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A Netnography of the Starlight Children's Foundation's Online Community Livewire.org.au: Exploring Youth and Condition Based Selves

by Michelle Platcher

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Certificate of Original Authorship

CERTIFICATE OF ORIGINAL AUTHORSHIP

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Abstract

Online communities are promising avenues for young people living with an illness or disability to access developmental, psychosocial support in addition to their clinical care. While studies have explored the impact of these communities on young people’s condition-based needs, less is known about how these platforms support young people’s development in relation to youth culture and being a young person beyond their condition.

The purpose of this study is to explore how the Starlight Children's Foundation (SCF) online community, Livewire.org.au (LW.org.au), functions as a developmental, psychosocial intervention for young people living with a condition with a focus on examining the developmental task of identity formation in the context of peer relationships online. The study employs a netnographic methodology to understand how the concept of 'developmental appropriateness' is operationalised and implemented within the online community from the organisational, chat-hosts’ and young person perspective. It also considers the identity practices, help-seeking and engagement behaviour of young people online. Analytical techniques include a priori and emergent coding, and positioning theory data analysis.

Findings illuminate identity tensions between the young person self and the facet of the self associated with their condition. They highlight how young people negotiate these challenges through moderated conversations with peers and chat-hosts in a medical-free setting. They also demonstrate how developmental appropriateness can be operationalised and implemented through integrating preventive and promotive strategies, while still working from a medical-free ontological position.

The study contributes new insights into how peer-driven online communities can foster identity development, and demonstrates how accepted categorisations of identity may not be appropriate to the experiences of young people living with a condition. A key contribution is explicating how LW.org.au establishes legitimacy in its field of practice, while noting tensions that arise in relation to the implementation of the LW.org.au program through the role of the chat-hosts. The positioning of prevention and promotion as tactics, rather than conceptual approaches, shows how a community-based approach can incorporate aspects generally associated with the biomedical model without adopting the core values of that model. Methodologically, the study is innovative in its use of netnography, an approach not frequently found in the literature. Positioning theory, an analytical tool usually used in organisational studies, is used here to explore how identity and the local moral order are created at the micro-level.

A key area for future research is exploring young people's help-seeking and engagement practices through their interactions with community-based initiatives such as LW.org.au.

Chapter 1 Introduction

Background to the Study

The late Claire Wineland—a young cystic fibrosis (CF) activist and founder of the not-for-profit Claire's Place Foundation at age 13—outlined in her keynote address to the 'Essentials of Emergency Medicine' conference in 2018 how biomedical assumptions about health ripple into the mainstream discourse of society and influence public perceptions of young people living with a condition. These assumptions include an understanding of health centred around the absence of disease or disability and on treating conditions, rather than enhancing a person's quality of life while living with a condition more broadly. In her address, Claire alluded to how this had impacted her own identity when she said, 'I didn't have anything to really call my own besides CF, besides the medical world. I didn't really feel like I had any value to give besides being a patient' (Essentials of Emergency Medicine, 2018, 12:32).

It is in this context the importance of the current study is set. Within both scholarship and practice, the voices of young people living with an illness or disability are often absent from the discourses and conversations surrounding their health and healthcare (Patton et al., 2016; Sawyer et al., 2007). Consequently, their lived experience is also missing (Azzopardi, 2012; Kang, 2013). This absence is notable as the marginalisation of young people's subjectivity and voice from these discourses and conversations is a core issue underpinning the schism between biomedical and biopsychosocial or socio-ecological understandings of health (Azzopardi, 2012). This, in turn raises the risk that young people living with a condition will be subjected to discourses of pity and disempowerment as patients or counter discourses of inspiration and empowerment as role models—both of which divorce representations of illness and disability from everyday reality.

This context has implications for designing and evaluating developmentally appropriate interventions for young people living with conditions at a stage of life when the line between the self and society blur (Patton et al., 2016). This is pertinent considering exploring and experimenting with one's identity through engaging in social interactions and environments constitutes a core developmental task of adolescence and emerging adulthood (Erikson 1968, 1994). However, how best to incorporate condition-based care at the community level, while facilitating youth development and cultures within medical contexts, is an under-explored area.

A promising arena for striking a balance between community-based, developmental support and the condition-based care provided by the medical field is the online sphere. The advent of social media platforms and online communities signals new opportunities for social connection and engagement, especially for young people who are disconnected or under-supported developmentally and medically within community contexts (Gibson et al., 2016; Kirk & Milnes, 2016; Third & Richardson, 2010). Consequently, the online realm can be considered a liberating force, facilitating the expression and exploration of counter discourses about illness, disability and health, and challenging dominant or oppressive views (Angulo-Jiménez & DeThorne, 2019). In this way, the online space becomes an important arena for identity expression, experimentation and patient advocacy, but it is not without its dangers (Third & Richardson, 2010). However, the impact of social media platforms and online communities on the identity development of young people living with a condition is still an emergent and under-researched field.

The current study arose from an alignment of research agendas between the researcher, the Starlight Children's Foundation (SCF) as an industry partner and the University of

Technology Sydney. The researcher's interest in exploring the SCF's online community, Livewire.org.au (LW.org.au), was inspired by her prior research on bounded online communities during her undergraduate degree, where she examined how young people construct meaningful realities online through discourse. Here, Foucault's (1979) work influenced her understanding of the ways discourses infuse spaces with knowledge structures and systems that can challenge mainstream society. In that project, she saw how young people who identified and connected with potentially harmful health-based communities regarded these online sites as anonymous, safe spaces where they could discuss subversive or controversial ideas and express and explore taboo or stigmatised facets of the self that resisted medical understandings of their identity (Bell, 2007; Keipi et al., 2017; Margherita & Gargiulo, 2018). However, she also became aware of how these peer-oriented, online spaces were understood as dangerous from the standpoint of health professionals and parents. From their perspective, the private and unregulated nature of these communities perpetuated and normalised harmful ideas and behaviours that could have real-world consequences for young people's health (Bell, 2007; Keipi et al., 2017; Margherita & Gargiulo, 2018). Thus, the researcher was drawn to how online communities, often celebrated in the literature as a democratic force for marginalised or stigmatised identities, could also be dangerous.

However, the SCF's online LW.org.au community presented a counter to the researcher's earlier experience. Here, the researcher was intrigued by how the organisation had utilised the online medium to create an empowered space for highly vulnerable young people that mitigated many of the challenges she observed in her earlier undergraduate research. The LW.org.au online community offered a perspective that arguably aligned with the existing scholarship on self-help and online condition-based communities within the field of intervention. This scholarship proposed that these platforms could function as Goffman

(2009) terms safe havens for vulnerable young people to share knowledge and experiences that fell outside the mainstream or norms of society. Consequently, online communities became enclaves for the celebration of patient expertise and advocacy that resisted medicalised understandings of the self (Kirk & Milnes, 2016; White & Dorman, 2001). However, observing this in tandem with her earlier work, the researcher was motivated to understand how some communities, such as LW.org.au, created positive communities around illness or disability identities, whereas other sites remained harmful. How did bonding over a condition and sharing patient expertise engender promotive impacts in some online communities but detrimental effects on young people's health in others? What features of the community promoted positive outcomes that could inform best practice within the field of developmentally oriented interventions and services?

The researcher was also drawn to how the SCF organisation built a moderation model that seemed to forge positive relationships and engagement with young people that for the most part appeared absent within the hospital context with which these young people were so familiar. Intriguingly, LW.org.au presented a moderation model with adults that appeared to circumvent young people's resistance to adult supervision online (Third et al., 2013). This focus provided an interesting comparison with the literature where the emphasis had predominantly centred on how online communities foster peer support, camaraderie and a shared understanding around conditions (Kirk & Milnes, 2016; White & Dorman, 2001). The literature also seemed to place little emphasis on identity development, particularly the tension among young people in striving to resist the patient role and their condition-based identity online. This apparent gap in the literature piqued her interest in learning how engagement in such a moderated community influenced young people's health and identity development.

Here, the work of Turkle (2011)—who examined how online mediums could facilitate the experimentation and exploration of diverse facets of the self, particularly those not commonly expressed offline—and Goffman (1959), on how people engage in impression management to control the presentation of the self, were influential in shaping the researcher's understanding. Similarly, Shapiro and Margolin's (2014) assertion that the internet and social media's capacity to influence young people's social and identity development is an under-explored field, further motivated her interest.

This background brought the researcher to the SCF as a place to work, but also as a place to investigate some of these under-researched topics. Several years of experience working with the SCF in different roles sharpened her interest and motivation to explore these research questions.

An opportunity to explore these research interests arose after a re-design of the LW.org.au platform when the SCF was eager to explore the workings of the online community and bring an evidence-based approach to any investigation on the topic. This emphasis on an evidence-based approach led the SCF to the significant decision to offer an industry-based PhD scholarship in collaboration with a university. The University of Technology Sydney became that collaborator. The project's core goal was identified as demonstrating in a scholarly manner how LW.org.au, as an online community where adults' moderate interactions between young people living with a condition, was valuable for understanding the notion of 'developmental appropriateness'.

The study is significant in bringing together the ground-breaking practices of SCF with the research culture of the University of Technology Sydney, which places a strong emphasis on social impact. This collaboration facilitates the enhancement of the legitimacy of community-based interventions. The study brings to the fore the role of medical-free spaces in the support of young people living with a condition, and focuses on the burgeoning use of online spaces as sites for identity development. In addition, it highlights the involvement of intermediaries in that process: the LW.org.au chat-hosts. Importantly, through a netnographic (Hine, 2000, 2015; Kozinets, 2010, 2015) methodology, it employs the voices of young people to document their own explorations of their developing selves beyond being a patient.

Outline of Chapters

This introductory chapter has elucidated the scholarly and practical background informing the study's conception and the researcher's positionality. It has briefly outlined the significance of the work for understanding the notion of developmentally appropriate interventions in the online realm for young people living with a condition and the merit of extrapolating the principles of interpretative ethnography (Geertz, 1973, 1974) by employing the innovative methodology of netnography (Hine, 2000, 2015; Kozinets, 2010, 2015) to give prominence to the young person's perspective. Finally, it highlights the value of fostering a collaborative partnership between scholarship and industry as part of a doctoral study.

Chapter 2 sets out the context informing the study and the rationale for the need to implement developmentally oriented, psychosocial interventions for young people living with a condition in addition to their clinical care. In a review of the literature, this chapter outlines common psychosocial challenges confronted by young Australians living with an illness and disability before explicating why adolescence and emerging adulthood is a critical life stage to intervene to optimise health, wellbeing and developmental outcomes for vulnerable youth. Through problematising current approaches to operationalising developmental appropriateness, particularly in relation to the clinical and community sectors and dominant models of health, it illuminates shortcomings within the field that the current study seeks to address.

Chapter 3 presents the theoretical framework and literature informing the socio-cultural understanding of identity relevant to this study. First, it reviews Erikson's (1968, 1994) seminal work outlining identity formation as the core psychosocial developmental task of adolescence and emerging adulthood. It explores how Neo-Erikson scholars have operationalised Erikson's (1968, 1994) theory to illuminate identity forming processes and statuses that relate differentially to health outcomes. It identifies a gap in the literature regarding the understanding of how intervention contexts impact these processes of identity formation. It draws on the narrative work of McAdams (2008, 2011) to illuminate how meaning-making within culture influences young people's understanding of the self in relation to the illness and disability experience and discourses of health. Last, it employs the work of Mead (1934), Cooley (1983) and Goffman (1959) to highlight the interactional and presentational nature of identity construction, particularly in relation to the online medium, recognising that this is also an under-explored area in the literature.

Chapter 4 introduces the site of the study, the SCF's online community, LW.org.au. It describes the online community's purpose and connection to the hospital context. It provides background information on the site's recent re-development, and outlines the online community's layout, membership and security protocol. Finally, it addresses the study's practice gap.

Chapter 5 describes the methodological approach and research design for the study. It provides an overview of the study's research purpose, which is to explore how LW.org.au functions as a developmental, psychosocial intervention for young people living with a condition in relation to the developmental tasks of social engagement and identity formation, and to investigate the social identity categories of their young person and condition-based selves. It presents the value of utilising a constructivist (Guba, 1990) approach and extrapolating the principles of interpretative ethnography (Geertz, 1973, 1974) to the online realm through a netnographic (Hine, 2000, 2015; Kozinets, 2010, 2015) methodology to give prominence to the organisations, practitioners' and young person's perspectives concerning the operationalisation of developmental appropriateness within the online community. It also outlines the value of employing a netnographic (Hine, 2000, 2015; Kozinets, 2010, 2015) methodology to explore cultures, communities and identities online. Finally, it touches on the ethical implications of working with a vulnerable group and details the techniques of data collection and analysis used in the study. It concludes with a brief overview of the process of writing up ethnography.

Chapter 6 presents the findings from the netnographic (Hine, 2000, 2015; Kozinets, 2010, 2015) investigation of the SCF's LW.org.au online community. It outlines the cultural model of the site and the norms governing interactions within this medical-free space from the organisations, chat-hosts' and young people's perspectives. Next, it delineates the site's membership and the factors influencing young people's help-seeking and engagement with the site that informs how the online community functions as a developmentally appropriate intervention. It follows this with an examination of identity exploration and expression online in relation to the social identity categories of 'young people' and their condition-based selves. It also sets out the processes of disclosure and validation that capture the interactional nature of identity construction online. This emphasises the influence of peers and chat-hosts in supporting young people's developing sense of self in relation to dominant models or discourses of health, and youth culture more broadly.

Chapter 7 discusses the key contributions the thesis makes to identity scholarship in relation to understanding the processes of identity exploration, integration and formation (Luyckx et al., 2008b; Marcia, 1966) online by young people living with a condition, and the moderation strategies of chat-hosts influencing these developmental outcomes. It also explores the contribution made by the study to the understanding of developmental appropriateness within the field in relation to preventative and promotive approaches to designing and evaluating interventions (Catalano et al., 2002; Czeresnia, 1999), and how these approaches can be employed to enhance the legitimacy of the community sector within scholarship and practice. It demonstrates how the use of the innovative methodology of netnography (Hine, 2000, 2015; Kozinets, 2010, 2015) and positioning theory (Bamberg & Georgakopoulou, 2008; Harré et al., 2003; Harré & Van Langenhove, 1998) as an analytic tool contributes to our understanding of the interactional nature of identity construction online, and the contextual factors impacting young people's understanding of the self in relation to dominant models of health and youth cultures.

Chapter 8 presents the conclusions drawn from the study in relation to the notion of developmental appropriateness and enhancing the legitimacy of the community sector in the field of developmentally appropriate interventions for young people living with a condition. It also draws conclusions on how to support identity development among these young people online. After acknowledging the study's limitations, the chapter outlines recommendations for enhancing future practice and areas for further research

Chapter 2 Health and Young People—Evolving Theories and Approaches

Introduction

The Australian Institute of Health and Welfare (2014) identifies chronic conditions as the nation's leading cause of morbidity, disability and death, accounting for 85% of the country's disease burden in 2014 and 90% of fatalities in 2011 (Australian Institute of Health and Welfare, 2014). Chronic illnesses and disabilities are characterised by ongoing physical, psychological, cognitive, emotional or social impairments that impose functional limitations upon the individual, and can engender a high reliance upon medical services (AIHW, 2014; Suris et al., 2004). Although such concerns are generally associated with older Australians, a small but significant number of young people aged 10–24 years also face them (AIHW, 2014). Epidemiological findings vary, but the estimated prevalence of chronic conditions, among young Australians (0-25 years) is 25-35% (Australian Bureau of Statistics, 2018). These statistics are conservative relative to older populations, but alarmingly, rates of psychosocial comorbidity are equally high, estimated as a one in five likelihood that increases by 20% with each subsequent condition (AIHW, 2014). These high rates of psychosocial comorbidity are significant as many young people's primary health conditions diagnosed during childhood or adolescence—such as Asthma, Cancer, Cerebral Palsy, CF and Spina Bifida—may not be preventable by lifestyle change, only manageable (Sawyer et al., 2007). However, there is reason to assume that the factors engendering high levels of psychosocial comorbidity, especially those related to the poor management of young people's primary health condition or their mental health, are both pre-emptible and treatable by community intervention and lifestyle means (AIHW, 2014; Sawyer et al. 2007).

Consequently, there has been a growing awareness among medical professionals, researchers and community advocacy groups of the need to implement effective developmental, psychosocial interventions to attenuate these disconcertingly high levels of psychosocial comorbidity among young people living with a condition (Alderman et al., 2003; D'agostino et al., 2011; Steinbeck et al., 2014; Treadgold & Kuperberg, 2010). These interventions strive to adhere to biopsychosocial (Borrell-Carrió et al., 2004; Engel, 1960, 1980, 1989), socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006), resilience (Fergus & Zimmerman, 2005; Haase, 2004) and positive youth development (Catalano et al., 2002; Hinson et al., 2016; Leffert et al., 1998; Lerner et al., 2005; Lerner et al., 2000) frameworks. These frameworks align with the conception of health proposed by the World Health Organization [WHO] (1948) that views the construct holistically as ‘a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity’ (International Health Conference, 2002, p. 1). This is significant as these current approaches move us beyond biomedical understandings that continue to view health, illness and disability from a deficit perspective focused on treating disease or disability primarily in terms of biological determinants and risk factors (Engel, 1989; Havelka et al., 2009; Leffert et al., 1998). In contrast, current approaches offer models that give greater recognition to the role played by psychological, social, cultural and developmental factors in treating conditions and, more importantly, pre-empting and preventing them (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1960, 1980, 1989; Leffert et al., 1998; Lerner et al., 2005).

On a broader level, the value of these frameworks is that they offer stronger person-centric care (Phelan et al., 2020). This humanises health services by placing the young person, not the condition, at the centre of practice and attends not only to the risk factors engendering disease, disability or comorbidity, but also to the ‘protective and promotive factors’ buffering against such challenges both during and before their onset (Fergus & Zimmerman, 2005;

Phelan et al., 2020). ‘Protection’ or ‘promotive’ factors arise from slightly different frameworks and approaches to operationalising developmental appropriateness, including prevention and promotion (Catalano et al., 2002; Czeresnia, 1999). However, both refer to (a) internal assets, such as identity formation and agency; and (b) external environmental resources, including social connection and peer support that can be built into interventions, health services and socio-cultural environments to support young people’s health, development and condition-based needs (Fergus & Zimmerman, 2005; Hinson et al., 2016; Leffert et al., 1998).

These assets and resources intercept to empower young people to overcome negative health trajectories through various pathways (Fergus & Zimmerman, 2005; Hinson et al., 2016; Leffert et al., 1998). These include (a) diminishing or eradicating risk factors; (b) moderating the negative outcomes of risk; and (c) enhancing the presence of previously latent promotive factors (Fergus & Zimmerman 2005) in the case of prevention. In terms of promotion, they facilitate an individual’s health and unique potential, even in the absence of disease or disability (Catalano et al. 2002; Hinson 2016; Leffert et al. 1998; Lerner et al. 2005; Lerner, Fisher & Weinberg 2000). An additional value of promotion is its capacity to celebrate the strengths of illness and disability alongside the strengths of the young person. This involves going beyond biomedical models of disease and disability to explore the ‘lived’ experience’ of conditions (Finlay, 2009; Phelan et al., 2020; Trahearn et al., 2021).

The significance of this for young people is manifold. First, in moving beyond biology, these approaches not only highlight the role of psychological, emotional, social and cultural influences in health, but also emphasise the specific developmental opportunities and vulnerabilities unique to this phase of the life-course (Patton et al., 2016; Sawyer et al., 2012;

Sawyer et al., 2007). This is important as much of the etiology underlying the high levels of psychosocial comorbidity among young people living with a condition resides beyond biology with the interaction between the psychological, emotional and social challenges characteristic of this life stage within the human trajectory (Halfon et al., 2014; Sawyer et al., 2012; Sawyer et al., 2007).

Second, emphasising protective and promotive factors recognises resilience not as a fixed, static or genetic trait, but as a multifaceted dynamic process that is contextually responsive and sensitive to enhancement via health promotion, prevention and treatment (Fergus & Zimmerman, 2005). This moves us beyond addressing health and wellbeing issues primarily within the medical field to considering the critical role that transdisciplinary, locally contingent, community-based interventions and initiatives can play (Catalano et al., 2012; Catalano et al., 2002; Haldane et al., 2020; Patton et al., 2016; Trickett et al., 2011).

Last, focusing on the young person's unique potential beyond risk, disease or disability celebrates their personhood beyond the confines of their condition (Patton et al., 2014; Patton et al., 2016). This adds value by locating the sources of disease and disability not with the individual and their impairments, but also with the dis-enabling perceptions, attitudes and behaviours of others within their socio-cultural ecologies (Lindsay & McPherson, 2012; Patton et al., 2016). Such approaches are preferable and ultimately are a more affordable step to address health inequities, defined as 'health differences that are socially produced, systemic in their distribution across the population, … and unfair' (VicHealth, 2015).

The Importance of Intervening During Adolescence

This focus on development (Halfon et al., 2014; Patton et al., 2016; Sawyer et al., 2007), resilience (Fergus & Zimmerman, 2005) and the celebration of the individual within their socio-cultural environment (Bronfenbrenner & Morris, 2006; Hinson et al., 2016; Patton et al., 2016), rather than emphasising their condition, takes on a unique poignancy during adolescence and emerging adulthood (D'agostino et al., 2011; Patton et al., 2016). A critical impetus behind the call for developmental, psychosocial interventions and youth-friendly services (Tylee et al., 2007) is the growing recognition that adolescence and emerging adulthood constitutes a distinct, complex, yet formative phase within the life-course where the 'opportunities for health are great' (Sawyer et al., 2012, p. 1630) as are the developmentally specific vulnerabilities (D'agostino et al., 2011; Steinbeck et al., 2014; Tylee et al., 2007). This assertion may seem like common knowledge, but in practice the developmental needs of young people have historically been eclipsed by a medical focus on paediatrics and adulthood (Sawyer et al., 2016; Steinbeck et al., 2014).

Notably, adolescent and young adult medicine (AYAM) became recognised as a legitimate speciality only in 2017 by the Australasian College of Physicians (RACP) (Sawyer et al., 2016; Steinbeck et al., 2014). Similarly, the first adolescent ward worldwide was created as recently as 1951 at Boston Children's Hospital, while the first such ward in Australia came into operation less than 40 years ago, in 1983 at Westmead Children's Hospital, Sydney (Alderman et al., 2003; Gallagher, 1982; Sawyer et al., 2016; Steinbeck et al., 2014). Prior to this, young people fell under the care of existing paediatric, adult or generalist departments with little attention paid to their unique developmental concerns (Sawyer et al., 2016; Steinbeck et al., 2014). However, with the advent of neuro-imaging studies corroborating behavioural and physiological reports since the seminal texts of Hall (1905) and Marshall &

Tanner (1969, 1970), a growing understanding of adolescence and emerging adulthood as a critical period in its own right warranting distinct developmental services has gained momentum due to the unique value this life-stage holds for health and wellbeing (Kang et al., 2013; Patton et al., 2016; Sawyer et al., 2016; Steinbeck et al., 2014).

This momentum is driven by an awareness that adolescence and emerging adulthood comprises a ‘sensitive period’ (Hubel & Wiesel, 1970, p. 422). ‘Sensitive periods’ are limited windows of heightened opportunity and vulnerability in the life-course, where certain environmental influences have a greater capacity to impact, shape and restructure the brain and behaviour in formative and long-lasting ways, more so than other developmental stages (Greenough et al., 1987; Knudsen, 2004; Montessori, 1966). In the case of adolescence and emerging adulthood, scholars speculate this stage may comprise a ‘sensitive period’ for social engagement (Piekarski et al., 2017), social-cultural processing (Blakemore & Mills, 2014), social stress (Fuhrmann et al., 2015; Leussis & Andersen, 2008) and the onset of mental illness (Fuhrmann et al., 2015; Leussis & Andersen, 2008; Patton et al., 2016). This is because adolescence and emerging adulthood are marked by high plasticity, second only to foetal development in scope and complexity (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017). Here, immense biological, cognitive, emotional, social and sexual change coalesce to propel young people towards novel social roles, relationships and environments as they strive to achieve greater independence, autonomy and a unique sense of their own identity (Blakemore & Mills, 2014; Crone & Dahl, 2012; Patton et al., 2016; Piekarski et al., 2017; Sawyer et al., 2012).

However, as a ‘sensitive period’, this life stage also sees young people become intimately re-sculpted by their socio-cultural milieus in manifold ways as the presence and quality of their social engagement at this time can engender more facilitative outcomes (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017). This includes offsetting prior health challenges and re-directing the young person towards more promotive health and wellbeing pathways (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017). However, the absence or low quality of such stimuli may have a greater deleterious impact, propelling young people towards more risk-oriented trajectories at a time when such challenges could easily be circumvented through cost-effective, psychosocial interventions (Fuhrmann et al., 2015; Knudsen, 2004; Patton et al., 2016; Sawyer et al., 2012).

Adolescence as a Sensitive Period and Adolescent-specific Risk

This heightened sensitivity of young people towards social engagement during adolescence and emerging adulthood is supported by converging lines of research. This includes neuroscientific studies demonstrating that changes in the young person's dopamine reward system result in them receiving higher levels of reward activation—compared with adults and children—for novelty-seeking, sensation-seeking and adaptive risk-taking, particularly within peer-driven contexts, including social media platforms (Carola, 2017; Chein et al., 2011; Sherman et al., 2016; Steinberg, 2008; Telzer, 2016). This is evolutionarily advantageous as it impels young people to engage in social experiences that facilitate the acquisition of skills connected to the core development tasks of adolescence and emerging adulthood, including identity formation (Patton et al., 2016; Piekarski et al., 2017). However, this heightened reward activation has also been negatively associated with greater levels of impulsive and maladaptive risk-taking during this life-stage. This tendency towards maladaptive risk-taking is evident with the leading causes of adolescent and emerging adult morbidity, mortality and disability being accidental injury in the presence of peers and intentional self-harm related to young people's poorer psychosocial and mental health (Patton et al., 2016). Moreover, Sawyer et al. (2007) suggested that young people living with a condition are not exempt from these challenges, but may be ‘doubly disadvantaged’ (p. 1481).

Studies have further demonstrated this maladaptive risk-taking during adolescence and emerging adulthood with young people engaging in greater risk in ‘hot’ or emotionally arousing conditions (Figner et al., 2009). Gardner and Steinberg (2005) suggested that peers may function as an ‘emotionally hot’ context, as young people double their degree of risk-taking within driving simulations where peers are present, despite exhibiting lower and similar levels of risk to adults when driving in ‘cold’ or ‘emotionally neutral’ situations alone. Both Smith et al. (2014) and Sherman et al. (2016) have noted that this ‘peer effect’ (Smith et al., 2014, p. 1564) possibly extends to online contexts among anonymous peers. They attributed this to young people receiving greater dopamine reward activation in their socio-emotional brains within ‘hot’ peer-driven contexts, while their later-maturing cognitive control capacities remain less engaged and unable to moderate this peer-induced risk-taking effect (Sherman et al., 2016; Smith et al., 2014). This is known as the ‘imbalance model’ (van Duijvenvoorde et al., 2016, p. 136) of adolescent brain development.

However, Telzer (2016) suggested that young people’s brains elicit greater reward activation not only for maladaptive risk-taking, but also for prosocial behaviour. Further, her study indicates that the reward elicited for prosocial behaviour may engender longitudinal declines in depressive symptomology and maladaptive risk-taking itself (Telzer et al., 2013). This finding was also demonstrated in Telzer et al. (2015) and Cascio et al.'s (2015) studies involving driving simulation experiments with young people. In those studies, young people drove (a) with a parent and alone (Telzer et al., 2015), or (b) with a risk-cautious and risk-oriented peer (Cascio et al., 2015). In both studies, the reward elicited for prosocial behaviour in the parent or risk adverse peer situation, attenuated the reward activated for risk-taking in general. It also induced greater cross-talk between the young person's socio-emotional and cognitive control faculties. The latter provides evidence for a 'dual processing' model (Crone & Dahl, 2012) of adolescent brain development that challenges the imbalance model mentioned above.

The dual processing model suggests that connectivity between the young person's 'emotional' limbic system and cognitive control faculties can be activated or inhibited during adolescence and emerging adulthood, depending on the quality of the norms operating within young people's socio-cultural environments. This is significant, because it suggests that while young people are primed to engage in peer and novel social situations, this does not always engender greater risky behaviour or negative health trajectories. In contrast, it may facilitate adaptive risk or prosocial behaviour that enhances wellbeing and health outcomes, depending on the quality of peer and social norms (Telzer, 2016). This implies that peer and mentor support may be a promising avenue for designing developmentally oriented, psychosocial interventions for young people that not only moderates and diminishes risk, but potentially amplifies the presence of existing promotive factors. This has greater value for vulnerable young people, such as those living with conditions, who often find themselves in peer and social contexts with norms that do not always support their condition-based needs and their wider sense of self as a young person (Telzer, 2016).

Moreover, alongside socio-emotional shifts in young people's dopamine reward systems, extensive structural and functional changes occurring within the young person's socio-cognitive faculties also render young people more sensitive to evaluations of the self by peers. Studies (Dumontheil et al., 2010; Sebastian et al., 2008) indicate that peer evaluations during adolescence and emerging adulthood, in comparison with those during childhood, appear to have a greater impact on young people's self-worth, self-esteem and self-concept at a time when their self-concept is undergoing significant re-development (Blakemore & Mills, 2014; Erikson, 1994; Sebastian et al., 2008). This heightened susceptibility to peer evaluation is due to both socio-emotional and socio-cognitive changes enhancing the young person's ability to understand the perspective of others (Dumontheil et al., 2010). This allows young people to attribute mental states to others' thoughts, feeling, intentions and beliefs (Blakemore, 2008; Kilford et al., 2016). Elkind's (1967) notion of the 'imaginary audience' suggested young people could think more abstractly and hypothetically, taking both their own and others' thoughts, including thoughts about the self, as objects to evaluate (Elkind, 1967). However, Elkind (1967) claimed that adolescent 'ego-centrism' (p. 1025) resulted in young people failing to differentiate between the object of their thoughts and others. This led them to assume others were as pre-occupied with them as they were. Thus, they were more sensitive to peer appraisals.

Similarly, Sebastian et al. (2008) demonstrated this sensitivity by showing how young people employed reflexive neural strategies during self and other evaluations, whereas adults relied on existing social scripts. Consequently, young people in the study were more sensitive to the current 'reflected appraisals' (Sebastian et al., 2008, p. 441) of their self by others. This was positive when these appraisals were favourable and enhanced the young person's internal assets of self-worth, self-esteem and identity formation, but negative when they diminished them. The latter has relevance for young people living with a condition who are more likely to receive negative appraisals by others due to the challenges of their condition and may more readily internalise these during a highly reflexive stage of their identity development.

Further, the deleterious effect of peer and social environments on young people's health was also evident with young people demonstrating a heightened sensitivity not only to the rewarding presence of peers and the positive or negative effects of peer evaluations, but also to the negative effects of social isolation, social exclusion, social disruption and bullying (Blakemore & Mills, 2014; Carola, 2017; Crone & Dahl, 2012; Gunther Moor et al., 2010, 2012; Leussis & Andersen, 2008; Masten et al., 2010, 2011). This was evident in a number of 'cyberball' studies (Gunther Moor et al., 2010, 2012; Leussis & Andersen, 2008; Masten et al., 2010, 2011), in which young people exhibited a heighted distress response to peer rejection within the *subgenual anterior cingulate cortex* (ACC), the centre responsible for social pain being experienced as physical pain. In contrast, adults recruited both the ACC and the *dorsalsteral prefrontal cortex,* suggesting while they felt social rejection, they were better able to rationalise away its deleterious effects (Gunther Moor et al., 2010, 2012). Intriguingly, young people who possessed a rich social network beyond the cyberball study were also able to buffer the deleterious impact of the peer rejection they felt online (Masten et al., 2010). However, young people who did not possess this social support presented with increased depressive symptoms the following year (Masten et al., 2011).

Exposure to social distress during adolescence and emerging adulthood has also been related to the onset of mental health conditions, including Anxiety and Depression. This has led scholars to speculate that adolescence and emerging adulthood may comprise a 'sensitive period' for the development of mental illness (Blakemore & Mills, 2014; Carola, 2017; Crone & Dahl, 2012; Leussis & Andersen, 2008). This has been attributed to these social stresses interacting with changes occurring within the young person's *hypothalamic–pituitary–adrenal* and *hypothalamic–pituitary–gonadal* axes (Carola, 2017; Marceau et al., 2015; Patton et al., 2016; Schulz & Sisk, 2016). However, research in this area has also indicated that social support may be an effective strategy in addressing and mitigating these mental health concerns (Gibson & Trnka, 2020; Lawrence et al., 2015; Rickwood et al., 2016). In alignment with this research, studies have noted that young people are more likely to reach out to informal sources of support, including friends and mentors, rather than health professionals or clinical services (Gibson & Trnka, 2020; Lawrence et al., 2015; Rickwood et al., 2016). While informal supports are valuable for creating initial rapport, there are concerns around whether these informal supports are equipped with the knowledge and skills to support young people's mental health long-term and encourage them towards professional avenues of help-seeking and care, especially in more serious cases (Gibson & Trnka, 2020; Lawrence et al., 2015; Rickwood et al., 2016; Trahearn et al., 2021). Therefore, creating bridges between informal networks of support and clinical services is essential, particularly for young people living with conditions.

Defining Adolescence in Relation to Health and Wellbeing

As demonstrated above, the reciprocal relationship between the biological and the social appears to permeate every aspect of adolescence and emerging adulthood (Blakemore & Mills, 2014; Crone & Dahl, 2012; Sawyer et al., 2012). Even the construct itself is defined by this duality, evident with its onset precipitated by the hormonal and physiological event of puberty, and its culmination dictated by the attainment of adult social roles across various domains, including education, career, relationships and family (Crone & Dahl, 2012; Sawyer et al., 2012). Further, while biological and sociological markers of adolescence and emerging adulthood historically coincide in close proximity, in today's modern, globalised, neo-liberal society, adolescence and emerging adulthood persists for an extended period. This is because the age of pubertal onset is declining in most developed countries and the attainment of adult social roles is occurring much later in life, sometimes well into the mid-twenties or early thirties (Patton et al., 2016; Patton & Viner, 2007; Sawyer et al., 2012). The latter coincides with neuroscientific studies demonstrating that young people's brain development continues well into the mid-twenties as well (Blakemore & Mills, 2014).

The significance of this is threefold, as discussed in the following.

Definitional Significance of Enhancing Adolescent Visibility.

On a definitional level, delineating adolescence and emerging adulthood via age brackets is a tricky endeavour (Kang, 2013; Sawyer et al., 2012). This contributes to the omission of young people from health data sets and hinders the implementation of developmentally oriented services (Patton et al., 2014; Patton et al., 2016; Resnick et al., 2012; Sawyer et al., 2012). To aid visibility and enhance consistency in measuring the health challenges characteristic of this life stage, and the efficacy and effectiveness of programs designed to attenuate risks, the definitions outlined by Sawyer et al. (2012) are presented in Table 2.1. With respect to the current research, the term 'young person' is employed to refer to the individuals who participated in the study as this coincides with the dominant age bracket of the members engaged in the psychosocial intervention under investigation: 12–21 years.

Table 1. Definitions of Adolescence and Emerging Adulthood

Construct	Definition/Measurement
Adolescence	Derived from the Latin *'adolescens'* meaning 'growing up', in contrast to *'adultus'*, which means 'grown up'. It refers to individuals between the ages of 10 and 19 years (WHO, 1986, as cited in Sawyer et al., 2012).
Youth	Originating in 1985 in the lead up to the International Year of Youth, the term refers to individuals aged 15–24 years (United Nations, 1985, as cited in Sawyer et al., 2012).

Emerging adult	Coined by Arnett (2000) to suggest that late adolescence and early adulthood comprise a demographically and subjectively distinct cohort within modern society; therefore, he employed the term to refer to individuals aged 18–25 years.
Teenager	A term originating in the United States in the 1920s and popularised after WW2, it refers to individuals aged 13–19 years (Sawyer et al., 2012)
Young people	A less formally defined termed, it is an accumulation of the aforementioned definitions, referring to individuals aged 10–24 years (Kang, 2013; Sawyer et al., 2012). The composite term 'adolescents and young people' refers to the same age range (Kang, 2013; Sawyer et al., 2012).

Adolescence as a Sensitive Period for Socio-cultural Influence

Adolescence and emerging adulthood are recognised as a possible 'sensitive period' for socio-cultural engagement. This suggests that while socio-cultural determinants, such as peer influence may impact health and wellbeing at all stages of the life-course, their effects during the adolescent and emerging adulthood years may be particularly pronounced (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017; Smith et al., 2013). This is both in terms of engendering risk and ameliorating it in the form of interventions, particularly peer support and online communities (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017; Smith et al., 2013).

Formative Time for the Resetting of Health Behaviours.

With adolescence and emerging adulthood being a crucial period for re-setting health and wellbeing behaviours amid burgeoning independence and autonomy, the adolescent and emerging adult years (Arnett, 2000) becomes a critical time to intervene. Not only are many promotive or risk-oriented behaviours that prevent or engender psychosocial comorbidity and chronic conditions later in life initiated during adolescence and emerging adulthood, they also are done under the influence of social-cultural forces (Patton et al., 2016; Sawyer et al., 2012).

Specific Psychosocial Risks of Adolescents Living with a Chronic Condition

In the case of chronic illness or disabilities, their impact on the development and psychosocial health of young people is complex, varied and dependent on an array of factors including the nature of the condition, its severity, visibility, disruption to daily life, quality of care given and the amount of social support available (Stein & Jessop, 1982). However, studies employing Stein and Jessop's (1982) non-categorical approach, including the current research project, have aimed to highlight common risks that cut across disease-specific divisions. The value of this approach is that it focuses on shared challenges and highlights factors engendering 'socially-mediated comorbidity' (Sawyer et al., 2007, p. 938) that can be prevented and treated through intervention efforts.

In the literature exploring the impact of an illness or disability upon a young person's health and development, some studies have recognised these individuals as being equally as resilient as their 'healthy' peers (Luyckx et al. 2008b; Rassart 2012), while others have noted they are at a heightened risk of experiencing social isolation, social exclusion, stigmatisation and bullying (Collard & Marlow, 2016; Lounds Taylor et al., 2017; Pittet et al., 2010; Sawyer et al., 2007). These risks are attributed to regular school absences, hospitalisation or their condition dislocating and inhibiting their participation in important recreational, school or social activities with peers and friends (Sawyer et al., 2007; Suris et al., 2004; Yeo & Sawyer, 2005). These concerns are significant considering social participation, social connection and social support are recognised as constituting valuable sources of resilience for these vulnerable individuals (Arnone & Fitzsimons, 2012; Collard & Marlow, 2016; Docherty et al., 2015; Foster et al., 2017; Lounds Taylor et al., 2017; Orsmond et al., 2013; Taylor et al., 2008). With regards to social isolation, one participant in Winger et al.'s (2013) qualitative investigation voiced how this induced a feeling of being 'forgotten, invisible' (p. 2654); as if the 'world goes on without them' (Winger et al., 2014, p. 2653). Pittet et al. (2010) noted that young people living with a chronic condition are three times more likely to be the subjects of social exclusion at school, with this exclusion taking both implicit and explicit forms (Collard & Marlow, 2016; Lindsay & McPherson, 2012; O'Hagan & Hebron, 2017).

Implicit forms of exclusion are related to social isolation and often involve attempts to accommodate to the young person's illness or disability, but with a lapse in sensitivity for their developmental or psychosocial needs (Giordano, 2016; Lindsay & McPherson, 2012; O'Hagan & Hebron, 2017). In Lindsay and McPherson's (2012) study, this phenomenon was reflected in an incident where a teacher allowed a student in a wheelchair to use the lift marked disabled while her peers used the stairs. Although this constituted a supportive act, its meaning for the young person was experienced somewhat differently: she said, 'you feel strange that you're using an elevator that's got a different label on it … I have to leave my friends in order to do this so it does still feel exclusionary' (Lindsay & McPherson, 2012, p. 104). Similarly, young people granted special provisions to sit for exams in separate rooms or have a teacher's aide present felt that this isolated them both physically in terms of space and emotionally when they consistently had to explain to their peers why they were granted exceptions. Moreover, in the case of the teacher's aide, the student felt their presence inhibited her ability to make friends as she felt peers would think, 'oh she is with someone, so we won't bother her' (Lindsay & McPherson, 2012, p. 105). In the study, this was amplified by the teacher's aide continuing to accompany the student not only in class, but also in the playground.

The above is an example of over-protection by adults, which can include teachers, medical professionals and parents who—in an effort to cater to the young person's condition-based needs in terms of their illness or disability—overstep the mark and impede their autonomy and independence at a developmental stage when the drive for self-determination and 'adaptive' risk-taking within novel and peer-driven contexts is increasing (Blakemore & Mills, 2014; Collard & Marlow, 2016; Crone & Dahl, 2012; Foster et al., 2017; Lindsay & McPherson, 2012; Sawyer et al., 2007; Suris et al., 2004). Collard and Marlow's (2016) study demonstrated this type of over-concern when medical professionals advised against exercise for young people living with epilepsy, because of the fear that it would complicate their condition, despite young people reporting psychosocial and illness benefits from the activity. This suggests when intervening and devising strategies to support young people living with a condition, it may be about balancing both condition and developmental needs rather than substituting one for the other (D'agostino et al., 2011; Sawyer et al., 2007; Suris et al., 2004). Similarly, in Lindsay and McPherson's (2012) work, teachers would prevent young people from participating in sports as they perceived these students as fragile with a greater potential than other students to be hurt.

Thus, while adults acted with good intentions in the above cases, they inadvertently responded in terms of risk or deficit models. This engendered a sense of disempowerment as young people were perceived in terms of the limits of their condition and what they could not do (Engel, 1989; Fergus & Zimmerman, 2005; Sawyer et al., 2012; Sawyer et al., 2007). In contrast, young people required perceptions and responses that empowered them to move beyond their illness or disability and focus on what they could do. This would involve attending to their unique needs as an individual or young person (D'agostino et al., 2011; Hinson et al., 2016; Steinbeck et al., 2014). Taylor et al. (2008) asserted this encompasses an acute desire to belong, fit in and be seen as similar to their peers. Consequently, while these young people were present in school, sport or recreational settings, and attempts were made to accommodate their conditions, they still felt a painful sense of isolation and exclusion in terms of engagement and access to peer-driven spaces, activities and interactions. This intensified their sense of difference (Collard & Marlow, 2016; Ferguson & Walker, 2014; Lindsay & McPherson, 2012). As a result, strategies that were designed to be inclusive took on the opposite tone and had a contrary meaning for the young person. This indicates the importance of considering young people’s voices and perspectives when devising responses and interventions to accommodate their conditions (Lindsay & McPherson, 2012; Patton et al., 2016; Tylee et al., 2007).

Interestingly, however, despite being isolated on school grounds, these young people also asserted they felt more connected at school than when they went home. This indicates that the sense of isolation is magnified outside peer-driven settings (Lindsay & McPherson, 2012; O’Hagan & Hebron, 2017). In these instances, it appears that the presence of peers—even in the absence of quality inclusion—is preferable to no engagement at all. This suggests online platforms may be an important source of support. The stronger degree of absence beyond the school setting was evident in Lindsay and McPherson’s (2012) study when one participant commented, ‘I actually felt more exclusion outside of school than at school, … it was like as soon as I went home I had no contact with any of my peers’ (p. 105). O’Hagan and Hebron (2017) noted a similar sentiment among young people with Autism. Intriguingly, when asked why they had no contact with peers at home, these young people cited distance as the reason, despite their parents suggesting otherwise. This response appeared to function as a protective mechanism for young people to buffer against or conceal the pain of acknowledging social rejection. Consequently, both O'Hagan and Hebron (2017) and Taylor et al. (2008) noted that the desire for friendship and peer connection among young people living with an illness or disability is as salient and all-consuming as that experienced by their age mates, even if opportunities for this connection and engagement are less available.

Cases of Social Support

It is important to stress that not all young people living with conditions perceive school or engagement with peers as an isolating or exclusionary experience. Some studies have reported that young people living with conditions maintain robust and meaningful friendships and social networks (Adriaensens et al., 2017; Foster et al., 2017b; Rassart et al., 2012). Adriaensens et al.'s (2017) innovative investigation using a social network approach demonstrated that young people who stuttered maintained similar degrees of popularity, closeness and betweenness in the classroom social network as did their peers. However, Adrianensen et al.'s (2017) findings contrasted with those of Davis et al. (2002), who also utilised a social network analysis, but found that young people who stuttered were less popular and more likely to be socially rejected or bullied. Adriaensens et al. (2017) attributed this to differences in sample sizes and procedural methods. However, these findings may also reflect changes in societal perception and policy over time with young people living with conditions becoming increasingly integrated into regular school systems, thus overcoming social stigma (Davis et al., 2002; Dominiak-Kochanek, 2016). Another crucial feature was whether these studies were testing popularity based on leadership or social participation as young people who stuttered were less likely to be perceived as leaders by peers, but more likely to be seen as co-operative (Adriaensens et al., 2017; Davis et al., 2002). The latter was used as a strategy by young people who stutter to protect themselves against bullying (Davis et al., 2002).

In alignment with Adriaensens et al.'s (2017) study, Rassart et al. (2012) found that for young people living with congenital heart disease, the quality of their peer relationships was higher than that of healthy controls. However, Rassart et al. (2017) speculated that this may be because of biases introduced through the use of self-reporting in their study. In particular, they cautioned that young people living with a condition may over-estimate the subjective value of their friendships, as the challenges of living with a condition often promote greater perspective-taking (Rassart et al., 2012). This may have resulted in these young people appreciating their connections and experiences with peers more fully than did their healthy counterparts (Rassart et al., 2012).

Thus, while studies indicate the potential for young people living with a condition to maintain healthy peer, parental and even school connections—especially in terms of trust, assistance and belonging (Adriaensens et al., 2017; Rassart et al., 2012; Raymaekers et al., 2017)—they also identify challenges in this domain. This includes elevated risks of social isolation, exclusion and over-protection, sometimes within the same cohort (Collard & Marlow, 2016; Davis et al., 2002; O'Hagan & Hebron, 2017). This alludes to the importance of attending to the quality of these engagements rather than their quantity, particularly quality considered from the young person's perspective and the meanings they attribute to these interactions (Rassart et al., 2012). However, it is also essential to consider quality across multiple dimensions, including the bonding and bridging capital of similar and dissimilar others, as well as parental and teachers' views that may highlight a lack of connection beyond the young person's awareness (Collard & Marlow, 2016; Davis & Calitz, 2016; Rassart et al., 2012). This is significant as young people who report higher levels of peer, parental and school connection appear to experience a ripple effect of promotive factors, with strengths in one area enhancing strengths in another or buffering against risk (Adriaensens et al., 2017; Rassart et al., 2012; Raymaekers et al., 2017). In one study, those with weaker connections appeared more susceptible to having strengths diminished across multiple domains and contexts, rendering them more vulnerable to psychosocial comorbidity and adjustment issues (O'Hagan & Hebron, 2017). Conversely, those with stronger connections were more likely to have fewer adjustment issues, better self-management of their condition and more positive psychosocial health overall.

Explicit Social Exclusion and Bullying

Regarding explicit or intentional social exclusion, the effect of the dis-enabling attitudes of others upon the perceptions of and opportunities for young people living with an illness or disability takes on greater importance (Giordano, 2016; Lindsay & McPherson, 2012). Explicit exclusion is strongly related to bullying and stigmatisation and involves not only deliberate attempts to ostracise or inhibit the inclusion of young people living with chronic conditions but also direct acts of verbal, relational, emotional, physical or cyber-bullying (Blake et al., 2012; Lindsay & McPherson, 2012; Pinquart, 2017; Pittet et al., 2010). While studies have consistently reported higher levels of explicit exclusion and bullying among this cohort (Bauman & Pero, 2010; Bear et al., 2015; Blake et al., 2012; Carroll & Shute, 2005; Faith et al., 2015; Gibson-Young et al., 2014; Lindsay & McPherson, 2012; Pinquart, 2017; Pinquart & Pfeiffer, 2011; Pittet et al., 2010; Rose et al., 2015), it is important to recognise that both issues are a pervasive concern among young people in general. Moreover, few studies have specifically explored these constructs in relation to young people living with an illness or disability, despite there being a pressing need to do so and to contextualise these findings into the broader youth problem (Pinquart, 2017). Further, many relevant studies have used small samples (Pinquart, 2017). Consequently, there is variability in results in terms of effect sizes, especially for different conditions (Pinquart, 2017). Nonetheless, several emerging trends have been highlighted within the literature and are worthy of comment here.

First, young people living with a chronic condition are generally recognised as being at a heightened risk of social exclusion, bullying and stigmatisation in peer-driven contexts (Pinquart, 2017). Blake et al. (2012) asserted that once targeted, young people living with a condition are five to seven times more likely to be re-targeted. Pittet et al. (2010) suggested they are also at a higher risk of experiencing two or more forms of bullying. Pinquart (2017) observed this included physical, verbal, relational and cyber-bullying as the most common types encountered with illness-specific teasing being an important sub-division for those living with a condition. In the latter study, young people living with an illness or disability were also at a higher risk of being pinpointed in cases where their condition was clearly visible and indicating difference (Pinquart, 2017). Visibility refers to both physical visibility, such as burns or craniofacial abnormalities, and emotional or psychological visibility, such as in cases of emotional disturbances, behavioural problems or poorer social functioning, where the young person is viewed not only as different but potentially weaker in defending themselves, and therefore an easy target (Bauman & Pero, 2010; Lau & Van Niekerk, 2011; Pinquart, 2017).

Interestingly, Pinquart (2017) found that in some cases young people living with an illness or disability were bullies themselves. However, in an earlier study by Bauman and Pero (2010), they qualified that while they had found cases of ‘pure bullies’ among young people without a disability; that is, bullies who had experienced no victimisation. In contrast, among disabled participants they found no cases of ‘pure bullies’, only ‘pure victims’. This suggested that among young people living with a condition who engaged in bullying behaviour, this was often in retaliation to the social challenges of their condition and having had experienced bullying themselves (Rose et al., 2015; Turner et al., 2011). Pinquart (2017) concurred, stating this is especially the case among young people living with conditions characterised by emotional or social disturbances, such as Autism or Aspergers syndrome, as these individuals are more prone to externalising behaviours in response to social exclusion and victimisation.

Disturbingly, Lindsay and McPherson (2012) noted that social exclusion was not only perpetuated by peers, but also on occasions by teachers who held attitudes shaped by ‘ableism’ (Wolbring, 2008). This was evident in one study when a teacher refused to allow a student in a wheelchair to press a button to indicate his need to go to the bathroom, suggesting this would be too distracting for his classmates. Similarly, in the case of a girl with Cerebral Palsy, her teacher would not include her in class discussions and turned off her speaking device. This not only silenced her and rendered her condition glaringly salient, but indicated to her peers that her voice as a person beyond her condition was irrelevant (Lindsay & McPherson, 2012). It is critical to point out that these incidents probably reflect the bias of particular teachers, and not an attitude shared generally, as many teachers were also found to be highly supportive (Lindsay & McPherson, 2012). However, in cases where teachers were biased, this set the tone for peers to be the same. This indicates that social norms and culture play a prominent role in condoning or prohibiting such behaviour, especially when enacted by authority figures, mentors or popular peers (Lindsay & McPherson, 2012).

In the case of peers, explicit exclusion and bullying stemmed from the fear of difference and misperceptions about an illness or disability, such as in Admi’s (1996) study on CF, where peers erroneously thought they could contract the condition. Consequently, social exclusion and bullying were intimately tied to stigmatisation and the attitudes of others (Admi 1996). They were also related to the associated paradox of visibility and invisibility (Lau & Van Niekerk, 2011; Lindsay & McPherson, 2012; Salmon, 2013). This issue of visibility and invisibility was evident in Lau & Van Niekerk's (2011) study where young people with burn injuries suggested they had become more aware of their condition and difference upon entering school and witnessing the reactions of others. Negative reactions connected to teasing, bullying and ostracism not only made these young people feel different but engendered a sense of being—as expressed by one participant—'deficient or sub-human …, they treat you like you are the mad one, some of them treat you like you are not normal' (Lau & Van Niekerk, 2011, p. 1170). This evoked responses from participants, such as, 'they should accept what I look like, and accept that I'm still a human being' (Lau & Van Niekerk, 2011, p. 1170). Thus, similar to cases of implicit exclusion mentioned above, young people felt that they became invisible to others under the over-bearing presence of their condition. Many suggested this masked their true self and who they were beyond their illness or disability. This was compounded by a 'longing to be recognised as a person with feelings, wants and desires' (Lau & Van Niekerk, 2011, p. 1171) as most peers judged them instantly without taking the time to get to know them.

However, while some young people may resist such stigmatising notions (Lau & Van Niekerk, 2011; Salmon, 2013), for others they intensify feelings of self-stigma, evident by comments like, 'I felt like I'm nobody. I don't deserve to be in the world' (Lau & Van Niekerk, 2011, p. 1172). Further, constant scrutiny by peers had the potential to engender heightened self-consciousness and body image issues (Hörnquist et al., 2014; Knight et al., 2016; Knudsen et al., 2017; Olenik-Shemesh & Heiman, 2017; Oliver et al., 2014; Patterson, 2010; Salmon, 2013; Snöbohm et al., 2010; Stinson et al., 2015; Tierney, 2012), including feelings of being less attractive and desirable, not only to peers, but to potential romantic partners (Stinson et al., 2015). This may be associated with lower self-esteem, global self-worth and quality of life (Olenik-Shemesh & Heiman, 2017; Snöbohm et al., 2010; Sodergren et al., 2017; Tremolada et al., 2017).

O'Hagan and Hebron (2017) noted that young people living with disabilities became more aware of the stigmatising attitudes of others as they grew older, but lacked the ability or opportunity to develop the social skills to counter such beliefs, and therefore experienced greater degrees of social isolation with age. A critical issue identified in Bauman and Pero's (2010) work on bullying was that young people often felt self-shame or stigma for being bullied, and therefore failed to disclose such experiences, perpetuating the cycle long term. Further, many young people in that study reported that they lacked the skills to deal with and respond to both offline and online bullying (Bauman & Pero, 2010). This identifies a space for future interventions with respect to building assets and resources to foster skills and relationships to buffer young people against these challenges (Bauman & Pero, 2010). This is especially the case given Blood and Blood's (2016) finding that bullying among these individuals produces poorer psychosocial health into adulthood, including higher levels of social anxiety, lower self-evaluation and poorer quality of life in the long term.

Similarly, Young-Southward et al. (2017) alluded to the long-term effects associated with stigmatisation among young people living with disabilities as they transitioned beyond school into the adult world, suggesting 'ableism' continued to mar their inclusion as they struggled to find meaningful work and adequate support networks. This caused higher levels of anxiety. Coduti et al. (2016) also noted elevated distress and anxiety levels among young people with disabilities as they moved into university settings. This was related to lower beliefs in their self-efficacy by tutors and peers, academic challenges and the stigmatising or isolating attitudes of others (Coduti et al., 2016). Alarmingly, this induced higher levels of suicide ideation, suicide attempts and non-suicide self-injury among these individuals compared with their peers. Both Chou et al. (2016) and Hannon and Taylor (2013) noted higher levels of suicide ideation among young people living with Autism. Honey et al. (2011) also acknowledged a greater propensity for psychosocial comorbidity and mental health challenges among young people with disabilities, but positively noted such tendencies were circumvented and ameliorable by improving these individuals' social and financial status, and coping resources.

Similarly, McDonnell et al. (2017) discovered higher levels of Anxiety among Cancer patients, related to the 'late' effects of a Cancer diagnosis, including clinically significant Post-Traumatic Stress (PTS), as well as Cancer-related worries. With regard to Cancer-related worries, Lu et al. (2013) found elevated levels of suicide ideation and attempts among young people recently diagnosed. Both Foster et al. (2017) and King et al. (2017) noted that a diagnosis of Cancer or Diabetes respectively engendered negative responses such as 'why me? … I felt like I was being punished' (Foster et al., 2017, p. 380) and 'I couldn't take it all in … I couldn't understand it really' (King et al., 2017, p. 27). The inability to comprehend the complexity of their condition resulted in poorer illness management. However, both studies also reported incidents where young people responded promisingly and proactively. King et al. (2017), in alignment with Honey et al.'s (2011) work, suggested this was due to greater social support, both in terms of peers and family who served as points of distraction and a source of normalcy for these young people. Ferguson and Walker (2014) recognised practising normalcy as a powerful source of resilience for this vulnerable cohort. In particular, they stressed the value of emphasising self-efficacy regarding future plans and goals, promoting optimism (Oliver et al., 2014), and celebrating one's individuality and personality beyond their condition (Ferguson & Walker, 2014).

However, it was noted by Ferguson and Walker (2012) that efforts to celebrate young people's individuality at times could diminish important sources of condition-based support from these individuals as they 'slip under the radar' (p. 235). This was related to a lack of disclosure and the concealment of one's condition within school and peer-driven settings, because of the fear of encountering the stigmatising attitudes of others. Lack of disclosure and concealment were compounded by the desire of these young people to fit in and be seen as similar to their peers. Consequently, Ferguson and Walker (2012) outlined the importance of foregrounding the young person's individuality or unique identity while creating avenues for them to express, but not be defined by their condition, particularly in relation to interventions.

Online Interventions, Young People's Conditions and Identity

Interestingly, concerning interventions, studies have explored how young people utilise online communities and social media platforms to: (a) build important forms of informational, emotional and tangible support in relation to their condition and mental health (Gibson & Trnka, 2020; Kelleher et al., 2020; Rickwood et al., 2016; Salminen et al., 2019); (b) celebrate patient expertise and advocacy (Charbonneaux & Berthelot-Guiet, 2020; Gelfgren et al., 2020); and (c) foster social media and digital literacy skills (Caton & Landman, 2021). However, the literature exploring how young people utilise these platforms to express their identity in relation to their condition and wider sense of self, is still in its nascent stages.

While some studies have highlighted how these platforms have become important avenues for young people to present their wider sense of self beyond their condition (Bowker & Tuffin, 2007; Kelleher et al., 2020), they have also noted young people engage in strategies, such as concealment, particularly within mainstream social media platforms to be seen as normal and avoid negative reactions, including bullying in relation to their condition (Bowker & Tuffin, 2007; Kelleher et al., 2020). Other studies centred on understanding how young people explored their condition and their sense of self in terms of their illness or disability online (Clerici et al., 2012; Gibson et al., 2016; Pereira et al., 2017; Pereira et al., 2020), but similarly acknowledged that identity tensions affected young people's engagement with these communities (Angulo-Jiménez & DeThorne, 2019; Mazanderani et al., 2012) In particular, these identity tensions included fears of becoming overly defined or negatively defined by their conditions online (Mazanderani et al., 2012). This undermined young people's efforts to reach out and sustain engagement with these online interventions and supports (Mazanderani et al., 2012). Similarly, concerns around whether young people would become overly defined by biomedical discourses—which primarily perceive of conditions in terms of deficit or impairment—versus biopsychosocial and ecological understandings that emphasise neuro-diversity in the online sphere, were also present within the literature (Angulo-Jiménez & DeThorne, 2019). An equally interesting trend, was how young people appropriated the 'inspirational' culture of social media platforms to present their condition in positive ways but without giving equal prominence to the distressing aspects of their condition (Stage et al., 2020). This appeared to reflect efforts by these young people to fit in and accord with regular social media platform norms (Stage et al., 2020).

Significantly for this thesis, studies have highlighted the importance of foregrounding the young person's individuality and wider sense of self online as a strategy to enhance psychosocial health (Gibson et al., 2016; Mazanderani et al., 2012; Pereira et al., 2017). However, despite endorsing this strategy, these scholars did not explicitly explore the expression of this facet of young people's identities within their studies, rather they focused on examining condition based identities and concerns (Gibson et al., 2016; Mazanderani et al., 2012; Pereira et al., 2017). Consequently, there is a need to explore how online communities support young people in terms of their condition-based needs and condition-based self, while also attending to their wider developmental needs and identity beyond their condition to foster normalcy (Ferguson & Walker, 2014). At the same time, there is a need to mitigate identity tensions related to concealment and disengagement from online support services (Angulo-Jiménez & DeThorne, 2019; Kelleher et al., 2020; Mazanderani et al., 2012). This requires an investigation into how the constructs of 'developmentally appropriate' and 'psychosocial support' are conceived within the field, and the different approaches to designing and evaluating interventions to meet this dual concern.

Developmentally Appropriate Interventions

The previous section reviewed common psychosocial and developmental risks or challenges often encountered by young people living with a condition. A critical insight to emerge from this—which aligns with the literature outlining adolescence and emerging adulthood as a sensitive period for socio-cultural engagement—is the importance of addressing risk in terms of not only the young person, but also the quality of their socio-cultural environments. This concerns the cultures and norms operating within these spaces. This has implications for designing and evaluating 'developmentally appropriate' (D'agostino et al., 2011) interventions for young people living with a condition as these programs and services play a central role in providing these enabling structures, and modelling promotive cultures and norms for vulnerable young people. This section outlines dominant approaches to ‘developmental appropriateness’ and core challenges related to the conceptualisation and operationalisation of ‘developmental appropriateness’ as a construct. This is especially in relation to health models, and the types of developmentally appropriate services and interventions available and researched within the field for young people living with a condition.

Prevention and Promotion Approaches

The literature exploring the importance of designing and evaluating developmentally appropriate interventions for young people living with a condition arguably reflects two dominant approaches: prevention and promotion (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999; Gillham et al., 2002).

Prevention Science

Prevention is concerned with protecting young people from risk by pre-empting and predicting risk factors and pathways engendering negative developmental, psychosocial and condition-related health outcomes or trajectories (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999; Gillham et al., 2002). In the context of interventions, prevention aligns with resilience (Fergus & Zimmerman, 2005; Shean, 2015) and positive youth development models (Catalano et al., 2012; Catalano et al., 2002; Gillham et al., 2002; Hamilton et al., 2004; Lerner et al., 2011) that strive to mitigate or moderate the negative effects of risks by employing a range of evidence-based strategies. These include direct efforts towards risk minimisation and reduction, and the inclusion of promotion-based strategies, such as the implementation of protective or promotive resources including peer and mentor support into the design of an intervention (Catalano et al., 2002, 2012). The latter endeavours to build promotive assets and resources within young people and their environments, respectively (Catalano et al., 2012; Catalano et al., 2002; Hamilton et al., 2004; Hinson et al., 2016).

The infusion of promotion-based strategies alongside direct risk minimisation and reduction efforts associated with prevention-based approaches, emerges from a recognition within scholarship that similar risks tend to underlie a multitude of maladaptive, developmental, psychosocial and condition-based outcomes and trajectories among young people in general, including those living with a condition (Catalano et al., 2012; Catalano et al., 2002; Lerner et al., 2011). Kirby (1997) suggested no single risk factor produces a pronounced effect in contributing to negative outcomes or trajectories; rather it is the cumulative effect of multiple risks, such as socially mediated comorbidities (Sawyer et al., 2007) that are more significant for research and interventions to address. This has greater value when designing and evaluating developmentally appropriate services. An effective strategy for targeting cumulative risk identified in the literature is fostering strengths-based development for young people by building promotive assets and resources (Catalano et al., 2012; Catalano et al., 2002; Lerner et al., 2011). This strives to empower young people to overcome risk within and beyond the intervention context through resilience; with resilience being defined specifically as thriving in the presence of risk (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999; Fergus & Zimmerman, 2005).

For health models, this emphasis on addressing risk through resilience and positive youth development strategies in relation to young people and their reciprocal relationship with the environment, results to some extent in prevention-based approaches adhering to the biopsychosocial (Engel, 1980, 1989) and socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006) models of health. This includes efforts through prevention-based approaches to extend the scope of health influences and determinants beyond the biological to include psychological, social, cultural and developmental risk factors, as well as protective and promotive assets (Catalano et al., 2012; Catalano et al., 2002; Lerner et al., 2011). This emphasis is also evident in prevention-based approaches conceiving and evaluating the environment and interventions more broadly in terms of the bi-directional relationships (Catalano et al., 2012; Catalano et al., 2002; Lerner et al., 2011). In alignment with Bronfenbrenner's (1979) microsystem, mesosystem, exosystem, macrosystem and chronosystems model, this includes the bi-directional relationships between the different layers of an individual's social ecology and the proximal, distal and developmental factors influencing risk and promotive resources supporting intervention efforts (Catalano et al., 2012; Catalano et al., 2002; Lerner et al., 2011).

However, despite prevention-based approaches extending the scope of health determinants and the conceptualisation of the environment to better reflect biopsychosocial and socio-ecological models of health (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989), Czeresnia (1999) argued on a philosophical or ontological level prevention-based approaches remain entrenched within biomedical understandings of disease and disability. This is primarily due to prevention's strong emphasis on identifying, predicting and pre-empting risk (Czeresnia, 1999). Thus, interventions informed by prevention approaches are predominantly designed and evaluated with a high problem-centric focus, despite applying promotive-based strategies to facilitate resilience within them (Czeresnia, 1999; Gillham et al., 2002; Hamilton et al., 2004). Consequently, while prevention conceives of health through a broader lens, its approach to supporting psychosocial development and condition-based concerns nonetheless remains deficit oriented (Czeresnia, 1999; Gillham et al., 2002; Hamilton et al., 2004).

Similarly, prevention's emphasis on prediction also results in the developmental appropriateness and effectiveness of these interventions being evaluated within scholarship predominantly in terms of positivist and post-positivist paradigms (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018). These paradigms foreground general effects, as well as mediating and moderating pathways, often in relation to (a) specific risk factors; and (b) a limited number of promotive assets and resources with a strong emphasis on promotive assets rather than resources being embedded in intervention designs (Gillham et al., 2002; Lerner et al., 2011). Thus, Catalano et al. (2002) argued that, despite prevention's wider scope to capture a vast array of complex bi-directional relationships between the individual and their environment—the latter of which is critical for intervention-based research and is an advantage not often drawn upon within scholarship—in practice, most studies continue to evaluate prevention-oriented interventions primarily in terms of the individual (Gillham et al., 2002; Lerner et al., 2011). Similarly, they emphasis promotive assets over resources and focus on reductive solutions centred on cause and effect relationships, rather than the perceptions and meanings driving young people's behaviours in relation to risk or their help-seeking or engagement patterns with interventions (Czeresnia, 1999; Gillham et al., 2002; Lerner et al., 2011; Webb & Karlis, 2020). In addition, a limited number of studies have explored how these interventions are evaluated in terms of developmental appropriateness from the practitioner's perspective.

As a result, the impact of these biomedical undertones informing prevention-based approaches, and the dominance of positivist and post-positivist research as ways to assess the developmental appropriateness of these interventions on a practical level, means that most prevention-informed interventions adopt a top-down, prescriptive approach to designing and evaluating these programs (Hamilton et al., 2004; Webb & Karlis, 2020). This adheres to the generalised understandings of cause-and-effect relationships outlined by positivist and post-positivist research as the standard of best practice (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018). A critical concern arising from this, in relation to operationalising developmental appropriateness, is the awareness that this top-down, prescriptive approach—while supportive of young people's development at the service or program level—to some extent undermines the participatory ideals encompassed in the notion of developmental appropriateness at the philosophical or ontological level (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). This is particularly evident in relation to the concept of person-centric care or placing the young person at the centre of practice (Phelan et al., 2020). Research indicates that prevention's top-down, prescriptive approach at times results in young people's voices and experiences being marginalised in relation to discourses concerning the design and evaluation of developmentally appropriate interventions implemented to support them (Azzopardi, 2012; Hamilton et al., 2004; Webb & Karlis, 2020). This marginalisation occurs in both a formal capacity within scholarship, and informally with respect to a lack of feedback mechanisms and the building of rapport with adults and practitioners within interventions (Hamilton et al., 2004; Webb & Karlis, 2020).

The latter was highlighted by Webb and Karlis (2020) who indicated that when researchers and practitioners rely on this top-down, prescriptive approach to designing interventions and tailoring activities within them to achieve developmentally enhancing effects, in practice young people fail to reach out and sustain engagement with these services as they perceive the culture of these programs and the way the activities are run within them as being too much like school or drills. Webb and Karlis (2020) proposed that this undermines young people's agency and ownership of programs, indicating a power imbalance between researchers, practitioners and young people's voices in this dynamic. Consequently, while generalised approaches to designing developmentally appropriate interventions and activities may result in programs possessing developmental value on a scientific or scholarly level, a prescriptive approach can inhibit meaningful engagement at the level of culture and practice (Hamilton et al., 2004; Webb & Karlis, 2020). This is due to prescriptive approaches failing to create interventions that tap into youth engagement practices and interests (Hamilton et al., 2004; Webb & Karlis, 2020). Therefore, they also fall short of providing avenues within these programs for the inclusion of young people's voices and feedback. Similarly, Hamilton et al. (2004) asserted that prescriptive or generalised approaches fail to account for individual difference and meaning. Consequently, they suggested that even the best tailored developmentally appropriate intervention may not be 'developmentally enhancing for all' (Hamilton et al., 2004, p. 9). This is due to the inhibition of choice within these programs, which is critical for fostering young people's agency and engagement within these services, and building egalitarian relationships and partnerships with young people.

In addition, both Gillham et al. (2002) and Hamilton et al. (2004) recognised that young people also remain reluctant to reach out to these services and interventions because of prevention's over-riding problem or deficit focus. Hamilton et al. (2004) noted this potentially induces a stigmatising or 'labelling effect' (p. 7) among young people. They suggested that when the goal of an intervention is to support young people in relation to risk, this can sometimes lead young people to personalise or identify with the risk, problem or issue being pre-empting (Hamilton et al. 2004). This 'labelling effect' can occur at the universal, selective or indicative level of developmentally appropriate interventions (Catalano et al., 2012).

Universal interventions are those designed for all young people and therefore address general risk irrespective of exposure. Emphasis on risk or negative outcomes at this level to some extent can reinforce Hall's (1905) seminal assertion of adolescence and emerging adulthood (Arnett, 2000) as a period of storm and stress, which engenders a negative or deficit view of young people and this life stage. However, the introduction in recent times of positive youth developmental frameworks and the application of promotive strategies within prevention-based approaches, to a large extent has overcome this negative perception (Catalano et al., 2002; Lerner et al., 2011). Of more critical concern, particularly for young people living with a condition, is the emphasis on risk or problems within selective and indicative interventions (Catalano et al., 2012). Selective interventions are those designed for young people at a heightened risk of exposure to negative outcomes or trajectories (Catalano et al., 2012). This includes young people living with a condition being at an elevated risk of social isolation, exclusion, stigmatisation and bullying, and the negative psychosocial, mental health and condition-based outcomes that can result (Collard & Marlow, 2016; Lounds Taylor et al., 2017; Pittet et al., 2010; Sawyer et al., 2007). Indicative interventions are those supporting young people already exposed to risk and presenting with negative outcomes and trajectories, such as those mentioned above (Catalano et al., 2012).

With respect to Hamilton et al.'s (2004) labelling effect, 'prevention-oriented' selective and indicative interventions can sometimes re-enforce a negative view of young people's conditions through their emphasis on risk and negative outcomes. Consequently, while these interventions may include promotive-based strategies to support young people's psychosocial development and condition-based concerns, at their core, prevention-based services primarily continue to conceive conditions in terms of deficit models, reductive solutions and treatment, rather than as a source of strength (Hamilton et al., 2004; Webb & Karlis, 2020). This can undermine positive or strengths-based understanding of illness and disability within these spaces that are critical for countering ableism, and conceiving illness and disability beyond impairment, but rather in relation to the enabling and dis-enabling structures, attitudes and perception operating within society (Hamilton et al., 2004; Webb & Karlis, 2020). The latter of which is more reflective of biopsychosocial and socio-ecological understandings of health (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989).

In terms of help-seeking and engagement, this labelling effect can discourage young people from reaching out and sustaining participation with offline and online support communities because of a fear they will become overly or negatively defined by their condition within these spaces (Angulo-Jiménez & DeThorne, 2019; Kelleher et al., 2020; Mazanderani et al., 2012). This occurs even though these communities provide valuable sources of informational, emotional and tangible support in relation to young people's condition, and their psychosocial development and mental health more broadly (Gibson & Trnka, 2020; Kelleher et al., 2020; Salminen et al., 2019). This was evident in Locock and Brown's (2010) study where, despite the camaraderie and support offered online, tensions emerged within the support community when individuals began defining themselves in terms of their condition, rather than someone 'living' with a condition. This was particularly the case with downward social comparison when there was a decline in someone's health (Locock & Brown, 2010). While the latter engendered relief from some individuals that their situation was not as bad, the thought that they might end up in that position in the future created an identity tension (Locock & Brown, 2010). An important strategy employed by individuals to mitigate this identity tension online was leaving or taking breaks from the support community, which prevented them from receiving the support offered (Locock & Brown, 2010).

Mazanderani et al. (2012) noted a similar identity tension within their study. However, rather than seeing individuals leave the community, they highlighted how fostering the strategy of 'being differently the same' (p. 546)—which celebrated the heterogeneity or diversity of one's condition-based experience—functioned to mitigate the distress emerging in relation to condition over-identification or negative identification online, thus sustaining stronger engagement. Arguably, diversity in celebrating the young people's wider sense of self alongside the heterogeneity associated with their condition-based experiences, may also be an effective strategy for facilitating help-seeking and engagement within condition-based communities, both offline and online (Ferguson & Walker, 2014; Gibson et al., 2016; Pereira et al., 2017; Pereira et al., 2020). However, this remains a fragmented and under-researched area within the field.

Promotion Approaches

At this juncture, the promise of promotion-based approaches to designing and evaluating 'developmentally appropriate' interventions for young people becomes valuable (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). Positive youth development frameworks predominantly inform promotion-based approaches to developmental appropriateness (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004; Lerner et al., 2011). Consequently, they adopt a strengths-based approach to health and development that goes beyond and directly challenges prevention's emphasis on risk. The latter is critical and emerges from an awareness among early prevention researchers that 'problem free is not fully prepared' (Catalano et al., 2002, p. 232). This acknowledges that mitigating or moderating risk and negative outcomes and trajectories does not necessarily equip young people with the skills, assets and resources to actively contribute to the self, others and society in meaningful, engaging and identity-affirming ways essential for their healthy development (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004; Lerner et al., 2011). Instead, this requires a holistic conceptualisation of health, such as that articulated by the WHO (1948) as a ‘state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (International Health Conference, 2002, p. 1). More critically in terms of developmental appropriateness, WHO also outlined this involves the right to ‘informed opinion and active co-operation’ (International Health Conference, 2002, p. 1) by the public in the factors affecting their health. This includes involving young people’s voices and experiences in the design and evaluation of interventions and services implemented to support them (Bennett, 2009; Haldane et al., 2020; Steinbeck et al., 2014).

Inclusion of young people’s voices, experiences and participation in the design and implementation of services highlights a core distinction between prevention and promotion approaches, particularly in their ability to realise the aspirations of the biopsychosocial and socio-ecological models of health (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989), and the notion of developmental appropriateness encompassed within positive youth development frameworks (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004; Lerner et al., 2011; Webb & Karlis, 2020). While prevention acknowledges the merit of a holistic understanding of health—and strives to enact this at the level of scholarship and practice by extending the scope of its design and evaluation to encompass biological, psychological and social determinants and the bi-directional relationship between them—it is limited in its emphasis on generalised effects and prescriptive approaches (Hamilton et al., 2004; Webb & Karlis, 2020). This marginalises young people’s voices and experiences from these discourses (Azzopardi, 2012). Moreover, on a practical level, while prevention employs positive youth development as a strategy for fostering promotive assets and resources within interventions with the intention of building developmental strengths and resilience for meaningful engagement in society, its emphasis on predicting and addressing risk and negative outcomes results in the enactment of this strategy being primarily from a biomedical perspective (Engel, 1989). Thus, from young people's perspectives, these interventions and services continue to contain biomedical undertones or a clinical culture that perpetuates an understanding of the self and their condition that is deficit oriented (Hamilton et al., 2004; Webb & Karlis, 2020). Moreover, these interventions and services also engender relationships with practitioners and researchers where adults retain the upper hand or authority, despite their efforts to foster engagement (Hamilton et al., 2004; Webb & Karlis, 2020). Thus, at a cultural level, egalitarian and participatory relationships with young people are undermined.

Promotion-based approaches arguably are better able to realise the aims of the biopsychosocial and socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) models of health, in that they adopt a holistic understanding of health that goes beyond extending the purview of health determinants and the conceptualisation of the environment to consider that the biological, psychological and social domains are spheres that 'do not easily converse with each other' (Czeresnia, 1999, p. 705). Rather, new methods of evaluation within scholarship and practice are needed to discern how these domains and their influence on health can be integrated within interventions to support young people's development (Hamilton et al., 2004; Webb & Karlis, 2020). Thus, promotion is concerned with understanding young people's strengths in relation to their health and development, not predicting or pre-empting them in relation to risk (Hamilton et al., 2004; Lerner et al., 2011; Webb & Karlis, 2020). Consequently, promotion embodies positive youth development principles on a philosophical or ontological and epistemological level, rather than merely as a strategy within practice to build promotive assets and resources within interventions (Catalano et al., 2002; Czeresnia, 1999). In this sense, promotion is concerned with the reciprocal relationship between the individual and their environment in terms of assets and resources (Lerner et al., 2011). However, it recognises the importance of dismantling biomedicine—and positivist and post-positivism's stronghold—which focuses on qualifying these variables and bi-directional relationships in terms of generalisation and prescription that subsumes the psychological and social into the biological domain of the natural sciences (Czeresnia, 1999).

In contrast, promotion advocates for the importance of attending to young people's subjective meanings, perceptions and experiences in relation to their health and interventions. Czeresnia (1999) argued that promotion 'strengthens health by building a capacity for choice' (p. 706), and engagement, which 'is not really the sphere of knowledge, but value' (Czeresnia, 1999, p. 707). As a result, promotion as an approach is more adept at accounting for the intentionality of young people and practitioners in relation to developmentally appropriate interventions and individual differences (Czeresnia, 1999; Hamilton et al., 2004). Thus, promotion lends itself to constructivist and participatory research that moves beyond a prescriptive list of assets and resources to understanding how these assets and resources are perceived from young people's perspectives (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018). This opens the opportunity to explore additional influences at the ground level. Consequently, as an approach, promotion embodies positive youth development principles.

In practice, promotion facilitates the design of interventions for young people living with a condition that focuses on the young person and their development as paramount, with their condition as secondary. This has the potential to over-ride prevention's 'labelling effect'. As noted by Hamilton et al. (2004), 'if all youth need support in their development, then participating in a program is no longer stigmatising' (p. 7). Moreover, the universal approach of promotion also facilitates the design of interventions where young people are offered choice in relation to their engagement with the activities offered. This was evident with Hamilton et al. (2004) acknowledging that while all young people need 'opportunities to learn, explore, play and express themselves' (p. 7) in relation to their development, this does not necessarily mean they all need the same thing. Agency and autonomy are critical (Hamilton et al., 2004). Therefore, these interventions conceive of health in terms of fostering positive relationships and interactions with young people and their environments, but recognise the value of retaining choice in allowing young people to interact and assign meaning to these supports as they wish (Czeresnia, 1999; Hamilton et al., 2004; Lerner et al., 2011). Thus, social media platforms are a promising avenue for promotion-oriented interventions as their design and layout facilitates this opportunity for choice and engagement. Moreover, in alignment with Bronfenbrenner and Morris (2006), promotion-oriented interventions concede that the strongest drivers of development are proximal processes, which include regular, enduring and challenging activities, but more crucially activities that involve relationships with others, particularly when these relationships are 'regular, enduring and reciprocal' (Hamilton et al., 2004, p. 9). Thus, promotion approaches attend more acutely to culture, norms and meanings operating within interventions, and are potentially better placed to foster egalitarian partnerships.

Therefore, with respect to evaluation, promotion approaches and interventions—rather than striving to qualify their merit against biomedicine or the natural sciences through predominantly positivist and post-positivist research—recognise that a holistic and inclusive conceptualisation of health requires interdisciplinary and inter-sectorial action at the level of scholarship and practice that does not perpetuate old binaries, but moves dialogue forward

(Czeresnia, 1999; Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018). Thus, promotion advocates for the importance of assessing the contribution of interventions through constructivist and participatory paradigms, and combining this with research findings to create stronger conversations and engagement between young people, practitioners and researchers, as well as industry and scholarship (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018).

With respect to interventions within the field, the tension between prevention and promotion approaches emerges most acutely in relation to the clinical and community approaches to operationalising developmental appropriateness (D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014; Tylee et al., 2007). In short, clinical approaches are more likely to work within a biomedical (Engel 1989) model of the young person, and to favour the prevention approach to developmental appropriateness; while community-based (Trickett et al., 2011) approaches favour biopsychosocial or a socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) models. Although there may be different sub-groupings within clinical approaches—such as medical and hospital services (Bennett, 2009; Sawyer et al., 2019; Steinbeck et al., 2014); allied health supports (Bennett, 2009); and pre-screening counselling services, such as eheadspace (Rickwood et al., 2016)—they are all institutionalised under a therapeutic umbrella and there is little difference in the way that the balance between prevention and promotion is implemented and evaluated (Catalano et al., 2012; Sawyer et al., 2019; Steinbeck et al., 2014). However, at the community level, differences in sub-groupings are more apparent, with some interventions coming from community-based organisations, such as the SCF (Third & Richardson, 2010), Canteen (Mooney-Somers & Lewis, 2010) or Chronic Illness Peer Support (ChIPS) (Lewis et al., 2016; Olsson et al., 2005) and others coming from the grassroots, with self-help communities and groups forming for example on social media platforms (Angulo-Jiménez & DeThorne, 2019; Gibson & Trnka, 2020; Prescott et al., 2020). In community-based organisations, as noted above, the balance is more towards promotion, with an emphasis on young people outside a biomedical frame of reference (Czeresnia, 1999).

Prevention and promotion (Catalano et al., 2002; Czeresnia, 1999) approaches to developmentally appropriate services operate at two levels: the ontological or ideological level and the strategic or tactical level. It is here that tensions become apparent (Catalano et al., 2002; Czeresnia, 1999). Clinical services provide support to young people using a range of strategies and tactics. While many are clearly developed from prevention, others would seem to derive from promotion, yet an examination of the ideological or ontological position of these clinical services reveals that, ontologically, the underlying approach is that of risk aversion and prevention (Catalano et al., 2002; Czeresnia, 1999; Lerner et al., 2011). That is, strategies of promotion are used to support a prevention agenda (Catalano et al., 2002; Czeresnia, 1999). Thus, the enactment of developmental appropriateness within this approach predominantly operates at the level of service, but not culture (D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014; Tylee et al., 2007). Therefore, it becomes vital for community-based services using these strategies within a promotion agenda to assert the value of the ontological position that places the young person at the centre of interactions (Phelan et al., 2020), and seeks to call out clinical services that might seem to claim a shift towards promotion because of the strategies they use, but whose ideological position remains allied to the biomedical model (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). In this regard, promotion as an approach has the potential to foster a developmentally appropriate culture beyond merely a point in service (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004).

Practice and Literature Gaps

In reviewing the literature in relation to the design and evaluation of developmentally appropriate interventions (D'agostino et al., 2011) for young people living with a condition, this chapter has identified some significant gaps within scholarship and practice that warrant further investigation.

First, the review acknowledges a strong emphasis on exploring the developmental appropriateness (D'agostino et al., 2011) of clinical and community interventions for young people living with a condition in terms of prevention approaches (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999). This foregrounds risk and generalised evaluation of interventions. Thus, young people’s and practitioners’ voices are often marginalised from this discourse (Catalano et al., 2002; Czeresnia, 1999).

Second, a limited number of studies have explored the developmental appropriateness (D'agostino et al., 2011) of clinical and community interventions in terms of promotion approaches that have the ability to give greater recognition to young people’s and practitioners’ voices (Catalano et al., 2002; Czeresnia, 1999). This is significant as understanding these perspectives may have implications for enhancing young people’s help-seeking and engagement behaviours by revealing mechanisms and processes operating at the ground level (Bennett, 2009; Lawrence et al., 2015; Sawyer et al., 2010; Steinbeck et al., 2014).

Similarly, the emphasis on prevention to some extent undermines the legitimacy of community interventions within the field (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999). This is exacerbated by the fragmented nature of studies exploring community-based interventions under different disciplines and theories. Thus, there is a need to create a consistent framework to explore these services in tandem with clinical supports.

Last, the emphasis on prevention also results in interventions being designed with a strong condition focus (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). Consequently, current approaches predominantly operationalise developmental appropriateness at the level of particular points in service (D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014; Tylee et al., 2007); however how to infuse the tenets of developmental appropriateness at the cultural level of interventions and industry sectors remains under-conceptualised.

Thus, this study strives to contribute to the scholarship and practice related to the concept of developmental appropriateness by exploring the broad research question:

> How does the Starlight Children's Foundation's online community LW.org.au function as a developmental, psychosocial intervention for young people living with a condition from the perspective of the organisation, practitioners and young people?

This is intended to (a) grant recognition to the role of community interventions; (b) highlight young people's and practitioners' views on the notion of developmental appropriateness; and (c) propose a framework to explore clinical and community supports.

Chapter Summary and Conclusion

In conclusion, this chapter has provided a rationale for the need to provide young people living with a condition with developmentally oriented, psychosocial interventions in addition to their clinical support (Alderman et al., 2003; D'agostino et al., 2011; Steinbeck et al., 2014; Treadgold & Kuperberg, 2010). It outlined how scholarship and practice recognise the value of creating developmentally oriented services and interventions that align with biopsychosocial and socio-ecological models of health that have the potential to facilitate stronger person-centric care for these young people (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989; Phelan et al., 2020). This has allowed researchers and practitioners to go beyond conceiving young people's conditions in terms of biological determinants, risk factors and impairments to consider the critical role played by psychological, social, cultural and developmental factors.

The chapter also indicated that adolescence and emerging adulthood is a critical life stage to implement these community-based (Trickett et al., 2011), developmentally oriented, psychosocial interventions and supports (D'agostino et al., 2011) by demonstrating how socio-cultural influences on young people's understanding of their condition and health are more pronounced during this time (Blakemore & Mills, 2014; Crone & Dahl, 2012; Piekarski et al., 2017; Smith et al., 2013).

Further, the chapter outlined dominant approaches to operationalising developmentally oriented, psychosocial support and interventions within the clinical and community sectors. These included prevention and promotion approaches (Catalano et al., 2002; Czeresnia, 1999; Lerner et al., 2011).

The chapter concluded that, in spite of the large body of literature, there are gaps related to understanding how a promotion-based, ideological approach to developmentally oriented, psychosocial interventions and services can support young people living with a condition (Catalano et al., 2002; Czeresnia, 1999; Lerner et al., 2011). This has implications for supporting young people’s identity development beyond their condition (Ferguson & Walker, 2014). The following chapter will explore the literature in relation to identity development among young people in general as well those living with a condition.

Chapter 3: Identity Theory and Literature

Introduction

‘Identity’ and the related terms ‘self’, ‘self-identity’ and ‘self-concept’ are complex, multidimensional, but powerful constructs informed by psychological and sociological scholarship (Oyserman et al., 2012; Tsang & Yip, 2006; Vignoles et al., 2011). The value of these concepts to the social sciences is indisputable. However, their definition and application within scholarship is far from unified, rather the identity literature is highly fragmented as its richness in scope results in scholars diverging on how they conceptualise, measure and appraise this construct (Tsang & Yip, 2006; Vignoles et al., 2011). This fragmentation results from philosophical, disciplinary and methodological differences that render the identity scholarship a contested space, but one that continues to warrant investigation because of the pragmatic value it holds for fields as crucial as health and as emergent as digital media (Shapiro & Margolin, 2014; Subrahmanyam & Šmahel, 2011; Vignoles et al., 2011).

Identity as a Multidimensional Construct

The following outlines how the construct of ‘identity’ is conceived in the current study from three diverse angles, including the (a) personal, (b) interpersonal, and (c) collective standpoint. Each standpoint has relevance for understanding identity development in relation to the illness and disability experience and beyond it in relation to the individual.

Personal Identity

On the personal level, identity as a construct is primarily concerned with the question, ‘who am I?’ (Tsang & Yip, 2006). Embedded in this standpoint are layers of complexity, including an awareness of the self as an embodied, physical and material entity housing a subjective sense of a psychological self consisting of ideas, beliefs, personality attributes, hopes, fears, dreams, goals, feelings, experiences and a life story (Cooley, 1983; Hattie, 2014; James, 1890; Markus & Nurius, 1986; McAdams, 2011; McAdams & McLean, 2013; Oyserman et al., 2012; Oyserman & James, 2011; Vignoles et al., 2011). This duality between young people's physical and subjective sense of self is significant for young people living with a condition as the visibility of their condition may inhibit the recognition of and opportunities to develop their wider sense of self in relation to the subjective aspects of their identity. This is often attributed to the over-bearing physical presence of their condition (Lau & Van Niekerk, 2011; Lindsay & McPherson, 2012; Salmon, 2013). Moreover, while both the physical and subjective elements of the self are perceived as constituting a stable and fixed structure, this structure is also temporal in nature, consisting of a past, present and future, rendering it subject to change across time and space (Hattie, 2014; Markus & Nurius, 1986; Oyserman et al., 2012). Both Bury (1982) and Charmaz (1983, 1993) alluded to the disruptive, intermittent and intrusive nature of conditions that cause breaks in time and young people's understanding of the self.

Further, Burke and Stets (2009) 'identity theory' highlighted how individuals choose to foreground or background various elements of their physical and subjective selves in different contexts across time. In relation to young people living with a condition, this was evident in Ferguson and Walker (2014) and Kelleher et al.'s (2020) studies with young people concealing their illness in specific peer-driven and online settings to accentuate their normalcy. Bowker and Tuffin (2007) indicated that in the online realm this allowed individuals to be seen beyond their condition and in terms of their contribution to society based on their skills, talents and interests or 'subjective selves'. However, Hendry (2020) noted while the online medium allowed young people to control the 'presentation of the self'

(Goffman, 1959), it also created an identity tension through concealment. At other times, Hendry (2020) indicated young people's condition intruded upon the impression of the self they tried to maintain online (Goffman, 1959). Thus, consensus between the various layers of an individual's personal self are not always achieved (Vignoles et al., 2011). Therefore, as Giddens (1991) suggested, the personal self is agentic and reflexive as it actively strives to discover, re-construct and work through identity tensions to maintain identity stability, while being flexible enough to respond situationally and contingently to the affordances and constraints present in the individual's environment (Mead, 1934; Oyserman et al., 2012; Stryker & Burke, 2000; Vignoles et al., 2011).

Interpersonal Identity

However, identities are not only personal but social in nature (Cooley, 1983; James, 1890; Mead, 1934; Oyserman et al., 2012). How one perceives, constructs and negotiates the dimensions of their personal identity intersects with how they are understood, validated or dis-acknowledged interpersonally in various social conversations, positions, roles and contexts (Cooley, 1983; Festinger, 1954; Goffman, 1959; Mead, 1934; Van Langenhove, 1998; Vignoles et al., 2011). Thus, the question 'who am I as an individual?', entails the corollary 'who am I in relation to others?' (James, 1890; Vignoles et al., 2011). This can be considered from a matrix of viewpoints, including the individual's personal perspective encompassing their internal definition of the self in comparison to how they view others, as well as from the reverse angle of how others choose to perceive the individual in relation to them (Code & Zaparyniuk, 2010; Festinger, 1954; James, 1890; Mead, 1934; Van Langenhove, 1998). Cooley (1983) introduced a third dimension, suggesting that individuals not only compare their personal perception of the self—adjusting or dis-regarding it in relation to the positive or negative feedback they receive from the external evaluations of others—but that, embedded within their internal understanding is an imagined dimension of the external perceptions of others towards them, whether this coincides with the individual's existing internal perception of the self, or the actual external perception of 'others' regarding them (Elkind, 1967; Mead, 1934; Oyserman et al., 2012). Nonetheless, all three dimensions have a significant bearing on the individual's personhood, affecting their self-esteem, self-worth and ability to individualise and take action (Cooley, 1983; Festinger, 1954; Rogers, 1959; Tajfel & Turner, 2004). This has relevance for young people living with a condition whose personal definitions of the self are sometimes at odds with how others understand or respond to them interpersonally.

Group or Collective Identity

A third perspective, adding another layer of intricacy, is that an individual's personal and interpersonal understandings of the self at times may be subsumed or negated under an over-arching group identity, namely 'who are we as a collective or social category?' (Lewis, 2012; Vignoles et al., 2011). Collective identity homogenises the self beyond personal definitions into dominant, although not always truthful stereotypes that dilute the heterogeneity between members of the same social space or category through mechanisms, such as deindividuation (Tajfel, 1982; Tajfel & Turner, 2004). This moves us beyond individual or interpersonal understandings of the self that operate in and between group members, to a solely group definition based in and between groups, not individuals. This may be advantageous in some circumstances but disadvantageous in others (Tajfel, 1982; Tajfel & Turner, 2004). However, one's personal understanding of the self may not align with that of the group or social category to which they are assigned (Tajfel, 1982; Tajfel & Turner, 2004). Further, individuals often belong to multiple groups and social categories with different aspects of their personal and collective identities becoming more or less salient in various contexts

(Stryker & Burke, 2000). Thus, the social identity that an individual wishes to present in a particular setting may not be the one others within that space choose to see, once again engendering an identity tension in need of negotiation in the context of one's social interactions and experiences (Goffman, 1959; Stryker & Burke, 2000; Tajfel, 1982; Tajfel & Turner, 2004; Van Langenhove, 1998). This has value in relation to young people living with an illness or disability who are often seen categorically in the identity category of being a patient or in the 'sick role' (Parsons, 1975), rather than in terms of their individuality beyond their condition. It also has relevance for understanding how these collective identities homogenise the group and fail to capture the heterogeneity contained in the 'patient' identity category or 'illness or disability' experience.

Significance

The value of these different perspectives outlined above is they highlight the complexity of a construct as multifaceted as 'identity' (Oyserman et al., 2012; Vignoles et al., 2011). Thus, it is important to re-iterate a few crucial points. First, while identity constitutes a 'self-structure' (Marcia, 1980, p. 159) consisting of content including drives, beliefs, goals, experiences, social relationships, roles, social categories and a life history that maintains continuity across time and space, its polysemic nature also renders it a dynamic, active, ongoing and fluid process, whereby tensions between multiple parts of the self, including one's personal, interpersonal and collective identities are negotiated. Further, the implicit and explicit understandings harboured by individuals in relation to these domains are continually, reflexively and regularly negotiated in the context of individuals' social experiences, environments and relationships (Tajfel, 1982; Tajfel & Turner, 2004; Van Langenhove, 1998; Vignoles et al., 2011). Therefore, the quality, norms and values of one's social relationships and contexts become a crucial background for meaning-making in the construction of the self, potentially engendering promotive or risk-oriented trajectories in response (Mead, 1934). This has important implications for interventions and warrants exploration not only of the content comprising identities, but of the processes, interactions and environments re-shaping these understandings of the self.

Theoretical Framework Overview

The theoretical framework of this thesis in relation to identity is principally underpinned by the seminal works of Erikson (1968, 1994), Mead (1934), Goffman (1959), Turkle (1994, 2011) and Tajfel and Turner (2004). While each of these theorists understands identity as being socio-culturally constructed, the lenses through which they examine this construction differ. In particular, Erikson's (1994) psychosocial model of human development—whereby 'identity formation' constitutes the core psychosocial task of adolescence and emerging adulthood—predominantly conceives identity from the personal and developmental standpoint. The 'identity status' models of Marcia (1966, 1993), Luyckx et al. (2006) and Crocetti (2018) informed by Erikson's (1968, 1994) theory, emphasise identity-forming processes especially in relation to health and wellbeing outcomes. The narrative work of McAdams (2011) conversely highlights identity content. Further, McAdams's (2008, 2011) theory intercepts with the studies of Bury (1982), Charmaz (1983, 1993) and Goffman (2009) on biographical disruption, the loss of a valued self and stigmatised or spoiled identities, respectively. In contrast, Cooley (1992) and Mead (1934) shift the perspective of the self to the interpersonal and interactional. Thus, they extend the scope of McAdams's (2008, 2011) work to not only consider how the individual personally narrates their life story, but to illuminate how these understandings of the self are negotiated, validated, disputed and modified in the context of one's social experiences. Goffman's (1959) work aligns with that of Cooley (1902) and Mead (1934), focusing on the presentation of the self in social and online spaces (Bullingham & Vasconcelos, 2013; Miller, 1995). This connects with Turkle's (1994, 2011) assertion that the internet is a unique platform for the presentation and experimentation of multiple selves. Last, Tajfel and Turner (2004) explore identity from the collective perspective and examine how the presentation and expression of the self, aligns with social categories, such as (a) living with a condition or (b) being a young person that can either enhance or diminish one's self-esteem.

Erikson

Socio-Cultural Construction of Self.

Erikson's (1968, 1994) epigenetic model of psychosocial development across the lifespan asserted that individuals experience eight psychosocial 'crises' in the attainment of a healthy personality. Each crisis is characterised by a bipolar challenge encompassing a promotive and risk-oriented duality—such as trust versus mistrust or industry versus inferiority—that the individual must resolve by confronting both its syntonic and dystonic elements to re-emerge with an 'increased sense of inner unity' (Erikson, 1968, p. 92) in their identity. How one masters each challenge aims to be both a unique expression of the self and a 'successful variant of the groups [approach]' (Erikson, 1994, p. 21) to synthesising that facet of the human personality.

Therefore, Erikson (1968, 1994) employed the term 'crisis' not to connote a threat, disaster or catastrophe (Sokol, 2009), but consistent with the work of developmental psychologists', he used it to suggest a 'sensitive period' (Fuhrmann et al., 2015). Here, both a 'crisis' or 'sensitive period' indicates a 'turning point, a crucial moment when development must move one way or another' (Erikson, 1968, p. 16) marked by heightened potential and vulnerability. This heightened potential and vulnerability is because of the emergence of certain biological and psychological drives at specific life-stages that impel individuals towards decisive encounters with others in their socio-cultural ecology (Erikson, 1968, 1994). These encounters have the potential through their engagement to either facilitate or hinder the acquisition and expression of the psychosocial ability in question, such as trust versus mistrust, in a manner that reflects the individual and the values, models and archetypes salient in their society (Erikson, 1968, 1994). Thus, for Erikson (1994), personal identity encompasses a sense of invigorating 'selfsameness and continuity in time [and space]' (p. 16), recognised by both the individual and others in their socio-cultural milieu. He proposed the term 'ego-identity' as the mechanism through which the individual marries this tension between the self and their social world.

The significance of this is that while Erikson (1968, 1994) understood identity development to be a lifelong project, he argued it assumed special significance during the adolescent and emerging adult years (Sokol, 2009). In particular, his model proposed that 'identity formation' (Erikson, 1968, p. 159) constituted the core psychosocial task of adolescence, whereby individuals relinquished their childhood identifications with the admired traits of significant others—notably parents that they acquired during earlier psychosocial stages—and attempted to re-forge a unique, independent sense of self moving into adulthood. This emphasis on identity re-synthesis during adolescence is attributed to the cascade of biological, cognitive, emotional, social and sexual changes characteristic of this period that impel individuals to re-consider 'who they are', 'who they want to be' and 'what their unique place in the world may be' (Erikson, 1968, 1994; Marcia, 1980; Sokol, 2009). Thus, young people crave creative self-expression, a recognition of their specialness, and diverse social spaces, such as peer groups, work environments and online platforms to experiment, explore, question, discover, negotiate and re-confirm their individuality across various domains, including vocations, relationships, ideologies, worldviews and their sexuality (Erikson, 1994;

Turkle, 2011). If granted this time and space to explore while receiving support for their efforts, young people often re-emerge from this period with a renewed sense of self and inner wellbeing (Erikson, 1994). However, if thwarted in their attempts, they risk 'identity diffusion' (Erikson 1968, p. 159). This sees them retreat towards the identities offered to them by peer cliques, parents or 'risk-oriented' cultures, which may not be a true reflection of the individual and have the potential to engender more deleterious psychosocial outcomes (Erikson, 1968, 1994).

Identity Status Models

Various scholars extended Erikson's (1968, 1994) theoretical insights to further illuminate this association between psychosocial health and adolescent identity formation (e.g. Crocetti, 2018; Luyckx et al., 2006; Marcia, 1966, 1980). Most notably Marcia (1966, 1980) operationalised Erikson's (1968, 1994) theory, arguing while the content of one's identity may change throughout the life-course, the processes by which they make identity decisions remain the same. In particular, Marcia (1966, 1980) suggested that identity formation' is the product of both (a) a crisis period, whereby individuals explore and experiment with a diversity of identity options across multiples domains, also known as 'exploration in breadth' (Luyckx et al., 2006, p. 367), and (b) a commitment-making phase, during which the individual invests and settles on the identity choices most meaningful and true to them. Luyckx et al. (2006) and Crocetti (2018) both extended Marcia's (1966, 1980) model, arguing 'identity formation' is not a single endeavour, but a dynamic, re-iterative process, whereby individuals not only explore identity options 'in breadth' and 'commit' to viable identity decisions, but continue to re-evaluate their current choices in light of their burgeoning talents, abilities and shifting social experiences. Thus, Luyckx et al. (2006) included two additional processes, namely 'exploration in-depth' and 'identification with commitment' (p. 367). These involve the individual re-considering their current identity choices through everyday discussions with friends and family to re-affirm they are still ‘a good fit’ (Crocetti, 2018, p. 12) with their existing and possibly changing internal standards. If this is the case, ‘identity formation’ results; if not, the individual re-cycles through the whole identity exploration process (Luyckx et al., 2006). Crocetti (2018) proposed a more parsimonious ‘three-factor model’ (p. 12) but for the sake of brevity this thesis focuses on the work of Luyckx et al. (2006).

Identity Statuses and Psychosocial Health

The value of these models in the current research is that they not only delineate measureable ‘identity formation’ processes, but also acknowledge that not everyone engages in these processes to the same extent. This gives rise to four identity statuses in the case of Marcia (1966, 1980) and six for Luyckx et al. (2008a), which differentially relate to health and wellbeing outcomes. These are *‘identity achievement’*, *‘identity foreclosure’*, *‘identity moratorium’*, *‘ruminative moratorium’*, *‘carefree diffusion’* and ‘*diffusion diffusion’* (Crocetti, 2018; Luyckx et al., 2008a; Marcia 1966, 1980). *Identity achievers* are individuals who proactively engage in the identity exploration process both in breadth and in depth, and subsequently commit to identity decisions that strongly resonate with who they are (Luyckx et al., 2008a). These individuals demonstrate the greatest synergy between the self and society, and maintain a balance between the need for stability and flexibility in their identity. Therefore, they exhibit the most agency and experience the most positive psychosocial outcomes (Erikson, 1968, 1994; Luyckx et al., 2008a; Marcia, 1966, 1980).

In contrast, individuals in the *identity foreclosure* category invest minimally in their identity exploration process, but nonetheless commit strongly to identity decisions (Luckyx et al., 2008a; Marcia 1966, 1980). However, these decisions are often based on the traditional or accepted views of parents, significant others or dominant discourses in society, and therefore may or may not be a true reflection of the individual's unique goals, visions and talents (Marcia 1966, 1980). Thus, while these identities demonstrate high stability, engendering positive psychosocial health, they also display less flexibility, agency and an external locus of control. This renders their self-esteem and self-concept more dependent on the positive and negative opinions of others (Erikson, 1968, 1994; Luckyx et al., 2008; Marcia, 1966; 1980). In terms of intervention, *identity foreclosure* recognises the importance of providing young people, particularly those living with conditions with opportunities to engage in identity exploration with peers as these opportunities may be limited in their current circumstances (Erikson, 1968, 1994; Luckyx et al., 2008; Marcia, 1966; 1980).

Identity Achievement

In the case of young people living with an illness or disability, *identity synthesis* or *achievement* is postulated to function as a promotive resource assisting these young people with coping and adjusting to the challenges of their condition (Luyckx et al., 2008b; Tsang & Yip, 2006). Thus, practitioners and community advocates aim to provide services that facilitate this development (Luyckx et al., 2011; Luyckx et al., 2008b; Rassart et al., 2012). Scholars such as Gavaghan and Roach (1987) and Verschueren et al. (2017) asserted that young people living with chronic conditions, including Cancer or Eating disorders, respectively, were less likely to fall into the *identity achieved* category; whereas others such as Madan-Swain et al. (2000), Luyckx et al. (2008b) and Rassart et al. (2012) refuted this, suggesting that among young people living with Cancer, Diabetes and Congenital Heart Conditions, the likelihood of achieving *identity synthesis* was equally as high as their healthy counterparts, thus attesting to their incredible resiliency. Nonetheless, these latter scholars also acknowledged that despite this, these individuals more frequently fell into the *identity foreclosed* category (Luyckx et al., 2011; Luyckx et al., 2009; Madan-Swain et al., 2000; Rassart et al., 2012).

Identity Foreclosure

Similar to *identity achievement*, *identity foreclosure* appears to function as a protective resource for young people living with an illness or disability by aiding them in coping with the challenges of their condition, and mitigating against the ambiguity and uncertainty accompanying it. This includes a fear of death and the possibility of having one's life inhibited in a myriad of ways in contrast to 'healthy peers'. The latter has greater relevance during a developmental period, where immense change may exacerbate the destabilising impact of a chronic condition. Conversely, a chronic condition may simultaneously inhibit the energy and resources available for developmental tasks, including identity exploration (Luyckx et al., 2011; Luyckx et al., 2008b; Madan-Swain et al., 2000; Phipps & Srivastava, 1997; Phipps et al., 2001; Sawyer et al., 2007; Stern et al., 1991). This is evidenced by Madan-Swain et al. (2000), who indicated that *identity foreclosure* significantly relates to the severity of disease symptoms and the likelihood of individuals experiencing Post-Traumatic Stress and Anxiety as a result. Further, *identity foreclosure* was associated with family conflict and parenting styles characterised by greater rules and restrictions (Madan-Swain et al., 2000). This was proposed to assist parents in coping with their child's diagnosis, but in a manner that possibly impinges on the young person's identity and social development through over-protection (Madan-Swain et al., 2000).

Therefore, the value of *identity foreclosure*, in contrast to *identity achievement*, appears mixed. While it may foster stability, strength, a sense of control and normalcy during trying times by maintaining existing identifications, parental ideals or dominant discourses, others suggest it may do so in a way that foregrounds the individual's condition, rather than the individual, depending on the norms salient within their socio-cultural ecology (Luyckx et al., 2011; Luyckx et al., 2008b; Madan-Swain et al., 2000; Phipps & Srivastava, 1997; Phipps et al., 2001; Sawyer et al., 2007; Stern et al., 1991). Further, Rassart et al. (2012) asserted this has the potential to engender (a) over-identification with one's condition while overshadowing the expression of their 'true' personal self, and (b) concealment which celebrates the individual while undermining the needs of one's condition. This is significant as Luyckx et al. (2008b) noted in their study that despite *identity foreclosure* being dominant among emerging adults with Diabetes, those who did engage more proactively in identity exploration to attain *identity achievement* were better able to integrate their condition into their overall sense of self, rather than keeping the two sequestered. This integration facilitated greater illness management. Rassart et al. (2012) concurred, highlighting that the quality of one's peer relationships enhanced the identity exploration process and the positive psychosocial outcomes associated with it.

Identity Moratorium

Thus, *identity moratorium* becomes a significant phase in the 'identity formation' experience as it represents individuals currently engaged in identity exploration, who are yet to commit to any solid identity options (Luckyx et al., 2008a; Marcia, 1966, 1980). However, as seen with *identity foreclosure*, Luyckx et al. (2008a) noted that individuals in this category also presented with mixed psychosocial outcomes. While some appeared to move through this active exploration period displaying a keen sense of openness, curiosity, adaptive risk-taking, enhanced perspective-taking and a strong engagement in novel relationships that facilitated the progression to an *achieved identity*, others became marred by heightened Anxiety, Depression and excessive worry that impeded this progress (Luyckx et al., 2008a). Thus, Luyckx et al. (2008a) further delineated between two distinct exploratory styles engendering different moratorium statuses, namely (a) *reflective moratorium* and (b) *ruminative* *moratorium.* The reflective exploration and *reflective moratorium* status involves exploration both ‘in breadth’ and ‘in depth’, and represents individuals positively experimenting with their identity choices, utilising their high flexibility to move towards greater stability and agency (Luyckx et al., 2008a). In contrast, *ruminative moratorium* characterised by ruminative exploration reflects individuals who are engaged in a maladaptive exploratory style characterised by excessive, repetitive and passive re-consideration of the same identity questions that sees these individuals becoming stuck in the exploration process, resulting in their flexibility undermining their stability and agency. This leads them towards *identity dissolution* or *diffusion*, rather than *achievement* (Luyckx et al., 2008a).

Identity Diffusion

With respect to *identity diffusion*, which in Erikson’s (1968, 1994) original postulation indicated an individual who invested minimally if at all in any identity exploration process and exhibited little to no commitment, Luckyx et al. (2008a) further classified this into two additional statuses: (a) *carefree diffusion* and (d) *diffusion diffusion*. *Carefree diffusion* reflects an individual scoring low on all identity measures, but remaining un-phased by their lack of engagement (Luyckx et al., 2008a). Some scholars speculated this may be a defence mechanism buffering against the negative feelings of possessing an unsure sense of self (Luyckx et al., 2008a). In contrast*, diffusion diffusion* represented an individual scoring low on both exploration and commitment, but interestingly high on ruminative exploration (Luyckx et al., 2008). Thus, these individuals experience the most deleterious psychosocial outcomes, possessing a highly unstable self, lower agency, poorer self-esteem and an external locus of control, which renders them more vulnerable to risky peer or societal influence (Marcia, 1966, 1980).

The findings of research among young people living with a chronic illness or disability echoed these findings (Luyckx et al., 2011; Morsunbul, 2013; Verschueren et al., 2017). Scholars noted that these individuals more frequently fell into the *identity foreclosure* category, and to a lesser extent the *carefree diffusion* category, the latter of which also appeared to be somewhat protective in assisting these individuals in buffering against the lack of identity development due to the challenges of one's condition limiting their opportunities in this area. Others with chronic conditions who did engage in ruminative exploration—subsequently falling into either the *ruminative moratorium* or *diffusion diffusion* category—displayed the highest distress, lowest quality of life, poorest treatment adherence, greatest likelihood of comorbid conditions including Anxiety, Depression and emotional problems, and were least likely to reach out, communicate, and maintain contact with medical professionals and support services (Luyckx et al., 2011; Verschueren et al., 2017). With both ruminative exploration and low identity commitment being recognised as risk factors engendering negative psychosocial outcomes and health trajectories, two important questions emerge, namely (a) why do some individuals progress through the 'identity forming' process more successfully than others?, and (b) how can we assist those who are struggling? (Luyckx et al., 2009).

The Role of Internal Assets and Environmental Resources

Here, the quality of one's socio-cultural ecology and the norms embedded within it are paramount. In particular, Luyckx et al. (2009) and Morsunbul (2013) demonstrated that 'needs satisfaction'—encompassing (a) autonomy, defined as the 'need to experience choice in the initiation, maintenance, and regulation of behaviour' (Luyckx et al., 2009, p. 278); (b) agency, understood as the desire to take responsibility for one's life direction and decisions (Morsunbul, 2013); (c) competence, referred to as the drive to succeed at challenging tasks and attain desired results; and (d) social relatedness understood as the will to 'establish mutual respect and connectedness among significant others' (Luyckx et al., 2009, p. 278)—was a vital support as it was positively associated with reflective exploration, identification with commitment, quality of life and positive identity progression over time. Verschueren et al. (2017) found 'needs satisfaction' to be the lowest among those in the *ruminative moratorium*, *diffusion diffusion* and an additional *disordered identity* categories. Thus, in terms of intervention, Luyckx et al. (2009) stressed the importance of providing young people with environments that amplify their internal and external assets as these can have a facilitative effect on their identity formation and overall health. This aligns with Côté's (1997) work on identity capital, which suggested that environments providing young people with a 'goodness of fit' (Crocetti, 2018, p. 12) in terms of their unique skills, talents and potentials have the capacity to have compensation and acceleration effects on their identity development that can make up for past developmental lags or psychosocial challenges. This reflects socio-ecological, resilience and positive youth development frameworks (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Fergus & Zimmerman, 2005; Lerner et al., 2005). However, the literature exploring the impact of interventions on identity forming processes among young people living with a condition is limited.

Neo-Erikson Literature Gaps

A review of the Neo-Eriksonian literature exploring identity formation among young people living with a condition allows for some important points to be made. First, few studies have explored identity formation processes and statuses specifically among young people living with a condition. Among these studies, inconsistent results have been reported, with some scholars suggesting young people living with conditions move through the identity forming process as adeptly as their peers, while others acknowledge challenges in this regard indicating intervention could help.

Further, the majority of studies have explored identity formation among young people living with a condition as a global measure, rather than in relation to specific identity domains or contexts such as school, relationships or careers. This is significant as a study by Dominiak-Kochanek (2016) demonstrated that young people living with a motor disability displayed differential degrees of identity formation, exploration and commitment across multiple domains, including school, peer and parental relationships. Moreover, Schwartz et al. (2015) suggested that identity domain measures provide a more accurate reflection of young people's identity formation than do global measures, and have greater relevance for designing interventions to support young people living with a condition in areas were their identity development is challenged.

Similarly, no studies have explored identity formation, exploration or commitment in relation to the experience of living with a condition as an identity domain or category in its own right like ethnic or gender identity (Syed & Azmitia, 2008; Syed et al., 2013); rather the impact of a young person's condition on their identity formation has been explored as an outcome variable such as a coping strategy (Luyckx et al., 2008b). Oris et al. (2018) devised an alternative measure titled the *Illness Identity Questionnaire* to explore the degree to which a young person's condition defines or dominates their identity through categories such as engulfment, rejection, acceptance and enrichment. However, this instrument does not measure young people's identity formation in relation to their wider sense of self alongside their condition-based selves. Exploring both facets of the self is important for facilitating integration between them, particularly with respect to interventions. This demonstrates the existence of a gap in the literature.

However, despite disparities in the limited literature exploring identity formation in relation to young people living with a condition, a consistent finding among all studies is that these young people exhibit less identity exploration in breadth and in depth than their healthy peers overall. This is significant as Luyckx et al. (2008b) indicated that increasing young people's identity exploration processes enhances both condition coping and the integration of their condition into their wider sense of self. Moreover, Raymaekers et al. (2017) and Rassart et al. (2012) highlighted that peers are a valuable resource in facilitating this exploration process. However, Rassart et al. (2012) noted that the ways in which peers support identity formation, such as through peer validation and norms, have been under-researched and under-conceptualised, and therefore constitute a significant gap in the literature. Similarly, Côté (1997) suggested that providing young people with a 'goodness of fit' with their environment enhances the identity forming processes. However, beyond studies exploring 'needs satisfaction' (Morsunbul, 2013) —as internal and external assets and resources and antecedent factors such as parenting style (Madan-Swain et al., 2000; Raymaekers et al., 2020) influencing identity formation—no study has explored this in terms of interventions designed to support young people's identity development in relation to their condition, particularly the culture and norms operating within these interventions.

The Value of Meaning and Socio-Cultural Norms in the Construction of Self

Thus, it becomes important to highlight how Côté (1997) and Côté and Schwartz's (2002) concept of a 'goodness of fit' involves not only assets and resources as outcome variables, but also the culture and norms operating within young people's social environments, and how these are internalised by young people either positively or negatively through meaning and meaning-making practices (McAdams, 2008b, 2011; McLean & Syed, 2015). This requires us to not only understand the mechanisms or processes of identity formation as is common in identity status literature (Erikson, 1968, 1994; Luyckx et al., 2008a; Marcia, 1966, 1980), but also the content of identity formation, particularly how this identity content relates to the values, meanings, narratives and discourses salient within young people's socio-cultural milieu (McLean & Syed, 2015). This is significant in relation to young people living with a condition as the literature suggests young people's understanding of the self, particularly in terms of their condition are often constrained by biomedical discourses of illness and disability permeating not only medical contexts, but also public perception more broadly. The latter was evident within Angulo-Jiménez and DeThorne's (2019) study examining Autism narratives through Youtube videos online, and how individual's defined the self and the Autism experience in terms of medical or neurodiversity paradigms. This included contrasts in the expression of the self in terms of deficit or difference respectively.

Thus, to understand identity formation in terms of identity content, and how this connects with wider discourses in society, the work of McAdams (2008, 2011; 2013) on narrative identity becomes informative. McAdams (2011) conceived identity as 'an internalised and evolving story of the self' (Schwartz et al., 2011, p. 99) constructed by individuals during adolescence and adulthood to give meaning to their (a) past (where they come from); (b) present (where they are); and (c) future (where they aim to be and how they intend to fit into the world). Consequently, narrative identity organises the self in time, space and culture. It gives young people a sense of unity, directedness and purposefulness to their identity, goals, visions and action, as well as other's perceptions of them. (McAdams, 2008a, 2011; McAdams & McLean, 2013). However, narrative identity as a construct doesn't always correspond to literal, historical truth, but rather narrative fidelity on the part of the story-teller (McAdams, 2008a, 2011; McAdams & McLean, 2013). Consequently, narrative identity highlights the young person's voice as agent, actor and author in the construction and re-construction of the self (McAdams, 2011). This is significant because while narrative identity scholarship acknowledges young people's life narratives and autobiographic stories (Habermas & Bluck, 2000) are the product of macro (McLean & Syed, 2015) and micro discourses (Pasupathi & Hoyt, 2009), this literature predominantly explores identity in terms of the individual's definition of the situation in relation to the shifting plot-lines, settings, characters, themes and discourses constituting their everyday experience. Consequently, Pasupathi and Hoyt (2009) and McLean and Syed (2015) argued there is a need within narrative identity scholarship for studies to explore how interpersonal dynamics and cultures within contexts or interventions impact young people's identity formation. This gap will be discussed below.

However, first, narrative identity studies involving young people living with an illness and disability often emphasis the intrusive and disruptive nature of their condition upon the understanding of the self. Bury (1982) asserted the illness and disability experience constitutes a "biographical disruption" (p. 167) to the meaningful structures, routines, goals and relationships of an individual's life and their identity. This was evident in Woodgate's (2005) study that explored the impact of the cancer experience upon young people. Woodgate (2005) asserted the cancer experience created new "ways of being in the world" (p. 4) that resulted in young people aligning with identities, such as the klutz and alien to capture how their condition rendered their bodies "unruly and unreliable" (Woodgate 2005, p. 5) or foreign to them and their pre-illness self. This was because of symptoms, such as trembling hands, puffy faces, weight loss and extreme tiredness (Woodgate 2005). Gibson et al.'s

(2016) echoed these findings in their study exploring young people's cancer narratives through video diaries posted to the JTV Cancer Support private online community. Similarly, Modica et al. (2018) outlined the intrusive impact of Systemic Juvenile Idiopathic Arthritis (SJIA) upon young people's understanding of the self through their exploration of condition based posts on Facebook, Instagram, Tumblr and Twitter. Gibson et al. (2016) and Iannarino (2018a) noted how the illness experience disrupted young people's social relationships, education and future goals. Pereira et al. (2020) alluded to how the illness experience impeded young people's ability to achieve developmental milestones. In Woodgate's (2005) study, the prisoner identity captured how the Cancer experience inhibited young people from gaining independence during a critical life-stage, and engaging in social contexts, such as school due to being trapped in the hospital. Gibson et al. (2016) also acknowledged how the hospital experience impeded upon 'normal life'.

Further, Charmaz (1983) highlighted how the disruptive nature of the illness and disability experience to an individuals' life story or biography often engendered a "loss of a valued self" (p. 168) without "equally valued new [selves]" (Charmaz, 1983, p. 168) to replace it. This was evident within Woodgate's study with young people idealising their pre-illness self. Similarly, Polidano et al. (2020) noted in their exploration of young people's narratives who were living with Inflammatory Bowel Disease, how the disruptive nature of the condition inhibited these individuals from realising hobby and career goals. This was evident with one participant stating her condition put her dream of being a paramedic on hold. For Angulo-Jiménez and DeThorne (2019), the loss of a valued self, alluded to the loss of selves valued by society. This related to how young people living with Autism became overly defined by their condition and dis-empowered identities connected to their condition, because of the dominance of biomedical discourse, rather than neuro-diversity paradigms influencing public perception of Autism. Similarly, within Lau & Van Niekerk's (2011) study exploring the narratives of young burn victims, they noted how young people lost a valued sense of self because of others perceiving them as a victim, sub-human and deficient, which had a deleterious impact on their psychosocial and mental health.

In all these instances, biographical disruption (Bury 1982) and loss of valued selves (Charmaz 1983) resulted in the illness or disability experience and its associated identities challenging young people's understandings of what constitutes 'normal' and what society conceives as normal. Thus, this literature recognises that the illness and disability experiences often causes these young people to stand out or become visible in a manner that does not fit social and peer norms. This can be dis-heartening for young people during a critical time in their identity exploration and development. However, it also recognises the importance of creating opportunities for young people to go beyond definitions of the self connected to their condition to express their true self; to be seen as 'normal'; and to foreground who they were as individuals or young people beyond their condition (Lau & Van Niekerk, 2011; Woodgate, 2005). Gibson et al. (2016) highlighted how celebrating young people's, 'young person' self beyond their condition alongside illness and disability concerns was an important strategy, but failed to illuminate this expression of the self in their study online as they focused on the illness experience. Angulo-Jiménez and DeThorne (2019) and Hammond and Teucher (2017) similarly indicated creating positive representation of illness and disability identities was an valuable tactical approach.

Thus, an important dimension of narrative identity scholarship is this re-storying of the self in relation to the illness and disability experience. In this literature, redemption narratives that involve young people creating positive meaning from the illness and disability experience are proposed to facilitate positive re-adjustment to their condition and facilitate the reclaiming of valued selves (McAdams & McLean, 2013). This is similar to *identity achievement*. In contrast, tragic narratives that fail to understand the illness and disability experience beyond its disruptive effects are demonstrated to be disempowering in this process (McAdams & McLean, 2013). Tragic narratives often connect with ruminative exploration and its associated identity statuses. Central to how young people narrate the self are turning points (Marin & Shkreli, 2019). However, turning points appear to be affected by condition factors, such the experience of a highly intrusive, severe or visible condition that renders the re-storying process more difficult, particularly because these conditions do not follow a linear trajectory to recovery due to their intermittent nature (Hammond & Teucher, 2017; Iannarino, 2018b; Kelleher et al., 2020; Marin & Shkreli, 2019; Woodgate, 2005).

Alongside condition factors, Adler et al. (2021) outlined how young people's re-storying of the self also impacted the degree to which they integrated the illness or disability experience into their wider sense of self. In this regard, Adler et al. (2021) highlighted four identities—*adapter, wanderer, drifter and resistor*—that coincide with Marcia's *achieved, moratorium, diffusion and foreclosed identity* statuses. Similarly, Marin and Shkreli (2019) explored how identity statuses and reflective and ruminative exploration processes impacted the ability of individuals to derive meaning from tragic experiences through self-event relations. They also explored the level of identity integration achieved and the psychosocial distress experienced. However, few studies have combined an understanding of (a) identity statuses, exploration and commitment processes with (b) narrative or meaning-making. Further investigation in this area is essential for understanding the meaning young people attribute to their condition-based identities and how they integrate this understanding of the self into their wider identity as a young person through meaning-making and exploration processes. This is pertinent considering Luyckx et al. (2008b) acknowledged that integrating one's condition into their wider sense of self facilitates illness coping, positive psychosocial and mental health, and promotive identity formation.

Alongside integrating one's condition into their wider sense of self another important element to the re-storying process is how young people use this to reclaim positive or empowered identities related to their conditions, not just their young person self, such as the survivor, fighter and battler. This was evident in Angulo-Jiménez and De Thorne's (2019) study celebrating neurodiversity with respect to Autism. It was also present in Hammond's et al.'s (2015) study, where the 'trickster' identity created an empowered understanding of the self among young people. The trickster identity captured the biographical disruption (Bury 1982) of the Cancer experience, but also created new possibilities and ways of being that had strengths beyond traditional understandings of normal related to young people's conditions. Thus, Hammond's et al.'s (2015) work challenged accepted understandings of illness and disability identities, and alluded to how young people utilise narrative identities to create meaning from their experience that defies norms. This is particularly the case when there is a lack of nomenclature or existing representations to express the self (Hammond et al., 2015).

Further, Hammond and Teucher (2017) extended on their earlier work to illuminate—in an additional study with young people living with Cancer—how young people not only created subversive identities, such as the 'trickster' identity, but also developed subversive understandings of traditional condition-based narrative identities. This included the 'survivor identity' (Mullan, 1985). The survivor identity is often celebrated as an empowered identity in resistance to biomedical understandings of the self. However, Hammond and Teucher (2017) illuminated how the survivor identity is not always understood in this manner by young people. In their study, young people had a contentious relationship with the survivor identity. This included (a) feeling that it was one part of their journey; (b) that it underlined that the cancer experience was never over; and (c) that they potentially lacked the legitimacy to earn the survivor title (Hammond & Teucher, 2017).

A similar contention appears to exist around the 'supercrip' identity in the disability literature (Schalk, 2016; Silva & Howe, 2012). The supercrip identity has been associated with individuals who defy their impairment to live an ordinary life (Silve & Howe, 2012) or perform extraordinary feats beyond what healthy individuals may achieve, such as Paralympians (Schalk, 2016). Core criticisms connected to the supercrip identity and its associated discourse, are it undermines the social causes of disability, such as dis-enabling attitudes and perceptions, and therefore reinforces biomedical understanding of disability by emphasising exceptionalism, particularly in media representations of disability (Schalk, 2016; Silva & Howe, 2012). Further, this is seen to disempower realistic or everyday representations of disability that are often missing from mainstream discourse and scholarship (Schalk, 2016; Silva & Howe, 2012).

Thus, in relation to issues connected to the 'survivor' and 'supercrip' identity, Hammond and Teucher (2017) argued the need for scholarship and practice to explore how young people in particular express their identity in relation to the illness and disability experience utilising alternative identities, such as the diva and ninja not only to amplify the representations of illness or disability—particularly strengths-based or empowered condition identities—but also to enhance therapeutic rapport and relationships with young people. This also strives to enhance the developmental appropriateness of clinical and community services. However, the literature exploring how young people narrate the self in relation to their condition on their own terms is sparse and fragmented.

Moreover, while narrative identity focuses on the meanings individuals personally assign to the self, symbolic interactionists acknowledge that these understandings arise and are subsequently re-affirmed, negotiated, explored, modified and contested in the context of one's social experiences and interactions (Blumer, 1986; McAdams, 2008a, 2011; McAdams & McLean, 2013; Mead, 1934). Thus, these scholars view the construction of the self and one's personal narrative not as a monologue, but a dialogue continually re-shaped, reviewed, edited and re-considered through engaging interpersonally with others in everyday discourse (Blumer, 1986; Mead, 1934). Therefore, symbolic interactionists conceive the self in 'action' and 'interaction', and therefore as being inherently social in nature (Blumer, 1986; Mead, 1934). Cooley (1983) conceived individuals as viewing the self through a 'looking glass' (Cooley, 1983, p. 185) containing three key elements: (a) how we imagine we appear to others; (b) the judgement we imagine others have in relation to this appearance; and (c) the feelings of pride, shame or happiness elicited in response. Similarly, symbolic interactionists view individuals as engaging, understanding and acting towards things—including people, places, situations, ideas, social categories, experiences and most notably the self—based on the meanings attributed to these objects through the process of symbolic interaction and interpretation (Blumer, 1986; Mead, 1934). Symbolic interactionism involves the use of significant signs, gestures, speech acts and language to indicate meaning to others, by evoking the same response or understanding in them (Blumer, 1986; Mead, 1934). If there is consensus shared meaning results, if not re-negotiation occurs (Blumer, 1986; Mead, 1934).

Symbolic interaction's emphasis on meaning in negotiation with others renders it a valuable approach for exploring identity formation and negotiation online (Blumer, 1986; Mead, 1934). Nonetheless, in relation to online platforms, most studies have explored the self in terms of Goffman's (1959) 'presentation of the self' and narrative identity in online blogs. Less emphasis has been placed on the interactive nature of identity exploration, experimentation and formation online. This is significant as the online medium is a valuable platform to explore these negotiation and validation processes on an everyday and long-term basis. Moreover, this has merit for examining the revision or re-storying of the self in relation to peer's feedback online, and in illuminating the role peers play in the identity formation and integration process of young people living with a condition (Rassart et al., 2012).

Studies such as Angulo-Jiménez and DeThorne (2019) and Gibson et al. (2016) make an attempt to address how the norms of online platforms, particularly condition based communities, create safe spaces to discuss illness and disability concerns and empowered or subversive identities, but do not delve greatly into the role of interactional dynamics or how functional features, such as likes and comments on social media platforms impact identity construction. Stage et al. (2020) explored how young people's presentation of the Cancer experience on social media platforms focused on presenting 'vital' or positive representations of their condition experience to accord with the 'inspirational' or 'positive' norms of social media platforms, and is one of the few studies exploring how likes from peers online influenced the content expressed. Kelleher et al. (2020) and Modica et al. (2018) examined how norms on social media platforms resulted in young people concealing their condition online to avoid negative reactions. While Mazanderani et al. (2012) highlighted identity tensions related to the norms of condition based communities impacting help-seeking and engagement through over-identification with one's condition online. Gibson and Trnka

(2020) and Modica et al. (2018) explored how young people appropriated social media practices, such as hast-tags, private messages and comments to create communities of support around conditions related to mental health conditions and Systemic Juvenile Idiopathic Arthritis/ Still's disease respectively. However, more research in this area is needed.

In addition, another important feature of the online medium is that it can illuminate how young people forge identities around what Tajfel (1982) and Tajfel and Turner (2004) termed social identity categories, including condition-based identities and their young person self. This is because online communities create spaces for what Goffman (2009) termed stigmatised or spoiled identities. They provide safe havens for young people living with a condition to connect with others in a similar position. Consequently, online communities have been demonstrated to provide valuable sources of information, emotional and tangible support (Gibson & Trnka, 2020; Kelleher et al., 2020; Salminen et al., 2019). However, as noted in the *Developmentally Appropriate Interventions* section in Chapter 2, young people's engagement with these communities is also marred by the identity tension of condition over-identification and negative identification (Mazanderani et al., 2012). Foregrounding both empowered understandings of condition-based identities and young people's wider sense of self is demonstrated in the literature to be an effective strategy for mitigating condition over-identification and negative identification online. However, while the literature explores the expression of condition-based identities in these online communities, few studies have explored how young people concurrently express their 'young person selves' in these contexts, and how they integrate this with their condition online.

Narrative Identity Literature Gaps

Having reviewed the literature exploring narrative identity among young people living with a condition, several points can be made. First, similarly to the Neo-Eriksonian 'identity status' literature (Erikson, 1968, 1994; Luyckx et al., 2008a; Marcia, 1966, 1980) mentioned above, a limited number of studies have explored narrative identities among young people living with a condition; the majority of studies have focused on adult populations. In addition, few studies have explored narrative identity in relation to the diversity of conditions among young people. This is significant as not all conditions follow similar trajectories. Therefore, concepts such as 'biographical disruption' (Bury, 1982) and 'loss of a valued self' (Charmaz, 1983) may have different degrees of relevance. This is evident in studies that have focused on the impact of the Cancer experience on young people's narrative identity revealing that a loss of a valued self means the loss of selves connected to young people's pre-illness identity (Woodgate, 2005). Conversely, studies on young people living with Autism have connected a loss of a valued self from the perspective of society with the visibility of their condition leading to their whole self being seen in terms of a disempowered, medicalised identity (Angulo-Jiménez & DeThorne, 2019). Thus, the nuances of how different conditions affect meanings is important.

Of greater value for this study is the majority of studies that have explored narrative identity among young people living with a condition have primarily done so by utilising life story interviews (Adler et al., 2021; Hammond & Teucher, 2017; Iannarino, 2018a, 2018b; Woodgate, 2005). Few studies have examined narrative identity in relation to social media platforms and online communities, despite the potential of this medium for identity presentation and experimentation (Gibson et al., 2016; Gibson & Trnka, 2020; Modica et al., 2018; Pereira et al., 2020; Stage et al., 2020). Similarly, among studies that have explored narrative identity in relation to social media platforms and online communities, the majority focused on illness blogs or videos (Angulo-Jiménez & DeThorne, 2019; Pereira et al., 2020) that examined the self from the personal perspective, rather than in relation to the interactional dynamics of online platforms, such as likes and comments (Gibson et al., 2016; Gibson & Trnka, 2020; Modica et al., 2018; Stage et al., 2020). This is significant because the literature fails to capture how processes of peer validation impact young people's understanding of the self online. This has implications for designing interventions. Similarly, while some studies have explored how cultures such as biomedical discourses influence young people's narration of the self in terms of their condition (Angulo-Jiménez & DeThorne, 2019), few have explored how cultures embedded within social media platforms and online community interventions impact young people's identity construction (Modica et al., 2018; Stage et al., 2020). Last, among studies that have explored young people's narration on the self online, the predominant focus was on examining young people's identity in relation to their condition. In contrast, the literature places little emphasis on how they narrate their young person self in tandem, which has implications for fostering integration in relation of both facets of the self online.

Thus, to broadly address these concerns, this study endeavours to answer the following research question:

> How do young people construct their identity in relation to their condition and their wider sense of self within the LW.org.au online community?

Research Questions for the Study

In summary, Chapter 2 identified gaps in the literature in relation to understanding and operationalising the construct of developmental appropriateness within the clinical and community sector, particularly with respect to designing and evaluating interventions for young people living with a condition. It alluded to the dominance of prevention-based approaches that focus on how interventions support young people's development in relation to their condition. It argued for the need to explore interventions through promotion-based approaches to enhance help-seeking and engagement behaviour and the legitimacy of the community sector. It also highlighted the absence of young people's and practitioners' perspectives within scholarship.

To address this absence, this study aims to answer the research question:

> How does the Starlight Children's Foundation's online community LW.org.au function as a developmental, psychosocial intervention for young people living with a condition from the perspective of the organisation, practitioners and young people?

Chapter 3 outlined gaps in relation to the diverse strands of identity literature to illuminate the limited number of studies exploring identity formation among young people living with a condition in relation to a range of conditions. It also illuminated the lack of studies exploring the expression of young people's identity in terms of their condition and their wider sense of self. This has implications for understanding the mechanisms involved in identity integration. In addition, it highlights the lack of studies exploring how identity construction online is influenced by interactional dynamics and validation processes with peers, and the culture of interventions.

Thus, this study aims to address the following research question:

> How do young people construct their identity in relation to their condition and their wider sense of self within the LW.org.au online community?

Chapter Summary and Conclusion

In conclusion, this chapter has outlined the theoretical framework and literature informing the study's socio-cultural understanding of identity. It began by highlighting the complexity of identity as a construct that can be viewed from the personal, interpersonal and collective perspective, and then outlined Erikson's (1968, 1994) theory of psychosocial development across the lifespan to illuminate how identity formation comprises the core psychosocial task of adolescence and emerging adulthood. It reviewed the Neo-Eriksonian 'identity status' literature to examine identity formation in relation to the processes of exploration and commitment, and how these impacted the psychosocial health and condition outcomes of young people living with a condition. It identified two significant gaps in the limited literature, including (a) studies examining the illness and disability experience as an identity domain, and (b) studies conceptualising pathways and mechanism through which promotive assets and resources enhance identity forming processes in intervention contexts.

The chapter also reviewed McAdams's (2008b, 2011) concept of narrative identity to illuminate how a 'goodness of fit' encompasses the dominant cultures and norms circulating in young people's environments, and the influence of this on their construction of the self through meaning and meaning-making practices. It identified a gap in the narrative literature around exploring the construction of identity in interactional contexts such as social media platforms, and the norms and cultures operating in intervention settings. It consolidated these gaps into a single research question related to identity development by young people living with a condition.

The chapter concluded by bringing together the two research questions developed here to address gaps in the literature related to the concepts of developmental appropriateness and identity development by young people living with a condition.

Chapter 4 Introducing LW.org.au

This chapter introduces the SCF's online community LW.org.au. It outlines the purpose of the online community and its integration with the SCF's Livewire hospital program.

Profile of Livewire.org.au

This research examines the SCF's social media site, LW.org.au. LW.org.au is a secure, actively moderated peer support network and online community designed specifically for young people living with an illness or disability between the ages 12-20 years (Third et al., 2013; Third & Richardson, 2010). Originally designed by the SCF in 2008 as part of the Australian Government's 'Clever Networks Program' the online community operates alongside Livewire's hospital program (Third & Richardson, 2010). The hospital program was implemented by the organisation in 2012 to deliver diversional therapy and creative skills workshops to young people across six paediatric hospitals in Australia (Third & Richardson, 2010). Livewire's online community (LW.org.au) complements the hospital service by providing a fully functioning social media site for young people living with a condition to connect with others in a similar position, including young people they've met on the wards and in workshops as part of the hospital service, as well as those in other hospitals (Third & Richardson, 2010). Synergy is maintained between the online community and hospital service with each Livewire hospital program possessing a group page on the site. Here, Livewire facilitators post status updates about workshops, events and competitions in the hospital, and upload videos of various activities for young people to participate in and comment on from their beds at home or in the wards. However, while the SCF greatly endeavours to ensure integration between both the online and offline services, due to the constraints of scope this project predominantly focuses on Livewire's online community (LW.org.au), while remaining mindful of its connection and linkage to the hospital program.

In 2017, the LW.org.au online community underwent re-development to ensure the site's design and functionality remained responsive to trends emerging within the rapidly changing digital and social media landscape. The SCF's intention for the re-design was to ensure the online community continued to appeal and cater to the evolving e-needs of this vulnerable population. Insights from LW.org.au's youth members were included in the re-design through online focus groups, online interviews and member prototype testing. In November 2017, the newly designed and developed LW.org.au online community was officially launched with enhanced features, including:

a) An online chat-room heralded the 'hero' of the site (Third & Richardson 2010). The chat-room is open between 12pm-12am, 7 days a week and provides young people the opportunity to engage in conversations with LW.org.au chat-hosts and members in both a public chat-room that is visible to everyone, as well as through a private message function for one-to-one personal or special group conversations. All conversations and activity in the chat-room, including private messages, are actively monitored and moderated by LW.org.au chat-hosts who are employed and trained by the SCF;
b) Profile pages for all LW.org.au members, chat-hosts and hospital programs. Profile pages allow individuals to upload a profile and cover photo. They also allow individuals to post status updates in the form of text, images, videos or blogs. These status updates appear on both the individual's profile page, and the public newsfeed. All status updates have 'liking' and 'commenting' functionality, so peers can interact and support each other's content;
c) A public newsfeed, which is similar in design to Facebook. The newsfeed collates all posts to a common homepage. It includes all profile photos, cover photos and status

updates made by members, chat-hosts and Livewire hospital teams. It also includes recently posted articles, competitions and events;

d) An articles section with content written and posted by LW.org.au's members and chat-hosts across topics as diverse as health, well-being, sport, comedy, and art;
e) Online interest and illness/disability groups;
f) Competitions and games;
g) A private messenger function that operates alongside and outside chat-room hours.

LW.org.au Membership

In terms of membership, LW.org.au supports young people living with a diversity of medical conditions, including those with a diagnosis of Anorexia Nervosa, Anxiety, Aspergers, Autism, Bulimia Nervosa, Cancer, Cerebral Palsy, Cystic Fibrosis, Depression, Diabetes, Dissociative Disorder, and Spina Bifida to name a few. Members are recruited from four main sources, including: (a) Livewire's hospital program; (b) outreach initiatives by the SCF to other youth illness and disability advocacy groups; (c) by referral from hospital staff or play therapists; and (d) via the internet sign up page. All members undergo a rigorous sign up procedure, including obtaining parental consent and a three point identity authentication process (Third & Richardson, 2010). Moreover, the online community is password protected and possesses clear privacy guidelines to ensure the anonymity of all members is maintained. Young people are guided to choose usernames that do not disclose their 'real' offline identity. If under 18 years, they require parental consent and approval from LW.org.au's chat-hosts to share personally identifying information, such as their full name, phone number, email, or contact details for other social media networks through a private message on the site (Third et al., 2013). All activity on LW.org.au is monitored by 'chat-hosts' trained by the SCF in adolescent, health, well-being, development and child protection (Third et al., 2013). These individuals perform a ‘big brother’ or ‘big sister’ mentor role on the site, actively engaging and guiding young people’s conversations, managing disagreements, implementing behavioural management, screening mental health concerns, writing creative content, and approving links to other sources on the web (Third et al., 2013).

Addressing a Practice Gap

Livewire’s online community (LW.org.au) and hospital program arose in response to a growing awareness among adolescent healthcare professionals and the SCF of the need to provide young people living with an illness or disability between the ages of 12-21 years with interventions that cater to their unique developmental and psychosocial needs distinct from paediatrics and adulthood and in addition to their clinical care (D'agostino et al., 2011; Patton et al., 2016; Sawyer et al., 2016; Steinbeck et al., 2014). These interventions sought to demonstrate a sensitive understanding and attentiveness to addressing the inter-related socio-emotional, socio-cognitive and physiological changes of adolescence and emerging adulthood (Arnett, 2000; Blakemore & Mills, 2014; Crone & Dahl, 2012; Patton et al., 2016; Piekarski et al., 2017). These interventions recognise that these inter-related changes result in these individuals possessing a heightened need to engage in peer relations and explore novel, social contexts, including social media platforms (Patton et al., 2016) as these environments provide a fertile testing ground for experimenting and establishing one’s unique identity, while building important life skills essential for the transition to adult autonomy (Blakemore & Mills, 2014; Crone & Dahl, 2012; Patton et al., 2016; Piekarski et al., 2017). Moreover, depending on the quality of peer norms, this social engagement, identity construction and positive youth development (Hinson et al., 2016; Lerner et al., 2005), has the potential to offset prior health challenges and facilitate promotive health trajectories into the future (Blakemore & Mills, 2014; Crone & Dahl, 2012; Patton et al., 2016; Sawyer et al., 2012).

However, the SCF acknowledges young people living with an illness or disability are beset by unique challenges in this regard. In particular, these individuals are at a heightened risk of experiencing social isolation, social exclusion, stigmatisation and bullying due to the visibility of their illness or disability, alongside other challenges associated with their condition (Collard & Marlow, 2016; Giordano, 2016; Lau & Van Niekerk, 2011; Lindsay & McPherson, 2012; Olenik-Shemesh & Heiman, 2017; Pinquart, 2017; Pittet et al., 2010; Snöbohm et al., 2010; Winger et al., 2014). This results in these individuals attempting to conceal their condition in peer driven settings and mainstream social media platforms to appear 'normal' (Ferguson & Walker, 2014; Oliver et al., 2014). However, while 'practising normalcy' functions as important source of resilience for these individuals, it also can pilfer from them critical sources of illness or disability specific support (Ferguson & Walker, 2014). This limits opportunities for these individuals to accept and integrate their condition into their wider sense of self and has the effect of engendering poorer psychosocial health long-term (Ferguson & Walker, 2014; Luyckx et al., 2008b; Rassart et al., 2012). In the case of online communities, concealment also leads to these young people failing to reach out or sustain engagement with illness and disability focused interventions, due to a fear they will become overly defined by their condition within these contexts to the negation of expressing and being acknowledged on the merit of their unique young person or teenage self (Locock & Brown, 2010; Mazanderani et al., 2012; Third & Richardson, 2010).

To address this concern and practice gap, the SCF created the LW.org.au online community with a threefold aim as follows:

a) To counter the social isolation and loneliness experienced by young people living with an illness or disability due to their condition dislocating, excluding or stigmatizing them within important peer-driven settings and mainstream social media platforms;

b) To enhance the psychosocial health of young people living with an illness or disability by fostering a sense of connection with other young people by engaging them in 'everyday' social media activities, such as building a profile page, writing blogs about events, hobbies and interests along with their illness and disability experience, commenting on users posts, and interacting in an online chat-room that discusses youth culture alongside condition specific concerns;

c) Focuses on celebrating the young person's 'young person' identity and individuality, while providing them a safe space for them to discuss illness and disability concerns in a manner that potentially allows them to integrate their condition into their overall 'self-concept' and 'sense of self' more holistically.

Chapter Summary and Conclusion

This short chapter has provided an overview of the SCF's online community LW.org.au, its purpose and ways of working. It outlined the SCF's participatory approach to re-designing the online community, and explicated the site's main features, membership, and security protocols. The chapter also outlined the practice gap. In particular, it draws attention to the need to provide young people living with a condition with developmentally oriented condition based support, and peer driven spaces where they can explore and be validated for their wider sense of self as a young person in tandem with their condition.

Chapter 5 Research Methodology

Introduction

This chapter outlines the methodology used in this study, including (a) the research purpose; (b) the approach taken; (c) the research methodology; (d) the sample studied; and (e) the methods of data collection and data analysis. It also addresses ethical considerations involved in conducting research with a vulnerable community.

Research Purpose

The purpose of this study was to understand how the SCF's online community, LW.org.au functions as an intervention and provides developmental, psychosocial support (D'agostino et al., 2011; Sawyer et al., 2007) for young people living with an illness or disability between the ages of 12-21 years. The study sought to understand the developmental value and appropriateness of the online community in relation to the culture and peer norms enacted and embodied online and how these impacted young people in their ability to engage in two core adolescent developmental tasks demonstrated within the literature to play an important role in influencing health, well-being and developmental outcomes for young people in general as well as those living with a condition (Blakemore & Mills, 2014; Crone & Dahl, 2012; Patton et al., 2016; Sawyer et al., 2007; Telzer, 2016; Telzer et al., 2013; Third & Richardson, 2010). These developmental tasks included (a) forming and maintaining peer and mentor relationships within a novel, social environment online (Blakemore & Mills, 2014; Shapiro & Margolin, 2014), and (b) experimenting, exploring and establishing a unique sense of self within the context of these online interactions and experiences (Shapiro & Margolin, 2014).

The study also sought to examine this development in relation to two personal and social identity domains (Tajfel, 1982; Tajfel & Turner, 2004) demonstrated within the literature to have unique ramifications for these vulnerable young people (Collard & Marlow, 2016; Foster et al., 2017; Lounds Taylor et al., 2017; Luyckx et al., 2011; Rassart et al., 2012; Third & Richardson, 2010). These identity domains included exploring (a) how young people construct and perform their identity in relation to their 'young person' self or selves (Goffman, 1959; Luyckx et al., 2008b; Third & Richardson, 2010). This involved examining how young people express the self and build social connections around shared youth interests, such as talents, skills, hobbies, goals and pop-culture that accentuate the young person's individuality beyond definitions centred solely on their condition (Third & Richardson, 2010). Secondly, it sought to (a) investigate how young people present and disclose the self in relation to their condition and examined how they fostered social connections based on peer support and empathy (Cassano et al., 2008, p. 193) around the shared understanding and lived experience of illness and disability (Goffman, 2009; Third & Richardson, 2010). This study terms this facet of young people's identity their condition based self or selves' (Goffman, 1959, 2009). However, it recognises the use of the phase 'condition based self or selves' may imply biomedical undertones that run counter to the ethos of this thesis that stresses the importance of going beyond one's illness or disability. However, the use of this phase primarily facilitated brevity and created a bridge between the dominant biomedical model and the move towards biopsychosocial, socio-ecological and positive youth development frameworks that continues to be an evolving and fragmented process within the field.

The significance of examining the developmental appropriateness of the LW.org.au community and its impact on the developmental tasks of (a) peer and mentor relationship building and (b) identity formation in terms of the two identity domains mentioned above, was the study endeavoured to uncover how the cultural model of the site addressed two concerns within the field. These concerns connect to a lack of help-seeking, meaningful engagement, participation, and the screening of psychosocial and mental health distress among young people living with a condition (Coduti et al., 2016; Ferguson & Walker, 2014; Locock & Brown, 2010; Mazanderani et al., 2012; Third & Richardson, 2010). These include the issue of (a) illness and disability 'over-identification' or negative identification in relation to clinical or preliminary screening counselling services and online communities with a high condition focus. Over-identification and negative identification are demonstrated within the literature to be core factors inhibiting young people from reaching out (help-seeking) and engaging with these services as young people fear becoming overly defined by their condition to the marginalisation of expressing and gaining support for their young person self. This is significant as the latter is recognised in the literature as functioning as a valuable source of resilience for these young people in terms of coping, accepting and integrating their condition into their wider identity (Locock & Brown, 2010; Mazanderani et al., 2012; Shama & Lucchetta, 2007; Third & Richardson, 2010). Secondly, the study sought to address the issue of (b) illness and disability concealment regarding community, positive youth development, youth-oriented and social media based interventions and services. This was driven by the recognition that while these interventions offer valuable youth-oriented and developmental support for young people, they also had the effect of undermining young people's ability to receive important sources of condition based support. The latter was the result of young people becoming adept at 'practising normalcy' within these spaces to hide their condition and fit in with their healthy peers (Collard & Marlow, 2016; Ferguson & Walker, 2014).

Therefore, by garnering insight into how the LW.org.au online community and young people manage this dual challenge in relation to their identity and receiving developmental and condition-based support online, the study endeavoured to gain a nuanced understanding of the types of interventions, cultures, norms, therapeutic relationships and conversations that foster or inhibit young people from building positive youth development assets (Fergus & Zimmerman, 2005; Hammond & Teucher, 2017; Hinson et al., 2016; Lerner et al., 2005; Patton et al., 2016). These include assets that would assist young people in integrating the various aspects of their identity into their wider sense of self online to enhance their overall health and well-being (Hinson et al., 2016; Luyckx et al., 2008b; Rassart et al., 2012). However, such insights required a research approach that went beyond current understandings to address these concerns at the level of 'lived experience' and from the perspective of young people and practitioners (chat-hosts). This strived to reveal hidden influences at play and how best to discern effective and novel solutions forward with these factors in mind.

Research Approach

To achieve this purpose, a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach was used as it aligned well with the interpretative (Schwandt, 1994, 2000), cultural (Geertz, 1973) and exploratory nature of the study. Constructivism is a research paradigm or philosophical approach that explores social reality and social phenomena, such as online communities, like LW.org.au, and the culture, practices, identities and relationships enacted and embodied online, in terms of the perceptions, meanings and understandings individuals, including the SCF organisation, the chat-hosts and young people bring to the site and negotiate in interaction with each other online (Schwandt, 1994, 2000). Thus, a core strength of a constructivist approach is its ability to highlight a diversity of perspectives.

This is due to constructivism adopting an ontological position of relativism (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018). Relativism claims reality is socially constructed from the sense-making and meaning-making activities of intentional human beings in symbolic interaction with each other within culture (Crotty, 1998; Guba, 1990; Guba & Lincoln, 1994; Scotland, 2012). From this perspective, reality is understood as multiple, shared and situated. There can be as many understandings of reality as there are individuals experiencing it. This results from reality arising from the subjective and inter-subjective accounts of individuals in response to the contingencies of everyday life, including the physical elements of one's illness and disability, particularly how these are interpreted in negotiation with others within culture (Crotty, 1998). Thus, what is valuable about constructivism is its ability to highlight both consensus, and more importantly, difference in the construction and understanding of reality (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018). Thus, constructivism as a research approach is more adept than other research paradigms, such as positivism and post-positivism (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) commonly employed within health research, in capturing the complexity of 'lived experience' and 'practice' at the ground level of intervention. This is a product of constructivism's emphasis on holism, multiplicity and embodiment. Both positivist and post-positivist (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) approaches are limited in this capacity due to their focus on cause and effect relationships, rather than meanings. Therefore, positivism and post-positivism emphasise general laws or norms that account for objective reality, rather than the contradictions contained within various perspectives of lived reality.

Thus, a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach was appropriate in this study to explore how the LW.org.au online community, its culture, and the relationships and identities enacted and embodied online, were constructed and understood from the diverse perspectives of young people, practitioners and the SCF organisation. Culture, in this sense, was conceived dynamically in terms of structure and agency (Crotty, 1998). Structure explored how subjective and inter-subjective understandings coalesced to produce the objective, discursive reality of the online community and its culture (Crotty, 1998). This involved exploring how the SCF constructed the sites culture in terms of its design, as well as its policies, protocols, procedures and practices. This established the organisational or institutional reality of the site with respect to its vision, ideals, goals, values, norms, expectations, rules and boundaries. In contrast, agency explored how the organisational or institutional reality was perceived, understood and interpreted by young people (LW.org.au members) and practitioners (chat-hosts) engaged with the site in practice. This examined how young people and practitioners actively participated in and maintained the culture of the community through their actions and interpretations online, but also where they challenged it. Efforts to actively maintain and internalise the culture and ethos of the community demonstrated where young people and practitioners valued the site and its ability to support these young people's developmental and condition-based needs, while points of challenge or difference indicated where the community and its culture potentially fell short in addressing these concerns.

With respect to identity formation (Erikson, 1968, 1994), constructivism's emphasis on sense-making and meaning-making within culture (Crotty, 1998) was valuable in illuminating the socio-cultural construction of identity, particularly in terms of how young people's identity formation online and the expression of their (a) young person and condition-based selves was influenced by the culture and peer norms operating on the site. Constructivism's (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) ability to capture plurality also revealed how identity formation online was similarly responsive to the cultures and norms operating within other medical or youth-oriented settings, such as the hospital and school context. The latter was discerned through the stories young people shared in their posts and conversations online. Thus, an important element of adopting a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach in this study was its ability to capture the multi-faceted and dynamic nature of identity construction (Erikson, 1968, 1994) during adolescence and emerging adulthood within the online space. This included how expressions of the self in online posts and conversations aligned or challenged each other across contexts as expressed through online stories and posts. A valuable component of this was that it allowed the study to also explore the diversity of the expression of the self across the two identity domains mentioned above, and the integration between these identity categories (Luyckx et al., 2008b). This insight facilitated an understanding of the expression of the self in relation to different models of health, including the biomedical, biopsychosocial and socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) models.

In addition, constructivism's (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) emphasis on symbolic interaction (Mead, 1934) rendered it more adept at capturing the interactional nature of identity construction and negotiation online. This is how young people validate, challenge and re-consider theirs and other's identities across the two identity domains in response to the feedback they receive from peers and chat-hosts in the form of likes, comments and conversations online. Thus, constructivism (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) was more adept at capturing young people's agency in the construction of theirs and other's identities within the online realm. This is useful for understanding the therapeutic value or affordances (Gibson & Trnka, 2020) of this medium and online interventions in supporting young people's developmental and condition-based needs.

On an epistemological level, a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach was valuable for broadening the study's understanding of the notion 'developmental appropriateness' (D'agostino et al., 2011) in scholarship and practice. This was achieved through constructivism (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) emphasising the partial, plural and plastic (Schwandt, 1994, p. 125) nature of knowledge: partial in that knowledge of reality is always from the standpoint of an individual within culture; plural in that there can be multiple accounts of reality based upon different perspectives operating within the space which are equally valid (Greene, 2000; Guba, 1990; Guba & Lincoln, 1994; Schwandt, 1994; Smith & Deemer, 2000); plastic in that these accounts of reality are always in the process of being modified and negotiated or 'stretched and shaped' (Schwandt, 1994, p. 125) to fit the intentional actions of agentic human beings in dialogue with each other (Gadamer, 1989; Greene, 2000; Guba, 1990; Guba & Lincoln, 1994; Schwandt, 1994).

In this study, this understanding of knowledge construction allowed the researcher to illuminate how the online community functioned in a developmental capacity as a 'developmentally appropriate' intervention (D'agostino et al., 2011) from the diverse perspectives of young people, chat-hosts and the organisation. Each perspective provided unique insights into the construct. The SCF organisation's efforts to establish the culture of the community comprised the institutional approach to developmentally appropriateness informed by existing scholarship and practice. However, young people and practitioner's responses to the culture of the community and its ability to support their developmental and condition-based needs illustrated where the institutional approach did not align with both young people and chat-host's everyday reality. Thus, the holistic and embodied nature of constructivism (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) allowed the study to go beyond disciplinary understandings of ‘developmental appropriateness’ (D'agostino et al., 2011) commonly employed within the field to explore why these approaches failed to work within this context with these young people. Thus, this approach gave prominence to young people’s and practitioners lay expertise and lived experience.

On an axiological level, a constructivist (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) approach was more adept at highlighting voice. In this study, this involved highlighting young people and chat-host’s views. This was important as young people are often marginalised from discourses concerning their health, well-being and development. Therefore, a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach allowed this study to attend more acutely to the human dimensions of illness and disability to understand the developmental value of interventions. It also granted greater recognition to the voice of practitioners, such as the chat-hosts, who play a key role in bringing disciplinary and institutional approaches to developmental appropriateness (D'agostino et al., 2011) to life within interventions. However, practitioners, such as chat-hosts also have direct knowledge of where disciplinary and institutional approaches fail to capture the complexity of operationalising this construct in practice. Thus, their grounded knowledge alongside young people’s understanding of what developmental appropriate interventions (D'agostino et al., 2011) means to them in their everyday experience, is significant for strengthening scholarship. This is particularly in terms of broadening the construct to reflect these young people’s reality, and to unearth novel solutions to common concerns faced by them and organisations designing and evaluating interventions.

Further, a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach strongly supports the exploratory (Stebbins, 2001) nature of the study, which strives to go beyond existing conceptualisations and disciplinary understandings of developmental appropriateness (D'agostino et al., 2011) to better operationalise the construct in a manner that allows interventions to address complex challenges within the field; challenges that current models appear limited or inadequate in resolving. These include garnering an understanding of the hidden factors influencing help-seeking, meaningful engagement, and participation among young people living with a condition, and the screening of their psychosocial and mental health distress (Lawrence et al., 2015; Patton et al., 2016; Sawyer et al., 2010). Similarly, this study sought to illuminate the relationship between these issues and the challenges of condition (a) over-identification, (b) negative identification, and (c) concealment online (Kelleher et al., 2020; Mazanderani et al., 2012). Constructivism's (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) ability to grapple with and glean insight from the contradiction and complexity contained within different perspectives concerning the notion of developmental appropriateness (D'agostino et al., 2011) and its associated challenges, is useful in allowing this approach to unearth latent factors, mechanisms or pathways to enhance the effectiveness of developmentally-oriented and online interventions in meeting and addressing young people's developmental and condition-based needs. Positivist and post positivist (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018) approaches would not have been suitable for this agenda as their emphasis on objective reality and cause and effect relations privileges current disciplinary and institutional approaches to developmental appropriateness (D'agostino et al., 2011) that do not account for and fail to detect hidden or latent factors. A constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach employs induction to access this knowledge and lay expertise operating at ground level of practice.

Similarly, concerning the construct of 'identity formation' (Erikson, 1968, 1994), a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach was valuable in exploring identity, its content, and its processes of enactment in practice, by observing the impact of these factors in the community from the perspective of diverse strands of scholarship, including identity status (Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966), narrative identity (McAdams, 2011), and sociological (Côté, 1997) identity literature. This functioned as a source of conceptual triangulation (Denzin, 2007). By exploring identity through these different perspectives of scholarship, it enabled an understanding of how personal identity content and processes intertwine with interpersonal and cultural processes. This provided a more dynamic and contextual understanding of identity formation (Erikson, 1968, 1994), which was significant for understanding how to support identity formation within interventions as the latter remains an under-researched and under-conceptualised area within the field.

It is also important to acknowledge on an epistemological level that a constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) approach recognises that because knowledge is interpretative and based on perspective, it is impossible for the researcher to step outside their own positionality. Therefore, the researcher's rendering of the online community, and the subjective and inter-subjective understandings that comprise it, is also a construction. The researcher must remain cognisant of how their values are impacting the inquiry process and their engagement with the study site and research participants. However, this does not remove or bracket the researcher's positionality or bias, which is common within positivist and post-positivist (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) research that strives to discern one true, objective reality. In contrast, constructivism (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) conceives eliminating bias from the inquiry process as constituting a source of bias itself as it marginalises too many voices and perspectives whose stake in the claims being made are equally as valid, and potentially offer insightful contributions to address unresolved challenges within the field (Lincoln et al., 2011). This results from constructivism taking a broader view on reality to encompass the embodied aspect of 'lived experience' and lay expertise. It views the researcher's positionality and values as facilitating the goal of constructivist inquiry being *verstehen*' (Dilthey, 2010) or understanding.

The researcher's positionality within this study became a springboard for facilitating dialogue and engagement with young people, chat-hosts and the SCF organisation to gain greater insight into their experience and understanding of the online community, its developmental appropriateness, and the relationships and identities online. In doing so, it allowed the researcher to gain access to the emic (Lincoln et al., 2011) perspective in terms of the meaning systems operating within the space, and how these influenced young people and chat-hosts understandings of complex issues related to help-seeking, engagement, participation and screening (Lawrence et al., 2015; Patton et al., 2016; Sawyer et al., 2010), as well as condition over-identification, negative identification and concealment online (Mazanderani et al., 2012). This allowed the study to uncover novel pathways and solutions to address these challenges, which could only emerge through accounting for 'lived experience' and 'lay expertise'.

Constructivism (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) views scholarship as an exercise in 'phronesis' (Gadamer 1989) or 'moral practical wisdom'. Phronesis moves beyond assessing the merit of research and scholarship in terms of objectivity, accuracy and reliability, to understand the value dialogue and engagement with the communities and individuals that research and practice seeks to support holds for enhancing scholarship, particularly by placing greater emphasis on discerning the right action for the people who these challenges directly effect and whose voices are often marginalised from being heard (Gadamer 1989). As Cannella and Lincoln (2011) aptly express, ‘if you want to research us, then you can go home. If you have come to accompany us, if you think that our struggle is also your struggle, we have plenty of things to talk about’ (p. 83).

However, to initiate this dialogue and engagement to better understand the lived experience, perspective and voices of these individuals, it was important for this study to employ a research methodology that situated the researcher within the online community, and the subjective and inter-subjective reality of these individuals.

Research Methodology

To achieve this research purpose of understanding and examining the developmental appropriateness of the LW.org.au online community for young people from the diverse perspectives of the organisation, chat-hosts and its youth members, the study employed the methodology of netnography (Kozinents, 2010, 2015); an online application of ethnography (Geertz, 1973, 1974), involving close observation and engagement with a community, its culture and the behaviour, interactions and practices of its members over time.
Ethnography (Geertz, 1973, 1974) was a valuable tool for immersing the researcher within the symbolic, meaning-making reality of the LW.org.au online community and elucidating the diverse and situated perspectives of the organisation and the individuals engaged with the site. This included how the SCF established the cultural model of the community through its policies and procedures, and how young people and chat-host’s interactions, interpretations and involvement online shaped the culture, meaning and value of the site, its relationships

and practices. Immersion in the online community also highlighted how ‘inside’ knowledge of the community informed wider issues concerning the operationalisation of developmental appropriateness within the field of interventions, and young people’s help-seeking and engagement practices in relation to their condition and youth concerns. The latter of which has value for enhancing screening efforts by practitioners. Thus, in this context, ethnography is understood as no longer being confined to the study of a group in a location, of the kind that anthropologists such as Geertz (1973, 1974) carried out, nor is it only used in the context of an organisation or other face to face groups. It is also applied to online settings and the study of online communities and cultures in everyday life.

However, the extrapolation of ethnography to the online space has not been a straight forward process with scholars offering varied conceptualisations, including ‘virtual ethnography’ (Hine, 2000, 2015) ‘netnography’ (Kozinets, 2010, 2015; Kozinets et al., 2014) and ‘digital ethnography’ (Pink et al., 2015) to name a few. Netnography (Kozinets, 2010, 2015), arguably, has been the dominant approach for translating ethnographic principles specifically to the study of online communities, cultures and social media networks in comparison to the wider focus of virtual (Hine, 2000, 2015) and digital ethnography (Pink et al., 2015) that encompasses the internet and digital technology more broadly. Therefore, the term ‘netnography’ will be employed in this study to reflect this narrower scope.

However, relevant to the current research is while Kozinets (2010) original conceptualisation of netnography outlined clear procedural, ethical and methodological guidelines to systematically study cultures and communities online, his early work (2010) has been criticised for being less explicit about the ontological and epistemological implications of this approach. This includes addressing issues surrounding the ‘fluidity’ of the constructs of culture and community in the post-modern, digital era and the extent to which the online and offline world interact. Kozinets' (2015) later work responded to these concerns by focusing on the concept of sociality, particularly networked sociality and networked individualism to account for how the online sphere destabilises traditional understandings of culture and community tied to a specific place or field-site as is common in tradition ethnography. However, this notion of sociality and connectedness, when applied to the study of cultures and communities online, is best suited to the study of multi-sites; that is communication of many individuals across many sites. This approach, while valuable for understanding the online sphere, was not relevant to the current research because LW.org.au is a bounded community. Therefore, this study was not concerned with how the young people at the centre of the research interacted with other online platforms. The boundedness of the LW.org.au online community has been put in place to protect the vulnerable nature of its community members. This specific security structure keeps the community separate from other networks on the internet. The community is also bounded by socio-cultural identities: young people and those living with any illness or disability. In addition, Kozinets' (2015) emphasis on sociality also understates the interconnection between the online and offline spheres, which are valuable for supporting this study's understanding of developmental appropriateness.

Therefore, on a conceptual level, this study found Hine's (2000, 2015) notion of 'virtual ethnography' and 'ethnography for the internet: embedded, embodied and everyday' better suited. Hine's (2000, 2015) more adeptly considered the ontological and epistemological implications of extrapolating ethnography to the online sphere, arguing the need for ethnographies of and for the internet to stay true to their anthropological roots by exploring online communities, cultures and platforms in terms of their "locally situated character" (Hine 2000, p. 5) or the mundane, everyday meanings that specific people in specific contexts bring to their engagement with these sites both online and offline (Pertierra, 2018). Thus, her original conceptualisation of virtual ethnography (2010) explored online communities both as a (a) place and space for culture and a (b) cultural artefact. The former aligns with the work of Boellstorff (2008) and Kozinets (2010, 2015), who argued online communities and cultures can be studied as ‘valid and complete forms of social interactions in themselves’ (Pertierra, 2018, p. 1922). This involves examining online cultures and communities, particularly bounded communities like LW.org.au, in terms of the identities, relationships, practices and meanings enacted and embodied in these spaces.

However, in alignment with Miller and Slater (2020), Hine’s (2000) notion of examining online communities as a cultural artefact also stresses the importance of situating young people’s understandings and interpretations of online communities in terms of wider systems of meanings and discourses, including those existing offline. Thus, Hine’s (2000, 2015), in contrast to Kozinets (2010, 2015), more acutely considers how digital technologies are connected to offline meaning-systems related to the production of an online community or intervention through an organisation. This was relevant for this study to understand the SCF’s approach to operationalising developmental appropriateness online, and its reception from the standpoint of chat-hosts and members. It also facilitated a greater understanding of how socio-cultural identities operating in the offline world impacted online identity construction and practices.

However, Hine’s (2000) use of the term ‘virtual ethnography’ has been criticised for perpetuating an understanding of virtual or online worlds as being separate and less ‘real’ in consequence and influence than the offline world. Hine’s (2000, 2015) qualifies she did not use the term ‘virtual’ to signal this division or binary. Indeed, her conception of the internet as both culture and cultural artefact precludes this (Hine 2000). Rather, her use of the term 'virtual' was to indicate, like Kozinets (2010, 2015), the necessity of providing a distinct term for ethnography of and for the internet to attend to the different affordances and challenges the new medium poses without losing the principles integral to the practice of ethnography itself. However, due to these out-dated connotations, Pink et al.'s, (2016) notion of digital ethnography appears more appropriate for capturing the interconnections between the offline and online space. However, due to digital ethnography's (Pink et al. 2016) broad focus on technology in general, netnography (Kozinets 2010, 2015) was better suited to the current study's nuanced focus on online communities and their embeddedness in wider contexts of meaning.

As a research practice, netnography (Kozinets, 2010, 2015) informed by Hine's (2000, 2015) conceptual framework, allowed the researcher to actively engage and participate in the socio-cultural world of the LW.org.au community to gain insight into how reality and phenomena, including the site's culture, practices, identities and relationships (D'agostino et al., 2011) were experienced from the organisation, chat-host and LW.org.au's youth members unique 'native point of view' (Geertz 1974, p. 27) or perspective. This immersion allowed the researcher to observe, interact and participate in the everyday activities, conversations, events and routines of the community. Through this engagement, the researcher was able to fashion a rich, holistic contextualised account or grounded narrative of the LW.org.au community from the perspective of the people within it (Tedlock, 2003; Vidich & Lyman, 2003). It also allowed the researcher to reflexively consider how meaning-making practices online connected to and informed wider issues and challenges occurring within the field, such as how best to operationalisation the construct of 'developmental appropriateness' within interventions to support young people's help-seeking and engagement behaviour, and screening efforts by practitioners. This involved describing, interpreting and representing the socio-cultural world, knowledge and practices of the LW.org.au community, in terms of its locally situated meaning systems, social processes, social interactions, and symbolic actions (Tedlock, 2003; Vidich & Lyman, 2003).

In alignment with the study's constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) framework, this emphasis on meaning systems and symbolic action led to the study's netnographic (Kozinets, 2010, 2015) methodology, being informed by Geertz's (1973) conception of culture as "webs of significance man himself [sic] has spun" (p. 311). Geertz's (1973) viewed culture symbolically as the meaning-systems that shape our understanding of reality; informing our interpretations of the world. More specifically, his approach which aligns with Hine's (2000, 2015), explored how these meanings-systems are constructed through symbolic communication and interaction by specific people within specific contexts at specific times (Geertz, 1973). Therefore, he considered behaviour in the form of performative or symbolic action, such as speech acts and gestures as the articulation of culture, and the means through which it can be examined, interpreted and understood (Geertz, 1973).

Therefore, for Geertz (1973) ethnography was an exercise in "thick description" (Geertz 1973). Thick description is best illuminated by the distinction between a twitch or a wink (Geertz, 1973). While a twitch is merely a physiological reaction observed as the physical closing and shutting of an eye with no meaning attached; a wink is infinity more complex possessing multiple meanings, for multiple people based upon the way that wink is conceived within a specific meaning system, by a specific person, at a specific time (Geertz, 1973). In alignment, with Geertz's (1973, 1974) understanding of ethnography as thick description, this study’s approach to netnography focuses on ‘thickly describing’ the culture, practices, identities and relationship enacted and embodied on the LW.org.au site, which requires immersion within the bounded community and an understanding of its connection to wider contexts of meaning.

In applying Geertz’s (1973, 1974) notion of ‘ethnography as an exercise in thick description’ to the online realm, Hine’s (2015) notion of the ‘embedded, embodied and everyday’ nature of the internet becomes valuable. Her notion of embedded acknowledges how online technologies and communities, like LW.org.au, are entwined and embedded in “multiple context and frames of meaning-making. This recognises how the internet and online communities, are not objects, but phenomena that need to be subjectively understood from a multiplicity of perspectives with a plurality of meanings attached. These meanings and interpretations need to be ‘thickly described’ to understand the value they hold for addressing broader issues, such as how best to operationalise developmental appropriateness within the field of intervention. It also acknowledges how the culture and practices of the LW.org.au community are situated in broader networks, such as the SCF organisation and the hospital context.

Embodied, for Hine (2015), involves understanding how online communities and technologies are an embodied medium that requires explication of how people physically relate to internet based communities. In terms of identity, embodiment in alignment with Turkle (1994) acknowledged that online communities can be considered disembodied spaces where we can explore parts of our identity that we are unable to express because we are bounded by our physicality. This is relevant for this online community because many of these young people do feel as though in their offline world they are very much bounded by their physicality or the presence of their condition. However, when they go online they become disembodied from their conditions, which enables them to express their identity in more experimental, exploratory ways. At the same time, Hine's (2015) also argues that people embody or re-embody the self online through interaction and communication. With respect to LW.org.au's youth members this means they can choose how to express their condition through their online communication, including on their profile pages. Thus, by thickly describing the tensions between these different levels of embodiment, a richer notion of young people's identity construction and relationship with online communities can be ascertained.

Last, for Hine's (2015) the everyday use of the internet is not something that stands out as distinct any longer, along with mobile phones and social media it is part of our everyday activities. Interacting in online communities is no longer a novel phenomenon. It is so common place that we use it in an everyday fashion and it has become part of how we conceive our everyday world. However, despite this everydayness, Hine's (2015) argues for problematizing what is familiar about our 'everyday' approach to the internet and online communities to illuminate what is puzzling and unique about their adoption and reception within locally situated contexts. This involves 'thickly describing' the use and meaning of these communities and technologies from the emic point of view. In this study, this included how young people and chat-hosts' perceive the LW.org.au community, and its developmental value in supporting help-seeking and engagement behaviour and screening efforts

Research Methods

This section outlines the methods of data collection for the current project, including (a) the researcher's entrée into the online community of LW.org.au, (b) the sampling and recruitment of research participants, (c) the use of the data collection techniques of participant observation, online focused groups, online interviews, field-notes, and memos; (d) methods of data analysis, including a priori and emergent coding, and positioning theory; and (e) the writing up of the final ethnography.

Participant Observation

Participant observation (Aktinson & Hammersley, 1998) comprises the core of the netnographic (Hine, 2000, 2015; Geertz, 1973; Kozinets, 2010, 2015) inquiry. It involves the researcher seeking direct engagement with the community or culture they seek to understand to (a) observe the everyday activities, routines, conversations, interactions and events that occur within this space and to (b) participate within them. This dual focus between observing and participating is central for constructivist (Crotty 1998), ethnographic (Geertz 1973) and netnographic (Kozinets, 2010, 2015) research, in that it not only allows the researcher to directly witness the everyday happenings of the community, but through participating within them, it enables the researcher to delve below the surface to comprehend the tacit understandings shaping the culture, identities, relationships and practices enacted and embodied on the site, as well as the everyday contingencies moulding individual responses and interpretations to incidents and events that occur within this space. Kawulich (2005) refers to this split focus between observation and participation as the difference between the intellectual and embodied understanding of the community. Geertz (1974) conceives it as the difference between ‘experience distant and experience near’ renderings of the culture (p. 28). Essentially, this distinction highlights how observing as a technique brings us close to the action to discern the ‘others’ point of view, but still from a somewhat distant or outside perspective. In contrast, participating becomes the means through which the researcher really learns how to see, think, feel and act, sometimes like the insider or a member of the community. It is the participating that allows the researcher to grasp, what Geertz (1974) refers to as the 'native point of view' (p. 43) or in this case, the young person and chat-hosts understanding or interpretation of the situation.

However, observation still plays a crucial role in this process (Aktinson & Hammersley, 1998). While participation socialises or encultures the researcher into the community—by building rapport and allowing the researcher to experience and understand everyday reality from the inside perspective through using themselves as a research instrument to apprehend what members consider meaningful and important—it is the observation that allows the researcher to step back, and analyse what is happening not from what 'I', the researcher see, but what do these people see themselves as doing? (Aktinson & Hammersley, 1998). The observation component allows the researcher to describe and translate the 'inside' socio-cultural world to an outside audience. But more importantly, it is the means through which the researcher questions and challenges their own outside assumptions of the community against the inside understandings they develop through their (a) direct participation within it, and their (b) engagement with member's interpretations. It also allows the researcher to uncover the disconnects, misinterpretations and biases. However, because participant observation is a recursive activity, these misinterpretations also inform what the researcher might next ask members about or participate in the subsequent round of participation. Thus, it is this dual activity of participant observation that guides the inquiry towards 'thick description' (Geertz 1973)

Within the literature, Gold (1957) outlines four possible stances of participant observation that delineate varying degrees of involvement, including (a) complete observer, (b) participant as observer, (c) observer as participant and (d) complete participant. This study employs the observer as participant stance. This involves the researcher gaining direct access to observe and participate in the community of interest. Direct access and approval to observe and participate within LW.org.au was sought by the researcher from the SCF and LW.org.au's internal management team. The researcher's prior status as a chat-host on the site and the SCF's funding of the project facilitated these negotiations.

Ethics

To undertake the netnograhic (Kozinets, 2010, 2015) investigation of the LW.org.au online community, the researcher gained ethics approval from the University of Technology Sydney's Human Research Ethics Committee (Application no. ETH18-3031). For approval of the study by the University's Human Research Ethics Committee, it was imperative that the researcher conduct an overt participant observation of the site. Overt observation means all members of the community are informed and are aware of the researcher's presence on the site, and that the researcher will be observing the community for research purposes during their participation. A disclaimer notice was displayed on the site in relation to this.

In terms of the participant observation itself, the following was taken from the application to the University's Human Research Ethics Committee for approval to conduct the study: "The researcher will actively observe and participate in LW.org.au's online community and chat-room for a period of 3-4 months, approximately 2-3 times a week for roughly 5-6 hours each session. During the participant observation, the researcher will observe and take part in the day to day happenings of the site, including the events, conversations, interactions and activities that occur on the newsfeed and in the chat-room. The researcher will also observe members profile pages and activity in the online groups, competitions, games and articles sections of the site. The participant observation will be supported by archival data from the online community, including chat-room transcripts and digital artefacts from the newsfeed activity".

Online Semi-structured Focus Groups

In conjunction with the participant observation, this study employed online semi-structured focus groups (Kitzinger, 1995) to gain greater insight into how young people perceive and experience: (a) LW.org.au's online community; (b) the friendships and chat-host connections they build online; (c) their identities and conditions; and (d) other aspects of the site that inspire or inhibit their engagement with the online community. The study was concerned with eliciting young people's thoughts, feelings, attitudes, values, and beliefs, while also observing the culture, dynamics, norms, social interaction and language of the site in an organised, focused, but friendly and familiar manner.

Semi-structured focus groups (Kitzinger, 1995) are a data collection technique that involves 'researcher-facilitated' discussions with a small group of individuals to provide an informal forum for these individuals to chat, comment and share personal experiences, ideas, beliefs, perceptions, values, attitudes and meanings on topics of specific interest to the study in interaction with others. Kitzinger (1995) argues this emphasis on social interaction and engagement, is the crucial and core feature of focus groups that distinguishes it from other research techniques, such as in-depth interviews. While interviews encourage a one-to-one direct conversation with the researcher, focus groups are more concerned with initiating discussion between participants. Thus, the researcher may ask questions to: (a) prime conversation; (b) subtly influence its direction; (c) address key or salient points; (d) tease out deeper issues and areas of difference; and (e) facilitate social dynamics within the discussion, such as ensuring all members have an equal opportunity to share ideas. However, the prime role of the researcher's engagement and mediation in the conversation is to enable and encourage interaction, discussion and deliberation between participants (Kitzinger, 1995).

Focus groups (Kitzinger, 1995) not only allow the researcher to gain insight into the personal views of individuals on specific topics of interest, but more significantly it enables an exploration into how these views shift, shape and take form within a particular social context, culture or group dynamic. This has relevance for the current study as it focuses on understanding not only LW.org.au member's personal perceptions of the: (a) online community, (b) their condition, (c) identity and (d) the relationships enacted and embodied online, but also how these understandings change in response to social interaction on the site, including how LW.org.au members either confirm, validate, modify or challenge each other's points of view. Focus groups (Kitzinger, 1995) have the potential to elicit a plurality of perspectives among participants, illuminating: (a) points of consensus; (b) areas of tension and difference; (c) moments of re-evaluation and re-consideration of ideas in response to the discussion; and (d) issues of significance and meaning within the community.

Another important feature of focus groups (Kitzinger, 1995) is they allow the researcher to observe specific cultural elements of the site in a more nuanced form, including its interactional norms, social order and language by reviewing which members: (a) drive the discussion; (b) sit back and listen; (c) encourage others members to chat and share ideas; and (d) how members use language to convey ideas and build connection, including the use of colloquial terms and 'inside jokes'. Moreover, in contrast to participant observation (Aktinson & Hammersley, 1998), focus groups (Kitzinger, 1995) provide a unique opportunity for the researcher to more comfortably or less intrusively ask questions about intriguing situations observed within the field during the participant observation and online focus group. This facilitates an understanding of the member specific meanings of these incidents from multiple members' point of view in a dialogue.

In this study, two 60-90 minute online semi-structured focus groups with 6 purposely selected LW.org.au's youth members were conducted, one during the beginning of the participant observation period and one towards the end of participant observation period. The online semi-structured focus groups sought to gain insight into how LW.org.au members perceive, value, experience and attribute meaning to (a) the online community in the context of their everyday life; (b) the relationships and connections they form online; (c) their identity and condition; and (d) characteristics of the site that encourage or inhibit their engagement with the community. Focus groups also strived to delve into any significant themes, insights or issues that emerged during the participant observation, field-noting and reiterative coding of this content. With respect to the second focus groups, this included any themes, insights or issues that emerged within the first group that required further clarification.

The online focus groups were conducted like a regular online chat-room session. However, it took place in a private chat-room on the site, which only the researcher, chat-host on duty (for safety and ethical reasons) and members who were involved and had provided consent to participate in the focus group, could access. LW.org.au members were able to leave the online focus group at any time, by just clicking the close chat-room button, if they were feeling uncomfortable and wished to discontinue. In addition, LW.org.au members were also able to private message the chat-host on duty, or seek support and advice from their parents if they were present at home with them in the event they became distressed during the focus groups. The researcher recorded field-notes while conducting the focus groups. Both focus group conversations were supported by archival transcript data from the site.

Online Interviews

In addition to the participant observation and semi-structured focus groups, this study also utilised online, unstructured interviews (Leech, 2002) with LW.org.au's trained chat-host to gain insight into what LW.org.au's youth members find meaningful and valuable about the online community in its role as a developmental and psychosocial support from the chat-hosts point of view. The unstructured interviews (Leech, 2002) functioned as a source of data triangulation (Denzin, 2007) within the study, introducing an additional perspective alongside the researchers and members accounts of the online platform.

The value of the chat-hosts perspective was as leaders or facilitators of the community they are highly familiar with the site's explicit and implicit culture, rules, norms, values, activities, events, interactions and conversations as they play a pivotal role in not only constructing these features, but actively moderating them to ensure the safety of the community. Therefore, as facilitators they are cognisant of the way members co-construct, adapt, adhere and enforce the community's culture, as well as the ways members may struggle to socialise into the environment due to challenges connected to their condition. Thus, the chat-host perspective provides insight into strategies LW.org.au and its facilitators may implement to support its members with respect to: (a) fostering socialisation onto the site; (b) building skills to engage, interact and participate within the online community; (c) providing techniques to assist members in managing disagreements or challenging situations online; and (d) connecting members to additional supports in moments of crisis. Chat-hosts are also able to provide details on: (a) member's unique identities; (b) the relationships they form online; (c) how they support each other through challenging situations or experiences; (d) the impact their condition has on their everyday life; and (e) the history of their engagement with the online community over time, and how this may have changed during specific moments or incidents in their life. Therefore, the chat-host perspective enabled the research to explicitly tap into the way the online community functions as a developmental, psychosocial support, particularly in terms of building positive youth development assets for these vulnerable individuals.

Unstructured online interviews (Leech, 2002) were considered an appropriate data collection technique for this area of the study, because in contrast to the online focus groups (Kitzinger, 1995) that emphasised interaction, the unstructured online interview (Leech, 2002) allowed the researcher to delve into the personal experiences and understandings of the chat-host through a one-to-one exchange. Moreover, the unstructured nature of the interview built rapport and enabled the researcher to probe beyond set questions garnering a richer insight into the community and chat-hosts point of view (Leech, 2002). In this study, 6 unstructured online interviews were conducted with individual chat-host who provided consent. The online interviews were between 60-90 minutes long and covered how the chat-host perceived: (a) young people's engagement and interaction with the site; (b) the value of LW.org.au friendships for its members; (c) the ability of the site to facilitate identity experimentation, exploration and development; (d) strategies chat-host use to counter challenges and build positive youth development assets; and (e) the effectiveness of the site in supporting young people's psychosocial development, health and well-being. The interviews were conducted through a private Skype chat at a time that was convenient for the chat-host. The researcher recorded field-notes during the interview, and the interview conversation was recorded and supported by transcript data.

Data Collection

This section outlines the techniques and methods used to facilitate the data analysis and researcher's reflexivity during this process.

Field Notes

Field-notes (Emerson et al., 2011) were recorded during all phases of the research. These recorded observations "translate experience into text" (Clifford 1986, p 115) and inscribe observation and participation into social discourse (Geertz 1973). Researchers use various narrative techniques and conventions to capture field-notes, which in their final form comprise a written record of the 'happenings' of the study setting for further analysis (Emerson et al., 2011). This study employed field-notes (Emerson et al., 2011) to fashion a rich, contextualised and detailed account of the participant observation (Aktinson & Hammersley, 1998) component of the study, the online semi-structured focus groups (Kitzinger, 1995) with young people, and unstructured interviews (Leech, 2002) with chat-hosts. While these components of the data collection are supported by archival data, such as chat-room transcripts and digital copies of the newsfeed content from the site; this archival data fails to 'thickly describe' (Geertz, 1973, 1974) the experiential aspects of observing and participating within the online community, which constitutes the core of the ethnographic (Geertz, 1973, 1974) and netnographic (Kozinets, 2010, 2015) strategy.

In contrast, the study's field-notes captured richer descriptions of the field-site or online community's: (a) material physicality with respect to: layout, typeface and navigational ease; (b) explicit and implicit culture; (c) member's identities and everyday stories; (d) peer relationships; (e) conversations, social processes, interactions; and (e) the activities, events and competitions (Kozinets, 2010, 2015). The researcher sought to capture 'thick description'

(Geertz, 1973) of these features of the site by attending to: (a) their own initial impressions of the look, feel and sound of the site, its members' digital representations and the online interactions; (b) the researcher's personal inferences or sense of what appeared important within the setting, which was often guided by strong emotions to particular situations, people or events; (c) what members or chat-hosts appeared to consider important or meaningful within the course of the site's activity, indicated by the people, conversations or topics they frequently attended to; and (d) the local meanings or language of the site (Kozinets, 2010, 2015).

These richer impressions and ideas were captured initially through mental notes or jottings and scratch notes, which were keywords or ideas that acted as a mnemonic device for the researcher to flesh into a fuller description when not immersed within the participant observation, online focus groups or interviews (Emerson et al., 2011). Fuller descriptions of the day's events or happenings, included: (a) accounts of the site's conversations, episodes, incidents and stories in a temporally sequenced narrative; (b) sketches of scenes depicted in conversations or on member's profile pages; and (c) narrative tales that followed a particular storyline or member across episodes and situations (Emerson et al., 2011). By putting events into a temporal sequence and following members across incidents and situations, the researcher was able to garner preliminary analytic insights. Moreover, embedded within the field-notes, the researcher also included analytic asides, commentaries or in-process memo, which were supported by theoretical memo-writing in the final coding stages (Emerson et al., 2011).

Journal

In this study, the purpose of the journal was to provide a space for the researcher to record insights and ideas that emerged during the focus group and online interview phases of the data collection and to conceptualize and experiment with theoretical ideas or analytical concepts that emerge during field-noting and the coding phase of the research (Charmaz, 2014; Emerson et al., 2011). It provided an opportunity for the researcher to reflect upon significant ideas and directions that the coding led to and to explore how these connected to broader topics. The use of a journal also allowed the researcher to reflect upon their own positionality and orientation towards the research, and the coding and the data that emerged from the site. It is in this reflective use that it differed from field-notes (Charmaz, 2014; Emerson et al., 2011).

Data Analysis

This study employed a combination of a priori and emergent coding (Blair, 2015) reiteratively and recursively to understand how the LW.org.au online community functioned as a developmentally appropriate, psychosocial intervention (D'agostino et al., 2011) for young people living with a condition in terms of the culture, norms, relationships and identities enacted and embodied online. It also sought to uncover how these phenomena were experienced and enacted from the diverse standpoints of young people, chat-hosts and the SCF organisation (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000). Together, this approach endeavoured to broaden the understanding of developmental appropriateness (D'agostino et al., 2011) in scholarship and practice by exploring how the construct took shape in local form, and how young people constructed and enacted their identities online in relation to the two identity categories of (a) young person and (b) condition-based selves (Geert, 1973). Thus, an integrated approach to a priori and emergent coding was warranted.

Blair (2015) asserted coding is a valuable way to ascertain ‘meaning from qualitative data’ (p. 14). Miles et al. (2018) suggested codes function as “prompts or triggers for deeper reflection on the data’s meanings” (p. 64). Charmaz (2014) stated coding enhances the analytic import of the work by weaving two major threads; ‘theoretical statements [or concepts] that transcend specific times and places, and contextual analyses of actions and events’ (p. 113), which allow for a grounded understanding of the study site and the core constructs, relationships and mechanisms at play. Thus, coding and the meaning it ascribes to phenomena can arise both deductively and inductively.

A Priori Coding

Deductive coding involves a priori or template coding (Blair, 2015). In this study a priori codes (Blair, 2015) are pre-determined from the study’s theoretical framework and included central concepts identified within the literature review. Within positivist and post-positivist (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018) research, a priori coding (Blair, 2015) often takes the form of coding frameworks that are imposed upon empirical data to discern whether it confirms or dis-confirm various theories, cause and effect relations or norms. However, within positivist and post-positivist (Guba, 1990; Guba & Lincoln, 1994; Lincoln et al., 2018) research, there is little room for the coding framework to by modified in response to the empirical data, which is critical for broadening the understanding of theoretical frameworks and constructs to better reflect ‘lived reality’ and diverse perspectives operating within the field. In contrast, a priori or template coding within a constructivist paradigm can be understood in terms of what Blumer (1954) referred to as ‘sensitizing concepts’ (p. 7). Sensitizing concepts provide the researcher with ‘a general ... reference and guidance in approaching [the] empirical [world]’ (p. 7). He asserted ‘whereas definitive concepts provide prescriptions of what to see [as is common within positivist and post-positivist research], sensitizing concepts merely suggest directions along which to look'. (Blumer, 1954, p. 7). Faulkner (2009) argued 'sensitizing concepts emerge when the [researcher] discovers something worth problematizing, addressing the concept to the objects of investigation, producing precise and accurate evidence of chosen phenomenon'.

In this study, a priori coding (Blair, 2015) was employed in alignment with the constructivist (Crotty, 1998; Lincoln et al., 2018; Schwandt, 1994, 2000) paradigm to discern central concepts from the study's theoretical framework and literature review to function as sensitizing concepts. The use of 'sensitising concepts' (Blumer, 1954) created a coding framework to guide the study, but did not define or limit its exploratory potential. The latter was facilitated by a priori coding being employed in tandem with emergent coding. However, a priori coding frameworks were useful for placing boundaries around the study's scope to assist with time management and ensured the data analysis remained centred on answering the research question. The approach sharpened the researcher's ability to discern the presence of these constructs and code their unique form within the 'lived reality' of the LW.org.au online community. They also facilitated flexibility and responsiveness in allowing the study to go beyond these constructs to problematise and 'thicken' (Geertz 1974, P. 6) their conceptualisations in scholarship and practice by exploring how they were expressed and experienced from the diverse perspectives of young people, practitioners and the SCF organisation, and in terms of the hidden factors evident within the online community, but which remain unaccounted for in the literature.

In terms of developmental appropriateness (D'agostino et al., 2011), particularly with respect to understanding how the construct was operationalised and experienced within the LW.org.au online community, this study created a coding framework of core features and issues related to the notion of developmental appropriateness (D'agostino et al., 2011) in the clinical, community health and positive youth development literature. This included features and issues, such as help-seeking; reaching out; engagement; participation; screening; disclosure, egalitarian relationships; person-centred care; safe places; and boundaries (Patton et al., 2016; Phelan et al., 2020; Sawyer et al., 2010) to outline a few. However, as might be expected, this coding framework was modified in a recursive fashion throughout the data analysis process in response to earlier a priori and emergent coding within the field. This allowed the study to remain responsive to the ‘lived reality’ of the online community as noted above.

Similarly, with identity formation (Erikson, 1968, 1994), an a priori coding framework was devised to reflect identities that had been attributed to young people by themselves or others in relation to their condition in the clinical, community health, narrative and social media literature. This included identities, such as the survivor, patient, sick role, trickster, advocate, and prisoner to outline a few, and how these were represented in the LW.org.au online community. However, similar to developmental appropriateness (D'agostino et al., 2011), this framework was recursively modified during the data analysis process to capture additional identities, and to broaden these identity categories to reflect young people’s meanings, particularly when discrepancies emerged between how these identities were defined in the literature and experienced by young people. This was evident with the survivor identity being considered an empowered identity within scholarship (Hammond & Teucher, 2017), but in practice young people expressed differential, and sometimes negative or conflicting, understandings of the term. Moreover, a priori coding was also employed to capture identity processes across identity scholarship, including exploration in breadth; exploration in depth, ruminative exploration; commitment making; and commitment identification from identity status (Crocetti, 2018; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966) literature, and self-event relations (Pasupathi et al., 2007) of change, stability and insight from the narrative literature. This approach functioned as a form of conceptual triangulation (Denzin, 2007) and strived to capture the diversity of identity development and integration online.

Emergent coding

While a priori coding (Blair, 2015) provided a framework to guide the data analysis, emergent coding (Blair, 2015) was critical in grounding the study within the lived reality of the LW.org.au online community and to grasp an understanding of its culture, norms, relationships, identities, and the core constructs outlined within the a priori coding frameworks from young people, chat-hosts and the SCF organisations perspective. Emergent coding (Blair, 2015) is inductive, meaning it arises from the data. However, this does not suggest meaning resides within the data waiting to be discovered as is the case in positivist and post-positivist research. In contrast, constructivist research acknowledges emergent coding is an interpretative exercise informed by the researcher's positionality, and continually revised through their engagement with the community and the perspective of research participants (Charmaz, 2014). This approach to coding is a dialogic and hermeneutic activity that facilitates the fusion of perspectives to provide a richer account that is reflective of 'lived reality' and 'lay expertise' through the inclusion of multiple voices and experiences in interaction with each other (Charmaz, 2014).

In this study, emergent coding (Blair, 2015) was important for building an understanding of how the SCF organisation constructed the discursive reality of the site through its policies, procedures, protocols, practices and infrastructure, which established the organisation's institutional approach to developmental appropriateness (D'agostino et al., 2011). It was also valuable in capturing the differences in young people and chat-hosts understandings and experiences of the construct of developmental appropriateness (D'agostino et al., 2011) within the online community in response to the institutional approach. The latter was crucial for unearthing hidden factors at play that impacted the effectiveness of help-seeking, engagement, participation and screening support (Patton et al., 2016; Sawyer et al., 2010) for young people engaged with the site. By unearthing these factors, the study was also able to uncover novel solutions to address these concerns. Emergent coding (Blair, 2015) was also useful in broadening or thickening our understanding of core concepts outlined within the a priori coding scheme from young people, chat-hosts and the organisations perspective. This included using the phrases of the young people and chat-hosts through ‘in vivo’ coding (Charmaz, 2014). It also allowed the study to capture divergent meanings, particularly with respect to broadening identity categories and illustrating the degree of diversity encompassed in the use of specific terms, such as the survivor identity possessing a multiplicity of understandings with not all being congruent. It also facilitated the development of new codes and categories to better reflect young people voices in relation to their identity formation and integration.

In endeavouring to stay close to the ground and capture the lived reality of the LW.org.au community, and lay expertise encompassed within it, emergent coding involved a micro analysis of incident by incident and person by person coding to build up larger categories through open and focused coding in tandem with the a priori frameworks. In so doing, the study was able to capture, as Charmaz (2014) stated above, how ‘broad theoretical concepts take shape in local form’ through the events and activities engaged in online.

Positioning Theory

In addition to a priori and emergent coding (Blair, 2015), this study employed the analytic framework of positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) to explore identity formation (Erikson, 1968, 1994) in terms of the identity claims or positions young people adopted or others attributed them within the context of the LW.org.au online community. However, the analytic framework of positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) was also significant in illuminating the interpersonal, interactive dynamic of identity construction online in terms of the negotiation and validation processes young people and chat-hosts engaged in on the site, through its micro level and cumulative analysis of utterances. This was particularly pertinent for capturing identity construction and negotiation with others in relation to the online medium were identity formation, exploration and negotiation is often episodic and fragmented in posts and chat threads, rather than cohesive and linear as is the case in life narratives or blogs.

In this study, two analytic frameworks of positioning theory were employed in tandem to capture these different layers of identity formation, exploration, experimentation and validation online. Harré and Van Langenhove (1998) positioning triangle—which includes the vertices of: (a) position or identity claim; (b) speech act; and (c) storyline, and how this relates to rights and duties in terms of the local moral order of the LW.org.au online community and other contexts, such as the hospital or school setting—was used to tap into institutionalised identities and cultures. This includes identities, such as the patient and the nurse, where the patient has a right to be cared for and the nurse the duty to care, which is often reflective of the biomedical model of health. Harré and Van Langenhove's (1998) model was effective in capturing the interactional nature of identities outlined within the a priori coding frameworks. However, Harré and Van Langenhove's (1998) model was limited in capturing both the interactional dynamics of the online medium in terms of the LW.org.au site dynamics and young people's idenity claims, especially those that differed from institutionalised roles or identity narratives. This included young people's interpretations of terms such as survivor that ran counter to these dominant discourses.

Therefore, to capture identity positioning and negotiation at the emic level, this study also employed the positioning framework of Bamberg and Georgakopoulou (2008) who outlined three levels of positioning, including (a) the storied level, which included characters portrayed at the level of experineces or events shared in young people stories about the self online; (b) the interactive level, which included positions young people and chat-host adopted in terms of the conversational dynamics of the community, such as listener, speaker, mentor, and chat-host; and (c) the discursive level, which included how identities expressed at the level of (a) story-telling related to wider discourses or instutionalised identities, such as those captured in Harré and Van Langenhove's (1998) framework and the study's a priori coding. As a result, Bamberg and Georgakopoulou's (2008) approach was more attuned to interactional dynamics and validation processes, but also identity claims outlined through the process of emergent coding, which generally related to positive youth development frameworks and socio-ecological models of health, and more acutely captured the young person's perspective. Employing both positioning frameworks created a bridge between a conceptual and grounded analysis of the online community.

The use of positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) in this context was innovative. Although positioning theory was originally designed to capture the micro dynamics of inter-personal relations, it has predominantly been employed within public relations studies to explore positioning in relation to organisations. This study recognised the merit the framework has for capturing identity negotiation within the online realm. Furthermore, positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) was also valuable for exploring how identity formation and exploration (Erikson, 1968, 1994) was influenced by the culture and norms of the LW.org.au online community, and how these aligned or contrasted with the identities young people were positioned in in terms of other medical or youth-oriented settings, such as the hospital or clinical context. In this way, it shed light on how the cultures connected to the different models of health, such as the biomedical, biopsychosocial and social-ecological models (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) impacted identity formation (Erikson, 1968, 1994) within LW.org.au. The latter has implications for designing 'developmentally appropriate' interventions (D'agostino et al., 2011), as the notion of celebrating the young person's, 'young person self' connects strongly with the concept of person-centric care (Phelan et al., 2020) or placing the individual at the centre of practice in developmental literature.

Writing up the Ethnography

A significant challenge of writing an ethnography (Geertz, 1973) or netnography (Kozinets, 2010, 2015) following the data analysis, is translating to an 'outside' audience the complexity and diversity of the meaning systems and perspectives comprising the 'lived reality' of the online community by providing them with a rich context to understand this inside world, but in a manner that also adds depth and insight to our existing understanding of broader topics or issues, such as developmental appropriateness, help-seeking, engagement, participation and screening (Patton et al., 2016; Phelan et al., 2020; Sawyer et al., 2010). While the final ethnographic (Geertz, 1973) or netnographic (Kozinets, 2010, 2015) text was a construction of both the participants' and researcher's point of view in dialogue with each other, ultimately the responsibility of the final text resided with the researcher. However, in this context, the researcher needed to ensure what was written within the text was authentic to the accounts of the individuals and the situations as they occurred within the field. Thus, the practice of 'thick description' (Geertz, 1973) and utilising methods and coding frameworks that captured the depth and complexity of the meanings and perspectives operating on the site in relation to the whole, particularly the site's culture and institutionalised approach to developmental appropriateness (D'agostino et al., 2011), was important for producing this holistic, contextualized account of the workings of the online community of which young people living with a condition are a part.

This also facilitated a richer understanding of their identity construction and negotiation online in relation to inter-personal dynamics and the culture of the online community. This is crucial for understanding the role and value interventions can play within the field in fostering stronger identity formation, exploration and integration in young people living with a condition online. Thus, the goal of a good ethnography (Geertz, 1973) was to adhere to the criteria of trustworthiness and credibility. This study strived to achieve this by providing an authentic account of the actual happenings of the site from young people, chat-hosts' and the organisation's point of view by staying true to the eyewitness accounts gathered during the data collection.

On a broader level, the value of the rich, contextual understanding of the site the final ethnography (Geertz, 1973) and netnography (Kozinets, 2010, 2015) produces for scholarship and practice, is it allows more meaningful dialogue and engagement with the communities and individuals research seeks to support by peeling back the latent layers of interpretation comprising the ‘inside’ world, perspectives and ‘lived reality’ of the online community in a hermeneutic fashion to reveal this complex, but cohesive context. By doing so, this strives to enable the reader to move beyond their own perspective and create what Gadamer (1989) terms the ‘fusion of horizons’ in understanding the online community, and how its culture, norms, practices, relationships and identities relate to and inform wider issues, such as help-seeking, engagement, participation, and the screening of psychosocial, mental health and condition based concerns. By facilitating this ‘fusion of horizons’ or perspectives (Gadamer, 1989), the final ethnography (Geertz, 1973) and netnography (Kozinets, 2010, 2015) enacts the ethos and practice of ‘phronesis’ (Gadamer, 1989) allowing scholarship and practice to deliberate the ‘right action’ for specific individuals and communities in response to specific issues or concerns that generalised approaches fail to address, especially for those whose experience lies outside these norms, such as young people living with a condition. Thus, this ethnographic (Geertz, 1973) and netnographic (Kozinets, 2010, 2015) account goes beyond current understandings and approaches to encompass the outliers voice and perspective and render it a valuable part of the whole.

Chapter Summary and Conclusion:

In conclusion, this chapter has outlined the methodological approach and research design of the current study. It began with elucidating the research purpose which seeks to understand how the SCF’s online community functions to reveal the ways in which the site provides developmental, psychosocial support for young people living with a condition, and to examine the identity development processes of these young people.

It justified the value of employing a constructivist approach and netnographic methodology to examine the social reality of the LW.org.au online community, and the culture, identities, relationship and practices enacted and embodied online in terms of the perceptions and meanings young people, chat-hosts and the SCF organisation bring to the site.

It outlined the methods of data collection and data analysis that were essential to facilitating this diverse understanding of the LW.org.au community, including participant observation, semi-structured focus groups with young people, unstructured interviews with chat-hosts, field-notes, journaling, a priori and emergent coding and positioning theory. It also delineated ethics protocols for researching vulnerable young people within an online community.

The next chapter reveals the findings from this constructivist oriented, netnographic investigation of the LW.org.au online community. It includes the diverse perspectives of the SCF organisation, chat-hosts and young people, as well as the breadth and depth of young people's identity construction online in relation to the social identity categories of their (a) young person and (b) condition based selves.

Chapter 6 Findings

This chapter presents the findings of this netnographic (Geertz, 1973; Kozinets, 2010, 2015) study into the SCF's, LW.org.au online community. In doing so, it provides insights into how the online community functions as a developmental, psychosocial support for young people living with a condition, and examines how young people construct and perform a young person identity alongside their condition online.

The SCF's approach to providing developmental, psychosocial support to young people living with a condition through an online intervention is explored through the organisations vision and purpose for the LW.org.au online community, its design and layout, and the procedural guidelines and norms governing its operations. This provides the cultural model of the online community in which young people interact. This includes the standards and expectations set by the organisation, which are then monitored and enacted by the chat-hosts, and acknowledged performatively by the members. Next, it explores how young people's identity in terms of their (a) young person and (b) condition based selves are constructed on the profile pages and in the chat-room interactions. Finally, it examines the processes of disclosure and validation in the online community and chat-room interactions. The findings presented here are drawn from the Livewire.org.au website and associated policy documents; from interviews with chat-hosts; focus group discussions with young people; an analysis of the profile pages created by the young people; and transcripts from the chat-room where the interactions, which are the focus of this study take place.

Research Participants:

Research participants were recruited through the SCF's database. For ethical reasons, this was obtained from the organisation to accord with the University of Technology Sydney's

Human Research Ethics Committee's protocol (Application no. ETH18-3031). Young people and their guardians were sent a 'youth friendly' and 'parent version' of the 'Participant information sheet' and 'Consent form' for the participant observation, online focus groups and online interviews components of the study. Following recruitment ten LW.org.au members consented to participate in the study. All of these participants were female. Concerted efforts were made to recruit males to the study, but due to ethical challenges this was not realised. The LW.org.au members ages ranged from 14 -20 years and these young people lived with primary and secondary or comorbid conditions including: Anxiety, Arachnoid Cyst, Asthma, Autism, Cerebral Palsy, Chrohns disease, Ehlers Danlors syndrome, Epilespy, Gastrointestinal disorder, Intellectual disability, Klippel-Feil syndrome, Mucopolysaccharidosis Type IV (MPS6), Maroteaux-Lamy syndrome, and Non-Classic Cystic Fibrosis. LW.org.au member participants can not be identified any further due to issues connected to confidentiality related to Ethics. In addition, nine chat-hosts participated in the observation and six participated in the online interview component. Three of the chat-hosts were male and six were female. Only one male chat-host participated in the online interview component.

A Unique Space – Context of Interactions

The Organisational Approach:

The Starlight Children's Foundation (SCF) positions Livewire.org.au (LW.org.au) as an online community for young people living with an illness or disability and their siblings between the ages of 12-21 years. The online community operates in conjunction with a Livewire hospital program that delivers creative arts-based workshops and diversional therapy to young people in the hospital environment. The site's primary mission or purpose, as articulated on the *'Discover Livewire'* homepage, is to: "connect, support and empower" (Starlight Children's Foundation, 2017) young people by providing them with a safe, fun place as suggested on the website to: "share stories, ask for ideas and talk about whatever is going on in their life from operations, MRIs …to family and friends - even the frustration of missing out on going to the beach because of another hospital experience" (Starlight Children's Foundation, 2017). Thus, the online community offers young people living with a condition opportunities to connect with others in a similar situation who 'get it' (Starlight Children's Foundation, 2017). Implicit in this notion of 'getting it', is recognising young people living with a condition often confront 'tricky situations' that are hard to deal with, and not everyone understands. Thus, having a place to connect with others who do is crucial. Therefore, the organisation safeguards the community by providing a bounded space, actively moderated by chat-hosts trained by the organisation in adolescent health, development and well-being. The organisation and the online community also maintain open channels of communication with parents, health professionals, and other support services to ensure the online program remains responsive and capable of catering to the diverse needs of its members.

Consequently, the SCF organisation and LW.org.au community provides a unique platform for these young people to connect, share stories, create friendships and have fun with other young people who understand. In the field of online peer support and social media interventions for young people living with a condition, LW.org is perceived by its members and chat-hosts as fulfilling a distinct gap and offering a unique form of support. Comments included:

"I haven't come across anything like it before" (Member 6);

"It's such a unique platform" (Chat-host 1);

> "Point blank it's separate from anything else, it's completely unique in what it offers" (Chat-host 2);

> "There's things like Facebook and different support networks that offer such a small amount of what LW.org offers" (Chat-host 3).

To understand this especial quality of the LW.org.au community from the perspective of those engaged with the site, this study examines the site's culture, its norms of interaction, and how these emerge in response to the diverse needs of the site's membership comprised of the shared identity categories of being a (a) young person and (b) someone living with a condition. It also reviews the site's moderation model and the role of chat-hosts.

Cultural Model of the LW.org.au Online Community

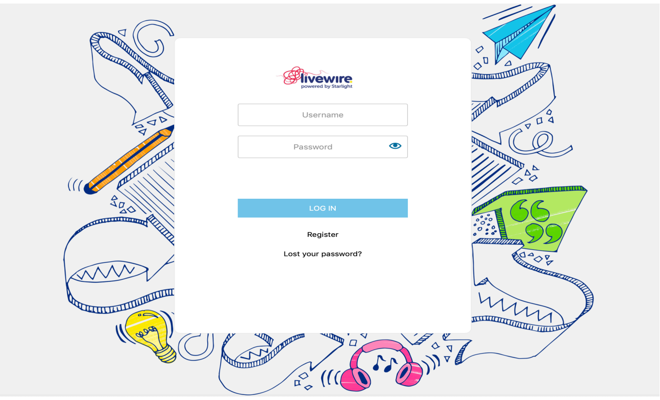
The unique 'culture' and norms of interaction on LW.org are a product of both the sites structure and practice. On a structural level, the SCF's intention and vision for the community is articulated through the site's interface, design and layout. Here, LW.org.au both conforms to and challenges tradition understandings of social media platforms for young people. It conforms to traditional perceptions of social media platforms through its design, layout and functionality that offers various levels of engagement for young people. In the online interviews, chat-hosts highlighted how the new design of LW.org.au was similar to Facebook, offering a sense of familiarity when socialising into the community. One said: "I feel like logging on and having a Facebook style newsfeed is a really good way to get kids comfortable with the website" (Chat-host 1).

It is important to note, this study is only concerned with young people's profile pages and their interactions in the chat-room. However, it acknowledges, when young people interact with each other and the chat-hosts online, they do not ignore the other features of the site. Thus, to provide a context, these features are briefly set out below.

These features include:

(a) A ‘sign up’ and ‘login’ page with the ‘Livewire Powered by Starlight’ logo clearly displayed above the ‘username’ and ‘password’ tabs.

Figure 1. LW.org.au Login Page



(b) A public newsfeed displaying recent posts, comments and likes by members, chat-hosts and hospital groups in written, image or video form. Here, members and chat-hosts can upload a new status, image or video directly from the newsfeed or their profile page. There is a 'search bar' in the top right corner of the newsfeed and quick links to various features of the site on the side, including member's profile pages, messages, groups, events, articles, LW TV, podcasts, music, and e-versions of the Livewire zine (magazine). When members log on to the site, the chat-room instantly pops up in the bottom right corner of the newsfeed page, and can be maximised or minimised for use. There are also toggle switches on the newsfeed page as a form of assistive technology, allowing members to change the site's font and colour for their convenience. Also, all images on the newsfeed have captions written above to facilitate inclusion.

(c) A profile page for each member, chat-host and hospital team. Profile pages are similar in design to Facebook, with a cover image and profile photo followed by a space to write statuses. Profile pages display all statuses by or to LW.org.au members and chat-hosts from others on the site.

(d) Private message function similar to 'Facebook Messenger' where members and chat-hosts can send 'private messages' asynchronously.

(e) LW.org.au groups that members and chat-hosts can join. These include groups relating to young people's condition, such as the 'Cystic Fibrosis' or 'ChIPS' group, and their general youth interests, like the 'Comedy' or 'Harry Potter' group.

(f) Events pages where members can click attending and receive reminder notifications. These include events such as special guest chats, chat trivia nights, workshops on demand, and livestreams from the hospital.

(g) An article's section with content written by both chat-hosts and members on various topics.

(h) Livewire TV where chat-hosts and members post video content and livestreams from the hospital.

(i) A podcasts section that connects to a private Livewire account on SoundCloud.

(j) Zine uploads providing access to the printed Livewire 'Zine' or magazine that features content written by Livewire facilitators and young people in the hospital and online.

(k) Music, which features an album of songs created and produced by Livewire facilitators with young people in the hospital.

(l) A Chat-room where members can chat in a public chat with everyone or engage in a private chat with members or chat-hosts in real-time synchronously. There is also the option for private groups for special events, such as a chat with a special guest, which

> included a book club chat with Markus Zusak, author of the 'Book Thief' within this study.

The SCF’s vision for the community, or more aptly its ‘intended culture’ is articulated through its guidelines and policies as they provide the context within which online interactions take place. Relevant documents include: ‘Terms & Conditions’ (T&C), and policies and guidelines, such as: ‘Livewires values and community standards’; ‘Livewires social media and moderation policy’; ‘Safeguarding children and young people’s policy’; and ‘Privacy policy’.

As a fully functioning social media platform, the SCF draws upon the developmental literature and social media norms of young people to design a site that recognises, as stated by one chat-host: “being a teenager is all about being social. It’s all about those social networks” (Chat-host 1) both offline and online. Here, the SCF responds to young people’s developmental need for heightened social connection and engagement, and recognises social media platforms as a valuable avenue for facilitating this social connection due to their pervasive presence in the ‘everyday’ lives of young people. This was evident with another chat-host commenting:

> “We shouldn’t under-estimate how vitally important social media actually is for teenagers. It’s not something you can remove them from in any way. You get your social circle and most of it happens online these days” (Chat-host 2).

By providing young people living with a condition with a space for social connection and participation that aligns with wider social media norms, the SCF responds to young people’s developmental need for social inclusion and integration in youth culture and contexts. However, the organisation also acknowledges that for young people living with a condition, opportunities for social connection may be limited due to the challenges of their condition. Consequently, providing a safe space for these young people to feel valued and accepted is important. This was reflected by one chat-host who stated:

> “When you have a condition or a disability and those social connections and networks aren't as strong as they potentially could be its soul crushing. I think it’s important for teenagers to have a place like Livewire where they are accepted and people are always happy to see them …I think it’s a soft place for them to land”. (Chat-host 1).

Thus, the SCF’s guidelines and policies are what set it apart from other mainstream social media platforms and online communities as they offer higher levels of protection for young people who are vulnerable due to their condition, but still eager for social connection and engagement like their peers. The SCF and LW.org.au community recognise other social media platforms may not have these safeguards in place to support young people developmentally alongside their condition based concerns. Thus, the SCF provides an online space which responds to young people’s need for social connection, but understands those living with a condition are more likely to experience social isolation, dislocation, exclusion, stigmatisation and bullying due to the: (a) visibility of their condition marking them as different; (b) inhibiting or restricting their participation in peer related activities or settings, including other social media platforms; and (c) detracting from them important forms of condition-based support. The latter is particularly relevant for socially adept young people and LW.org.au members who become apt at practising normalcy in other settings to fit in. Therefore, providing a space that offers social engagement as well as condition support was highly valued by these and other members. These sentiments are echoed in the current research with young people citing the main reasons they initially decided to join LW.org.au was to connect around condition based concerns to counter the lack of relatability in other contexts. Comments from members included:

> "I was excited to join Livewire to talk to people going through similar things and who were more likely to understand me" (Member 7);
>
> "I was so happy I had finally found people I could relate to as my main friends [offline] only had a limited understanding of my medical experiences" (Member 6);
>
> "I'm anti-social in real life. Livewire gave me the confidence to socialise and make new friends. I found people with disabilities like me" (Member 9);
>
> "My able-bodied peers don't really know how to talk to me about my disability or illness … I think it comes from not wanting to say the wrong thing or focus on it too much; … also not having experiences to relate to like being in hospital or the big questions like children or the future, which look different when you have a chronic condition" (Member 6).

It was clear that members appreciated LW.org.au's capacity to provide a unique space for them to connect with other young people who "just get it". One chat-host stated: "they … felt really unheard, really unsupported or like no-one really understood them" (Chat-host 2) in other spaces. This included not only peer-driven settings like school, recreational activities and sport, but also the hospital context, where young people found themselves either on adult wards in private hospitals or among paediatrics in the major hospitals with minimal attention paid to their unique development needs as adolescence and emerging adults.

The Members and their Context

This awareness that young people living with a condition are at a heightened risk of social isolation, exclusion, stigmatisation and bullying in other peer driven settings is echoed in the perceptions of the chat-hosts. The creation of a ‘safe’ environment was significant for all of them. For example, one chat-host (1) said: “I think the people who are on Livewire really, really need it. It is their main social interaction because they don’t have that safe environment for them to interact socially without being bullied or questioned offline”. The sense that the LW.org.au site might provide the main social interaction, expressed by Chat-host 1, was echoed by other chat-hosts. Chat-host 2 noted that LW.org.au could be accessed at school during lunchtime when other possible social interactions were not available because of this sense of social isolation and exclusion. She stated: “sometimes its loneliness … and especially like at lunch time and free periods or when it’s a horrible feeling of sitting by yourself in the playground, they can get out their phone and jump on Livewire”. Another chat-host (5) mentioned LW.org.au offered support when hospitalisation had created a rupture in the lived experience of being at school and with peers. She commented:

> “sometimes they are having issues with school itself because you know with long periods in hospital you are kind of missing out on all that time in your standard school, and as good as hospital school can be it just doesn’t compare. You are kind of missing out on that social aspect being with friends and learning with peers” (Chat-host 5).

Chat-hosts also noted that the platform itself was accommodating of young people with particular conditions who may struggle in other social contexts or become overly defined by their condition because of its visibility among peers. Chat-hosts commented:

> "it's beneficial for kids on the spectrum because there's no eye contact, there's no intimidating face to face. They can take their time and formulate their replies" (Chat-host 1);
>
> there's a lot of value especially for kids ...who have bad social anxiety" (Chat-host 2);
>
> "for members with physical disabilities they're not judged on it whatsoever …like for members with Cerebral Palsy … they can present their own identity and their own interests without having judgements about how they look influence how people see or treat them online" (Chat-host 3).

However, isolation and exclusion, and their effects are not constrained to peer settings in the school context. Chat-hosts and members also acknowledge how these experiences extend to the hospital context in various ways. This includes isolation imposed by hospital staff due to the medical concerns or challenges of specific conditions restricting young people from attending peer related workshops in the hospital organised by Livewire's hospital team, play therapists or diversional supports. One chat-host (5) commented:

> "We just had a policy change in our hospital, which meant that our CF (Cystic Fibrosis) patients couldn't come to see us and attend workshops anymore and so we were finding at different times we were having, you know, seven, eight isolated patients on the ward that were just CF. Plus, you know, a whole other part of a ward might not be able to make it because they might be ED (Eating Disorder). And so, yeah, we're just finding more and more teens were isolated and weren't able to take part".

This is significant especially as the hospital context is often felt to be an isolating place for young people, particularly those outside of children wards in adult settings or in private hospitals. To elucidate this one member commented:

> “When I was in hospital last year, I had a particularly rough night where I couldn't get much sleep. Visiting hours ended at 8pm and adult hospitals are very lonely places. It was nice to chat to the chat-host and members about the show I was watching and such and just have company other than beeping machines for that night” (Member 6)

While chat-hosts directly referred to experiences of isolation, exclusion and bullying being a key motivation for why young people reach out to the site, members were less direct discussing it through the theme or issue of a lack of relatability with others. This was evident with young people citing the main reason they initially joined LW.org was to build connection with other young people in a similar situation to them. Members commented:

> “I was excited to join Livewire to find friends with the same illness as me who can understand better than my school friends. Livewire definitely made me more confident to socialise and make new friends” (Member 1);
>
> “Joining LW.org.au was great, because I could chat about my disability and chronic illness with others who could understand, and encourage, and support me, and we lift each other up” (Member 2);
>
> “It’s harder to connect with the real world and my friends when I’m unwell, so it’s nice to have a place like Livewire to pass the time with others who can relate” (Member 6);
>
> “My friends on Livewire ‘get’ me better… They understand more what I’m going through and can sympathise with us whether it be about hospital or being sick” (Member 5).

Similarly, a chat-host (5) also confirmed this perception, stating members had mentioned: “they don't really feel comfortable talking to their school friends or their regular friends about their condition. They don’t really understand what it’s like or how hard it is". This lack of relatability lead to young people living with a condition feeling disconnected with one chat-host (2) commenting as stated above: “they …felt really unheard, really unsupported or like no-one really understood them”.

While this has greatest relevance for young people who are isolated, for members on LW.org.au who are more socially adept in other contexts and who are less likely to experience socially isolated due to their ability to “practise normalcy” (Ferguson and Walker 2014), it is also significance as it recognises their desire to be part of the site and support members who are experiencing challenges socialising. This allows these young people to act as mentors to these peers. It also acknowledges, despite their social connectedness in other contexts, they are also equally driven by the motivation to connect with others who understand or ‘just get it’ (Starlight Children’s Foundation, 2017). This is particularly evident through the LW.org.au mentor and representative program, when young people can return to the LW.org.au community as an older member in the role as mentor (21 years or older), or take on a leaderships role as a rep (representative) of the community (10-21 years).

Engagement

Having set out the vision of the SCF, the design and infrastructure of the LW.org.au site, and the characteristics of LW.org.au members, this section presents data on approaches used by the SCF in its policy practices and procedures, and through the work of the chat-hosts to ensure members can contribute to the overall mission of the SCF and benefit from their participation in LW.org.au.

The SCF views engagement as connecting with young people and providing a service that responds to their needs. Here, connecting involves meeting young people at their level and including their voice in the design and evaluation of programs. This understanding of ‘connecting’ and ‘engagement’ by the SCF was evident with young people being included in the re-design of the LW.org.au site in 2017. One chat-host (2) stated: "we did interviews with young people at RCH (Royal Children's Hospital Melbourne) to work out the new site". It was also explicated in the SCF's 'safeguarding statement for young people', which articulated: 'we believe you should be able to make suggestions and give feedback on any activity, event or program that you have been involved in' (Starlight Children's Foundation, 2020b).

Engagement for the SCF also recognises young people are distinct from patients in paediatric settings, and therefore require services catering to their unique developmental interests and concerns. These developmental concerns include a heightened need for social connection and engagement through social media platforms, as stated above by one chat-host (1) who commented: "being a teenager is all about being social. It's all about those social networks" and supported by another chat-host (2) who reiterated: "we shouldn't underestimate how vitally important social media actually is for teenagers". The difference in engagement between paediatrics and adolescence and emerging adulthood was also explicated by the distinction between the chat-host and the captain's role within the study. The latter of which was central to the SCF's children hospital program, known as the Captain's program. One chat-host (4) explained stating: "chat-hosting is more a moderation role with facilitation, while being a captain in the hospital, you are actively trying to entertain". Thus, engagement in the LW.org.au program is about relatability involving connection, not performance. This includes: connection to young people, connection to chat-hosts, connection to the SCF, connection to the hospital program and community, and connection to other services. The SCF also recognises conversation as central to building and sustaining that connection with one chat-host (4) expressing: "they love a good conversation and chat".

Engagement for chat-hosts aligns with the over-riding view of the SCF in that it is centred around building, sustaining and strengthening connections. This is not unexpected given the training that chat-hosts undergo. It is also evident in the manner chat-hosts talk about how members respond to the sign-up process when joining the site, stating the main reason young people reach out is for social connection. One chat-host (2) expressed: “initially when they’re jumping on the site, like it’s obviously for the purposes of wanting a bit of interaction, socialisation, support; all that sort of stuff’. However, chat-hosts also recognised not all young people were comfortable making this leap. Another chat-host (3) explained:

> “sometimes we come in contact with some patients through the hospital program and you know they’re really going to thrive in this community, but it’s just kind of a push to get them on there and understand what it’s going to be like. With that being said, it’s also very easy for some young people in making that initial interaction”.

In recognising each young person is different, the chat-hosts make a special effort to adapt the program to the individual when building initial rapport and sustain this through the members experiences online. The chat-host’s ability to achieve this is strengthened by the LW.org.au community being a fully functioning social media platform, offering, as one chat-host (4) mentioned: “different ways of engaging and different levels [of engagement]”. Another chat-host (5) reiterated:

> “You can literally be super passive and just watch a video and not comment or anything, or if you want to just comment on videos you can do that too. If you want to become more active and share a little more about yourself, you can post in the newsfeed or chat-room”

The chat-hosts also recognise the possibility of being a member and deriving benefit without being an active contributor to the chat-room. One chat-host stated: “the good thing is there’s the option for members who don’t really like to say anything in chat” (Chat-host 1). Thus, choice of level of engagement is fundamental and this notion of choice is critical. One chat-host (2) pinpointed this in the online interview stating:

> "I think the flexibility and general autonomy of use on LW.org is a big reason why young people stay. There's no pressure, it's totally up to them how they want to interact with LW.org, how much, how often".

A place for engagement is also as one chat-host (5) expressed: "something chat-hosts try to make the site". This chat-host emphasises diversity as important to the SCF's purpose of engagement. She continues: "We're always trying to make the site different enough each day so that young people keep wanting to come back" (Chat-host 5). This diversity of engagement is also connected to the chat-hosts personality and skill set. Another chat-host (1) highlighted:

> "some chat-hosts have a mental health background, others are more creative or nerdy and into gaming. … with different skill sets and different avenues to connect and communicate with members, I think this creates a really strong (chat-host) team and really strong strategies to ensure we're giving the best support to each member".

However, while chat-hosts suggest these various layers of engagement and the diversity they promote are a great means for striking initial rapport, they predominantly state it is the chat-room and peer connections that are the heart of the site. Chat-hosts commented:

> "In terms of young people staying on the site, I really believe it has a lot to do with the chat-room. As much as we try to get them to branch out and see and interact with everything on the site, it's really the place they want to hang out, and I get that, that's just what teenagers want to do. They just want to sit and chat, and that's so normal for them" (Chat-host 2);

> “I think the over-arching thing is social connection. I don’t think its necessarily the articles or the content that we come up with as chat-hosts that make people stay. I think it’s connecting with other young people and forming real friendships” (Chat-host 5).

These peer connections, which are based on the site’s social interactions, are also linked back to the needs of the individual, giving a personal element to the site. Chat-host 3 mentioned: “a lot of members don’t really know how fun and personal the site can be, and that’s kind of what really hooks them in. There’s kind of a lot of fun, lively people online”. Engagement is thus connected to the notion of fun. It is also connected to the notion of friendship. He continued: “I think it comes down to if you’ve got those friendships on there, we see you on more often” (Chat-host 3).

From the perspective of chat-hosts engagement must be related to the ‘everyday’. This concept of the everyday is interpreted differently by the chat-hosts. One chat-host (2) said: “Some members are on every single day and every hour of every day” indicating that the everyday is about the minutiae of life. Another chat-host consider the ‘everyday’ as relating to the circumstances of the young person living with illness or disability. They said: “we’re constantly chatting about stuff going on in popular culture, movies, and TV shows …but then again, we’re chatting about TV shows because they’re stuck in hospital, so that’s sort of still their condition” (Chat-host 4). There is also a recognition by chat-hosts that the ‘everyday’ relates to the challenges of members’ conditions intruding or punctuating into their everyday lives, and the value of LW.org.au to provide support in this context. This was acknowledged by Chat-host 1 who stated: “sometimes it’s just about listening to them that day and providing validation saying, you don’t deserve that and that sucks that that’s happening to you”.

A final characteristic of engagement is the creation of a safe space specific to the needs and interests of young people. Both young people and chat-hosts suggest that young people are more likely to connect to LW.org.au while in hospital; when dealing with the challenges of illness or disability; or being isolated, excluded or bullied in 'normative' peer settings. Chat-hosts were aware that hospital experiences, so much part of the everyday life of members, could reinforce this sense of not fitting in. Chat-host 1 spoke of the problems that can arise from having teenagers in children's wards in hospital, she said;

> "it really drove home for me how important it is to have something for teenagers ….to give them the space to feel okay about being sad because when its full of little kids like you don't want to talk about that kind of thing".

Similarly, Chat-host 3 noted:

> "you could see that gap there very much".

Young people or members' perceptions of engagement coincide with those of the chat-hosts. Young people perceive the site as engaging because as one member (7) suggested "there is always something to do and get involved in". This member acknowledged the importance of diversity, both in relation to the topics of discussion and in the approaches of chat-hosts. She continued: "I enjoy talking about different things with different hosts" (Member 7). Members may not analyse their perceptions of engagement in the way that the chat-hosts do, but the way they talk about their involvement in the chat-room provides evidence that they recognise engagement as a complex phenomenon. Member 2's discussion of engagement demonstrates this complexity. She highlights the importance of choice and the ability of the site, through the skills of the chat-hosts, to match the needs of the individual. She saids: "I like to talk and chat a lot, but everything is pretty cool" (Member 5). She noted the importance of that sense of personal support for engagement in social activities and sustaining connection to the site.

She continued: “when I first joined there was a member that welcomed me and was so sweet. There was also a chat-host, [Jane]. She was so lovely and always there for me” (Member 5). She mentioned the chat-room was a ‘really warm space’ which reinforces that notion of a safe, everyday space. Finally, when asked about the role of chat-hosts in facilitating engagement, this member noted the importance of diversity among the chat-hosts when she said: “Oh yeah it does depend on the chat-host. I reckon some chat-hosts support you more in a professional way, and some are a bit more friendly and fun” (Member 5).

In this consideration of engagement, it is important to recognise that there are technical issues that impede engagement because they prevent potential members from taking part in the chat-room. As in many other settings, people who use assistive technologies to communicate in their everyday lives may discover that the LW.org.au site is not as easy to access. The SCF has been responsive to the concerns expressed, including captions for all visual text and a toggle on and off switches to ensure the site is accessible to everyone. These technical fixes go some way to providing the complex experience of engagement.

“Getting it” – The Norms of this Unique Space

LW.org.au is a social space in which members of a community interact. The previous section has presented findings on engagement in the LW.org.au site, particularly the chat-room. This section reports findings on how the members and the chat-hosts identify and perform the norms that create the unspoken rules for interaction on the site, especially within the chat-room. Through the policies and guidelines mentioned above, the SCF explicitly or implicitly has established norms for interactions on this platform, and the training of chat-hosts further reinforces these norms

Acceptance is essential to the functioning of this site, and serves to counter the sense of disconnection that all members experience. The sense of disconnection is part of the broader lack of relatability these young people experience – other young people (mostly) cannot relate to the lived experiences of illness and disability that is the everyday reality of these young people, as already noted above, and there may further be a disconnect between the young person as a teenager and the young person as someone with illness or disability.

Sharing

The key norm operating in LW.org.au among chat-hosts and members is that of ‘sharing’. The discourse of LW.org.au reinforces this word, which contains within it the notion of an interaction involving others equally. The phrases ‘shared experiences’ and ‘shared understanding’ are frequently used by all participants in this study. In reality, neither the experiences nor the understandings are actually ‘shared’. However, the use of this term facilitates a sense of relatability largely missing from the everyday lives of members. However, the more factually accurate term, common, as in ‘common experiences’ or ‘common understanding’, does not reflect social interaction, nor does it reflect that notion of ‘getting it!’; that special understanding that arises from participating in a group with clear but implicit norms. This ‘getting it’ subsequently functions as a springboard to celebrate diversity in relation to the young person’s everyday life and teenage identity.

These shared experiences and shared understandings are based on another sharing, that is, the bringing together of two facets of the lives of these young people; their everyday ‘young person’ selves and their everyday selves who live with an illness or disability. As noted above, the members of LW.org.au experience a lack of relatability with their peers who often see them only as a person with an illness or disability and do not recognise the young person with interests beyond their condition, or who overlook the illness or condition in an attempt to relate to the young person. Thus, acknowledgement of these two facets of life is a key norm in LW.org.au, one that is lacking in everyday life.

Member 6 expressed her frustration and disappointment that her peers at school overlooked her condition. She said: “my condition is just as much a part of me as my hobbies are – it has made me who I am”. This member’s reaction seems to suggest that in becoming adept at “practising normalcy” (Ferguson & Walker, 2014), it detracted from her important forms of support connected to her condition, namely the recognition and integration of her condition into her wider identity, everyday life and conversations with others. Chat-host (3) confirmed this experience of a lack of relatability with peers around condition concerns, stating:

> “I hear most from the members that …their ‘normal’ friends just don’t understand …like they try to, but it becomes a negative thing to explain what’s going on, and then they are not understanding or appreciating how hard it is”.

He went on to suggest while ‘normal’ peers might tend to overlook the challenges of how difficult it may be to live with a condition, it was the identity of living with a condition that become most salient in their eyes. This was especially the case for LW.org.au members with visible physical and behavioural concerns, or evident intellectual disabilities. This was acknowledged by Member 6 who in response to being wheelchair bound found she was frequently overlooked by her peers for sport activities.

This inability to bring together the two facets of their selves was not limited to ‘normal’ peers. Another member (9), suggested it was she who could not relate to her ‘normal’ peers. As mentioned above, she defined herself in the online focus group, saying: “I am anti-social in real life” (Member 9). However, this trait seemed to dissipate in the LW.org.au community and a Facebook disability group, where she became more confident and social among others like her who understood, even though she remains anti-social offline.

The importance of equal acknowledgement of these two facets of the self was seen as a benefit of the LW.org.au community in comparison to other peer-driven settings, because its members were able to relate, understand and sympathise with each other, whether it be about their condition, school, hospital or something else as one member (7) stated: It's not always about hospital stuff". This sentiment was articulated by Member 6, who suggested that on LW.org.au, it was understood by other members that her 'condition was just as much a part of her as her hobbies, interests and talents'.

With members of LW.org.au not needing to over-explain their condition, because there is an instant sense of knowing, they are able to celebrate both the dark and light elements of living with a condition. This gives rise to humour, an understanding of the pervasiveness of their condition in their everyday life, and an opportunity to be seen as a whole person. This provides the site with another norm, a sense of authenticity, arising from the 'everydayness' of the illness or disability experience. Young people living with an illness or disability seek to have their condition and the challenges associated with it recognised, understood and in some senses validated, by those who can relate. However, an equally immanent theme in the data is the desire to be recognised as a young person not defined by their condition. Yet at the same time, this does not render their condition entirely absence from their everyday life or sequestered from their identity as a whole. Arguably, their condition plays such a pervasive role in their everyday experience and sense of self, it almost creates a new 'normal' for these individuals with Member 6 suggesting earlier, even a different future. It was also clearly demonstrated when members suggested that alongside the core benefits of LW.org.au being that they could talk and relate to other young people who understand, was that in juxtaposition to 'normal peers', those on LW.org.au or with conditions could laugh and joke with them. One member (6) commented:

> “members online know it’s okay to laugh with me about things. I find a lot of my friends with conditions like me have quite a twisted sense of humour and it’s okay to poke fun as long as the question is coming from a good place”.

One could argue that this ability to make light of the situation is a product of a shared understanding that renders it ‘politically acceptable’ to do so with others who have that shared experience. Without this, ‘normal’ peers feel uncomfortable not only to make light, but also to know how to approach or talk to someone about their condition, even if this is done with the best of intentions. Often this inability to communicate results in the young person with a condition being seen only as their condition, or conversely as a young person with their condition and its prominence in their everyday experience being overshadowed. When asked what would foster better understanding and rapport with ‘normal’ peers, LW.org.au members suggested open conversation with humour, while chat-hosts proposed giving young people living with a condition the skills to have a voice in other settings. This was suggested by Chat-host 3, who commented: “I think Livewire gives members the confidence to know it’s alright to speak up and have a voice”. Nobody mentioned the implicit norm operating on the LW.org.au site, being trust.

Another norm of the LW.org.au site is continuity. It is almost a truism that social media sites obscure the notion of physical location. Members noted that their need to visit or go to hospital often disrupted their everyday life, planned goals, future aspirations, and isolated them from ‘normative’ peer settings. This was evident when Member 10 stated: “It’s my friend’s birthday this weekend and I was supposed to go, but can’t, because I’m stuck in the hossie (hospital)” However, the LW.org.au site is there and accessible, regardless of where the member might be. Another member (9) noted:

> “When I came out of surgery and couldn’t walk properly, I jumped on Livewire to distract myself haha ☺. Lying in bed all day is kinda boring. I was literally lying like a potato, so it was nice to jump online and chat and play games”

A Space for Young People

A space for age-appropriate conversations can be challenging in the hospital setting. Sometimes these young people are treated in adult wards, but more generally they are treated in children’s wards. However, both contexts do not always cater developmentally to the needs of young people as an adolescent or emerging adult. A benefit of LW.org.au in these settings and beyond them, is it provides a space for young people to be ‘young people’. The importance of this emerged with Chat-host 1 mentioning that when young children are in the Starlight room, young people (adolescents or emerging adult) often refrain from talking about things that are relevant to them, because they’re not appropriate or relatable to children. She noted: “they become very attuned to not letting stuff affect these younger [individuals]” (Chat-host 1). On many occasions, they adopt a protective or more adult stance towards them. Therefore, the LW.org.au chat-room provides a conversational space for young people to talk about the challenges they are facing and what upsets them separate from other children. This is especially the case, when they are dealing with highly abnormal experiences, such as bereavement, operations and illness, frequently in isolation. However, young people also stress the importance of having a space to share the good things, especially around the hospital experience. One member (6) expressed:

> “I think coming away from a hospitalization with positive memories is so, so important, especially for young kids. Being able to engage with Livewire online and doing the fun things makes it a lot easier. It is distraction without minimizing or suppressing the hard

> bits. I think that is the most important thing, that you can laugh about it and play games but also say that today really sucks".

This sentiment was reflected during the observation when one of the members jumped online into the LW.org.au chat-room while she was in hospital and having a particularly bad day. The members were already aware that she had been in hospital for surgery and asked her how she was doing. She specifically said she had jumped on LW.org.au to distract herself from the pain and lonely hospital experience. Hearing this, members empathised with her about how difficult it is to be in the hospital environment, and shared funny and humorous stories about how they mucked up in the hospital, sneaking down to the cafeteria without the nurses knowing and just being general 'teenagers' to cheer her up.

A Medically Free Space

A crucial norm of the LW.org.au site is that it provides young people with a 'medical free' space to connect with other young people who understand. This not only differentiates LW.org.au from other illness or disability focused offline and online communities, but also separates the chat-host role from other clinical and allied health professionals. The focus group discussions indicated that being a medical free space was particularly valuable. Many members suggested that the inclusion of a professional counselling or medical component would detract value from the site. They felt this had the potential, as one member (6) suggested: "to bring everyone down". However, it is important to contextualise this understanding and commentary. The reason why many members felt the inclusion of professional counselling or medical support within the LW.org.au community would bring the site down, was in response to these young people's awareness of the high focus placed on their conditions and the tendency to situate them within the patient role in other medical settings or condition-based online communities. Moreover, in these other online communities, participants suggested that these were primarily there to serve a crisis function; allowing young people to reach out in times of crisis to gain support in relation to a specific incident or experience before being referred onto other services, or to provide them with a space to ask questions in relation their condition. The difference with LW.org.au is its ‘everydayness’. Here, being a medical free space makes it accessible to members at any time, to talk about everything and anything, illness and disability focused, or not.

Diversity of Topics

The diversity of topics that can be discussed in the LW.org.au space, are reflective of the concerns and interests of the members themselves, who are adolescents. The clearest illustration of this, was in an interview with Chat-host 4 who stated: “Livewire is great place for members to kind of explore and find their adolescence who otherwise would have trouble going through these developmental stages in normal peer groups”. The members themselves appear not to reflect on this, but their participation in the chat-room shows evidence of the diversity of topics and interests characteristic of adolescents in action.

Big Brother, Big Sister

Strongly associated with the understanding of LW.org.au as a medically free space and place for adolescence, is the important and unique role played by the chat-host, who are seen by LW.org.au members as a ‘big brother or big sister’ and a friend, rather than a medical professional. One member (6) stated: “the chat-host are more like friends and mentors”. Members were keenly aware that chat-hosts were not medical professionals and do not behave as their doctors, nurses, social workers, therapists and so on do. One behaviour singling out this difference was note taking. Chat-host do not take notes, when as one member (7) suggested: “even the music therapist takes notes”. This concept of ‘note-taking’ made young people feel like they were constantly being monitored or medicalised within other settings. In contrast, chat-hosts seemed more like peers offering an open, egalitarian relationship. Picking up on the same point, a chat-host (1) asserted: “we have no dog in this fight … we’re not nearly important [enough] to be let anywhere near your medical files, let alone take notes”.

The Discourse of the Chat-Room

The words used to refer to a phenomenon indicate explicitly or implicitly the meaning given to it by people engaged in shared interactions. When asked in the online focus groups and interviews, ‘what five words would you choose to describe LW.org.au and why?’, the over-riding response from members and chat-hosts included, in order of frequency: (1) supportive; (2) fun; (3) safe; (4) engaging (5) inclusive; (6) grounded/authentic; and (7) community. Less frequently expressed, but nonetheless still important to the discourse about the site, were terms including: connection, socialisation; warm; welcoming; non-judgemental; kind; generous; caring; easy/effortless; personal; uplifting; hilarious; silly; crazy; adolescent; special; family; fantastic, and amazing.

Figure 2. Word Cloud Depicting the Perceptions of the LW.org.au site

An analysis of this vocabulary provides further insight into the way in which LW.org.au is understood and experienced. It goes beyond the expectations and practices designed and implemented into the site by the SCF, and beyond the norms which regulate the practices of the chat-hosts and members. It indicates the relationship of concepts and ideas that members and chat-hosts express, adding another layer of complexity to the understanding of the cultural model of the site.

At the centre of this web of descriptive labels is ‘supportive’, which appeared to be integral to members and chat-hosts understanding of the community, with 70% of participants citing it as the first word that came to mind in relation to LW.org.au. However, understandings of ‘supportive’ or ‘support’ did not stand alone; they were intricately tied to members and chat-hosts subsequent conceptions of the terms ‘community’ and ‘safe’ with ‘connection’ and ‘socialisation’ being the core purposes underlying each of these secondary terms.

Fun emerged as the second most salient term with 60% of participants citing it as either the first, second or third word that arose. It was primarily connected to the site’s aim to provide diversion for young people during the challenges of their condition. ‘Safe’ followed ‘fun’ with 50% of participants mentioning it. This was surprising, considering ‘safe’ was as inherent as ‘support’ to the overall understanding that members and chat-hosts had of community, and was frequently talked about as a key feature of the site. ‘Engaging’ was the fourth most salient term. However, further analysis indicated that it could be considered a sub-dimension of fun. This placed it alongside a range of other terms – personal, uplifting, hilarious, silly and crazy – that together comprised ‘diversion’, which could be seen as a form of support. This analysis has demonstrated the most commonly given words do not stand as separate concepts, but rather represent a constellation of ideas around the notion of support.

Other terms were pervasive in the discourse of members and chat-hosts as they explained their meanings. One such term was ‘inclusive’. While ‘inclusive’ was not as frequently stated, its importance was evident with members and chat-hosts mentioning two to three additional terms among their five choices that could be seen to be related to the concept of inclusiveness. These were: warm/welcoming, non-judgemental, kind, caring, generous, and easy/effortless. While ‘supportive’, ‘fun’ and ‘safe’ appeared to be the dominant or explicit understandings of the site, ‘inclusive’ emerged as the over-riding tacit or implicit value through its frequent association with other words. This demonstrated members and chat-hosts were not as consciously aware of its influence, but commented on it at a subtle level.

The values of support and inclusion could be seen to be instrumental in moving LW.org.au beyond being a community based primarily on place and presence, to one fostering a strong degree of personal and psychological identification. Here, the site was perceived as somewhere where members spent a large portion of their ‘adolescence’ to the extent that they talked about the site as being ‘special’, and even like a ‘family’.

Thus, in summary, members and chat-hosts predominantly defined LW.org.au as a supportive, fun, safe and inclusive community providing opportunities for connection, socialisation and diversion for young people living with an illness or disability to meet similar others who ‘just get it’ and understand. These characteristics were linked to the concept of grounded authenticity, the notion that members and chat-hosts spoke from a position of experience, both personal and shared.

It was not possible to elucidate further the significance of these core understandings and their relation to the ‘norms’ of LW.org.au without understanding how LW.org.au is seen as a ‘community’. This notion of community is constructed in several ways. First, embedded within the notion of community was a recognition that the SCF, as chat-host 4 mentioned: “actively works to build” a sense of commonality and communality on the site. Creating, she continued: “a community that is not static” (Chat-host 4) but “dynamic” (Chat-host 4), and responsive to the emerging needs of its members. This encouraged choice, agency and autonomy in the process. As noted above, this sense of commonality is fostered through the criteria for membership on the site. However, beyond that commonality is emergent and related to three distinct understandings of community implicitly stated by members and chat-hosts in the online focus groups and interviews. These include an understanding of the LW.org.au community as a (a) place, space or presence; (b) a network or systems of relations and resources; and (c) a 'real' sense of communality that elicits a personal and psychological identification with the site.

At the most basic level and in accordance with traditional notions of community in scholarship, members and chat-hosts dominantly conceived LW.org.au as a community through it being a supportive and safe place or space. Stability of location is traditionally seen as a fundamental aspect of community. This highlights the sociological origins of the concept, where geographic location and its permanence were fundamental. Within LW.org.au, stability emerges as a 'constant presence' in the lives of young people living with a condition; providing a dependable sense of connection to those who often feel disconnected. This was evident when Chat-host 4 expressing: "members know there is still this constant presence that is always there and they can step in any time they like if they are feeling overwhelmed or down"

Central to the notion of space was an awareness of the site's 'boundedness'. The bounded or closed nature of the community was a valued feature and central for evoking a sense of safety, authenticity and privacy that strongly appealed to members. The site's boundedness speaks to its 'boundaries' at a structural level. This includes the site being password protected and restricted to 'validated' members. The SCF's 'safeguarding children' and 'validation' processes require all chat-hosts to be authenticated with 100 points of personal identification, a police-check and in the possession of valid ‘Working with Children’s’ registration number, while members require 100 points of identification and parental confirmation if under 18 years to access the site. This validation process functions to induce a degree of security by ensuring as Chat-host 3 asserted: “everyone is who they say are”. It was also evident with one member (1) stating: “it is hard to connect with people on other sites like Facebook, because you never know who they are, but here I know I’m building connections with other young people”.

This sense of security engendered from, ‘knowing who people are’, is interesting, especially when considered in tandem with the SCF and LW.org.au’s ‘Safeguarding Children’ and ‘Privacy Policy’. These policies clearly outline the norms and behaviours expected of chat-hosts and members, stating that chat-hosts and members agree not to upload or disclose any personal information, such as their full name, address, phone number or social media accounts. In other words, this sense of connection is not necessarily forged with known others. If members do wish to swap contact details, they are permitted to if LW.org.au receives confirmation from parents, if under 18 years, or consent from both members if older. Chat-hosts are never permitted to share or interact with members beyond the boundaries of the LW.org.au space. Thus, it is intriguing that chat-hosts and members continue to feel a strong sense of being among ‘real people’, even though all users online are only known by their user names in the online space. As one member (2) noted: “I’ve come pretty close to many of the hosts and members. They are like family. Even those I’ve never met feel like we’ve met”.

To appreciate this sense of closeness, it important to delve further into two factors, the openness of communication and the privacy created through the bounded nature of the community. The high flow of conversation and disclosure appeared to be a defining feature of the site alluded to by chat-hosts in the following statements:

> “I remember being a bit blown away by how much was happening online” (Chat-host 1);
>
> “I remember going on there and just watching the conversation flow and being like, whoa, like they've got this whole language on here” (Chat-host 2).

Chat-host 1 expressed the particularity of this closeness in observing: “I would never spend five hours talking to one kid in the hospital, but I might do that online if they are online for 5 hours”. At the same time openness of communication is valued and supported, there is the acknowledgement that information disclosed or shared within the context of LW.org.au remains within the boundaries of the community. This was highlighted in the following statements by chat-hosts:

> “Members can throw up all their photos and their thoughts and feelings …and know they're not going to come back as a screenshot in five years time to haunt them … it's all contained” (Chat-host 2);
>
> “Members are able to chat about things that I don't think they would necessarily put on other sites knowing it’s private and it won't go further than here” (Chat-host 4).

Presenting and Validating Identities

The age group of LW.org.au’s members is one where developmentally they are forming a sense of self, trying out different kinds of identities and coming to terms with who they are. The ten young people who took part in this study are no different at one level, but at another level, their very membership within LW.org.au means that they are developing their identity as a young person in the context of an identity as someone living with a condition. This section sets out the findings related to both types of identity. It shows the identities that members present online and how these identities are validated or as one member (3) suggested: “how [they] are treated by others”. It considers evidence of how the two identities are managed and the tensions that sometimes arise between them. The section concludes with a detailed analysis of how identities are validated within the chat-room.

Young Person Identity

In the context of this study, the ‘young person’ identity is defined as how LW.org.au members present themselves as ‘people’ and ‘everyday teenagers’ through expressing their talents, interests, skills, hobbies, dreams and goals online. In essence, it celebrates their individuality beyond their condition. It also explores how they perform ‘everyday social roles’, such as the student, worker and family member. This presentation involves being recognised as a person beyond their condition, or more aptly as an individual. This emphasis on personhood and individuality means the identities LW.org.au members claim as young people online are diverse. This diversity provides the opportunity for experimentation and exploration. It allows members to express their unique personality, interests, tastes, hobbies, skills, talents, dreams, goals and life experience, and connect with others who share or challenge these identity claims.

Members are aware that they may be perceived, first and foremost, as people living with an illness or disability, but they insist that it is important to go beyond that identity to acknowledge the presentation of their identity as a young person. Two posts aptly describe how members perceive this tension. The first includes an opinion piece submitted by a member (3) into the ‘Livewire’s Got Talent’ (LWGT) competition, where she critiques ableism, arguing:

> “Many disabled people, though not ashamed or embarrassed by their disability, want to live as normal a life as possible and to be treated as such by others … People with disabilities are exactly that. People with disabilities. They’re people who just happen to have a disability, maybe it’s the result of an illness, an injury, or the result of something in their genes, but their disability isn’t them. They are not their disability”. (Member 3)

While this opinion piece primarily champions the perspective of those with a disability, its sentiments are echoed by another member (2) in relation to illness more broadly. Her post, presented on her profile page and within the ‘epilepsy group’, recounts her experience of being diagnosed, living with and managing her condition. In this post, she asserts: “you may live with epilepsy, but epilepsy isn’t you” (Member 2).

From these posts three important ideas emerge that capture how the ‘young person’ or ‘everyday teenager’ identity is implicitly conceptualised by the researcher and LW.org.au community. First, ‘young person’ as suggested by Member 3, means simply that ‘people’; ‘people who just happen to have a disability’. Here, LW.org.au members are seeking to be seen or present the self in relation to their ‘personhood’ or ‘humanness’ as ‘everyday’ teenagers and individuals, who adopt a number of roles. However, the concept of ‘everydayness’ also speaks to the notion of ‘normal’, and how LW.org.au members confirm or re-define existing understandings of ‘normal’ through their presentations of self.

Identity Claims

The members of LW.org.au who took part in this study expressed many different identities, which can be categorised as follows: (a) social identities, including as examples, family member, student, worker and supporter of a societal group; (b) performative identities, such as writer, photographer, traveller, cook and hobby-related activities; (c) narrative identities, such as advocate, champion, hard-worker and trailblazer; and (d) career and aspirational identities related to hopes for the future, including astronaut and nurse.

Social identities

Social identities are important in fostering a sense of belonging. Not unexpectedly, there is little emphasis on familial identities as these might be seen to fall outside the purpose of LW.org.au. But, being a sister, daughter and friend is brought out in relation to social activities, such as when Member 9 recounts how she went to her brother's DEB ball sporting a stylish hairstyle requiring 57 bobby pins to hold it together or when Member 2 expresses pride, stating: "being the best aunty ever to two beautiful kids".

There is however, quite some emphasis on pets as members of the family. This was evident with Member 6 posting: "Took some photos of the family pup Hugo the other day. He poked his tongue out for one lol". It was also present with Member 8 sharing: "Who wants a bunch of photos of Hendrix!!! Too bad, it's already here lol. Man, I love this boy".

Similarly, there is an emphasis on the identity of student or worker. The student identity is expressed through members sharing study tips, waiting for school holidays and graduation. Members commented:

> "I won't be on Livewire until Nov 14th as I'm finishing up with Yr 12, and I'll be studying for exams and finalising assignments" (Member 1);
>
> "I thought I'd share some study hacks with you all to hopefully get you through exam season. Here are some tips;
> 1. List, lists, lists: Make physical lists of what you need to do, the satisfaction of crossing activities off is amazing

> 2. Study cards: Study cards are so great, and the act of writing them in the first place is great for memorising new content and revising old ideas" (Member 10);
>
> "Today we graduated" (Member 6);
>
> "Last week was the final week of Exams for Yr 12. On Tuesday, I submitted my final lot of digital media assessments and on Thursday at 3:40pm I walked out of my last exam; psychology! It feels strange to no longer be studying and completing assessments, but it's definitely incredibly relieving" (Member 3).

Other identities included those connected to social groups and advocacy, such as the LGBTIQA+ community. This was evident when one member expressing her interest in feminism after visiting the Comicon exhibition. She exclaimed:

> "Got to meet my favourite actress, Hayley Atwell, best known for her role as Peggy Carter [feminist icon within the Marvel universe] in the marvel cinematic universe aka my favourite Marvel character at comic con today?" (Member 4).

It was also evident with Member 3 sharing a photo of a mug, stating: "A woman's place is in the house and the senate"

Figure 3. A Woman's Place is in the House and the Senate Mug Post.

A young person's life is also marked by rites of passage and two examples were found in the data. Member 9 became a learner driver, a significant rite of passage for young people in Australia. She exclaimed: "Hey everyone, I got some exciting news. Today I went for my learner's test and I passed whoohoo ☺ With a fabulous 84%" (Member 9). Coming out, revealing sexual preferences, is another rite of passage for some young people, often related to familial relationships. One member expressed: "hearing some slightly homophobic comments from my grandparents. It was said in a way that I believe they weren't meaning to be rude or anything, but it was still hard for me to hear and makes me feel slightly anxious about when I do come out" (Member 3).

Performative identities

LW.org.au members express a very wide range of performative identities. Young people in Australia live very busy lives, engaged in many activities. There is no claim that the performative identities expressed during the time of data collection are representative of LW.org.au members or of young people in general. All of those identified from the ten participants in the study are listed here: artists; cartoonist; photographers; creatives or crafts-makers; actors; musical theatre performers and fans; athletes; chefs or cooks; musicians; song-writers; rapper; comedians; wordsmiths; writers; readers; film buffs; travellers; adventurers; gardeners; flower enthusiasts; nature lovers; animal lovers; dog-lovers; cat-lovers; pet owner; environmentalist; board game enthusiasts; computer or video gamers; vegetarians; academics; tea lovers; mug collectors; marvel fans; inventors; innovators; fashionistas; bullet journal makers; space lovers; hair stylists; stop motion animators; and anime collectors.

Some activities are elaborated below to show the diversity of identities co-existing at any time in the LW.org.au chat-room and online community.

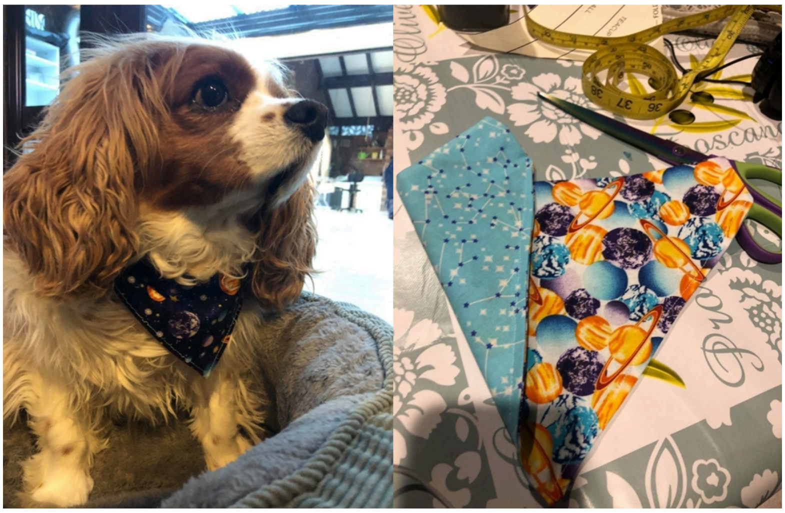
The creative identity

The creative identity appears to be one of the most dominant online and is frequently connected to the Livewire hospital program's creative arts and crafts focus. This is evident when Member 5 jumps online to quickly share her tote bag craft from the 'workshop in demand' initiative. The 'workshops in demand' are craft packs sent to members with all the materials to re-create the craft workshop from the hospital at home or in their hospital ward if they could not attend the workshop in the Starlight room. LW.org.au also features a video of how to make the craft. The member (5) exclaimed: "Hey hey! …here is a pic of my workshop on demand Halloween craft!". The importance of LW.org.au programs in supporting performative identities is reinforced when Member 5 posts an image of her entry into the LWGT photography competition, where she expresses:

> "Here is my entry into the LWGT competition. It was hard to pick just one piece of photography, so I thought I'd give a taster of everything …Photography gives me a way to express myself and escape from the day to day struggles, both mentally and physically. To me, it's just like therapy. I love it".

Members frequently present themselves as artist, cartoonists or photographers when expressing and sharing their artwork, photos and talents on their profile page and in the newsfeed. Most artworks by members tend to draw upon pop-culture, depicting characters from their favourite movies and books. This was evident with Member 2 sharing hand-drawn artworks and cartoon figures from her favourite cartoon movies 'Despicable Me' and 'The Smurfs'. It was also apparent with Member 3 sharing a cartoon image of Arthur Dent, a character from the book she was currently reading. Members also demonstrate a sense of pride and achievement when sharing their work. This was evident with Member 2 asserting all her artworks were hand drawn, stating: "these artworks are done free-hand, no tracing or anything. All my drawings I do, are done by me and only me”. Member 6, on the other hand, used drawing as a way to be innovative by trying new things and drawing subjects important to her. She expressed: “I’ve recently got an apple pencil for my Ipad, so I thought I’d share my little sketch of Casey (assistant dog)” (Member 6). Another example of the creative identity focusing on the relationship with a pet comes from Member 4, who made spaced themed bandanas for her beloved pooch. She exclaimed: “Had a crafty afternoon (a craft-noon, you could say) today and made my dog two reversible spaced themed bandanas that slide over his head”.

Figure 4. Pet Bandanas Post



LW.org.au programs and competitions provide opportunities for members to present their identities as musicians. Member 6 posted: “Lovely morning busking at the markets”, and writes about her ‘Country music on the Banjo’ entry in the LWGT competition. Being a musician occurs in other posts, for example when she writes: “So today I stopped procrastinating and actually redid my broken guitar string. Featuring my Livewire guitar pick”. Similarly, Member 10 takes on the rapper identity, one which is frequently expressed in the chat-room when members come up with rap names based on the last food they ate as a source of diversion and fun. This was evident in Member 10’s entry into the LW.org.au rap competition where she writes: “Hey Y’all Lil Lollipop here let’s go ….I’m fun to chat with and maybe even rap with”. The musician identity is also associated with members sharing their love for music through musical tastes and asking for recommendations around favourite artists or tracks. Member 10 posted: “QOTD [question of the day]! Fav song? I’ve just been absolutely loving the song ‘Fire on Fire’ by Sam Smith recently”. However, it also relates to members who are passionate and possess talents as a musician.

Opportunities to engage in performative activities also occurred outside of LW.org.au, especially through school. Member 3 and Member 6 actively participated in school theatre performances and concerts: They expressed:

> “I miss a midsummers night dream!” I love working on a play with my awesome fellow theatre kids and friends. I’m so grateful that I got the opportunity to play a character as fun as Peter Quince” (Member 3);
>
> “So here are more production photos that I have! I had the best time performing in the school of rock. The cast and crew were so lovely and supportive, and I can’t wait for 2021” (Member 6).

Members frequently expressed their identity as a ‘movie lover’ through sharing the movies they love online and offering and asking for recommendations. The movie lover identity takes on unique relevance within the context of the online community as LW.org.au members commonly watch movies because they are stuck and bored in hospital. Therefore, this identity offers a unique form of escapism and a means of bonding or connecting with peers and youth culture online during difficult times. While some members expressed a general interest in movies, others adopted this role to a stronger degree asserting themselves as a ‘movie expert’ or ‘movie buff’ through their good taste. Member 3 writes: “I’d love to see everyone’s top ten films! Here are mine at least at this point in time”. Member 1 asked:

“Happy Slumber Saturday! Does anyone have any recommendations on some good TV shows or movies?” She received some recommendations from chat-hosts and members, who replied:

> “What have you been watching recently?? If you're looking for something short and fun, I've always highly recommend “Nailed it”. “Brooklyn nine (M) if you haven’t already seen it, it’s a classic” (Chat-host 4);
>
> “Have you seen Gilmore Girls? it's pretty great” (Member 4).

LW.org.au members also express their identity as fans of musical theatre, book readers and players of cards, video games and board games. Member 5 wrote about going to the theatre on more than one occasion. She posted:

> “So yesterday one of my friends and I were lucky enough to see Charlie and the chocolate factory at Her Majesty’s theatre. As it was the last day, we got to see some behind the scenes action. Being in the front row was an experience I’ll never forget”.

Member 3 was an avid book reader, sharing her love of bookstores and her current read on many occasions, stating:

> “I could spend all day in a book store, especially Harry Hartog”;
>
> “I’m currently reading Mythbusters and creative extraordinaire Adam Savage’s ‘Every tool’s a Hammer’, described by Nick Offerman as an imperative how to for creativity”.

Board games and card games are strongly connected to the Livewire hospital program and were occasionally mentioned online during the study period. Member 1, again eager for suggestions from others, asked: “Does anyone have any Nintendo switch game recommendations”. Member 3 shares her enthusiasm, this time for online games, stating; “I love playing Sims! This is my newest sim, Xavier and his dog Indiana”

Young people share their identity as chefs when celebrating their love of food or cooking as part of the everyday. Others, however, make the decision to become a cook or home chef in an endeavour to make healthy food choices, rather than settle for the fast food choices offered to them by their families. This showcases the young person’s efforts to assert independence and autonomy in making life choices based on their internal values and sense of self. Member 3 posted:

> “My family decided to get take away fast food for dinner, and I’m not really a fan of fast food burgers, so I opted to make my own dinner! I found a recipe online for a really simple one pot pasta, and changed it up a bit. This is the result. Super tasty and I have leftovers for two school lunches”

This healthy food choice is endorsed by the members and chat-host who responded:

> “Wow looking fabulous” (Member 10);
>
> “Yum, that looks delicious. Great you have some leftovers for school” (Chat-host 1)

Cooking is also celebrated as an identity when someone is considering becoming a vegan or vegetarian, and asks members for advice on good recipes and places to eat. This was evident with Member 10 stating: “Is anyone on here a vegan or vegetarian? If you would love to chat or share recipes message me”.

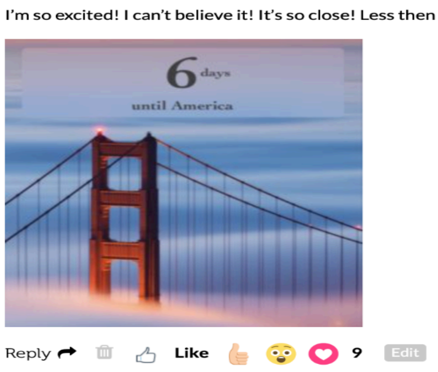
No group of young people would be complete without one person who makes light of the situation. Member 7 takes on the identity of comedian through recounting humorous tales and inside jokes shared with the ‘hossie’ (Hospital) Livewire crew online, where she makes light of the difficult situations she finds herself within. It’s again evident through her use of rhetorical language in her posts, where she states: “IDK why I was surprised when it started raining in a rainforest (Where do I get my logic from)” (Member 7). It’s also apparent when she shares a humorous story about a weight falling on her foot. This demonstrated how it is not always possible to see identities as only performative. The story concludes with her stating: “lesson learnt is my foot bones are stronger than I think and somehow didn’t break” even when the newly laid tiles of her floor did. This positioned her as an ‘unbreakable’ superhero and appears to be connected to her identity as a fitness-focused individual and comedian.

Some members relish the opportunity to engage in performative activities which are not part of the everyday. Member 3 went camping, sharing: “It was such a nice trip. Port Fairy is a beautiful place”. Member 1 went on a family trip to the USA, expressing her own excitement with a countdown clock shown below, and in travel posts with her stating:

> “We left Brisbane Saturday at 11am and arrived at Los Angeles Saturday at 7:30am. We lived Saturday twice.”;

> “We had a late lunch at the hard rock café Hollywood, where I had a delicious Oreo Milkshake”.

Figure 5. Travel Count Down Post



I’m so excited! I can’t believe it! It’s so close! Less then a week what?

Figure 6. Travel Count Down Post 2

This time tomorrow I will be on the plane and in the sky!

Narrative Identities and Career Aspiration Identities

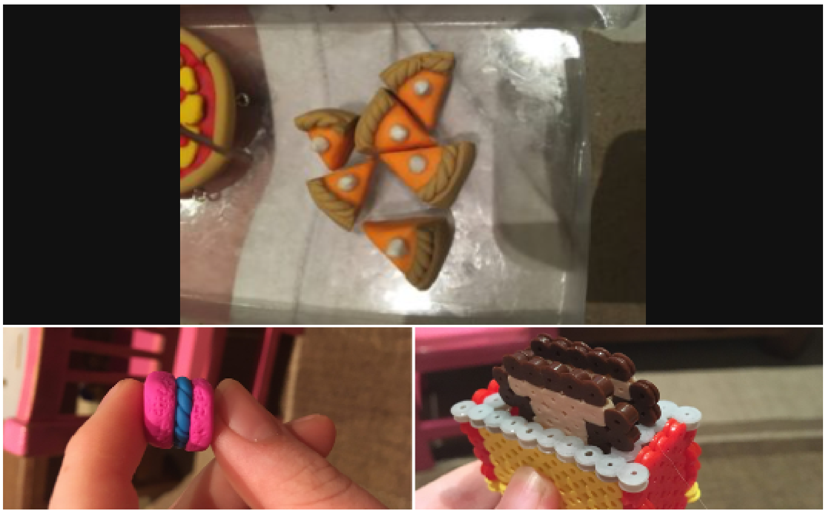
The narrative identities and career/aspirational identities are not as obvious from individual posts, but emerge over time from the collective of posts and interactions. Narrative and career/aspirational identities are clearly those connected to the identity category of ‘young person’. However, the presentation of these identities, which can equally be found among young people not living with a condition, is intricately tied in these instances to LW.org.au members’ conditions. Thus, it has proven difficult to separate them, and so they are presented together here. Aspirational identities are, as Markus and Nurius (1986) claim, hoped for or ‘possible selves’ (p. 952) that members strive for. In some cases, these are actually achieved (Erikson, 1994; Marcia, 1993) identities. Here, they will be considered under the same heading. The age range covered by LW.org.au (12 – 21yrs) means that some members are still in the process of imagining their future careers, whereas others have already begun the process of realising their aspirations. Some participants acknowledge that their condition means they will never achieve their aspiration, but nonetheless, they find ways to express it. This section begins by presenting the aspirational identities of younger members, before moving on to the experience-based aspirational identities of older members.

Aspirational identities may be unattainable due to the challenges of the young person’s condition. This was evident for Member 10, who stated: “I always wanted to be an astronaut, but can’t now. Oh well, I still love space”. Nonetheless, she continues to proclaim to be ‘a huge space nerd’, when she excitedly announces in the chat-room: “the international space station just passed overhead and I got to see it in the sky. It was heckinngg so awesome, and exciting, and crazy to think there are people in there” (Member 10). Despite, no longer being able to be an astronaut, she doesn’t lose her passion for space and appropriates her identity to match, rather than abandon it altogether.

Member 8 secretly harbours a desire to be a chef, but rarely cooks. Instead, she makes miniature hamburgers, oranges, ice-creams, macaroons and rainbows cakes with polymer clay or perler beads. This demonstrates her extraordinary expertise in this craft, evident with her posting:

> “Crafts update: I made a pumpkin pie and a 3D perler bead toaster. The macaroon is the one I made in the hospital on Monday. It’s the best I could do with what we had” (Member 8).

Figure 7. Polymer Clay and Perler Beads Post.



Another example of an aspiring, yet-to-be-achieved-but-still-possible identity, is Member 7’s wish to become a nurse in the future. This was evident, when she shared a humorous post over Christmas, depicted below, that expressed her sympathy for the plight of nurses in the hospital.

Figure 8. Jingle Bells Nurse Style Post

Jingle Bells
(nurses style)
Dash-ing through the ward
No help on the way
In ste-rile fields we go
Char-ting all the day

Pa-tients call bells ring
Makes me want to cry
Oh what fun, pass-ing out
Meds to them all night

Jin-gle bells, pa-tient smells
Ad-mits on the way
Oh what fun it is to work
E-very hol-i-day

Achieved Identities:

Three members have what can be considered ‘achieved’ identities’. These young people are older members of the LW.org.au. community. Not only have they achieved at least some of their aspirations in the scholarly or technical sense, they can also be seen as ‘high achievers’ in an everyday sense. The identity of ‘high achiever’ means that they are expected to act as advocates or spokespersons for an organisation or for their team. Member 2 is an athlete, who has competed at several levels, including, as she states: “local, state, and just recently the country”. In 2019, she participated in the Paralympics in Dubai. In her efforts to present her identity as an elite athlete within the LW.org.au community, she comments: “I have done multiple speeches. From schools to big business and big events” about her sport and the special Olympics. It was also evident in a post where she shares highlights from these experiences, writing:

> “Two of the big events I have been to are the Victorian Disability sports award night where I was a keynote speaker and spoke in front of 150 people …then, a few weeks later, I topped that, doing a speech in front of 300 people at the Special Olympics Soar and Roar festival luncheon” (Member 2).

She has also received public recognition and accolades for her sporting efforts, including being a nominee and winning receipt of the Herald Sun Local Sports Star Award in 2019

Achievement is central to Member 2’s story, however she can also be defined as an extremely hard worker. She celebrates her achievement at work, when she is promoted to group leader, exclaiming:

> “Well, today was a very exciting day at work for me. I officially got my group leader vest. I am officially a group leader for my group after being on a three month trial and going through an interview phrase. I got the job. So, proud. For someone that only has been there for one year, I've achieved so much in that year. A lot more than I ever thought I would ...I can't wait to see what the future holds at this amazing workplace” (Member 10).

A second ‘almost achieved identity’ is Member 3. She is academically-oriented and frequently showcases her intelligence in the chat-room while talking about her school assessments. She uses her academic prowess and skills as a debater and advocate, particularly for the marginalised, including those with disabilities and the LGBTIQA+ community. This was evident in an opinion piece she submitted into the LWGT competition critiquing ‘ableism’ mentioned above. This piece not only demonstrated her talent and identity as a writer, but also affirmed her identity as a ‘critic’ of the system. In discussions in the chat-room, she presents as a strong supporter of the LGBTIQA+ community, leading her to question why sexualities other than heterosexual were not included in her PDH/PE curriculum.

The third ‘achieved identity’ is Member 6, who at 21 years has recently graduated successfully as valedictorian of her university year and gained acceptance into her dream course being a Masters of Speech Pathology. She has pursued a career in the public eye as an advocate for inclusion and diversity, working alongside local hospitals, her university and QLD health to create positive change for people with disabilities. She has received well-deserved accolades for her efforts, such as a ‘Student Excellence Award’ from the City Mayor for championing for diversity. For Member 6, employing her academic and public speaking skills, as an individual to gain a voice at the table and speak equally as a ‘normal person’ among other experts, is integral to her story and sense of self. It also illuminates how her identity and life story are informed by her condition, but not overly defined by it.

Validation of Young People’s Identities

It is a rare occurrence for LW.org.au member’s ‘young person’ identities to not be validated online with respect to their individuality and everyday teenage personalities. Most of the time these identities are affirmed through likes and comments as is expected in social media. On occasions a member’s ideas are challenged in the chat-room. However, this is always done respectfully as was the case with Member 3 concerning the LGBTIQA+ issue, where she responds to the member upon leaving, stating: “Goodnight! Thanks for being respectful in our discussion”

Similarly, the chat-hosts also validate the member’s young person identities online through likes and comments. However, on occasion, they affirm members’ identities by collaborating artistically with a member through their profile posts. This occurred for Member 7, when she shared two photographs of a flower with a bee and another delicate white flower with the caption stating: “Happy to see Melbourne is at least getting some spring weather. Love this photo of the bee though”. This post expresses her identity as a photographer and nature lover.

In response, a chat-host (1) online validates her identity as a photographer and artist by producing a beautiful sketch of the delicate white flower captured by Member 7. The chat-host (1) posts her sketch onto the newsfeed with the caption, stating: “Hey @[M7]! I did a sketch of one of your photos yesterday in one of our workshops. I love drawing flowers and this was such a good shot”. Member 7 replies: “Wow, that’s amazing! Feel free to use my pictures anytime”.

Figure 9. Chat-hosts Validation of Members Post

This confirmation of a member’s identity also occurs for Member 10, when she posts in the QOTD stating: “Fav music? I absolutely love ‘Fire on Fire’ by Sam Smith at the moment”. The chat-host (9) responds to her post with the intention of making a music cover of the song as he is a singer and guitarist. In this way, the skills and talents of the chat-host support and affirm the talents of the young people, which in the case of Member 10, is that of a music lover.

The only identities that are not affirmed as strongly by the chat-hosts are those that may be seen to foster dependence. This appeared to be the case when members identified themselves in relation to family. Here, rather than celebrating the family identity, LW.org.au appears to celebrate the young person identity presented in tandem. This suggests an implicit norm of the LW.org.au community may be to affirm the young person's independence, rather than dependence. This was evident in the following interaction involving Member 1 and a chat-host (4) in the Warm and Fuzzy initiative. (The Warm and Fuzzy initiative runs online every Tuesday called Tingly Tuesday were members share something that they love, made them feel happy, or brightened their day.) Member 1 writes: "My warm and fuzzy is that last night I got to video chat with my cousin for the first time in years. After always being on different sides of the world". Chat-host 4 responds: "how awesome is technology! I love that we can connect and engage in this way". Here, it can be seen that the chat-host affirms her identity as a digital communicator, rather than her family identity of cousin.

The concept of validation is connected to the culture of the site and its community values that foster inclusion and encourage support. There is also an implicit understanding to celebrate the young person. Thus, LW.org.au foregrounds the 'young person' identity and its members' individuality, rather than placing emphasis on medicalised understandings of illness or disability and the identities associated with it. When identities related to medicalised understandings of illness or disability are presented online, chat-hosts acknowledge the challenges faced by the young person in relation to their condition and provide sympathy, but frequently attempt to divert the member's attention towards celebrating their 'young person' selves or the positive and strengths-based aspects of their condition-based identities.

Condition-Based Identity

In the context of this study, the 'condition-based identity' refers to how LW.org.au members identify with their condition through the newsfeed, profile page, online groups and chat-room. It is important to note, similarly to the 'young person' identity category that is characterised by diversity in an endeavour to capture member's individuality as artists, athletes and musicians, the 'condition based identity' category is also multifarious. This multiplicity demonstrates how young people perceive, respond, manage and renegotiate the self in relation to the ebbs and flows of their condition. Thus, there is not a single 'condition-based identity', but multiple positions within the 'condition-based identity' category that LW.org.au members present and adopt online at different stages in their illness or disability oriented experience. Some of these condition-based identities or roles align with the medical model. Others centre around subversion and empowerment. Members, on occasions, enact two or more condition-based identity roles simultaneously in their posts and chats. This has the effect of illustrating points of tension and resolution in the young person's re-storying of the self. The validation offered to LW.org.au members by their peers and the chat-hosts online are useful resources for affirming these condition-based identities or challenging members' responses to their condition. Validation also affirms LW.org.au member's 'young person' identities alongside their 'condition-based selves'. This, in some instances, allows for the former to function as a source of resilience (Ferguson & Walker, 2014).

Prominence of Condition-Based Identity

First, within the context of the LW.org.au community, members 'young person' identities are foregrounded. However, their condition or 'condition-based self' is not absent. This coincides with a previous study by Third & Richardson (2010) on the LW.org.au community, where they asserted that LW.org.au members' conditions are "present, but not focal" (p. 45). In the current work, a similar finding emerges in relation to member's condition and the presentation of their 'condition-based selves'.

Out of the ten members who participated in the netnographic observation, three members rarely discuss their condition on their profile page or in the chat-room. Most conversations centre on their young person selves. The most salient evidence of their condition is the condition-specific groups they join, including the Anxiety, Cerebral Palsy, Complex Regional Pain, and the Dysautonomia and POTS group. Two members occasionally present and discuss their condition on their profile page and in the chat-room, but the majority of their conversations highlight their young person selves or integrate their condition-based identity and condition into their young person roles. This includes Member 6 becoming a public speaker or professional advocate for inclusion. Three of the members equally discuss their condition and their young person identities on their profile page and in the chat-room. However, their condition-based and young person identities are less integrated than that of the public speaker and professional advocate. One member discusses her condition frequently on her profile posts and in the chatroom. This means the majority of her conversations present her condition often alongside her young person self, but usually in a sequestered form. One member occasionally presents her condition on her profile page, but frequently discusses her condition in the chat-room. This indicates her profile page functions more like a ‘highlight reel’ for her young person self, while the chat-room offers a safe platform for her to vent her everyday frustrations around her condition and results in her embodying her condition-based identities within these conversations.

The variance in the presentation of the condition-based identities and member’s condition in relation to their young person selves in this study, can be attributed to different factors. These include: (a) the stage of the member’s diagnosis and condition; (b) the intrusiveness and complexity of their illness or disability into their everyday lives; and (c) the member’s age. Members who present their condition-based identity or condition moderately to frequently on either their profile posts or in the chat-room are generally in the early stages of diagnosis or struggling to find a diagnosis for their symptoms. Therefore, the intrusion of their condition and its symptoms into their everyday experience at home, school, work and during recreational activities appears more common and destabilising. Thus, the LW.org.au community provides a safe space for these members to share, vent, gain support, and receive condition-based advice during these times.

In contrast, members who speak moderately to frequently about their condition, but who are not in the early stages of diagnosis are usually members whose conditions are highly pervasive. This means their condition is prone to moderate to severe episodic or consistent reoccurrence, such as is the case with Epilepsy, Cystic Fibrosis and Migraines. Therefore, despite these individuals being aware of their diagnosis, their condition is still intrusive. Consequently, the expression of their condition-based identities, emerges in response to this intrusion. This is particularly the case for Member 10 who is regularly hospitalised because of her condition Cystic Fibrosis [CF]. Similarly, for members with complex or comorbid conditions, such as Member 2, —who presents her condition-based identity frequently alongside her 'young person' self, but often in sequestered form —the multiple dimensions of her condition, mean that she presents an array of condition-based identities to manage and cope.

Members with congenital conditions or who receive diagnosis early, and those whose conditions are more discrete, tend to present the young person self more frequently than their condition-based identity online. Similarly, these members usually present their young person and condition-based selves in a more integrated fashion. Age also appears to be a factor influencing the presentation of young people's condition based selves, as does the degree of success achieved by the young person self in other domains, such as school or career. Whether, the lives of the members who present the condition-based identity less frequently online are punctuated as much by their conditions as members who express their condition-based identity more often, cannot be discerned from this study alone.

In summary, it can be asserted the condition-based identity is generally represented intermittently online when the symptoms, limitations and challenges of young people's conditions, intrude upon their everyday routines, plans, goals or aspirations that are often connected to their young person selves. This included instances when members condition: engendered crises at school and work; affected their ability to participate in planned events such as performances and musicals; foreclosed the opportunity for one member to potentially compete in the Paralympics; and crushed hope for another member to pursue space exploration as a future career. The intrusion of LW.org.au member's conditions into the continuity and flow of their 'everyday' life, challenges these young people's sense of control, certainty and the expectations they hold for themselves, their future and the world in general. Thus, the presentation of the condition-based identity in its various guises emerges in response to these intrusions to function as a 'narrative resource' that assists these individuals in re-storying the self.

The diversity of condition-based identities emerging within the LW.org.au community demonstrates a high degree of variability in the way members choose to individually engage in this process and re-story the self in relation to their condition. This assists them in coping, managing and recovering from these incidents. It is during this re-storying process that the condition-based identity interacts with the various selves of the young person identity, such as the artist, photographer or athlete. This interaction reflects the individuality of each member in how they experience and respond to their condition, and attests to how the re-storying process is a personal journey, that nonetheless benefits from support offered by LW.org.au members and chat-hosts in the form of validation online. However, in alignment with the condition-based identity being intermittently presented, it is appropriate to note this re-storying process is not linear, but episodic to reflect both the unpredictable nature of living with a condition, as well as the fragmentary, discontinuous and conversational way stories about the self are shared through the online social media medium. The condition-based identity also emerges at times to reflect how members integrate their condition into their young person self and worldview. In this study, this resulted with some members building careers from their illness experience.

The Condition-Based Identities of Livewire.org.au

In the LW.org.au community, the condition-based identity category presents a degree of diversity, not as extensive as that of the young person identity category, but equally rich in complexity and depth. Some of these positionalities reflect traditional understandings of the ‘patient role’ connected to the medical model of illness and disability. Others challenge these assumptions through subversion, defiance and empowerment. Multiple positions that constitute the condition-based identity category emerge within this study and include in no particular order: the sick role; emergency patient; victim; prisoner; dependent; vulnerable; sympathetic patient; responsible patient; recovered patient or survivor; rehabilitative patient (or athlete); frustrated patient; trickster; empowered patient; defiant patient; reckless patient; hero, battler and warrior; advocate, activist, ambassador and champion; ninja (adaptor); critic or truth-teller; expert and burden.

To make some sense of these multiple positions, these have been clustered around three categories: the illness experience, the treatment experience and the empowered patient.

The Illness Experience

The illness experience included a number of positions that are primarily connected or associated with the ‘sick role’. The ‘sick role’ draws upon the work of Parsons (1975) and is closely aligned with the medical model of illness and disability. In this study, LW.org.au members present the sick role when their condition intrudes or disrupts their everyday life and ability to maintain their young person identities or social roles, such as the athlete, performer or student. Therefore, members express this identity during: (a) crises or emergency situations; (b) hospitalisation; and (c) when the limitations of their condition are most keenly felt. Essentially, the sick role captures the illness experience. However, it is best expressed through an array of sub-identities, including the emergency patient; victim; prisoner; dependent; vulnerable patient; sympathetic patient; and burden. These are outlined below.

Emergency Patient

The emergency patient emerges when the illness experience gives rise to a crisis or emergency situations at home, work or school. This usually requires immediate medical attention and often hospitalisation. This was evident for Member 2, when her migraines resulted in her passing out at work and lead her to experience a series of epileptic seizures requiring hospitalisation. She writes:

> "I have had constant migraines all week. Then on Thursday I went to work and after lunch …I went back to my locker, put my lunch box away and started to walk to my spot on the work line. Next minute I passed out. From there, all I remember was opening my eyes and seeing my supervisor and HR staff around me who rang the ambulance. Before the ambulance arrived, I went into an epileptic seizure. I was rushed to hospital and had two more seizures in the ambulance. They put me on oxygen while I was in the ambulance because while having the seizures I stopped breathing and went blue. I was rushed straight to emergency …The life of epilepsy and chronic migraines" (Member 2).

Member 5 also presented the emergency patient when she experienced a medical episode at school which disrupted her musical production rehearsal and resulted in her being taken away in an ambulance. She posted:

> "Most of you would have heard by now, I'm in a production for the school of rock. I thought I'd attached a few photos in rehearsals. Included in the pictures are one of me when I ended up getting rushed to hospital in an ambulance haha" (Member 5).

A corollary to the sick role, especially the emergency patient is with the resumption of duties and social roles upon recovery, LW.org.au members also mentioned the need for special provisions at their workplace and school. When these were given, it created a positive sense of external social support for the young person and re-affirmed the value of their 'everyday teenage' identity beyond their condition. This was evident for Member 2 when she returned to work after her emergency appendix removal surgery. She writes:

> "So, you all know that about 3 weeks ago I had a very scary time when I had to have emergency appendix removal surgery. Well 3 weeks later, I'm back at work, which is great to see everyone again, and everyone has been really supportive looking out for me, helping with heavy lifting and making sure I'm feeling okay". (Member 2).

However, these provisions are not always guaranteed. When this occurs, it creates a degree of anxiety and frustration within the LW.org.au member. In these instances, validation from LW.org.au members and chat-hosts proves pivotal in both affirming the challenges unfairly imposed by the sick role or emergency patient disruption, and how valuable the young person's 'everyday identity' is despite the situation. This was evident for Member 5 when repeated medical episodes during her school musical rehearsals result in her director suggesting she might not be able to continue in the production. She states:

> "On Monday, exactly 6 weeks from when I had the last medical episode (we're unsure of what it is), I had another one of the same severity …It's superrrr annoying because both events have happened at production rehearsals and if it happens again the director will

> have to consider cutting me from the show. It sucks if that is the case because we only have 4 weeks until opening night" (Member 5).

LW.org.au members validate this experience stating:

> "Sending love and healing vibes your way. Sucks this is happening, but you can and will get through it" (Member 10);

> "Hope it goes well, so you can do the show" (Member 8).

This is valued by the Member 5, who responds:

> "Awww you are so sweet. Thank you. Can't wait to chat soon".

Victim

Another sub-identity that acutely captures the sense of disempowerment engendered by emergency situations, and the onset or prolonged experience of illness in the form of the sick role is the 'victim identity'. The victim identity does not occur often on LW.org.au, but does emerge when patients hit low points in the illness experience, and seek to regain their sense of control and power that has been usurped by the intrusion of their condition. This was evident for Member 2 with respect to her migraines. In this instance, the victim identity emerged alongside the 'battler, warrior or fighter' identity, when she writes:

> "Dear migraine,
>
> If I could have my life back, that'd be great. See the thing is I wasn't finished with it yet.
>
> Sincerely me". (Member 2)

The victim identity was salient again when members felt unable to fulfil the social responsibilities or expectations of either their young person identity or another condition based identity, such as the ‘responsible patient’ outlined below, because the ‘sick role’ and their condition intruded upon their ability to sustain these identities.

Prisoner

The prisoner identity was most frequently presented when members felt trapped by their condition. This emerged in the hospital context or when members were unable to participate in everyday teenage events. Member 10 presents the prisoner identity online on multiple occasions, evident in the quotes below where she states:

> “Here are some photos I took whilst downstairs, unhooked and free to kinda roam”;
>
> “Hey, I got leave from the hossie to go to my school’s final social. It was so amazing and I had so much fun”.

Dependent

Dependence is expressed by LW.org.au members when their condition requires extra support for them to fulfil their social roles and duties in their everyday life. This is evident for Member 2 when her disability requires assistance from a support worker. Interestingly, while she is included in learning the skills, she does not play an active role or participate in deciding what skills she would like to learn. This is decided by her mum (guardian) and support worker independent of her direct input. Thus, while both individuals strive to support her, to some extent, this also undermines her agency and participation. This is implicitly expressed when she writes:

> “With my support worker, she is helping me learn skills at home. So, we did some washing and folded the clothes. Then my mum arrived. I played with my nephew, while my support worker and mum sat down together and sorted out a plan for the next few

> weeks. They do this every couple of weeks. They sit down and work out when I need my support worker and what activities and life skills I need to work on" (Member 2).

The dependent role is also evident with Member 10 in the context of the hospital environment, when friends, nurses and family assist her while she is stuck in bed. However, her attitude of gratitude reframes her dependency positivity and offers back a sense of empowerment. This is evident, when she posts:

> "Things I'm thankful for. My beautiful friend for staying with me before iso; my nurses for bringing me balloons and a card whilst I was alone; my nurses for giving into my sweet talking and letting me have jelly at any given moment; my new treatment team, old team, doctors and nurses; all of you on LW; my dad for unlimited data" (Member 10).

Similarly, Member 4 and Member 6's use of assistive dogs connected to their need to be wheelchair bound illustrates dependency. However, by the same token, this can also be seen as an expression of independence in that these animals allow both members to move freely without assistance from other people. This is evident when Member 4 expresses: "Introducing Sally, my new labradoodle. She's currently six weeks old and absolutely adorable. The hope is that I will be able to train her to be an assistance dog to help me with my disabilities".

The relationship both members share with their assistance dog demonstrates a level of inter-dependence that challenges traditional notions of the dependent role. Member 6 attended her graduation with her assistance dog Casey and claimed: "Today, we graduated" featuring a photo of her and her assistance dog both in graduation gowns.

Vulnerable Patient

The vulnerable patient is connected to a sense of feeling alone and often emerges during times of uncertainty when members are experiencing symptoms that they have either no explanations for or are resisting diagnoses, and when the young person is confronting new treatments or surgeries they have never experienced. The vulnerable patient is associated with the emotional dimension of the sick role, and often results in members reaching out to the community for support, comradery, patient advice and expertise. This was evident in the following posts by members where they write:

> "I've recently been referred to an orthopaedic surgeon due to knee pain and crunching and grinding in my right knee because of cerebral palsy causing my leg not to be straight. I have been really lucky to avoid any surgery apart from Botox injections when I was young. I have never been in this situation before and I was wondering if anyone has any tips on how to get through these times" (Member 9);
>
> "I was born with …Syndrome and while my family and friends have always been incredibly amazing and helpful. I wanted to talk to people who had had similar experiences to me I didn't think this was possible because I had always heard the internet was dangerous and not a place to meet new people." (Member 3);
>
> "I've been struggling a lot mentally at the moment dealing with the whole invisible and undiagnosed illness then …But one of my teachers, she could tell I was drained because of the physical and mental reasons and took me out of class so I could vent. I cried heaps but she helped me get through it. It's moments like these I'm truly grateful for. She took the time for me to express myself and I feel so much better now" (Member 5).

Sympathetic (Cheerleader)

Members presented the sympathetic patient when they were demonstrating empathy and concern for others in relation to their condition, and the limitations and challenges imposed upon them. Their empathy was the product of having been in a similar situation themselves. This resulted in the member making efforts to alleviate the limitations and encourage inclusion. In this sense, they are countering ableism by enacting an environment that is responsive to the needs of a diverse range of individuals.

An example of this position is found when Member 1 shares an article on ‘Daylight Saving’, recognising for members with disabilities who rely on routines this can be disorienting, especially as it alters the times the LW.org chat-room is open. This was evident through the opening line of the article, where she states:

> “It can be difficult to figure out the time difference now that daylight saving has started. I have created a list of all the places in Australia as well as New Zealand, and explain the time difference as well as the chat-room opening and closing hours” (Member 1).

Member 2 also showed concern for individuals living with epilepsy when she forewarned other members before they potentially visited a particular musical theatre show to be aware of the lights based on her experience watching the performance. She posted: “I will say this as a warning, if you suffer from epilepsy, migraines or don't go well with flashing lights, there are a few scenes where you might need to close your eyes” (Member 2)

Treatment Identities

The second category treatment identities, contains fewer positions. The first is the commonly found position of the responsible patient who represents the person who recognises the expertise of the medical staff and wants to do what is expected to get better. All the members of LW.org.au who took part in this study, acknowledged the identity of the responsible patient. For members, this is an identity they are used to assuming. An example from Member 7 demonstrates this, she writes:

> “End of August, I got what we thought was just regular cellulitis on my wrist. After tablets weren't working, I was admitted for a few days to give IV antibiotics a shot. They were working so I went home with HITH (Hospital In The Home). By the end of the week, my wrist had stopped improving. So, I had to have the abscess surgically drained/cleaned. A few more abscesses came up, but no surgery was needed. Home time!” (Member 7).

When she returned home she continued to demonstrate the need to be a ‘responsible patient’, posting: “I’m thinking I should turn my whole room into a gym for physio” (Member 2). This intercepted with her young person identity that enjoyed fitness and sports. Member 5 also presented herself to be a responsible patient when she wrote:

> “My health as some of you know has been up and down. I did find out some not great news this week with results from a test I had, but now that I know what’s causing the symptoms, we can work with the diagnosis and work out what the best treatment is” (Member 5).

Frustrated Patient

The position of the frustrated patient emerged when members had been a responsible patient, but it appeared that medical staff have not fulfilled their roles appropriately. This included when doctors had failed to reach a diagnosis or recovery had not been achieved. Member 5 confronted the lack of diagnosis over a period of time, and her frustration was apparent from these two quotes, where she writes:

> “The results came back fine, but for people like me who are fed up with no answers and know they need them, it honestly hurts. I would just rather answers …I’m still annoyed about my medical stuff especially because it happened again last night”;
>
> “So, my hopes are that we get some answers, good or bad so we can start treating this issue!”

Rehabilitation/ Athlete

The rehabilitated athlete is an interesting identity as it demonstrated when a member employed a facet of their young person self to re-storying the disruption they felt in relation to their condition. It also indicated when members were striving to defy being positioned in roles connected to the medical model to sustain a sense of normality. This was evident when Member 2 was recovering from an injury related to her condition, but employed her athlete identity to re-frame this injury in terms of the discourse of sport. She posted:

> “So, my heath this week has been really good. The best I have felt in over 6 months. My hip rehab is going great. Been back in the pool for 2 weeks now and I’m feeling great. Things are improving quickly faster than my physio thought but he is really happy. We’ve gone from getting told I am out for the remainder of the year 3 months ago to now 3 month later and back in the pool training. I am now back in the pool doing 25% of my normal training session. Which is great” (Member 2).

Recovered

Only one member provided evidence of the ‘recovered’ position’. The recovered patient position was presented in the community predominantly as an ‘aspirational’ position. It was often connected to the ‘responsible patient’ with members expressing ‘recovery’ as the ‘ideal’ goal or outcome for being dutiful and acquiescing to medical advice, treatments and procedures. This conforms to a progressive narrative and confers a sense of hope and control for members in the situation. However, the attainment of the recovered' identity was frequently problematized and punctuated by the re-emergence of a condition and the ineffectiveness of diagnosis and treatment.

Member 2, the Paralympian is the only member who strongly expressed the recovered patient position, evident when she writes:

> "Yeah actually at the moment, it's going pretty. Well, I have had a quick recovery from my surgery. My hip is great. Been back in the pool twice training and feeling great. I am having little issues with like my stomach and constantly having indigestion" (Member 2).

To a large extent, this was because she has subsumed this position into her young person identity as an elite athlete, where injury is to be expected and recovery similarly can be expected to follow.

Subversive and Empowered Identities

The trickster identity was often presented in tandem with the responsible patient, but allowed the member to escape the clinical or 'sick role' by making light of the situation. As a result, the trickster identity strongly interacts with the member's young 'person identity'. The comedian seems an obvious pairing, but the disobedient streak in many young people pushing the boundaries, is not to be discounted. In the example below, Member 10 employed the trickster identity to defy the 'sick role' and escape the imprisonment and dislocation she felt in the hospital context by utilising her digital and 'photobooth' skills to humorously 'escape to the tropics'. In this instance, the trickster identity functioned as a form of diversion, while still allowing the LW.org.au member to maintain the responsible patient role. This was evident, when Member 10 posts:

> "What a wild ride! Today has been HECTIC! Back at my usual hossie again and guess what the family is here. Also, took a quick trip to the tropics and an aquarium. Was so great! (ps… has anyone actually been successful at using photobooth backdrops)".

In the example below, the member was being a responsible patient in the hospital, but in order to escape the sick, dependent and imprisoned role, she makes light of the situation through humour. She posts:

> "Day 7 of being in the hospital PS half satire:
>
> Hour 157 is about to begin. I guess hour 155 and a half if we take away the time in the ambo during patient transfer. I've seen things no one should see …I've seen two whole seasons of Orange is the New Black in one sitting; I've seen a child drop jelly and proceed to eat it off the floor before their mum caught them; I've seen an old man dress up like a clown letting kids shave his head; I've sweet talked nurses into getting me free jelly; I've recreated about 20 scenes from five feet apart at my nurse's request. I've decorated my room only to move after 113 hours; I've spent hours labouring over a photo wall – which might I add is spectacular. I've ordered bubble tea from uber eats about 5 times. …
>
> There have been not so great things like tubes being blocked; double IVs, sleepless nights, pain, NU placements, you know….the reason I'm in hospital in the first place" (Member 10).

A third example of being a trickster involved acting up in the hospital or deliberately disobeying the rules and reclaiming the young person identity. This deliberate flouting of the rules acknowledged by members is clear in this interchange between Member 10 and Member 4, expressed below:

Member 10 reported:

> “I got in trouble last Thursday. I was in the hospital and in my room. But the patient wifi isn’t as good as in the café in the foyer. So, I yeeted down with my IV pole to foyer to watch the end of catch phrase (RCH Livewire’s Livestreaming), ended up missing DOOLS (Days of our Livewirians) anyway”.

Member 4 replies

> “Good a reason as any to break the rules”

Member 10 continues:

> “It happened like last year as well, but that time my friend and I went across the entire hospital to the store with the best hot choc, only to find out it was closed and ran into our nurses on the way back.

Member 4 jokes:

> “Awww no mission abort”

Member 10 further comments:

> “Yep, except that was at the children’s hospital. Now my hospital is adults, but I’m on the children’s ward as it’s private – and the ward has so many security and double doors to make sure little kids don’t wander off for safety”.

The position of the trickster also emerged as a form of defiance, particularly in the subversion of medical norms or directives. A sense of achievement emerged from this position. Member 9 wrote:

> “Doctors told me I can’t drive for a few months. Although I drove up to the hospital for the last time …I was paralysed when I went to hospital, but eventually I started getting movement and strength. I will never forget the first time I stood on my own. I was in the bathroom and I was sick of everyone telling me I couldn’t try. So, I got out of my wheelchair and stood.”

The trickster position is important as it allowed members to assert their will against their condition and against the constraining environment in which they found themselves. They did not always succeed in gaining a lasting sense of autonomy, and sometimes there are consequences for having broken rules. However, this position enabled members to reclaim their young person selves. They were also able to reclaim some semblance of their autonomous, young person identity by attending the LW.org.au and Starlight workshops. This may be facilitated by these activities building young people’s skills and resources to take responsibility for some aspect of their health. This was evident when Member 5 posted: “I’ve finally reached out for proper help with regards to my mental health”. While this action could be seen to relate to the ‘responsible patient’ position, the difference here is the member has and uses her agency to take action, rather than doing something which is merely set out in her healthcare treatment plan” (Member 5)

Another empowered position facilitated by LW.org.au, was when young people adopted the role of advocate. This was evident when member 10 states: “Hey all! Cutting off 25cm of my hair tomorrow to donate! Posting here so I don’t change my mind”. A chat-host (3) replied: “For cure". Member 10 confirmed: “no variety”. Variety is a charity that makes wigs for cancer patients from donated hair. Member 10’s efforts were supported by Member 7 who commented: “Great work I’m sure it will look fantastic!”. The empowered patient identity also presented itself when Member 5 was offered the opportunity to be an ambassador for

LW.org.au and the SCF at the Australia Association for Adolescent Health (AAAH) conference. She posted: “Yesterday I shared the Stage at the AAAH health conference. We spoke about the Reps and all things Livewire online”.

Condition-Based Identities and Young Person Identities

The findings presented here on identities demonstrate that identity is complex for these members with both their young person identities and their condition-based identities being multifaceted. The condition-based identities tended to be more time contingent than the young person identities in that they interfered, intruded or disrupted the everyday, and had become such a pervasive part of the young person’s life, they were accepted as the ‘everyday’.

Tensions existed between these sets of identities as members confronted the challenge of determining what is a ‘normal’ balance of these identities for each of them. The LW.org.au community re-defines normal through the community and member’s common knowledge or experience. Members have a shared understanding of their lives being punctuated by hospital experiences with their conditions intruding into their everyday life and disrupting their routines. They were also aware they lacked control or certainty in this context due to the unpredictable and intrusive nature of their conditions. However, they understood that the ‘normal’ or ‘common ground’ within the community was different from the experiences of other young people who do not live with a condition, where individuals are consistent and reliable with their social roles and their lives are not punctuated as significantly by disruption.

Member 2, the athlete had two understandings of ‘normal’ operating at the same. The normal created by the LW.org.au community and her patient identity, as well as the normal of being an athlete in competitive sports. To marry the tension between her two identities, she often appropriates the medical discourse of treatment in relation to her condition into rehabilitative or coaching terms. This enables her to sustain the identity of the recovered patient or survivor, which in her experience is a more intermittent self.

The tension for Member 5 is expressed through her condition affecting her ability to perform in the school musical. A significant element about her condition was that it was still in the early stages of diagnosis and the diagnosis remained unclear, despite her efforts to be the responsible patient. This left her frustrated and turning to school teachers and the LW.org.au community to validate the difference between her (preferred) young person's performative identity and her unresolved 'patient' identity.

Member 6 challenged the idea of 'normality' by being a chameleon and adapting to the world of academia better than those without conditions. She demonstrated that she is equally if not more competent than her able-bodied peers. This approach to identity may reflect the 'supercrip' identity found in the literature. However, while she did not overly present her condition online —preferring to foreground her 'young person' self as a confident, high-achieving, bubbly career woman and activist— she did challenge the supercrip identity and concept of 'normality' by forcing society to see beyond her wheelchair to focus on the undeniably brilliant mind, fearless risk-taker and passionate individual beyond it. She could be seen as an example of a new normal. However, beyond this public persona was a more private young person. This was revealed in her posts about being a musician and home cook.

Members deal with the tension between their identities in different ways. Whereas Member 6 established a critique of 'normality from inside the system and redefined it, Member 3 critiqued it from the outside; putting a spotlight on what's wrong with the system from a diversity of marginalised perspectives.

Authenticity

The validation of identity is an important aspect of engagement in LW.org.au. Identity claims online are often accepted at face value without the need for explicit validation. Although any discrepancies will soon be identified by regular participants in the chat-room or by the chat-hosts and gently probed. However, validation within the LW.org.au community is not the only source of validation of identity for most members. The hospital context is important, as most members of LW.org.au do engage with the Livewire hospital team when in hospital and many LW.org.au hospital facilitators are chat-hosts. Therefore, if any discrepancies emerge in either context, it is picked up and reported. Some members recognise that aspects of their identity are validated externally through their performative activities. Key examples here are the athlete who had been selected to represent her country and the university student who was Valedictorian of her year. Some members, however, appeared to have little in the way of external sources of validation of their identities and in these circumstances, the LW.org.au community becomes a vital source of validation and support.

Creating the Moral Order of these Identities

To understand how individuals construct and negotiate the self in relation to 'local moral orders' (Harré & Van Langenhove, 1998, p. 1), positioning theory was used as an analytical tool. Local moral orders are conceived as the meaning systems delineating 'rights, duties and obligations' (Harré & Van Langenhove, 1998, p. 1) to particular positions in society, such as the doctor has a duty to care for a patient and the patient has the right to be cared for. However, local moral orders operate on various levels, including the macro level of institutionalised society or discourse, as well as the micro level of community culture and conversational dynamics (Bamberg & Georgakopoulou, 2008; Hirvonen, 2016). Local moral orders speak to the norms of a community, and how these norms come into being through the stories individuals tell and the characters they choose to enact within these conversations.

Thus, this section of the findings seeks to explore how the local moral order of LW.org.au or the norms of interaction, are constructed through the conversations and interactions its chat-hosts and members share and engage in online. Through these conversations, young people present their identity, both in terms of their condition (illness or disability) and young person self. They also position themselves in relation to wider discourses, such medical discourses about the role of doctors and patients within narratives of treatment and care, and whether the individual's experience and understanding of the self, corresponds to or challenges the assumptions embedded within these discourses. These young people draw upon existing narratives or positions as resources to understand the self, and experiment with multiple positions within conversations to explain their actions in relation to deeper issues or themes, including balancing multiple conditions and the goals of adolescent and emerging adult life. The findings in this section, show how individuals intentionally position the self within everyday stories and how they situate themselves in the conversations with others. This latter illuminates the roles community members play in supporting or challenging the individual's identity claims and demonstrates how the 'local moral order' of LW.org.au emerges from these conversations.

In the flow of the conversation, participants can take on one or more of several roles such as inquirer/questioner and responder, or expert and student. These roles can also be assigned by others in the interaction or outside of the interaction. When an individual disagrees with a role assigned to them, they can use stories from their own life or experiences to counter that role. The findings presented below show that members use stories from their own lives and experiences to challenge institutionalised or societal norms. Storylines are seen as part of the cultural model of LW.org.au created by members and chat-hosts in their profile pages and the online chat-room.

Two examples of these processes are set out below, revealing insights into the young person's identity, their condition and their interactions with chat-hosts and members on the site. While the examples deal with different topics, each example exhibits a common theme in the way LW.org.au members approach these issues. In particular, the examples highlight how the interactions balance the identities of the young person and that of someone living with illness or disability by celebrating the expertise and interests of the individual and their peers at the same time as attending to their concerns. The interactions are set out following the prescriptions of positioning theory.

Illness-identity: Local Moral Order of Treatment/Care, and the Role of Doctor and Patient

The first example involves a story about Member 1 who upon entering the chat-room is asked by the chat-host (4): "How's it going?". This functions as a source of phatic communication in the form of a greeting and an act of forced self-positioning by Chat-host 4 to Member 1. The phatic communication positions the chat-hosts as a friend, but the directive nature of the colloquial question, opens the opportunity for Member 1 to account for her day. Member 1 accepts this position, stating: "I'm annoyed". This indirect complaint functions as a form of third order deliberate self-positioning through the use of 'I' indexing personal agency in reference to a story about wrong-doing from Member 1's lived biography, where she is positioned as someone who has been aggrieved, and therefore has a right to compensation or apology from the guilty party. However, within the context of the interactional dynamics of the community, Member 1's terse statement also functions as a form of intentional first order positioning of others. This impels Chat-host 4 and other members to inquire “why”, in the role of confidantes.

Member 1 subsequently reveals that she has “had bronchitis”, positioning her as someone who has been ill or unwell, and therefore deserves a right to concession or leniency. She continues ‘due to [her bronchitis], she hasn’t been able to wear her retainer [and] now it no longer fits’. It is at this juncture the plot thickens. Member 1’s story of wrong-doing appears to be embedded in a larger personal narrative of managing one’s condition or balancing competing health concerns. This is indicated by Member 1’s deliberate third order positioning of the self as an orthodontic patient, who was unable to fulfil her commitment to her orthodontist of wearing her retainer due to her bronchitis. Thus, her illness, bronchitis, has subsequently been positioned as the guilty party or wrong-doer disrupting Member 1’s plans to be a ‘responsible’ patient. In this instance, her story alludes to a wider cultural narrative or ‘local moral order’ of the doctor (orthodontist)/patient in treatment and care, whereby the orthodontist has a duty to care for their patient by prescribing the right treatment, and the patient while possessing the right to be cared for, has a duty to be responsible for their health by following through with the treatment plan.

Member 1’s’s desire to uphold this commitment of being ‘responsible’ is further indicated in the subsequent statement: “I need to make a decision, whether I spend more $$$ to get a replacement or give up now”. Two things occur within this. First, Member 1 returns to first order positioning of the chat-hosts and members with the commissive statement: “I need to make a decision”, which indirectly functions as a directive asking the members and chat-host to help her with this decision, thus positioning them as confidantes and advisors. Secondly, this decision functions as a moral dilemma. Does she continue enacting agency and take responsibility for her health by investing in remedial action at a large consequence to herself.

This positions Member 1 as a fighter or hero in the silent battle against her wrong-doer, bronchitis. Or does she give up, defeated, resulting in her being seen as irresponsible by her orthodontist. Member 1's further re-iterates that even if she invests in a replacement retainer, it will only be for a short while before she has to have jaw surgery. Again, positioning surgery or an element of her condition as an impeder to her ability to manage competing concerns. In Member 1's eyes, she feels she's fighting a losing battle. Moreover, she re-iterates 'she's annoyed, because she knows her orthodontist will be mad with her. But it's not her fault'. This is the crux of the issue, Member 1 feels she will be wrongly accused for something (bronchitis) that was beyond her control and she feels she deserves concession for, but which the orthodontist does not see.

The chat-host subsequently adheres to Member 1's forced positioning and steps in as the advisor. Through second order positioning the chat-host re-negotiates Member 1's understanding of herself and her orthodontist by claiming: "I'm sure you did what was best for you at the time, it's frustrating it does not fit, but I'm sure your orthodontist would not be upset if they knew the full story". This accounts for Member 1's inability to remain committed to wearing her replacement by referring to her experience or lived expertise, rather than just the happenings of her biography. Moreover, she refutes Member 1's view of her orthodontist as not being understanding if they knew the circumstances. Member 1 responds: "I know". The interesting feature about this is how Member 1's understanding of her doctor (orthodontist) confirms to a biomedical or clinical 'local moral order' of treatment/care, where the doctor treats the patient in terms of their speciality or condition, rather than holistically. The story also contrasts this with how Member 1 potentially views the 'local moral order' of LW.org.au, being somewhere where she can vent these concerns in a manner that she feels she can not with her orthodontist. Here, LW.org.au confirms her need to be understood holistically, and this interaction possibly functions as a resource or support for her in mediating these issues in the future. This is especially pertinent when the local moral order of the site, through the chat-host, seeks to position her lived experience as equal expertise.

Athlete’s Identity as a Resource for Managing One’s Condition

Member 2 also recites a similar tale of needing to manage both an injury alongside the complications of her conditions, but in contrast to Member 1, she positions her story of illness management and recovery predominantly within the discourse of coach and athlete, rather than doctor/patient. This is pertinent as Member 2 prides herself on her athlete/swimmer identity having competed in the Paralympics.

Her story valuably demonstrates how again the ‘local moral order’ of LW.org.au continues to view its members holistically even when talking about health-oriented concerns, which for Member 2 has the added value of witnessing her swimmer/athlete identity function as a possible source of resilience for her (Ferguson & Walker, 2014).

Member 2 enters the chat-room and is asked by the chat-host (9): “How’s your health going?”, which is an act of forced other positioning by the chat-host that requires Member 2 to account for her condition either positively or negatively. This subsequently positions the chat-host in a friendly caretaker role or as an assessor amidst a storyline of checking in. Member 2 responds positively through second order positioning stating: “everything is going pretty well”, offering a storyline of her health being on track. This is followed by deliberate self-positioning, stating: “I’ve had a quick recovery from surgery. My hip is great. Been back in the pool twice training and feeling great!”. Member 2’s story positions her as experiencing a fortunate speedy recovery amid a storyline of getting back to normal. She qualifies this, stating: “I’ve had little issues with my stomach and epilepsy” positioning her in an unwell or sick role, and therefore deserving of concessions. But, similarly to Member 1, she also positions herself as a responsible patient, taking agency in regards to her health with the commissive promise: “but seeing my neurologist next Wednesday about that?”.

While Member 2 evokes the discourse of doctor/patient in her conversation, she dominantly draws upon the concurrent discourse of coach/athlete through the storyline of monitoring her health like a track record. The chat-host validates this responding with congratulations: “wow that’s great to hear. Can’t believe you’re already back in the pool”. This evokes a storyline of achievement, positioning Member 2 as a success. Member 2 supports this stating: “I know considering three months ago I was told I would be out for the rest of the year”, again drawing upon sporting metaphors that align with a storyline of making a comeback. Member 2 attributes her comeback to hard work. This again evokes the dual discourses of responsible doctor/patient and coach or trainer/athlete. She acknowledges that it has been a hard five months with her health, which similarly to Member 1 positions her as a fighter, but her athlete’s identity, rather than viewing her health setback as defeats, re-positions them as achievements. This is confirmed by her hard work and training. As a result, Member 2 also subsumes her doctors, including neurologist and physiotherapists into the role as coaches to complete her story. Thus, it appears that the local moral order of LW.org.au by attending to her and her health holistically, also influences how she views the medical community at large.

Chapter Summary and Conclusion:

This chapter outlined the findings from the netnographic (Geertz, 1973; Kozinets, 2010, 2015) investigation into the SCF’s online community LW.org.au in two parts. It explored the cultural model of the site as set by the SCF organisation, and monitored and enacted by the chat-hosts and members online respectively. It elucidated the online community’s purpose and the unique gap it fulfils in practice from the perspective of chat-hosts and members. It outlined young people's help-seeking and engagement behaviours online by examining the site's core membership and young people's reasons for reaching out to the community from the perspective of both chat-hosts and members. This illustrated it was young people's conditions and the sense of relatability they experienced in response to their condition that constituted their primary reason for reaching out to the community, but it was the peer connections in relation to youth culture that sustained their engagement long term. Thus, LW.org.au's ability to create a safe, but medically free space was pivotal. Similarly, its youth oriented moderation style was highly valued by young people.

The second part of the chapter outlined young people's identity presentation and exploration online in relation to the identity categories of their (a) young person and (b) condition based selves, and highlighted the processes of disclosure and validation experienced from mentors and peers online. Both identities categories revealed a breadth of diversity, however the culture of the community appeared to facilitate more in depth expression of members (a) young person selves, rather than their (b) condition based selves. The implications of this for identity expression and integration online will be discussed in the following chapter. It also indicated how young people employed both their young person and condition based selves to re-define normalcy and re-story the self in relation to the illness and disability experience. In addition, it outlined different member characteristics impacting this process. Last, it illuminated how stories expressed online connected differentially to the local moral order of the LW.org.au community and other medical or youth-oriented cultures offline through a positioning theory analysis.

The next chapter will discuss the findings in relation to the literature and outline core contributions of the study for scholarship and practice.

Chapter 7 Discussion

Introduction

The Research Purpose and Goals

This study involved a netnographic (Geertz, 1973; Kozinets, 2010, 2015) investigation of the SCF's online community, LW.org.au to explore how it functions as a developmental, psychosocial intervention for young people living with an illness or disability between the ages of 12 and 21 years. It sought to understand how the unique culture that is enacted and embodied online impacted young people in their ability to achieve the developmental tasks of (a) forming and maintaining peer relationships and friendships within a novel, social environment online; and (b) examining how they experiment with, negotiate and establish a unique sense of self in the context of these online interactions and experiences (Erikson 1968, 1994)**.**

This discussion chapter begins by addressing the contribution the study has made to the understanding of identity and the processes of creating identity within the LW.org.au online community (Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966, 1993; McAdams, 2011). Following this, it outlines the tensions that arise in relation to LW.org.au's claims to legitimacy in the community-oriented space in which it operates, drawing in particular on the role of the chat-hosts (Haldane et al., 2020; Third et al., 2013). Third, it explores the concept of developmental appropriateness in the context of the findings of this study, demonstrating the contribution the study has made to an understanding of the concept. It also explores the notion of developmentally appropriate interventions and considers the implications for LW.org.au (D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014; Tylee et al., 2007). It continues with a consideration of the two approaches to developmentally appropriate interventions—(a) the risk-averse preventive approach and (b) the universal, promotive approach—emphasising the strengths and weaknesses, conceptually and practically, of taking an integrated approach (Catalano et al., 2002; Czeresnia, 1999; Lerner et al., 2011).. The fifth section of the chapter addresses the contributions the study has made to research in this field through the netnographic (Geertz, 1973; Kozinets, 2010, 2015) methodology it employed and the use of positioning theory (Bamberg & Georgakopoulou, 2008; Harré et al., 2003; Harré & Van Langenhove, 1998) as an analytical tool.

Identity and its Construction

The findings from this study support Erikson's (1968, 1994) assertion that identity formation constitutes an important psychosocial and developmental task of adolescence and emerging adulthood. This was evident through the high degree of identity exploration exhibited online, and the way young people employed identities as narrative resources (Hammond & Teucher, 2017; McAdams, 2008b, 2011) to personalise the illness and disability experience and make sense of it in the context of their everyday life. The study also extends Erikson's (1968, 1994) postulation and Oris et al. (2016), Rassart et al. (2012) and Raymaekers et al.'s (2017) claims that peer and mentor connections play a crucial role in facilitating or inhibiting young people's identity exploration and commitment processes. It does this by demonstrating pathways through which LW.org.au members and chat-hosts support or challenge young people's identity exploration and negotiation online. This includes validation processes as well as efforts to reframe or reposition (Bamberg & Georgakopoulou, 2008; Harré & Van Langenhove, 1998) young people's understandings of the self to promote more agentic definitions of their identity in conversations where young people ruminate on disempowering or medicalised selves. However, similarly to the work of Raymaekers et al. (2017) and Wiebe et al. (2016), this study suggests that the positive or negative impact of peer and mentor connections and online interactional dynamics on young people's identity formation, and exploration and commitment processes, is dependent on the social context, particularly the culture and norms operating in the space. By addressing these concerns, this study contributes to the paucity of research exploring identity development among young people living with a condition in general (Dominiak-Kochanek, 2016; Luyckx et al., 2008b; Madan-Swain et al., 2000), and in relation to how the interactional dynamics and cultures operating within online communities and social media interventions influence the identity development process (Oris et al., 2016; Rassart et al., 2012; Raymaekers et al., 2017; Raymaekers et al., 2020; Wiebe et al., 2016).

The use of netnography (Geertz, 1973; Kozinets, 2010, 2015) as a methodology facilitated the study in making this contribution as it allowed the researcher to explore identity development from the perspective of three diverse strands of identity scholarship emerging from Erikson's (1968, 1994) seminal work. These include the identity status works of Crocetti (2018), Luyckx et al. (2006); Luyckx et al. (2008a) and Marcia (1966) who operationalised Erikson's conceptualisation of 'identity formation' in terms of exploration and commitment processes that relate differentially to health and condition outcomes. The second strand involves McAdams (2001); McAdams and McLean (2013), McLean et al. (2016) and Pasupathi et al.'s (2007) work on narrative identity that explored identity formation in terms of content, meaning and meaning-making processes. The third strand involves the work of Côté (1997), Côté and Schwartz (2002) and Mead (1934), who combined psychological and sociological understandings to highlight the role of context in inhibiting or facilitating identity development through a 'goodness of fit' with the assets and resources available in young people's environments, and the role of interactional dynamics.

While exploratory studies have attempted to integrate at least two of these strands of identity scholarship (Luyckx et al., 2009; Marin & Shkreli, 2019; McLean et al., 2016), no study has demonstrated how identity formation occurs across all three. The current study has made a preliminary effort to address this concern. In doing so, it broadens our understanding of each perspective (Côté, 1997; Côté & Schwartz, 2002; Crocetti, 2018; Luyckx et al., 2006; Marcia, 1966; McAdams, 2001, 2011) and the points of intersection between them. This integrated approach has value for enhancing our knowledge of the role interventions play within the field (Raymaekers et al., 2020; Wiebe et al., 2016), which is both an under-researched area of identity scholarship and one that is potentially best addressed through interdisciplinary efforts.

By applying a netnographic (Geertz, 1973; Kozinets, 2010, 2015) methodology to examine identity development among young people living with a condition, the study balances the high emphasis within identity scholarship on identity statuses (Crocetti, 2018; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966) and narrative identity (McAdams, 2001; McAdams & McLean, 2013; Pasupathi et al., 2007) that highlight the personal or psychological aspects of identity formation to give greater recognition to the role of the sociological elements of identity formation (Côté, 1997; Côté & Schwartz, 2002; Raymaekers et al., 2020; Wiebe et al., 2016), particularly how the cultures and norms of specific environments or interventions facilitate or inhibit the processes of identity construction (McLean & Syed, 2015). Further, the study extends the sociological literature (Côté, 1997; Côté & Schwartz, 2002; Raymaekers et al., 2020; Wiebe et al., 2016)—that tends to examine contextual factors as either antecedent or outcome variables, such as peer support (Raymaekers et al., 2020; Wiebe et al., 2016), peer orientation (Raymaekers et al., 2020; Wiebe et al., 2016) and relatedness (Luyckx et al., 2009)—to better represent the bounded nature of these processes within an intervention and how they operate interactively on an everyday level as norms, rather than as discrete variables at specific points in time. Therefore, this study illuminates how interactions with members and chat-hosts online impact identity exploration, commitment (Luyckx et al., 2006; Luyckx et al., 2008a) and meaning-making processes (McAdams & McLean, 2013; Pasupathi et al., 2007) among young people with a condition, and demonstrates the strengths and weaknesses of the site's cultural model in aiding these processes.

In addition, by exploring these constructs through a netnographic (Geertz, 1973; Kozinets, 2010, 2015) methodology this study distinguishes between how everyday experiences (Pasupathi et al., 2007) or small stories (Bamberg & Georgakopoulou, 2008; Ochs & Capps, 2009) expressed in young people's posts, statuses and conversations online, impact identity formation in tandem with more cohesive life narratives (Habermas & Bluck, 2000; McAdams, 2001, 2011). This has relevance on both a methodological and developmental level. On a methodological level, in relation to social media platforms and interventions, it reflects how postings and conversations online influence identity formation incrementally through everyday identity content and the patterns of identity-making practices over time, rather than by attending only to identity-defining moments shared in hindsight, as is common in life narrative research (Habermas & Bluck, 2000; McAdams, 2001, 2011). This demonstrates identity formation in action (Mead 1934). On a developmental level, the emphasis on identity content and the patterns of identity-making over time, indicates how exploration processes in early–mid-adolescent, allow young people to build identity content online that informs their identity, but does not necessarily define it to the same extent as explicit, thematic, meaning-making practices, evident among older adolescents' and emerging adults' exploration and commitment processes do (Habermas & Bluck, 2000).

Thus, the study highlights how exploration and commitment processes relate to narrative identity meaning-making practices, but despite their similarities tap into different dimensions of the identity-forming process that can account for differences in stages of adolescent development (Habermas & Bluck, 2000).

Identity Statuses

Concerning the identity status literature (Crocetti, 2018; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966), this study extends scholarship by exploring identity formation and identity statuses through qualitatively observing young people's exploration and commitment processes in their interactions and conversations online, and in relation to the meanings they ascribe to specific identities in negotiation with others (Bamberg & Georgakopoulou, 2008; Harré & Van Langenhove, 1998; McAdams & McLean, 2013; McLean et al., 2016). This approach moves beyond exploring identity formation through questionnaires and combines narrative and contextual components (McLean & Syed, 2015) to highlight the valence of identity expression, including whether young people are exploring or committing to identities that align strongly with medicalised, subversive or empowered understandings of the self (Angulo-Jiménez & DeThorne, 2019; Hammond et al., 2015; Stage et al., 2020; Vidamaly & Lee, 2021). This also captures the influence of culture on identity development processes, and the difference between the cultural models of the LW.org.au community, and those operating in other settings within which these young people find themselves. However, the latter are beyond the scope of this thesis.

The study further contributes by examining identity statues, and exploration and commitment processes in relation to the cultural or identity domains of being (a) a young person, and (b) someone living with a condition (Luyckx et al., 2008b; Oris et al., 2018; Syed & Azmitia, 2008; Syed et al., 2013). This challenges the emphasis within the identity status literature of scholars exploring identity formation among young people living with a condition using global measures (Luyckx et al., 2008b; Schwartz et al., 2015). This approach foregrounds their young person self and only attends to their condition as an outcome variable, such as condition coping or integration (Luyckx et al., 2008b; Madan-Swain et al., 2000; Verschueren et al., 2017). Similarly, this study extends the identity status literature that focuses on examining identity formation in relation to specific identity domains by challenging the emphasis placed on domains primarily connected to the identity category of being a young person, such as career, school and relationships (Dominiak-Kochanek, 2016). Both approaches hamper the opportunity to explore 'living with a condition' as a valid cultural category or identity domain, such as ethnic or gender identity (Syed & Azmitia, 2008; Syed et al., 2013). This has value for these young people because the illness or disability experience is a central aspect of their lives. Without exploring 'living with a condition' as a cultural category or identity domain, we are hindered in our ability to understand how young people explore and commit to identity choices connected to the roles, positions or selves they enact or assume in relation to the illness and disability experience (Hammond & Teucher, 2017).

Further, this undermines our ability to examine how these individuals integrate these understandings of the self into their identity as an 'everyday' young person, or employ their young person selves to make sense of their condition (Hammond & Teucher, 2017; Luyckx et al., 2008b; Oris et al., 2018). Thus, this study also challenges the approach to understanding how young people integrate their condition into their wider sense of self that focuses on the 'illness identity questionnaire' (Oris et al., 2018), which examines identity integration in terms of the processes of rejection, engulfment, acceptance and enrichment, not the identities themselves. By facilitating the expression and exploration of both the (a) young person and (b) condition-based selves of young people, the study recognises that identities connected to the illness and disability experience, in some instances, may become foundational to a young person's wider sense of self, and that illness and disability identities can be strengths based, rather than just being related to disempowered roles connected to medical models of health (Angulo-Jiménez & DeThorne, 2019; Hammond & Teucher, 2017).

By applying this approach, this study revealed that identity statuses were differentially represented online between LW.org.au members' (a) young person and (b) condition-based selves, and that levels of identity integration differed between these two identity categories. Only one member (6) fell into the *achieved* identity status category and exhibited substantial integration between her young person and condition-based self online and offline (Luyckx et al., 2006; Marcia, 1966). Most LW.org.au members presented a sense of self that was reflective of the *moratorium* identity status (Luyckx et al., 2006; Marcia, 1966). Similarly, the degree of integration they demonstrated between their condition-based and young person selves was less cohesive, meaning that while some members' identity formation in relation to their young person self reflected the *moratorium* status, the expression of their condition-based selves online exhibited a style of identity exploration and commitment reflective of the *foreclosed* or *diffused* identity category (Luyckx et al., 2006; Marcia, 1966). Only one member presented a *foreclosed* identity in both her young person and condition-based self (Luyckx et al., 2006; Marcia, 1966). Interestingly, because of her strong external achievements offline, this member frequently considered herself an *achieved* individual. This finding highlights the importance of observing identity formation in practice and not just through self-reports or questionnaires, as how one perceives their identity achievement may differ from how it is understood by others. No member exhibited an overall identity characteristic of the *diffused* identity status; however on some occasions the presentation of members' condition-based selves indicated elements of *diffusion* as discussed below (Luyckx et al., 2006; Marcia, 1966).

The difference in identity status prevalence, and exploration and commitment processes among LW.org.au members online, might result from a range of factors, including developmental age, achievement of developmental milestones, degree of external support young people received offline, and condition variables. For example, the *achieved* member (6) was substantially older (20 years) than the other LW.org.au members involved in the study (Habermas & Bluck, 2000; Luyckx et al., 2006; Marcia, 1966). She also was further along in completing important developmental milestones, such as graduating from her undergraduate degree, receiving acceptance into her master's degree of choice, and attaining public recognition for her work on disability inclusion. This enhanced the external support she received for both her young person and condition-based identities offline. Thus, she demonstrated greater integration between her young person and condition-based selves online (Luyckx et al., 2006; Marcia, 1966).

She also exhibited a higher level of internal validation. This rendered her less reliant on the LW.org.au community for support. However, despite her lower need for external validation through the interactional dynamics of the LW.org.au community, she remained responsive to the identity needs, youth interests and condition concerns of others online. This responsiveness to validating others within the LW.org.au community was a core feature distinguishing her as *achieved* in comparison to other LW.org.au members who were still in the process of affirming their identity choices and commitments online, rather than validating others as strongly (Luyckx et al., 2006; Marcia, 1966). Her lower need for validation from the

LW.org.au community may have been influenced by the high degree of external validation she received for her identity choices and commitments offline, such as recognition from the university (Morsunbul, 2013; Raymaekers et al., 2020). Thus, she exhibited what Luyckx et al. (2006) term high identification with her identity commitments beyond the LW.org.au site.

This finding highlights the important reciprocal role that context plays in affirming identity choices (McLean & Syed, 2015; Morsunbul, 2013; Raymaekers et al., 2020). In contrast to Luyckx et al. (2011), it also alludes to how the ability to gain external validation for identity decisions may be impacted by the severity or intrusiveness of young people's conditions. This was evident in the case with the *achieved* member (6) being substantially impacted by her condition on a physical level, but excelling beyond 'healthy peers' in other areas, such as academically, emotionally and socially. However, the ability of other members (1, 2, 5) to garner external recognition, support and acceptance for their identity choices in relation to both facets of the self was more challenging (Angulo-Jiménez & DeThorne, 2019; Kelleher et al., 2020; Lindsay & McPherson, 2012). This was attributed to their conditions interrupting or intruding upon their ability to function in multiple domains outside the LW.org.au community context (Bury, 1982). Thus, their reliance on the LW.org.au community for this validation and support was more pronounced.

Among members falling into the *moratorium* identity status category, the factors of developmental age, developmental milestones, external support and condition variables were influential (Crocetti, 2018; Luyckx et al., 2006; Marcia, 1966). A core characteristic of the *moratorium* identity status in this study and the literature more broadly, is the high degree of variability between members due to this status's high focus on exploration, rather than commitment processes (Crocetti, 2018; Luyckx et al., 2006; Marcia, 1966). Thus, in this study, the *moratorium* status better captured differences in developmental age and milestones (Habermas & Bluck, 2000; McAdams & McLean, 2013).

This was evident with one member (3) falling into the *moratorium* identity status category in relation to her young person and condition-based self, but arguably could be seen to be approaching the *achieved identity* status (Meeus, 2011). However, unlike the *achieved* member (6), this member (3) —by virtue of being 18 years of age and in the process of finishing high school—was yet to test her ideas, values and identities choices in broader society. Thus, she retained an openness to being repositioned towards alternative identities within the LW.org.au community that was not observed amongst the *achieved* member (6), whose identity was characterised more by stability (Luyckx et al., 2006; Marcia, 1966). However, the *moratorium* member (3) approaching *achieved,* was firmer in her identity decisions and the identity integration between her young person and condition-based self than were other members (5,7 & 8) of the LW.org.au community, who were in their early–mid-adolescent. In contrast, these members (5,7 & 8) utilised the *moratorium* stage to discover and explore their identity predominantly within the confines of the LW.org.au community, rather than to affirm their burgeoning sense of self beyond it in the way the approaching *achieved* member (3) did (Habermas & Bluck, 2000; McAdams & McLean, 2013). However, in contrast to the *achieved* member (6), the *approaching achieved* member (3) engaged with the LW.org.au more frequently to passionately espouse and affirm her identity choices and decisions. Thus, she was more reliant on the community for validation than was the *achieved* member (6), but less so than those in the early stages of *moratorium.*

In addition to there being differences in developmental ages in relation to the *moratorium* category, one member (1) in her early–mid-adolescence reflected a *moratorium* identity status that was characterised by *ruminative* rather than *reflective moratorium* (Luyckx et al., 2008). This contrasted with the *reflective moratorium* status highlighted by the early–mid-adolescent members (5,7 & 8) mentioned above. This resulted in this member (1), on occasions, exploring her identity in maladaptive ways and integrating her young person self into identities connected to her condition that strongly aligned with the medical model that disempowered her sense of self and agency (Hammond & Teucher, 2017). This member (1) also exhibited less openness to her identity being re-positioned in positive ways in comparison to other members (5,7 & 8) at the *moratorium* stage, despite needing similar levels of validation from the community for her sense of self (Bamberg & Georgakopoulou, 2008; Harré & Van Langenhove, 1998). This finding highlights the importance of understanding young people's identity formation styles (Luyckx et al., 2008) and the identities (McAdams, 2001) they choose to integrate—particularly if they are positive or negative—to illustrate how strategies to re-position, validate and explore young people's identities are successful with some members and not others (Bamberg & Georgakopoulou, 2008; Hammond & Teucher, 2017; Harré & Van Langenhove, 1998). This has implications for interventions.

Another critical factor accounting for the variability among members presenting in the *moratorium* category was the integration of their young person and condition-based selves (Luyckx et al., 2008b). In this study, only Member 9 reflected *the moratorium* status in relation to both her young person self and condition-based identity online (Luyckx et al., 2006; Marcia, 1966). Two other members (5 & 7), in the early–mid-adolescent range exhibited a *moratorium* status in relation to their young person selves, but despite efforts to engage in identity exploration in relation to their condition-based identities online, at times, the presentation of this aspect of their identity exhibited a status more reflective of *diffusion*

(Luyckx et al., 2006; Marcia, 1966). However, in both instances, the young person was struggling to receive an official diagnosis from the medical community. Thus, their attempts to explore and understand their condition outside the LW.org.au community were often thwarted by a lack of solutions from medical professionals. Thus, *diffusion* in relation to their condition-based selves was the result of an external constraint (Luyckx et al., 2006; Marcia, 1966; Morsunbul, 2013). In these instances, their reliance on the LW.org.au community to express this facet of the self and the frustration that resulted, was critical in supporting their exploration process (Luyckx et al., 2006; Marcia, 1966; Morsunbul, 2013). It was also valuable in supporting the exploration and expression of their young person self as a resource to cope with this challenge and move beyond *diffusion* (Luyckx et al., 2008b).

In contrast, two other members (1 & 8) in the *moratorium* category and early–mid-adolescence age range, exhibited behaviours characteristic of *moratorium* status in relation to their young person selves, but moments of *foreclosure* with respect to their condition-based identities (Luyckx et al., 2006; Marcia, 1966). However, *foreclosure* in this regard presented in diverse ways for both members. For Member 1, *foreclosure* represented a tendency to fall back on institutional roles reflective of medical discourse in relation to her condition-based self, despite attempts by both chat-hosts and members to reframe her understanding to align with empowered or subversive condition-based identities (Hammond & Teucher, 2017; Luyckx et al., 2006; Marcia, 1966). In contrast, Member 8 presented a *foreclosed* status in relation to her condition through an inability to explore in breadth and in depth the emotions connected to her condition-based self (Luyckx et al., 2006; Marcia, 1966). As a consequence, rather than *diffusion* or medicalised identities, she retreated towards her young person self to utilise it as a resource to mitigate the discomfort she felt in response to the condition-based experience (Luyckx et al., 2008). However, in contrast to Members 5 and 7 mentioned above, whose moments of *diffusion* were precipitated by external constraints, the *foreclosure* status of members 1 & 8 appeared to be reflective of internal limitations (Morsunbul, 2013) possibly connected to the constraints of their condition and its associated developmental challenges.

This finding highlights how members employ different strategies to integrate the two facets of the self for different agendas. While Member 6 had successfully integrated her identity through the use of external support and recognition, and Member 3 had gained validation from the LW.org.au community, Member 5 utilised her young person self to 'reflectively' make sense of her condition, but also to divert away from ruminating unnecessarily on its challenges (Hammond & Teucher, 2017). In contrast, Member 8 foregrounded her young person self and integrated her condition alongside her youth-based identities to avoid dealing with or exploring the complexities of her condition. This to some extent inhibited both reflective and ruminative exploration of her condition and its associated identities that were essential for fostering stronger identity integration (Luyckx et al., 2008b). Thus, in both instances, member's young person selves were employed as a resource, but each approach facilitated a different outcome. One strategy, encouraged greater exploration in breadth and depth of the member's (5) young person and condition-based selves in a manner that supported identity integration (Luyckx et al., 2008). The other, foregrounded exploration in breadth of the member's (8) young person and condition-based identities, but without a similar degree of exploration in depth or complex meaning-making connected to her condition-based identity. This conversely limited the degree of identity integration achievable (Luyckx et al., 2008). Interestingly, the latter appears to reflect a norm within the LW.org.au community.

In contrast, Members 10 and 1 utilised their condition-based identities to support their young person selves. Member 10, who fell into the *moratorium* identity status category in relation to both identity categories, interestingly integrated the expression of her condition-based self into her young person identity through appropriating positive psychology discourse (Angulo-Jiménez & DeThorne, 2019; Stage et al., 2020). To some extent, this reflected a level of *foreclosure* as she retreated to institutionalised identities to reflect her understanding of her condition, rather than delving into its complexity. However, unlike Member 1 who focused on disempowered medicalised identities, she emphasised empowered, inspirational identities (Angulo-Jiménez & DeThorne, 2019; Hammond & Teucher, 2017; Stage et al., 2020).

The significance of this is that it indicates LW.org.au demonstrates a tendency as a community to encourage exploration in breadth of members' young person and condition-based identities (Luyckx et al., 2008). The strength of this approach is that it counters the issue of illness or disability over-identification and negative identification (Locock & Brown, 2010; Mazanderani et al., 2012; Oris et al., 2016). This creates a strong sense of continuity back to youth culture that is often missing in the lives of these young people (Ferguson & Walker, 2014). It also creates opportunities for the expression of member's youth-oriented selves to attenuate the effects of hospitalisation, dislocation, stigmatisation and bullying (Ferguson & Walker, 2014). However, as the approach does not equally attend to exploration in depth or complex meaning-making in relation to both member's young person and condition-based identities online, members tend to remain in the exploration in breadth and commitment-making phases within the confines of the community, and fail to move towards identification with commitment, which has greater relevance for engaging with wider society (Luyckx et al., 2008(McLean et al., 2016). It also diminishes opportunities for young people to truly embrace and integrate both aspects of the self by using youth-oriented or empowered condition-based identities to divert from complex issues in relation to their condition or condition-based selves (Ferguson & Walker, 2014), rather than addressing them.

Creating Legitimacy

This section emphasises the contribution that the SCF makes to the field of interventions for young people living with a condition through the way it creates its legitimacy. Exploring this contribution highlights how the SCF implements policies and practices at various levels that allow the organisation and LW.org.au program to accrue certain forms of 'legitimacy' as 'capital' that establish and enhance the credibility, trustworthiness and accountability of the organisation and LW.org.au online community among stakeholders including clinicians, parents and young people (Davis & Calitz, 2016; Haldane et al., 2020; Patton et al., 2016). In particular, it demonstrates how LW.org.au is able to address the divergent needs of these various stakeholders and position itself as a viable and valid option in a field marked by extensive fragmentation and limited integration (Catalano et al., 2012; Haldane et al., 2020). This fragmentation and lack of integration results in 'legitimacy', as a source of power or capital within the field, being unequally distributed among sectors and services with some—such as clinical-based services—acquiring greater privilege or credibility than community and peer-driven initiatives (Czeresnia, 1999; Sawyer et al., 2019; Sawyer et al., 2014).

To some extent, this echoes challenges in relation to legitimacy at the theoretical level between biomedicine, and biopsychosocial or socio-ecological models of health (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989). However, by exploring how the SCF embeds different sources of 'legitimacy capital' into the LW.org.au program, this study demonstrates how the SCF capitalises on the strengths that each sector offers the field, while mitigating their weaknesses (Haldane et al., 2020; Patton et al., 2016; Trickett et al., 2011). Thus, it extends scholarship and practice by highlighting potential pathways that may facilitate integration between clinical and community-based approaches, at the same time enhancing the legitimacy of community and peer-driven initiatives within the field (Patton et al., 2016; Steinbeck et al., 2014). Importantly, the study also reveals tensions and challenges that emerge from the integration of these approaches and sectors, primarily in relation to the ‘chat-host role’ and the LW.org.au moderation model.

The SCF builds legitimacy as a source of capital into the organisation and into the LW.org.au online community in a variety of ways. The findings of this study demonstrate (a) the complexity of this process; (b) the strengths of these approaches; and (c) the tensions experienced by one group involved in the LW.org.au online community—the chat-hosts.

More than a Community or Peer-driven Initiative

While the SCF is a community initiative, it draws on its association with and endorsement by the medical and hospital context to position the LW.org.au program as more than that. In this way, the organisation recognises the implicit dominance that the biomedical model (Engel, 1989) and positivist or post-positivist (Lincoln et al., 2018) evidence-based practice continues to hold within the field in terms of legitimising an organisation’s or program’s ‘expertise’ to address the complex and diverse needs of young people living with a condition. This acceptance of the biomedical model may be strong in the case of parents, where the issue of ‘over-protection’ (Collard & Marlow, 2016; Foster et al., 2017; Lindsay, 2014) may arise and result in the merit of a program being discerned primarily in terms of its capacity to support the young person in relation to their condition, with youth-based concerns as secondary. Regardless, there is a tension between the dominance of the biomedical model (Engel, 1989) and the community, peer-driven approach of LW.org.au, with arguably the latter being equally or more beneficial for young people living with a condition in meeting their developmental and psychosocial concerns. Nonetheless, the clinical approach retains its stronghold in the claims for legitimacy (Czeresnia, 1999; Sawyer et al., 2019). This tension can be seen to de-legitimise community, peer-driven approaches.

However, the findings demonstrate that if we delve further into this issue, what emerges is not a de-legitimisation of what community and peer-driven supports can offer young people living with a condition, but rather an awareness among clinicians, parents and young people that clinical, biomedical (Engel, 1989) and evidence-based disciplines and approaches (Czeresnia, 1999) garner greater acceptance, because they are more established and regulated frameworks. Therefore, they are understood as having stronger ethical and accountability measures and mechanisms embedded into their policies and practices to protect and safeguard young people from a multitude of risks at various levels of an organisation or program (Catalano et al., 2002). Other community or peer-driven supports may lack the infrastructure, resources or training to provide these (Gillham et al., 2002; Hamilton et al., 2004; Webb & Karlis, 2020). From this, one could conclude a lack of integration between the clinical and community sector. This results in legitimacy being unevenly distributed within the field. More importantly, it highlights a lack of cohesion between services and supports within the community sector itself. This lack of cohesion, resources and training at the community level (Gillham et al., 2002; Hamilton et al., 2004; Webb & Karlis, 2020), serves to detract from the credibility, trustworthiness and legitimacy of these services, despite the considerable value and merit they offer vulnerable young people and the field of practice.

The SCF's approach to integrating clinical and established protocols and mechanisms into community-based interventions for young people living with a condition can function as an example of best practice in the field. The findings show how the SCF demonstrates its contribution in three ways, by: (a) implementing pathways to enhance the legitimacy of a community-based service; (b) fostering cohesion within the community sector; and (c) encouraging collaboration with the clinical sector to re-distribute 'legitimacy capital' more equitably within the field.

Professional and Legal Frameworks

The SCF builds legitimacy into the LW.org.au program by drawing on its adherence to professional and legal frameworks or standards, such as national and state policies for 'working with young people' and its preventive approach (Catalano et al., 2002; Starlight Children's Foundation, 2020a, 2020b). This assures clinicians, parents and young people of the organisation's ability to safeguard and protect vulnerable youth engaging with the LW.org.au program from a multitude of risks (Catalano et al., 2002). These policies and practices operate on the level of professional, legal and industry standards that supersede the clinical context to include all professions, social services and public institutions engaging with young people, including teachers, social workers and day-care staff (Starlight Children's Foundation, 2020a, 2020b). This suggests that rigorous ethical and accountability protocols and practices are integral to the community sector, and that it is feasible to integrate and implement them at the industry, institutional and program levels.

In the LW.org.au context, the value of this in relation to 'medically vulnerable' groups of young people is that the practices of the organisation (Starlight Children's Foundation, 2020a, 2020b) demonstrate how it is possible to over-ride the implicit assumption that safeguarding protocols and standards are only applicable and assured through clinical-based services or interventions (Catalano et al., 2002). Thus, the SCF legitimises the safeguarding expertise that operates within the community sphere and the evidence-based practice that can be built into community services in relation to this cohort. At the same time, implementing these 'safeguarding' policies, procedures and practices (Starlight Children's Foundation, 2020a, 2020b) in alignment with the clinical sector's high 'duty of care' (Sawyer et al., 2019) and the SCF's preventive approach (Catalano et al., 2002), illuminates how the clinical and community sectors' safeguarding practices can operate in tandem to more effectively tailor their support to protect young people in general, as well as in relation to their condition-based concerns.

Further, the SCF enhances its credibility, trustworthiness and legitimacy by gaining external accreditation and endorsement from an independent community organisation, the Australian Childhood Foundation, in relation to its 'safeguarding children and young people' policies and practices (Starlight Children's Foundation, 2020a, 2020b). This is important, because while both the community and clinical safeguarding policies and practices outlined above operate on the macro level in industry sectors where established frameworks and systems provide easy access to resources and training (Webb & Karlis, 2020), accreditation through the Australian Childhood Foundation demonstrates efforts by the SCF to build these systems among the community sector (Patton et al., 2016). This includes the field of 'developmentally appropriate' (D'agostino et al., 2011; Sawyer et al., 2019; Sawyer et al., 2010) and 'positive youth development' (Lerner et al., 2011) programs, where most individual programs operate outside the mainstream with little integration between them.

This accreditation through the Australian Childhood Foundation adds a level of rigour to the accountability practices of organisations by ensuring that their services are not only internally monitored in accordance with these frameworks and professional standards, but also independently regulated (Patton et al., 2016; Starlight Children's Foundation, 2020a, 2020b). This independence or objectivity provides a level of assurance for clinicians, parents and young people that breaches of conduct will not only be picked up within the organisation, but reported in accordance with external standards and channels.

A further example of this best practice is that the SCF organisation makes a concerted effort to ensure its 'safeguarding children and young people' policies and practices are transparent to parents and young people (Starlight Children's Foundation, 2020a, 2020b). In particular, they ensure access to these policies through their website in both a 'parent friendly' and 'youth friendly' format. This transparency and accessibility allows the organisation to establish clear expectations and boundaries with parents and young people from the outset (Starlight Children's Foundation, 2020a, 2020b). Thus, the SCF also demonstrates a significant aspect of best practice in that it not only adheres to professional and legal frameworks and standards for 'safeguarding children and young people' (Patton et al., 2016), but also illustrates how these national or state policies and protocols can be operationalised or enacted and embedded at the micro level of programs, in a manner that stays true to the credibility and integrity of the organisation itself. This is significant, because translating these broader frameworks into practice is not always readily achievable (Patton et al., 2016; Steinbeck et al., 2014) Further, the SCF validation protocol, moderation model and chat-host training—in relation to both young people's psychosocial development and professional boundaries online (Starlight Children's Foundation, 2020a, 2020b)—are core mechanisms that amplify the organisation's legitimacy as a community initiative and exemplify potential methods that other community or peer-driven services can model and implement to achieve similar results.

A key contribution emerging from the SCF's efforts to capitalise on its association and endorsement by clinical and hospital services, as well as its endeavours to build 'safeguarding children and young people' protection and prevention mechanisms into its organisation and programs (Catalano et al., 2002; Starlight Children's Foundation, 2020a, 2020b), is that it highlights pathways and mechanisms that facilitate inter-sectorial or interdisciplinary integration or collaboration (Patton et al., 2016). However, it could be suggested that the hierarchical nature of this approach fails to foster true inter-sectorial or interdisciplinary dialogue. A tension continues to exist between the biomedical model (Engel, 1989) and the community-based approach (Haldane et al., 2020; Trickett et al., 2011). It could be argued that the community sector is appropriating and qualifying itself against clinical or pre-existing macro discourses and structures (Czeresnia, 1999; Gillham et al., 2002; Haldane et al., 2020; Lincoln et al., 2018; Trickett et al., 2011), rather than such discourses being responsive to legitimising and incorporating the merits offered to the field by community-based initiatives. Consequently, while the SCF enhances its legitimacy as a community intervention in terms of established or accepted approaches (Starlight Children's Foundation, 2020a, 2020b), the recognition that the organisation does not completely align itself with these frameworks is paramount. This ensures that the 'legitimate' contributions of community and peer-driven services to the field are acknowledged, particularly in terms of how their youth-focused approach (Hamilton et al., 2004) addresses limitations inherent in these dominant models.

The second source of 'legitimacy capital' that the SCF builds into the LW.org.au program is that it capitalises on the limitations of clinical and macro approaches, and strives to distance itself from them in an endeavour to foster what might be termed 'street credibility' in relation to youth culture (Hamilton et al., 2004). This youth-oriented legitimacy or credibility capitalises on the implicit 'trust' circulating in informal social and peer networks (Hamilton et al., 2004; Lawrence et al., 2015), and strives to position the organisation and LW.org.au program as primarily there 'for young people'. It separates itself from clinicians and parents to foster what has been termed 'medically free and youth only' spaces, by suggesting that chat-hosts are like peers and the organisation is predominantly there to create partnerships with young people on their terms. The SCF fosters allegiance and camaraderie with vulnerable youth, which creates meaningful engagement and participation (Hamilton et al., 2004; Patton et al., 2016) in ways in which clinical services are inhibited from achieving. This has implications for help-seeking, engagement and screening (Lawrence et al., 2015; Patton et al., 2016) as illustrated in the *Developmental Appropriateness* section below.

An additional insight is that the SCF is also able to confer legitimacy upon young people themselves to become spokespersons or advocates through their affiliation with the organisation on issues related to their conditions (Charbonneaux & Berthelot-Guiet, 2020; Gelfgren et al., 2020; Patton et al., 2016); that is, illness or disability advocates. This also provides opportunities for them to connect and build skills as leaders in other domains (Hinson et al., 2016; Lerner et al., 2011), such as through being champions for the LGBTIQA+ community through advocacy, or external recognition as artists and writers through competitions and events organised by the online service. As a by-product of these sources of 'legitimacy capital' that are primarily connected to promotive approaches (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004; Lerner et al., 2011), the organisation is also able to confer ‘legitimacy’ for the right of young people to be considered equal stakeholders in relation to discussions about their health or condition (Haldane et al., 2020; Trickett et al., 2011), and their lives more generally. More importantly, it ‘legitimises’ the rights of ‘medically vulnerable young people’ to be seen as ‘young people’ beyond their condition, as well as in connection to their condition. This is significant because it qualifies the need for ‘promotive, positive youth development and youth-oriented interventions’ for this cohort (Catalano et al., 2002; Czeresnia, 1999; Haldane et al., 2020; Hamilton et al., 2004; Lerner et al., 2011; Trickett et al., 2011). It also speaks to the legitimacy of holistic models of health (Czeresnia, 1999), which are able to effectively operationalise biopsychosocial and socio-ecological approaches to health (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) in practice, both in conjunction with and independent of biomedical or clinical interventions.

The Contribution of the Chat-hosts and LW.org.au Moderation Model

At the core of the LW.org.au program is the potential to transform public perceptions of health beyond clinical approaches (Engel, 1989) to embrace the ‘legitimacy’ of community initiatives. The findings show how the SCF extends scholarship and practice by building legitimacy through integrating clinical and community approaches (Patton et al., 2016), and demonstrating pathways or mechanisms to facilitate greater levels of inter-sectorial and interdisciplinary collaboration. However, the findings also demonstrate tensions at the point of interaction between the program and the young people; that is, in the role of the chat-host. The chat-hosts become the intermediaries through which tensions embedded in combining clinical and community approaches at the level of practice emerged. A central concern is that chat-hosts questioned whether they were adequately ‘trained and resourced’ to meet the complex and diverse needs and responsibilities their role placed upon them (Lawrence et al., 2015; Sawyer et al., 2019; Webb & Karlis, 2020). The findings identify mixed opinions. While some chat-hosts demonstrated a high degree of acceptance of the SCF's policies, and confidence in their abilities and training to effectively meet the demands of their intermediary role, others expressed concern and ambivalence.

This tension was most pronounced in relation to whether chat-hosts were supported to screen young people for signs of mental health challenges, distress and condition-based complications (Lawrence et al., 2015). While the SCF embeds protective and preventive-based (Catalano et al., 2002) measures into its policies and programs (Starlight Children's Foundation, 2020a, 2020b) to create a sense of assurance that the organisation and LW.org.au program are capable of safeguarding young people—and it is stated in the 'terms and conditions' of use that LW.org.au is not a medical service, nor should any information or support shared online replace or substitute professional or medical advice and expertise—members of LW.org.au do from time to time express significant distress, and chat-hosts must respond.

This is a demonstration of how policies and lived experience do not always align (Czeresnia, 1999). The SCF has established boundaries around LW.org.au's legitimate ability to function as a clinical, medical or counselling service (Lawrence et al., 2015; Rickwood et al., 2016; Starlight Children's Foundation, 2020a, 2020b). It has also established boundaries around the chat-host role in relation to counselling and providing medical support that informs the training chat-hosts receive. This encompasses (a) training in adolescent health, wellbeing and development; (b) general training in recognising different conditions, signs and symptoms, particularly in relation to mental health; and (c) comprehensive boundaries training (Starlight Children's Foundation, 2020a). Evidence that some chat-hosts received occasional training with specialist hospital departments led other chat-hosts to suggest they would like further training in relation to the conditions they were confronted with online, particularly with specialist departments such as the Cancer ward or Eating Disorder unit. Their reasoning was not so that they could replace clinicians or provide expertise, but so they would have a more comprehensive understanding of the effects of different conditions on young people's psychosocial health from a lived perspective, and from this informed basis, be able to respond in a sensitive and appropriate manner to young people's conversations online about the hospital or lived experience of their condition, and the psychosocial impact it had on the rest of their life (Peat et al., 2018; Webb & Karlis, 2020).

Chat-hosts also advocated for greater mental health and counselling-based training (Lawrence et al., 2015). Again, this was not to over-step their role and assume the role of counsellor—particularly as this would detract from the medical-free nature of the site that is highly valued by young people—but to ensure they could effectively handle complex situations that emerged, especially through the preliminary screening role (Gibson & Trnka, 2020; Peat et al., 2018; Rickwood et al., 2016). This approach was not intended to minimise the value of the SCF protocols for dealing with young people in a highly distressing situation, but to support the chat-host in the challenge of 'holding space'. Holding space, in this context, refers to the ability of the chat-host to sustain empathetic rapport with a young person (Gibson & Trnka, 2020; Rogers, 1959, 1995) when a crisis or distressing situation is revealed through their conversations. These conversations strive to make the young person feel seen, heard and understood, and to build trust that enables the chat-host to offer strategies to support or alleviate the young person's distress at these critical moments. On most occasions, the chat-hosts referred to relying on their own instincts and experience to find the right words and actions to employ. The findings indicate that significant responsibility falls on chat-hosts at the point where institutional policies and practices are difficult to apply.

The role of chat-hosts in contributing to the legitimacy of LW.org.au should not be underestimated, as they: (a) oversee and enact institutional policies in a meaningful and situation-specific manner; (b) put into practice both the preventive and promotive aspects of the program; (c) support developmentally appropriate conversations; and (d) maintain the medical-free nature of the space. From this perspective, the tension expressed by chat-hosts, indicating their own need for greater insights from the biomedical perspective, suggests that there is more work to be done to understand the relationship between community-based initiatives such as LW.org.au and the biomedical model.

Developmental Appropriateness

This study supports the importance of providing young people living with an illness of disability with developmental, psychosocial support and interventions in addition to their clinical care (D'agostino et al., 2011; Sawyer et al., 2019). Central to this, the study acknowledges the importance of providing adolescent-specific services distinct from paediatrics and adulthood (D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014), and advocates for the benefits of attending to the psychosocial needs of young people both in clinical contexts and, more importantly, beyond them in community-based settings (Peat et al., 2018). This section sets out how the interpretation of the findings from this study contributes to a wider understanding of the literature, going beyond mere agreement with the literature to argue in favour of 'youth friendly'(Peat et al., 2018; Tylee et al., 2007) services for young people in general, as well as those living with a condition.

The Need for Developmentally Appropriate Intervention

The findings of this study provide strong support for arguments advocating for the need to provide ‘developmentally appropriate, psychosocial interventions, programs and practices’ for vulnerable youth at both the clinical and community level (Azzopardi, 2012; Blakemore & Mills, 2014; Crone & Dahl, 2012; D'agostino et al., 2011; Patton et al., 2016; Sawyer et al., 2007; Sawyer et al., 2016; Steinbeck et al., 2014), although its focus is on the community level. This argument has emerged from a growing awareness among medical health professionals, researchers and community advocacy groups of the need to provide young people living with a condition with ‘developmentally appropriate, psychosocial interventions’ in addition to their clinical care.

The study recognises that the term developmentally appropriate is widely used, resulting in multiple understandings of the term within scholarship. Thus, it is necessary to clarify how the term ‘developmentally appropriate’ was employed in the current work and how this conceptualisation relates to others in the literature (Patton et al., 2016; Sawyer et al., 2019; Tylee et al., 2007). In doing so, the study strives to strengthen both scholarly and practical understandings of the term. By teasing out the tensions or differences that emerged throughout the course of this study with respect to the various conceptualisations and applications of ‘developmentally appropriate’ within the field (Patton et al., 2016; Sawyer et al., 2019; Tylee et al., 2007), the boundaries and contribution of the present work become more salient. Moreover, the limitations encompassed within dominant conceptualisations and applications of the term ‘developmentally appropriate’ within the field are highlighted (Catalano et al., 2002). This is significant for broadening our awareness of the complexity and diversity encompassed in the use of the phrase in both theory and practice (Catalano et al., 2002; Czeresnia, 1999). The highlighting of limitations also provides insight into why theoretical ‘ideals’ connected to the construct fail to be actualised or realised at the ground level of professional practice (Catalano et al., 2002; Czeresnia, 1999). In demonstrating these limitations, the findings from the present study provide insight into possible pathways and mechanisms (Patton et al., 2016) that may be influential in addressing some of these challenges at the community level, to a greater or lesser extent.

In exploring this issue, a starting point is that there are two distinct strands of scholarship related to the concept of ‘developmentally appropriate’ interventions for young people. The first involves scholars and practitioners advocating for the need to design, implement and evaluate ‘developmentally appropriate’(D'agostino et al., 2011; Patton et al., 2016; Sawyer et al., 2007; Steinbeck et al., 2014), ‘youth friendly’ or (Tylee et al., 2007) and ‘adolescent responsive’ (Patton et al., 2016) services and practices with respect to general medical practice, clinical services and hospital contexts (Sawyer et al., 2019; Sawyer et al., 2014; Tylee et al., 2007). This discourse is concerned with making medical, clinical and hospital spaces more ‘adolescent friendly’ or appealing to young people to facilitate greater help-seeking behaviour, engagement and participation (Patton et al., 2016; Sawyer et al., 2019; Sawyer et al., 2014; Sawyer et al., 2007; Tylee et al., 2007). On a developmental level, this approach seeks to optimise opportunities for young people to use their burgeoning independence, autonomy and decision-making skills in an informed manner with healthcare professionals (Patton et al., 2016; Sawyer et al., 2019; Sawyer et al., 2014; Sawyer et al., 2007; Tylee et al., 2007). The latter is also concerned with ensuring young people have access to youth-oriented spaces to connect with other young people in clinical settings (Sawyer et al., 2019; Sawyer et al., 2014). In this context, it is recognised that the use of online platforms could be particularly advantageous (Patton et al., 2016).

Consequently, this scholarship approaches health, wellbeing, development, illness and disability from a biopsychosocial (Engel, 1960, 1980, 1989) or socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006) standpoint. It considers: (a) the developmental opportunities and vulnerabilities of adolescence and emerging adulthood in relation to clinical and hospital care (Patton et al., 2016; Sawyer et al., 2012; Sawyer et al., 2007); (b) attends to the psychosocial dimensions of healthcare, such as therapeutic relationships and the need to communicate health information about conditions in an adolescent-friendly manner (Sawyer et al., 2019; Sawyer et al., 2014); and (c) considers biopsychosocial-ecological variables involved in health. However, by virtue of these services being primarily medical or clinical in nature, the philosophical assumptions underpinning biomedical models (Engel 1960) of health, can be seen to continue to dominate the over-riding culture of these spaces, the meanings young people associate with them and the relationships that develop with clinicians in these settings.

This study demonstrates tension between the ability of clinical and hospital supports to fully realise the culture of the biopsychosocial (Engel, 1960, 1980, 1989) and socio-ecological models (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006), and the latent dominance of the biomedical approach informing clinical healthcare practice. This tension was most evident in the manner in which young people expressed divergent experiences in relation to medical, clinical and hospital supports in their discussions online with chat-hosts and other LW.org.au members. Here, two perspective emerged. Some young people's expressed experiences that provided support for the literature advocating and indicating a movement within the field towards more 'developmentally appropriate' clinical services and practices (Sawyer et al., 2016; Sawyer et al., 2010; Steinbeck et al., 2014) in which 'developmentally appropriate' is equated with 'youth friendly' (Tylee et al., 2007). This was evident when participants recounted experiences of: (a) 'person-centric' care; (b) egalitarian-oriented relationships and decision making with clinicians about their condition; and (c) opportunities for youth engagement (Phelan et al., 2020; Sawyer et al., 2016; Sawyer et al., 2010; Steinbeck et al., 2014),.

Other narratives countered this perception of 'youth-friendly care' (Tylee et al., 2007) suggesting biomedical cultures within clinical spaces remained strong. Thus, 'youth friendly' was only implemented at points in service, rather than at the cultural level more broadly. Therefore, these counter narratives revealed experiences indicating that 'developmentally appropriate' may be equated with 'youth friendly', and that the implementation and integration of 'youth friendly' services and practices within this service based approach in clinical and medical contexts, is at best ad hoc or piecemeal. Thus, while some participants reported that some clinical services and clinicians readily adopted and incorporated 'developmentally appropriate' and 'youth friendly' structures and practices into their healthcare, others reported that they experienced services and professionals strongly constrained by biomedical understandings at the root level (Catalano et al., 2002; Czeresnia, 1999). Reasons for this constraint and the sustained dominance of biomedicine were implied by young people to be the result of over-taxed, under-resourced and under-staffed health systems and spaces that resulted in professionals retreating to institutional protocols and procedures to manage demand. In these instances, young people recounted experiences far from 'developmentally appropriate' or 'person centric' (Phelan et al., 2020). Rather, their experiences indicated a generalised, impersonal approach where (a) the individual was considered merely a patient or a number; (b) clinical relationships demonstrated power imbalances; and (c) opportunities for engagement with young people within these contexts were limited or outsourced (Engel 1989). These descriptions of the experiences of these young people painted a picture of a lack of integration between clinical and allied or community health supports (Bennett, 2009).

From this perspective, the concept and operationalisation of ‘developmentally appropriate’ appears to function in silos, with each silo or disciplinary area possessing a different understanding and application of the term (Bennett, 2009; Patton et al., 2016). Different silos enact the concept to varying degrees and there is an apparent lack of consistency within silos or disciplinary approaches (Bennett, 2009). Similarly, a common strategy to manage the diversity of approaches that medical, clinical and hospital services can take to implement and enact ‘developmentally appropriate’ structures and practices is the outsourcing of these developmentally appropriate supports and initiatives to allied and community services (Bennett, 2009; Patton et al., 2016). Developmentally appropriate is considered at the systems level with each silo enacting a different role or function; some are more amenable to adopting the concept of ‘developmentally appropriate’ into their practice in a more holistic manner than others.

At the conceptual level, this poses the question as to whether medical, clinical and hospital services are able to fully realise the aims of ‘developmentally appropriate’ (D’Agostino & Edelstein, 2013; Sawyer et al., 2010) services through their allegiance to biopsychosocial and socio-ecological frameworks (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989), since their cultures are fundamentally entrenched with biomedical ideas. This also raises questions at a broader level about whether strategies from health frameworks—such as the biomedical, biopsychosocial and socio-ecological models that are mutually exclusive at the ontological level—can be applied at the level of practice in a bricolage manner. This would allow the constructs of ‘developmentally appropriate' and 'person-centric care' to break free from the constraints of these silos (Bennett, 2009; Czeresnia 1999).

At this juncture, it is important to outline the second strand of scholarship concerned with the notion of 'developmentally appropriate' (D'Agostino & Edelstein, 2013; Sawyer et al., 2010). This is the community-oriented strand, including allied and community supports in relation to health (Haldane et al., 2020; Trickett et al., 2011). This is significant for this study, because it is where LW.org.au is situated. In this context, 'developmentally appropriate' is frequently paired with 'healthcare', rather than with 'youth friendly' (Haldane et al., 2020; Trickett et al., 2011). This scholarship and practice understands 'developmentally appropriate' and 'healthcare' in relation to biopsychosocial and socio-ecological models that challenge biomedical understandings of illness and disability at a cultural level (Czeresnia, 1999; Hamilton et al., 2004). This facilitates a broader base for consideration, beyond the focus only on certain factors of service, such as the clinician–young person relationship, as frequently occurs with the clinical approach (Bennett, 2009; Czeresnia, 1999; Hamilton et al., 2004).

Studies representing this second strand of literature have tended to take an institutional approach to the establishment of services (Haldane et al., 2020; Trickett et al., 2011). In this context, they have predominantly focused on bi-directional relationships between risk and protective factors or assets and resources in relation to individuals and their environments. As a result, they are more adept at highlighting enabling and dis-enabling structures, as well as attitudes and behaviours in an individual's ecology that are important for supporting their health, wellbeing and development (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Lerner et al., 2011). This approach to 'developmentally appropriate' views health more holistically in relation to social determinants at various levels of the individual's socio-cultural ecology.

A key objective of this study, was to clarify understandings of 'developmentally appropriate' in this second strand of scholarship. Findings from the netnographic (Geertz, 1973; Kozinets, 2010, 2015) investigation into LW.org.au attest to the value of providing young people living with a condition with developmentally appropriate, psychosocial support (Haldane et al., 2020; Hamilton et al., 2004; Trickett et al., 2011). More specifically, the findings support an argument for the importance of fostering and enacting greater collaboration and integration between community and clinical supports to ensure that the health, wellbeing and development of young people living with a condition is holistically attended to (Eckersley, 2009; Hamilton et al., 2004; Patton et al., 2012; Sawyer et al., 2016; Steinbeck et al., 2014). However, the pathways or mechanisms by which to create 'developmentally appropriate' interventions at both the community and clinical level—as well as how to best promote interdisciplinary dialogue, communication and action between the different silos of the health system striving to engage and support young people living with a condition—are less well conceptualised within the field (Eckersley, 2009; Hamilton et al., 2004; Patton et al., 2016). Thus, while this study supports the need for developmentally appropriate, psychosocial interventions, its primary contribution to scholarship and practice centres on garnering insight into the pathways, mechanisms and processes that may allow us to actualise the concept of 'developmentally appropriate' intervention more effectively in practice.

In this context, the fostering of egalitarian-based relationships and partnerships between young people, and community and health professionals is especially relevant as it offers the possibility of promoting holistic health treatment and places the young person at the centre of practice (Bennett, 2009; Peat et al., 2018; Phelan et al., 2020; Waters & Buchanan, 2017).

Paramount to this concern and the design, implementation and evaluation of such services, is the recognition that there are interventions with the potential to place the individual at the centre of practice (Phelan et al., 2020; Waters & Buchanan, 2017) in a manner not wholly achieved by clinical supports predominantly driven by biomedical models or understandings towards health, wellbeing, development, illness and disability. In this study, the value of placing the individual or young person at the centre of practice resulted in LW.org.au members feeling—as expressed by one of the chat-hosts—'seen, heard, understood, supported and validated' in ways not commonly experienced in other clinical contexts or youth-oriented spaces. Articulating the mechanisms and features of the LW.org.au online community that facilitate this experience of 'person-centred care' (Phelan et al., 2020; Waters & Buchanan, 2017) is central conceptually for strengthening our understanding of 'developmental appropriateness'.

In particular, LW.org.au—while catering to a medical or health-oriented cohort—is primarily a youth-focused, developmental and psychosocial intervention (Hamilton et al., 2004). Its aim is to address the shared psychosocial and developmental challenges that emerge through living with a condition (Sawyer et al., 2007), rather than attending directly to one's condition or the mental health stresses that may result, and that require more clinical-based support. Nonetheless, through building strong, enduring relationships with young people over time (Bronfenbrenner & Morris, 2006; Hamilton et al., 2004), LW.org.au appears uniquely placed to fill a gap in services that is crucial for fostering help-seeking behaviour among this cohort and supporting them by screening for possible psychosocial and mental health risks

(Lawrence et al., 2015; Patton et al., 2016; Rickwood et al., 2016). In the Lancet commission on adolescent health and wellbeing, Patton et al. (2016) asserted that because of the immense biological, cognitive, emotional, social and sexual changes of adolescence and emerging adulthood, young people are uniquely primed for meaningful engagement beyond the family context. They are also in a position to take greater autonomy over their health and wellbeing, setting up health behaviours and illness management regimes that promote positive health trajectories into the future (Patton et al., 2016). However, meaningful engagement requires young people to have the assets and resources to enact this meaningful participation, which is not always the case for young people living with a condition.

An issue impeding help-seeking behaviour and screening among this cohort is that while they may be frequently located in medical and hospital settings, their developmental and psychosocial needs—while understood as important—are often secondary to the care and attention placed on their primary condition and clinical concerns (Bennett, 2009; D'agostino et al., 2011; Sawyer et al., 2019; Steinbeck et al., 2014). This is not to suggest that clinical professionals and hospital environments do not make a concerted effort to create youth-friendly spaces or pick up on risk-related signs, but that by virtue of being within these medical spaces, there is an almost implicit assumption by young people to accord with the norms and identities of the medical model (Hammond & Teucher, 2017). This perception, understanding and evaluation by different members of the self and hospital experiences in alignment with the medical model, was evident in this study on frequent occasions in the chat-room. These experiences, as expressed by LW.org.au members, were often characterised by identities, positions and themes where the young person lacked voice, agency and empowerment (Hammond & Teucher, 2017; Woodgate, 2005). There were also episodes online when young people deferred to parental authority or nurses as their voices were considered less legitimate than these individuals in these settings.

This is significant because adolescence and emerging adulthood is considered a time when young people can enact more independence and autonomy by reaching out and discussing with medical and allied health staff not only primary health concerns, but also developmental and mental health issues (Bennett, 2009; Patton et al., 2016; Sawyer et al., 2019; Steinbeck et al., 2014). However, as illustrated above it is arguable whether clinical and hospital-based contexts have the mechanisms and youth-friendly cultures in place to facilitate this behaviour in a manner that counteracts the barriers young people may feel in response to the implicit assumptions and explicit structures that arise from these settings and professionals being dominantly associated with identities and discourses connected to the medical model (Bennett, 2009; Sawyer et al., 2019; Steinbeck et al., 2014). It is also unclear whether these contexts and relationships have the approachability and rapport to facilitate the types of discussion and conversation that may allow young people to open up and disclose sensitive or personal information about the self and their health that goes beyond routine, institutional check-ups (Hammond & Teucher, 2017). This establishment of rapport with young people is a key reason why school teachers are more likely than medical professionals to be the first to notice psychosocial, mental health and distress symptoms in young people.

Problematising Developmentally Appropriate

The study also problematises the concept of what 'developmentally appropriate, youth friendly or adolescent responsive, psychosocial support' (D'Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) really means for a specific cohort. This becomes most salient when designing, implementing and evaluating interventions. Bridging conceptual understandings with practice, is not a straightforward process.

On a practical level, concerns around how to address and enact appropriate levels of developmental intervention—both initially and in the long term—go beyond the broad awareness of the general developmental needs of a cohort (Hamilton et al., 2004), such as identity formation and social connectedness being important for all adolescent and emerging adults (Erikson 1968, 1994), not just one tier in the developmental category. Further, the pertinence of this issue intensifies when interventions are seeking to support cohorts that may be susceptible to or present with developmental delays, as is the case with LW.org.au members. This challenges whether the concept of 'developmentally appropriate' is one size fits all (Hamilton et al., 2004), and proposes that 'developmentally appropriate' (D'Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) must be considered in light of not only manifest or general developmental needs, but latent nuances in a developmental category or population. It is essentially an argument about macro and micro understandings of the term. This has implications not only for designing interventions with general or targeted cohorts in mind, but also measuring and evaluating them by utilising macro understandings and methods (Gillham et al., 2002; Guba & Lincoln, 1994; Lincoln et al., 2018), or qualitative measures. Geertz (1974) suggests, the latter, 'thickens' our conceptualisation and operationalisation of constructs, such as 'developmentally appropriate' for particular communities.

It is also important at this juncture to make a comment on LW.org.au's non-categorical approach to illness and disability (Stein & Jessop, 1982); by this, I mean it does not focus on one specific condition, such as young people living with Cancer, but multiple conditions and the shared or general challenges of all. In contrast to the importance of attending to diversity with respect to different developmental ages or adolescent tiers (Hamilton et al., 2004), as mentioned above, a non-categorical approach (Stein & Jessop, 1982) to conditions appears not to detract from the quality of support offered, but rather predominantly benefits young people within the LW.org.au community. Arguably, however, this benefit is derived from and connected to the youth-oriented focus and medical-free culture of the LW.org.au community. Thus, it functions to celebrate diversity springing from a shared commonality and allows individuals to go beyond clinical and medical understandings of their condition, as well as their condition itself. This is important to highlight, because it speaks to the difference between clinical online interventions and positive youth development or community supports, with the latter emphasising 'development' as a construct in terms of youth culture (Hamilton et al., 2004; Hinson et al., 2016; Lerner et al., 2011; Webb & Karlis, 2020), and the former attending to 'development' from a medical or counselling perspective where condition-specific knowledge and expertise may be more pertinent (Bennett, 2009; Peat et al., 2018; Rickwood et al., 2016; Sawyer et al., 2019; Steinbeck et al., 2014).

LW.org.au and Life Stage

In the case of adolescence and emerging adulthood, a core challenge in discerning what constitutes 'developmentally appropriate' (D'Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) in terms of the design, implementation and evaluation of a program is the diversity in the life-stage or developmental category of adolescence itself (Hamilton et al., 2004). Research suggests what is developmentally appropriate for early adolescence may not have the same value, import or efficacy for mid-adolescence, late adolescence or emerging adulthood (Habermas & Bluck, 2000; Hamilton et al., 2004). This was evident in this study with early–mid adolescents engaging in identity exploration processes more reflective of the ‘personal fable’ or episodic identity integration on the site, rather than the cohesive and thematic understanding and integration of identity exploration and formation in late adolescence (Habermas & Bluck, 2000). This suggests certain exploration practices (such as exploration in breadth or exploration in depth and meaning-making) are more or less effective for different adolescent groups (Habermas & Bluck, 2000). This feature renders it difficult to discern, let alone implement, which practice of identity exploration as a strategy is best for which developmental tier, unless a nuanced investigation is conducted and contextualised.

In alignment with both strands of scholarship, this thesis supports the need for developmentally appropriate, psychosocial interventions (D’Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) for young people. Despite tensions regarding how best to conceptualise and operationalise this construct in scholarship and practice, the findings of this thesis support much of the general ethos in the literature in relation to the notion of ‘developmentally appropriate’, including:

a) The importance of moving beyond biomedical understandings of health, wellbeing, development, illness and disability towards biopsychosocial and socio-ecological frameworks that conceive health more holistically by considering the psychological, social, cultural and ecological influences upon health (Catalano et al., 2012; Catalano et al., 2002; Patton et al., 2016; Sawyer et al., 2012; Sawyer et al., 2007).
b) The power of this approach to facilitate better ‘person-centric care’ (Phelan et al., 2020). by placing the individual or young person at the centre of practice. The has implications for identity, which can positively impact help-seeking and engagement practices (Hargreaves, 2014; Patton et al., 2016; Rickwood et al., 2016).

c) The merit in acknowledging ‘development’ in terms of life-course or developmental psychology by attending to the specific developmental opportunities and vulnerabilities of adolescence and emerging adulthood for health. In tandem, this supports the need for adolescent-specific services distinct from paediatrics and adulthood in practice to capitalise on developmental strengths and mitigate risks (D'agostino et al., 2011; Steinbeck et al., 2014; Tylee et al., 2007).
d) The need for greater collaboration and integration between clinical and community sectors in relation to health to strengthen the conceptualisation and operationalisation of ‘developmentally appropriate’ within the field. This has implications for creating enabling structures that build assets and resources with young people at both the clinical and community level (Bennett, 2009; Catalano et al., 2012; Catalano et al., 2002; Gillham et al., 2002)

In contrast to research and practice that primarily conceives of community interventions such as LW.org.au as supplementary or secondary in value to clinical-based services (Catalano et al., 2012; Catalano et al., 2002; Sawyer et al., 2007), this study argues that these community supports are equally necessary. While not replacing the expertise offered by clinical services, developmentally appropriate, psychosocial community supports play a core role in the field in ensuring the health, wellbeing and developmental needs of these vulnerable young people living with a condition are holistically attended to. Moreover, this study argues for the need for greater collaboration and integration between both clinical and community sectors at the systems level to capitalise on the strengths of each approach, while mitigating their weaknesses (Bennett, 2009). This supports Bennett’s (2009) argument for interdisciplinary dialogue and action in relation to adolescent health, wellbeing and development in an endeavour to enact this holistic, ‘big picture’ (p. 1) perspective in practice, but in a manner that integrates the different silos and sectors and overcomes the current emphasis on ‘too many little solutions’ (Bennett, 2009, p. 7) that are inadequate for addressing the complex developmental, health and condition-based needs of young people living with an illness or disability.

Preventive and Promotive Approaches to Developmental Appropriateness

A significant challenge in considering findings related to the construct of developmental appropriateness (D’Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) is that the literature itself is highly fragmented with the concept being employed in divergent ways by multiple scholars. This lack of consistency in definition and conceptualisation results in constructs such as developmental appropriateness (D'agostino et al., 2011), youth friendly (Tylee et al., 2007), adolescent friendly (Sawyer et al., 2010) and adolescent responsive (Steinbeck et al., 2014) being confounded, as noted in the previous section. This creates challenges at the level of practice. This section is concerned with practical approaches to the implementation of developmentally appropriate interventions, labelled ‘prevention’ and ‘promotion’ in the literature (Catalano et al., 2002; Czeresnia, 1999). Programs are designed with preventive focuses, but claim that they are promotive on the basis of the strategies employed, rather than their approach (Catalano et al., 2012; Lerner et al., 2011). This leads to the undermining of the value of promotion as an ontological approach, especially for the cohort of young people living with a condition (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). The value in moving beyond promotion being considered epistemologically or practically, is that it facilitates viewing what can be achieved by considering its implementation ontologically.

In recent years, prevention and promotion approaches have become increasingly converged in their outlook as well as recommendations for designing and evaluating interventions and programs (Catalano et al., 2012; Lerner et al., 2011). However, at their core these approaches remain underpinned by divergent theoretical and philosophical roots that relate differentially to models of health, wellbeing, development, illness and disability (Catalano et al., 2012; Lerner et al., 2011). It is important to highlight this, because the literature recommends combining prevention and promotion frameworks in what has been termed a ‘dual’ or ‘integrated’ approach to designing and evaluating services. This results in these interventions or programs (a) having greater developmentally enhancing effects at the level of practice, and (b) allowing researchers to more acutely observe the various mechanisms and pathways producing these effects (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999; Lerner et al., 2011). However, in reality, combining these two approaches has led to the value of promotion being subsumed into the over-riding philosophical viewpoint of prevention (Catalano et al., 2012; Catalano et al., 2002; Czeresnia, 1999). Thus, how a promotive approach on a philosophical level can enhance practice and scholarship, is under-researched (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004), especially in relation to interventions designed for the vulnerable cohort of young people living with a condition, where preventive approaches are dominant, because of this cohort and their health’s close association with clinical services.

Thus, this study problematises what ‘developmentally appropriate’ (D’Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) means for practice. Several key questions arise. How do organisations and practitioners bring the core tenets of the notion of ‘developmental appropriateness’ (D’Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) to life through their interventions, policies and procedures? (Hamilton et al., 2004). More significantly, how are these designs, interventions and policies received by young people? Are the developmental goals that institutions, organisations or service providers build into or encode within their programs and services experienced or decoded in the same manner by the practitioners and young people who use them (Hamilton et al., 2004; Webb & Karlis, 2020), or do the points of view of these stakeholders differ? If so, how can we detect and resolve these differences through the program's evaluation? Essentially, the concern for practice is whether programs are having their desired 'developmental' effect on young people or whether there are unintended effects both positive and negative that emerge from analysing these different perspectives, which may provide insights into how to address common, unresolved challenges within the field (Hamilton et al., 2004; Webb & Karlis, 2020). This consideration of what the construct means for practice also has the potential to enhance future scholarship and practice.

These questions are pertinent when exploring the online program of LW.org.au in the context of the field as they provide a means to bridge the conceptual with the practical in this study. Analysing LW.org.au's programs through these multiple lenses also provides insight into how to design and evaluate community interventions and programs in a manner that potentially enhances our ability to support help-seeking and engagement behaviour (Patton et al., 2016; Rickwood et al., 2016; Sawyer et al., 2010) among young people living with a condition, and discern pathways that may facilitate systematic linkages between clinical and community interventions at the macro level (Bennett, 2009; Patton et al., 2016; Steinbeck et al., 2014).

Prevention and promotion (Catalano et al., 2002; Czeresnia, 1999) are approaches to operationalising the construct of 'developmentally appropriate' (D'Agostino & Edelstein, 2013; Sawyer et al., 2010; Tylee et al., 2007) in practice by providing frameworks delineating an array of protective factors, assets and resources shown in the literature to have developmentally enhancing effects that institutions, organisations and service providers can build into their programs or interventions to ensure they achieve this. However, despite the convergence in philosophical standpoints and recommendations linking prevention and promotion approaches, these approaches emerge from different philosophical roots (Catalano et al., 2002; Czeresnia, 1999). A reminder of these ontological differences is useful in revealing pathways and mechanisms for addressing issues that emerge in practice, including challenges in encouraging help-seeking and engagement (Patton et al., 2016; Rickwood et al., 2016; Sawyer et al., 2010) that cannot be adequately addressed when a program or service is designed on the basis of a single framework.

The prevention approach (Catalano et al., 2002; Czeresnia, 1999), which can be seen to align with biomedical and positivist or post-positivist paradigms, primarily strives to pre-empt, reduce or protect young people from developmental vulnerability and risk. So, it has come to be operationalised as being about finding ‘youth friendly’ ways to address developmental challenges (Catalano et al., 2002; Czeresnia, 1999; Tylee et al., 2007). Risk minimisation remains the core focus, although a holistic strategy of utilising both direct (preventive) or indirect (promotive) methods to mitigate risk may be adopted.

In contrast, promotion primarily strives to enhance developmental strengths and opportunities by adopting a universal approach (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004) that seeks to address health, wellbeing and development more holistically in alignment with biopsychosocial and socio-ecological models (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989). Promotion is more adept at capturing individual choice, difference and cultural meanings in relation to the ‘developmental appropriateness’ of programs, policies and practices (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). It can also provide insight into how practitioners and young people perceive, engage and appropriate these policies and practices to meet their own developmental needs within interventions (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004).

This study shows that LW.org.au takes a position that is relatively rare, providing services and programs based on the dual role of both prevention and promotion (Catalano et al., 2002; Czeresnia, 1999). Further, the netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach to this study, has facilitated a level of exploration unusual in the field. Thus, it is possible to go beyond the argument that it is important to adopt an integrated approach to the design and evaluation of services in relation to prevention and promotion (Catalano et al., 2002; Czeresnia, 1999), and to highlight that it is important to do so in a manner that does not obfuscate the subtle philosophical differences underpinning each framework, so that each approach can be valued for its own strengths (Catalano et al., 2002; Czeresnia, 1999). The following paragraphs demonstrate how LW.org.au has implemented each approach, and how even with this strong approach to providing a developmentally appropriate program, weaknesses are still evident.

LW.org.au protects young people from risk through the site’s ‘exclusive’ membership being restricted to the identity categories of young people living with a condition, and is enacted at the level of practice through the organisations validation policy and password protected or bounded community (Starlight Children’s Foundation, 2020a). This enables LW.org.au to protect young people, both in terms of their condition and their development. It also protects them through its moderation policy (Starlight Children's Foundation, 2020a). Here, the organisation strives to pre-empt and protect young people from the risks of experiencing social isolation, exclusion, stigmatisation and bullying (Collard & Marlow, 2016; Lounds Taylor et al., 2017; Pittet et al., 2010; Sawyer et al., 2007) in relation to their condition, which is something many of them experience in other settings. By providing a space where illness and disability are the norm, a second objective as suggested by Goffman (2009), is LW.org.au creates a safe haven where young people with a stigmatised or spoiled identity can connect with others to (a) feel seen, heard, understood and validated; (b) share tricks of the trade or patient expertise in terms of information, emotional and tangible support; and (c) challenge dominant misperceptions of their condition and the self by taking off the mask and going beyond definitions of their condition with others who understand. It can also be used to foster a sense of illness or disability pride through advocacy (Charbonneaux & Berthelot-Guiet, 2020; Gelfgren et al., 2020).

However, this study shows that despite an exclusive membership striving to protect against the risk of isolation, exclusion, stigmatisation, bullying and concealment, some of these issues emerge in new ways. While LW.org.au is able to counter social isolation, exclusion and bullying within the confines of the community through moderation (Starlight Children's Foundation, 2020a), the challenge of stigmatisation and concealment persist. In particular, the stigma of becoming over-defined by their condition (Angulo-Jiménez & DeThorne, 2019; Hamilton et al., 2004; Locock & Brown, 2010; Mazanderani et al., 2012) online results in these individuals failing to reach out and sustain engagement with the community, even though the site is known to provide valuable sources of condition-specific, community and identity support. The findings show that a preventive approach is not always adept at addressing these challenges, despite the evidence base suggesting such pathways provide these benefits.

Developmentally, LW.org.au also protects young people through its exclusive membership by creating a space for young people living with a condition to connect with other young people away from medical and parental supervision (Starlight Children's Foundation, 2020a) It creates what can be termed a 'medical-free space', protecting them from becoming overly defined by their condition and the 'patient role' as it is expressed in relation to biomedical models (Engel, 1989) and discourses of illness and disability in both clinical and community contexts. At the same time, it creates a 'youth friendly' (Tylee et al., 2007) space to openly discuss patient experiences of illness and disability, and validate patient expertise. This challenges medical or clinical perspectives, and the lack of confidence young people feel to discuss these concerns in clinical spaces. This space can be seen as 'youth friendly' (Tylee et al., 2007) not only because of the stance of the chat-hosts to communication, but also for its range of developmentally focused approaches. It facilitates youth autonomy and independence in decision making and perspective taking in relation to their health (Bennett, 2009; Haldane et al., 2020; Hamilton et al., 2004; Steinbeck et al., 2014). It also fosters youth autonomy and independence with respect to parents and adults by creating a space for young people to express themselves and how their experiences fit into wider society in terms of their health and beyond it as a young person (Bennett, 2009). This represents an endeavour by the organisation to protect young people from the issue of 'over-protection' (Collard & Marlow, 2016; Foster et al., 2017; Lindsay, 2014), which they often experience offline from parents and adults as a result of their condition implicitly defining them in a role of dependence. In this way, it reflects how the organisation strives to protect youth development alongside condition concerns.

A core reason young people valued the LW.org.au online community, is they knew they were talking to real people. This phrase referred to 'real people' with conditions, and not those pretending to have a condition to be part of the community for other agendas. LW.org.au, working in the social media space, where people are not always what they seem, protects young people from concerns around predators and grooming (Caton & Landman, 2021).

Another example of how LW.org.au balances youth autonomy, the creation of a medical-free and parent-free space, and the risk of young people sharing ill-informed patient or youth-oriented advice (Greene et al., 2011; Rueger et al., 2021), is its embedding of a youth-friendly moderation model and mentors in the site's practice (Starlight Children's Foundation, 2020a). Chat-hosts are able to guide and scaffold young people's conversations away from risky topics or ideas. This is particularly the case as the site's moderation policy states that any medical information or advice shared on LW.org.au should not replace the professional advice given by a young person's medical or clinical team (Starlight Children's Foundation, 2020a). Thus, while LW.org.au provides a space for patients to vent and air condition-based concerns, arguably it also inhibits the full expression of the patient and young person voice, adopting an institutional approach, which in some ways is bound to clinical expertise and responsive to parental concerns.

LW.org.au's moderation model and chat-host training also protect young people from developmentally inappropriate conversations online (Starlight Children's Foundation, 2020a). They ensure all content remains developmentally appropriate for every member online and thus cater to the youngest member in the room (Starlight Children's Foundation, 2020a). While this is beneficial in a developmental sense for younger adolescents, on the flip side, a preventive design and approach potentially inhibits the quality and diversity of conversations in which older adolescents can engage. From this perspective, it detracts from the developmental potential older adolescents can gain from the site, and even inhibits the site's ability to pre-empt and mitigate risk in this regard. Not allowing older adolescents to discuss 'risky' topics such as relationships, sexuality, intimate partner conflict and alcohol may result in them not having these conversations at all, or having them in riskier settings.

Another valuable way in which the site is risk adverse and that is of great benefit to the field, is that LW.org.au's moderation model has the capacity to function as an indicative intervention by screening mental health challenges through informal conversations or relationships built online (Catalano et al., 2012; Lawrence et al., 2015). Thus, LW.org.au is able to capitalise on what Bronfenbrenner and Morris (2006) termed 'proximal processes' to mitigate risk by detecting concerns very early and through a platform that potentially can connect them to professional clinical support if necessary (Bennett, 2009; Lawrence et al., 2015; Rickwood et al., 2016). This is both a strength and a weakness: despite the preliminary screening capacity, some mental health challenges may fail to be detected and, if they are detected, may not be acted on, especially as young people may be less likely to reach out to formal channels.

Considering LW.org.au through the use of a promotive perspective and approach, reveals the SCF's attempts to operationalise the notion of 'developmental appropriateness' in a manner that supports young people's 'developmental strengths beyond risk'(Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). This aligns strongly with biopsychosocial and socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) models of health, wellbeing, development, illness and disability as expressed in the community literature reviewed in Chapter 2, and is more suited to capturing the culture of holism in relation to both healthcare and development.

In this sense, promotion is concerned not only with fostering ‘youth friendly’ strategies or methods for addressing developmental risks and the psychosocial, mental health or illness management challenges related to one’s condition, but also with a broader notion of ‘developmental appropriateness’ related to young people in general, along with youth culture and wellbeing (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). A consequence of this, is the emphasis on facilitating ‘meaningful engagement, participation and collaboration’(Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004; Patton et al., 2016) in programs, communities, cultures and societies. In this context, ‘developmental appropriateness’ builds skills in young people to become active citizens and contributors to their communities at both the program level and beyond (Hinson et al., 2016; Lerner et al., 2011). There was evidence of this in the current study when participants become leaders or mentors within the SFC community through the LW.org.au mentor and rep (representative) program that supports the development of leaders who facilitate engagement in diverse ways within the LW.org.au community. There was also evidence of young people developing skills in relation to advocacy (Charbonneaux & Berthelot-Guiet, 2020; Gelfgren et al., 2020) in terms of their condition, as well as in response to social justice issues, such as gender diversity, equality, environmentalism and the rights of young people to be taken seriously as young people and informed citizens.

It is important to acknowledge that whereas prevention focuses on aspects of a young person that may mark them as different, the promotive approach is in essence a universal, inclusive and holistic approach (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). By treating its members as young people—at one level like all other young people—LW.org.au is able to sustain engagement with these young people in a manner that a purely preventive approach would inhibit, especially since the prescriptive approach of prevention often results in institutions or practitioners—in accordance with the institutional stance—being the ultimate drivers or moderators of those conversations (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). Thus, LW.org.au is recognised as a leader in providing developmentally appropriate services in this regard. There is evidence that other services in the field, such as eheadspace, are attempting to adopt the 'promotive developmentally appropriate' model of LW.org.au as it embeds 'forums about youth culture and developmental issues on the site' (Rickwood et al., 2016). However, their approach arguably continues to implement this feature in a prescriptive, institutional manner (Hamilton et al., 2004). Thus, the culture created online through LW.org.au's 'promotive model'—where young people also become key drivers of these conversations in an informal manner through their active 'everyday' engagement, membership and citizenship within the community and in partnership with chat-hosts online—is lost in its adopted form. LW.org.au demonstrates its ability to capture the value of peer-to-peer conversations and egalitarian relationships with mentors and chat-hosts, an approach that contrasts with the culture of other services.

Another key way in which promotion fosters meaningful engagement online through its universal and inclusive approach is having an emphasis on development more broadly, rather than one's condition. This means that promotion more effectively overcomes the issue of illness and disability over-identification and stigmatisation online (Hamilton et al., 2004; Mazanderani et al., 2012). This supports the understanding that LW.org.au aims for young people to connect with other young people on the online site, rather than predominantly being a place to connect around one's condition. There is something of a paradox here: even though the latter becomes a core reason for young people to reach out to the site, it is the youth-oriented nature of the community and the relationships they build online around youth culture that are the key reasons they sustain engagement with site.

Another way in which promotion's universal and inclusive approach facilitates meaningful engagement is through providing young people with choice in how they engage with the community (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). This is also facilitated by the design of the site being a fully functioning social media network similar to Facebook. Once validated into the community, young people are free to engage with the program and the developmentally appropriate assets and resources embedded into the site's design as they wish (Hamilton et al., 2004; Lerner et al., 2011). From this perspective, a universal approach allows both the chat-hosts and the organisation to respond better to individual needs within the program, in contrast to the prescriptive approach found in developmental or condition-based groups (Hamilton et al., 2004). Thus, promotive approaches provide more room to explore the young person's perspective in relation to the individual and cultural meanings they bring to their engagement with the community, and how they appropriate the features and practices of the community to meet their individual developmental and condition-based needs (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004).

This section has shown how the tensions between a preventive approach and a promotive approach can play out in practice, through the policy and practice of LW.org.au. However, the section would not be complete without a consideration of how bringing the two frameworks together affects the experiences of the young people themselves, especially in meaningful engagement—a concept that includes the three behaviours of help-seeking;

engagement; and participation (Patton et al., 2016; Rickwood et al., 2016; Sawyer et al., 2010).

Help-seeking and Engagement

Help-seeking is an area where the tensions between a preventive and promotive perspective emerge (Catalano et al., 2002; Czeresnia, 1999; Rickwood et al., 2016; Sawyer et al., 2010). Help-seeking involves young people's active efforts to seek help or support in relation to their health, wellbeing, development or condition (Sawyer et al., 2010). A core goal of this study and its emphasis on understanding young people's engagement with the community in relation to the two identity categories of young person and those living with a condition, was to explore why young people either reach out or fail to reach out (help-seeking) (Locock & Brown, 2010; Mazanderani et al., 2012) to condition-based interventions known to provide important sources of condition and developmental support (Gibson & Trnka, 2020; Kelleher et al., 2020; Rickwood et al., 2016; Salminen et al., 2019), and—if they do reach out—what determines whether they sustain that engagement.

A prevention approach fostering exclusive membership around one's condition has been shown to facilitate help-seeking by providing young people the opportunity to gain valuable condition-based support, such as information, emotional and tangible support (Davis & Calitz, 2016; Jiang, 2017; Nicholas et al., 2007; Treadgold & Kuperberg, 2010). However, it has also been demonstrated to have the reverse effect with young people failing to reach out or sustain engagement with these communities through a fear that they will become overly or negatively defined by their condition online, to the detriment of the expression of their wider sense of self (Locock & Brown, 2010; Mazanderani et al., 2012). This study demonstrates that employing a promotive approach, (Czeresnia, 1999; Hamilton et al., 2004) that foregrounds youth culture and youth identities in tandem with condition-based concerns, is an effective method for mitigating this concern around help-seeking. In fact, young people in the study suggested that while connecting with others in a similar situation in relation to their condition was the main reason they reached out to the site, it was the relationships and connections they built online around youth culture and their young person selves that sustained engagement, creating a link between help-seeking and engagement.

The merit in understanding the mechanisms behind facilitating help-seeking and sustaining engagement is significant (Patton et al., 2016; Sawyer et al., 2010), because this process illustrates that no matter how well designed an intervention is in employing preventive or prescriptive approaches (Hamilton et al., 2004), unless young people are connecting and actively engaging with these programs the value of both the condition and developmental support offered online is lost. Moreover, an absence of help-seeking and engagement (Patton et al., 2016; Sawyer et al., 2010) does not mean these young people are no longer exposed to the risks of social isolation, exclusion, stigmatisation, bullying and the poorer psychosocial and mental health outcomes that result (Collard & Marlow, 2016; Lounds Taylor et al., 2017; Pittet et al., 2010; Sawyer et al., 2007) from not reaching out. In fact, this lack of help-seeking and engagement (Patton et al., 2016; Sawyer et al., 2010) may result in these young people not reaching out to any services at all, so that their challenges go unnoticed, creating a greater burden of disease in the future. Alternatively, it may result in young people finding riskier channels for help and support. The findings of this study suggest that providing mechanisms that encourage help-seeking and engagement (Patton et al., 2016; Sawyer et al., 2010) for young people living with a condition can facilitate better screening of these individuals through informal support channels with friends and mentors (Lawrence et al., 2015), which these young people are more inclined to use.

Participation

Creating opportunities for young people to become active participants in the design, implementation and evaluation of services emerges as a core issue in the literature regarding young people and their health (Haldane et al., 2020; Patton et al., 2016; Sawyer et al., 2010; Steinbeck et al., 2014). This concept of participation also involves collaborating and creating egalitarian partnerships between young people and adults (Patton et al., 2016; Sawyer et al., 2010; Steinbeck et al., 2014). Currently, feedback and collaboration occurs in formal ways, separate from the operation of programs and the ground level practice of working with young people. However, a promotive approach allows us to envisage how it may be possible to create these participatory and egalitarian cultures and relationships in an intervention program through an emphasis on 'meaningful engagement' (Hamilton et al., 2004). This may be more effective at the level of practice as this would provide a capacity to be more responsive at the ground level (Hamilton et al., 2004). By creating a collaborative culture of engagement and feedback within programs themselves, an organisation may be able to mitigate challenges in a more timely fashion and do so with the young person's perspective in mind. The potential for this was evident in the LW.org.au community, with young people fostering strong relationships with chat-hosts and the organisation, that in turn, resulted in them giving feedback on the LW.org.au programs and features they would like to see offered online, especially through their interactions with the chat-hosts creating informal and formal channels for this occur.

The findings from the current study contribute to the literature by demonstrating that utilising both preventive and promotive approaches (Catalano et al., 2002; Czeresnia, 1999) to exploring the practices of LW.org.au reveals a more holistic and nuanced understanding of how the online community supports the competing health, wellbeing and developmental needs of young people living with a condition in relation to both their condition and who they are as a young person beyond it. Thus, a dual preventive and promotive approach (Catalano et al., 2002; Czeresnia, 1999) to evaluation reveals how an organisation manages tensions between competing health, wellbeing and developmental needs that a purely preventive or promotive approach would fail to detect. Moreover, identifying how interventions such as LW.org.au manage these tensions between condition-based and developmental needs, reveals latent mechanisms and pathways at play. This addresses common challenges confronted within the field, such as illness over-identification (Mazanderani et al., 2012) that inhibit young people from reaching out to the illness or disability-based communities designed to support them. Further, it demonstrates the potential to inform future interventions.

Positioning Theory and its Role in Understanding Identity Construction

This study employed the conceptual and analytic framework of positioning theory espoused by Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al. (2003), and extended by Bamberg and Georgakopoulou (2008) in relation to narratology, to explore how LW.org.au youth members construct, perform and negotiate their identity within the online community's chat-room. This use of positioning theory sought to understand how young people discursively construct their identity in interaction with others and in response to the socio-cultural norms (or local moral order) (Harré et al., 2003; Harré & Van Langenhove, 1998) of the LW.org.au chat-room and wider society in general, such as the hospital context. Contradictions and tensions emerged in how the young people participating in the study positioned themselves in response to the local moral order (Harré et al., 2003; Harré & Van Langenhove, 1998) of the LW.org.au community and wider society. Online discussions became a platform for the expression and exploration of a multiplicity of selves and perspectives on identity positioning. LW.org.au members and chat-hosts predominantly provided support and reframed negative positioning or understandings of the self in relation to one's condition and their young person selves in agentic terms, in line with the organisation's local moral order (Harré et al., 2003). This indicates that the norms of LW.org.au may emphasise positive positioning of the self with less room to delve into negative understandings, particularly in relation to the disempowerment felt in other contexts (Harré et al., 2003). In this local moral order, some members appeared more responsive to reframing efforts, while others persisted with their original standpoints, indicating the presence of different identity exploration processes online (Erikson, 1994)

This study extends our understanding of positioning theory and its application to exploring identity construction in interactional contexts, in that it combines Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al's. (2003) original conceptualisations with Bamberg and Georgakopoulou's (2008) subsequent work that emphasises the story-telling component of the positioning theory framework. The intention behind combining these two approaches was to address shortcomings identified by positioning theory scholars in relation to Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) orginal conceptualisation. In this study and in scholarship in general, the work of Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al. (2003) are heralded as providing a detailed conceptual and methodological framework for understanding the tenets of positioning theory, as well as how to apply these to the analysis of conversations within everyday life. However, in practice, their model, which has been widely used, has been operationalised in different ways, leading to inconsistency in focus. The current study contributes to this inconsistency in the literature by adopting a novel, integrated approach to more adeptly capture both macro (Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) and micro (Bamberg & Georgakopoulou, 2008) positionings.

A core reason for the inconsistent operationalisation of Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) model is that while their positioning theory framework clearly elucidates how positions relate to rights, duties and obligations that facilitate or constrain various lines of action in relation to the local moral order, understanding how to detect which storylines or positions are at play from the interaction itself is less well formulated. Positioning theory researchers and critics such as Bamberg and Georgakopoulou (2008); and Deppermann (2013) have suggested that Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al. (2003) rely on positioning participants in relation to macro or institutionalised storylines, which assume background knowledge that might not be apparent to the researcher. In essence, identifying the positions and storylines towards which participants are orienting in their conversations and how these positions relate to the identities evoked by participants in their story-telling actions online is not so straightforward in research practice. Moreover, while Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al. (2003) have stressed the dynamic nature of positions and positioning within their framework —in contrast to the more static notion of role (Goffman, 1959)—by not fully operationalising how positioning relates to storylines and discourse on the micro, performative level of conversation, positioning theory scholars have suggested these scholars nonetheless retain some of the more institutionalised and ritualistic aspects of roles in their notion of positioning and its analysis and interpretation.

To address this concern and more efficiently operationalise Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) positioning theory framework at the micro, performative level, this study combined the conceptual and macro-level strengths of these scholar's work with Bamberg and Georgakopoulou's (2008) narratology-based model. The value of Bamberg and Georgakopoulou's (2008) approach is that it delineates how positions and storylines can be ascertained. This facilitated an analysis in the current study of three distinct levels of conversational discourse: (a) the storied level, depicting the characters salient in the tales shared by LW.org.au members online in the chat-room; (b) the interactional level, which includes how the LW.org.au members positioned themselves and the LW.org.au audience in relation to the characters positioned in stories shared online, and how LW.org.au members and chat-host either confirmed or challenged this positioning; and (c) the discursive level, which alludes to the macro-level positioning evident in Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) approach, as well as the more enduring features of identity positioning that extend beyond the interactional context. By employing Bamberg and Georgakopoulou's (2008) approach in tandem with that of Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) work, the study more effectively demonstrates how macro-level discursive identities emerge from micro-level positioning dynamics.

However, in contrast to Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al's. (2003) work, Bamberg and Georgakopoulou's (2008) emphasis on the story-telling component of positioning means their model less effectively taps into the difference between the local moral orders or socio-cultural norms that emerge from positioning individuals in terms of rights, duties and obligations at the three levels of discourse. By operationalising the work of both Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al. (2003) with Bamberg and Georgakopoulou (2008) in an integrated fashion, this study contributes to positioning theory scholarship by mitigating the shortfalls of both approaches and achieving more through their integration than each framework could deliver on their own.

The value of this for the current project is significant as the study sought not only to understand how members construct and negotiate their identities through micro-positioning practices (Bamberg & Georgakopoulou, 2008) online, but more importantly how differing norms or local moral orders (Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) facilitate or constrain certain forms of positioning and identity construction. In particular, the study shows how the local moral order of LW.org.au compares and contrasts with the local moral order of the hospital or school context as articulated from the perspectives of members in their stories (Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998). Thus, it more effectively elucidates how different socio-cultural ecologies, which can be considered similar to the notion of a local moral order, encourage different forms of identity exploration and development (Davies & Harré, 1990; Erikson, 1994; Harré et al., 2003; Harré & Van Langenhove, 1998). This approach connects with the work of Bronfenbrenner's (1979), who suggested that adolescent development occurs in multiple settings, including the micro, meso and macro level and the relationships between them. Therefore, by combining Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al's. (2003) work with the approach of Bamberg and Georgakopoulou (2008), this study provides preliminary understandings on how to operationalise and explore the effect of these relationships on identity development (Erikson, 1968, 1994) at a discursive level; an approach that is particularly valuable in the context of identity development among young people with an illness or disability. This approach holds promise for future research in highlighting the ripple effect of promotive or risk-oriented trajectories at the level of meaning-making and practice.

An additional value of combining these two positioning frameworks is that many scholars have suggested that for micro-identity positioning (Bamberg & Georgakopoulou, 2008) to have relevance for macro (Harré et al., 2003; Harré & Van Langenhove, 1998) or discursive identity construction (Davies & Harré, 1990), studies employing models such as that of Bamberg and Georgakopoulou (2008), should combine ethnographic (Geertz, 1973) methods to contextualise the results. This study achieves this not only by embedding the positioning theory analysis within a wider netnographic (Kozinets, 2010, 2015) investigation of the LW.org.au community, but by demonstrating how this concern can be addressed at the level of positioning theory analysis itself.

Methodology and its Contributions

It should be noted that this study also supports the value of exploring psychological and social phenomena from a socio-cultural and discursive perspective rather than an experimental approach as this provides for a more comprehensive explication of the role of meaning-making in identity exploration and development.

The Value of Ethnography

This study demonstrates that an interpretative, ethnographic approach (Geertz, 1973) to understanding how the LW.org.au online community functions as a 'developmentally appropriate, psychosocial intervention' extends scholarship and practice by a providing a holistic, contextualised and grounded approach to the exploration of the site. It challenges the tendency in scholarship and practice to employ positivist and post-positivist approaches (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) to ascertain how practice conforms to or aligns with established conceptual and practical frameworks. While positivist and post-positivist research (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) helps refine our understandings of the complexity of the processes involving specific variables, it does not necessarily extend or broaden our ontological understanding of the constructs or frameworks themselves or what phenomena may be missing from these studies.

In contrast, an ethnographic (Geertz, 1973, 1974) approach focuses on interactions within a defined context, facilitating the interpretation of concepts and explaining how these interpretations shape the meaning these concepts attain ‘culturally’ in practice among different participants in the study context. The emphasis placed by ethnography (Geertz, 1973, 1974) on multiple perspectives is significant because in this study it illustrates how established understandings of concepts such as ‘developmental appropriateness’ (D'agostino et al., 2011), ‘prevention’ and ‘promotion’ (Catalano et al., 2002; Czeresnia, 1999) and their corresponding frameworks are embedded into interventions through the SCF’s institutional approach in the form of policies, protocols and practices that reflect these macro conceptualisations, while also providing insights into the micro level of their implementation by chat-hosts and members of LW.org.au community. Thus, the ethnographic (Geertz, 1973, 1974) emphasis on meaning-making provides a window into the complexities and tensions inherent in the workings of LW.org.au, including (a) cyber-security concerns, such as authenticating and validating identities; (b) condition-based issues, including providing confidentiality, privacy and a safe space for young people to discuss condition-based knowledge and experiences; and (c) youth-oriented challenges involving the mitigation of developmental risk and the promotion of development through ‘medically free’ and ‘youth only’ spaces.

The ethnographic (Geertz, 1973, 1974) approach allows us to ‘thicken’ our conceptualisations of specific phenomena and interactions in this context so that we can understand these in a deeper way. Through gaining this multi-level view, we can also bring a much more nuanced approach to understanding phenomena in their cultural context. This reveals the limits that a generalised framework and conceptualisation can impose on practice. Therefore, ethnographic (Geertz, 1973, 1974) approaches not only expose tensions not apparent through other research methods, they may also have a greater capacity to help the researcher to suggest novel solutions to problems. These tensions can emerge around points of dissension or divergence, such as in relation to the chat-hosts’ role and the tension between a biomedical model (Engel 1989) and a community-based initiative (Trickett et al., 2011), particularly concerning arguments surrounding legitimacy in terms of screening, ‘holding space’ and receiving adequate training. Ethnography (Geertz, 1973, 1974) demonstrates that interactions in a context do not neatly follow a conceptual model, but are messy, filled with contradictions and tensions. In this study, the ethnographic (Geertz, 1973, 1974) approach has identified challenges around translating ideals into practice, providing insight on how the lived experience challenges the conceptual.

Ethnography (Geertz, 1973, 1974) creates mid-range theories (Merton, 1949) that are more responsive to the needs of communities because these theories arise through careful observation, participation and dialogue with the participants themselves, leading to systematic explication. The method more adeptly captures the notion of ‘phronesis’ (Gadamer, 1989), in contrast to the ‘techne’ (Gadamer, 1989) of positivism and post-positivism (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018); it is not concerned with arriving at an objective, generalised truth, but with understanding that the multiplicity of truths and perspectives at various levels enable us to deliberate and discern the ‘right course of action for specific communities'. Moreover, this 'right course of action' arising from engagement at the ground level, has the potential to unearth conceptual insights that can inform scholarship and practice precisely because these problems and solutions lie in the spaces between models, paradigms and approaches (Gadamer, 1989).

This study demonstrates how ethnography (Geertz, 1973, 1974) is a more incisive method for grappling with complexity and contestation in a field. At the same time, it is important to acknowledge that the findings of ethnographic (Geertz, 1973, 1974) studies will not necessarily lead to clear, simple, standardised solutions; although they will add depth to our understanding of specific situations. This study also illuminates how this depth enriches or thickens conceptual models and frameworks in a manner that allows us to deliberate in informed, but nuanced ways. As Geertz (1974) suggested, the value of ethnography is that 'it is marked less by perfection of consensus than a refinement of debate. What gets better is the precision with which we vex each other' (p. 322). Therefore, ethnography (Geertz, 1973, 1974) sits strongly in the space between established understandings, participatory insights and transformation action.

Another value of ethnography (Geertz, 1973, 1974) is that it allows us to move from devising solutions on the epistemological level to consider the ethical or moral implications of our scholarship and practice. It enables us to diversify or pluralise scholarship, by creating a medium through which voices and experiences not often included can be observed in their context. In this study, the voices and experiences of young people emerge clearly to shed light on the key concepts of this study being developmental appropriateness (D'agostino et al., 2011) and identity creation (Erikson, 1968, 1994). The inclusivity of the voices and experiences of young people goes a step further in this study (Haldane et al., 2020; Steinbeck et al., 2014); young people living with a condition are to some extent on the margins of society and often characterised by a high degree of invisibility in society, but in this study they are a central focus. The more nuanced and holistic perspective of an ethnography (Geertz, 1973, 1974) can legitimise their viewpoint and allow them to become part of the conversation, in terms of not only practice, but also scholarship. Ethnography (Geertz, 1973, 1974) allows us to challenge the privilege embedded in scholarship and the notion of ‘expertise’ by situating young people as key participants in these social worlds, and consequently key participants in scholarship.

Netnography

This study also contributes to scholarship by employing an innovative methodology of netnography (Kozinets, 2010, 2015) to extrapolate the practice of ethnography (Geertz, 1973, 1974) to the online realm. However, in alignment with the work of Hine (2000, 2015) and Geertz (1973, 1974) the study utilised netnographic (Kozinets, 2010, 2015) to view the online world of LW.org.au and the identities, practices and relationships embodied in the space subjectively, rather than objectively in terms of the meaning-making practices and interpretations that organisations, practitioners and individuals bring to the online sphere. This extends scholarship by allowing us to examine the medium beyond variables and processes, as are commonly the focus in the field, to contextualise these factors within wider cultural interpretations operating in the space (Geertz, 1973). Moreover, this approach better illuminates how online communities are not de-contextualised from offline worlds, but are embedded within them, because these meaning-making practices cross over between the two interconnected spheres (Hine, 2000, 2015).

Thus, employing a netnographic approach (Geertz, 1973; Kozinets, 2010, 2015) in this study, has demonstrated how cultural interpretations and meanings that have relevance for enhancing the 'developmental appropriateness' of online communities, such as LW.org.au, not only are applicable within the online sphere, but also have poignancy for informing policy, practice and scholarship offline and in integration with online platforms. This is evident with the SCF's promotive and universal approach having the potential to facilitate help-seeking behaviour, meaningful engagement (Patton et al., 2016; Sawyer et al., 2010) and tailored responses to young people's individual needs not only online, but also offline, where the issue of prescription continues to impact the recruitment and retention rates of both preventive services and youth-based promotion programs offline (Catalano et al., 2002; Hamilton et al., 2004). Netnography (Geertz, 1973; Kozinets, 2010, 2015) similarly demonstrates how the application of a promotive approach online can inform how we effectively facilitate egalitarian relationships between adults and young people offline as well (Hamilton et al., 2004; Patton et al., 2016).

Similarly, the notion of embeddedness that arises from employing a netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach has relevance for enhancing our understanding of identity formation (Erikson, 1968, 1994), exploration (Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966) and meaning-making practices (McAdams, 2011) online in connection with offline worlds. A netnographic (Geertz, 1973; Kozinets, 2010, 2015) study, is more adept at illuminating how meanings and identity claims shared online are informed by offline experiences and understandings of the self. This more acutely depicts how these interpretations can be confirmed, contested or modified in the online realm to feed back into offline contexts in a manner that potentially challenges structures, attitudes and norms that inhibit 'authentic' identity expression for young people living with a condition.

It also demonstrates how, conversely, online cultures and norms (McLean & Syed, 2015) can empower identity construction and formation for this vulnerable cohort. The netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach contributes to scholarship by highlighting that identity expression and meanings are contingent on the quality of cultural norms and opportunities for identity expression within and across contexts (McLean & Syed, 2015). This study provides preliminary insights into the promotive resources that can facilitate the building of identity assets for this vulnerable cohort in the online space with implications also for offline contexts (Côté, 1997).

Moreover, the use of a netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach demonstrates the embeddedness of identity formation (Erikson, 1968, 1994), exploration (Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966) and meaning-making practices (McAdams, 2011) within online and offline worlds. Thus, the study is also able to highlight how identities within online communities reflect both embodied and disembodied expressions of the self (Hine, 2015; Turkle, 1994, 2011). Embodiment demonstrates how young people living with a condition utilise online communities to represent an ‘authentic’ sense of self that is very much grounded in the meaning-making practice of ‘everyday’ ‘reality’, rather than employing social media space to create fictional or imagined selves as suggested by Turkle’s (1994, 2011) early work. However, by facilitating the exploration of identity in online spaces, a netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach also demonstrates how young people can utilise these mediums to give greater prominence to certain facets of the self, while strategically choosing to conceal or hide others. Therefore, in cases of disembodiment, particularly due to one’s condition, netnography (Geertz, 1973; Kozinets, 2010, 2015) reveals the young person’s agency.

A final note on the contribution of netnography (Geertz, 1973; Kozinets, 2010, 2015) to this study is that similar to interpretative ethnography (Geertz, 1973, 1974) which informs it, it is better equipped to capture and grapple with the high levels of fragmentation, diversity and plurality characterising online spheres. It is also more adept at capturing the degrees of fragmentation and contention between offline and online realms. The merit of this for scholarship is that it enables the researcher to explore and respond to the differences between those two spaces, revealing points of consensus in a manner that facilitates specific forms of integration between the two spheres and allows us to provide programs and services that demonstrate greater responsiveness to the needs of particular communities than a standardised, generalised view would allow.

Positioning Theory as an Analytical Tool

This study also employed positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) as an analytical tool and thus contributes to scholarship by using this approach to analyse how individuals position themselves in relation to each other and organisations. This is significant because while positioning theory was originally intended as a way to analyse individual- or person-level interactions (Davies & Harré, 1990; Harré et al., 2003), in recent years its application has predominantly focused on how organisations positions themselves within the field (James, 2014), or how individuals position themselves in relation to institutional roles (Kuusela et al., 2020; Shi, 2020). Therefore, re-invigorating how positioning theory (Davies & Harré, 1990; Harré et al., 2003) can be employed to analyse individual positioning in relation to institutional roles—alongside personal stories that contest and challenge these roles at the macro and micro level—is a valuable addition that has implications for understanding online contexts that rely on person-to-person interactions.

In particular, this study demonstrates that positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003) allows us to capture the precise or specific moment of interaction through which meaning-making takes place, and how these interactions validate, contest and prompt individuals to renegotiate their identity contents. It captures both process and content simultaneously as well as stability and change with an emphasis on the symbolic and nuanced nature of interactions, rather than a retreat to generalised processes. As a result, it is more adept at revealing both the macro or institutional components of identity, the micro, personal understandings, and the tensions between them (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003).

Positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003) is also more effective than other methods in revealing that contexts consist of local moral orders that engender institutionalised roles and personal reactions to these roles. It also demonstrates that in one program or context, multiple cultures and local moral orders may exist at one time. An example of this is the local moral order of the medical context constraining a young person’s ability to position themselves as empowered in the stories they share online, despite the local moral order of the LW.org.au community striving to counter this and facilitate positive expressions of the self through the chat-hosts’ and other members’ contestation of these negative views. As an analytic tool, positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003) reveals how individuals may be caught between two competing local moral orders within one interaction. As a result, it is more adept at highlighting the strategic choices that individuals make to negotiate these tensions and define the self, as well as the strategic choices their interlockers make to support or constrain them (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003). Thus, it explores not only the positioning, but its immediate and long-term effect. Further, as an analytic tool, it reveals the symbolic processes through which young people challenge oppressive structures and local moral orders, or gain a sense of empowerment and voice from them through their engagement with others (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003).

Chapter Summary and Conclusion

The contributions of the current study to scholarship and practice were set out in this chapter. It explicated the value of employing a netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach to understand identity construction (Erikson, 1968, 1994) online, which allowed the study to analyse young people's identity exploration and negotiation in relation to three core strands of identity scholarship (Côté, 1997; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966, 1993; McAdams, 2011). Combining these perspectives allowed the study to go beyond the literature's strong emphasis on the personal dimensions of identity formation to grant greater recognition to the interactional and contextual nature of identity exploration, negotiation and validation online (McLean & Syed, 2015; Raymaekers et al., 2017). This has significance for understanding the role of interventions. However, the study identified a gap in LW.org.au's practice in relation to encouraging exploration of identity in breadth and depth (Luyckx et al., 2006; Marcia, 1966), and notes the implications of this for help-seeking and engagement behaviour (Patton et al., 2016).

The chapter also demonstrated how the study contributes to the understanding of developmental appropriateness (D'agostino et al., 2011) and developmentally oriented interventions and services for young people living with a condition. It highlighted mechanisms and pathways for the community sector to enhance its legitimacy, and encourage greater collaboration with the clinical sector (Bennett, 2009; Patton et al., 2016; Steinbeck et al., 2014). However, it revealed new tensions in relation to the chat-host role with this approach. It also outlined the value of prevention and promotion (Catalano et al., 2002; Czeresnia, 1999) approaches to designing and evaluating developmental, psychosocial interventions and how a combined approach mitigates the shortfalls of each.

The chapter concluded with a consideration of the value of employing the innovative methodology of netnography (Geertz, 1973; Kozinets, 2010, 2015) and the use of positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998), particularly in relation to the online medium, to understand complex phenomena from diverse perspectives to enhance scholarship and practice.

The following chapter outlines the core conclusions and recommendations emerging from the current study. It also identifies the study's limitations and suggests areas for future research.

Chapter 8 Conclusion

This chapter summarises the concluding statements and implications emerging from the current work for scholarship, practice and policy. It begins by re-iterating the research question and purpose, and highlighting the study's methodological innovations. This is followed by a review of the core findings and contributions in relation to the concept of developmental appropriateness, the design of developmentally appropriate interventions, and the merit of integrating prevention and promotion approaches to enhance help-seeking, engagement behaviour and the screening of psychosocial and mental health concerns among young people living with a condition through these services. Following this, it outlines the core contributions to understanding developmental appropriateness in relation to the developmental task of identity formation online for young people living with a condition. Finally, it highlights areas for future research and indicates the limitations of the study. It concludes with the merits of the study for broadening of our vision beyond illness and disability and current disciplinary and sectorial approaches to reveal innovative pathways going forward that strive to address long-standing challenges in the field with the aspiration of further enhancing the health, wellbeing and development of these young people in the future.

Research Question and Purpose

First, this study responded to the research questions and purpose outlined in Chapters 3 and 5, respectively, including how does the Starlight Children's Foundation's online community LW.org.au function as a developmental, psychosocial intervention for young people living with an illness or disability between the ages of 12 and 21 years. The study sought to understand how LW.org.au functions in this capacity from the diverse perspectives of the organisation, chat-hosts and young people along with the culture and peer norms enacted and embodied on the site. More specifically, it endeavoured to uncover how the culture and norms of the community impacted young people in their ability to engage in the developmental tasks of (a) forming and maintaining peer and mentor connections in a novel social environment online, and (b) experimenting, exploring and establishing a unique sense of self in the context of these social interactions, relationships and experiences (Erikson, 1968, 1994). Moreover, it sought to understand this development in relation to two social identity domains (Tajfel, 1982; Tajfel & Turner, 2004) demonstrated in the literature to have significant implications for young people living with a condition. This involved the exploration of how these young people present, perform and disclose the self in relation to what this study terms their (a) 'young person' self, focusing on how they express the self in relation to their 'everyday teenage identity' and individuality beyond their condition in terms of hobbies, interest, talents, skills and youth culture more generally, and how they build peer and mentors connections around this. Secondly, it aimed to examine the presentation of young people's (b) condition-based selves in its various guises, to understand how they express the self in relation to their condition, and forge peer and mentor connections around the shared understanding and experience of living with an illness or disability.

The methodological approach of this study was particularly valuable in allowing multiple perspectives to emerge simultaneously. This is one of the advantages of netnography (Hine, 2000, 2015; Kozinets, 2010, 2015), as informed by the interpretative ethnographic approach of Geertz (1973, 1974), that enables the researcher to observe ordinary activities and to interpret them in a broader cultural and conceptual context. The second methodological innovation was the use of positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) as an analytical tool, which facilitated an understanding of the episodic, fragmented and interactional nature of identity formation online. Neither of these approaches is common in the literature within this field, and each offers significant possibilities in developing a more detailed and nuanced understanding of interactions in developmentally oriented programs and services, and the outcomes related to the processes of identity formation respectively (Erikson, 1968, 1994).

Contributions to Scholarship

Developmental Appropriateness and Developmentally Appropriate Interventions

With respect to the notion of developmental appropriateness (D'agostino et al., 2011), this study makes a significant contribution in clarifying the concept of developmental appropriateness and demonstrating how practices involved in designing and evaluating developmentally appropriate interventions for young people living with a condition can inform future scholarship, practice and policy. Based on its findings, the study emphasises the importance of providing young people living with a condition with developmental, psychosocial interventions in addition to their clinical care (Alderman et al., 2003; D'agostino et al., 2011; Steinbeck et al., 2014; Treadgold & Kuperberg, 2010). However, at a broader level, it champions the merit in facilitating greater access to ‘developmentally appropriate’ services, supports and spaces in both clinical and community contexts. Further, this study recommends the need to foster stronger interdisciplinary and inter-sectorial collaboration, integration and dialogue between the clinical and community sectors (Bennett, 2009; Steinbeck et al., 2014) in an endeavour to enhance each sector’s ability to realise the core principles and goals encompassed within the notion of ‘developmental appropriateness’ holistically in practice and policy. From this perspective, the study argues that each sector is stronger together than in isolation.

This is significant, because while the study primarily focused on the community sector, its findings nonetheless indicate that both the clinical and community spheres confront unique challenges and shortcomings in operationalising the core tenets of ‘developmental appropriateness’ in practice. These manifest most acutely in the form of persistent concerns or issues in the field, such as those related to a lack of help-seeking; meaningful engagement; participation; and the screening of psychosocial and mental health distress among young people living with a condition (Bennett, 2009; Lawrence et al., 2015; Sawyer et al., 2010; Steinbeck et al., 2014) that compromise the care they receive and require researchers and practitioners to go beyond discipline- or silo-specific solutions. Therefore, an integrated approach is warranted (Catalano et al., 2002; Czeresnia, 1999). However, this study recognises that the mechanisms and pathways for fostering this integration and dialogue in a manner that grants equal standing to each sector are under-conceptualised within the field. Thus, the study contributes to scholarship and practice by highlighting these challenges and shortcomings, and demonstrating potential mechanisms and pathways towards strengthening the cohesion and legitimacy of the community sector, while fostering integration and dialogue with the clinical field. This approach better supports the ‘developmental needs’ of young people living with a condition in a holistic manner. The study also proposes areas for future research that are important for realising this approach in practice.

This study contributes to scholarship and practice by problematising the construct of ‘developmental appropriateness’ (D'agostino et al., 2011) to reveal its fragmented and diverse conceptualisation and application within the field, particularly in relation to the clinical and community sectors. This is significant, because while this study acknowledges consensus in relation to the core principles and goals underlying the notion of ‘developmental appropriateness’ (D'agostino et al., 2011) within scholarship, it argues that in practice the ability of various disciplines and sectors to operationalise and realise these theoretical aspirations is limited by the constraints imposed upon them by the implicit perceptions and cultures dominating these institutional spaces. In some respect, these are connected to the models of health, including the biomedical, biopsychosocial and socio-ecological models and the ability of each sector to fully realise the tenets underlying these frameworks.

This tension is most keenly expressed in relation to the operationalisation of ‘developmental appropriateness’ (D'agostino et al., 2011) in clinical, medical and hospital contexts. Despite their best efforts to implement ‘developmentally appropriate’ (D'agostino et al., 2011) and ‘adolescent friendly’ (Sawyer et al., 2010) services, spaces and cultures, in practice this sector has only been able to realise these aspirations in an ad hoc or piecemeal manner. As a consequence, it has implemented these principles and features in terms of specific points of service; among certain practitioners; and in particular organisations, rather than consistently across the sector. The findings from this study suggest this results from the implicit dominance of the biomedical model (Engel 1989), which continues to permeate the culture and perceptions operating in this space, alongside the lack of funding, resources and staff in an over-taxed, high-demand field. Thus, as a pragmatic reality, the clinical field needs to recognise the skilled contribution that allied and community interventions can make in assisting young people, particularly in terms of their development, and youth culture more broadly.

This proposed shift to community-based interventions (Trickett et al., 2011) is not without its challenges. First, there is a lack of integration, particularly in terms of referral pathways to connect young people with allied and community supports from clinical and hospital services, despite these supports potentially being in a stronger position to realise the principles and goals encompassed with the notion of ‘developmental appropriateness’ (D'agostino et al., 2011), because of their natural alignment with biopsychosocial and socio-ecological (Bronfenbrenner, 1979; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 2006; Engel, 1989) models of health.

Second, there is a tendency for allied and community supports and programs to measure themselves against the clinical sector and prevention-based models of ‘developmental appropriateness’ (D'agostino et al., 2011). Consequently, the legitimacy, credibility and expertise of the community field and promotion-based approaches to developmental appropriateness on an ontological level, are undermined (Catalano et al., 2002; Czeresnia, 1999).

This is connected to the third challenge, which involves a lack of cohesion in the community sector and in promotion-based services both conceptually and practically. Conceptually, this results from the literature evaluating community and promotion based approaches and interventions under a variety of terms, including community health (Trickett et al., 2011), peer support (Olsson et al., 2005), self-help communities (Prescott et al., 2020), art- and music-based therapies (Burns & Waite, 2019; Datlen & Pandolfi, 2020), affordance theory (Gibson & Trnka, 2020; O'Leary et al., 2020) and social media platforms (Gibson et al., 2016; Pereira et al., 2020) more generally, to name a few. Thus, this study suggests the importance of creating a systemised way to integrate this disparate literature, such as standardising definitions and their operationalisation, so that the value this scholarship holds for practice is more apparent.

Further, the scholarship tends to privilege positivist and post-positivist (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018) evidence-based research and studies above interpretive or constructivist accounts, which may more closely reflect and capture the reality of providing promotion-based services in the community. The outcomes of this study strongly support the need for qualitative research (Guba & Lincoln, 1994; Lincoln et al., 2011, 2018), because as it has been made clear in this study, such an approach allows us to go beyond generalised solutions and their shortcomings. This enables us to unearth latent factors at play that can provide new, effective and comprehensive pathways to move forward away from persistent problems or challenges within the field for which current approaches lack solutions and face roadblocks.

On a practical level, although outside the scope of this study, a lack of cohesion among community-based interventions, is also acknowledged. Some interventions emerge in response to the needs of specific communities, and thus are not always designed with industry standards in mind. Fostering stronger integration and building industry frameworks for this sector to provide resources, training and funding, could enhance its legitimacy and accountability, and focus attention on the significance of community and promotion-based services.

Prevention and Promotion

In addition to the exploration of developmental appropriateness (D'agostino et al., 2011) in relation to clinical and community supports, this study contributes to scholarship and practice by demonstrating the merit of adopting an integrated approach to prevention and promotion (Catalano et al., 2002; Czeresnia, 1999). These two valuable approaches are commonly employed to operationalise developmental appropriateness within the design and evaluation of interventions. Employing an integrated approach, would facilitate the adoption of strategies that go beyond silo or sector-based solutions to promotion (Bennett, 2009; Catalano et al., 2002; Czeresnia, 1999). This could lead to organisations and institutions tailoring their interventions, programs and services to meet the unique and sometimes conflicting needs of young people living with an illness or disability in a manner not commonly observed within the field and foster greater integration and dialogue between the clinical and community spheres.

This study addresses a very significant tension. It records a challenge within the field of the need to create ‘developmentally appropriate’(D'agostino et al., 2011) interventions, programs and services that—in alignment with prevention approaches—have the infrastructure, training and resources to cater to and protect young people from a myriad of risks detailed in the study, as well as the ability to go beyond protection and risk, beyond illness and disability, to celebrate the young person holistically, including their strengths, diversity, individuality, development and engagement in youth culture (Catalano et al., 2002; Czeresnia, 1999). In other words, what emerges here is a tension, because of the need to create spaces that are medically safe but also medically free. There is no easy way to resolve this tension.

While clinical services strive to enact ‘developmental appropriateness’ (D'agostino et al., 2011) and ‘adolescent friendly’ (Sawyer et al., 2010) cultures, the implicit dominance of the biomedical (Engel, 1989) model often leads to this sector only being able to realise this in an ad hoc manner. In contrast, while community supports excel in offering promotion-based support, the lack of protective mechanisms, particularly in relation to the young person’s conditions sometimes undermines the credibility of these services (Catalano et al., 2002;

Czeresnia, 1999; Hamilton et al., 2004). This in turn can make some young people reluctant to engage with these services, while others conceal their condition to focus on the developmental and youth-oriented benefits of engagement offered through these programs.

This has implications for help-seeking, as well as for meaningful engagement and participation (Patton., 2016; Sawyer et al., 2010). While protection facilitates credibility in terms of expertise, trustworthiness and accountability that strengthens help-seeking behaviour, it can also undermine it with an emphasis on risk and one's condition (Catalano et al., 2002; Czeresnia, 1999). This in turn detracts from meaningful engagement and participation in the long term. By the same token, while promotion facilitates help-seeking through an emphasis on youth culture beyond illness and disability, it can detract from it through a lack of protection or expertise in terms of one's condition. Nonetheless, promotion and involvement in youth culture, has a stronger potential to facilitate meaningful engagement and participation over the long term, than does prevention (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004). The mechanisms and pathways through which this tension could be resolved are under-conceptualised. Thus, this thesis contributes to scholarship by elucidating mechanisms and pathways that could be explored with implications for improving help-seeking, meaningful engagement, participation and screening.

Legitimacy

Alongside the discussion of prevention and promotion (Catalano et al., 2002; Czeresnia, 1999) approaches in relation to developmental appropriateness (D'agostino et al., 2011), this thesis demonstrates how organisations and institutions, particularly those in the community sector, can foster two sources of legitimacy, including: (a) that which resides in institutionalised approaches and in established, regulatory frameworks; and (b) that which emerges from the ground with respect to promotion and the ‘street cred’ and trust embedded in informal peer and social networks.

This study, through its exploration of the work of LW.org.au, demonstrates the value that accrues to community interventions when they receive endorsement from the clinical sector. Such an approach appears to represent a valuable mechanism for enhancing the standing or legitimacy of community interventions within the field and fostering greater integration with clinical supports. However, a concern with fostering legitimacy and integration through endorsement by the clinical sector, is that this action, to some extent hinders the opportunity to facilitate inter-sectorial dialogue and leads instead to further destructive comparison.

Thus, a key contribution of this study is the documenting of how community interventions, like LW.org.au can foster legitimacy in terms of expertise, that strengthens their credibility, trustworthiness and accountability independently of the clinical sector.

In considering the implications of this study, a valuable mechanism to achieve this legitimacy at the macro level might be through gaining external accreditation from an independent body within the community sphere and ensuring these services are available in the community sector. In this study, this involved the SCF gaining external accreditation from the Australian Childhood Federation. Such accreditation facilitates the institutionalisation and professionalisation of the community sector to elevate its standing within the field of scholarship and practice. Further, this study has implications for practice, by demonstrating how community interventions can take these national and state policies and implement them at the micro level of their programs in an effective manner through establishing policies of validation and moderation in the social media space. These can serve to: (a) safeguard vulnerable young people; (b) train chat-hosts, especially to negotiate the boundaries of acceptable interactions; and (c) provide parents and young people with transparent and accessible information on these policies.

A limitation of this approach should be noted. The SCF emphasis on risk aversion, aiming as it does to protect the most vulnerable by virtue of their age or condition, can sometimes detract from the value of the conversations online. This, in some respects, can impede upon the meaningful engagement and participation of those not so vulnerable. Some chat-hosts were aware of the consequences for them and their role of taking a risk-averse approach, emphasising youth culture and the development of the individual in that context. They identified a tension between the training they received and their perception of the need for a greater level of understanding of psychosocial and mental health issues. This tension suggests the need for further research into the roles of chat-hosts in negotiating the boundaries of interactions and the topics raised in online forums by young people with a condition.

This thesis also demonstrates that promotion (Catalano et al., 2002; Czeresnia, 1999; Hamilton et al., 2004), with its emphasis on youth culture and the building of strong relationships through everyday conversations, potentially has value as it capitalises on the tendency of young people to reach out more readily to informal networks of peer and mentor support about developmental and mental health concerns than they do to official services. Thus, designing interventions with this youth-oriented and medical-free model holds merit for facilitating help-seeking and screening in a manner that even preliminary screening services fail to address, because of their clinical emphasis.

Identity

In addition to its exploration into the concept of developmental appropriateness and the practice of designing and evaluating developmentally appropriate interventions in relation to the dominant models and approaches to health within the field, this thesis strives to understand developmental appropriateness in terms of the developmental tasks known to be important for the adolescent and emerging adulthood life-stage. These developmental tasks include how interventions impact identity formation in the context of peer and mentor connections online.

In terms of identity development, this study was informed by the seminal work of Erikson (1968, 1994), and strongly supports his prime assertion that identity formation comprises a significant psychosocial and developmental task in adolescence and emerging adulthood. In alignment with Erikson's (1968, 1994) original conception of 'ego identity', this study contributes to scholarship by stressing the importance of observing, understanding and evaluating identity formation in young people living with a condition with an emphasis on highlighting the reciprocal relationship or interplay between the individual and their social context, an approach not common in the literature (Luyckx et al., 2006; McAdams, 2011; McLean & Syed, 2015; Raymaekers et al., 2017). This approach involves understanding not only the individual and their shifting internal self-conceptions, values and standards across multiple identity categories—something that is common within the field—but also how these emerge in response to and are negotiated through interpersonal connections and a diversity of social contexts and cultures online (Luyckx et al., 2006; McAdams, 2011; McLean & Syed, 2015; Raymaekers et al., 2017) This contribution is significant because identity scholarship has predominantly focused on exploring identity formation from the personal perspective of the individual in terms of identity statuses and processes (Luyckx et al., 2006; Marcia, 1966,

1993) or identity content in terms of narrative identity, meaning and meaning-making practices (McAdams, 2011); less attention has been given to exploring identity formation in relation to culture and context (Côté, 1997; McLean & Syed, 2015), particularly how these intersect online.

The study's netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach was advantageous in facilitating this contribution to 'identity' scholarship. Its holistic approach allowed the study to explore 'identity formation' (Erikson, 1968, 1994) from the perspective of three distinct strands of identity scholarship, including (a) identity statuses and processes, (b) narrative identity, meaning and meaning-making processes, and (c) context in terms of culture and norms (Côté, 1997; Luyckx et al., 2006; McAdams, 2011; McLean & Syed, 2015; Raymaekers et al., 2017). These strands of identity scholarship are often explored individually, or at best in tandem with one other strand, such as (a) identity statuses and processes with (b) narrative identity and meaning-making or (a) identity statuses with (c) needs satisfaction analysis in terms of context. To the best of my knowledge, no study has employed all three strands simultaneously (Côté, 1997; Luyckx et al., 2006; McAdams, 2011; McLean & Syed, 2015; Raymaekers et al., 2017), possibly because of the methodological approach used. By analysing 'identity formation' in relation to these three strands of scholarship, this study has been able to provide an understanding of each perspective that is more nuanced than could have been reached by considering each separately. This is significant, because the current challenge within the identity literature is that there exists large, established bodies of knowledge around each perspective, but limited exploration into the points of intersection between these perspectives. Thus, this study made a preliminary effort to explore these points of intersection and unearth their merit for future research and practice.

This study contributes to the first strand of identity scholarship (Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1993) by focusing on the vulnerable cohort of young people living with a condition. The literature tends to focus on conditions such as Cancer (Madan-Swain et al., 2000), Cardiac or Congenital Heart conditions (Luyckx et al., 2011; Rassart et al., 2012), Diabetes (Luyckx et al., 2008b), Eating Disorders (Verschueren et al., 2017) and Attention Deficit Disorder (Çuhadaroglu-Çetin et al., 2013), rather than considering a group with diverse conditions. This study made a preliminary effort to broaden this scope by exploring identity formation among young people who do not share a condition.

There is an argument in the literature that global identity—that is, identity development across multiple domains—may not accurately reflect the processes of identity formation especially among culturally diverse groups, such as those living with a condition whose life experience may lie outside the norm (Schwartz et al., 2015). Thus, domain-specific knowledge may be more reflective of these young people's development, strengths and weaknesses, than global measures (Schwartz et al., 2015). Moreover, many studies in this area have been quantitative, demonstrating low internal consistency between domain identities and global identity overall, because of their focus on specific variables (Schwartz et al., 2015). Exploring global identity from a qualitative perspective, facilitates a focus on domain-specific identity knowledge, allowing this study to demonstrate the strength of this approach through its nuanced and culturally sensitive insights.

This study contributes significantly to scholarship through its focus on identity domains that are culturally relevant to the young people under study. To the best of my knowledge, no study has explored 'living with an illness or disability' as a distinct identity domain or cultural category in its own right. This has significant implications for understanding identity integration among young people living with a condition (Luyckx et al., 2008b; Oris et al., 2018; Rassart et al., 2012), and its role as a promotive resource (Lerner et al., 2011). In the literature, it is argued that fostering 'normal' identity formation and development among young people living with a condition facilitates positive condition management and the integration of their condition into their wider sense of self (Luyckx et al., 2008b; Oris et al., 2018; Rassart et al., 2012). This study moves beyond merely viewing living with an illness or disability as an external factor impacted by identity formation statuses and their subsequent processes, to explore living with a condition as an identity category, similar to the categories of ethnic or gender-based identity (Syed & Azmitia, 2008; Syed et al., 2013). This approach challenges the marginalisation of illness and disability identities often absence from mainstream discourse by rendering it a legitimate identity category worthy of investigation.

The second strand of identity scholarship—narrative identity (McAdams, 2011), with its focus on identity content, meaning, and meaning-making practices—elucidates the sense of power in an identity. Such an approach can challenge the stigmatisation of illness and disability identities by identifying how empowered condition-based identities can function as promotive assets in facilitating integration (Hammond & Teucher, 2017). This contrasts with other literature that predominantly understands integration in terms of the condition being integrated into the strengths of the young person identity (Luyckx et al., 2008b; Oris et al., 2018; Rassart et al., 2012). In this context, one's condition is always viewed as the risk factor and is precluded from being seen as a source of strength or promotion. Acknowledging that condition-based identities can function as a source of strength is valuable for broadening the representations of illness and disability operating in mainstream society (Hammond & Teucher, 2017). The absence of these identities in discourse and scholarship squanders the opportunity to consider how young people are appropriating illness and disability identities in their everyday language, conversations and identity exploration, and blocks insights into how they are contesting these meta-narratives (Hammond & Teucher, 2017). Broadening our understanding of how young people create their own identity in relation their illness and disability, also has implications for clinical practice and the building of therapeutic relationships and rapport with clinicians and practitioners.

This study shows how narrative identities are more useful for tapping into the episodic identity expression that occurs online (McLean et al., 2016; Pasupathi et al., 2007). By showing how meaning connects to identity through self-event relations or how identity emerges from posts over time, this study provides a new dimension to understanding the processes of exploration in breadth and in depth by bringing a change at a methodological level. This facilitates an understanding of identity construction online based on short postings that accumulate over time, rather than continuing to explore identity formation through extensive life narratives or interviews that may not be entirely suitable for this medium (Habermas & Bluck, 2000; McAdams, 2001, 2011).

This study has implications for interventions designed by organisations to support young people living with a condition by revealing whether practices online facilitate exploration in breadth or in depth (Crocetti, 2018; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966), in relation to different identity domains. A core finding from this study is while the LW.org community did foster a high degree of exploration in breadth of the young person identity, it did not appear to foster a similar degree of exploration in depth in relation to young people's condition-based selves. While exploration in breadth was a valuable strategy for overcoming the issue of illness over-identification (Mazanderani et al., 2012) and stigmatisation online, it was less effective in fostering high levels of identity integration (Luyckx et al., 2008b; Oris et al., 2018; Rassart et al., 2012) between young people's 'young person' and condition-based selves, especially in terms of exploring the disempowering components of their illness and disability experience and its associated identities to work through these challenges.

The third strand of identity literature examines how the culture and norms of the community impact those identity meaning-making practices and content (McLean & Syed, 2015). This study employed positioning theory in a novel way that allowed for the delineation of the different cultures and norms online, combining two approaches from the literature. Combining Davies and Harré (1990), Harré and Van Langenhove (1998) and Harré et al.'s (2003) work to elucidate the local moral order and the macro cultures at play impacting young people's identity formation online with Bamberg and Georgakopoulou's (2008) model that is more adept at exploring how postings relate to small stories and interpersonal positionings, facilitated the exploration of how posts that young people created were being validated online and how these were connected to the local moral order of LW.org.au and to other settings, such as the hospital context and youth-based environments.

Positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998) and netnography (Geertz, 1973; Kozinets, 2010, 2015) are innovative methods for exploring identity formation (Erikson, 1968, 1994) online, where identity formation is more episodic and fragmented. Their focus on a micro approach to identity formation, is valuable because there is a tendency in the literature to explore identity formation in terms of macro approaches, such as life narratives or blogs, which are less adept at capturing the influence of episodic development and interactional processes online.

Recommendations for Practice

Significance of Adopting a Dual Approach to Designing ‘Developmentally Appropriate

With respect to developmentally appropriate (D'agostino et al., 2011) interventions, this study highlights the importance of designing services with a dual prevention and promotion (Catalano et al., 2002; Czeresnia, 1999) approach in mind. This ensures these interventions possess the mechanisms to safeguard young people from challenges related to their condition-based concerns, as well as risks related to social media platforms, child protection concerns and precarious youth-cultures. However, a dual approach (Catalano et al., 2002; Czeresnia, 1999) also arms services with the ability to facilitate meaningful engagement and participation through promotive strategies that conceive ‘developmental appropriateness’ (D'agostino et al., 2011) beyond service features to foreground youth culture and development as paramount. This has the potential to: (a) put the individual, not their condition at the centre of practice (Phelan et al., 2020); (b) foster egalitarian relationships with youth people and adults (Hamilton et al., 2004; Patton et al., 2016); and (c) allow services to be more responsive to the adolescent perspective and voice (Haldane et al., 2020; Steinbeck et al., 2014). It also offers greater room for individualised care. Therefore, the importance of adopting a dual approach (Catalano et al., 2002; Czeresnia, 1999) to designing developmentally appropriate interventions allows organisations and practitioners to create medical-free spaces at the ontological, rather than the epistemological level, while still catering for condition-based concerns.

On a more practical level, this study recommends further exploration into the workings of the LW.org.au model of moderation. A micro-level study, for example using positioning theory (Bamberg & Georgakopoulou, 2008; Davies & Harré, 1990; Harré et al., 2003; Harré & Van Langenhove, 1998), could shed light on: (a) how youth-focused egalitarian relationships develop; (b) how young people understand meaningful engagement; and (c) how participation and the informal feedback that emerges in conversation contribute to the processes and outcomes of moderation (Haldane et al., 2020; Hamilton et al., 2004; Steinbeck et al., 2014).

This study also identifies online communities and social media networks as valuable avenues for fostering ‘medical-free’ spaces for vulnerable young people. This is particularly pertinent when these young people are situated in medical or clinical contexts that predominantly conceive and enact ‘developmental appropriateness’ (D'agostino et al., 2011) in a manner that is more service based, rather than holistic. Therefore, young people’s expressions of the self and understanding of their condition in these contexts tends to be strongly influenced or constrained by the implicit dominance of biomedical (Engel 1989) culture operating in these spaces. In this regard, online communities such as LW.org.au provide easy access to ‘medical-free’, ‘developmentally appropriate’ (D'agostino et al., 2011) and ‘youth friendly’ (Tylee et al., 2007) spaces or enclaves that provide continuity with youth culture that allows young people to challenge and contest clinical definitions and meanings imposed on them by this biomedical (Engel 1989) culture, while still being cognisant of their condition-based concerns. These communities also have the potential to foster empowerment through safe, youth-friendly conversations and engagement with implications for building positive youth development (Lerner et al., 2011) assets and identity integration.

Value of a Dual Approach to Supporting Identity Formation

This study further recommends the need for services that facilitate identity formation (Erikson, 1968, 1994) and development in relation to one’s condition and youth-based culture. This approach has value for fostering integration between both facets of the self

(Luyckx et al., 2008b; Oris et al., 2018; Rassart et al., 2012) and implications for enhancing help-seeking (Sawyer et al., 2010) behaviour among this cohort by mitigating issues connected to illness over-identification, stigmatisation and concealment (Mazanderani et al., 2012) through this dual approach to developmental appropriateness. However, the study also recommends that for the value of this approach to be fully realised and effective, it is important that services implement policies and practices that encourage exploration both in breadth and in depth in relation to identity (Crocetti, 2018; Luyckx et al., 2006; Luyckx et al., 2008a; Marcia, 1966). This is useful because while exploration in breadth has merit for help-seeking and engagement in terms of mitigating illness over-identification and stigmatisation online (Mazanderani et al., 2012), exploration in depth allows for greater opportunity for young people with a condition to integrate their condition into their wider sense of self as a promotive asset, which has benefits beyond the intervention itself.

Limitations and Future Research

Every study has its limitations and this study is no exception. The challenges related to obtaining consent from young people to participate in the study, because of the vulnerable nature of the community, meant that this study was unable to influence the demographic characteristics of participants. For example, all participants were female; unfortunately, no males opted to participate in the study, despite concerted efforts by the researcher and the SCF to engage them. This is a significant limitation of the study. There is an awareness from previous studies (Lawrence et al., 2015; Rickwood et al., 2016) that young men are less likely than females to reach out to these services and this study was unable to shed light on this issue.

A related limitation arose, because those who had consented to take part in the study engaged in conversations with others who had not consented, thus these conversations could not be considered part of the data. It could be argued that those who participated in the study were the core members of the LW.org.au community and therefore the topics of their conversations were a good representation of the topics discussed. However, it was evident that there were conversations involving those with a more tenuous relationship to the community that revealed more risks or condition-based concerns, and these by necessity were excluded from the study.

The literature also recognises the value of creating gender-based strategies to support both males and females in reaching out to these interventions and sustaining engagement (Lawrence et al., 2015; Rickwood et al., 2016). Therefore, there is significant scope for future research with young men with a condition.

A related limitation is the lack of cultural diversity among the participants. It would appear that the young people who were members of LW.org.au at the time of the study were a relatively homogenous group from an ethnic perspective. This may present an opportunity for SCF to consider how to broaden its services to meet the needs of young people from culturally diverse backgrounds.

A second set of limitations arose because the conversations that formed much of the data for this study occurred in the open forum. Approval was not granted by the University’s Human Research Ethics Committee (Application no. ETH18-3031) to gather data from private messages between members and chat-hosts. Private messaging is a feature of the site, where many of the more distressing conversations occur. This limitation of the study, highlights a strength of LW.org.au policies, as it demonstrates the importance of screening. At the same time, it highlights the role played by chat-hosts in regard to working with young people with a condition, and reveals challenges evident in the role. As noted above, these challenges have implications for future research; for example in identifying the strategies used by chat-hosts that may have merit for other services, and revealing areas where training for chat-hosts to effectively navigate these challenging situations online could be enhanced. Moreover, exploring the difference in conversations between the main chat and private messages would provide more information about how LW.org.au deals with those more distressing situations that could not be ascertained during this study.

Concluding Remarks

In conclusion, this thesis undertook an exploratory investigation into the LW.org.au community to understand how the site functions as a developmentally appropriate (D'agostino et al., 2011) intervention for young people living with a condition with an emphasis on understanding the culture and peer norms, and identity formation enacted and embodied online. A core strength of this study was its innovative netnographic (Geertz, 1973; Kozinets, 2010, 2015) approach that allowed it to view: (a) the construct of developmental appropriateness (D'agostino et al., 2011); (b) the practice of designing and evaluating developmentally appropriate interventions; and (c) the developmental task of identity formation (Erikson, 1968, 1994) from multiple perspectives. These include perspectives that strove beyond disciplinary and siloed boundaries to illuminate novel solutions to complex challenges within the field. These challenges involved issues related to a lack of help-seeking, meaningful engagement, participation and screening of psychosocial and mental health distress among young people living with a condition (Bennett, 2009; Lawrence et al., 2015; Sawyer et al., 2010; Steinbeck et al., 2014). Thus, this thesis responds to the need to foster greater interdisciplinary and inter-sectorial collaboration and dialogue (Bennett, 2009; Steinbeck et al., 2014), but recognises that current efforts often fall short because of assumptions underlying the dominant perceptions and cultures operating in these spaces and interventions, alongside pragmatic constraints.

To some extent, this thesis plays devil's advocate by shining a light on these shortcomings and de-constructing current approaches to re-construct them in a manner that breaks ground and broadens our horizon to create pathways forward that are more adept at realising the ideals of developmental appropriateness (D'agostino et al., 2011) and the vision of interdisciplinary collaboration and dialogue (Bennett, 2009; Steinbeck et al., 2014) holistically in practice. Moreover, this study demonstrates the implications of this for scholarship, practice and policy, particularly in terms of harnessing social media platforms to cultivate medical-free spaces and developmentally appropriate (D'agostino et al., 2011) support for young people living with a condition. Thus, the value of this thesis is its ability to catalyse new lines of inquiry both theoretically and methodologically. Its intention was always to go beyond the limitations of our current vision, both in terms of illness and disability, and the scholarship, practice and policy that support it.

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