David does not talk much about himself on a personal level in his vlogs, he talks about his cancer and its progression. He talks about trying everything to see if he can prevent it from spreading or cure it and that is the main fixation of his vlogs.

Francesca was 22 years old when she received her diagnosis and 23 years old when she died. She was newly married and lived with her wife. Frankie describes herself as “strength, ambition, addict, nutrition addict, personal trainer” and she finds it challenging that someone in such peak physical condition can have cancer all around her body. This is something that we see play out in the vlogs, the challenge between accepting her palliative state and not wanting to accept it. Frankie has posted tens of videos that document her cancer journey and her personal narrative that goes along with this. She appears in some of her videos with her girlfriend (who becomes her wife during the series) and some on her own.

Gemma was 16 years old when she was diagnosed with cancer and was 19 years old when she died. Gemma describes herself as a “typical teenage girl” and spends time in her videos talking about fashion, theatre trips and friendships. Gemma describes the “new confidence” that having cancer has given her and tries to find the positives in having cancer. Gemma talks about growing old and does not appear to acknowledge that she is palliative. She was hoping to go to university and lived at home with her parents. She talks about her family in the videos, particularly her brother as he takes her out on trips which she describes as “amazing”, however none of her family or friends feature in her videos.

Harry was 15 years old when he was diagnosed with cancer and was 20 years old when he died. He lived at home with his parents and aspired to become a doctor. Harry was diagnosed with cancer whilst still studying at high school, despite the challenges that came with his treatment and diagnosis, he continued to attend school. Harry used his social media to make people aware of his cancer and to start a bucket list which he worked through in the last years of his life. He focused his time on the bucket list and fundraising and his social media accounts are peppered with campaigns and things he did for various charities.

5.4.2.2 Relationships

Each participant talks about the importance of support from others and how that improves their quality of life and lessens the impact of having cancer on their lives. This can be heard as their polyphonic voice describing the hopes and expectations they had for their lives and the views of their loved ones.

Adam’s mum appears in the vlogs and talks about how she already felt that she knew something was wrong “I think mothers know things don’t they”, and how they feel “it’s pretty tough” and for his dad “It’s the worst nightmare”. Both his parents cry during their parts of the narrative whilst looking directly at the camera rather than at Adam. It is not typical for parents to care for their child who is dying and what you can see in the vlogs is them trying to navigate this. They want to be there for Adam but are struggling with their own emotions and on one occasion Adam puts his hand on his Mum’s to comfort her.

Billy’s narrative opens with him sharing the memory of when he first met his wife, and they shared this together. They maintained eye contact with each other whilst sharing this, with little acknowledgement that there was a camera or anyone else watching. There was such as sense of deep meaningful love in that moment, and this drew in the audience to want to know more about Billy’s life and his relationship.

B: When I first met Sally (wife) we fell in love basically.

*S: We met up in Boots, *everything went from there really*.*

B: You were very nervous to meet me

S: [Yes] (laughs)

B: (laughs) We were 2 opposites and I think that’s what’s made us.

Billy then took the opportunity to thank Sally, *“Sally certainly stuck to her vows, in sickness and in health. I don’t think any other girl in this world would do what she’s done for me”.*

For Billy and his wife, they display a sense of being strong for each other, there is evidence that suggests there are strong effects of marital status on psychological wellbeing. Research indicates that those in a caregiving role can experience grief and loss at multiple stages throughout the progression of an illness which can impact on relationships (Sanders & Corley, 2003).

There is a lovely demonstration of a mother and son relationship with David’s vlogs, with his mother not only is his mother supporting him in practical ways such as getting him a coffee and driving him to his appointment, but also providing emotional and social support by laughing and joking with him even in moments of anxiety, fear and the unknown. This is clearly seen as they have regular and prolonged eye contact when speaking, they smile a lot at each other, and she reaches over to place her hand on his arm when he starts to find it difficult to speak or becomes teary.

There is a distinct difference with the way Francesca presents emotions, the self, and nuances in her inner thoughts when she is in the presence of her partner versus on her own. Frankie often thinks about the impact of her having cancer on her wife and in one exchange she says “, the worst thing about it is my wife…I feel awful”, (reply from her wife) “what do you feel awful for, you’ve given me like the best 4 years of my life” and she says, “but I want to give you 40”. In her vlogs she talks about how important her relationship is saying “we usually…face it with strength and positive and love”. They spend a lot of time together in the vlogs going to the gym and out for lunch, her wife reports “I think we cope by being positive and also spending loads of time together”. This demonstrates how important close supportive relationships are for the person and their families / friends in coping with cancer. They also talk about day-to-day life as a couple “I stayed up watching the last 2 episodes on my own, oops, that’s against the grain for any relationship, it’s not allowed” (Frankie’s wife) to which she replies, “you cheated on me with Happy Valley”. This also demonstrates some elements of them grounding each other and trying to show the other side to their lives aside from cancer.

Gemma posts all her videos in a monologue style in her bedroom, others do not feature directly in the vlogs, but she does refer to others when telling stories or sharing information with her followers. She talks about a trip to the theatre with her brother, but she does not share with her audience/followers’ details about her brother, e.g., his age, whether they are close etc. She does not refer to her parents in her videos specifically but does talk about ‘family’. Other than in her final video where her mother speaks the words she has written as she is too unwell, the audience does not have insight into her family.

5.4.2.3 Audience

As all the vlogs are posted on YouTube for the public to access, the audience in this case is anyone who views the vlogs. I have not analysed the comments posted by viewers within this study, but I acknowledge the impact that these have had on the participants and within each of their vlogs they comment on how positive and supportive the comments have been and how that has made them feel. Of the 6 participants, 2 have only posted one video and therefore they do not reference the audience in terms of thanking them for their comments. This gives insight into why they are telling the story (question 3, table 3), as they are sharing it for a purpose such as seeking support, helping them express themselves and to share their individual experiences.

As with the other vlogs, David thanks people for supporting him “thank you for being there for me”, commenting “thank you for commenting”, and liking his vlogs “thank you for liking” which he feels is supporting him whilst this is “traumatic for me”. David struggles with some of his vlogs describing it as “the hardest video I have ever done” when he talks about his latest test results. After this reflection narrative, David continues to post further vlogs documenting the deterioration in his presentation. His final vlog is when he is in the hospice and very unwell “I don’t wanna do a massive update because I am too unwell, but I’ll update people when I can”.

Francesca ends her vlogs by thanking people for their support for both her and her wife, e.g., “thank you so much for all supporting me, loving my videos erm and giving me feedback. Well, I love you all, thanks so much you’re my support”. She also talks directly about her subscribers, which is unique to her in relation to the other participants “I’m really nearly at 50,000 subscribers which is mental…pretty cool though. I’ll see you in the next video”. Frankie also sets up question and answer sessions live on YouTube although she reports “I don’t like Q&As if you haven’t guessed”. Frankie has an interesting relationship with her audience, and it does appear that she uses the vlogs not just to engage with people but also as her coping mechanism to express her emotions, her day-to-day life and at times it does feel that she has become dependent on the vlogs to keep going.

Gemma also appears to use the audience as her coping mechanism and seeks feedback from them to reassure her. She appears to want to get the videos right and unlike the others who appear to film and post raw footage, she cares more about the image she is portraying “this is my 3rd time filming this video, so hopefully 3rd time lucky”. In her vlogs she always thanks people “thank you so much for my lovely comments and erm subscribing and liking and everything else. So, thank you for watching and I will continue to keep you guys updated”.

Unlike the other vlogs Harry’s contains lots of brief interviews with other people. These are people who are considered important to him, such as his parents and best friend, and others whom he has touched during his life, such as his teachers and people who have been part of the charitable events he has set up. These are interspersed into his monologues and include quotes such as:

“he’s inspired and motivated so many people”.

“The most powerful thing I have ever seen is when you actually meet Harry, because Facebook is one thing, and you can see all the positivity he brings out, and he really does bring this out together, but when you meet him, the effect is tenfold”.

“He’s extraordinary with his positivity in terms of it doesn’t matter what life throws at him, he’s still going to make the best out of every situation”.

“He knows he’s in a bad situation, but he makes the best out of it and gets the best out of other people as well and not just himself”.

“His focus and drive and passion and burst for life I just find absolutely staggering, erm, and his desire, his genuine desire to help other people who are in difficult situations as well is an absolute inspiration”.

These quotes lend themselves to ‘heroic’ narratives, as they list qualities that would often be used when describing someone heroic or inspirational.

5.4.3 Structure and Sequence

5.4.3.1 Quest Narratives

Departure Phase

The *departure,* which is typical in quest narrative, is introduced by Adam as he moves to outlining his symptoms and essentially the start of this particular narrative, a very quick progression from initial symptom to significant deterioration and end of life. This section for Adam’s narrative is very short and his main focus is on the *initiation* stage.

The *departure is where* Billy outlines how his illness journey actually started *“I was so tired (2.3), no strength, I was collapsing on the floor and shaking (1.6) and some days I couldn’t move”.* Whist Billy was explaining this, he had long pauses, as if remembering each moment in detail in his mind but then only sharing the summary of this with the audience, *“Before we started putting things in place (4.2) to get married and stuff (3.8). Shannon certainly stuck to her vows (1.2), in sickness and in health”.* He was careful over each word, with some slight over-articulation, a gentle and soft tone to his voice and audible breathlessness at the end of the sentence. He spoke as though he wanted the audience to really listen to each symptom in turn and to really grasp the impact that this was having on his life. This was polar opposite to Sally's description of the start of the journey, and instead she rushed through the sentences at a fast pace with the sense that if she said it all quick enough, that she did not need to dwell on what had happened and the impact of this, almost as if it was pressured speech. This demonstrated for Sally that she had probably not moved to the acceptance phase of the illness journey, and almost as if she still could not quite believe it was happening to her and to Billy; *"Billy gone and got his blood test and the consultants came in and said to me, Billy you've got a type of leukaemia. I just stared out the window, I didn't know what to do or what to say and I can just remember bursting into tears".* At this stage in the narrative, neither Billy nor Sally knows the extent of Billy's diagnosis or prognosis and are therefore both hopeful that the treatment will support Billy to get better. There was some understanding of the worst-case scenario "Sally was heavily pregnant, and I might not be here within a week or two".

Francesca starts her vlogs (*departure phase)* with outlining where she is currently up to in her diagnosis story, "*So I got some results yesterday and basically things are too great. Er, the lump in my chest (1.1) is cancerous. It is melanoma, it's erm basically a tumour that is grown from my original source of cancer*.*"* Francesca is very articulate with how she is feeling in relation to this news, *"This is not good at all, and it's actually really panicked me".* It is clear from the language that she uses to describe the cancer that she is finding her diagnosis really difficult:

"Er, it's scary because, it's right there, it's on my chest, and it's like, it's almost suffocating (1.1) you know I almost feel suffocated by it, it's tiny, you know it's not going to suffocate me like (gestures with hand to throat multiple times) it's just

because it's there, it's on my chest, it's probably, you know along with the brain tumour it's probably one of the worst places I've felt like I've had it."

Within one of her vlogs, she is reviewing her cancer journey so far, *"So this is the, one, two, three, four, five, sixth place, seventh, wow seventh place the melanoma has spread to".* She outlines the impact that finding out there is a new tumour has on her life:

"Incredible, that's like, it can go round so quickly and then I've just been again like woken up, you know. You have these hints of shit reality and like I could have been dead by now. And then you kind forget about it when you get good results, you forget about it and you get sucked into work, life, stresses that really matter to you on a day-to-day basis but really in the grand scheme of things are nothing you know. And I've just been woken up once again by this like cancer just reminding me, you know I'm lucky to be alive. No day is promised with cancer, and you know no day is promised even without cancer. And you just kinda realise that a little bit more".

Although Gemma has posted tens of videos, in the initial vlog that she posted she outlines her diagnosis and when she found out she had cancer. Gemma's *departure* stage of her narrative starts with her telling her story about what happened.

"I'm gonna start from the beginning and then just basically give you the story. So erm a few days ago I was having a really bad pain in my earlobe, this is my left earlobe. And I originally thought it was due to erm like my earrings because they are from Primark, and I wasn't you know sure. But I've never had a reaction to earring erm so I took them out and the throbbing still went on for a couple of days. It was really weird; it was just in my earlobe and then it started to stretch down here and erm I just didn't know what it was. I didn't think anything of it. Because it's such a weird thing

and I didn't think that could be anything. Erm, and then fast forward to 2 days ago I was out and I started to feel kind of sick erm very like wobbly and I had a really bad headache as well and also my eyes started to kind of like feel they were rolling around and stuff. So, erm then yesterday me and my parents went up to the hospital to see my consultant and told him about these symptoms and erm he did a few tests. Erm, like getting me to walk in a straight line and all that and erm basically he said that these are symptoms and I was kinda expecting symptoms but they hadn't happened so erm, I was, I couldn't really tell if they were symptoms or not because they were so weird like in my earlobe but he said that this erm, this is the kinda thing to expect, especially with a brain tumour because obviously your brain controls everything. So even something like the throbbing on my ear was explained and expected because the brain does weird things and so erm and so I got put on some medication yesterday and I have been taking it." Gemma goes into such specific level of detail so that the audience can experience everything with her, she hasn't chosen to omit details or prioritise what she wants to tell the audience, but to tell her story unfiltered with all the details. This is something that Gemma continues to do throughout her vlogs.

Initiation Phase

Grief

For Adam, the initiation stage is one that on some level appears to reflect the five stages of grief, and this grief is for his perception of self and the understanding of his life change. The five stages of grief are denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 2021). Kübler-Ross (2021) reports that people can move back and forth between stages, which is reflected in the vlogs as each individual appears to go through phases in which they accept their illness and then moments in which they appear in denial or angry. Neimeyer (2001), says that people look for ways to make meaning of loss and this comes out in their narratives. This is present in the data as each individual talks about how their illness has given them a different meaning in life. There are other models of grief, such as the six ‘R’ process (Rando, 1993) and Bowlby’s attachment theory (Bowlby, 1998); however I feel that the data supports the Kübler-Ross (2021) model because of the way in which the participants move through the stages. The main critique of the Kübler-Ross (2021) model is that individuals processing of death is unique and complicated, which in turn makes it difficult to evidence and verify (Sánchez & Campus, 2005). I have used the model in a flexible way to outline how the participants experience the loss of their future and their acceptance of death. Adam does not appear to reflect in this narrative any specifics for the denial phase (first stage of grief); however, there are long periods of time within the narrative in which it is apparent he is doing deep contemplation, which is represented by his silence, his glazed over eyes, the lack of expression in his face, and the inability to articulate how he is feeling. These moments are very powerful in aiding the understanding of the difficulties that can be present in putting words to how you feel, and that sometimes a quiet moment with no words says everything that is needed to be said. This can be thought of as narrative silencing in the presence of grief and anticipatory loss, which is equally as important as what has been said (Fivush & Pasupathi, 2019) and is part of the social construct of the narrative. Individuals choose to withhold information as part of their self-presentation in an attempt to regulate emotions or as a voice itself, which in this case appears to be sadness. There then appears to be moments of anger (second phase of grief) and the sense of ‘Why me?’. Adam does not have the traditional presentation of anger in the sense of a raised voice and a reddening in his face, but instead he has subtle changes to his mood, which is presented in increased rigidity in his body stance, a tightening in his jaw as he fights to get the words out through the tension, over-articulation of each word to add strong emphasis and emotion and a fixated eye contact that pushes the observer to a place of slight discomfort due to its intensity. "*Being told at the age of 24 you probably won't see 30 that's a <u>moment you never forget</u> (2.6)".* For the bargaining phase (third phase of grief), Adam did not verbalise his feelings; however, he appeared in the video with his dad who said, *"he persevered, he carried on, he never quit, did slowed down a little bit now I must admit."* Adam's lack of comments here suggests a sense of hopelessness and a move to the depression stage (fourth stage of grief). *"You know it's depressing in all likelihood that you're going to die young (1.6). You're not gonna grow old, you're not gonna have kids, you're not get married and have a house hh and all those things that *you kinda expected you would do*". "Before I was diagnosed, before I went into hospital, I was thinking of progression professionally. I was thinking about saving a bit of money and putting a deposit on a house. <u>Now it's all what do I do with the moment</u>, what would be a real shame if I didn't accomplish this before my prognosis runs up (3.1)".*

<u>Relationships</u>

The *initiation* begins with Billy having his treatment in hospital *"Being in hospital, Sally was there every day, every single morning <u>7 days a week from 8am to 10 o'clock at night heavily pregnant</u> *until she dropped*".* Whilst saying this, Billy did not look to the audience but instead looked directly at Sally; it seemed like he was using this as an opportunity to let her know how grateful he was for her in his life and wanting others (the audience) to know how invaluable her support was. He was directing the audience to the other actor within the narrative and imbuing ethical and moral integrity to Sally. Sally averted her eyes from his, and instead continued to face forward (towards the camera) and look down at the floor. This may be a sign of her personality and finding it difficult to accept compliments (as many people are), or an indication that she was just about holding it together and that a glance in Billy's direction may have caused her to break-down. Silence can be used for a range of reasons which can include to retain one's self-respect, as a strategy for survival (Porter, 2016) and in moments of reflection. The silence here could also represent a shared understanding (Fivush, 2009), which is present between people in deep and meaningful relationships. Silence can be associated with grief and in this case the anticipatory grief for Sally. Anticipatory grief requires effort to regulate emotions (Coelho et al, 2020) and in this moment it does appear that Sally is using silence to support her to do this. Silencing has been used to describe the experience of a profound loss. Campbell et al. (2022) refer to the death of a child as "unspeakable" in response to the trauma that occurs before, during and after the death. The challenge of speaking about the experience of dying for young people and their families can be difficult (Bates & Kearney, 2015; Hooghe et al., 2018) which can then lead to further difficulties in defining 'dying well' (Campbell et al., 2022). Those moments in the narrative give incredible insight into the impact of an illness journey on a relationship, and the importance of love and support. There is a sense of protectiveness from Sally to Billy, which is often found in couples. Research particularly into couples where one person has a chronic condition or dementia research (Adams, 2006) shows that often people feel an increased level of protectiveness and tenderness towards each other.

This moment of love is followed by a moment of mixed joy and sadness, which is echoed in Billy's intonation patterns and broken smile. *"<u>She's perfect</u>. You couldn't* *ask for a better baby. I'm glad we had her when we did otherwise, I might never have had the chance to have a baby hh (4.2)".* Following this long pause, there is some tears that roll down Billy's face and he has a moment of reflection and quiet. There is no audible sobbing, no redness in the face, just silent tears. Sally reaches over to squeeze his hand, and they both continue to look down at the floor. This is a really difficult moment to watch for the audience, as the social construct of the birth of a first child is usually matched with feelings of joy, happiness, and hope for new parents and those around them; but in this moment, there is sorrow and sadness for Billy and Sally clouding that joy. This feels like an intimate moment which has been captured in a very public way and as an audience member it has the potential to feel like an intrusion into the grief of someone else, which can be emotional charging.

Hope

Hope appears to be a theme that is threaded through all the vlogs. Adam's dad says, "He never did quit" and he reported "you keep fighting". Frankie's wife says, "The nurse called you a miracle and I truly believe that's because of your positive mindset".

Following the birth of his child, Billy moves to a place of temporary hope and optimism as he talks about his treatment *"The cancer is very rare. It's going to my brain and it's in my spine. I started radio, it's not the easiest thing with being trapped under a mask for a long period of time. You're lying there hh and you're feeling what's happening to you hh. I can feel myself getting tired as the day goes on. It's not too easy on my wife she's minding the baby while I have my treatment each day".* He appears to understand that whilst optimistic, there is always a chance of his prognosis worsening *"There's always that possibility of something going wrong with* *the treatment as well"* but he does not dwell on this, and his tone of voice appears happier and more settled. He has a moment where the realisation of losing his family creeps in and his voice is that of contemplation *"What I wake up for at 3am is that she'd a widow so young, she's only just turned 22".*

Gemma says, "I'm not going to lose hope" and she continues to have this mindset even when she is no longer able to speak in the vlogs.

<u>Humour</u>

The initiation *phase* of the narrative for David in this video is the journey to the hospital appointment. This opens with a jovial conversation with his mother in the car and is not dissimilar to conversations that would be had with any mother and son on a car journey. *"Right, I'm in the car, we are on our way to the hospital, <u>again</u>. Erm, there's my mother, my mother is moaning at me because I said she can't have her pastries [my Danish pastries] {pastries, that's the one, until she went on camera} {laughing, a ha, ha poor woman}. She's crying now like oh dear, terrible, terrible behaviour [they are one of my favourites as well, apricot and custard]. Well, she can't have a Danish until she has performed".* The light-heartedness of the conversation continues in the car park, *"We've got here but we've been waiting in traffic in the car park for ages to try and find a space. How annoying is it mum [it is very very annoying], very annoying, very very annoying"?* It appears in this video that David is using humour to detract from the situation. His mother has been to get him a coffee and has difficulties with pronouncing it, so he is asking her to repetitively say it and then laughing at her *"What did you get me mum [{caramel macchiato or something}] {laughing 1.2}. Nice". "What coffee was it mum, {laughing} what coffee was it mum* *{laughing} [caramel macchiato] yes! You got it, that's annoying. I'll ask you again later".* Humour is often used in difficult situations as a coping mechanism.

There is a smile when he says about removing his "*entire back"* and this appears his way of using humour as a coping mechanism when sharing his news. He then goes on to discuss his prognosis "*I have been told to enjoy the next 2 weeks (1.6) as I am rapidly declining again hhhh. 'It's hard'".* So, David suggests that from health care professionals there was a directive to "enjoy" life.

For Frankie she is talking about a new tumour which has appeared on her chest, and she opens her narrative with "I want to get this off my chest (laughs) not funny…" but then bursts into laughter and needs to pause the video. This demonstrates that even with some bad news she is still trying to see some humour.

The *initiation phase* for Harry has several episodes to it, and this does appear because of all the participants. Harry's battle with cancer went on for 5 years, and he therefore had a longer period in which to experience the journey with the ups and downs. Rather than choose to dwell on any of the negatives of the surgery or its side effects, Harry instead opted for sharing a funny story with the audience, which is in keeping with his aim of sharing his story, to not to be defined by his illness.

"One week after the original operation took place to remove the tumour from the bowel, and one day after I was out of hospital, I ended up going to fancy dress party. Surgeon gave me advice to go home, take it easy and basically do nothing. But I decided to go to this party dressed as a granny in a wheelchair, and because of how much weight I had lost and because of how thin and pale I was pretty convincing. Erm, by the end of the night I was being pushed around in my wheelchair having an

absolutely fantastic time. And this was me from the off making a statement of how I was going to overcome my illness."

Return

Reflection

The start of Adam's narrative opens with feelings of reminiscence about the life he used to have; *"If you fight somebody where it's a close match - up it's like physical chess, you've got to outthink your opponent, that physical one on one can't really be replicated." H*e had a smile, his eyes gleaming and he appeared vibrant in himself, and then there was a noticeable change. The underlying intonation pattern of his voice, his averted eye gaze and the pauses in his voice appear to indicate a grief for this life that he is no longer able to lead and an acknowledgement that things are 'different' for him. "*When you get out there in front of a crowd, if you catch somebody perfectly with a throw, you're winning the fight. There's not many feelings like that"; "now I know I won't ever compete again".*

After a period of a day or so, David posted a video which is his reflection of what happened the day at the hospital, and what he is now planning to do; this continues the *initiation* phase of the narrative. David opens the video with being transparent about how he is feeling, not only about the news of his prognosis but about sharing it with his followers; *"This is probably going to be the hardest video I have ever done. For many reasons (1.4) I am going to try and get through it without crying, get through it without being sick".* He chooses to outline in detail his diagnosis and does this in a very matter-of-fact way showing little emotion at this point in the video. This is summarised below.

*“I went into hospital today to find out my results and they weren’t good (1.2). None of my site’s bar one which was miles away hh were clear (2.4) So every tumour that we thought was cancerous (1.1) but ‘more than that’ it’s *everywhere* (1.6). There’s not margins, there’s no margins, they did the first stain, and the stain was clear. And then they did a ‘secondary’ hh and it’s deposited everywhere (3.5) with deep spread (2.6). Unfortunately, they can’t remove my entire back, my entire side, my entire lymph node system (1.9). So, surgery is now not an option, and the likelihood is chemo and radiotherapy will not work. (2.9)”*

David’s *return* phase of his narrative concludes with his reflection and acknowledgement of how this is making him feel *“I can’t even explain how traumatic this is for me, and how worrying (1.3).”*

Acceptance and Hope

The *return* phase of the narrative shows Adam accepting his illness, his fate, and no longer being controlled by the illness but taking back that control. “*I think the mentality of a fighter h that’s the way I am treating this battle (1.1). You go down, you get up, you keep fighting it. You know with every fight there’s gonna be an end and a winner and a loser. I suppose you kinda got that with cancer as well. *I might lose at the end* hh but I’m gonna get a few big throws in along the way.*” He says “what would be a real shame if I didn’t accomplish this before my prognosis runs up”; which is indicative that he is accepting that he isn’t going to survive and yet he is hopeful that he has more time to accomplish more things.

There is a sudden change is Billy’s physical health presentation and his prognosis moves to end of life. Within Billy’s stance, he sits hunched forward as if exhausted and defeated, he takes an audible inhalation followed by a pause as if he was going to say something and then does not. He looks down at the floor, takes a moment and then looks up with a sense of purpose in his eyes, which is to tell the audience the next chapter of his story. *"This is the last chance saloon because they've told me it's more than likely going to kill me. They went 'we're sorry that you really don't have time left' (3.5)."* After he has finished there is an extensive pause; some researchers would describe the extensive pause as a silence (Watson, 2019). The purpose of the extensive pause or silence is difficult to interpret as this can have a range of meanings, in this case it is unlikely to be related to factors such as indecisiveness or lack of willingness to speak (Watson, 2019), but may be linked to difficulties in knowing what to say or emotional processing. Within the extensive pause, he continues to look straight down the camera for the entirety of that pause, as if he had come to peace with the likely outcome of his journey. I got this sense of peace from Billy because he looked calm in the face and his overall demeanour appeared relaxed. That was his final sentence uttered in the video and he died shortly after that. That sentence was his return, ending his narrative.

David states "that's something I have to come to terms with", "I am now documenting the end of my life" which indicates a level of acceptance. The coda "It's hard" was framed in emotional charged speak, for him, this was no longer a possibility. When David says *"It's hard"* he averts his eyes from the camera and looks down; he appears to be holding back tears and his voice slightly wobbles. The words are over-articulated and emphasised; it is as if this is a realisation for him that his life is not only hard now but about to be even harder. However, he immediately followed this with a rebuke related to his rapid decline and the unrealistic expectations associated with enjoying life, "I'll still be doing everything everyone says to try", which then suggests he may not have accepted his prognosis.

The *return* phase is seen in Francesca's last video, which appears in 3 distinct sections; firstly, before going to get the results, *"It is results day, results day means (3) what determines, the next couple of weeks, months, years, hopefully years".* She starts off with optimism *"I mean I have lived two months into our marriage which was what they thought they would never see so we are (unclear speech but then increased effort into articulation), we are already defying the objects, defying the odds. Which is good, which is really good."* The interaction which she has with her wife, Helen, is also optimistic:

Francesca – How you feeling about results?

Helen – I mean they can't tell me any worse than you're gonna die in a week so, we've already been told that

Francesca - {we have been told that, so}

Helen - I'm not laughing about it, I'm just like, I feel like,

Francesca - {It couldn't get any worse}

Helen – It couldn't get any worse, you know when people say rock bottom, I'm like

Francesca - {we've been there}

Helen - We've been there, we've already been told the worse of the worse, so and you're defying the odds. And like I always say at the end of the day like I always say

Francesca - {you've forgotten what you were gonna say}

Helen - No you're the same now, you're gonna walk in there in exactly the same, with the same amount of stuff in your body, that your gonna know when you walk out, even if they say you've got 26 tumours, your gonna have those 26 tumours in *you right now, and yet you've just been to the gym, and you went out for a meal until 10 on Saturday. So, it doesn't really matter, it's your still in control of it and I'm still in control of it.*

Francesca- {hum}

Helen - that's the thing, there just helping us by telling us the facts, the facts don't always, matter

Francesca - the facts don't always matter

What is interesting here is that Francesca herself does not answer the question of how she feels about her results, she appears to deflect to Helen to provide the answers and emotions attached to them. This continues in the second stage of the *return* narrative when they return home from finding out their results:

Helen - let's just appreciate the ice-cream before we talk about cancer.

Francesca - is it chocolate? The cone?

Helen - I don't know

Francesca - how do you feel about the results anyway?

Helen - yes, it is chocolate

Francesca - wow

Helen - I don't really care

Francesca - (laughs) brilliant

Helen - because you're living like a miracle now, you just gotta keep doing what you're doing

Francesca - I suppose

This is an interesting insight into how they are both feeling immediately following the results and prognosis being shared by the medical team. It does appear that they are both, perhaps, in the denial phase of grief in that they are using topics such as ice-cream to detract for being able to truly express how they are feeling. In this shot, Francesca is holding the camera and therefore we are unable to see her reaction to Helen's candid comment of, *"I don't really care"* and it would have been interesting to analyse the non-verbal response that she presented with.

The third stage of the *return* narrative is the day after 'results day' and Francesca does this section of the vlog on her own. The camera appears propped on the table, and she spends most of the video with her head in her hands or her hands rubbing over her shaved head. She does make eye contact with the camera (her audience), but she also spends time looking down at the table and what appears to be off in the distance (a glazed overlook). She describes herself as lacking in emotion; yet, within the vlog, appears almost at the point of tears, her eye contact averted for most of the vlog, and her voice wavers with emotion. Therefore, it almost comes across as though she is saying that she is fine, yet her nonverbal communication is giving us insight into her not being okay:

"I just think (3) to talk about results, I'm not really, I'm quite emotionless. I'm quite like numb towards them all, I think you can't (hh), there's only so many times you can be told, hh It's widely spread, it's widely spread, really, it's about quality of life, hhhh I'm just over it really hhh. <u>Over it.</u> Just got to ppppower on for life kinda thing. Just got to power on and get better at life. If that makes sense to anyone (3) it does to me (4). I've got no more tears to cry really, it's really interesting because you become like,

like numb (hand gestures), there's no more tears to cry, at all (4). Which is good because I'm not going to show any more emotion, I cannot give, (2) cancer cannot get any more emotion out of me".

In one of Francesca's vlogs, she says "Because you've actually got to talk about what you want to happen to you when you're dying. You've got to talk about it. It's probably the worse conversation you can ever have in your life, but you've got to have that conversation otherwise your partner doesn't know what you want". This indicates that she is aware of her prognosis and feels that it is important to set in motion the relevant plans and therefore has accepted this.

The *return* phase of Gemma's narratives is that of hope, yet denial about the prognosis of her condition. She reports, *"I don't know, you know really how long I'll be here for but for every day that I get I am forever grateful, and I wake up with a smile on my face. I strongly believe I will be here for years, until I am 90 years old." "I am not going to lose hope, I personally feel that I'm still here getting myself dressed, I'm still able to do all of my normal things and erm I don't feel it's my time yet."*

Within this vlog, Gemma talks about reaching 90 years old, which demonstrates some evidence of her being unrealistic in her expectations. Her marker of success in life appears to be carrying out normal activities such as getting dressed rather than ambitions of career, family, etc.

In Gemma's last vlog, she is not able to verbally communicate due to the severity of her speech impairment (dysarthria), along with her increased fatigue and general deterioration in her health. Therefore, she has written the words, and appears sat facing the camera but the words are spoken by her mum (who is off screen). Again, even in light of her apparent deterioration and struggles, she continues to have ‘hope’, yet this is one of the only times she openly acknowledges that life is a struggle. *“I have to be honest, life at the moment is a real struggle with little to look forward to. Hopefully the medication is working, and my body may begin to repair the damage caused. My brain is all there it’s just the rest of me that is struggling. It is my birthday in 2 weeks, and I will be 19, it would be really good to see an improvement by then.”* Within this vlog, Gemma maintained eye contact with the audience, she did not openly display any specific emotion and she attempted a smile at one point (although given her Oro-motor weakness this was difficult). As she did not speak the words herself, it is difficult to fully ascertain whether she remained to have hope, or whether saying this aloud was her way of coping with her prognosis.

Even when talking about his prognosis, Harry has this incredible level of optimism in his voice, he smiles, he maintains good eye contact, he shows positivity in his vocal tone, and has a relaxed open body posture. *“I do not know how long I have left to live, but one of the reasons for that is that I haven’t asked. And that’s because I don’t see the point, in measuring life in terms of time anymore. I would rather measure it in terms of what I actually achieve, I would rather measure it in terms of making a difference, which I think is a much more valid answer and pragmatic measure”.*

Similarly, to the other participants Harry talks about not wanting to die and not feeling like he has had enough time; his *return* is his acceptance that he will die at some point but that he wants to continue living until then. *“For whatever reason life has given me cancer, I don’t really want to die, but if my story teaches others not to take life for granted then so be it. In the meantime, I’ll be trying to enjoy every second as much as possible. Cancer sucks but life if great”.* The last sentence appears a clear summary of intention from Harry.

Harry’s videos are scattered with elements of hope and humour, which he uses to cope with his on-going diagnosis and prognosis. Out of all participants, he appears to accept his prognosis early on in his journey and he remains optimistic and upbeat throughout the vlog. He posts only the one vlog, which contains clips of him talking in a colloquy, and clips of images and videos of his achievements with an auditory commentary provided by Harry. Several others feature in his narrative in the form of adding quotes about who Harry was and how he touched their lives. It does appear that the purpose of the video is to raise awareness of cancer in young people, and to celebrate the life achievements of someone who is dying of cancer. He specifically references within the narratives that he wants to use his vlogs to show people what it is really like living with cancer and to encourage people to try to see the positives in every situation, even seemingly very negative ones.

5.4.3.2 Chaos Narratives

There are times in the narratives in which the participants present with a chaos narrative in which they envision life never getting better.

Adam says “You know it’s depressing in all likelihood that you’re going to die young (1.6) You’re not gonna grow old, you’re not gonna have kids (1.6), you’re not get married and have a house hh and all those things that (1.6) * you kinda expected you would do” it takes Adam a long time to say this sentence as you can see from the length of the pauses. It is as if he is struggling to understand that his future will not be what he thought.

For David, what we see is the aftermath of that sudden change of the pre-appointment optimism, the unexpected news, and the immediate impact that this has on both David and his mother. “*I’ve just come out of the hospital, mum don’t drive yet* *[mum is crying], alright. Erm (1.2) they've basically just told me that its inoperable now, surgery didn't work, h erm (1.2) no-one knows how long I have got left now and that's that".* This is an example of narrative of uncertainty. The jovial, happy, and laughing mother and son from less than 30 minutes earlier are now broken, sad and shocked with the news; sat in the car sharing a different moment. Not a shared moment of laughter but a shared moment of sadness in which they cry together. That moment is the *return* in this narrative and outlines the moment that the illness took hold of David.

5.4.3.3 Restitution Narratives

A restitution narrative represents an individual who is currently unwell but who wants to return to their previously healthy state. This is compounded by the social construction and expectation that individuals that are unhealthy will become well. For most of the participants they have demonstrated a level of acceptance that they will not become healthy and therefore don't display restitution narratives specifically. However, there are elements of restitution narrative within their wider narratives. Often battle metaphors are used in restitution narratives which De Clercq et al. (2016) states bring together suffering into a collective experience and empower individuals experiencing illness. They also found that this was the most common narrative type in parent's account of their child's illness, and parents would refer to their child as a 'fighter'. However, Myers (2002) stated that illness narratives, particularly restitution narratives can lead to delaying treatments and underuse of hospice care (Ezzy, 2000; Davies, 1997) as they can limit the individual into hope for a cure and reduced acceptance of their terminal illness (Myers, 2002).

Billy talks about a "last chance saloon" as he talks about having every treatment that they offer him just in case that's the one that works. This indicates that he is willing to try everything to become healthy again. This can lead to consideration of ‘over treatment’ and silencing discussions about advance care planning.

David then moves his narrative into a ‘fighter’ or restitution narrative (Frank, 2013); he talks about several things that he will keep doing to try to get better; despite being told of his poor prognosis, “_We are going to try hh. We have got back in touch with some of the world leaders in it and we are going to see if there’s something they can do (1.8) but for now, *there’s nothing*”._ But then almost immediately he talks about nothing working to help him; “_Diet won’t change this, changing how my body is alkaline or anything like that won’t change this. My cancer is deposited almost everywhere (2.4) there’s nothing at this point that will change it. And that’s something I have to come to terms with (4).”_ He appears to flit between the concepts of trying to do something to get better despite the odds, versus feeling the need to accept the news and renegotiating hope. This inner turmoil is played out in his narrative; you can see his emotional instability and fragility present in his non-verbal communication. “_Erm, still going ahead with all the DNA sequencing, even though it probably won’t help me, but it’ll help people in the future (1.3)”;_ when he says, “_won’t help me”_ he is looking down at the floor with tears in his eyes; he then looks up directly at the camera, smiles and says, _“but it’ll help other people in the future”,_ which is consistent with legacy work. This appears to be him coming to terms with and accepting his prognosis and that despite his efforts, it is unlikely that anything he will do will help him get better, and the only positive he has to hold onto is that he may help others. He further demonstrates his acceptance, _“And the spread is rapid. And going based on other people’s papers and hh all the research we’ve done ‘the timescale for me is limited’. (3.0) So, I am now documenting ‘the end of my life’. (3.0) And that’s hard (crying 1.0) and *that’s hard*.”_

Frankie says “I’m sure I’ll give it my best shot at surviving” despite knowing at this point her prognosis is terminal, as she talks about the idea that she could be the miracle that outlives the medical prognosis.

Gemma’s vlogs have a lot of restitution narrative within them, “I strongly believe I will be here for years” and “it would be good to see an improvement by then”; which is at the time when she is very unwell in the vlogs and is hopeful that she will be better in time to celebrate her birthday in a few weeks. She also talks about “we are looking at clinical trials and obviously my consultant is searching you know every corner of the world to try and find something for me”.

5.4.4 Purpose

The purpose links back to ‘why’ is someone telling the story (question 3, table 3) and to a certain extent includes what they have riding on telling it (question 4, table 3). The purpose of each narrative appears to have some common themes threaded through them which are raising awareness, helping others, helping themselves to cope and leaving a legacy for their loved ones. Some of the participants have overtly stated their purposes whilst others it appears implied by them either in the narrative or in the editing of the vlog.

5.4.4.1 Raise Awareness and Support Others

Both Adam and Billy’s vlog do not state the purpose of the vlog, however at the end of the vlogs there is some text which has statistics about TYA’s with cancer and asks for donations to a specific cancer charity. Therefore, indicating that the purpose of Adam and Billy sharing their narratives is to support fundraising and raise awareness of TYA cancer. There are references throughout Adam’s video to a particular cancer charity, which is indicative that the purpose of the video is to share his journey to inspire others, particularly in fundraising. Within the vlog, Adam appears to have followed the concept of a quest narrative as he outlined his illness as journey. He appears to use the vlog both as a memoir, but also in some ways as a manifesto; he is sharing his personal experience of his illness and suffering. However, with his reference to the charity, he is trying to use his experience to promote donations to support with improvements to assessment and treatments for cancer.

Billy's vlog appeared to have two purposes; one to highlight the impact that cancer has on families and young people to provoke potential fundraising, but also a way to demonstrate his appreciation for his wife and her commitment to him. This can be thought of as an example of legacy work. He uses the video as an opportunity to talk about how amazing his wife has been throughout and the incredible support that she had given him. The vlog followed a very similar structure to Adam's in that it presented with a quest narrative structure and used illness as a journey.

Initially, David's narrative appeared to have the purpose of sharing his story to help others; however, as his narrative progresses it does appear that the purpose has shifted to being used as a coping mechanism for him as his prognosis worsens. David says, "It will help people understand what this is more and how it spreads" and "It takes one person sometimes to make a difference, and hopefully I can be that one person, who can create this little catalyst to fix stuff".

Harry states *"I was diagnosed in September 2010, altogether I have undergone 7 lots of surgery, 30 sessions of radiotherapy and 4 different regimes of chemotherapy and soon I'll be starting a 5th. The aim of my story is to spread as much positivity as possible. To show people what it's like to have something go wrong in your life but not be defined by it".* Unlike some of the other narratives, Harry maintains good eye contact with his ‘audience’; it feels like whilst it is genuine hope he is describing, he has said that line so many times it almost felt rehearsed.

5.4.4.2 Legacy

All the vlogs are posted online which in essence means that they are leaving them as a legacy to their loved ones but also the public. Whilst they may not overtly state that they are posting them as a legacy they are in the format of memoirs which outline what has happened in their lives and where they are up to.

Adam talks about what he has achieved in his life “I was ranked number one…” and goes on to talk about how that made him feel and what his future would have been. He talks about the fact that because he was ranked number one on some level people will remember him and he will have left a legacy.

Billy’s vlog, it appeared to be in the format of a memoir (as it had a clear autobiographical timeline within it) and he talks about making memories with his wife and new baby being important to him. He talks about the baby being his legacy “I’m glad we had her when we did otherwise, I might never have had the chance to have a baby”.

Francesca does not overtly talk about leaving a legacy, but she posts tens of videos documenting her journey every step of the way and she includes her wife in the vlogs so that they can make memories together as a couple. This is unique compared to the other vlogs because Francesca rarely does one on her own.

David reports that he wanted to document his life and whilst that became hard as it was the end-of-life he says “I am going to continue to do it. I started something and I will finish it”. He also acknowledges that he is doing what he can to document things because he feels that he could be “the little catalyst to fix stuff” for other people. He sees being able to help others through his vlog as his legacy.

Harry does appear pre-occupied in his narrative about his legacy in terms of what he is able to achieve, the difference that makes to others and how he will be remembered, *“I don’t want to be remembered as someone who didn’t fulfil their potential, my original goal was to become a doctor erm and to help others that way. Unfortunately, my diagnosis means that I won’t be able to fulfil that dream, erm, however my core purpose of helping others is still the same”.* Evidence suggests that young people in particular use blogs and vlogs to support their processing of emotions, and this provides a space for grief for loved ones after they have died (Keim-Malpass et al., 2015).

Gemma wanted to post vlogs to share tips on fashion, beauty and “her beloved handbags”, which then progressed into her talking about her cancer journey. She does not overtly say that she wants to use the vlogs as a way of raising awareness or leaving a legacy, but this is what they appear to transform into from her initial vlogs.

5.4.4.3 Coping mechanism

It emerges throughout David’s narrative that his coping mechanism to manage his prognosis is to ‘keep trying’. As discussed above, he wants to try a range of things to help him (and possibly others in the future). This continues as the narrative progresses, *“I’ll still doing everything everyone says to try, to fix it, (1.1) that’s within medical science and as the doctors said today everything that I’ve said and everything that’s gone through and what we’ve researched and found out is alright”* and *“It takes one person sometimes to make a difference, and <u>hopefully I can be that</u>*

<u>one person</u>*, who can create this little catalyst to fix stuff".* David uses the vlogs as a way of telling people what he is going through, and he acknowledges the importance of the support that he is getting from others who are watching the vlogs and posting comments "Thank you for supporting me".

Francesca has posted tens of videos since her diagnosis, and she refers to the function of the vlogs as, "*I'm going to be vlogging as much as I can because it's gonna be the thing that's keeping me sane".* She even says that the vlogs are "how I am coping".

It is clear from the narratives that Francesca finds it difficult to remain positive and she describes cancer as a hurdle multiple times, "*So yet again I have another hurdle to cover, another hurdle to cross,* <u>*in the cancer journey.*</u> *Scary times ahead"* and *"That is rubbish. It's another hurdle in my journey".* She uses very emotive words to describe things, *"I am really annoyed, I am almost angry"* and *"It's not good at all, it's, I was really, how would you say it, I was really loving life, I was really ceasing you know work, training, relationship, family, everything was positive, everything was great. And as soon as you like kinda get, a curve ball like this, you just down (gestures with hand) straight back down."*

5.4.5 Place

The location of the vlogs helps the viewer to understand the nuances of the narratives, gives more insight into the individuals lives and can increase the understanding of what voices are heard (question 1, table 3). It can suggest the codes used in the narratives and how they might alter based on the situation that is visually present within the vlogs.

Adam’s vlogs take place in his living room, in some of the scenes he is on his own in the living room and in other scenes he is with his parents in the living room. Filming the vlog in your house and posting this publicly provides more insight on a personal level and this can increase the viewers’ perceptions of the genuineness of the narrative. The video appears to have been taken at the same time; however, has been edited into separate scenes. The video sections appear to follow a monologue approach, like other memoir vlogs found on YouTube. The vlog has music in the background of the video which appears to have the aim of setting a sombre ambience while watching. The use of music to evoke emotions is well established as a media tool based on neuroscience; the auditory cortex has a role as an emotional hub and the hippocampus in “attachment-related emotions and social bonding” (Koelsch, 2020, p.1).

Billy’s video took place at his home whilst he was sitting on the sofa next to his wife. The video shots that Billy is in are all in a monologue style with him looking between the camera and his wife. There are sections in which his voice appears as an audio overlay to images of him, his family, and his friends. This is often used to evoke emotions in the audience as it allows them to see personal elements of your life, and literature appears to suggest that this sharing of personal information and images makes the followers feel closer to the person posting the video (Senft, 2008). Creative storytelling can be achieved through visual images, especially when language is then used to convey further meaning to the narrative (Lukin et al., 2018).

Francesca has the ‘mobile’ style we have previously discussed as she has vlogs that are at the hospital, in the car and in outdoor locations; however, she also has vlogs where she is at home either in her kitchen or garden. Generally, her vlogs do not differ in their communication style, and she is very open, reflective, and emotional during all her vlogs regardless of their setting. She will often look straight at the camera with an intensity in her eyes and speaks with a slight croak in her voice as if trying to hold it together and trying not to cry. She has watery eyes, but she does not cry in the vlogs generally (although in the series there may be some in which she does cry). She uses a lot of gesture to support her descriptions and is very emotive with these gestures.

David does his videos in two different ways, and it is worth noting the subtle undertones which are present in each type. David makes videos documenting the moments he is living life, such as being in the carpark outside the hospital, waiting in the waiting room, and immediately after the appointments. These have a rawness to them, in that there are no edits and no filters; you can see David in the moment and things impact him at the time. The other videos he posts are filmed after a period of reflection and careful thinking about what he wants to say in the video, in a more consciously framed narrative. They are done as a soliloquy and are coherent and structured; however, there still are times of floods of emotion that alter the flow of the narrative. Emotions, however, can still represent coherence and structure through their association with a ‘chaos’ narrative (Frank, 2013).

David’s series of vlogs are varied in their setting. He started his series of video blogs/vlogs in a monologue style; however, this has then evolved into a “mobile follow me” style (Snelson, 2015, p.322; Marôpo et al., 2020) which shows the person’s daily hobbies and activities as the camera is taken outside and follows them doing things. David does appear to have a difference in his communication style during these ‘mobile’ outside sessions, as he is much more factual in his communication to the camera; whereas, when he is at home, and he is talking to the camera in a monologue style, he is more emotive and reflective about things that are going on and how he shares information with his followers.

Harry’s vlog contains a lot of different settings, he does some of the monologues in his home environment and some in an outdoor location. He has others being ‘interviewed’ who vary from his parents at home, his friend, and teachers in the school playground area, and others in what appears to be office who have been involved in the charity work he has undertaken. In addition, he shares photographs from things that he has been involved in or done since his diagnosis, as what appears to be his way of celebrating his achievements and sharing these with his followers. For example, he opted to share photographs of the night of the fancy dress party he went to, which as he described, showed him slightly frail in terms of physicality; however, showed him smiling, having fun and essentially being a ‘typical’ 15-year-old with his peers. This image is contrary to images often shown in the media when people are going through cancer treatments, and I think that this his choice to share both the story and images have been a conscious decision to go against this norm. This may be considered a challenge to culturally popular cancer tropes.

All of Gemma’s videos take place in her bedroom, which as she lives with her parents is probably a space in which she is most comfortable and considers ‘hers’. She refers to other places in the vlogs, e.g., places she has visited such as the theatre or hospital appointments/admissions, but she does not do vlogs from any of these areas.

5.4.6 Imagery

Imagery and metaphors are used in all the narratives to describe their cancer, their emotions, or their actions. The importance of imagery and metaphors is discussed further in the discussion chapter. Battle metaphors are the main ones used within the narratives, including the use of words such as “fight” and “battle”.

Adam’s narrative ends with an acceptance of his cancer (final stage of grief), with fleeting glimmers of hope in his narrative. He moves away from the mentality of someone who has lost his fight “you’re winning the fight” and towards someone who whilst acknowledging they are fighting a losing battle, will continue to participate in that battle “you keep fighting it”. Gemma also talks about “I’m still fighting daily”. This is like a restitution narrative (Frank, 2013), and the use of the battle metaphor in the context of cancer is very interesting. A restitution narrative reflects people’s desires to get well and stay well, the use of a battle metaphor goes against Parsons (1978) theory of the ‘sick role’; as Adam is not accepting that he is ‘sick’ (Frank, 2013).

Francesca’s vlogs are scattered with emotive language and connotations. She appears to fluctuate between positive thoughts, such as ‘cancer is not stronger than me’ and ‘no room for negativity’, and an openness of difficulty managing with her diagnosis, such as ‘This is just horrendous’, ‘cancer took this away from me’ and ‘things just got worse’. This ties in with fighting/battling metaphors, as if negativity will cause the cancer to ‘win’.

There are positive metaphors used to describe the ‘journey’ of having cancer. There are words such as “miracle” used by Francesca to describe how she feels she is still here despite the spread of her cancer. Francesca also talks about having “another hurdle to climb” and “another hurdle with my journey” but feels that this is achievable. Harry says “It doesn’t have to be about suffering” when referring to his journey.

The imagery used in Francesca’s vlog is emotive and gives a sense of helplessness “like imagine a big black hole in the middle of the earth I feel like I’m just about to jump into that”. She says, “it’s right on my chest (points) and it’s like, it’s almost suffocating”.

5.4.7 Narrative Tone

Within the narratives there is an underlying theme of the individuals trying to establish their sense of self, particularly considering their cancer diagnosis and the impact of this on their lives, development and who they see themselves to be.

Francesca really enjoys going to the gym and considers this part of who she is, in one of her vlogs she goes to the gym “first time without my hat at the gym” as she has no hair in this video. She says this with a sense of pride of her achievements of accepting that she has no hair and that is now part of who she is, but also with some anxiety about this. She follows it up with saying “I can’t believe I forgot a bloody hat, first time ever. People don’t treat you different people just don’t acknowledge it do they?” Her partner also feels that she has been able to remain herself despite the illness, *“She was Francesca until the end”* (Participant Francesca’s wife Helen).

In her vlogs Gemma covers a whole range of topics and starts with how she views herself, *“Currently right now I have a pretty bad headache and I’m not feeling great even though I look pretty good, I don’t look very ill”.* Gemma does mention the way she views herself throughout the vlogs, and in line with a ‘typical teenager’ she is conscious about how the cancer is affecting her appearance.

In her subsequent vlogs, she has an underlying assumption that the audience have seen the previous vlogs and there is little acknowledgement that this may be the first one people have seen. Therefore, she refers to information stated in previous vlogs. Her vlogs include further details about her physical symptoms, and within each vlog, she provides an update on how she is getting on from a physical perspective. She doesn't really recognise her emotions within the vlogs or talk specifically about how things are making her feel. For example, *"so far, I'm doing okay erm I sound a bit funny I know that erm my eyes I'm having to wear my glasses a lot because erm I'm actually struggling to sort of see things at the moment. But I can make out things and like I can get myself around".*

"I wanted to sort of show you the erm physical symptoms I have got, erm, if you, if I try to smile (Smile attempted) you notice this cheek goes up instead of smile (smile attempted) but this one, this side isn't responding and isn't doing anything. So, I've been told that I need to do sort of mouth exercises such as like (smiles) and (opens mouth) cause it actually hurts for me to like open my mouth. Erm and basically that's because of the nerve endings. So, I need to basically teach myself to smile again".

Despite the deterioration of her physical symptoms, she remains optimistic and hopeful of a recovery, *"hopefully I'll be back on track as soon as possible."* Which is later further discussed in the *return* phase of her narrative.

Gemma posted tens of videos, most of which were not about her cancer. She wanted people to see her as a 'typical teenager' who was into fashion, make-up, music, films, and the theatre. She started her very first vlog by stating "*I'm just like any other typical teenage girl but I have a twist. The twist is that I have cancer".*

Gemma talks about the physicality of not being able to smile but doesn't talk about how not being able to smile impacts on her perception of the 'self', how it makes her feel, and the impact that this is having on her life. It is interesting that she opts for descriptions of things that are visible, i.e., physical symptoms, rather than any deeper reflections on the hidden elements of her cancer or life. She describes her approach to her vlogs as, *"quite candid with you all erm and really open up*" yet does not share her emotional side. It would be worthwhile considering here whether given her age at diagnosis was 16 years old, whether her level of emotional maturity and ability to externalise an internal feeling has not developed to a point in which this would be demonstrated in her vlogs, if it was the impact of a brain tumour on her level of cognition, or whether this is a coping mechanism that she has adopted to support herself.

The advancing of her symptoms includes worsening of the speech and yet despite all this she continues to vlog, *"I'm hoping that my speech is getting better erm it's still very er slurred. I still sound very drunk erm so yeh."* This demonstrates the confidence she is feeling in the 'self' as she is showing the audience how she is at her worst, rather than feeling self-conscious about this and not wanting to post because of those feelings. She acknowledges in one of her vlogs that she feels that cancer has given her a newfound confidence, *"I've found a new confidence and really a new life. Everything around me I appreciate a thousand times more than I did before".* Her speech continues to deteriorate, *"I'm still feeling a bit funny, erm, I will, my voice still very funny and unfortunately things have taken a turn for the worse",* and at this point in the narrative Gemma's voice is completely slurred (dysarthric) and is very unintelligible. She started her narrative by saying, *"I don't look very ill"* which has moved now to, *"I'm looking a bit worse for wear."* However, despite not looking her best and not being very clear in her speech, she continues to post her vlogs. Gemma openly talks within her vlogs about acceptance of people and not defining them by their cancer, *"I feel like you should always approach somebody who has been diagnosed with cancer as you would normally approach them, just because they've been diagnosed with something doesn't make them any different."*

Harry sets the tone of the vlog with a quote that cues the audience immediately into his fun loving and optimistic personality, "*The old saying when life gives you lemons, make lemonade, but what do you do when life gives you cancer? This is not a sob story; this is my story."* Throughout the vlog, Harry continues to remind the audience; that his story isn't one of sadness but one of hope and achievement, *"You can't give me your time to make me live longer, but what I can try and do is to give you a bit of my motivation you know, to go out there and achieve something, to go out there and help others, to go out there and enjoy life, to continue the work of a foundation, and <u>I will say it one more time to make a difference</u>".*

Harry talks about his cancer as a thing that he has but not something that defines him *"To show people what it's like to have something go wrong in your life but not be defined by it."* He refers to cancer as being a positive trigger in his life to motivate him to achieve better things and doesn't talk about it in any negative ilk, *"In a way I treated my first cancer diagnosis as a good thing, it was a huge kick up the backside that gave me a lot of motivation for life".* This is an example of a quest narrative (Frank, 2013). Like many people who learn of their pending death, Harry started a bucket list which he shared on social media. He reported that he didn't share the list with the aim of people giving him money or helping him achieve what was on the list, but as a way of sharing his life experiences with his friends, to inspire his peers to be positive when facing life challenges, and as a legacy for people to remember him by.

His list contains what would be considered typical for a bucket list, *“sky diving, crowd surfing in a rubber dingy, to drum in front of a huge crowd”.* Following the social phenomenon that his bucket list became on social media; he began to have people offer to raise money for him or pay for things. Rather than accept those, he decided to use his platform to raise money for others, knowing that although he cannot be cured, there may be developments that help others in the future, “*I’ve actually refused and decided to give the money to charity instead. Since starting the bucket list, my life has changed completely, erm I am now doing so many weird and wonderful things so much more erm the amount of opportunities sent my way is absolutely immense and the one thing I’ve really enjoyed is the fundraising and helping others. So that’s the main thing I now want to concentrate on”.* His selflessness is not only apparent in his narrative, but in the narratives of those who shared their experiences of meeting Harry. It can be considered typical to create a ‘bucket list’ when faced with a terminal prognosis (Campbell, 2015; McCosker & Darcy, 2013).

5.5 Summary of Chapter

This chapter has identified and analysed the narratives of six TYAs with cancer at the end of their lives who shared their experiences via YouTube. This is a dialogical narrative analysis of collecting the voices of those with similar experiences and supports with the aim of the study of exploration of the impact of cancer on the individual’s well-being. The data has demonstrated that each individual experience is unique and complex; however, they have similar underlying currents that run throughout their narratives. In line with the second aim, they each share their experiences of palliative care. The analysis that I have offered within this chapter offers some insights into each individual narrative through the lens of quest narratives as this appeared the way in which most participants framed their experiences. There was evidence of positivity throughout the narratives in the themes of sense of self, relationships, and interactions with others, helping to cope/acceptance, quality of life, and humour. However, there were clear descriptions within the narratives of a sense of injustice and difficulties in coping with their diagnosis, symptoms, and prognosis.

Chapter 6 Discussion

6.1 Introduction

Within this chapter I will discuss what has arisen within this research and discuss how these relate to the wider existing literature and national cancer picture. I will evaluate the study; the study will be interrogated to see if it meets the study aims, answers the study questions, and considers its limitations. I will discuss the implications for further research and build to the conclusion of this thesis.

A cross narrative analysis is where the narrative for each individual participant will be further analysed to draw conclusions on the similarities/themes across the narratives (Bold, 2012). McAdams (2005) uses an approach which looks at narrative tone, imagery, and themes. I have utilised this approach to understand and analyse the data I have gathered within this research. This will look at narrative tone, imagery, themes, and context emerging from the narratives.

6.2 Narrative tone

Narrative tone is often thought to be the most pervasive feature within personal narratives, and this is conveyed within both the content and form of the narratives (Lyons & Coyle, 2007). For TYAs there is a sense of burden or responsibility in coping with their diagnosis during a period of development in which they are still forming their identities and sense of self in the world (Erikson, 1968). It has been noted that using a virtual platform to share your experience can alleviate some of the burden associated with disease (Ohno-Machado, 2012). However, others would argue that they are in a generation stuck in extended adolescence in which they are desperately trying to avoid the responsibility that comes with adulthood (Gordon & Lahelma, 2004).

Whilst the narratives follow a quest narrative structure, it could be considered that there are elements of restitution narratives (Frank, 2013). The participants, for example David, outline desires of wanting to be healthy and the social construct of illness is often reflected in people's expectations that people will get better, especially if they are young and healthy.

TYAs reference their sense of accomplishment or competence across areas such as education, leisure, and relationships (Hanneth, 1995).

6.2.1 Sense of self

As we are aware, TYAs are in a complex and critical stage of their development (Dyson et al., 2012), and they are in the process of developing their own identity and sense of self (Sodergren et al., 2018a). A diagnosis of cancer during this time requires them to renegotiate their sense of self (Sodergren et al., 2018b) and redefine who they are in the context of having cancer and being end of life. Within the illness trajectory we can see that their concept of self (how they see themselves and their self-esteem) will change (Hinds, 2004; Lonardi, 2007). We can see this from the data, as all the participants at some stage within their narrative are seeking to re-establish their identities in the context of their illness and in response to the ever-changing nature of their lives. Narrative identities are formed due to complex interactions between numerous factors such as events, imagination, routines/habits, and the structure of the person's soliloquy that forms the person's self-narrative (Ezzy, 1998), which in this case is demonstrated through the use of vlogs as they attempt to feel a sense of being normal (Liu et al., 2015). For the 'z generation' (people born between 1995-2012) youth identity is intermeshed within social media (Briandana et al., 2021; Sajithra & Patil, 2013; Turner, 2015). Briandana (2021) reports that approximately 85% of the 'z generation' use YouTube, and this platform has transformed into user generated content (Holland, 2016). TYAs are in a transitional phase of developing their self-identity (Briandana et al., 2018) and social media is a place where self-actualisation is realised (Scharrer & Ramasubramanian, 2015).

It is believed that people will modify their identities to support how they feel it will best help them to live in the context in which they find themselves in (Baumeister & Muraven ,1996). An online sense of self can be perceived as a developed persona or a ‘bare face’ persona (Berryman & Kavka, 2018) which can impact on the development of their overall sense of self. TYAs appear to seek their self-worth online through the use of posting photos, blogs, and vlogs (Silva, 2013). Their identities will change over time depending on where they are in their cancer journey (Hammond & Teucher, 2017) and these turning points are apparent within the data when the participants move between a sense of hope versus hopelessness. For example, “I learned something about myself because of my cancer” “It impacts you as a person, I am now a more positive person” (Sodergren et al., 2018a, p. 457). The increased positivity is also a way of helping to cope.

The sense of individuality is present throughout the vlogs and how those fits into society is explored during TYA development (Moshman, 2005). Saying I am more than just my dying.

This is in line with literature which appears to indicate this overwhelming desire to feel ‘normal’ (Carr & Rosengarten, 2021; Malbasa et al., 2007; Kondryn et al., 2009; Stinson et al., 2012), and this will allow them to be part of normal activities and have an improved quality of life (Carr & Rosengarten, 2021). Within the data, there is a sense of ‘normal’ being something that those around the participants see and that the participant themselves strives for; however, it is not clear whether the participants feel that they achieve a true sense of normality.

This research has found that TYAs use telling narratives as a way of developing their identity and building relationships with others. The participants sharing their narratives appears to have positive effects on their psychological wellbeing, like other studies (Verduyn et al., 2017). Individuals sharing their illness stories, particularly on social media, create a social construct of their own psychological wellbeing. This involves their positive adjustments and negative maladjustments to their illness (Houben et al., 2015) and impacts on their overall self-esteem, social wellbeing, and quality of life (Luo & Hancock, 2020). TYAs consistently prefer to be “known as a teenager who happens to have cancer, instead of the other way around” (Pereira et al., 2017, p.198), and feel sharing their stories promotes a sense of normality in their lives (Lea et al., 2018a). Individuals have noted that sharing their narratives gives them a sense of social support (Luo & Hancock, 2020), which improves their recognition of self-worth. The data in this study shows that individuals feel very positive about sharing their narrative and use this as a coping mechanism and a way in which to engage with others wider than their immediate social networks.

There is often thought to be a delay in seeking care within the TYA population, literature suggests this is related to multiple causes. For example, the feeling of ‘invincibility’ which is apparent within the TYA population which leads to minimising the symptoms and the popular notion that TYAs are ‘not supposed to have cancer’ (Albritton & Bleyer, 2003; Carr & Rosengarten, 2021). A lack of understanding of treatments and desire to lead a normal life can lead to non-compliance for traditional cancer treatments in TYAs (Wicks & Mitchell, 2010).

6.3 Imagery

The starting point is to think about the linguistic forms and then develop this into understanding what those forms accomplish in social interaction (Duranti, 2009). It is important to think about the kind of language that is used in describing life events, people, and feelings; particularly the imagery of that language used. The imagery that we use demonstrates how we make sense of who we are/kind of language used (e.g., metaphors). This can give insight into how we see ourselves (Crossley, 2000) and our social constructs of the world. Looking at the cultural constructs, such as gender, disability, conflict, and emotions, and the social process, such as healing, and conflict, verbal performance (Duranti, 2009) can be seen within the performance of the narrative. In its simplest terms a metaphor is a term in which one word is substituted for another with an apparent different meaning, comparing one idea to another or using language to create an analogy or simile (Ritchie, 2013). Stories are devices for people to come to terms with their own individual vulnerability (Holloway, 2007), and through these stories people can dramatize their experience for maximum effect (Frank, 2000). Metaphors describing illness as a ‘constant battle’ or ‘fight for survival’ are used as part of this dramatization (Frank, 1995).

Metaphors have been found to be common when discussing illnesses (Bowker, 1996; Domino et al., 1992; Gibbs & Franks, 2002; Harrington, 2012). These are particularly used to make sense of a chaotic world (Byrne, 2008; Reisfield & Wilson, 2004), express emotions or experiences that would otherwise be difficult to express (Skott, 2002) or to discuss sensitive issues (Spall et al., 2001). Metaphors are often used in narratives about cancer as it gives the person a way of externalising the cancer and making it separate from the person experiencing it. These are most commonly found in restitution narratives.

The metaphors can sometimes be contradictory, and this may be to reflect the persons internal struggles and to find meaning in their challenging lives (Gibbs & Franks, 2002).

Within the field of cancer war analogies (military metaphors) are the most common type of metaphors used by the individual experiencing their cancer, those around them and the mass media (Harrington, 2012; Hommerberg et al., 2020; Reisfield & Wilson, 2004). This movement started in the US in 1971 when the National Cancer Act introduced military metaphors to describe cancer. A study found that metaphors to do with violence (battle /fighting) are the most commonly used metaphors when people who experience cancer write online blogs (Demmen et al., 2015; Semino et al., 2017a & 2018). The image of fighting was used to indicate the seriousness and invasiveness of the disease (Reisfield & Wilson, 2004). Individuals could imagine the cancer as though it were a foreign enemy that has invaded their bodies (Harrow, 2008; Jobst et al., 1999; Luker, 1996; Reisfield & Wilson, 2004; Skott, 2002).

Within the vlogs in this study, there are some dominant metaphors used such as ‘battle’, ‘beat’ and ‘fight’, which revolve around a wartime rhetoric (Hansen, 2018) and are associated with being ‘aggressive’ and ‘masculine’ (Reisfield & Wilson, 2004; Harrington, 2012; Hauser & Schwarz, 2015). This is consistent with the ‘Metaphor in end-of-life care’ project which conducted a corpus analysis of online discussion forum posts written by people living with advanced cancer in the UK (Semino et al., 2018; Semino et al., 2017b) who found that within the 27 blogs the words ‘journey’, ‘battle’, ‘imprisonment’ and ‘burden’ to be the most significant. To ‘fight’ cancer may have very different meanings to different people depending on their psychosocial experiences, environmental factors, and external influences (Penson, et al., 2004). Different metaphors are used differently by individuals in both empowering and disempowering ways (Semino et al., 2017b & 2018; Hendricks et al., 2018).

The battle metaphors are used as people see it as a battle, which if they win, they are cured and if they lose, they are not (Hansen, 2018); which is consistent with the vlogs analysed above, as the individuals describe the battle they are fighting and see themselves as having lost. Military metaphors can have negative consequences as they have been known to influence individuals into suppressing their more distressing emotions in order to externalise a 'fighting spirit' (Byrne, et al., 2002; Donovan & Mercer, 2003). A 'fighting spirit' is one of the five categories in the Mental adjustment to cancer scale (Hendricks et al., 2018) which is reflected in the data. People seeing cancer as the enemy often exhibit maladaptive coping mechanisms (Harrington, 2012). It can have negative adverse effects as there is an implication that those that have 'lost the battle' have not tried hard enough to win (McCartney, 2014; Hui et al., 2018, Reisfield & Wilson, 2004). Semino et al. (2017a) found that individuals reported "I feel such a failure that I am not winning this battle' (p.63) which is also present in the data. For individuals who are considered palliative they can be emotionally harmed by the ideal of conquering, what is for them, an unbeatable disease (Harpham, 2007; Penson, 2004).

In obituaries people will often describe their loved one as having 'lost the battle to cancer' (Hui et al., 2018; Ellis et al., 2015).

In contrast to military metaphors there are 'journey metaphors. Linguistic anthropology studies the meaning of linguistic messages, and this is important to consider in the context of this research (Duranti, 2009), for example, the word 'journey' appears in all the narratives and is used to describe what they are going through. The dictionary definition of ‘journey’ is ‘the act of travelling from one place to another’ (Dictionary, 2021), with most definitions including the physical move from one place to another in a form of transport or walking as standard. However, in the narratives they are using a much deeper and psychological rooted definition of the word ‘journey’ to mean they are experiencing change in their lives and emotionally going from one place to another. Journey metaphors shift the focus away from an illness battle to an illness experience (Reisfield & Wilson, 2004) and are more commonly associated with being ‘peaceful’ and ‘reflective’ (Reisfield & Wilson, 2004; Byrne, 2008). This in turn tends to lead to an individual having a more positive outlook on their experience of illness (Corei et al., 2004). This is apparent in the data as some of the participants report feeling more optimistic and use the word journey when talking about this.

It is important to think here about the purpose of the story, for example are the participants telling it because they want to let the world know they haven’t given up, is it a way of coping with what they are going through, or is it information sharing about a cancer journey from diagnosis, treatment, and supportive care? For some of the participants, they state clearly in their narrative the purpose is to inspire others and raise awareness/money for cancer charities. However, they also serve as a legacy to those they are leaving behind, and whilst they don’t openly acknowledge this, this is a by-product of their vlogs.

6.4 Themes

I will outline in more detail the analysis of persistent or dominant themes that run throughout the narratives (Lyons & Coyle, 2007) or specific themes that the individual has identified as being important.

6.4.1 Relationships

6.4.1.1 Audience

It is also useful to consider here what are the motivating themes related to the researcher and/or the person editing or putting the vlog out there. For myself as the researcher, my underlying motivation for observing and analysing the vlogs is to conduct research; therefore, there is subjectivity in the analysis and reflexive processes are in place to support this. The motivating theme relating to the person editing or posting the vlog goes back to what is the overall purpose of the vlog, and this will impact on what themes come through in the analysis. For example, in vlogs posted by 'Stand up for cancer' they are often edited in such a way as to dramatize individuals' cancer stories with the aim of evoking emotion in people with the hope that will inspire them to donate. For the participants in this study, their narratives are essentially true to their real life, in that they are sharing their experiences with their followers as they happen (although the vlogs may have been edited or filmed multiple times before posting). The themes have been further analysed below.

Raising awareness and giving voice to a private experience in a public way (Frank, 1994) is often the purpose of TYAs sharing their narratives, and stories create sanctuaries in which to do this. There is an underlying desire to help others and for improvement in this clinical area for TYAs (for them to have an impact beyond themselves) (Pereira et al., 2017). This follows the concept of 'the dragonfly effect', in which people use an engaging narrative to gain attention for their cause with the aim of inciting action (Guevara, 2011). For example, using these narratives to raise money for the cause. It has been found that platforms such as YouTube are an important venue for TYAs in the production and dissemination of their perspectives (Raby et al., 2018). Whilst there is research focusing on raising awareness about political causes, ethics, e.g., animal cruelty in the beauty industry, and for advertising purposes; there remains little research about the use of YouTube to raise awareness about health conditions, particularly palliative care, and end of life.

Analysis of the whole narrative allowed me to treat the participant and the data with respect and gave an ‘undistorted’ representation of the story (Viney & Bousfield, 1991). Having access to the “individuals internal mental state, identities, senses of self and real, lived experiences” (Smith & Sparkes, 2008, p.9) has enriched the data. However, we need to be mindful that there is not dramatization of their story due to posting on social media, and therefore a misunderstanding of information shared with their audience (Strekalara, 2017).

This can also be linked to the performance of their narrative, and how they are performing their narrative to the audience is linked to what they conceive the purpose of their narrative is. This will have an impact on what they say within their narratives, for example, David openly says that he is *“going to try and get through it without crying, get through it without being sick.”* Which is an element of performance as he is choosing to share how he is feeling in this way. This shows that he may only wants to show certain elements of his journey, his life, and his narrative with his audience, and therefore, performs what he has selected. Bamberg (2012) noted that there are three types of performance dilemma, uniqueness versus representativeness of shared personal experience, audience identification versus distancing and emotional control versus loss of control. There is thought that in posting online there is a constant negotiation within these dilemmas which impact on what individuals chose to share. This negotiation apparent within David and other vlogs, particularly the shift from affective positioning of being in control to losing control (Giaxoglou, 2020; Giaxoglou & Georgakopoulou, 2021).

There is a fine line between being authentic and appearing ‘brave and relatable’ by talking about past struggles that have been overcome, versus ‘whining’ about your experiences (Ashton & Patel, 2018; Dunn, 2015). Establishing a level of rapport with the audience supports the audience in perceiving the person as ‘authentic’ and therefore creating empathy for them (Ashton & Patel, 2018). It can create an ‘electronic intimacy’ between them and the audience (Gibson, 2016; Rosen, 2012), this connection can improve their ability to cope with psychological distress (Sangerozon et al., 2019), along with developing peer support networks which is integral to support quality of life (Pagoto et al., 2019; Haldar et al., 2020).

The audience is a factor in how a sense of self is developed and YouTube is one of the many platforms for ‘expression and socialisation’ (Bhatia, 2020). Amongst other things, YouTube has been used for people to support identity-construction and has been used by some groups of people to address ‘problematic social narratives by engaging in trending vlogging practices’ (Bhatia, 2020). An example of this is the movement of Muslim women using vlogs to articulate their identities to wider communities (Bhatia, 2020; Anarbaeva, 2016; Phelps-Ward & Laura, 2016). The ability to be able to have ‘self-representation’ is something that appears strongly through the vlogs within this data set, as many of the participants have chosen to vlog to show their family/friends and wider communities what it is like to have cancer from their perspective in their own words.

In all situations, there is on some level an audience and a performer regulating his or her own performance (Christian, 2009). This is particularly pertinent in vlogs, as people are actively posting something online with the aim of having an audience for their performance/narrative. Boyd et al., (2007) analysed Myspace profiles and found that the pages allowed users to construct what they considered an acceptable ‘self’ and receive immediate feedback from the audience on their views of the ‘self’ they had constructed. Users found this level of immediate feedback helpful in their journey of self-construction. YouTube’s slogan of “Broadcast yourself” is expecting users to post vlogs about themselves, and this promotes the monologue style of vlogs that is commonly seen on YouTube with the vlogger looking directly at the camera in usually a close-up shot (Christian, 2009). As vlogging is relatively new in terms of a form of communication and conversation, it has been noted to lack conventions which other monologue style communication, such as lectures or news reports would have. Signs of nervousness or hesitation such as laughter; would generally not occur in lectures, but are commonplace in vlogs (Frobenius, 2011). Generally, vlogs have free reign on choice of topic and no temporal restrictions so can be posted and viewed at any time of the day. In addition, they can be shot and re-shot depending on whether the person wants to say something differently than the in the first version. Vloggers appear to have a concept of a constructed or imagined audience that helps them shape the way in which they communicate through their vlogs, for example, this will influence how they start their vlogs and greet their followers. Some will directly address their followers, and some will not directly reference an audience at all. So, for example in the vlogs included in this study all of the participants directly address the audience, thank them for their comments and inform them of when they will be posting again. How they present themselves in the opening of the vlog is part of their sense of self and how they frame themselves to others. Frobenius (2011) analysed 41 vlogs and found that the opening sequence of the vlog was very important in relation to the sense of self and the purpose of the vlogs being well communicated.

When people post on social media, they are aiming to interact with those that view their posts, which is present in most of the participants narratives. This is in the form of them directly referring to ‘audience’ or ‘subscribers’, as they say things such as “thanks for listening”. For example, in both Gemma and Francesca’s vlogs they specifically mention how many followers they have and how this makes them feel as though people care about them and about what they have to say. They do this to gain a sense of connectedness and relatedness with another person (Baumeister & Leary, 1995), and this is amplified when sharing in a public way (Utz, 2015). Posting their narratives online has been found to reduce loneliness (Bazarova & Choi, 2014), and those who are constrained from posting online have reported to feel disconnected and lacking in belonging (Tobin et al., 2015). In 2008, Facebook introduced the “like” button which promoted interaction with other people as they could show the person posting the status update that they had seen their post and liked it. This was also found to promote possible future interactions with people, as the person posting may then get in touch with someone who has liked their post which they may not have otherwise done (Page et al., 2013). The use of the like button more than doubled between 2010 and 2012. This can be seen as a minimal effort validation of the person’s post and allow for this interaction to be deemed positive. However, this is not always viewed as a positive, as the person posting can see who has liked their post and may feel a sense of conflict towards people who have not liked their post, particularly if they have liked other people’s. In Page et al.’s (2013) study, interviews of Facebook users found comments such as “you liked their post but not mine” occurring frequently within their participants responses. In addition, there has been a rise to people raising the need for a “dislike” button, as this would allow them to dislike content without the need for writing a protracted comment (Page et al., 2013). This would be for posts which have inappropriate content. It has been noted that social media sites have been working to remove negative content and continue to have processes in place to support this. Page et al. (2013) found that comments made on Facebook were similar to those across other social media sites and they enable forms of collaborative narratives. They found that comments on status updates or posts included evaluation of the same story (generally positive statements), an extension to that narrative/story, and parallel but separate narratives (e.g., telling a related but secondary story). Within this study, the comments and “likes” were not analysed; however, they generally were positive comments such as, “You are brave”; “RIP, sending love to your friends and family”. In addition, YouTube has a functionality for thumbs up (like) and thumbs down (dislike), and therefore this is unique in comparison to other social media sites.

Using social media to talk about their life and their emotions is becoming increasingly popular, particularly amongst adolescents (Vermeulen, 2018; Bazarova, 2015; Rimé, 2009). People generally share emotions to fulfil two distinct needs; to share their personal experience and to receive feedback from others (Choi & Toma, 2014). TYAs will often post their emotions on blogs (Vermeulen et al., 2018), instant messages to others (Dolev-Cohen & Barak, 2013), and social networking sites (Jordán-Conde et al., 2014). They learn about sharing emotions from their peers, and observing other behaviours (Boyd, 2014) and by navigating the social norms of what to share publicly, e.g., how emotional should a Facebook status be (McLaughlin & Vitak, 2012), and what should be shared privately and away from social media (Bazarova, 2012; Bazarova & Choi, 2014; Bazarova et al., 2015). For TYAs, these lines can be blurred and can vary based on individual personalities, support networks, and the context of what they are sharing. TYAs are generally in a period in their life where they are developing their self-concept and who they are, which for some can be a time of fragility (Vermeulen et al., 2018). TYAs during this time may experience pressure from their peers or others to express (or not express) emotions in a particular way, regardless of their true feelings (Wilson & Wilson, 2014). However, for TYAs, there is thought to be some positive effects to sharing emotions. Vermeulen et al. (2018) interviewed 22 adolescents and asked them about sharing their emotions and others sharing emotions on social media. They reported enjoying getting likes and positive comments from others, and it felt good to vent negative emotions and it gave them a sense of relief. They did report that the relief felt was temporary, which is in line with previous studies (Rimé, 2009), with Choi & Toma (2014) finding that some modes of social media are better for sharing than others. Within this study, it does appear that the TYAs benefitted from the positive comments, and this was evident in those that had posted multiple vlogs as they specifically stated things, such as, *"I really appreciate your comments"* (Participant Gemma) and, *"Thank you for watching, thank you for being there for me, thank you for commenting, thank you for liking everything, and thank you for supporting me"* (Participant David). They appeared to use the vlogs as a way of sharing their experience and emotions to help them cope better with what was happening to them.

Some have reported that the emotions shared publicly are less intense than those they share privately (Bazarova, 2012); however, within the vlogs in this research, the emotions that have been shared appear to have been very intense and raw emotions that did not appear to be them holding back because they were being shared publicly. However, this is not something that was focused on within this research. Some have claimed that the internet has helped those who felt 'trapped' in a private space to extend their social worlds (Henderson et al., 2007). The use of internet as support network has been well documented, for example, “I made new friends at the hospital…we helped each other feel positive about the future” (Sodergren et al., 2018a, p. 457).

Vloggers who are successful see themselves as ‘role models’ (Marôpo et al., 2020), and that disclosing things about themselves promotes a trusting relationship and sociability with their audiences. An example of this within the data is Gemma’s vlogs refer to fashion and makeup, with some of them containing ‘how to’ demonstrations. By sharing personal things, it helps them feel closer to their followers (Senft, 2008) and using the monologue style of communication (Bakioğlu, 2018). They choose to represent themselves as real, authentic, and ordinary, which has been found to increase positive reactions to vlogs (Marôpo et al., 2020; Stein et al, 2020; Rizzolatti & Sinigaglia, 2008). When people post positive comments on the page of the vlogs, it in turn makes the person posting the vlog feel more positive and able to cope with what they are going through.

6.4.1.2 With others

Seeking friendships is part of adolescent and adult development and serves the purpose of social, emotional, and cognitive development, in particular notions of self-worth and social needs (Jackson & Goossens, 2006); *“I’m looking a bit worse for wear”* (Participant Gemma). Without developing good peer relationships, the sense of self can change and become withdrawn (Grinyer, 2009) and individuals can lack a sense of belonging (Smith et al., 2007; Sawyer et al., 2007).

Some studies have suggested that TYAs identified elements of their parents’ role that both facilitated and constrained their communication, and although they wanted support, they reported that at times this left them feeling uneasy and constrained

(Young et al., 2003). Understanding the narratives can offer a practical approach to support parents living with a child having cancer treatment (Bally et al., 2014) and to support them in the grieving process after their child has died. TYAs communicate their narratives and experiences based on the audience they are communicating too. For example, Gemma talks about fashion and makeup as her vlogs are aimed at her peers who are likely to be interested in the same things. Whereas David is aiming his vlog at others who are going through similar experiences, and he talks about treatment options and clinical trials. It is well established in literature that the way in which teenagers communicate with their family is different from their peers, and that this continues to change as they move through various life experiences and developmental periods (David-Barrett et al., 2016). However, there is limited research into the behaviours of TYAs with healthcare professionals and within research and if this differs from how they behave and interact with their peers and family.

There is a considerable amount of very interesting literature on the dynamics of couples experiencing a terminal illness, and the positive implications of dyadic coping (Traa et al., 2015; Altschuler, 2015). Whilst they experience the journey together, they may not experience the same things at the same time (Weingarten, 2013) and a poor prognosis can cause a disjuncture between the expected and lived experience for the individual and their partner (Altschuler, 2015). We know from research on chronic illness the importance of relationships (Warner et al., 2016) and often the level of dependency on others increases (Wong et al., 2017; Zebrack et al., 2010) which we can see within the analysis to be the case. In Billy's vlog he talks about the support from his wife being invaluable and how difficult he is finding the anticipatory grief that he feels knowing that she will be alone once he has died. In

Francesca’s vlogs her wife participates in most of them, and they both describe the importance of having each other for support and that spending time together is their way of coping with what is happening.

6.4.2 Sense of Injustice

Previous literature has shown that TYAs have a fear of dying and did not expect that such a thing could happen to them (Sodergren et al., 2018a, p. 457); which is comparable to the data particularly for Billy, Gemma, and Francesca. It is a generation with a focus on aspirations and the future, e.g., going to university, buying a house, travelling the world. They also spend time hypothesizing about the future (Kroger, 2007), which for the participants they feel that they have now lost.

Within this literature, it is apparent that the participants had future aspirations and regrets of things they were not likely to be able to achieve. Adam talked about wanting to have a family and a house, *“You’re not gonna grow old, you’re not gonna have kids, you’re not get married and have a house hh and all those things that *you kinda expected you would do*.”* (Participant Adam). Whereas Harry talked about career aspirations, *“my original goal was to become a doctor erm and to help others that way. Unfortunately, my diagnosis means that I won’t be able to fulfil that dream”* (Participant Harry).

6.4.3 Helping to Cope and Acceptance

The vlogs demonstrated a journey through transitions, including uncertainty, anxiety, stress, and fear, while the thread of constant hope was apparent throughout. Narratives can help individuals to make sense of things in a meaningful way (Frank, 2010), with the disease often making them more mature than counterparts (Stark et al., 2017) which may increase their ability to cope. Posting blogs and vlogs have been found to increase individuals' ability to cope (Pereira et al., 2017; Gardano, 1994; Robb et al., 2014). Research suggests that individuals will often present with positive thinking as a way of masking their fear of the loss of hope and the difficulties in acceptance of their reality (Bally et al., 2014). When there is no hope for the person to be 'normal' again, their identity becomes intertwined with pain, uncertainty, and stigma (Hyden & Brockmeier, 2008). Participants Adam, Francesca, David, Gemma, and Harry all reported feelings of pain, uncertainty, and stigma.

Adam also displays some level of hope throughout his vlog, which in the context of end of life is an interesting concept. It is thought in western societies that hope at the end of life is either lacking or unrealistic, however Duggleby and Wright (2005) interviewed eleven palliative care patients and concluded that hope at end of life was "both essential and variable, transforming as their lives changed" (Eliott and Olver, 2009, p.611). For Adam he appears to be holding on to hope as something integral to his life and strongly associated with his treatments.

The idea of acceptance echoed in other forms of media and in other age groups, for example, Kate Gross (2015) wrote in her memoir, *"The acute period of misery was short-lived…. I think this was because we humans cannot exist in a state of heightened emotion for long. We are programmed to normalise, even after the worst news imaginable…. There is a point when everyone else has gone back to normal life, when the spotlight isn't on you anymore, and it is then that things are at their toughest…. there is a third state, between crisis and endurance: uncertainty."*

Death salience ("the degree to which individuals contemplate their mortality" (Tomer, 2005 p. 2) activates when a person is faced with a palliative prognosis, and this can initiate their coping mechanisms and can sometimes manifest as regret for things they wished they had time to do and for those they are leaving behind. A person's acceptance of their death is part of their coping mechanism and can significantly impact on their ability to cope and their quality of life. The social construct of 'acceptance' of death can be thought of in three ways; approach acceptance, escape acceptance and neutral acceptance (Tomer & Eliason, 2005). Approach acceptance is a belief that death is merely a passage to a happy afterlife, which does not seem to be present within this data set. This may be more present in the data if the participants were from countries where religion was more engrained in the communities. Escape acceptance is that death is the alternative to pain and suffering, which is also not considered within this data set. Neutral acceptance is that death is a natural part of life, which is referenced by some of the participants, "*that's something I have to come to terms with"* (Participant David). Literature suggests that approach acceptance is the most positive way to approach death (Wong, 2000); however, the literature does not account for the differences between older and younger people dying, and whether their ability to accept death differs.

Olsman et al. (2014) uses narrative theory using hermeneutics and language as the analysis method. Semi-structured interviews were conducted with healthcare professionals (HCPS) that worked with people considered to be palliative. The metaphors of hope were analysed using narrative analysis, with all authors contributing to this process (and all authors had extensive experience within the clinical field). The analysis led to conclusions about how people viewed the word 'hope', which was overall in a positive stance. The impact of this had provoked further discussions on how questions to patients should be worded and in fact rather than use the word 'hope', other words such as 'strength' be used as perhaps this is more reflective of what is intended by the word when it is used in this context and the imagery it aims to provoke.

Hyden & Brockmeier (2008) report that telling stories allow for the person to cope with the intrusion of their illness by situating this within the context of an on-going biographical narrative, "*I'm going to be vlogging as much as I can because it's gonna be the thing that's keeping me sane"* (Participant Francesca). Narrative is thought to be a natural way of talking about suffering and illness and helps them to accept their predicament (Hyden & Brockmeier, 2008).

In a life crisis people anchor their anxieties in established social institutions, e.g., religious establishments (Kleinman, 1988); however, it appears that for some TYAs, they seek this in the world of social media. It has been reported that health related vlogs have shown a significant positive impact on people's psychological health (Greenberg & Wang, 2012; Huh et al., 2014), and that this can be used as part of their illness management (Ohno-Machado, 2012).

People can feel a sense of catharsis and relief when talking about their life and their story (Munhall, 2012). To support with anticipated grief and loss families can participate in family-centred care (Gabriel et al., 2021) and 'dying well' has been described as one that includes acceptance of the death.

6.4.4 Quality of Life

Within these data there is reference to the impact the treatments had on the individual and the significance of this for their quality of life. HRQoL was outlined as an important factor for TYAs (Aldiss et al., 2019) as it supports empowerment (Kaal et al., 2017), positive social functioning (Wicks & Mitchell, 2010), and supports friendships (Sodergren et al., 2018b). Blogs and vlogs posted online have been shown previous to improve quality of life and reduce distress (Pereira et al., 2017; Craft, 2013).

Late adolescence and early adulthood are one of the most physically healthiest phases of the life span (Kroger, 2007). Therefore, it is not surprising that TYAs find it difficult to cope with the illness and its impact on things, such as being able to go out and do things that would be considered ‘typical’ for their age. This is often compounded by treatment side effects and symptom burden (Avis et al., 2005), which leads to poor quality of life (Collins et al., 2000). Within the data, there is examples of this being overcome:

“Last night I actually my brother and I went to London and erm we managed to do that and it was amazing, so erm yet. Really pleased about that.” (Participant Gemma).

“I ended up going to fancy dress party.” (Participant Harry).

Palliative treatment suggests incurable conditions and approaching end of life; however, the actual treatments received are often the same as curative treatments (Ohlen et al., 2013) (but with a different purpose). This can make the individual’s perception of receiving the treatments challenging (Friberg & Ohlen, 2007). Gemma is hopeful that the medication she is having is working despite being told it would be unlikely, *“Hopefully the medication is working, and my body may begin to repair the damage caused”* (Participant Gemma). David has unrealistic expectations of his hospital stay, despite being very unwell in the vlog both physically and emotionally, *“hopefully I’ll only be here for a few days”* (Participant David). Billy is realistic in his expectations of the treatment and is preparing himself for the worst, *“There’s always that possibility of something going wrong with the treatment as well.”* (Participant

Billy), and Francesca is very pragmatic about the steps in her treatment, *"they've just confirmed my surgery for the Thursday"* (Participant Francesca).

The data aligns with autobiographical accounts, such as John Diamond (2001) who stated, the cancer treatment and it' recurrence became mundane as life only consists of treatment regimes, and research based on interviews with TYAs report that difficulties in controlling pain can significantly restrict daily routines (Sodergren et al., 2018a). The inability to do 'normal things' plays a role within the data and previous research, e.g., playing sports and not going out due to lack of energy (Sodergren et al., 2018a) significantly impact on quality of life of TYAs.

6.4.5 Humour

Humour is defined as, "a type of mental play involving a light-hearted, non-serious attitude towards ideas and events" (Martins, 2007, p.1), and is a social phenomenon within healthcare (Tanay et al., 2013; Adamle & Ludwick, 2005; Scholl, 2007). Over time, humour has evolved into a social construct with phrases such as 'laughter is the best medicine' as an approach to the challenges of being unwell (Buiting et al., 2020), and Freud's (1962) theory that humour is the strongest defence mechanism. Humour has been used to provide people with a light relief from a serious or life-threatening situation (Demjén, 2016), and this can reduce the psychological impact of that situation on the person (Martin, 2007). This is consistent with the release theory of humour, 'people laugh to release pent-up psychic energy' (APA 2021; Demjén, 2016). Humour has been found to be used in a range of healthcare settings (Tanay et al., 2014), which include cancer (Chapple & Ziebland, 2004; Fallon et al., 2008) and palliative care (Dean & Gregory, 2004; Gramling & Gramling, 2012). It has been reported that humour helps us to cope in stressful situations (Samant et al., 2020; Tanay, 2014; Adamle & Ludwick, 2005; Chapple & Ziebland, 2004; Johnson, 2002), encourage participation in their care (McCreaddie et al., 2010), and be more open about how they feel and their illness (Tanay et al., 2014). Humour has also been found to build rapport with others such as healthcare professionals (Kovarsky et al., 2011; Dean & Gregory, 2004; Gramling & Gramling, 2012). Humour is widely used in online forums to reframe chronic illness using the humour to elicit empathy (Gonzalez-Polledo, 2016).

Humour has been found to ensure that people get a better response from others (Tanay et al., 2014) and helps others to cope (Roaldsen et al., 2015); which for those using social media, reaching out to others is something they may be conscious of. It has also been characterised as part of the individual's sense of self (Buiting et al., 2020), and within this study, the participants have at times used humour to demonstrate a growth in self and acceptance. Humour is a generally considered a social movement which is used as a social norm and for things such as diffusing or repairing unpleasant situations (Demjén, 2016). It also supports talking about sensitive topics in a more socially acceptable and normalised way (Olver & Eliott, 2014). It has been used to discuss more taboo based subjects, e.g., embarrassing bodily functions associated with cancer treatment, with other people either face-to-face or via social media (Demjén, 2016). There is some evidence of this within the study, as participant Gemma talks in detail and provides a demonstration of her lack of ability to smile and how odd her smile looks, "*I wanted to sort of show you the erm physical symptoms I have got, erm, if you , if I try to smile (Smile attempted) you notice this cheek goes up instead of smile (smile attempted) but this one, this side isn't responding and isn't doing anything…So I need to basically teach myself to smile again".* Within some studies, humour is used as the person will refer to themselves in the third person as a way of perhaps detaching themselves from the cancer or symptoms they are discussing (Demjén, 2016).

Within media, humour has been used for people talking about cancer, for example, BBC Radio Scotland (2015) had a radio show called ‘A funny kind of life and death’ in which comedians found humour in their loved ones dying moments. A sense of humour has been used in storytelling to mask fear, and irony is often used in the face of death by others. Within this study, participant Harry uses humour within his life as a coping mechanism to manage his cancer but also as a way of showing people he is more than his cancer, *“I ended up going to a fancy dress party. Surgeon gave me advice to go home, take it easy and basically do nothing. But I decided to go to this party dressed as a granny in a wheelchair, and because of how much weight I had lost and because of how thin and pale I was pretty convincing. Erm, by the end of the night I was being pushed around in my wheelchair having an absolutely fantastic time. And this was me from the off making a statement of how I was going to overcome my illness”.* Whilst he told the story images of him in the fancy dress appeared on the screen.

For this study, humour has been used in the form of analogies, such as, “I’m gonna get a few big throws in along the way” (Participant Adam), or by finding something funny in ordinary situations and being able to laugh with others, *“my mother is moaning at me because I said she can’t have her pastries [my Danish pastries] {pastries, that’s the one, until she went on camera} {laughing, a ha, ha poor woman}. She’s crying now like oh dear, terrible, terrible behaviour [they are one of my favourites as well, apricot and custard]. Well, she can’t have a Danish until she has performed”* (Participant David), and *“What coffee was it mum, {laughing} what coffee* *was it mum {laughing} [caramel macchiato] yes! You got it, that's annoying. I'll ask you again later"* (Participant David).

Whilst humour can be used in positive ways, it is worth noting that it requires reflection when using in serious situations such as palliative care; as there are situations when it would be deemed inappropriate (Tanay et al., 2014; Chapple & Ziebland, 2004; Fallon et al., 2008; Johnson, 2002), and with this in mind, people should be conscious of how it is used and perceived (Pinna et al., 2018). Along with consideration of the differences between how humour is received by others whether this is delivered in an online or offline situation (Giles et al., 2015).

6.4.6 Legacy

TYAs will develop blogs and vlogs as part of their legacy (Pereira et al., 2017; Akard et al., 2015). Legacy activities can be found to have a very therapeutic effect (McNees, 2009) and develop strategies for dealing with unresolved conflicts or 'unfinished business'. Bonia (2009) reports that even those who are critically ill can find the energy and motivation to review their life and put this in a narrative to pass on messages of wisdom and love. This has traditionally been in the form of a life story (McNees, 2009; Allen et al., 2008), which is put together in collaboration with family and friends. However, it has been acknowledged that often people can find it difficult and awkward to talk to people who are dying, and therefore, the interaction people can have remotely via watching and commenting on videos appears to remove some of this discomfort.

The narratives within this data followed the structure of a quest narrative which has been found to be how individuals with illnesses share their stories, and often choose to share them in a public way (Mason, 2018). A quest narrative gives the teller of the story a way in which to tell their story from their perspective using their voice, which is empowering. A quest narrative is sense-making, going on a journey to find out the ‘why’ and ‘how’ things are happening, but they can also be benefit-finding which identifies the ‘global value’ in what is happening to a person (Schaefer et al., 2021). The benefit-finding narratives have a focus on the personal growth, appreciation of life and often lead to more positive experiences (Park, 2013). Schaefer et al. (2021) found that benefit-finding narratives lead to people to ‘treasure each day’ and ‘made me more hopeful’ (p.5) when interviewing people about their experiences at end of life. This gave people a purpose and they felt they were leaving a legacy, were an inspiration to others, and they could ultimately help others (Schaefer et al., 2021). Narratives can be seen as one of many ways in which to leave a legacy to facilitate making meaning of life (Kobler et al., 2007). Studies with children and young people have found that artwork, video stories, and dignity therapy are all ways to support making meaning (Schaefer et al., 2019; Akard et al., 2015; Akard et al., 2020; Schaefer et al., 2020). Studies have indicated that children and young people are more likely to use benefit-finding narratives that sense-making narratives (Schaefer et al., 2021), with an innate desire to help others and be remembered after their death (Levetown, 2004). This is consistent with this research as individuals have shared their stories with some examples of sense-making, but predominantly benefit-making.

6.5 Place

How an audience perceives a vlog can often be based on the place in which the vlog took place. A residential setting has been known to increase the levels of positivity the audience have towards the vlog (Folkvord et al., 2019). If a vlog takes place within the person’s bedroom, then this can increase the intimacy between the vlogger and their audience which increases the overall perception of authenticity (Ashton & Patel, 2018).

For the participants all of them posted vlogs within their home environments which gave an insight into their lives which for the audience resonated with them and this was apparent with the number of views of the vlogs and the comments made from the audience. The comments have not been analysed within this research project; however, this would be interesting to consider in the future and to understand more about the audiences' perceptions of vlogs and if this impacts on the vloggers' content.

6.6 Study Limitations

All studies have some level of limitation to the research, and here I would like to acknowledge the main limitations for this study.

6.6.1 Recruitment: 'narratives of vulnerability'

Even once ethical approval had been received, challenges in recruitment remained ever-present, not only due to the participants not being forthcoming, but also related to the gatekeeping of the participant identification centres. HCPs had their own prejudice and reservations about the research, which impacted on them supporting recruitment, and therefore restricted the opportunity for those eligible to participate in the study. Anecdotally, they reported concerns about the vulnerability level of the participants and discomfort in using the words 'dying' or 'end of life'. It appears that this discomfort reflected their own emotions and experience, rather than necessarily being feedback from the potential participants. This level of challenge in HCP's supporting participation in research has been well documented in other clinical areas such as people living with dementia (McKeown et al., 2010) and those with intellectual disabilities (Forbat & McCann, 2010). There is an explicit notion that those at end of life are ‘vulnerable’, and therefore it is the role of a clinician to manage any posing risks and to ‘care’ for that individual, which some researchers would say is known as ‘protective power’ (Witham et al., 2015). It was the perception of some HCPs within the PICs that there would be considerable risk to the potential participants if the conversation of ‘dying’ or ‘end of life’ was overtly discussed on their psychological and emotional well-being, and therefore they were denied the opportunity to make that choice as they were not made aware of the research.

People may not have access to appropriate technology or social media sites to be able to post online, therefore the research will systematically exclude those people, which in turn means that the voice of those individuals is excluded from the research (BPS, 2021). This may lead to under representation, particularly from marginalised groups of people, and this factor is difficult to compensate for.

Some individuals set their social media accounts to ‘public’, and others prefer to post in closed online groups, which researchers would not necessarily have access to (Sannon et al., 2019). This is a critique of all research to a certain extent, as research relies heavily on the willingness of individuals to participate, and there will always be groups of individuals that this does not capture. Of those people who want to share their stories, there are further limitations in relation to their physical health deterioration and the impact that this has on their ability to post content. Some have turned to Twitter to post, as due to the limited number of characters, they feel that this is the least effortful way of posting content, whereas blogs or vlogs can be too physically and emotionally demanding for the person (Sannon et al., 2019).

It is difficult when using data from social media posts to verify the identity of participants, for example, determining the age of the participant and ensuring that the person is the minimum age required to give consent (BPS, 2021). Therefore, I ensured that for the vlogs selected it was explicitly stated in the vlog or associated blogs the age of the individual posting the vlog. However, this did lead to the elimination of some vlogs which could have presented with rich and meaningful data to include within this study.

Cyberbullying is prevalent in this age group, which could prevent people from posting online as they do not want to expose themselves to the possible negative emotional and social consequences of what they post (Pereira et al., 2017). Whilst there is evidence of cyberbullying of, for example, individuals who have intellectual disabilities, there is little evidence that suggests that this exists for individuals with cancer or those that are considered palliative.

It is worth acknowledging that although the range and diversity within the participants is varied, the study is limited to those individuals who have chosen to utilise YouTube to share their journey. Due to a range of contributory factors, such as digital deprivation, family dynamics, an individual’s personality, and many others, some individuals will not post their journeys online, and therefore the findings may not be transferrable to the whole population.

6.6.2 Reflexivity and Monologues

Using data from vlogs can reduce the researchers access to non-verbal cues which would normally be included in analysis. For written data such as blogs, emojis and emoticons can be used by the writer to express the intent or emotion related to what they have written (Markham, 2007). For the vlogs, there is non-verbal communication present which has been analysed; however, it would be fair to say that for face-to-face interaction these may be interpreted differently than seeing the video online.

The lack of control within the research procedure prevents researchers from monitoring the behaviours, reactions, and emotions of the participants (BPS, 2021).

6.6.3 Interpretation

A common consideration in qualitative research is the variety in the interpretation of data, as this can differ between narrative researchers based on the way in which the data has been conceptualised and the complexities surrounding that may differ between researchers as the analysis is subjective. It is also thought that if the researcher demonstrates reflexivity within the study and includes transparency about their interpretation, this is not a study limitation. Within social constructionism the thought is that as knowledge is socially constructed, we can never be sure that we have accurately depicted the real world (Smith & Sparkes, 2008) as no real world exists independent of our knowledge of it and epistemological constructivism (Smith & Sparkes, 2008). However, this study does not set out with intentions of understanding the ‘real world’ but focuses on understanding of the world through the eyes of the participants, therefore their perception of the world.

It would be interesting to consider whether the non-verbal communication of those appearing in the vlogs matches the language they are choosing to use, for example, are they smiling when they are talking about something happy or if you read their non-verbal body language and facial expression, does it appear to represent another emotion altogether. This is the advantage of choosing to analyse YouTube vlogs rather than textual based social media sites such as Facebook or Twitter. Some studies have started to consider non-verbal behaviour within social media posts as something worth exploring further (Biel & Gatica-Perez, 2010).

6.6.4 Storytellers

There is an acknowledgement in narrative analysis that the storyteller will select consciously what they think is important (Strauss & Corbin, 1998), and there is an assumption that people are honest about their views and feelings within their narrative (Carey, 2012). Often, stories are thought to be not fully developed, due to the complex nature of what people are talking about; they can be fragmented and undecided narratives as they try to find the right words to convey what they mean (Hyden & Brockmeier, 2008). However, with vlogs may have been recorded multiple times before the one shown to the public has been selected. They may have even been edited; therefore, vlogs whilst useful narratives, may not be the narrative that reflects the true experiences of the person. In addition, as the narratives in vlogs are ‘self-narratives’ with no interaction from the researcher, there is no opportunity for the researcher to ask any specific questions, and gain a more detailed understanding of the situation, actions taken, and the emotions involved.

The data for the vlogs is reliant on the participant’s willingness to share their stories (Riessman, 2007), which would also have been reflected within face-to-face interviews. There is an acknowledgement of a bias in that this data only reflects those who have wanted to post online (Hine, 2008) and share their experiences. Studies have shown that individuals feel more positive if they share positive emotions (‘capitalisation process’) (Luo & Hancock, 2020), and therefore positive disclosure occurs more frequently, which is known as ‘positivity norm’ of internet culture (Luo & Hancock, 2020). These positive posts have been found to increase social support for individuals (Metzler & Scheithauer, 2017; Vogel et al., 2018) and the feeling of connectedness (Utz, 2015). Those who share negative narratives have been found to have reduced engagement in the form of public responses (Ziegele & Reinecke, 2017), which is partly the purpose of posting a public vlog. Therefore, if individuals are more motivated to post positive narratives, then it may be that this is not a true reflection of how they are coping with their illness and how they are feeling. However, as the literature has suggested, an authentic narrative leads to social connectedness with the audience, which in turn improves well-being and self-esteem (Reinecke & Trepte, 2014), whereas inaccurate and unauthentic can lead to increased stress and anxiety (Grieve & Watkinson, 2016).

It has also been noted that to create the content for an online vlog which is meaningful, this requires significant time and effort (Ashton & Patel, 2018). For the individuals who have cancer, they may experience symptoms of the disease and side effects of medication, which include fatigue and therefore may not be able to share their experiences in this way. They may also experience difficulties with their ability to communicate, such as dysarthria and this was apparent in some of the findings. For some individuals, a communication impairment may prevent them from speaking publicly and sharing their stories.

6.7 Cultural Landscape for TYA

Youth culture prides itself on ‘embracing life’ and therefore death is often considered a topic of conversation for older people (Gerard, 2017). A community’s cultural expression of grief varies and for older people phrases such as ‘He led a full life’ are commonplace; whereas for young people ‘He was taken too soon’ are heard (Thorson & Powell, 2000). Often young people see themselves as immortal with years ahead of them (Højen et al., 2016), so when a young person becomes palliative instead of feeling they have lived a good life, they instead harness feelings of what they have missed out on. They can move between acceptance of illness and moments of anger and denial (Neimeyer, 2001) and the fear of dying (Sodergren et al., 2018a).

Within Smith et al (2018) study participants commented that they often denied or minimised the idea that they had cancer because ‘really old people got cancer’ and they did not always feel they were taken seriously when visiting the GP due to their age (Berry, 2011). Most participants reported that they had not met anyone in the ‘same boat’ as them which led to feelings of isolation and vulnerability. TYA are often thought to have the feeling of ‘invincibility’ (Miedema et al., 2007; Wickman, Anderson & Greenberg, 2008) and feel that their youthful immunity is challenged when they get a diagnosis of cancer (Smith et al., 2018). The feeling being invincible to life-threatening diseases was also seen during the COVID-19 pandemic, when large numbers of young people did not think COVID-19 was a threat to them given their age and health status (Leonhardt et al., 2021). Narratives generated from popular media often reinforce the homogenous view that older people are vulnerable (Swift & Chasteen, 2021; Ayalon, 2020). This is the opposite of how young people are considered, which is fit and healthy, with a lot of positive stereotypes (Bowen et al., 2020; Werner, AboJabel & Tur-Sinai, 2022); this social construct enhances the sense of injustice when a young person gets cancer and dies.

Taylor (2011) describes the utopian mindset of Neverland in Peter Pan, in which childhood is idealised as ‘place of perfect harmony; (p.420). Faulkner (2011) maintains that adults will often fixate on thoughts of innocence rather than worldliness (moral knowledge e.g., harm and desire)(therefore adults will filter their discussions to maintain innocence), which may deter them from discussing topics such as death with young people (Coombs, 2014). However, discussing death is no longer considered taboo and is moving into mainstream thinking and is ever-present in the media (Lee, 2008) moving from being private to being public (Coombs, 2014). Lim (2022) highlights that young people engage with the media more than any other type of activity and their exposure to death in the form of news, cinematic versions of dying, celebrity deaths and TV shows (documentaries, soaps)(Coombs, 2014). This can however provide a skewed understanding of death as it often omits experiences such as treatments, symptoms, and pain and shows death as conversely romantic, heroic, violent and glamorous (Coombs, 2014). Coombs (2014) study showed that young people think of action-packed deaths (heroic scripts) as inspirational and an attractive way of dying, rather than what death would be typically like, commenting on “life ending with a bang and not a whimper” (p. 293). Participants of Coombs (2014) study acknowledged heroic deaths are extreme and unrealistic they indicated this as their preference as it was “vibrant, purposeful…exciting” (p. 293).

Celebrity deaths are often depicted in the media as glamourous (Coombs, 2014) however in the case of Jade Goody her dying was depicted as redemption in which she attained social respectability through dying (Walter 2010). Jade Goody was on a British television reality show in 2002, which then led her into developing a media and business career. In 2002 the reality show highlighted her “loutish behaviour, crude language and ignorance” (Walter, 2010, p. 854) and subsequently on another reality show in 2007 she was accused of racism towards another contestant. She attempted to re-launch her career in a positive light by appearing on another reality show in 2008, and it was whilst on that show that she received a telephone call to inform her that she had cancer. Whilst undergoing cancer treatment in 2009 she signed a media deal for a reality show to share her story. Within the media there were multiple voices that represented her dying, all very differently and at times contradictory. Jade spoke of feeling ill, pain and fearing dying, which led to journalists describing her bravery and framed her pain in relation to overcoming ‘trials’. The photographs printed in magazines depict a healthy and smiley Jade, which contradicted the headlines and was not the usual representation of people with end stage cancer (Walter, 2010). This was reflected in the data for Coombs (2014) study as the participants wanted to be seen as a ‘fighter’ rather than a ‘victim’; and looking for meaning in dying (with a sense of social achievement). There remains stigma around cancer and the image of a ‘cancerous body’, which is seen to be sickly and diseased and where the “newly diagnosed must negotiate negative perceptions of the disease” (McLearney, 2019, p981). The negative perceptions that society attributes to a ‘cancerous body’ can make coping with cancer more difficult for TYAS (McLearney, 2019). The consequences of a ‘cancerous body’ e.g., muscle wastage, hair loss, can influence self-esteem which in turn impacts on ability to socially perform particularly in peer groups (McLearney, 2019). Coping performances can be seen as maladaptive behaviours as they resist a “cancer identity” (McElearney, 2019, p.983) and this is in line with the work on battle metaphors and for TYAs to appear ‘brave’ (Demmen et al., 2015; Semino et al., 2017a & 2018). Appearing ‘brave’, ‘youthful’ and ‘independent’ are the social and cultural expectation for TYAs and ‘cancer’ typically takes those qualities from TYAs.

In Coombs (2014) study young people highlighted that they felt there was a lot of publicity around famous people who die but not enough information about ordinary people. TYA’s also use technology as a form of self-expression and are often quick to voice their views online (Metzger & Erete, 2015); and this includes talking about death and dying. TYAs place a high value on social media (Pagoto et al., 2019) with 89% sharing on Instagram, 84% on Facebook and 16% on YouTube daily (Sannon et al., 2019). Therefore, for TYAs it is the norm and expected social construct to share views, stories, and experiences online.

6.8 Summary

This chapter has described the findings of this study and considered their importance within the wider literature. It has concluded that reciting a narrative in a video format has been found to identify gaps in health care, social isolation, effects cancer has on relationships, hopes for legacy and determination to help other TYAs.

Chapter 7 Conclusion

7.1 Introduction

This concluding chapter reviews the research aims and reflects on the overall research process. The chapter outlines the implications and contributions of this research to theory and clinical practice. The chapter includes a dissemination plan for this study and consideration is given to future research.

7.2 Review of research aims

1. To explore the online stories of young people who are dying of cancer and the impact of their diagnosis and treatment on their social well-being from the perspective of the young person (TYA) experiencing it.
2. To ascertain views of current palliative care from the perspective of the young people (TYAs) from information shared within their stories.

7.2.1 Research Aim 1

This has been the underpinning aspect of all elements of this thesis. Within Chapter 2, there is evidence that there has been consideration of the literature review surrounding social wellbeing in the context of the unique developmental life period of a TYA, specific services required for TYAs, the challenges of managing quality of life at the end of life and the role the internet/social media plays in the life of a TYA. To support the literature review within Chapter 2, the analysis of the narratives highlights that an TYA’s social wellbeing is dependent on several contributing factors such as peer relationships and developmental stage. Which appears to not only be relevant on an individual basis but are often replicated within the TYA participants of this study.

This study used YouTube vlogs to explore online stories of TYAs who are dying of cancer and within these vlogs the participants clearly outlined the impact that having cancer had on their experiences, quality of life and relationships with others. Their narratives provided a mechanism for them to share their experiences and use their voices to give insight into their lives. Posting vlogs online allowed a level of emotional intimacy and a relationship with the participant to be developed, which is unique and narrative analysis allowed for this to be explored in detail. The narratives showed participants navigating their diagnoses on a personal level with elements of their social constructs influencing this.

There are examples of this within other forms of media and within other age groups such as Kate Gross (2016) who writes in her book of her experiences of dying, *"Don't assume that you should crowd towards the centre of the spiral. Leave us space to breath".* She also talks at great length about having help to do things and the importance of peer support; but also, the challenges that can come with this, *"please don't treat me as if I'm a dying saint who has granted you an audience in her final hours", "don't make me feel as if this is the last time we will meet", and, "There is really nothing you can say that will make things worse".*

The implications of this research are that TYAs are experiencing a unique challenge in their lives in relation to socio-cognitive and emotional development. With a diagnosis of cancer, this significantly impacts on their development and sense of normalcy. To support their development, they turn to peers, family, and social media to seek information, share their narratives, and support them to cope with the challenges they are facing. In relation to research utilising social media to gain knowledge and insight into TYAs, this is vital in being able to develop meaningful services fit for purpose and engage with this age group.

Given this was an exploratory study in nature, to continue to develop an understanding there are several key areas that require further research, and these are discussed in more detail below.

7.2.2 Research Aim 2

The views of individuals within the TYA population were sought using vlogs. They had the opportunity within their vlog to talk about their experiences of having cancer, palliative care, and things that were important to them, which were their friends, family, and a sense of normality. They had full control of the dialogue and what they chose to share, which makes this a rather unique study.

The participants from the study referred to their treatment, symptoms and the HCPs that were supporting them. Whilst they did not overtly talk about what they feel is important in palliative care, conclusions can be drawn from the inferences they made about services and HCPs, from what they described as being important to them and how they presented themselves in the vlogs. These conclusions are that TYAs want to feel listened to and involved in decision-making about where they want to die, they want professionals to be kind and give them all the relevant information and they want to spend time with their family and friends. Within the vlogs we saw individuals posting vlogs from their homes, hospital appointments and the hospice which gave insight into their lives but also their experiences of their cancer journey. For some individuals they had accepted that they were end of life and therefore openly talked about palliative care, whereas others wanted to continue to have treatments in the hope that one of them would work and that they would not be end of life. This is an interesting point to discuss as the level of acceptance influences how the person, their loved ones and HCPs can approach palliative care.

The main components of dying well for TYA's are good communication, symptom management, acceptance, and preferences to be honoured, which is reflected in the data from this study. Good communication comes from honesty (Osborn et al., 2019) and good services/staff working with the individual and their families (Albritton & Bleyer, 2003; Aldiss et al., 2019; Gibson et al., 2021; Force et al., 2019). This is evident in the data as for some of the participants we get glimpses into their medical appointments and hear them talking to HCPs in a meaningful way. Within the data we can see that individuals refer to symptom and pain management regularly and the attempts to try to get this under control, this is supportive of a 'dying well' (Duran et al., 2020; Bovero et al., 2019). Effective pain management supports TYAs to participate in 'normal tasks' which improves their quality of life (Kaluarachchi et al., 2020). For preferences to be honoured individuals needs to be involved in shared decision-making (Hull et al., 2015), family-centred care and given choices (Gibson et al., 2021) as this allows them to maintain control over their healthcare (Rainsford et al., 2018). Within the study all the participants were actively involved in the decisions about their care and treatment.

There are limitations within the method of data collection, which will be further discussed below.

7.3 Implications of the Findings

7.3.1. Teenagers and Young Adults

The literature has identified that TYAs are in a unique developmental period, and as such, require bespoke specialist services to support their needs when experiencing cancer and end of life. In addition, it reflects that individuals are in the socio-cognitive stage of developing their sense of self, and this resonates with my data because their posting of their narratives supports this process.

Some individuals are at the developmental stage where they are confident in decision-making and their sense of self is well-established; however, others at the same age are still in a period of development and transition from childhood to adulthood. This is heavily dependent on their support network and their life experiences. Whilst the participants were all within the age range of 16-24 years, they presented with differences in their circumstances which impacted on how they experienced cancer and coped with their prognosis. Although the participants had these differences the analysis of the narratives presented with similar underlying themes. They used their narratives as a way of sharing their experiences, building relationships, coping with having cancer and to develop a newfound sense of self. This is important to consider as narratives for these individuals were cathartic, therapeutic and supported them in a way in which could be built upon in clinical practice as a therapeutic tool in end of life and grief therapies.

Narratives can be used for sense-making and benefit-finding, which marries up with the findings from this study. Individuals were sharing their narratives in a public place with either an intentional or unintentional purpose of social influence and igniting change. For those individuals, it gave them a sense of purpose and left them with a legacy.

7.3.2 Social Media

With the use of social media continuing to increase and access to social media available in most households (72% in 2020) (Gismondi, 2021) HCPs and researchers need to be mindful of the impact that these platforms have. For most people social media is now part of their day-to-day lives and place a high value on their ‘social media’ lives. The evolution of social media, particularly with the ‘z generation’, means that for both HCPs and researchers, we need to be more prepared to embrace social media as a way in which to gather information and engage with people to support them in their cancer journey. TYAs use social media for educational purposes, to create support networks and to seek validation/support the development of their sense of self. This is further highlighted in my research as it appears that the purpose of the individuals sharing their narratives was around developing their sense of self, helping to cope, and interaction with others.

TYAs are using social media to publicise their lives and for the participants in this study this is to help them cope with having cancer. They aim to connect with people who have similar experiences and to seek reassurance and emotional support from those peers. In this study the participants would often thank their subscribers for watching and for their comments and appeared to place a high value on these. Whilst posting online vlogs is not for everyone, for those that do feel they can engage with this, it could be used as a therapeutic tool to connect with others with similar experiences. In addition, if the aim of the vlogs is to connect with peers, then clinicians need to develop services which can enable this to happen in other forums and empower people to create those relationships with peers.

For some of the participants they used the vlogs as a way in which to leave a legacy for their loved ones but also for wider communities in terms of sharing their experiences. Legacy work can be supportive in therapeutic work around grief and loss and clinicians should be advocating for individuals early in their diagnosis to consider ways in which this can be facilitated.

7.3.3 End of life care

Although the findings of this study are focused on TYAs and those who have chosen to post their stories online, aspects highlighted within the analysis could be used to think about the important aspects for TYAs at the end of life, and to develop and improve specific services for TYAs. They provided insight into the experiences of people dying and what this looks like for TYAs. The implications for the findings along with previous literature (Barling et al., 2014; Rainsford et al., 2018; Bovero et al., 2019) suggest the importance of good communication, symptom/pain management, supporting individual's preferences and acceptance. Whilst everyone is considered unique these themes are considered important to most individuals and this is apparent within this study. The data indicated the importance of relationships and support from family and friends; further interviews or vlogs could be analysed with a specific focus on the narratives that exist within these relationships and the influence these have on how people cope at end of life. The data also indicated that individuals placed a high value on the relationship that they had with healthcare professionals, and it would be useful to conduct some observations on these interactions to understand what factors contribute to a positive relationship and the impact that this has on the individuals (and their families) on their end-of-life care experiences.

This study demonstrates that vlogs can be used to support individuals' ways to cope and accept their diagnosis and prognosis, by building relationships with peers, sharing their experiences and legacy making. Clinicians can build on these within their clinical practice to improve their communication style, involvement in shared decision making and supporting advanced decision making as early as deemed appropriate.

7.3.4 Clinical practice

The implications for clinical practice include increased confidence in the use of social media to support therapeutic interventions and development of peer support networks both physically and virtually for TYAs. In relation to Speech and Language Therapy, the implications of this study support the need to develop the role within palliative care, particularly around supporting communication and quality of life. For most individuals one of the most important things in their quality of life is being able to have meaningful relationships with those around them and this was evident in this data. For people with chronic health conditions, those having complex treatments and those approaching end of life, communication can significantly be impacted upon, and it is important that this can be maintained as much as possible to enable those relationships to continue. Speech and Language Therapists, such as I, can support the individual in maintaining their communicative functioning and support their loved ones in developing strategies to support communication. In addition, advanced care planning can become more difficult if the person has difficulties with communication and Speech and Language Therapists can provide support to increase the person's independence to engage with the decision-making process. I have already commenced developing clinical guidance for the Royal College of Speech and Language Therapist to support consideration of role within this clinical field.

7.3.5 Policies

Papers such as NHS long-term plan (2019) and National Palliative and End of Life Partnership (2015) state we need to improve service delivery and this data helps us to understand 'how' we can do that. The data within this study enables us to understand more about the use of the internet and social media in healthcare and provides insight on ways it could be used clinically and therapeutically to improve service delivery and overall improve the quality of life of individuals at the end of life. The data suggests that TYAs are using their peer networks as a coping mechanism and posting online to seek support. We know that for some individuals they do not have access to digital technology and therefore policy could be used to recommend technology as an intervention approach for TYAs. In addition, the data suggest the importance of relationships for support and the impact of anticipatory grief, family centred therapy could be recommended in national guidance and policy to increase TYAs access to this both digitally and face-to-face. The national policies need to have associated toolkits accompanying them which outline ways to improve service delivery as voiced by those experiencing it. This study demonstrates ways to begin to collate those voices and use them in a meaningful way to guide service delivery.

7.3.6 Research Dissemination

Following the completion of this thesis, I will be using the data within it to develop abstracts for publication around the use of social media in TYA research, what is important to TYAs who have cancer and how this can be used to improve clinical practice. I plan to apply to present at the International Cancer Conference for Nursing for a third year on TYAs at end of life, the International Teenage Cancer Trust conference and at the Royal College of Speech and Language Therapist's annual conference. I would also like to consider the future research projects that could be taken forward from this thesis and apply for grants to support this.

7.4 Original Contribution to Knowledge

This thesis presents a unique study specifically examining YouTube vlogs of TYAs at the end of their lives. It has brought up some interesting ethical issues, such as consent in social media, developmental challenges for TYAs and quality of life. In addition, there is data that suggests the importance of relationships with healthcare professionals and how they achieve this. The data has shown factors that are important to TYAs are the importance of feeling 'normal', quality of life versus treatment and benefit-finding (the importance of leaving a legacy or influencing social change). This will serve as a great foundation for future research studies.

7.4.1 Ethical considerations of social media

There were many ethical considerations during this research project as it included the use of data which existed in the public domain. The research addressed the concepts of consent to use the data for research projects, including GDPR, YouTube's terms and conditions and the HRA guidance. It highlighted gaps in policy to support researchers in using this type of data in the way in which I have used it; and these challenges have been articulated within this thesis.

Additionally, as the data is in the public domain and for narrative analysis the stories need to be in their entirety there were further complications of identification of the participants being apparent despite setting parameters of anonymity and pseudonyms. I have presented on the challenges of anonymity internationally, particularly when using social media as a data source. Looking at challenges, such as does anonymity really exist, do people want to be anonymised and what are the ethical implications for this as researchers.

Online ethical challenges also include thought as to whether TYAs are fully aware of the implications of posting online, in terms of its permanency and ownership. Their knowledge of this is likely to influence whether they post online, what they post and who they share this with. This would be interesting to further explore and would help to determine if the themes identified from within this study are representative of TYAs.

Whilst challenges exist in using social media, this research has demonstrated that it can be used effectively to gain access to groups of people who may not have traditionally chosen to be involved in academic research. It also shows a side of themselves that they may not have felt comfortable to share with a researcher. This makes this research unique as it gives a different perspective on what TYAs experience and share in terms of their cancer experience rather than what would be shared with an academic researcher in an interview or as part of a focus group.

7.4.2 Social Media

I have developed a particular interest in the way in which young people use social media to share their narratives to their friends and/or public. The language they choose to use, the images that accompany this, and the response they hope to achieve from sharing something. The data has highlighted the use of battle metaphors that TYAs frequently use to describe their experiences, and this gives us insight into how they are feeling and their understanding of their prognosis. TYAs using metaphors which indicate they feel they are ‘fighting’ and on a ‘journey’ can show those around them if they have accepted their prognosis, and this can enable them to have the right support based on this. It was clear in the data that some individuals had accepted their prognosis and were in anticipatory grief whereas others felt that acceptance meant that they had ‘given up’. This gave a unique insight into the TYAs experiences and could shape how services are offered in the future. The data shows that social media is used to share their experiences and seek validation, health professionals need to upskill themselves in how to utilise social media to support and policies needs to enable this. I feel that this can be used to further understand the challenges of young people, and whilst my study focused on cancer, further studies reviewing mental health and other chronic health conditions would be greatly beneficial in shaping how health professionals and the wider society can support young people. The themes that arose from this study such as ‘sense of self' and 'intimacy online' can be considered applicable in other areas of research such as mental health in young people, and these could be explored and built on further in future studies.

7.4.3 Analysis

Narrative analysis has been used in illness narratives and stories before; however, there is limited research that uses narrative analysis to analyse vlogs online. In addition, as some of the participants posted tens of vlogs it allowed for a different perspective to be developed on their narrative as it existed over several months rather than a single narrative from an interview or a one-off story. This provided a more detailed view of people's journeys and development of their sense of self over time, it gave moments of emotional vulnerability and those of strength which could be used within the analysis to understand more about their perspectives of having cancer. The thesis has identified the lack of clarity on what constitutes a story to be analysable and how does social media impact on this. Therefore, further guidance is required to support this, and this will be the foundation of my submissions to publications. This will aim to include developing a theoretical approach that supports social media posts (written, images and videos) using Franks narrative approaches and Pages understanding of online narratives.

As a Speech and Language Therapist I was able to use my clinical skills to analyse both verbal and non-verbal communicative functioning of the participants, which added another unique perspective on the narratives.

7.4.4 Positionality

This study has demonstrated and further supported the evidence that there is a role for Speech and Language Therapy within end-of-life care and within supporting

TYAs on social media as part of their clinical interventions. This requires further guidance within the profession to support therapists to understand the types of intervention, the purpose, and the professional boundaries within this. This would include the use of social media to deliver assessments, interventions and engage with TYAs. I have already commenced discussions with the Royal College of Speech and Language Therapists in relation to development of guidance, an associated toolkit and training to support the profession within this clinical field.

7.5 Suggestions for Future Research

The research presented in the thesis has provided a unique in-depth analysis of narratives presented by TYAs experiencing cancer and their end-of-life journey through online vlogs. The research has highlighted some key themes that would benefit from further exploration in future research.

7.5.1 Social Media

With the importance of social media to TYAs, it is emergent use for healthcare professionals is evident, but further research could look at the effectiveness of interventions delivered online, information available on social media, and how to engage young people in research through social media. This has implications for future service planning and delivery for not only TYAs but the wider population. If online interventions are found to be equally or more effective than face-to-face interventions, this would support the national agenda of moving away from a postcode lottery and open services to those in more remote areas. It would also be interesting to look at the role of peers in online forums in relation to how this improves the individual’s ability to cope, develop their sense of self and acceptance of their prognosis. The data refers to this but could be further expanded on with a focus on how clinicians can achieve this within services. There is some evidence that suggests posting online can lead to a sense of ‘empowerment’ and that this is more present in males than females. It would be worthwhile considering this in more detail as there are implications for service delivery if gender differences are found to be the case.

Therefore, I would like to consider further research projects that look at TYAs’ use of social media in chronic illness and mental health. I would like to consider written information as well as video-based information such as Facebook posts. In addition, with the emergence of Tik Tok videos I would like to see what videos TYAs with cancer are posting and how they are using this online forum differently to YouTube.

Within this study the responses from viewers were not analysed, which may have given some further insight into the intent of the vlog and the interaction between the person posting the vlog and the viewers. Within the fields of social psychology and counselling how to give and receive distress and emotional support has been studied (Burleson, 2009). Zhou and Jurgens (2020) have conducted studies with a focus on how people express distress on social media and how others offer condolences. In line with others, they found that often it is a way of seeking comfort, emotional advice, and social connections (Brubaker et al., 2012; Brubaker & Hayes, 2011). However, there is evidence that suggests that condolences online do not offer any actual support despite the intentions of those offering this being good (Zhou & Jurgens, 2020). This is felt to be because condolence is difficult for lots of people (Cameron et al., 2019) and usually people use standard phrases such as “I’m sorry for your loss” and “You are in my thoughts” as a way to compensate for the difficulties in emotional effort required for empathy and sympathy (Zhou & Jurgens, 2020).

7.5.2 End of Life

This research has shown the importance of benefit-finding for those considered end of life, particularly children and young people. Therefore, it would be useful to consider legacy work to enable those dying to be able to leave a legacy in some form and to support the bereaved family members/friends. Those posting on YouTube are primarily doing so from their bedrooms with no specific support in relation to things such as internet safety, filming equipment, editing, and emotional support following filming/posting. If legacy work was part of a recommended intervention for individuals, it would be beneficial for them to have access to those things, and this has implications for service planning and delivery in end-of-life services. The impact of having access to support in legacy interventions is under researched, and this field would benefit from further research.

As I work in forensic and secure settings clinically, I would like to expand the research to consider what is important to individuals within the secure and prison services who are palliative. This would be interesting and unique as what they have available is very different than those outside of the settings, and I am uniquely placed to access these individuals via my clinical role.

7.5.3 Policy Development

I think that there are some conclusions that can be drawn from this research that need to be developed as part of national policy on research, particularly around internet mediated research and ethics. This research can be used to influence positive changes to research protocols and develop ethical guidelines for governing bodies on internet mediated research, e.g., British Psychological Society, General Medical Council. The data indicates what is important to TYAs in terms of what support they benefit from having for example peer support, good relationships with healthcare professionals and to be involved in decision-making about their treatment, and this needs to be reflected in relation to commissioning, clinical practice recommendations such as NICE guidance and into local service policies. In addition, the data has shown the value of using vlogs as a data source and therefore in order for data such as this to be used for future research, researchers would benefit from having further guidance on consent and ethical challenges.

7.6 Reflection on the overall research process

From my perspective, I had started this research journey with the anticipation of conducting face-to-face interviews with individuals to be able to listen to their stories about their journeys and analyse the non-verbal communication that supports the interpretation of their story, along with the performance and context of their narrative. Due to the difficulties in recruitment, I had to be flexible in adapting my method of data collection to compensate for this and be open minded in my ability to use data taken from social media. I had to quickly develop my knowledge in 'the internet', the challenges that utilising data from the internet brought, and how to implement the narrative methodology to this new way of working. I had to consider the impact of COVID-19 on the research project itself and on the participants, not only did this change the methods of data collection, but COVID-19 had a significant impact on the use of social media, how we communicate with others and the sense of communities that developed online. This not only influenced my research, but this will continue to influence research moving forward.

I learnt skills in how to manage a research project from start to finish, the challenges of navigating the Health Regulatory Authority, confidence in speaking at international conferences and the skills to go on and deliver future research projects. I feel that I have been able to provide a unique contribution to the field and this has made me feel really proud of what I have achieved. I developed a greater appreciation for the process of research and valued the reflective discussions in supervisions, e.g., have you thought about this? Or tell me why? as they challenged my ways of thinking and enabled me to develop a more analytical approach to literature reviews, planning my project and analysing data.

Whilst conducting the research the world experienced a global pandemic, which particularly impacted on the NHS and those services supporting the NHS. This added many other challenges to the research which I had not anticipated when I started my part-time studying in 2016, and even whilst living through the experience in 2020. My clinical role within the NHS suddenly required longer hours in a more emotionally charged environment, this alongside analysing vlogs containing emotionally complex issues, meant I was spending significant amounts of time situated directly within highly affecting and challenging situations. The importance of ‘self-care’ through reflections and de-briefs both professionally and academically suddenly became incredibly important to help maintain resilience and a good emotional and psychological wellbeing. What this unexpected challenge brought to the research was an enhanced understanding of empathy for the participants, and whilst I have not shared the same experiences as them, I was able to reflect on things in my life that made me feel similar. This, in my opinion has enriched my analysis of the data.

Initially the method of data collection was face-to-face interviews recruiting from three ‘Teenage cancer trust’ units within the North of England. As previously reflected on within the limitations of the study, recruitment via this method was challenging and there became a point within the PhD where a decision had to be made to look for an alternative method. At the time, this made me quite upset as I had put a lot of work into planning the interviews, putting together participant information sheets, etc., but also because I really wanted the opportunity to meet individuals that were at the end of life, connect with them and ask them questions about their experiences. However, once I had started to look for other options to progress the thesis and started watching YouTube videos, it opened different opportunities for connecting with the participants and also the world of social media within research. Therefore, whilst I was initially upset at the prospect of changing the method of the thesis, it has given me the opportunity to broaden my research experience.

I also want to reflect that I really enjoyed listening to people's stories, especially how different they all are and then using narrative analysis to look for meaning in them and draw similarities. This has inspired me to think about how to develop other clinicians' skills in research and ensure that research is part of a clinician's job and included in their job planning.

7.7 Summary of contributions to literature

The main contributions this thesis has made to the literature focus on how TYAs adjust to having cancer, and particularly those with a palliative prognosis vary dependent on their individual circumstances, their ability to cope with the adversity that their diagnosis brings, and the support networks that they have around them. The themes around 'sense of self' have implications for other health related areas such as mental health and could be used to support shaping services for young people not just cancer services.

7.8 Summary of thesis

The research set out to understand more about the views of TYAs on their own cancer, the service offered and peoples experiences of dying. I have provided insights into these research aims, provided a unique contribution to the field, and learnt the skills to take forward my future research proposals. The thesis defines TYA's in relation to the age included within this, the use of the abbreviation and the uniqueness of their developmental stages (and how this influences their decision-making for treatments). It reviews available services, what is important to TYAs (e.g., quality of life, symptom burden, grief, and spirituality) and how they use social media in their everyday life. I have outlined the method of data collection using YouTube with rationale and justification for this choice. I have summarised the epistemological approach of social constructionism and how this links to narrative analysis. I have used dialogical narrative analysis and Franks (2010) framework (content, principal agents, structure / sequence, purpose, and place). I have further analysed the imagery and narrative tones of the narratives, alongside pulling out the key themes of relationships, sense of injustice, helping to cope and acceptance, quality of life, humour, and legacy. I have summarised the findings, outlined the limitations and provided suggestions for future research.

This research has identified a number of original contributions to research and future research topics for me to consider. The impact of this research is significant as it highlights developments in data sources, narrative methods, important factors to consider for TYA interventions and further policy requirements. Using YouTube as a data source for TYAs at end of life is under researched and applying narrative analysis is unique. The use of narrative analysis has enabled a richer understanding of the experiences of young people and given a strong sense of what is important to them. This could be applied to a different cohort of TYAs e.g., those experiencing anxiety and depression, for clinicians to further understand what is important to them. I have discussed with the Mental Health Research for Innovation Centre (MRIC) the possibility of funding to conduct qualitative studies of social media posts of TYAs with the aim of identifying key themes that can support development of effective interventions.

In order to use social media as a data source further policy development is required to support researchers with the ethical dilemmas and practicalities of this, therefore I plan to publish how I navigated this and how this could apply to others.

I have already commenced development of clinical guidance to support Speech and Language Therapists with the Royal College of Speech and Language Therapy; and I am in the process of developing publications for submission regarding narrative analysis of online stories and how this can be used to support future healthcare delivery.

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Appendix 1 – Study Procedure

Manchester Metropolitan
University

An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis.

Version 1.1 01/02/2018

Version 1.2 25/06/2020

Version 1.3 27/07/2021

MAIN SPONSOR: Manchester Metropolitan University

FUNDERS: Manchester Metropolitan University

STUDY COORDINATION CENTRE: Manchester Metropolitan University

NRES reference: 224690

Protocol authorised by:		
Name & Role	Date	Signature

Study Management Group

Chief Investigator: Krystina Crolla-Barker
Study Management: Dr Gary Latham Dr John Lancaster Professor Carol Haigh Dr Gayatri Nambiar-Greenwood

For general queries, supply of study documentation, and collection of data, please contact:
Study Coordinator: Krystina Crolla-Barker
Address***
Tel: ***
E-mail: 06232617@stu.mmu.ac.uk

Clinical Queries

Clinical queries should be directed to Krystina Crolla-Barker who will direct the query to the appropriate person.

Sponsor

Manchester Metropolitan University is the main research Sponsor for this study. For further information regarding the sponsorship conditions, please contact:
Research Governance and Ethics Manager
RKE Office
Manchester Metropolitan University
Ormond Building
Tel: 0161 247 0189

Funder

The study is a research project as part of a PhD, and the PhD (tuition fees only) has been funded by Manchester Metropolitan University.

This protocol describes the study and provides information about procedures for entering participants. Every care was taken in its drafting, but corrections or amendments may be necessary. These will be circulated to investigators in the study. Problems relating to this study should be referred, in the first instance, to the Chief Investigator.

This study will adhere to the principles outlined in the NHS Research Governance Framework for Health and Social Care (2nd edition). It will be conducted in compliance with the protocol, the Data Protection Act, and other regulatory requirements as appropriate.

INTRODUCTION

Background

The Department of Health published figures in 2014 which appear to indicate a rise in the number of people diagnosed with cancer (280,000) and people that die of the disease (133,000), with approximately 6.5 billion pounds spent on cancer services each year. Specifically within the North West UK regions, Cancer mortality rates are higher than the national average with North Manchester and Liverpool ranking within the top 5 highest mortality rates with 378.3 per 100,00 and 365.7 per 100,000 respectively (http://www.cancerresearchuk.org/cancer-info/cancerstats/local-cancer-statistics). It is estimated that 1/4 deaths of 16–40-year-olds is cancer related (www.brightlight.org.uk).

One in seven young people aged 13-24 years are diagnosed with cancer every day in the UK (https://www.teenagecancertrust.org/about-us) and the greatest increase in cancer mortality rates since the early 1970s has been in people within this age bracket (www.cancerresearchuk.org).

“In terms of health care delivery, it has become apparent that Adolescents and Young Adults patients tend to occupy a sort of no-man’s land, at home in neither of the two different worlds of paediatric or adult oncology” (Ferrari et al., 2010).

Within this population over the last decade there have been numerous organisations that have ignited a catalyst for change, including the services and information provided, e.g., Teenage Cancer Trust. Changes in medical treatment and support have emerged, focusing on improvement in more effective quality of life care and person-centred care.

The aim of the research is to explore the life stories of young people who are affected by cancer. With questions relating to before diagnosis and after diagnosis, which aim to further understand the impact of the diagnosis, social well-being and factors that are important to the participants. This will help to identify and synthesize “best practice” methods in palliative care and explore what makes dying easier from the viewpoint of the patient experiencing it.

The study will consist of Teenagers and young adults (TYA’s) aged 16-24 years with a diagnosis of cancer who are considered palliative and at the end of their lives. Within this study, I will explore the definitions and terminology used within existing literature and what are the preferences of TYA’s.

The study aims to have 5-8 people interviewed for the study, to gather a variety of opinions and experiences. The participants will be from the North via existing organisations who offer support for the recruitment of participants (Patient Identification Centres). The participants will be invited to a maximum of 2 interviews which will last approx.one and a half hour. In addition to this a review and analysis of vlogs[2] will be conducted. The aim of this is to enrich the data gathered from face-to-face interviews and to support any recruitment issues that can be foreseen with this vulnerable and small participant pool. The interviews will be audio recorded which will then be transcribed by the lead researcher. The Vlogs will be transcribed using the same format. The analysis will be done using a narrative analysis approach.

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[2] Vlogs as defined ‘blogs created in video form rather than textual (Molyneux et al, 2008) or a series of videos on a videosharing social media platform (Freeman & Chapman, 2007).

Rationale

It has been consistently reported that although there is an increase in specialist treatment centres for TYA's there remains insufficient recognition of the specialist needs of this population (Whelan, 2003). The importance of recognising patient's views and experiences in determining future care and influencing policy has been noted (Marris et al., 2011). It has been identified that young cancer patients have an increased desire to be treated as a partner and an integral team member within their treatment (Morgan, 2009). And that alongside physical health issues, a diagnosis of cancer is likely to significantly negatively influence social well-being (Warner et al., 2016). This study will focus on patients who are dying on cancer, the terms 'end-of-life' and 'palliative' are used within the literature; within this study I will be using the terms interchangeably, however I will focus on the World Health Organisation definition of 'palliative' as a benchmark[3].

Existing studies have highlighted that whilst there are some studies focusing on Adolescents and young adults (TYA) on coming to terms with dying, studies have recommended that further research in examining the needs of TYA's and their carers facing end of life care (Gibson et al., 2016). This can be used to further understand the impact of their diagnosis and treatment on their social well-being from the viewpoint of the patient experiencing it. With the aim of identifying and synthesising "best practice" methods in palliative care.

STUDY AIMS

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[3] "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (http://www.who.int/cancer/palliative/definition/en/)

Primary Aim

To explore the life stories of young people who are dying of cancer before diagnosis and after diagnosis to further understand the impact of their diagnosis and treatment on their social well-being.

To ascertain a comprehensive analysis of views of current palliative care from the perspective of the patients. to identify and synthesize “best practice” methods in palliative care and explore what constitutes a “good death” from the viewpoint of the patient experiencing it in order to facilitate conversation between health care professionals and patients in the future.

To understand what constitutes a ‘good death’ from the perspective of the young person experiencing it, including the impact of their diagnosis on areas such as education, friendships / relationships, and employment.

Primary endpoint/outcome

The outcome of this research is to provide rich meaningful data that will identify the key elements of the individuals experience of the palliative care journey and collectively embedded within this will be key themes to extrapolate to answer the primary aims. The primary outcome is to produce a thesis and additional publications.

STUDY DESIGN

Open ended interview questions have been previously used to effectively yield information from TYA’s in relation to their quality of life (Hinds); therefore, this will be utilised within this study. The participants will be invited to an interview (with the option of a second interview at the choice of the participant). The interviews will be conducted in a place in which the participant feels comfortable, this will can be either the participant’s home or a neutral location. The interview is likely to last approx. 2 hours in duration; however, if the issues discussed within the interview cause distress to the participant the interview will stop and only start again if the participant consents to continue. The interviews will be audio recorded and transcribed verbatim.

To meet the aims of the study, stories about life pre and post diagnosis will be described by the participants within the study, to give an insight into the impact this has had on specific areas within their life. Questions used to support the interview will be relating to things such as friendships, relationships, education, employment, interactions with healthcare and significant moments in their lives.

Vlogs

The social media platform ‘YouTube’ will be used to identify appropriate vlogs matching the participant criteria (where possible). The search terms used will be:

Cancer blog UK teenager

Dying of cancer my story

If the Vlog is part of a series of Vlogs, then the researcher will consider whether to analyse the series of vlogs to ensure adequate analysis of the data can be achieved or may choose to analyse a particular vlog and the evidence supporting this decision making included in the thesis.

The use of Narrative analysis on the transcribed data will provide insight into patient's views and experiences, which can then be used to structure thinking for determining future care and influencing policy (Marris et al., 2011). It has been identified that young cancer patients have an increased desire to be treated as a partner and an integral team member within their treatment (Morgan, 2009). And that alongside physical health issues, a diagnosis of cancer is likely to significantly negatively influence social well-being (Warner et al., 2016). Which I would anticipate being reflected within the data collected, specifically giving insight into personal experiences and ways this has been overcome (supportive strategies, services). Therefore, Narrative Analysis will be used to analyse the data and will support the researcher in answering the primary aims.

STUDY SETTING

The recruitment for the study will be conducted via Participant Information Centres, which have been selected as they are within the North of the UK and have Teenage Cancer Trust specialist services within the trusts.

Although all recruitment sites within North UK will be invited to participate in the study, within the final study sample all sites may not be represented due to participants not opting into the study from all sites.

In addition to face-to-face interviews, vlogs will be used to support difficulties in recruitment. Internet mediated research (IMR) is considered to be any "research involving the remote acquisition of data from or about human participants using the internet and its associated technologies” (BPS, 2017, p.3). In the context of IMR the term ‘public’ is defined as ‘readily accessible by anyone’ (BPS, 2017).

It is worth acknowledging that in relation to the internet; technological improvements and changes occur rapidly and so there is a constant need to review the salient considerations in relation to IMR (BPS, 2017). The guidelines that support ethical decision making in research are not always aligned to IMR and therefore require careful consideration and application to IMR research. The code of Human Research Ethics (2009) states that observation of public behaviour for research purposes can only take place in public situations where those would be expected to be observed. However, an online space such as ‘YouTube’ can be perceived as public. Often a video posted onto a social media space is posted to be intentionally ‘public’ and therefore should be perceived as within the public domain and usable for research purposes. However, some would argue that if the video is made in their home environment, then the video should be considered private; however, posting this video in an ‘open forum’ then converts the video to being considered public. In ‘open forums’ data is publicly visible, has traceability to the source and a level of permanence; therefore, the question is, does this make it ethically acceptable to use the data freely for research purposes? To support answering this question it is worth referencing the web service users licence agreements; these would typically require the person posting the ‘data’ to agree that this is public, grant other users of the service permission to reproduce, distribute and modify the data; along with clear guidelines of removal of the data should they wish to do so (YouTube, 2020). Whilst it may be impractical or unnecessary to gain explicit permission from the data owners; this needs to be balanced alongside the social responsibility of what the data will be used for (BPS, 2017).

There are guidelines for assessment the quality of video's (Gabarron et al., 2013) which will be used to support analysis of the Vlogs. The Vlogs will be transcribed verbatim as with the interviews; however, in addition to these relevant comments made about the vlog in the feed will be included within the analysis.

In summary, IMR evokes ethical considerations for researchers and there is "more than one ethically defensible response" (AoIR, 2019, p.6). As there lacks a clear and singular response to the ethical dilemma of whether it is ethically responsible to use videos from a social media website, it is the role of the researcher to outline the rationale for their decision. For this research the videos selected will be in line with the participant criteria, the content of each video individually reviewed by the researcher to ensure that the benefits outweigh any potential risks and that the process of anonymity for certain aspects of the videos is implemented as appropriate.

ELIGIBILITY CRITERIA

Inclusion Criteria for face-to-face interviews

Participant are aged 16-24 years and have received their diagnosis between the ages of 16-24 years.

Participants live within the North of the UK

Participants have a poor prognosis for their diagnosis.

Participants have a diagnosis of Cancer (specific type not required)

Participants are able to give informed consent to the interviews, including consenting to the audio recording of the interview content.

Male and Female participants.

Inclusion Criteria for Vlogs

Participants are aged 18-24 years and have received their diagnosis between the ages of 16-24years.

Vlogs dated from 2018-2021 from YouTube only.

Participants who live in the UK

Participants have a poor prognosis for their diagnosis.

Participants have a diagnosis of Cancer (specific type not required)

Exclusion Criteria for face-to-face interviews

Participants are not within the age of 16-24 years or have had their diagnosis prior to this age.

Participants live outside of the North of the UK

Participants have a good prognosis for their diagnosis or are considered curative.

Participants do not have a diagnosis of Cancer.

Participants are unable to give informed consent to the interviews, including consenting to the audio recording of the interview content.

Participants who are known to the Chief Investigator in a clinical professional capacity.

Exclusion Criteria for Vlogs

Participants are not within the age range of 18-24years or have had their diagnosis prior to aged 16 years.

Participants live outside of the UK.

Participants have a good prognosis for their diagnosis or are considered curative.

Participants do not have a diagnosis of Cancer.

Vlogs dated pre-2018.

Withdrawal Criteria

Participant chooses to end the interview and opts to have the data removed from the study (this can be done within 1 year of the interview).

For vlogs participant chooses to withdraw their data from the study to the best ability of the research team data is removed from the study and any distribution of the research, however acknowledging that this is not 100% guaranteed.

STUDY PROCEDURES

See Appendix 1 for Study recruitment procedure.

The timescale for the study procedures are as follows:

The recruitment of participants would commence once ethical approval has been received with the aim of a March 2018 start date. The recruitment would then continue for approximately 1 year or once a sufficient number of participants have been identified and consented to participate. The analysis of the data will commence following each interview and will be completed within 6 months of the final interview. The complete write up of the study is anticipated for completion by January 2022.

Vlogs will be analysed from the last 3 years based on the eligibility criteria stated in 5.1.

Recruitment for Interviews

The potential participants will be identified using Patient Identification Centres. The potential participants will be given the Participant information sheet (See Appendix 2) and the invitation to research (See Appendix 3). The potential participant will contact the researcher to discuss the study further and to consent to participation.

Recruitment for Vlogs

A search of YouTube will be conducted using the search terms:

Cancer, blog, UK, teenager, palliative

Dying of cancer my story, palliative

The videos will then be filtered to identify the ones that match the eligibility criteria.

Patient Identification for Interviews

The recruitment of potential participants will be supported by the Patient identification Centre's who will use the studies eligibility criteria to identify potential participants. The Patient Identification Centre will provide the potential participant information with the Patient Information Sheet and Invitation to research, therefore the researcher will only receive patient identifiable information (in the form of name, address, and contact information only, in order to arrange the interview) upon gaining consent from the potential participant, as per study recruitment procedure (Appendix 1).

Patient Identification for Vlogs

Within IMR consideration needs to be further given to the argument of anonymity for participants; particularly as any published quotes within the research may compromise any anonymity or confidentiality for the participant (BPS, 2017). Consideration has been given to the impact of this on this research and processes such as paraphrasing or combing quotes has been suggested as a compensatory strategy; however, this does not fit in with narrative analysis principles and therefore could not be utilised for this piece of research. In addition, the person is appearing in the video themselves and identifying themselves within the video using their real names. However, if the individual is not able to provide consent as they are deceased then they will be given a pseudonym. This also supports the understanding that within IMR and within research of specific clinical groups, true anonymity is difficult to achieve. This is further outlined in section 6.2.5. In addition, if any individuals or organisations are mentioned within the video; and the risk of harm to those is high as a result of what is mentioned then this will be omitted from the data set or anonymized.

Consent for Interviews

Participants be provided with the Participant information sheet and the invitation to research, they will then contact the researcher if they would like to participate in the research and can consent to arranging an interview.

Only participants who have capacity will be considered for the research.

Consent for Vlogs

All information collated via YouTube and other social media platforms is in the public domain and therefore participants will have provided consent for their information to be made available in the public domain by agreeing to the terms and conditions where they have posted the information. See section 4 for further information. In addition, See Appendix 8 for decision-making support for consent for participants for vlogs.

For those participants where there is no clear evidence that they have deceased attempts will be made to contact them via YouTube. If the person has as part of their YouTube profile the means to be able to contact them personally then they will be sent an email (see Appendix 9 for exact wording). If personal contact information is not available, then a comment will be left under the video (See Appendix 9 for exact wording). If the person does not get in touch following contact being made, then the vlog will not be used within the research.

The evidence that will be considered to clarify if the person is deceased would be:

Within the vlog itself there is reference to the person dying either from another person or written in text within the vlog

Within the comments underneath the vlog, it has been made clear that the person has died (must be multiple examples of the comments for them to be considered)

Further vlogs from the same individual or part of the series indicates that the person has died.

The vlog is part of a wider documentary series and within this it has been made clear that the person has died.

Withdrawal Criteria for Interviews

Once data has been collected from the participant the data will be included within the study.

Participants can choose to have their data removed from the study and following the data collection (interview) they will be given 1 year to withdraw.

Withdrawal Criteria for Vlogs

The information is within the public domain and the individuals within the Vlogs will not have the opportunity to withdraw. Due to the nature of the material and it being available in the public domain there is no way to withdraw from the study. However, if the video is removed from the public domain, then it would be removed from the study.

STATISTICS AND DATA ANALYSIS

Sample size calculation

Guetterman (Guetterman) found that no specific sample size is recommended for narrative inquiry. Therefore, I have selected 8 participants as I feel that given the eligibility criteria of participants and that they are opting into the research this would be a realistic number to aim for. However, it may be that less participants are achieved, which would still provide adequate data to be analysed for the purpose of this research.

Due to limited recruitment, analysis of vlogs is to be included as data within the thesis.

Planned recruitment rate.

Upon receipt of ethical approval recruitment will commence. Based on the population size eligible for the study and factoring the participants will opt into the research, it is estimated that the recruitment will take 12-18 months to achieve the identified participant number.

This has been extended due to the difficulties with recruitment from participant Identification Centres and the current climate, e.g., COVID-19.

DATA HANDLING

Data collection tools and source document identification

The researcher will only have access to participant's information (name and method of contact, e.g., phone number) once they have opted into the research.

Interview audio files and transcriptions will be collected at the time of interview.

Data handling and record keeping

All the information gathered as part of this study will be kept as per MMU Data Protection in research policy (See Appendix 5), which includes the use of data encryption to enhance security of information. MMU supports research data management by providing secure storage solutions for the data in the form of one drive.

Participants will be given a pseudonym; however, they will have the option to have their own name present in the research. If they choose to have their own name present in the research, it must be clearly stated on the consent form that this is their choice. If after the interview the participant changes their mind, they will be given a pseudonym. They will be given this choice up and can change their mind within 1 month of the interview. See Section 11.6 for further information.

The personal information held on record (participants real name and method of contact, e.g., telephone number) will be kept on an excel spreadsheet which will be password protected. The access to this spreadsheet will be limited to the researcher and supervisory team only. This information will be provided by the participant when they contact the researcher to opt into the research, therefore consent will be sought to save information in this way from the participant during initial contact.

Transcription will be carried out by the chief investigator only. The interview audio files, and interview transcriptions will be saved on the secure MMU drive and will be password protected. The files will be transferred there from the recording device within 2 hours of interview (allowing for travel time) and will be deleted from the audio device once transferred. The access to the recordings / transcriptions will be limited to the researcher and the supervisory team only. See Appendix 6 for further information).

The responsibility for data entry, storage and analysis is the chief researchers and will be supported by the supervisory team.

Access to Data

Direct access to the data from interviews will be limited to the chief investigator and the supervisory team only. Data from vlogs is available within the public domain.

Archiving

Archiving of study documentation will be authorised by the sponsor following submission of the end of study report. All essential documents (audio interviews and transcriptions) will be archived for 5 years after completion of the study by the researcher and following this will be upon authorization of the sponsor will be destroyed as per MMU Data Protection in research policy (See Appendix 5). All non-essential documents will be destroyed upon completion of the study.

Vlogs will be archived as per social media platform guidelines and terms/ conditions. The transcriptions of the videos will be archived for 5 years as per MMU Data protection in research policy.

Monitoring, Audit, and Inspection

The data included within the research will be discussed between the researcher and the supervisory team at intervals.

REGULATORY ISSUES

Ethics Approval

The Chief Investigator has obtained approval from the TBC Research Ethics Committee. The Chief Investigator will require a copy of the Trust R&D approval letter before accepting participants into the study.   All correspondence with the HRA will be retained in the study master file.

Amendments will not be implemented until the HRA department grants a favourable opinion.

An annual progress report (APR) will be submitted to the HRA within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended. The Chief Investigator will notify the HRA of the end of the study, and if the study is ended prematurely, the Chief Investigator will notify the HRA, including the reasons for the premature termination. Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the HRA.

Peer review

The study has been peer reviewed internally within Manchester Metropolitan University as part of the registration for a PHD process (RD1 form and RD2 form). The study was reviewed by two individidual experts.

Public and Patient involvement

As the research design is interviewing individuals to ascertain their feelings and views, their involvement is inherent and embedded within the research. The individuals are being given the option to use their own name in the research as a way of empowering them and giving them a voice.

Regulatory Compliance

The Chief Investigator will apply for NHS permission from each identified sites Research and Development (R&D) department before individuals are given the study information packs.

For any amendment that will potentially affect a site's NHS permission, the Chief Investigator will confirm with that site's R&D department that NHS permission is ongoing (note that both substantial amendments, and amendments considered to be non-substantial for the purposes of REC and/or MHRA may still need to be notified to NHS R&D).

Data protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing, and disclosure of personal and sensitive information and will uphold the Act's core principles.

See Section 8.2 Data handling and record keeping for further information.

The data custodian for this study is the Chief Investigator.

For this study, individuals will be given a choice as to whether to remain anonymous or whether to identify themselves. This is to allow recognition for their involvement if they choose to do so (Giordano et al., 2007) as often individuals, particularly in Narrative research, place a high value on their participation and engagement (Boman & Jevne, 2000). However, it must be made clear to the participant the way in which the data will be presented, e.g., for publication and consent must be clearly documented relating to confidentiality and anonymity.

See section 2 for further information about data protection and patient confidentiality in relation to the use of videos/ vlogs.

'If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk *e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see:* https://ico.org.uk/global/contact-us/*'*

Conflicts of Interest

The Chief Investigator professionally works within a geographical area in which participants may be recruited. Therefore, as per exclusion criteria, any potential participant known to the researcher in a clinical professional capacity will be excluded from participation within the research.

At the time of writing the protocol not all sites/personnel may have been identified. When this is the case then the protocol should state that this information will be collected and where it will be documented.

Indemnity

Manchester Metropolitan University holds insurance that provides cover for harm arising from the design, conduct and management of the research.

Amendments

If the sponsor wishes to make a substantial amendment to the HRA application or the supporting documents, the sponsor must submit a valid notice of amendment to the HRA for consideration. The HRA will provide a response regarding the amendment within 35 days of receipt of the notice. It is the sponsor’s responsibility to decide whether an amendment is substantial or non-substantial for the purposes of submission to the REC.

Amendments also need to be notified to NHS R&D departments of participating sites to assess whether the amendment affects the NHS permission for that site. Note that some amendments that may be considered to be non-substantial for the purposes of HRA may still need to be notified to NHS R&D (e.g., a change to the funding arrangements). For studies with English sites processed in NIHR CSP the amendment should be submitted in IRAS to the lead CRN, which will determine whether the amendment requires notification to English sites or may be implemented immediately (subject to HRA / REC approval were necessary).

All amendments are to be requested in writing (as stated above) and are the responsibility of the Chief Investigator. All amendments will be initially discussed with the supervisory panel and then distributed as appropriate to the relevant stakeholders (e.g., REC, study registries, R&D, regulatory agencies). The amendments will be documented clearly on the protocol and the protocol version will be changed via name to reflect this.

Request for amendment to include secondary data source sent in July 2020.

Access to the final study dataset

At the time of the interviews participants will be given the option as to how they would like the results of this study communicated with them. Given the sensitive nature of the issues discussed and the prognosis of the participant the way in which this information is communicated will vary based on the participants wishes. The options may include (but not limited to):

- No communication of the results of the study
- Executive summary sent to participant next of kin, family member (chosen by participant)
- Full study sent to participant, next of kin, family member (chosen by participant)

This will then be clearly documented on the consent form and a copy of the consent form is to be held by the participant.

DISSEMINATION POLICY

Participants will be offered within the consent form various ways in which they can receive copies of the research, including an executive summary. Participants are made aware within the consent forms the ways in which the research is likely to be disseminated, and they are made fully aware the information will be in the public domain (especially for those choosing to use their own name within the study). The research may be communicated via (but not exclusive to):

Conference presentations (including PowerPoint presentations, multimedia presentations – video and audio recordings)

Ethos online directory of PhD theses

Academic publications

Clinical publications, e.g., Royal College of Speech and Language Therapy monthly Bulletin

Other publications, e.g., charity website blog, magazine articles

Authorship eligibility guidelines and any intended use of professional writers

The final study report will be written by the Chief Investigator as part of a PhD. Publications related to the study will be written in collaboration with the supervisory panel and this will be reflected in the naming of authors for those papers. Any additional collaborators will be named as appropriately.

Appendix 2 - DPIA

STEP 1: GDPR SCREENING EVALUATION (NON-ETHOS PROJECTS)

You should complete this screening evaluation form if you are conducting a research project at Manchester Metropolitan University which involves the use of personal data[4], and an EthOS application has not been submitted (for example, for Heath Research Authority or Ministry of Defence projects).

Principal Investigator owning research data	Name: Krystina Crolla-Barker Email Address: 06232617@stu.mmu.ac.uk			
Department/ Centre	Health and Social Care			
Project Title	An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis.			
Status	Staff ☐	Doctoral researcher ☒	Postgraduate ☐	Undergraduate ☐

1) Data Protection Training	
The University is responsible for complying with the General Data Protection Regulation whenever personal data is processed. Under the Data Protection Policy, all staff and students have a responsibility to comply with the regulation in their day-to-day activities. The first step you can take to understand these responsibilities is to complete the University's Mandatory Data Protection Training. Data protection training is available on the intranet data protection pages (please follow this link), and student training available through the Student Resource area in Moodle (in the 'Skills Online' section – please follow this link). To make sure your knowledge up to date, all staff and students must complete the training annually every two years. If you have any issues in accessing the data protection training or have any questions about the training, please contact dataprotection@mmu.ac.uk.	
I confirm that I have completed the Data Protection Training in the last two years (please tick)	☒

2) High Risk Processing		
Does the research that you are conducting include any of the following (please tick all those that apply):		
High risk indicator	**Guidance notes**	**Checkbox**
a) Large Scale processing of special category[5] data or data relating to criminal convictions and offences	*The factors to be considered when determining as to what extent constitutes 'large-scale' are: a) the number of data subjects concerned, either as a specific number or as*	☐

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[4] Personal data is anything than can be used to identify a living individual, directly or indirectly. Pseudonymised data is still personal data. If your study uses secondary data that has been collected as part of a previous research exercise or relies on data gathered from other public sources such as social media or published or non-published material and that data includes personal data, you should still complete this form.

[5] Data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic or biometric data or data concerning health, sex life or sexual orientation. If your study is likely to lead to special categories of data being collected on a large scale, please tick this statement. For example, your study may not ask specific questions about medical background, but due to the topic, it is likely

	a proportion of the relevant population; b) the volume of data and/or the range of different data items being processed; c) the duration, or permanence, of the data processing activity, and d). the geographical extent of the processing activity *Research reviewing special category data from a large number of data subjects on social media platforms would meet this definition.*	
b) Systematic monitoring of a publicly accessible place on a large scale	*This may include monitoring of CCTV cameras, use of drone recordings or video or audio recording in public spaces.*	☐
c) Use of innovative new technologies in the data processing	*This may include the use of Artificial Intelligence or location tracking.*	☐
d) Processing of biometric or genetic data	*Genetic data means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.* *Biometric data means personal data resulting from specific technical processing relating to the physical, physiological, or behavioural characteristics of a natural person, which allow or confirm the unique identification of that natural person, such as facial images or dactyloscopic (fingerprint) data.*	☐
e) Matching or combining data sets from more the one source	*This may include combining data originating from two or more different studies or activities performed for different purposes. When combined, the data sets give a fuller picture of an identifiable data subject, in a way likely to exceed the reasonable expectations of the data subject. For example, combining information gathered from interview/ survey with information gathered from social media.*	☒
f) The processing of personal data which could result in a risk of harm to the data subject in the event of a security breach	*'Harm' can mean physical, material, or non-material damage, in particular: where a breach of the information may give rise to discrimination, identity theft or fraud, financial loss, damage to the reputation, loss of confidentiality or embarrassment. It can also refer to personal data protected by professional secrecy, or data that may lead to significant economic or social disadvantage in the event of unauthorised disclosure.*	☐
g) None of the above	*Please tick if none of the above statements apply to the proposed processing*	☐
Please contact dataprotection@mmu.ac.uk if you are not sure if any of the above applies to your research project.		

If you have answered yes to any of the areas identified above, then it will be mandatory to conduct a Data Protection Impact Assessment (DPIA). Please complete the Research Data Protection Impact Assessment template and send it to dataprotection@mmu.ac.uk.

Where you have answered no to any of the areas identified above, although a DPIA is not mandatory, you must retain the record of having conducted the screening assessment. Please send a copy of this screening evaluation to dataprotection@mmu.ac.uk.

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to be discussed in focus groups or interviews (e.g. a study involving perceptions of accessibility to public buildings is likely to lead to participants discussing background to their personal accessibility requirements and medical history).

STEP 2: RESEARCH DATA PROTECTION IMPACT ASSESSMENT (NON-ETHOS PROJECTS)

You should complete this research DPIA if you have ticked that any of the high-risk indicators (a-f) apply in screening question 2) above. If you have ticked that none of the above statements apply (question 2(g)), then you do not need to complete this section.

1) DPIA Requirement	
• Provide an overview of your proposed research project. You may find it helpful to refer or link to other documents here. • Outline the reason why the DPIA has been required (refer to the initial screening evaluation) and what part it plays in the overall research project.	The study will consist of Teenagers and young adults (TYA's) aged 16-24 years with a diagnosis of cancer who are considered palliative and at the end of their lives. Within this study, I will explore the definitions and terminology used within existing literature and what are the preferences of TYA's. The study aims to have 5-8 people interviewed for the study, in order to gather a variety of opinions and experiences. The participants will be from the North via existing organisations who offer support for the recruitment of participants (Patient Identification Centres). The participants will be invited to a maximum of 2 interviews which will last approx.one and a half hour. In addition to this a review and analysis of vlogs[6] will be conducted. The aim of this is to enrich the data gathered from face-to-face interviews and to support any recruitment issues that can be foreseen with this vulnerable and small participant pool. The interviews will be audio recorded which will then be transcribed by the lead researcher. The Vlogs will be transcribed using the same format. The analysis will be done using a narrative analysis approach. As videos from YouTube will be analysed DIPA is required. See Attached study protocol for further information.

2) Processing of personal data	
The Processing Lifecycle	
• Outline the purpose and benefits of the processing.	The study aims are:

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[6] Vlogs as defined 'blogs created in video form rather than textual (Molyneux et al, 2008) or a series of videos on a videosharing social media platform (Freeman & Chapman, 2007).

	1. To explore the life stories of young people who are dying of cancer before diagnosis and after diagnosis in order to further understand the impact of their diagnosis and treatment on their social well-being. 2. To ascertain a comprehensive analysis of views of current palliative care from the perspective of the patients. in order to identify and synthesize “best practice” methods in palliative care and explore what constitutes a “good death” from the viewpoint of the patient experiencing it in order to facilitate conversation between health care professionals and patients in the future. 3. To understand what constitutes a ‘good death’ from the perspective of the young person experiencing it, including the impact of their diagnosis on areas such as education, friendships / relationships, and employment. The outcome of this research is to provide rich meaningful data that will identify the key elements of the individuals experience of the palliative care journey and collectively embedded within this will be key themes to extrapolate to answer the primary aims. The primary outcome is to produce a thesis and additional publications. Therefore, in summary no-one will directly benefit from the research; however, the findings will be used to support a greater understanding of the needs to this clinical group and can be used to inform future service models and delivery.
• How will you collect, use, and store the personal data.	The social media platform ‘YouTube’ will be used to identify appropriate vlogs matching the participant criteria (where possible). The search terms used will be: - Cancer blog uk teenager - Dying of cancer my story If the Vlog is part of a series of Vlogs, then the researcher will consider whether to analyse the series of vlogs to ensure adequate analysis of the data can be achieved or may choose to analyse a particular vlog and the evidence supporting this decision making included in the thesis. All information collected will be in the form of video transcript for both interviews and vlogs and they will contain the first name of the participant only. All transcripts will be stored in line with MMU Data Protection in research policy. All consent forms that contain participant information these will be stored in line with the MMU Data Protection in research policy. Data will be analysed using Narrative analysis, which includes using quotations taken directly from the transcription.

	For interviews and vlogs, the transcriptions will not appear in their entirety within publications and any quotes that reference other people, organisations, identifiable information or may be considered distressing would be anonymised or not included within publications.
• Describe the personal data you intend to process. Does it contain special category data or data relating to criminal offences?	For interviews the person will provide their full name and a signed consent form. These will be stored in line with the MMU Data Protection in research policy, which includes them being stored on MMU servers, access limited to research team involved in this study only and archived in line with the policy. For vlogs the data will be anonymised at the point of transcription and therefore will not be stored as personal data within the study.
• Outline the number of data subjects and scope of data collection (e.g., how often are you collecting data, what is the geographical area?).	The study aims to collect approx. 5-6 participants. If a person carries out a series of videos they will be analysed together and considered to be a series of vlogs from one participant. Therefore, there may be more than 5-6 participants in the final thesis, but this may be a combination of interview transcripts, single vlog transcripts and a series of vlog transcripts. For those series of vlog transcripts, no more than 3 separate vlogs will be included within the series. All the videos will be collected and transcribed at once. All videos used for the study will be from the UK.
• Describe how you will keep the data secure: Who needs to have access to the data; how will access control be managed; what other information security arrangements are there.	All transcriptions will be electronic and saved as per MMU Data Protection in research policy, which outlines those transcripts will be saved on the MMU server and access is limited to the research team only. The video is available on YouTube and therefore sits within the public domain.
• Is personal data being shared outside of Manchester Metropolitan? If so, who with, and why? Please also stipulate which country they are based in. If you are sharing or transferring personal data or special category personal data outside of Manchester Metropolitan University to another organisation or individual, a data transfer agreement may be required. Please contact RKE contracts (RKE-Contracts@mmu.ac.uk) or Data Protection (dataprotection@mmu.ac.uk) to discuss this requirement.	The persons first name will be used within the write up of the study if the person has provided consent for this; however, if consent does not state that real names can be used, or the person has not been able to provide consent the person will be given a pseudonym (see later section on anonymity difficulties) and no other personal information will be used. For those who consent has been sought the consent forms (as approved by HRA) state the benefits and risks associated with their involvement in the study. The research may be communicated via (but not exclusive to): • Conference presentations (including PowerPoint presentations, multimedia presentations – video and audio recordings) • Ethos online directory of PhD theses • Academic publications • Clinical publications, e.g., Royal College of Speech and Language Therapy monthly Bulletin • Other publications, e.g., charity website blog, magazine articles

It is your responsibility to ensure that appropriate sharing agreements are in place prior to the sharing taking place. Have you discussed any personal data sharing with RKE Contracts or the Data Protection team?	Yes ☒	No ☐

• How long will the personal data be retained for? Will all the data be retained for the same amount of time? Please ensure you justify this retention period.	Archiving of study documentation will be authorised by the sponsor (in this case the sponsor for this study is Manchester Metropolitan University) following submission of the end of study report. All essential documents (audio interviews and transcriptions) will be archived for 5 years after completion of the study by the researcher and following this will be upon authorization of the sponsor will be destroyed as per MMU Data Protection in research policy. All non-essential documents will be destroyed upon completion of the study. Vlogs will be archived as per social media platform guidelines and terms/ conditions.
• Please specify who will have responsibility for ensuring this retention is met	The university will have responsibility of ensuring that this retention is met and that following the period of retention documents are destroyed in line with their policies. The PhD research supervisor (Dr Gary Witham) will maintain responsibility for this.

Has a mandatory Data Management Plan been completed for the project data? It is your responsibility to ensure that this is completed prior to the project commencing. The library has guidance on Research Data Management Plans, available here. Further information is available on MMU's website. Please contact rke-systems@mmu.ac.uk (RKE systems) or rsl@mmu.ac.uk (Library's Research Support Librarians) if you have any questions about the DMP.	I confirm that a DMP has been completed. ☒

The context of the processing	
• How will you recruit the data subjects/ research participants?	For interviews, the participants will be recruited via participant identification centres, which was outlined and approved by the HRA in 2018. Due to the subsequent changes required for the study the recruitment will now include vlogs. The social media platform 'YouTube' will be used to identify appropriate vlogs matching the participant criteria (where possible). The search terms used will be: - Cancer blog uk teenager - Dying of cancer my story If the Vlog is part of a series of Vlogs, then the researcher will consider whether to analyse the series of vlogs to ensure adequate analysis of the data can be achieved or may choose to analyse a particular vlog and the evidence supporting this decision making included in the thesis.
• How much control will the data subjects/ research participants have in how their data is used?	For individuals participating in the interviews consent will have been sought and therefore they will have full control and knowledge of their participation in the research.

All information collated via YouTube for the vlogs and other social media platforms is in the public domain and therefore participants will have provided consent for their information to be made available in the public domain by agreeing to the terms and conditions where they have posted the information. The research study protocol has a decision-making tool to support the researcher to establish how and when to seek consent for participants for vlogs. Within the decision-making tool it outlines that for those who are considered deceased then consent will not be sought.

For those participants where there is no clear evidence that they have deceased attempts will be made to contact them via YouTube. If the person has as part of their YouTube profile the means to be able to contact them personally then they will be sent an email (see below for exact wording). If personal contact information is not available, then a comment will be left under the video (See below for exact wording). If the person does not get in touch following contact being made, then the vlog will not be used within the research.

If consent needs to be sought and personal email address available, then the individual should be sent an email stating:
I am getting in touch as a research student based at Manchester Metropolitan University. I would like to invite you to take part in a study and the aim of this research is to explore your life story as a young person who is affected by cancer. Before committing to this research project, I will send you more information about what it would involve, what it might be used for and consent forms. I would also like to assure you that this study has received ethical approval and has processes in place to support you should you choose to participate, which I can review with you in more detail. If you would like to receive more information about this study or would like to get in touch to ask questions, please send me an email. My email address is 06232617@stu.mmu.ac.uk

If consent needs to be sought and personal email address not available, then a comment would be made in the comments section of the vlog:
I am getting in touch as a research student based at Manchester Metropolitan University. I would like to invite you to take part in a study and the aim of this research is to explore your life story as a young person who is affected by cancer. Before committing to this research project, I will send you more information about what it would involve, what it might be used for and consent forms. I would also like to assure you that this study has received ethical approval and has processes in place to support you should you choose to participate, which I can review with you in more detail. If you would like to receive more information about this study or would like to get in touch to ask questions, please reply to this comment and I can provide you with my contact details.
The evidence that will be considered to clarify if the person is deceased would be:

- Within the vlog itself there is reference to the person dying either from another person or written in text within the vlog
- Within the comments underneath the vlog, it has been made clear that the person has died (must be multiple examples of the comments for them to be considered)

	• Further vlogs from the same individual or part of the series indicates that the person has died. • The vlog is part of a wider documentary series and within this it has been made clear that the person has died. Therefore, in summary the 'participants' in the videos will have no control of taking part in this study, ethical considerations regarding this have been made and an amendment to the HRA ethics committee is being sought.
• Do the data subjects/ research participants include children or other vulnerable groups?	The study covers 16–24-year-olds; however, in order to ensure that the people uploading their videos were able to consent to the terms and conditions of YouTube and would not be considered vulnerable I will only be using videos where the participant in them is between 18-24 years.
• Are there any prior concerns over this type of processing or known security flaws? Is the research novel in any way? Does it use advanced technologies? Are there any current issues of public concern that you should factor in?	The individuals who have made these videos are talking about their lives with cancer, their treatment and are of a palliative nature; therefore, this could be considered sensitive nature. To support with this the researcher will review each video on a case-by-case basis and utilise clinical experience and knowledge to ascertain the risk level of the content of the video and any potential risk to the participant. If the risk will outweigh the benefit the video will not be used.

3) **Consultation process**	
• Explain any stakeholder engagement that has taken place to help shape your study (for example, would it be appropriate to consult a public group about your proposal, or conduct a pilot study? Have you sought any views of any IT or data protection specialists, academic experts, or used past studies to prompt your methods? If you would like further advice about information security measures, please contact infosecurity@mmu.ac.uk.	A meeting was conducted with one of the Participant identification centres, who work closely with the clinical group to discuss their views on using videos alongside interviews. The feedback gained at that meeting was that this would be beneficial and allow for more data to be analysed for a 'hard to reach' population and could add more depth to the study. It was discussed that young people will often use social media as a support network and somewhere to share their thoughts / feelings, which is echoed in the research. Therefore, it was felt on discussion with a key stakeholder that the benefits of using this data would outweigh any risks. In addition, views of supervisory panel, MMU ethics team and MMU data protection colleagues have also been sought to support thinking through any ethical issues and data protection / information governance issues.

- If no stakeholder engagement has taken place, explain why it was not appropriate to do so.	N/A

4) Necessity and proportionality	
What is your lawful basis for the processing?	As a public authority acting in the public interest, we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis. Where people consent to use their names for the publication and other distributions of the research (e.g., conferences and publications), we rely on consent and explicit consent for this. We will allow people to withdraw consent at any point.
Do you need to process personal data to meet the purpose of the research? Why can't anonymised data be used?	As the method for searching for the videos is clearly outlined and can be replicated easily; along with direct quotes being used within the study; true anonymity for the people in the videos is difficult to achieve. However, to manage the risks associated with this if the person has not consented to their real name being used or they have not been able to provide consent then they will be given a pseudonym. In addition, the full transcripts will not appear in the publications and quotes will have information that would be identifiable removed or anonymised. See section 6 for risk management plan.
How will you ensure data minimisation? (i.e., how have you determined that the level of personal data being collected is proportionate to your purpose for research?)	Only the first name of the person in the video will be used and therefore this is minimal personal data present in the study.
How will you tell the data subjects/ research participants about the processing? How will you ensure they read the Participant Information Sheet (PIS)? Are you using any other methods to provide this type of information?	For interviews individuals will be given the participant information sheet by the participant identification centre. For those individuals from the vlogs, they will be contacted as per section 2 'context of processing'.
How will you help support the rights of the data subjects/ research participants?	The likely intention of the person posting the video is to share their story wider than their immediate context; therefore, by using narrative analysis as the chosen approach in this study will support their intention of posting the video and the rights of the person posting it. For those individuals who participate in interviews they will have been given a participant information sheet and consent form prior to their involvement in the research.

5) Identify and assess risks

Describe the source of risk and nature of the potential impact on individuals. Concentrate on potential risks to privacy.		**Likelihood of harm**	**Severity of harm**	**Overall risk**
1)	A secondary data set is being used (videos taken from social media site you tube); therefore, researcher is unable to provide participants with information about the study or gain consent to participate in the study. The risk is therefore that participants wouldn't want their data to be used in the study.	Remote	Minimal	Low
2)	The research population is unique, the method of locating the videos is clear in the study protocol and direct quotes are being used from the videos. Therefore, the risk is that the person in the study can be identified.	Possible	Minimal	Low
3)	Risk to being identified within the archived data due to nature of the data for example despite being anonymised people may be identified from the full transcripts or direct quotes within publications.	Remote	Minimal	Low
4)	Within the consent forms it states that participants can withdraw at any point, unfortunately the research team can't 100% guarantee that this is achievable due to numerous reasons, for example: Once the data has been published it would be difficult to have data removed.	Remote	Minimal	Low

6) Identify measures to reduce risk				
Identify additional measures you could take to reduce or eliminate the risks identified in step 5				
Risk Number	**Options to reduce or eliminate risk**	**Effect on risk**	**Residual risk**	**Measure approved?**
1)	- If there is no clear evidence that the person is decreased; then attempts should be made to contact the person to provide them with information about the study. If they do not get in touch, then the data will not be included in the study. If the person has clear evidence (see previous sections) that they have deceased, then the data will be used, and consent not sought; however as in point 2 below the data set will be anonymised. - Participants will all be over the age of 18 years old and will have therefore signed the terms and conditions of YouTube to share a video. - The people in the video all have the likely intention of sharing their story with the wider community and therefore using a narrative analysis as the chosen approach will attempt to continue to support the person's intention. - The researcher will use their clinical knowledge and experience on a case-by-case basis to decide if the video meets the study criteria; but also, that the benefits	Reduced	Low	Yes / No

	outweigh the potential risks to participants.			
2)	**-** first names of the participants will be used if they have provided consent for this and have signed the consent forms stating this clearly. For those who do not consent to their real names being used they will be given a pseudonym. For those where consent cannot be sought, data will be used but they will be given a pseudonym. No other personal information will be included in the study; therefore, all family members, services / organisations and geographical areas will not be directly referenced within the data set. **-** The researcher will use their clinical knowledge and experience on a case-by-case basis to decide if the video meets the study criteria; but also, that the benefits outweigh the potential risks to participants. **-** Any comments that would be considered distressing or slanderous to the participant, other people or organisations will not be directly referenced within the data set. All comments that would contain identifiable information such as reference to people or places will be anonymised.	Reduced	Low	

7) Sign off		
Item	**Name / role/ date**	**Comments/ Advice**
Data Protection Subject Matter Expert (SME) advice:		
Research SME advice (e.g., supervisor or RKE representative):		
Data Protection and Research SME advice accepted or overruled by	*Name of Principal Investigator/ Lead Researcher*	

By signing this assessment, you are confirming that all details included in the form have been completed accurately and truthfully. You are also confirming that you will comply with all relevant UK data protection laws, and that that research data generated by the project will be securely archived in line with requirements specified in the University's Retention and Disposal schedule, unless specific legal, contractual, ethical, or regulatory requirements apply.

Name:	**Date:**

Please send completed forms to: dataprotection@mmu.ac.uk

Appendix 3 – Invitation Letter

Manchester Metropolitan
University

Krystina Crolla-Barker
Brooks Building
Birley Campus
Manchester Metropolitan University
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Address of Participant Information Centre

Date:

Dear Sir / Madam,

Cover Letter for request to become Participant Identification Centre

Study Title: **'An exploration of stories of people who are end of life aged 16-24 years using Narrative analyses.**

I am writing to request for the consideration to become a Participant Identification Centre for the above study.

This pack includes:

- Study Protocol Version 1.0
- IRAS form – full set of project data
- Participant Information Sheet Version 1.0
- Family / Carer / Friend Information Sheet version 1.0
- Participant invitation to research
- Consent form for participant
- Consent form for family / carer/ friend
- Interview Topic Guide

Please don't hesitate to contact me should you have any further questions relating to this study.

Many thanks

Krystina Crolla-Barker
PhD Student Manchester Metropolitan University

Appendix 4 - Participant Information Sheet

Manchester Metropolitan
University

Participant Information Sheet

Krystina Crolla-Barker
PhD Student / Primary researcher
Manchester Metropolitan University
Brooks Building
Birley Campus
M15 6GX
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Study Title

‘An exploration of stories of people who are end of life aged 16-24 years using Narrative analyses.

Invitation

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part. You can contact me to ask as many questions as you like. In order to take part, you would be invited to participate in an interview to talk about your life before your diagnosis and what your life is like now.

Brief Summary

The aim of the research is to explore your life story as a young person who is affected by cancer. Questions will be related to before your diagnosis and after your diagnosis. This will help me to understand the impact of your diagnosis, your social well-being and what is important to you.

I will be interviewing approximately 4-8 people to give me a variety of opinions and experiences.

Purpose of the Research

To understand the perspective of the young person experiencing cancer, including the impact of their diagnosis on areas such as education, friendships / relationships, and employment.

What will be involved?

I will describe the study and go through the information sheet, which I will give to you. I will then ask you to sign the consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. If you withdraw before the interview, then the interview will not take place and you will not receive any further contact from the research team. If you withdraw during or after any interview the data already collected up to that point will be used; but you will remain anonymous and will not receive any further contact from the research team.

If you agree to take part, you will be asked to participate in an interview (depending on how long you feel you can talk for). The interviews will be conducted where you feel comfortable, and we will agree to this beforehand. The location for the interview can be your home or a neutral location. The interview will consist of talking about your life and there may be things that you talk about that may make you feel upset. As part of the interview, you can talk about your diagnosis if you want but the focus of the interview is about your life. If you tell me anything that causes concern about your safety or well-being or impacts on other people, I may have to raise these concerns with the University or with other services.

You can choose to be interviewed by yourself or have another person of your choice present. If you choose to have another person present, they will also need to agree to the interview and complete a consent form. It is your choice whether to have someone present or whether you want the interview to take place with just you and the interviewer. The person you choose to have present is to provide support for you within the interview.

I will aim for the interview to last approx. 1 ½ hours. During the interview, we may talk about some things that you find upsetting, that make you angry and make you feel down, and this can be difficult. If this does happen and you want to take a break from the interview or stop the interview you can ask to do so and only start again if you feel okay to do so. If within 1 interview, we have not covered all the things you would like to talk about we can arrange a second interview. If you are then unable to attend the second interview the data from the first interview will be used unless you decide to withdraw from the study. The interviews will be audio recorded in order to capture all the details of the things that we talk about. At any point, you can stop the recording, rewind, and delete things if you feel you want to.

Once the interview has finished, the audio recording will be transcribed / written out and I will use the information to look for key themes which you have identified are important in your life. The analysis will be done using narrative analysis, which is a way of looking at the story you told and the experiences you have told me about.

After the interview if you feel like you want to talk about any of the issues raised in the interview in more depth with a professional, you can be referred on to other services for further support. If you feel that you would like to talk more then I will ask you key worker from the Teenage Cancer Trust to refer you to local services that can offer support.

Benefits of participating in the research

If you choose to participate in the research, you will be providing invaluable insight to the researcher about what life is like living with cancer.

Additional Information

If you agree to take part, all information which is collected about you during the course of the research will be kept strictly confidential. The audio recordings will be recorded on a university Dictaphone and transferred to a secure location on the university server. The audio recordings will remain there for the duration of the research (4 years), following this they will be deleted. Your personal information (name and contact information) will be kept on a password protected document and will not be present on the audio recordings. Access to the recordings and your information will be for the authorised persons such as the researcher and the supervisor.

When the research is written up you will be given a pseudonym (fake name); however, if you choose to have your own name present in the research this must be clearly stated on the consent form. If after the interview if you change your mind and would like your name removing from the research and given a pseudonym, you must inform the researcher within 1 month of the interview. In order to use your own name within the research, both you and anyone you choose to have present in the interview must be in agreement of this, otherwise you will be both be allocated a pseudonym. Once all the data has been collected and analysed it will be written up for publication in a professional journal and presented at conferences.

The research may be communicated via (but not exclusive to):

- Conference presentations (including PowerPoint presentations, multimedia presentations – video and audio recordings)
- Ethos online directory of PhD theses
- Academic publications
- Clinical publications, e.g., Royal College of Speech and Language Therapy Monthly Bulletin
- Other publications, e.g., charity website blog, magazine articles

Your personal data will be kept until the completion of the study or if you change your mind and withdraw. The interview data will be kept for 10 years. You are free to change your mind and withdraw at any time, without giving a reason or without it affecting your care. If you change your mind and withdraw, all the data collected until that point will be kept and used within the study and will be anonymised.

'If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/'

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer any questions (Krystina Crolla-Barker). If you remain unhappy and wish to complain formally you can do this through Professor Khatidja Chantler, k.chantler@mmu.ac.uk , 0161 247 1316, Brooks Building, Manchester Campus).

The research is being conducted as part of a research doctorate at Manchester Metropolitan University. The Patient Identification centres are supporting the recruitment of participants.

Further Information:
Researcher Krystina Crolla-Barker Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor
Dr Gary Witham, Manchester Metropolitan University, Brooks Building, Birley Campus, M15 6GX, G.Witham@mmu.ac.uk

Appendix 5 - Participant Information Sheet for Family/Carer's/Friends

Manchester Metropolitan
University

Participant Information Sheet for Family /Carer's/ Friends

Krystina Crolla-Barker
PhD Student / Primary researcher
Manchester Metropolitan University
Brooks Building
Birley Campus
M15 6GX
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Study Title

'An exploration of stories of people who are end of life aged 16-24 years using Narrative analyses.

Invitation

Someone close to you has been invited to participate in a research study. That participant has asked you to be present for the interview to provide them with support. Before you provide this support, it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part. In order to take part, you would be invited to support the participant in an interview in which they will be asked to talk about their life before their diagnosis and what life is like now.

Brief Summary

The aim of the research is to explore the life stories of young people who are affected by cancer. Questions relating to before the diagnosis and after the diagnosis. This will help me to understand the impact of the diagnosis, social well-being and what is important to that participant.

I will be interviewing approximately 4-8 people to give me a variety of opinions and experiences.

Purpose of the Research

To understand the perspective of the young person experiencing cancer, including the impact of their diagnosis on areas such as education, friendships / relationships, and employment.

What will be involved?

I will describe the study and go through the information sheet, which I will give to you. I will then ask if you consent to being present in the interview whilst it is audio recorded and also if you will consent to what you say in the interview being used as data within the study. I will then ask you to sign the consent form to tell me what you are willing to consent to. You are free to withdraw at any time, without giving a reason and this will not affect the care of the participant.

If you agree to take part, you will be asked to participate in 1 interview (depending on how long the participant wants to talk for). The interviews will be conducted where they feel comfortable, and we will agree to this beforehand. The location for the interview can be at their home or a neutral location. The interview will consist of talking about their life and there may be things that they talk about that may make them or you feel upset. As part of the interview, they can talk about their diagnosis if they want but the focus of the interview is about their life.

The participant was given the option to be interviewed by themselves or have another participant of their choice present. The participant has chosen to have you present; therefore, you will need to agree to the interview and complete a consent form.

I will aim for the interview to last approx. 1 ½ hours. During the interview, we may talk about some things that the participant or you find upsetting, that make them or you angry and make them or you feel down, and this can be difficult. If this does happen and either the participant or you want to take a break from the interview or stop the interview the participant or you can ask to do so and only start again if the participant feel okay to do so. If within 1 interview, we have not covered all the things and the participant would like to talk about we can arrange a second interview. If you are then unable to attend the second interview the data from the first interview will be used unless you decide to withdraw from the study. The interviews will be audio recorded in order to capture all the details of the things that we talk about. At any point, the recording can be stopped, rewound and things can be deleted if either the participant or you feel you want to.

Once the interview has finished, the audio recording will be transcribed / written out and I will use the information to look for key themes which the participant has identified as important in their life. The analysis will be done using narrative analysis, which is a way of looking at the story they told and the experiences they have told me about.

After the interview if you feel like you want to talk about any of the issues raised in the interview in more depth with a professional, you can be referred on to other services for further support. If you feel that you would like to talk more then I will ask you to contact the Teenage Cancer Trust who can refer you to local services that can offer support.

Benefits of participating in the research

If you choose to participate in the interview, you will be providing invaluable support for the individual who is participating in the research.

Additional Information

If you agree to take part, all information which is collected about you during the course of the research will be kept strictly confidential. The audio recordings will be recorded on a university Dictaphone and transferred to a secure location on the university server. The audio recordings will remain there for the duration of the research (4 years), following this they will be deleted. The participant information will be kept on a password protected document and will not be present on the audio recordings. Access to the recordings and participant information will be for the authorised participants such as the researcher and the supervisor.

When the research is written up you will be given a pseudonym (fake name); however, if you choose to have your own name present in the research this must be clearly stated on the consent form. If after the interview if you change your mind and would like your name removing from the research and given a pseudonym, you must inform the researcher within 1 month of the interview. In order to use your own name within the research, both you and the participant choose to have present in the interview must be in agreement of this, otherwise you will be both be allocated a pseudonym. Once all the data has been collected and analysed it will be written up for publication in a professional journal and presented at conferences.

The research may be communicated via (but not exclusive to):

- Conference presentations (including PowerPoint presentations, multimedia presentations – video and audio recordings)
- Ethos online directory of PhD theses
- Academic publications
- Clinical publications, e.g., Royal College of Speech and Language Therapy Monthly Bulletin
- Other publications, e.g., charity website blog, magazine articles

The personal data will be kept until the completion of the study or if you change your mind and withdraw. The interview data will be kept for 10 years. You are free to change your mind and withdraw at any time, without giving a reason or without affecting your care. If you change your mind and withdraw, all the data collected until that point will be kept and used within the study and will be anonymised.

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer any questions (Krystina Crolla-Barker). If you remain unhappy and wish to complain formally you can do this through Professor Juliet

Goldbart, Associate Dean & Research Institute Director, j.goldbart@mmu.ac.uk , 0161 247 2578, 1.14 Brooks Building, Manchester Campus).

The research is being conducted as part of a research doctorate at Manchester Metropolitan University. The Teenage Cancer Trust is supporting the recruitment of participants.

Researcher
Krystina Crolla-Barker
Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor
Professor Carol Haigh, Manchester Metropolitan University, Brooks Building, Birley Campus, M15 6GX
c.haigh@mmu.ac.uk

Appendix 6 – Participant Information Sheet - Vlogs

Manchester Metropolitan
University

Participant Information Sheet – Vlogs

Krystina Crolla-Barker
PhD Student / Primary researcher
Manchester Metropolitan University
Brooks Building
Birley Campus
M15 6GX
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Study Title

‘An exploration of stories of people who are end of life aged 16-24 years using Narrative analyses.

Invitation

I would like to invite you to take part in a research study. Before you decide you need to understand, why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or would like more information. Take time to decide whether or not to take part. You can contact me to ask as many questions as you like. In order to take part, you would be invited to participate in an interview to talk about your life before your diagnosis and what your life is like now or I would use the video that you have posted online if you would prefer.

Brief Summary

The aim of the research is to explore your life story as a young person who is affected by cancer. Questions will be related to before your diagnosis and after your diagnosis. This will help me to understand the impact of your diagnosis, your social well-being and what is important to you.

I will be interviewing approximately 4-8 people to give me a variety of opinions and experiences.

Purpose of the Research

To understand the perspective of the young person experiencing cancer, including the impact of their diagnosis on areas such as education, friendships / relationships, and employment.

What will be involved?

I will describe the study and go through the information sheet, which I will give to you. I will then ask you to sign the consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. If you withdraw before the interview or before the video has been transcribed, then the interview will not take place and you will not receive any further contact from the research team. If you withdraw during or after any interview or the video has been transcribed the data will be removed from the study and any future publications to the best of the researcher's ability. However, the removal of the data cannot be 100% guaranteed.

If you decide to take part in the interview: If you agree to take part, you will be asked to participate in an interview (depending on how long you feel you can talk for). The interviews will be conducted where you feel comfortable, and we will agree to this beforehand. The location for the interview can be your home or a neutral location. The interview will consist of talking about your life and there may be things that you talk about that may make you feel upset. As part of the interview, you can talk about your diagnosis if you want but the focus of the interview is about your life. If you tell me anything that causes concern about your safety or well-being or impacts on other people, I may have to raise these concerns with the University or with other services.

You can choose to be interviewed by yourself or have another person of your choice present. If you choose to have another person present, they will also need to agree to the interview and complete a consent form. It is your choice whether to have someone present or whether you want the interview to take place with just you and the interviewer. The person you choose to have present is to provide support for you within the interview.

I will aim for the interview to last approx. 1 ½ hours. During the interview, we may talk about some things that you find upsetting, that make you angry and make you feel down, and this can be difficult. If this does happen and you want to take a break from the interview or stop the interview you can ask to do so and only start again if you feel okay to do so. If within one interview, we have not covered all the things you would like to talk about we can arrange a second interview. If you are then unable to attend the second interview, the data from the first interview will be used unless you decide to withdraw from the study. The interviews will be audio recorded in order to capture all the details of the things that we talk about. At any point, you can stop the recording, rewind, and delete things if you feel you want to.

Once the interview has finished, the audio recording will be transcribed / written out and I will use the information to look for key themes, which you have identified, is important in your life. The analysis will be done using narrative analysis, which is a way of looking at the story you told and the experiences you have told me about.

After the interview if you feel like you want to talk about any of the issues raised in the interview in more depth with a professional, you can be referred on to other services for further support. If you feel that you would like to talk more then I will ask you key worker from the Teenage Cancer Trust to refer you to local services that can offer support.

If you decide to consent to the video, you have posted online being used; then an interview will not take place. The video will then be transcribed, and I will use the information to look for key themes, which you have identified in the video as being important in your life. The analysis will be done using narrative analysis, which is a way of looking at the story you told and the experiences you have told me about.

Benefits of participating in the research

If you choose to participate in the research, you will be providing invaluable insight to the researcher about what life is like living with cancer.

Additional Information

If you agree to take part, all information which is collected about you during the course of the research will be kept strictly confidential. The audio recordings will be recorded on a university Dictaphone and transferred to a secure location on the university server. The audio recordings will remain there for the duration of the research (4 years), following this they will be deleted. Your personal information (name and contact information) will be kept on a password-protected document and will not be present on the audio recordings. Access to the recordings and your information will be for the authorised persons such as the researcher and the supervisor.

‘If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner’s Office as the supervisory authority. Please see: https://ico.org.uk/global/contact-us/’

When the research is written up, you will be given a pseudonym (fake name); however, if you choose to have your own name present in the research this must be clearly stated on the consent form. If after the interview if you change your mind and would like your name removing from the research and given a pseudonym, you must inform the researcher within 1 month of the interview. In order to use your own name within the research, both you and anyone you choose to have present in the interview must be in agreement of this, otherwise you will be both be allocated a pseudonym. Once all the data has been collected and analysed it will be written up for publication in a professional journal and presented at conferences.

The research may be communicated via (but not exclusive to):

- Conference presentations (including PowerPoint presentations, multimedia presentations – video and audio recordings)
- Ethos online directory of PhD theses
- Academic publications
- Clinical publications, e.g., Royal College of Speech and Language Therapy Monthly Bulletin
- Other publications, e.g., charity website blog, magazine articles

Your personal data will be kept until the completion of the study or if you change your mind and withdraw. The interview data will be kept for 10 years. You are free to change your mind and withdraw at any time, without giving a reason or without it affecting your care. If you change your mind and withdraw, all the data collected until that point will be kept and used within the study and will be anonymised.

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer any questions (Krystina Crolla-Barker). If you remain unhappy and wish to complain formally you can do this through Professor Khatidja Chantler, k.chantler@mmu.ac.uk , 0161 247 1316, Brooks Building, Manchester Campus).

The research is being conducted as part of a research doctorate at Manchester Metropolitan University. The Patient Identification centres are supporting the recruitment of participants.

Further Information:
Researcher
Krystina Crolla-Barker
Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor
Dr Gary Witham, Manchester Metropolitan University, Brooks Building, Birley Campus, M15 6GX
G.Witham@mmu.ac.uk

Appendix 7 – Consent Form

Manchester Metropolitan
University

Krystina Crolla-Barker
Brooks Building
Birley Campus
Manchester Metropolitan University
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Centre Number:

Study Number:

Participant Identification Number for this trial:

CONSENT FORM

For the Participant

Title of Project: **'An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis'.**

Name of Researcher: **KRYSTINA CROLLA-BARKER**

	Please Initial all questions
1. I confirm that I have read and understand the information sheet (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from Manchester Metropolitan University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	

4. I agree to have the interview audio recorded.	
5. I agree to take part in the above study.	
6. I wish to either: a) be allocated a pseudonym for the research. b) have my real name included in the research?	Option a)
	Option b)
7. I give my permission for quotes from the interview to be used in the intended thesis and any published work.	
8. I would like: a) a family member / friend / carer / next of kin present for the interviews to provide additional support for me. b) To conduct the interview without a family members / friend / carer / next of kin present for the interviews	Option a)
	Option b)
9. I would like the results of the study communicating in the following way: a) No communication of the results of the study b) Executive summary (a short summary of the study) sent to me, next of kin, family member or other (delete as appropriate) c) Full study sent to me, next of kin or family member (delete as appropriate)	Option a)
	Option b)
	Option c)

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Further Information:
Researcher Krystina Crolla-Barker Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor Professor Carol Haigh c.haigh@mmu.ac.uk

Appendix 8 – Consent Form - Family

Manchester Metropolitan
University

Krystina Crolla-Barker
Brooks Building
Birley Campus
Manchester Metropolitan University
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Centre Number:

Study Number:

Family / Carer / Friend / Next of Kin Identification Number for this trial:

CONSENT FORM

For the Participant's family / carer / friend / Next of Kin

Title of Project: **'An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis'.**

Name of Researcher: **KRYSTINA CROLLA-BARKER**

	Please Initial all questions
1. I confirm that I have read and understand the information sheet (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that I am being asked to provide support for the participant within the interview.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	
4. I agree to have the interview audio recorded.	
5. I understand that relevant sections of audio recordings may be looked at by individuals from Manchester	

Metropolitan University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these recordings.	
6. I wish to either: a. be allocated a pseudonym for the research. b. have my real name included in the research?	Option a) Option b)
7. I give my permission for quotes from the interview to be used in the intended thesis and any published work.	

____________________ ____________________ ____________________

Name of Family / Carer/ Friend / Next of kin   Date   Signature

____________________ ____________________ ____________________

Name of Person taking consent.   Date   Signature

Further Information:
Researcher
Krystina Crolla-Barker
Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor
Professor Carol Haigh
c.haigh@mmu.ac.uk

Appendix 9 – Consent Form - Vlogs

Manchester Metropolitan
University

Krystina Crolla-Barker
Brooks Building
Birley Campus
Manchester Metropolitan University
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

Study Number:

Participant Identification Number for this trial:

CONSENT FORM - Vlogs

For the Participant

Title of Project: **'An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis'.**

Name of Researcher: **KRYSTINA CROLLA-BARKER**

	Please Initial all questions
1. I confirm that I have read and understand the information sheet (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I understand that relevant sections of my data collected during the study, may be looked at by individuals from Manchester Metropolitan University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	

4. I agree to have the vlog being transcribed.	
5. I agree to take part in the above study.	
6. I wish to either: a. be allocated a pseudonym for the research. b. have my real name included in the research?	Option a) Option b)
7. I give my permission for quotes from the interview to be used in the intended thesis and any published work.	
8. I would like: a. a family member / friend / carer / next of kin present for the interviews to provide additional support for me. b. To conduct the interview without a family members / friend / carer / next of kin present for the interviews	Option a) Option b)
9. I would like the results of the study communicating in the following way: a. No communication of the results of the study b. Executive summary (a short summary of the study) sent to me, next of kin, family member or other (delete as appropriate) c. Full study sent to me, next of kin or family member (delete as appropriate)	Option a) Option b) Option c)

___________________ ___________________ ___________________

Name of Participant Date Signature

___________________ ___________________ ___________________

Name of Person Date Signature

taking consent.

Further Information:
Researcher Krystina Crolla-Barker Krystina.crolla-barker@stu.mmu.ac.uk

Supervisor Professor Carol Haigh c.haigh@mmu.ac.uk

Appendix 10 – Email to seek consent.

If consent needs to be sought and personal email address available, then the individual should be sent an email stating:
I am getting in touch as a research student based at Manchester Metropolitan University. I would like to invite you to take part in a study and the aim of this research is to explore your life story as a young person who is affected by cancer. Before committing to this research project, I will send you more information about what it would involve, what it might be used for and consent forms. I would also like to assure you that this study has received ethical approval and has processes in place to support you should you choose to participate, which I can review with you in more detail. If you would like to receive more information about this study or would like to get in touch to ask questions, please send me an email. My email address is 06232617@stu.mmu.ac.uk

If consent needs to be sought and personal email address not available, then a comment would be made in the comments section of the vlog:
I am getting in touch as a research student based at Manchester Metropolitan University. I would like to invite you to take part in a study and the aim of this research is to explore your life story as a young person who is affected by cancer. Before committing to this research project, I will send you more information about what it would involve, what it might be used for and consent forms. I would also like to assure you that this study has received ethical approval and has processes in place to support you should you choose to participate, which I can review with you in more detail. If you would like to receive more information about this study or would like to get in touch to ask questions, please reply to this comment and I can provide you with my contact details.

Appendix 11 – Interview Topic Guide

Manchester Metropolitan
University

Krystina Crolla-Barker
Brooks Building
Birley Campus
Manchester Metropolitan University
Email: Krystina.Crolla-Barker@stu.mmu.ac.uk

‘An exploration of stories of people who are end of life aged 16-24 years using Narrative analysis’.

Interview Topic Guide

1. **Social context**
   E.g., Who do you live with now?
   Who did you live with before?
   Have you completed your education?
   Did you have employment?

2. **Life before diagnosis**
   E.g., what was your life like before you received your diagnosis?
   What was important to you?

3. **Cancer Journey**
   E.g., Describe how you initially your journey started?
   What has changed most about your life since you were diagnosed?
   Have you encountered health services? What has your experience with them been like?

4. **Life now**
   E.g., Tell me what your life is like now.
   What are the things about your life that you really like?
   What are the things about your life that you may want to change?
   Has there been any positives that you have experienced?
   Have your relationships/ friendships changed? If so, how?

Appendix 12 – HRA Approval Letter 2018

Miss Krystina Crolla-Barker
*****

Email: hra.approval@nhs.net

16 April 2018

Dear Miss Crolla-Barker

Letter of HRA Approval

Study title:	**An exploration of stories of people who are end of life aged. 16-24 years using Narrative analysis.**
IRAS project ID:	**224690**
REC reference:	**18/NW/0014**
Sponsor	**Manchester Metropolitan University**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, inparticular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities.
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g., R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the HRA website.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators",* issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through IRAS.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the HRA website.

Your IRAS project ID is **224690**. Please quote this on all correspondence.

Yours sincerely

Kelly Rowe
Assessor

Email: hra.approval@nhs.net

Copy to: *Ms Ramona Statache, Manchester Metropolitan University, Sponsor contact*
R&D office, The Christie NHS Foundation Trust, Lead NHS R&D contact

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [Chief Investigator Internal Agreement]	FINAL	23 November 2017
Covering letter on headed paper [Covering letter of changes]		
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Insurance Documentation]		28 November 2017
HRA Schedule of Events [Validated SOE]	1.0	04 January 2018
HRA Statement of Activities [Validated SOA]	1.0	04 January 2018
Interview schedules or topic guides for participants [Interview/ Topic Guide]	1.1	20 February 2018
IRAS Application Form [IRAS_Form_28122017]		28 December 2017
Letter from sponsor [Letter of Sponsorship]	FINAL	23 November 2017
Letters of invitation to participant [Invitation to participant]	1.0	18 December 2017
Other [Distress Protocol]		
Other [Scrutineers Report]		
Other [Scrutineers Report]		
Other [Clarification of Section A62]		
Participant consent form [Consent Form Participant]	1.1	20 February 2018
Participant consent form [Consent Form accompanying person]	1.1	20 February 2018
Participant information sheet (PIS) [PIS Family]	1.1	20 February 2018
Participant information sheet (PIS) [Participant Information Sheet]	1.1	20 February 2018
Research protocol or project proposal [Protocol]	1.1	01 February 2018
Response to Request for Further Information [Application clarification]		
Summary CV for Chief Investigator (CI) [Chief Investigators CV]		
Summary CV for supervisor (student research) [Supervisors CV G. Witham]		
Summary CV for supervisor (student research) [Supervisors CV Dr John Lancaster]		
Summary CV for supervisor (student research) [Supervisors CV Professor Carol Haigh]		

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor, and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Ms Ramona Statache
Tel: 01612472853
Email: ethics@mmu.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities will act as agreement of an NHS organisation to participate. No further agreements expected
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g., General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made; study is funded as part of a training award. The statement of activities confirms that there are no funds available to site from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC FO dated 27/02/2018
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will be participant identification centres, clinical teams will approach eligible patients about the study and give an information pack, and if patient is interested in taking part, they will contact the central research team.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach. to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each. type of participating NHS organisation in England and the minimum expectations for education, training, and experience that PIs should meet (where applicable).

A local collaborator is expected at site to identify potential participants and organise any access arrangements.

GCP training is not a generic training expectation, in line with the HRA/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
A Letter of Access (or equivalent) would be expected for any external NHS/research staff undertaking interviews within NHS facilities. Pre engagement checks should include standard CRB and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations inEngland to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 13 – HRA Approval Letter 2021

Northwest - Greater Manchester Central Research Ethics Committee
3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

11 October 2021

Miss Krystina Crolla-Barker
*****

Dear Miss Crolla-Barker

Study title:	**An exploration of stories of people who are end of life aged. 16-24 years using Narrative analysis.**
REC reference:	**18/NW/0014**
Protocol number:	**1**
Amendment number:	**224690_1**
Amendment date:	**17 August 2021**
IRAS project ID:	**224690**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

No ethical issues were raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [IRAS 224690 Completed amendment tool 28.09.2021]		28 September 2021
Confirmation of any other Regulatory Approvals (e.g., CAG) and allcorrespondence [Research DPIA Procedure]	Version 1	14 January 2021
Participant information sheet (PIS) [Participant Information Sheet]	Version 1.2	12 August 2021
Participant information sheet (PIS) [Participant Information Sheet Vlogs]	Version 1.1	12 August 2021

Research protocol or project proposal [Study Procedure]	Version 1.3	27 July 2021

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 224690: **Please quote this number on all correspondence.**

Yours sincerely

pp Matthew Mills

Dr Peter Klimiuk
Chair

E-mail: gmcentral.rec@hra.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Miss Krystina Crolla-Barker*

Northwest - Greater Manchester Central Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 07 October 2021

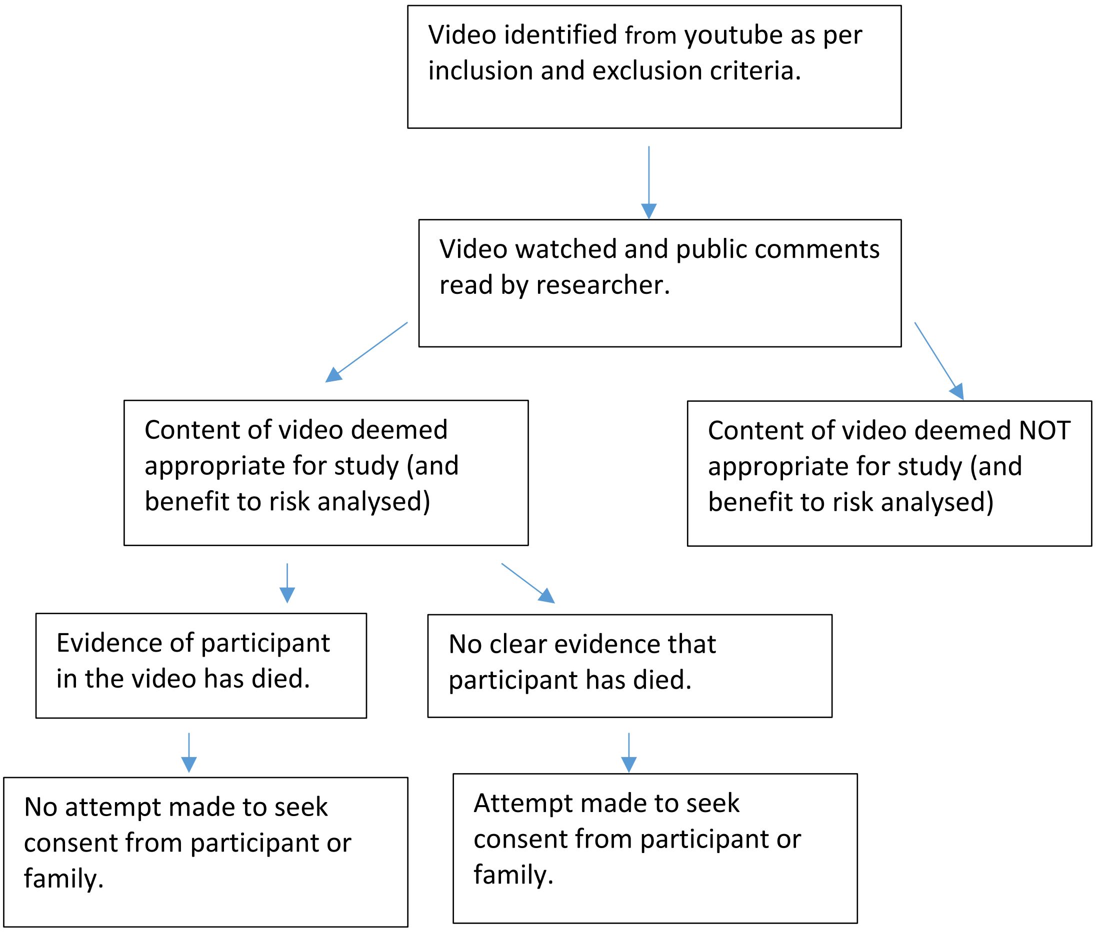
Committee Members:

Name	*Profession*	*Present*	*Notes*
Reverend Steve Burmester	Clergyman	Yes	
Dr Peter Klimiuk	Consultant Rheumatologist	Yes	(Chaired the meeting)

Also in attendance:

Name	*Position (or reason for attending)*
Miss Charlotte Miller	Approvals Administrator
Mr Matthew Mills	Approvals Administrator

Appendix 14 - Decision-making tool



Appendix 15 – Distress Policy

Manchester
Metropolitan
University

Advisory Distress Strategy for qualitative data collection

Professor Carol Haigh

&

Gary Witham

Department of Nursing

MMU

Review date 2020

Distress Protocol 1: The protocol for managing distress in the context of a research focus group /interview (Participants)

(Modified from: Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Distress

- A participant indicates they are experiencing a high level of stress or emotional distress. OR
- exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc.

Stage 1 Response

- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support.
- Assess mental status:
  - Tell me what thoughts you are having?
  - Tell me what you are feeling right now?
  - Do you feel you are able to go on about your day?
  - Do you feel safe?

Review

- If participant feels able to carry on;
  resume
  interview/discussion.
- If participant is unable to carry on
  Go to stage 2.

Stage 2 Response

- Remove participant from discussion and accompany to quiet area or discontinue. interview
- Encourage the participant to contact their GP or mental health provider OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow

- Follow participant up with courtesy call (if participant consents)

OR

- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group.

Distress Protocol 2: The protocol for managing distress in the context of a research focus group /interview management (Researchers)

Taylor, J., Bradbury-Jones, C., Breckenridge, J.P., Jones, C. and Herber, O.R., 2016. Risk of vicarious trauma in nursing research: a focused mapping review and synthesis. Journal of clinical nursing, 25(19-20), pp.2768-2777.

Pre-data collection

- The researcher should consider the potential physical and psychological impact on the researcher of the participants description of life experiences.
- The researcher should consider how many interviews could be undertaken in a week.
- The researcher should be aware of the potential for emotional exhaustion.

Data collection stage

- If the topic is potentially sensitive/distressing data collection to be undertaken bytwo members of the research team
- regular scheduled debriefing sessions with a named member of the research team
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches.

Analysis

- is alerted prior to transcription review of potentially "challenging" or "difficult" interviews.
- has regular scheduled debriefing sessions with a named member of the research team.

Follow up.

- Encourage the researcher to access a research mentor if he/she experiences increased distress in the hours/days following transcription.

Distress Protocol 3: The protocol for managing distress in the context of a research focus group /interview transcription.

(Wilkes, L., Cummings, J. and Haigh, C., 2015. Transcriptionist saturation: knowing too much about sensitive health and social data. Journal of advanced nursing, 71(2), pp.295-303.)

Pre-data collection

- The transcriber should be considered in any research proposal, with a clear indication of how this person will be provided with a "safe" working environment while also maintaining the "quality" of the research.

ethical review stage

- be included in the ethical clearance process.
- is informed of the nature of the research and the type of data.

Pre-transcription

- is alerted prior to the transcription of potentially "challenging" or "difficult" interviews.
- has regular scheduled debriefing sessions with a named member of the research team.

During Transcription

- has prompt access to an appropriate person for crisis counselling.
- has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work.
- may be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches.

Follow up.

- Follow transcriber up with courtesy call (if transcriber consents)
  OR
- Encourage the transcriber to call if he/she experiences increased distress in the hours/days following transcription.

Appendix 16 - Conference Outputs

- International Conference on Cancer Nursing (ICCN) 2022 Oral Abstract presentation ‘Narratives of Teenagers and Young Adults at end of life on YouTube’.
- International Conference on Cancer Nursing (ICCN) 2021 Oral Abstract presentation ‘Who decides? A narrative literature review exploring the challenges of anonymity for young adults in cancer research’.
- International Ethics Day MMU conference 2018 Oral Abstract presentation ‘Decision-making in young people affected by cancer: An ethical dilemma’.
- Consultant Lecturer for Edgehill University on PGCert Autism & Learning Disability, ‘End of life: Learning Disability and/or Autism’.