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## **Abstract**

This paper analyses the development of the specialism of Adolescent and Young Adult (AYA) cancer care via a Foucauldian lens to consider how knowledge and awareness have grown since questions were first raised about unmet needs of AYAs with cancer. The AYA specialism has gathered momentum over the last 30 years in the United Kingdom (UK) and is fast gathering pace internationally. Fundamental to this process has been the combined contribution from nursing and other health professionals, researchers, policy makers and philanthropists. From an initial process of problematisation, through a gradual growth in empirical knowledge and resultant shifts in health policy, a new nexus of expertise has emerged that enabled AYA cancer care to become recognised as distinct from either child or adult oncology. Different stakeholders contributed to the discourses that have underpinned this development; a process likely to continue as it expands further.

This paper draws on examples from the growth of the AYA specialism, the emergence of new professional roles and a growth in research. It illustrates how the coalescing of multiple perspectives allowed new discourses, and ultimately, new practices to be established that now have global impact.

Keywords: Adolescents, young adults, cancer, nursing, Foucault, power, governmentality, philanthropy

## Introduction

The focus of this analysis is the development of the specialism of adolescent and young adult (AYA) cancer care, and adopts a genealogical approach based on Foucault's thinking. The growth of this specialism provides a contemporary example of how ideas and practices once considered radical, can shift towards acceptability based on a process of shifting power dynamics and emergent discourses that both shape, and are shaped by, these new ways of thinking. One example of this from the iconic work of Foucault focussed on the emergence of mental illness and stemmed from recognition of the importance of the process of labelling (of madness as abnormal behaviour), leading to the rise in the acceptability of psychiatric diagnoses and the eventual disciplinary power that revolved around psychiatry itself (Armstrong, 1977).

In this paper we examine how AYA cancer care has progressed from a situation that stemmed from a process of problematisation, to one that increasingly became the focus of philanthropic support and a similar growth in empirical research, up until today where it attracts the attention of policy makers and those involved in such work on a global scale.

The paper recounts this process of development and draws on Foucault's (1977) concept of the gaze. This, we argue, has shifted attention away from cancer purely as a biological malfunction, towards one where 'the person' is recognised with, in this context, the requirement to cope with a cancer diagnosis in a social sense (as a member of kinship of friendship groups) during a specific phase of the human life-course (as an adolescent or young adult).

Foucault termed genealogy a form of reflection on the nature and development of modern institutions, such as medicine, and their associated sources of power, and is quoted as saying;

“One 'fictions' history starting from a political reality that renders it true, one 'fictions' a politics that does not yet exist starting from a historical truth” (cited in Dreyfus & Rabinow, 1982, p. 204). Whilst Foucault’s work may be considered complex in its interpretation of social movements, it is very often adopted and shaped by other author’s application of its core elements. Being mindful of this, it is anticipated that this genealogical interpretation seeks to uncover relationships from a range of perspectives and to suggest the links between power, knowledge and the emergence of specialist AYA cancer care in the present context. Furthermore, it will portray how this specialism is shaped by historical forces; the most relevant being the underpinning shifts in power away from paediatric or adult oncology models of care, within which the loci of power were located previously. The shift was towards something radical and new. An attempt to investigate the ‘history of the present of AYA care’ will be made by avoiding grand historical and social formations, but rather looking more towards the ‘numberless beginnings’, ‘accidents’, ‘errors’, ‘false appraisals’, and ‘faulty calculations’(Foucault, 1977, p. 145-6), that more often characterise the evolution of ideas. By adopting this genealogical approach, it is intended that this paper will highlight difference, abrogation and rupture, (Anais, 2013), rather than seeking simplistic answers as to why this occurred. However, we do not seek to trace AYA Cancer care from its beginnings to the present in a nuanced way but rather to suggest explanations primarily through accounts of the way that power, and in turn practice, has changed. Purposefully, this work also suggests that, although the specialism has developed considerably over the last 30 years, it may still be considered fragile and at risk of disruption based on resistance to further change from those who still hold positions of power and influence within adult or paediatric cancer fields, and who can prevent innovation if they feel this is against their own interests. The first step in the process of AYA cancer specialist was the process of problematisation that took place and the role of early champions and the ‘numberless beginnings.’ (Foucault, 1975, p.145).

### **Problematisation of cancer care for the young adult.**

Foucault (1986) asserts that *problematisations* emerge in tangible practices; they are not simply mental images or ideas. He describes “the problematisation of madness and illness arising out of social and medical practices” and “a problematisation of crime and criminal behaviour emerging from punitive practices” (Foucault, 1986, p. 12). In the context of examining AYA cancer care; a useful starting point is to explore polemical texts, meanings and problems associated with adolescent and young adulthood (and associated terms) so as to determine what the ‘problem’ actually is for those in these age groups when cancer is diagnosed, or indeed the extent to which age itself is problematic and meriting special attention. Furthermore, if it is a problem, who is it a problem for and what manner of problems need to be addressed?

### **The conceptualisation of childhood, youth and adolescence**

Fass (2012) suggests that modern childhood was idealized long before it was a serious reflection of child life (p.12). Childhood as a concept began to emerge in the 1700’s, (Ariès, 1962) further evolved in the late post-modern era (Docherty, 2014), and has since been accepted as a social reality (Pupavac, 2001; Valentine, Butler & Skelton, 2001). From Valentine, Butler & Skelton’s (2001) and Bell’s (2011) insights into this process of development, it is claimed that that it was not until the late eighteenth/nineteenth centuries that the modern construction of human childhood as a time of innocence started to gain prominence in Europe and North America. Before then, children, although living within the family unit, were usually depicted as savages, in need of strict control and corporal punishment and /or equated with adult expectations (such as expectations that they should work). Such changes in attitudes towards human childhood heralded new social action and what had previously been deemed true, was changed irrevocably.

In the past century, child development theorists such as Bronfenbrenner (1977), Erikson (1963), Freud (1952) and Piaget (1970) posit patterns in human development, which focus largely on the following areas; physical, psychological and cognitive, social and emotional, and sexuality and gender identity. They have stood the test of time and remain widely influential. These models which shape our understanding of how humans change over time have become increasingly complex and are now seated within multilevel dynamic systems.

Foucault suggested that, as a result, the family became a densely saturated, permanent, continuous physical environment that served to envelop, maintain and assist the child's growing body, (Foucault & Rabinow, 1991, p. 280). In addition, much of his work asserts that hospitals became institutions devoted to knowledge production, as much as caring for the sick, and that the health of children became a target for great enterprise (and social standing) for medical professionals who were gaining independence and esteem in the specialism of child health. Literary sources, driven by medical science, further educated the wider population on the issues of childhood and youth in an attempt to promote the value of health promotion for future generations (Bell, 2011).

What was missing in these early discourses was a clear differentiation between childhood and adolescence in chronological, legal or biopsychosocial terms.

Youth as a concept, has been the subject of much research and debate ever since. The common endpoint usually being that youth or young people represent a distinct body of the populace; with the common agreement that they are neither adults nor children but are in a state of becoming. Foucault & Rabinow, 1991, p. 279) spoke of childhood and adulthood as distinct entities; beyond childhood came adulthood, despite his employing the term 'youth' in regard to pre-adulthood. This stems from his views of the privileges of the child and the medicalization of the family.

What is often not posited in such a theory is the apparent love/hate relationship between youth and adulthood with negative connotations attributed to both. Diametrically opposed values and life experiences may be felt by both groups, with adults seeming to forget what it was like to be young and not having the experience of this age in the present moment, whilst youth forge ahead with fervour and tempestuousness. An often-attributed quote to Socrates is that “children now love luxury. They have bad manners, contempt for authority; they show disrespect for elders and love chatter in place of exercise”, so it appears that this divergence of understanding among adults and adolescents is age old (Birchwood & Singh, 2013).

Adolescence itself was given little credence prior to the end of the last century. Demos & Demos' (1969) literature review from the period 1800-1875 uncovered little or no usage of the word and postulated that there was a limited degree of concern with the life-stage and its characteristic behaviours. They add that it was around 1900 that G. Stanley Hall made adolescence the focus of a psychological study. What was questioned was not the concept of adolescence itself, but ideas related to their roles within the structure of the family.

In the context of modernity, and regarding cancer in adolescence, questions of independence or dependence are commonly associated with this age group, irrespective of the presence of a cancer diagnosis. The relationship within the family of the adolescent when cancer is present is therefore subject to disruption for multiple reasons, not least because of the uncertain nature of cancer itself ( Long, Ginsberg & Kolon, 2016; Loren et al., 2013 ). This includes demanding treatments and the impact that symptoms have on the transition towards independence. The power of cancer itself, lies in altering the status quo for the young person who is expected to continue transitioning into adulthood regardless of a life-threatening diagnosis.

Given the differentiation between childhood and adulthood there is also an assumption that a social infrastructure exists for children and young people to achieve a successful transition, including those with cancer. Similarly, whilst the development of the United Kingdoms (UK) National Health Service (NHS) in 1948 promised free healthcare from the cradle to the grave (Platt, 1959), it was not until the late 1990's that individuals began to suggest that adolescents with cancer had unmet needs (Whiteson, 2005, p. 1). Indeed, the World Health Organisation echoed this sentiment by stating that, in addition to child and women's health, adolescents were being marginalised and suffered from various forms of inequities and discrimination; including those based on gender, income, age, place of residence, and education level; all resulting in poorer health outcomes (Temmerman, Khosla, Bhutta, & Bustreo, 2015).

Furthermore, modern positivist bioscience (Bolte-Taylor, 2013; Casey & Jones, 2010; Foulkes & Blakemore, 2018) also were suggesting that neuro-biological changes occurring in the human brain may account for at least some of the behavioural responses of young people. Thus, in parallel with Foucault's (1978) work on sexuality and madness, society seemed to be experiencing an attitudinal shift in the connection between the negative discourse of the past in relation to young people, and the realisation that there may be novel biological and psychosocial explanations for (at least some) of their behaviour.

In the UK, the momentum for the initial focus on the needs of AYA with cancer stemmed primarily from the actions of key individuals with philanthropic intent. It is important to draw attention to the ways in which language was used to highlight their level of need (with common terms such as "unmet needs" (Palmer, Mitchell, Thompson, & Sexton, 2007, p.280), "lost tribe" (Stevens 2006, p.280) , "no-man's land" (Hollis & Morgan, 2001, p.43) being used. This highlighted further the isolation of the AYA cancer experience and this, in turn, influenced others in the field to challenge current health policy and societal attitudes towards



young people living with cancer (Hollis & Morgan, 2001). Over time these events evoked a shift in perceptions about professional/social/political identities within this newly emerging specialism. The challenge was for this process of problematising to be met with sufficient financial and professional support to develop specialist AYA cancer care on the ground.

### **Power and Philanthropy in AYA Cancer Care**

Bacchi (2012) advises that Foucault's process of problematising of social issues emerges primarily via discourses and practices; they are more than imaginings, mental images or ideas. Underpinning much of process is the combination of power, truth and impact on the self; and the relationships between each (Bacchi, 2012; Rabinow, 1991; Willig, 1999; Willig & Stainton-Rogers, 2008;). By focussing on power as the overarching concept, for example, a range of discourses can be identified by government, academics, clinicians or charities who either support or deny unmet needs or bring AYA cancer to the fore to gain support from the wider public.

Within this process of growing support can be seen the work of Hollis & Morgan (2001); two nurses who were amongst the earliest to write about the adolescent with cancer and suggested their location "at the edge of no-man's land" (p.43). Concerns were also being articulated at this time by prominent champions such as Whiteson (2003) a founding member (lay, non-clinician) of the UK charity Teenage Cancer Trust, (TCT). In addition, Eden, Barr, Bleyer, & Whiteson (2005) were also calling for attention to be paid to the AYA cancer patient population (Eden, Barr & Bleyer as specialist oncologists); thus, the issue was reaching a stronger state of being *problematised*. Importantly the problem was being constructed primarily through polemical texts and professional argument with the goal of gaining

credibility and support, with the ultimate end-result being a new discourse around AYA cancer care and the support needs of this age group.

From a philanthropic perspective this emerging, and still novel, discourse around AYA cancer care was also having an effect. The Oxford English dictionary (2018) defines philanthropy as “the desire to promote the welfare of others, expressed especially by the generous donation of money to good causes, (“philanthropy, 2017”).” Without financial support the needs of the group in question would probably never have changed.

Because of the process of problematisation, various philanthropic solutions emerged first in the UK that highlighted unmet AYA cancer needs and charities, such as TCT, sought to provoke health service providers, and governments, to act (Bacchi, 2011). However, Bacchi (2011) adds a note of caution about philanthropy as it can simultaneously support the very system it seeks to address:

“it disguises its own discourse in its portrayal of the mediums of consumption, profit, and media celebration as the basis for benevolent human relations. In its subordination of benevolence to money, the current texts of philanthropy stabilize the very system that results in suffering” (p. 2).

Charity is a word often used interchangeably with philanthropy. The Oxford English Dictionary (2018) defines charity as the “voluntary giving of help, typically in the form of money, to those in need” “charity, 2018”. Sulek (2010) suggests that philanthropy is ill defined but that it is generally recognised as the private giving of time or valuables (money, security, property) for public purposes. Furthermore, it is characterised as one of the forms of income of private non-profit organizations (Salamon, 1992).

Clearly little separates the intentions of charity and philanthropy but it would appear that philanthropy is more long-term, strategic and ‘big picture’ in its scope than charity- being based on longer-term vision, whereas charity is more allied to immediacy. In the case of AYA cancer care a relationship between philanthropists/charities and health service managers, clinical staff, and policy makers gradually developed, which was often purported to be based on the voice of young people themselves who were being presented as ‘unheard’ or ‘unable to be heard’ whilst also having unique unmet needs, (Kelly, Pearce & Mulhall, 2004; Hollis & Morgan, 2001; Morgan and Soanes, 2016; NICE, 2005; Smith et al., 2012; Smith, Mooney, Cable & Taylor, 2016). Words such as “neglected group”, “special needs”, “disadvantaged position” (Whiteson, 2005, p.1-10) were used in emerging research, policy and marketing literature with powerful effect.

In the early 1990’s these needs were commonly focussed on seemingly inadequate clinical environments (mostly by the UK charity Teenage Cancer Trust), who went on to fund up to 28 specialist units across the UK. This building programme was supported by emerging evidence of improved levels of satisfaction with age appropriate facilities, however, evidence of improved clinical outcomes has taken longer to emerge (Kelly & Hooker, 2007; Kelly, Pearce & Mullhall, 2004; Marris, Morgan & Stark, 2011; Teenage Cancer Trust, 2018a; Teenage Cancer Trust, 2018b; Teenage Cancer Trust, 2018c; University College London Hospitals, 2017). Another significant feature of the charity’s early work was the funding of specialist nurses to support these young people through the cancer experience (Morgan & Soanes, 2016; Smith, Mooney, Cable & Taylor, 2016).

Teenage Cancer Trust is only one of many charities in the UK focussing on supporting adolescents with cancer (Teenage Cancer Trust, 2018e) but claim they are the only one to provide specialist support. As each has developed they had to create an identity and convey their own market-based discourse of philanthropy which has included marketing of products

such as clothing (i.e., cause-related marketing) as well as endorsement by various media and celebrities (or “charitainment”) for benevolent outcomes (Mooney Nichol and Eikenberry, 2009).

Social theorists, such as Mooney Nichol & Eikenberry (2009) have posited binary tensions between such ‘marketised philanthropy’ that gives an impression of ‘giving back’, when in fact it is disguising action that it is based on ‘taking away’ (primarily money). Furthermore, the discourse underpinning contemporary philanthropy may, in fact, be creating a claim of unmet need without necessarily inducing transformative change for wider society, or ever truly seeking to eliminate the cause of such problems. This exemplifies the accidents or errors that may occur the shifting of power and the emergence of new discourses as proposed by Foucault (1977).

The dominant AYA discourse of unmet need could be reinforcing the demand for more philanthropy, or philanthropy as alternative social policy, within the current system (Eikenberry, 2006). High profile UK charity/media events (such as in the case of Teenage Cancer Trust, Royal Albert Hall rock and comedy concerts, with the involvement of major UK celebrities (Teenage Cancer Trust, 2018d), may be applauded for heightening public awareness (through a process of popular problematisation) and fundraising to provide financial support. Tester (2001) echoes this stance by arguing that such activity stirs individuals into moral action. However, there is also the less obvious conclusion that out of such problematising and philanthropic effort comes publicity and rewards for those who take part.

In 2013, a rather unique situation arose in the UK where, through social media, a 19-year-old Stephen Sutton, who was dying from cancer, became famous by seeking to raise large sums of money for the Teenage Cancer Trust. Rather than resulting in compassion fatigue as seen

with audiences over-exposed to celebrity figures, the public became engaged in his personal narrative and the nature of his dying (Grant, 2015; Lumb, 2014). Whilst celebrities may not always enable structural change or access scarce financial resources, it can be argued that Stephen Sutton did indeed achieve this goal, to some degree. His public campaign, being executed in parallel with his own demise, was supported by the charity to encourage engagement with the public and he has generated more than £5million to date (Grant, 2015; Teenage Cancer Trust, 2018b).

By so doing so, this individual rendered immediate the discourse of suffering in adolescents with incurable cancer to the wider population which, in turn, further highlighted the plight of cancer in these age groups as still inherently 'problematic'. Whilst Stephen Sutton also became a celebrity to some degree in the process, the public saw him an adolescent facing his death from cancer with courage, and in a uniquely positive spirit. This event challenged the binary tensions within celebrity endorsement as he became an important agent in the dominant problematising discourse around adolescent cancer.

In keeping with Foucault's (1977, p. 145-6), ) thinking it seems that Stephen's Story, although unique, is another series of "numberless beginnings", "accidents" or "errors", and as such has played a significant part in reinforcing the discourse for social change around adolescent cancer care. His dying now forms part of the Teenage Cancer Trust charity's own narrative and is used to leverage public engagement and donations to support education for professionals about young people with cancer.

### **Power, professionals and policy in AYA cancer care**

Ferlie, Mcgovern & FitzGerald (2011) argues that for Foucault, power resides in mundane day-to-day practices, dominant languages and taken for granted rationalities. Foucault's view is that Government, as a concept, is something existing beyond the institutions of political

power. Foucault (1977) coined the phrase *Governmentality* which refers to the way in which the state exercises control over, or governs, its populace. This infers that the balance of power shifted from a central authority, e.g. the state or an institution (controlled by laws and punishment), to be dispersed amongst the population so that it eventually becomes self-governing and concerned about the 'status of things'. What we commonly understand by the term 'Government' in its political sense is that the populace is governed by bureaucratic offices, and doing the work of the elected government, instead of sovereigns.

In AYA cancer specifically few, if any, rules had been set out until adolescents with cancer were acknowledged in UK policy in 1995 (Department of Health, 1995) and again via the National Institute for Health and Care Excellence (NICE) in 2005 and 2014 when further practice guidance and quality standards were launched (NICE, 2005; NICE, 2014). These later documents were set to further alter the landscape for this group of patients in England (and to some extent the rest of the UK) with the aim of ensuring that the development and standardisation of high-quality specialist and equitable care, (Pearce, 2009). This placed emphasis on centrality of quality/standardised care for all AYA's with cancer and highlighted the need for their choice in a place of care. As a result, the concept of 'age appropriate' facilities became part of the NHS lexicon. However, apart from one clinical unit, the NHS has not actually commissioned one AYA Cancer unit in the UK - all have continued to be funded by the Teenage Cancer Trust and staffed by a combination of NHS and other UK charity posts (e.g. Macmillan Cancer Support and Clic Sargent). So, whilst government have stipulated the ideal standard of care, the funding for AYA Cancer services remained the responsibility of the charity sector. Arguably though, had the same charities not lobbied for these changes in policy, there would be a lower profile for them and their future ambitions for further philanthropic endeavours.

Whilst emphasis may have been placed on the creation of the built environment and specialist staff by charities in the UK, there has also been development of multi-professional AYA cancer teams driven by the additional discourses and values underpinning multi-disciplinarity. Integral to this has been the influential role of nurses with leadership positions in AYA services, practice and research (Kelly & Gibson, 2008; Morgan & Soanes, 2016; Olsen & Smith, 2018; Smith, Mooney, Cable & Taylor, 2016; Taylor et al., 2016 a& b). July 2014 marked the launch of the first nursing specific publication on practice competencies entitled ‘Caring for Teenagers and Young Adults (TYAs) with Cancer: A Competence and Career Framework for Nursing’ (Teenage Cancer Trust, 2014). This set out ways that the AYA cancer nursing workforce should be developed and specified key competencies that should apply to nurses caring for AYA’s with cancer; acknowledging clinical practice, leadership, academic and research roles. This Framework is currently being introduced across regional AYA cancer services in the UK. Positioning itself as a distinct professional group, nursing has been successful in promoting its own professional status via such discourses that promoted its contribution to AYA cancer practice and service innovation.

In Foucauldian terms, self-governance also arises from acts of surveillance and so, in effect, from a ‘them and us’ stance. One key principles of Foucault’s notion of power is that it cannot always be located; it can also be universal and therefore located within each individual agent (Foucault, 1982: 779). In this sense it is worth examining the agents of power within the context of AYA cancer care in the UK. They now include:

1. **The National Health Service**, who fund and deliver cancer care to AYA’s with cancer and their families. Responsibility for standards of care for all healthcare lies with the Government.

2. **Charities** who pay for 'age appropriate' environments, fund specialist staff to meet the unique needs (non-medical) of young people with cancer, lobby Government for improved care and education.
3. **Academics** who seek to generate knowledge through research and teaching about AYA Cancer care.
4. **AYA Cancer Professionals** who deliver care and undertake research with Universities and the NHS who provide access to patients for research.
5. **Policy Makers** who respond to lobbying and perceived needs of AYA groups.
6. **Patients-** Perhaps the most important agent without whom there would not be a problem to be examined. Stephen Sutton is an example of this form of agency played out in the public arena.

This list suggests a range of interests and centres of power for all stakeholders as AYA cancer care has developed in the UK in the past thirty years. Currently all AYAs cared for in the UK are managed by multi-professional teams though some would argue that such teams may not always be fully aware of the background to current AYA cancer issues. When explored in greater detail, such as the competencies, knowledge skills and attributes required of professionals as postulated by clinicians and researchers, what is most often recognised are the needs of AYAs in general, as well as the specific needs of AYAs with cancer (Morgan & Soanes, 2016; Smith, Mooney, Cable & Taylor, 2016; Taylor et al., 2011; Taylor et al., 2016a & Taylor et al., 2016b; Teenage Cancer Trust, 2014).

The emergence of additional discourses around evidence-based AYA practice as a means of employing the best available, research-based assessments and treatments in day-to-day patient care and service delivery, has led to a more standardised approach to professional practice and service delivery. This knowledge is produced by academics /clinicians and shared in specialist peer reviewed journals, following pre-agreed academic discourses, and



now underpin the development of clinical guidelines and policy. The National Institute of Clinical Excellence and the National Cancer Research Institute, two influential UK government funded organisations are examples of the key agents who now draw on such empirical sources. In addition, some charities fund and publish also research findings on AYA cancer matters in peer-reviewed journals, and thereby remain in a position of power and credibility by claiming adherence to quality control, authority and evidence. Research produced in AYA cancer community currently spans the cancer experience of young people in clinical trials (e.g. Schafer & Hunger, 2011), through to applied psychosocial research (e.g. Zebrack et al., 2014) and research priority setting in this age group, (Aldiss, Fern, Phillips & Gibson, 2018)

Over the last 25 years we have seen more explicit evidence emerge to inform AYA cancer policy and standards in UK (NICE, 2005), and small but important advances in AYA cancer care such as highlighting issues with routes to diagnosis, (Fern et al., 2011; Gibson et al., 2013) and raising awareness of challenges for AYAs with cancer in accessing clinical trials (Fern & Whelan, 2010; Fern, Lewandowski, Coxon & Whelan, 2014; Fern & Whelan, 2013).

In Foucauldian terms, power lies with such elite knowledge producers, in this case clinical academics, who produce such formal research-based knowledge. Patients are viewed as important but, are often peripheral, though Taylor et al. (2011, 2015 and 2016a & b) have purposefully engaged AYAs with cancer in their recent national study evaluating specialist care models. One critique of this approach is that objectivity may be at risk in such approaches. On the other hand, the notion of patient engagement is often criticised as tokenistic, patchy and slow (Ocloo & Matthews, 2016) so it is encouraging to see that within the growing research in this field, empowerment of AYAs is now being encouraged to help shape research and service delivery. Whilst it is academics, nurses, clinicians, researchers and health economists, whose evidence is being used to shape practice, and who may be

perceived as key power brokers, it is those at the bedside such as nurses, junior oncologists or social workers, who are expected to implement care, whilst also holding less power than senior oncologists or service commissioners. In parallel, the power of charities is also noted, as their branding and marketing activities provide a strong social voice and help them leverage gains in other ways, (often using patient narratives), and to fund innovations in practice, without necessarily always waiting for research evidence. Through such action, AYA charities often remain the go-between, crossing the gap between state/academia and practice.

Foucault posits that '*Power is everywhere*' and '*comes from everywhere*' (Foucault 1978: 93). In AYA Cancer a duality of structure and agency exists between those who subscribe to the immediate development of the specialism via action (charities); and the knowledge creators operating within the slower confines of NHS and academic structures. AYAs with cancer continue to be treated in the NHS, however, everyday care is shaped by nurses and other professionals, but it is not without the voluntary acts of those whose financial contributions create additional sources of support (and power/agency to individual AYAs) that would otherwise be lacking.

### **Examples of an archive of the development of AYA as a specialism**

In assembling an archive of thought, Foucault (2002) argued that archives are not a totality, not "the sum of all texts" or "evidence of a continuing identity" (p. 145). Instead, they offer a set of discourses that are grouped together in distinct figures, composed together in accordance with multiple relations. Anaïs (2013) adds that the genealogist of thought or praxis does not look to a unified data set which can tell the whole story of a set of practices. Rather, they study the relational elements of discourse or events, and how these are articulated alongside other discursive formations. Therefore, in terms of a genealogical data

set, any archive is relatively amorphous but at the same time it is a collection of discursive materials for examination. Table 1 outlines examples of supplementary information that are relevant to this analysis of the development of specialist AYA care. The examples included here are not intended to be exhaustive but offer a range of materials on which the discussion here is built.

Table 1- Supplementary Information relevant to the analysis of the development of specialist AYA cancer care in the UK

<b>Textbooks</b>	<b>Journal Articles</b>	<b>Policy</b>	<b>Misc Media Outputs</b>
Eden, Barr, Bleyer and Whiteson (2005) <i>Cancer and the Adolescent.</i>	Hollis & Morgan (2001). <i>The adolescent with cancer—at the edge of no-man's land.</i>	Platt Report (1959) <i>The welfare of children in hospitals</i>	Daily Mail (2013) <i>Bereaved family calls for change in the law after teenage daughter died when she was denied cancer drugs</i>
Kelly & Gibson (2008) <i>Cancer Care for Adolescents and Young Adults</i>	Lewis, Fallon, Dongen-Melman, & Barr (2002) <i>Cancer and the adolescent: the second Teenage Cancer Trust international conference</i>	Department of Health (1995) <i>The Calman–Hine Report</i>	BBC News (2014) <i>Stephen's story: What's the secret to teen's fundraising success?</i>
Smith, Case, Waterhouse, Pettitt, Beddard, Oldham & Siddall (2012)	Whiteson, (2003) <i>The Teenage Cancer Trust—advocating a</i>	NICE (2005) <i>Guidance on Cancer Services: Improving</i>	ITV News (2015) <i>Life lessons from 'true hero' Stephen Sutton</i>

<i>A Blueprint of Care for Teenagers and Young Adults with Cancer</i>	<i>model for teenage cancer services.</i>	<i>Outcomes in Children and Young People with Cancer.</i>	
Smith, Mooney, Cable & Taylor (2016) <i>A Blueprint of Care for Teenagers and Young Adults with Cancer, 2<sup>nd</sup> Ed</i>	Kelly Pearce, & Mullhall (2004) <i>'Being in the same boat': Ethnographic insights into an adolescent cancer unit</i>	NICE (2014) <i>Children and young people with cancer, NICE quality standard 55. NICE</i>	Teenage Cancer Trust (2017a) <i>Support Outside Our Units</i>
Barr et al (2017) <i>Cancer in Adolescents and Young Adults</i>	Kelly & Hooker (2007) <i>Evidence based cancer policy: The Needs of Teenagers and Young Adults.</i>		Teenage Cancer Trust (2017b) <i>Stephen Sutton</i>
Olsen & Smith (2018) <i>Nursing Adolescents and young adults with cancer.</i>	Taylor et al (2011) <i>"Your Place or Mine?" Priorities for a Specialist Teenage and Young Adult (AYA) Cancer Unit: Disparity Between AYA and Professional Perceptions</i>		The Independent (2015) <i>Postscript: Jane Sutton on how 'Stephen Sutton effect' gives mum reason to stay positive</i>
	Marris, Morgan & Stark (2011)		

	<p><i>'Listening to Patients': what is the value of age-appropriate care to teenagers and young adults with cancer?.</i></p>		
	<p>Fern, &amp; Whelan, (2013)</p> <p><i>National Cancer Research Institute teenage and young adult clinical studies group: the United Kingdom approach to research. International perspectives on AYAO, part 4.</i></p>		
	<p>Morgan &amp; Soanes (2016)</p> <p><i>Nursing young people with cancer: What is different about it?</i></p>		<p>Teenage Cancer Trust (2018a). <i>Support Outside Our Units</i></p>
	<p>Taylor et al (2015). <i>Development and Validation of the BRIGHTLIGHT Survey, a Patient-Reported Experience</i></p>		<p>Teenage Cancer Trust (2018e). <i>Our Story.</i></p>

	<i>Measure for Young People with Cancer.</i>		
	Taylor et al (2015). <i>Development and Validation of the BRIGHTLIGHT Survey, a Patient-Reported Experience Measure for Young People with Cancer.</i>		Cavallo, J. ASCO Post (2018)  <i>Second Global AYA Cancer Congress Highlights Research Advances and the Global Burden of Cancer Among Young Adults</i>
	Taylor et al (2016b), <i>Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer</i>		Harrison, BBC Television (2018) <i>Teenagers vs Cancer: A User's Guide</i>
	Brightlight study (2017)  <i>Do specialist services for teenagers and young adults add value?</i>		Alsiss, Fern, Phillips & Gibson - James Lind Alliance (2018)  <i>Teenage and Young Adult Cancer Top 10 priorities</i>

	<p>Soanes &amp; Gibson (2018). <i>Protecting an adult identity: A grounded theory of supportive care for young adults recently diagnosed with cancer.</i></p>		
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The selection of materials listed in Table 1 are in keeping with the sentiments of Holloway (1989) who asserts that in such an analysis, the notions of statistical sampling and generalisation are abandoned as this “does not address the complex conditions of people and their conduct, either in their uniqueness or their commonality” (Hollway, 1989, p.15). The choice of text is guided rather by theoretical principles, purpose and relevance. The boundaries placed around the choice of texts are based purely on pragmatic considerations, as it is recognised that meaning is never achieved within a single work, sentence, or even an extract, but rather in an infinite network of relevant texts (Hollway, 1989). Therefore, in keeping with a Foucauldian approach ‘a corpus of statements’ has been gathered and organised over time and by type, this is intended to be relatively regular and systematic (Willig & Stainton Rogers, 2008).

The rationale for this paper was premised both on personal insights and professional experiences and can be supported further by a historical overview of the emerging empirical literature, policy and theory base (discourses of a more traditional nature are included within the Supplementary Materials). The process of problematisation that first began the development of AYA cancer care reveals the shifting nature of power and its relationship with philanthropy, professionalism and policy in keeping with Foucauldian thinking. This

also reveals the assumptions that first underpinned, and eventually prompted the growth of, this relatively new specialism to be seen as having clinical and social validity, and eventually to become established on a national, and now international level.

Table 1 lists key milestones in the emerging discourse of AYA cancer care since the early 1990's. Statements by Eden, Barr, Bleyer, & Whiteson (2005) were contained within early polemical textbooks that collected and shared the opinions of experts in the field and argued for attention to be paid to these patient's needs. Empirical work started to emerge slowly, and early examples include the work of Hollis & Morgan (2001), Lewis, Fallon, Dongen-Melman & Barr (2002) and Kelly, Pearce and Mullhall (2004).

What Table 1 also shows is that with this new and emerging discourse of challenge of the status quo, policy developments soon followed in the UK with the Improving Outcomes Guidance Document for Children and Young people with Cancer in 2005 (NICE, 2005) and updated quality standards in 2014 (NICE, 2014) .

The charity sector also responded alongside the growth of empirical research and reports included in the Supplementary Materials with recommendations for competency required of professionals and care standards outside of specialist AYA centres. Alongside these were accounts of young people dying from cancer (Daily Mail, 2013); one the best-known being Stephen Sutton, mentioned previously, whose death trajectory was relayed on social media, and captured the public's imagination and raised several million pounds for the UK –based Teenage Cancer Trust (Teenage Cancer Trust, 2018, b).

The scale of empirical research has grown in scope and ambition with the current Brightlight study exploring the benefits of specialist care for AYAs with cancer (Taylor et al., 2015).

More recently, the James Lind Alliance (Aldiss, Fern, Phillips & Gibson, 2018) reported after Priority Setting Partnership exercise on the top ten AYA cancer research priorities that



identified gaps and unanswered questions in research, the answers to which may reduce the individual and societal burden of young peoples' cancer.

As the empirical, policy, public and charitable discourses grew so did the public awareness of AYA cancer care and in 2018, documentaries on AYA cancer narratives are on primetime television (Harrison, 2018). Special units for AYAs expanded in number, and international influence also grew with congresses now taking place every two years in the UK or Europe, The United States or Australia (Cavallo, 2018; Lewis, Fallon, Dongen-Melman, & Barr, 2002). Philanthropic organisations have been established in each of these countries and work collaboratively with the UK Teenage Cancer Trust to raise the global profile of AYA cancer care. At the heart of their work is strengthening the case for ongoing support and establishing an international nexus of expertise to counteract the external threats that face any charitable endeavour from losing public support at the national or local level.

The 30 years over which this archive has drawn have witnessed change and development in AYA care, but challenges do remain. In a Foucauldian sense the growth of specialist AYA care began with an emerging process of 'anatomo-politics' driven often by individual champions who drew attention to the unmet needs of this group. A process of problematisation preceded a subsequent period of rapid growth in research, policy, philanthropic effort and changes to service provision and practice itself (Foucault, 2002). Importantly the voices of young people themselves were heard in each of these different forms of discourse adding further strength to the challenges that were put to long standing focus of professional power located within adult or paediatric oncology

### **Conclusion**

We suggest here that viewed through a Foucauldian lens the AYA cancer movement now operates as an established (although not universally) power/knowledge nexus that is realised

through innovative care practices, service developments, philanthropic endeavours and heightened public /health awareness.

The expanding empirical literature on AYA cancer care, which now must be seen within its own socio-political framework, has grown in tandem with the emergence of the specialism across diverse health systems across the UK, US & Australia. Entire careers are now built on this new specialism.

Through a Foucauldian lens therefore, the power base of AYA cancer care is not static but is open to further challenge as age appropriate services for this group become more established. However, the growth of AYA cancer as a specialism has had many forces to contend with and as it looks to its future and, we suggest, it may benefit from understanding the ways that power and associated discourses were challenged successfully to allow it to arrive at its present situation.

For the disproportionately small percentage of AYA patients who are diagnosed with cancer, the specialism now enjoys a powerful global voice, fuelled by committed philanthropical support with a growing empirical base and an emerging health policy discourse. Whilst it may struggle to maintain as much momentum as over the past 30 years, it may find that its experience can assist in the empowerment of other groups who also require age appropriate models of care. Importantly, the possibilities associated from a coalescing of historic, social, philanthropic and academic discourses may offer solutions, at least in part, to those who seek to advocate for the care of young people. Establishing AYA cancer care as a specialism has shown that existing power structures can be contested, and with the coalescing of empirical research, policy development and assistance from public philanthropy, changes can be achieved that echo at the global level.

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