Leven met een kankerervaring: Het belevingstraject van adolescenten met kanker en van adolescente overlevers van kinderkanker

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Phd proefschrift Universiteit Gent

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Proefschrift voorgelegd tot het behalen van de graad van “Doctor in de Gezondheidswetenschappen”

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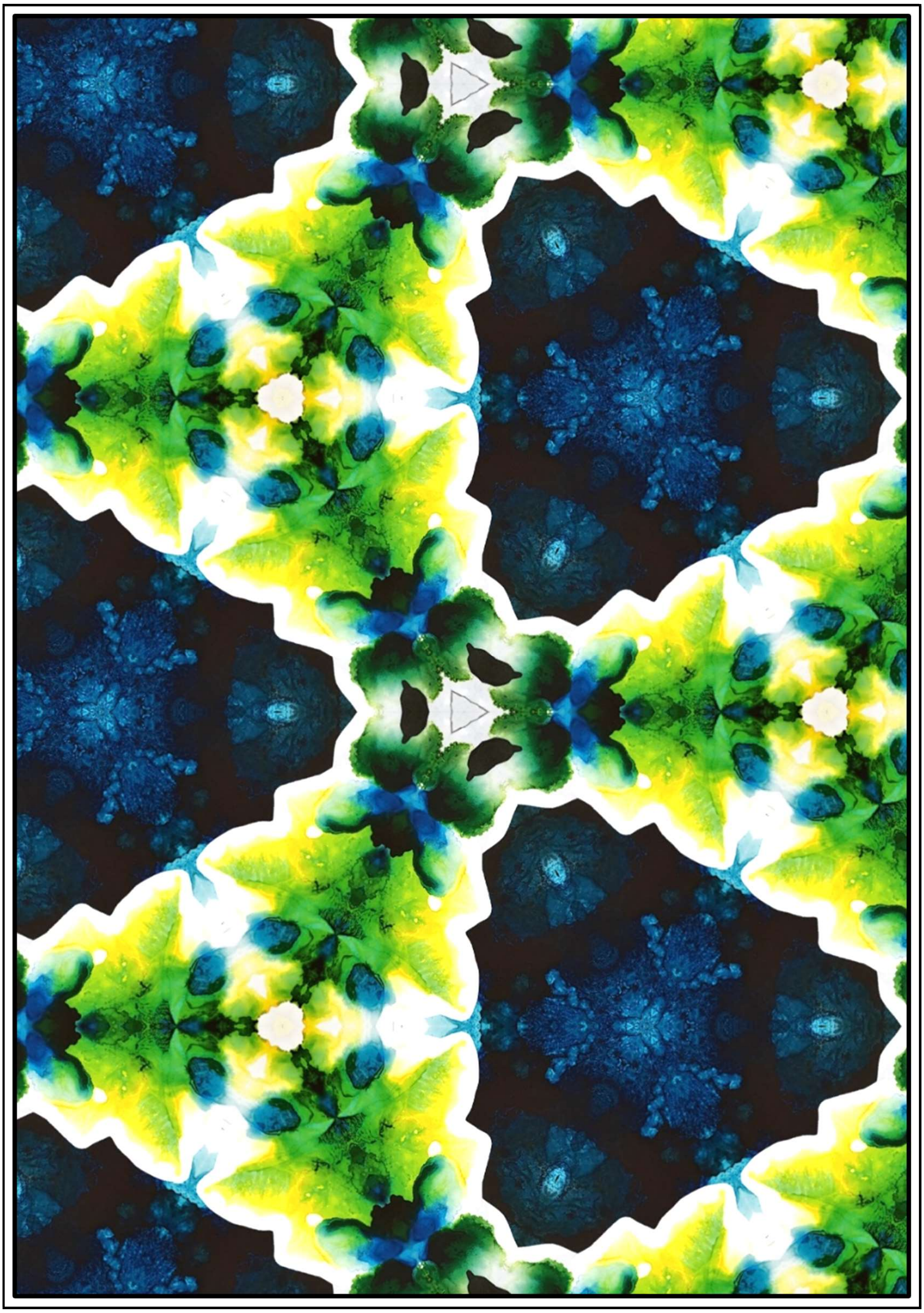
Inhoud

Deel 1. Het perspectief van de AYA's

Deel 2. Het perspectief van de AYA-overlevers

Hoofdstuk 1

Introductie en onderzoeksvragen



“Unfortunately, the adolescent is not amenable to analysis as is a sample of water or an autopsy specimen. On the contrary, in each individual, adolescence is a kaleidoscopic and complex thing, a maturation process compounded of chemistry and psychology, with maleness and femaleness and endocrines and emotions unsnarling themselves: a period of development and adjustment where a sense of insecurity darkens a childhood assurance of safety, where idols fall and independence beckons, where old interests are lost and the most enticing new ones are taboo. It is a beautiful and painful episode in human development and fortunately or unfortunately, nothing like its glow and shadow will ever come again”

(Mustard*[1],p 1312)

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*[1] Mustard H.S. The New Interest in Adolescence. Editorial. American Journal of Public Health and the Nations Health. 1941:1312-1313.

1. Adolescentie

Van oudsher wordt met aandacht gekeken naar de opeenvolgende transities die de menselijke levensloop typeren. Reeds in het oude Griekenland werden overgangsrituelen uitgevoerd die een nieuw ontwikkelingsstadium aan het einde van de kindertijd inluidden[1]. Pas in de twintigste eeuw werd de overgang van kindertijd naar volwassenheid als een afzonderlijke levensfase beschouwd, zijnde de adolescentie[2]. Dit resulteerde in een groeiende interesse in de jonge mensen die deze doorlopen; *"Young people are the constant object of fascination"*[3] (Muncie,p10). Een populair voorbeeld hiervan is het generatiedenken waarbij overeenkomsten binnen één generatie adolescenten tegen het licht van de heersende tijdsgeest en maatschappij worden gehouden en dusdanig gedefinieerd: van de Babyboomers, Generatie X, de Millennials tot de tegenwoordige Generatie Z of de 'Digital Natives'[4,5].

De veelheid aan omschrijvingen en kleurrijke termen maskeert echter het gebrek aan een duidelijke definitie. Traditioneel verwijst adolescentie naar de levensfase die aanvat bij de start van de puberteit en die eindigt wanneer economische en sociale onafhankelijkheid worden verworven[6]. Problematisch hierbij is dat dit type onafhankelijkheid maatschappij- en tijdsgebonden is en dus niet eenduidig te beoordelen. Daar waar het enkele decennia geleden nog gebruikelijk was om voor de leeftijd van twintig jaar een eigen gezin te starten, wordt vandaag de dag, in hoge-inkomenslanden, economische onafhankelijkheid op veel latere leeftijd verworven. Dit impliceert dat de beperkte duurtijd van de adolescentie in het verleden, nl. 2 à 4 jaar, doorheen de tijd tot een levensfase van 8 à 15 jaar (of meer) is uitgegroeid[2,7]. In literatuur wordt de adolescentie vaak afgebakend volgens chronologische leeftijdsgrenzen (i.e. het aantal jaren sinds de geboorte) maar kan een grote diversiteit worden opgemerkt. Zo definieert de Wereld Gezondheidsorganisatie (WHO) adolescenten als 10 tot 19-jarigen[8] maar vermelden andere bronnen 10-24 jarigen[9].

Hoewel een uniforme definitie ontbreekt, bestaat er ruime consensus over de verschillende evoluties die tussen deze flexibele leeftijdsgrenzen tot stand komen. De adolescentie kenmerkt zich door uitgesproken ontwikkelingen op lichamelijk, cognitief, psychologisch, seksueel en sociaal vlak, waarvan de uitkomsten een unieke basis voor het verdere leven vormen[7,10-14]. Bovendien onderscheiden adolescenten zich van kinderen en volwassenen in hun kracht en veerkracht. Adolescenten hebben meer weerstand, zijn sterker en sneller en beschikken over meer intellectuele capaciteiten dan kinderen. Terzelfdertijd zijn ze nog niet onderhevig aan het verouderingsproces zoals volwassenen dat zijn[7].

2. Definiëring ‘AYA’

In oncologische context worden adolescenten vaak samen genoemd met jongvolwassenen. Veelal wordt de afkorting ‘AYA’ gebruikt om naar ‘adolescents and young adults’ met kanker te verwijzen. Volgend op de ambigue leeftijdsafbakening van de algemene adolescentie, zoals hierboven beschreven, kan ook in de definiëring van AYA’s een grote variatie in de gehanteerde leeftijdsgrenzen worden vastgesteld[15,16]. Zo worden AYA’s in de literatuur omschreven als 12 tot 17 jarigen[17], 15 tot 19 jarigen[18,19], 16 tot 30 jarigen[20], etc. Algemeen wordt als ondergrens de start van de puberteit genomen[21] maar aangezien tal van factoren het tijdstip waarop de puberteit intreedt, beïnvloeden, is deze niet eenduidig vast te stellen[22]. Daarnaast worden meerdere bovengrenzen gehanteerd, in overeenstemming met de verschillende leeftijdslimieten die van toepassing zijn in pediatrische oncologische centra[23]. Tot voor kort gold als meest voorkomend in internationale praktijk en onderzoek, de definiëring van AYA’s als 15 tot 24-jarigen (voornamelijk in Europa en Australië) en 15 tot 39 jarigen (in de USA)[24]. Dergelijke ruime leeftijdsafbakening komt voort uit de eerder beperkt verbeterde overlevingskansen gedurende enkele decennia (zie verder), wat een includerende houding in AYA-onderzoek met zich meebracht[25]. Ook vanuit strategisch oogpunt is het volgens sommigen aangewezen om een ruimere afbakening te hanteren gezien de grootte van de patiëntenpopulatie bepalend is voor de financiering en de verspreiding van zorg[26]. Daartegenover kan worden gesteld dat het te ruim bepalen van leeftijdsgrenzen resulteert in een moeilijk werkbare heterogeniteit van de AYA-populatie, bv. inzake ontwikkelingsuitdagingen en dat dit gevolgen heeft voor de ontwikkeling van klinische interventies, interpretatie van bevindingen en generaliseerbaarheid van onderzoek[21,27,28].

Hoewel tot op heden nog geen globale consensus werd bereikt inzake de AYA-leeftijdsspreiding wordt sinds 2021 een lans gebroken om vooral de definitie 15-39 jaar breed door te trekken[29]. Hierbij benadrukken diverse auteurs om in de oncologische zorg niet al te rigide met chronologische leeftijdsgrenzen om te gaan maar zich veeleer te richten op het individuele ontwikkelingsniveau, de psychosociale context en de biologie van de kanker waarvoor de AYA wordt behandeld[30,31].

3. AYA’s met kanker

3.1 Incidentie, veel voorkomende kankers en behandelingen

In internationaal perspectief is kanker één van de belangrijkste bedreigingen voor de menselijke ontwikkeling, gezondheid en welzijn. Verwacht wordt dat het aantal kankerdiagnoses wereldwijd de volgende twee decennia zal verdubbelen, waarbij vooral de lage- en midden-inkomenslanden in toenemende mate zullen worden getroffen[32].

Kanker, de “keizer van alle ziektes”[33] is een levensbedreigende aandoening waar alle leeftijdsgroepen onder te lijden hebben. Hoewel ouderdom een belangrijke risicofactor is voor het ontwikkelen van kanker, worden ook kinderen en AYA’s niet gespaard. Naar schatting kregen in 2019 wereldwijd 1.335.100 AYA’s tussen 15 en 39 jaar oud een kankerdiagnose[34]. Algemeen neemt de incidentie bij AYA’s licht toe[35], hoewel grote verschillen kunnen worden opgemerkt tussen diagnoses onderling[36] en er ook sterke variatie is tussen hoge- en lage-inkomenslanden[34]. Kijken we er de cijfers uit België voor het jaar 2020 op na, dan werden er 338 nieuwe diagnoses gesteld bij 15-25 jarigen (203 mannen, 165 vrouwen). Indien de leeftijdsdefinitie ruimer wordt genomen, dan werden er 1706 diagnoses gesteld bij 16-35 jarigen (711 mannen, 995 vrouwen)[37]. Internationale cijfers duiden volgende kankers aan als meest voorkomend bij AYA’s tussen 15 en 39 jaar: leukemie, lymfomen, sarcomen, borstkanker, testiskanker, schildklierkanker, hersentumoren en dikkedarmkanker[29].

Net zoals bij de behandeling van kanker in andere leeftijdsgroepen, worden AYA’s vooral behandeld met chirurgie en/of systemische therapie (chemo- of hormoontherapie) en/of radiotherapie. De keuze van de behandeling wordt bepaald door het type kanker, het stadium en de eventuele aanwezigheid van metastasen[38].

3.2 Prognose

Daar waar de voorbije halve eeuw de overlevingskansen voor kinderen met kanker spectaculair zijn gestegen, van minder dan 30% tot meer dan 85%[39,40], werd bij AYA’s deze trend lang niet gevolgd[41]. In het tijdsinterval 1975-1997 was er bij AYA’s nauwelijks verbetering in de overleving merkbaar[38,42]. Nadien ging de overleving er bij bepaalde kankers bij AYA’s (15-39j) waaronder melanoom, acute en chronische myeloïde leukemie, non-Hodgkin en Hodgkin lymfoom, myeloom, Kaposi sarcoom, colorectale en borstkanker, wel op vooruit[43]. Recent onderzoek van data verzameld tussen 1988 en

2014 toont aan dat het historisch verschil in overlevingswinst tussen kinderen en AYA's in de Verenigde Staten is weggewerkt[44]. Ook Europees onderzoek (EUROCARE-5) bevestigt dat de overleving bij AYA's (15-39j) verbetert, en dit in gelijkaardige mate als bij kinderen. Echter, bepaalde soorten kanker bij AYA's kennen nog steeds een slechtere overleving dan bij kinderen, zoals acute lymfatische leukemie, acute myeloïde leukemie, non-Hodgkin en Hodgkin lymfoom, astrocytoom, Ewing's sarcoom, rhabdomyosarcoom en osteosarcoom[24,43].

Volgende factoren beïnvloedden de overleving van AYA's ongunstig en hebben tot op heden nog een significante impact op de prognose van AYA's:

Een laattijdige diagnosestelling en vertraging in de opstart van de behandeling

Doorgaans geldt dat de prognose van een kankerpatiënt verslechtert naarmate meer tijd verstrijkt tussen de eerste symptomen en het stellen van de diagnose, als ook het opstarten van de behandeling. Bij bepaalde kankers werd een dergelijk verband echter nog niet afdoend bewezen of blijkt eerder het tegendeel waar[45]. Deze uitzonderingen daargelaten, is een tijdige diagnosestelling en start van de behandeling van cruciaal belang. In vergelijking met kinderen, bij wie de orgaangroei de ontwikkeling van symptomen sneller duidelijk maakt, krijgen AYA's meer te maken met vertraging aan het begin van hun traject[24,46]. Daarenboven wordt het herkennen van symptomen bij kinderen vooral als een verantwoordelijkheid van de ouder aanzien, terwijl dit bij AYA's meer aan henzelf wordt toegeschreven[47]. AYA's blijken eigen symptomen vaak te minimaliseren of te normaliseren, soms uit een gevoel van onkwetsbaarheid[36]. Ook de omgeving van de AYA neemt soms de klachten onvoldoende ernstig, herkent symptomen niet tijdig of reageert niet adequaat. Eerder dan in verband gebracht met kanker, worden lichamelijke klachten niet zelden herleid tot normale klachten, eigen aan de adolescentie, zoals bv. groeipijnen[48].

Plaats van de zorg en keuze van behandelplan

Traditioneel worden AYA's op een pediatrische oncologische afdeling of op een oncologische afdeling voor volwassenen behandeld. In de Verenigde Staten worden AYA's tot 20 jaar over het algemeen behandeld in kinderkankercentra[49]. In België worden AYA's vanaf de leeftijd van 16 jaar behandeld in een oncologische zorgsetting voor volwassenen[50]. De plaats van de zorg heeft implicaties op de behandelingen die er geboden worden. De AYA's met een kanker die vaker voorkomt in de kindertijd zijn vaak meer gebaat bij een behandeling in een pediatrische setting of bij een pediatrische oncoloog dan bij een behandeling in de volwassenen oncologie[51]. Ook de keuze van behandelplan kan van invloed zijn op de prognose. Zo kan voor een AYA met acute lymfatische leukemie een pediatrisch behandelplan geschikter zijn dan een volwassenen protocol[52,53] maar kan een pediatrische behandeling minder aangewezen zijn bij een AYA met melanoom[39]. De keuze in de plaats van de zorg en het behandelplan dienen bijgevolg weloverwogen te worden.

Beperkte deelname aan klinische studies

Uit de literatuur is bekend dat in korte tijd grote vooruitgang werd geboekt in het behandelen van kinderen met kanker dankzij hun deelname aan klinische studies[49,54]. Dit werd ook in de AYA-zorg een na te streven gouden standaard en in 1983 werden in de Verenigde Staten Community Clinical Oncology Programs (CCOP) samengesteld met als doel de toegang tot klinische studies voor AYA's te verbeteren[55]. Dit bleek een grotere uitdaging dan oorspronkelijk werd aangenomen en de deelnamecijfers van AYA's aan klinische studies blijken wereldwijd nog steeds teleurstellend[36,56,57], met slechts 2-5% van de AYA's die aan klinische studies deelnemen[58]. Studies hebben nog niet ten gronde inzichtelijk gemaakt waarom deze *"AYA gap"*[59] blijft bestaan maar bepaalde factoren worden genoemd, zoals administratieve en logistieke problemen, de beperkte verwijzing van AYA's naar pediatrische behandelcentra waar klinische studies het meest voorhanden zijn, het laag aantal studies voor bepaalde kankers, mogelijke arts- en instelling gerelateerde barrières en de specifieke psychosociale behoeften, percepties en persoonlijke attitudes die AYA's belemmeren om aan een klinische studie deel te nemen[60-63]. De beperkte deelname aan klinische studies heeft onder andere tot gevolg dat inzicht in de tumorbiologie bij AYA's nog ontoereikend is en dat protocolontwikkeling en klinische samenwerking nog onvoldoende adequaat zijn in deze populatie[36].

Onvoldoende AYA-specifieke behandelingsrichtlijnen

In de adolescentie ondergaan AYA's verschillende biologische en fysiologische veranderingen waar in behandelingsrichtlijnen lang te weinig rekening mee werd gehouden[64,65]. Een voorbeeld is het ongelijk doormaken van hormonale veranderingen door mannen en vrouwen[66]. Dit resulteert in differentiatie wat betreft lichaamsgewicht en –lengte, vet en spiermassa, wat bijgevolg leidt tot variatie in de farmacokinetiek bij toediening van chemotherapeutische middelen. Het ontwikkelen van betere behandelingen die de overlevingskansen van AYA's verbeteren, vergt bovendien kennis over de biologische mechanismen die schuilen in de ontwikkeling van kanker. Pas recentelijk neemt de evidentie over de specifieke biologische karakteristieken van bepaalde AYA-kankers toe. Hieruit blijkt dat de kankers die AYA's krijgen zich onderscheiden van dezelfde type kankers die voorkomen bij kinderen of volwassenen[40,67]. Meer onderzoek is nodig naar het ontwikkelen van behandelingsrichtlijnen, niet alleen aangepast aan de fysiologie van de AYA maar ook aan de biologie van het type kanker[42].

Matig inzicht in de bijzondere psychosociale behoeften en noden

Overlevingskansen van AYA's worden tenslotte ook bemoeilijkt door een gebrek aan inzicht in en inachtneming van de unieke psychosociale noden en behoeften van AYA's in de zorg. Een voorbeeld hiervan is het relatief jonge onderzoek naar therapietrouw van AYA's, vooral bij orale medicatie inname, waarin wordt gesteld dat AYA's minder therapietrouw zijn dan jongere of oudere kankerpatiënten[68]. Dit wordt in verband gebracht met de complexiteit van behandelingsrichtlijnen maar ook met percepties van AYA's over hun eigen kwetsbaarheid en over de ernst van hun ziekte, hun persoonlijke gezondheidsovertuigingen, hun sociale ondersteuning, de verzoenbaarheid met hun normaal leven en emotioneel welbevinden[69-71].

3.3 De impact van een kankerdiagnose en behandeling in de adolescentie

In de transitie van kind naar volwassene, staat een adolescent voor verscheidene ontwikkelingstaken over alle domeinen van het leven heen. Zo vormt een adolescent een eigen identiteit, groeit hij/zij/hen in zelfstandigheid en wordt onafhankelijk van ouders. De adolescent ontwikkelt een zelf- en lichaamsbeeld, vormt een eigen seksualiteit en sociale relaties waarbij leeftijdsgenoten aan belang winnen. De adolescent stelt zich doelen voor de toekomst, investeert in studie of werk en gaat daarenboven ook nog intieme relaties aan waarin kinderwens al dan niet een plaats krijgt[72-74]. Een kankerdiagnose en behandeling in de adolescentie heeft bijgevolg een impact op dit gehele ontwikkelingsproces[75]. Normale maturatieprocessen kunnen stilvallen maar de impact van de ziekte en de behandeling kunnen ook in die mate de normale ontwikkeling verstoren dat er regressie optreedt[36].

Daarenboven ontstaan bijkomende uitdagingen, gerelateerd aan de kanker en de behandeling. Zo veroorzaken de ziekte en de aard van de behandeling bijna in alle gevallen een groot lichamelijk lijden[76-79]. Behalve tijdelijke fysieke ongemakken en problemen zoals misselijkheid, diarree, huidproblemen, gewichtsverlies of –toename, alopecia, vermoeidheid etc., kunnen ook gevolgen optreden die de fysieke ontwikkeling en mogelijkheden permanent beperken, bv. door functioneel beperkende chirurgie. Inherent verbonden aan de fysieke gevolgen en uiterlijke veranderingen, kunnen AYA's ook een verstoorde en gewijzigde lichaamsperceptie ervaren[36,80-83]. Aangezien lichaamsperceptie van vitaal belang is voor de identiteitsvorming en het verwerven van zelfvertrouwen kunnen storingen hierin verstrekkende gevolgen hebben, bv. bij het aangaan van sociale en intieme relaties en het beleven van seksualiteit. Bovendien worden lichamelijke gevolgen, die in de meeste gevallen een verlieservaring inhouden, vaak geassocieerd met psychische spanningen of depressie[84-86]. Daarnaast kan een kankerbehandeling nefaste gevolgen hebben voor de vruchtbaarheid van de AYA[27,81]. Het merendeel van de AYA's is nog niet bezig met gezinsplanning op het moment van diagnose. Hieromtrent noodgedwongen, verstrekkende beslissingen nemen, wordt als erg ingrijpend ervaren[87]. Verder gaat een pril verworven zelfstandigheid niet zelden gepaard met een hernieuwde afhankelijkheid van ouders, zowel praktisch, emotioneel als financieel[81], en resulteren een langdurige behandeling met veelvuldige hospitalisaties in de meeste gevallen in een onderbreking in studie en werk of een heroriëntering[20,81,88]. Relaties met naasten kunnen door het omgaan met de ziekte en de behandeling ontwricht geraken en het vertrouwde netwerk kan onder druk komen te staan[77,81]. Ten slotte kan het moeite vergen om de kankerervaring een plaats te geven[76,82,84]. Voor veel AYA's betekent hun ziekte een eerste confrontatie met hun eigen sterfelijkheid en kwetsbaarheid.

Een kankerervaring heeft bijgevolg het potentieel om de gehele verdere levensloop van de AYA te beïnvloeden[81] en kan aanleiding geven tot een breed spectrum aan psychologische gevolgen, gaande van post-traumatische stress tot post-traumatische groei[89,90].

3.4 Organisatie van zorg

Een focus op AYA's in onderzoek en zorg is een recent gegeven. Tot 40 jaar geleden werden AYA's niet als een afzonderlijke populatie met specifieke medische en psychologische noden beschouwd[38,91,92]. Een kentering werd kracht bij gezet door het ontstaan van enkele liefdadigheids- en patiëntenorganisaties wereldwijd. De belangrijkste voorbeelden hiervan zijn de organisaties CanTeen, opgericht door enkele jonge kankerpatiënten in Australië in 1985[93] en in Nieuw-Zeeland in 1988[94], de Teenage Cancer Trust in 1990 in het Verenigd Koningrijk[95] en de organisaties Livestrong[96], Teen Cancer America[97] en SeventyK[98] in de Verenigde Staten. Dichter bij huis ontstond het AYA Zorgnetwerk[99] in Nederland, Go-AJA In Frankrijk[100] en ook in België timmeren organisaties zoals Kom op tegen Kanker[101], Stichting tegen Kanker[102], Flaya[103] en Care4AYA[104] het laatste decennium hard aan de weg om zorg op maat van AYA's breed te realiseren. Behalve het publiekelijk verwerven van meer aandacht voor AYA's met kanker, zetten deze organisaties doelgericht in op de ontwikkeling van leeftijdsspecifieke interventies en voorzieningen. Toonaangevend is de ontwikkeling en implementatie van gespecialiseerde AYA-units geweest door de Teenage Cancer Trust in verschillende oncologische centra in het Verenigd Koninkrijk[105]. Deze units zijn voorzien van aangepaste accommodatie; worden gecoördineerd door een multidisciplinair team met expertise in AYA-zorg en bieden AYA's de mogelijkheid om in nabijheid van leeftijdsgenoten te worden behandeld. Momenteel kent het Verenigd Koninkrijk 28 units[106] maar bestaan er ook gelijkaardige AYA-units in de Verenigde Staten, Frankrijk, Denemarken en Italië[107-109]. Ook samenwerkingsinitiatieven tussen verschillende oncologische centra, overheden, liefdadigheidsinstellingen en patiëntenorganisaties legden fundamenten voor een internationaal AYA-beleid. Zo werd 'The International Charter of Rights for Young People with Cancer' samengesteld in 2011[110], ontstond ondermeer het European Network for Teenagers and Young Adults with Cancer (ENTYAC)[111], de Society for Adolescent and Young Adult Oncology (SAYAO[112]) en wordt jaarlijks de Global Adolescent and Young Adult Cancer Congress georganiseerd, het grootste symposium dat in het teken staat van medische en psychosociale AYA-zorg[113].

Hoewel deze initiatieven het belang van een internationaal gedragen AYA-zorgbeleid onderstrepen, wordt AYA-zorg vandaag heel uiteenlopend vorm gegeven met grote verschillen per land, regio en centrum. Ook België kent momenteel nog geen gedifferentieerde aanpak van AYA-zorg. Op basis van leeftijd wordt een AYA in een pediatrische setting (< 16 jaar)[50] of in een volwassenen setting behandeld. Niettemin zijn individuele uitzonderingen mogelijk en kunnen bepaalde AYA ≥ 16 jaar toch op een pediatrische afdeling worden behandeld, bv. omdat ze er deelnemen aan een klinische studie of omdat dit op basis van hun ontwikkelingsniveau of maturiteit meer gewenst is.

Recentelijk gaf de Belgische politiek meer aandacht aan AYA-zorg. Na een resolutie in de Kamer van Volksvertegenwoordigers[114] en een bezoek van de Eurocommissaris Gezondheid en Voedselveiligheid aan het AYACare@Gent project[115], volgde in september 2022 een mededeling vanuit het kabinet van de minister van Sociale Zaken en Volksgezondheid[116] dat er in 2023 financiering zal worden voorzien voor de uitbouw van zes AYA-zorgteams in België.

4. AYA-overlevers van kinderkanker

4.1 Definiëring

Naast de groep van AYA's die in hun adolescentie met kanker worden gediagnosticeerd, kan ook een groep AYA's worden onderscheiden die in hun adolescentie worden geconfronteerd met de (chronische) impact van een kankerervaring uit hun kindertijd. Deze AYA-overlevers van kinderkanker ervaren vaak lange termijn gevolgen, de tol die ze betalen voor hun overleving[117,118]. Noch in de literatuur, noch in het beleid bestaat er consensus over de functionele omschrijving van 'overleving van kanker', waarbij overleving gedefinieerd wordt als startende vanaf de diagnosestelling[119,120], vanaf een bepaalde tijd na de diagnosestelling (bv. na 3 maanden[121], 1 jaar[122], 5 jaar of de zgn. 'vijfjaarsoverleving'[18,123]), vanaf een bepaalde tijd na einde behandeling (bv. vanaf 1 jaar[117] of 2 jaar[124]), of vanaf een bepaalde tijd na een intensieve ingreep zoals een stamceltransplantatie[125].

4.2 Kinderkanker en lange termijn gevolgen

In 2022 waren er in de Verenigde Staten ongeveer 10.470 nieuwe diagnoses bij kinderen van 0 tot 14 jaar[35]. Europa telt jaarlijks 15.000 nieuwe gevallen bij kinderen onder de 15 jaar[126]. In België werden in 2022 in totaal bij 399 kinderen tussen 0 en 15 jaar kanker vastgesteld, waarvan 217 bij jongens en 182 bij meisjes[127]. Globaal groeperen leukemie, hersentumoren en kankers van het centraal zenuwstel de meest voorkomende kankers bij kinderen[35].

Zoals hierboven beschreven, zijn de overlevingskansen bij bepaalde kinderkankers de laatste decennia sterk gestegen[39]. De Verenigde Staten telde in 2011 ongeveer 388.501 overlevers van kanker, gediagnosticeerd op een leeftijd tussen 0 en 19 jaar[128]. In Europa zullen er naar schatting 750.000 overlevers zijn in 2030[126]. Wat België betreft waren in 2022 nog 2259 AYA's (15-25jaar) in leven van een totaal aantal van 5666 kinderen (0-14 jaar) die in de periode 2004-2020 een diagnose van kanker kregen. Van deze 2.259 personen waren er 2.026 die reeds minstens vijf jaar na hun diagnose overleefden[37, *2].

[*2] Dit aantal in leven zijnde kinderen en adolescenten met een kankerdiagnose in het verleden is een onderschatting. Immers, de diagnoses na 2020 zijn hierin nog niet opgenomen want zijn nog niet beschikbaar en diagnoses voor 2004 zijn hierin eveneens niet opgenomen uit gebrek van nationale cijfers.

De meeste AYA's die als kind kanker hebben gehad ervaren lange termijn gevolgen, veroorzaakt door de kanker en diens behandeling[129]. Aangezien chemotherapie, radiotherapie of chirurgie kan worden toegepast in zowat alle vitale organen, is de verzameling aan mogelijke lange termijn effecten erg uitgebreid en heeft die betrekking op schade aan de nieren, de lever, de longen, het hart, de hersenen, het voortplantingsstelsel etc.[59,130]. De meest voorkomende lange termijn effecten die de kwaliteit van leven sterk reduceren zijn secundaire kankers, orgaandysfuncties, endocriene en metabole aandoeningen, cognitieve en psychosociale problemen[131]. Gezien de comorbiditeit toeneemt met het ouder worden[59], hebben lange termijn gevolgen potentieel een verdergaande impact dan de initiële kankerbehandeling[132].

4.3 De impact van overleving van kinderkanker in de adolescentie

Op basis van de literatuur kan worden aangenomen dat AYA-overlevers van kinderkanker het psychosociaal gezien goed stellen, vergeleken met hun gezonde leeftijdsgenoten[133-135]. Psychopathologie bij AYA-overlevers is eerder uitzonderlijk en komt vooral voor in bepaalde subgroepen waarbij hersenbestraling, vrouwelijk geslacht, jonge leeftijd bij diagnose en een lage sociaal economische status als belangrijkste risicofactoren gelden[135-140]. Momenteel is er echter onvoldoende screening op psychosociale late effecten[132,141]. Bovendien kan worden gesteld dat psychosociaal welbevinden niet alleen door de aan- of afwezigheid van een diagnosticeerbare aandoening zoals een depressie, angst- of stressstoornis wordt bepaald. De aan- of afwezigheid van problemen of bekommernissen op het breder terrein van gedrag, sociale vaardigheden, lichaamsbeleving, educatie, werk, sociale interactie, enz. is eveneens bepalend[142,143].

4.4 Organisatie van zorg

Tot op heden is er geen consensus over de organisatie van follow-up zorg voor AYA overlevers van kinderkanker[144]. Traditioneel wordt nazorg voorzien door de pediatrische oncologische setting die het kind met kanker behandeld heeft. Dit betekent dat AYA-overlevers, ouder dan 16 jaar, vaak nog een paar jaar door een kinderarts worden opgevolgd. Een belangrijke bekommernis is dat pediatrische zorgverleners mogelijks minder op de hoogte zijn van gezondheidsnoden die volwassenen stellen. Dit kan zowel op medisch vlak, bv. de screening op diabetes type II of verhoogde bloeddruk[59] maar geldt evenzeer op psychosociaal vlak zoals bekommernissen omtrent seksualiteit[145].

Lange termijnsopvolging is noodzakelijk om een tijdige detectie en opvolging van late effecten mogelijk te maken[146]. Wereldwijd worden richtlijnen ontwikkeld die aanbevelingen formuleren om met de late effecten van kinderkanker om te gaan, zoals bv. Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers[147] of de richtlijnen van de Stichting Kinderoncologie Nederland[148]. De International Late Effects of Childhood Cancer Guideline Harmonization Group op zijn beurt wil overstijgend werken en beoogt een internationaal gedeelde strategie te ontwikkelen om met de verschillende richtlijnen om te gaan[130,149]. Desalniettemin blijkt er een grote nood aan nazorgmodellen en overlevingsprogramma's voor AYA overlevers van (kinder)kanker[36].

5. De stem van de AYA(overlever) in onderzoek en ontwikkeling van zorg

Zoals reeds in deze inleiding gesitueerd, is er veel evidentie voorhanden omtrent de specifieke kenmerken van de populatie van AYA(overlever)s en de uitdagingen die zich stellen in het verlenen van adequate AYA-zorg. Bekijken we echter het individuele traject van één AYA dan kan een grote verscheidenheid aan thema's en zorgnoden worden gedetecteerd, behoeften die zonder uitzondering een gepast antwoord verdienen. Hoogkwalitatieve zorg dient bijgevolg voor elke AYA(overlever) uit een geïndividualiseerde mix te bestaan van medische en psychsociale dimensies maar dient ook een continuüm van zorg te waarborgen, tijdens een leven met en na kanker.

In de literatuur wordt geijverd voor een patiëntgerichte aanpak bij AYA(overlever)s waarin hun stem wordt gehoord en hun waarden, noden en voorkeuren voorrang krijgen[150,151]. Dit impliceert een gevoeligheid bij zorgverleners om de subjectieve beleving van AYA(overlever)s in onderzoek en ontwikkeling van zorg voldoende rekenschap te geven. Niet alleen helpt dit zorgverleners om de leefwereld van de AYA(overlever) beter te begrijpen[152,153], draagt het bij tot meer evidence-based zorg[154], verduidelijkt het waar nog bijkomend onderzoek nodig is[155], studies tonen ook aan dat subjectieve ervaringen goede voorspellers zijn van kwaliteit van leven[156-158]. De literatuur die via zelfrapportage van AYA(overlever)s inzicht biedt in hun 'emic' perspectief[159,160] is echter nog beperkt[139,161].

6. Onderzoeksdoelstelling en methode

Op basis van het kader dat hierboven werd geschept, kan het volgende worden geconcludeerd: (1) het beschouwen van de AYA(overlever)s als een te onderscheiden populatie in de zorg is een recent gegeven, met ruimte tot verder onderzoek op meerdere domeinen; (2) hun heterogeniteit wordt bepaald door een breed spectrum aan ontwikkelingen en zorgnoden wat het ontwikkelen van een omvattende zorgaanpak bemoeilijkt; (3) hun percepties op en omgaan met de uitdagingen gerelateerd aan de ziekte, de behandeling en de nazorg beïnvloeden hun overlevingskansen; (4) inzicht in hun perspectief is essentieel voor zorgoptimalisatie maar tot op heden werd dit in onderzoek weinig belicht. Met dit proefschrift wordt beoogd de beperkte kennis over de belevingswereld van AYA's en van AYA-overlevers vanuit hun perspectief uit te breiden.

Hoofddoelstelling van dit onderzoek was het verkrijgen van inzicht in het belevingstraject van AYA's met kanker en van AYA-overlevers van kinderkanker; het bestuderen van hun ervaringen, behoeften en noden en het begrijpen van de betekenissen die zij hieraan verlenen.

Per populatie werden telkens twee onderzoeksvragen geformuleerd en onderzocht aan de hand van kwalitatief onderzoek. In tegenstelling tot een kwantitatief design faciliteert een kwalitatieve benadering immers dat participanten zich uitdrukken in hun eigen bewoordingen. Dit biedt ruimte voor complexiteit en diepgang[152,162,163]. In goed uitgevoerd kwalitatief onderzoek wordt het onderscheid tussen het onderzoeksubject en -object sterk gereduceerd wat tot rijke data en diepgaand inzicht kan leiden[164]. Op die manier beogen we zoveel mogelijk recht te doen aan de ervaringen van de AYA(overlever)s.

6.1 Het perspectief van de AYA's

In de hierop volgende hoofdstukken worden volgende onderzoeksvragen beantwoord:

1. Wat zijn de ervaringen, noden en behoeften van AYA's die op een leeftijd tussen 15 en 25 jaar een kankerbehandeling ondergaan? (Hoofdstuk twee)
2. Welke onderliggende processen geven deze ervaringen mee vorm? (Hoofdstuk drie)

Om het perspectief van AYA's met kanker diepgaand te onderzoeken, werd geopteerd voor een onderzoeksmethode gebaseerd op de principes van de Grounded Theory Approach (GTA), zoals beschreven door Glaser en Strauss[165]. De GTA werd ontwikkeld om psychosociale processen in hun context te identificeren en hun betekenissen te verduidelijken. Het kan beschouwd worden als een dynamische onderzoeksbenadering gezien relaties tussen verschillende concepten worden onderzocht van waaruit theorie kan worden gevormd. Hierin onderscheidt ze zich ondermeer van een fenomenologische benadering waarin beoogd wordt om de essentie of de betekenis van een bepaald fenomeen of “lived experience” te begrijpen door deze accuraat en rijk te beschrijven[166,167]. De GTA wordt aanzien als een combinatie van inductivisme en deductivisme en kan bijgevolg omschreven worden als postpositivistisch. Het inductieve karakter schuilt in de open onderzoeksvraag, de herhaalde waarneming onder een diversiteit aan participanten, het starten in de ruwe data en de flexibiliteit in het verloop van het onderzoek. De constante vergelijkingen, de selectieve codering en de theorievorming kunnen als deductivistisch aanzien worden aangezien de beginnende theorie getoetst wordt aan de data[168,169]. Kenmerkend voor de GTA is dat niet wordt vertrokken van een bestaand theoretisch kader en dat begrippen in de onderzoeksvraag niet op voorhand gedefinieerd of geoperationaliseerd worden[169]. Specifieke onderzoeksprincipes bewerkstelligen dat een theorie ‘gegrond’ in de data kan worden gevormd. De belangrijkste principes van de GTA die in deze studie werden gehanteerd, kunnen als volgt worden samengevat[170-174]:

- Het hebben van theoretische sensitiviteit of het in staat zijn inzicht te krijgen in de data, er betekenissen aan te koppelen en het relevante van het irrelevante te onderscheiden.
- Een gerichtheid op het ontwikkelen van theorie, door het verwerven van inzichten die in de originele, ruwe data zijn ‘gegrond’.
- Het coderen van de data op een systematische manier, het vormen van betekenisvolle eenheden of categorieën op een analytisch hoger niveau en het leggen van relaties tussen categorieën.
- Het doorlopen van een cyclisch of iteratief proces van dataverzameling, - analyse en reflectie waarbij voortdurend wordt teruggekeerd naar de data en de context totdat geen nieuwe betekenisvolle categorieën meer worden gevonden en dus ‘theoretische saturatie’ wordt bekomen.
- De toepassing van de methode van constante vergelijking waarbij data met elkaar vergeleken worden, data en categorieën aan elkaar worden getoetst en categorieën onderling worden vergeleken.

- Het hanteren van een theoretische steekproeftrekking of ‘theoretical sampling’ waarbij niet zozeer representativiteit voor een bepaalde populatie wordt beoogd, dan wel het realiseren van diepgang en verfijning van een bepaalde categorie wordt nagestreefd.
- Het aannemen van een open vraagstelling en het gebruiken van een topic guide.
- Het documenteren van het onderzoeksproces en de theorievorming aan de hand van memo’s of aantekeningen van de onderzoeker.
- Het koppelen van de bevindingen aan literatuur.

De data voor deze studies werden verzameld a.d.h.v. 22 individuele interviews met AYA’s. De gevolgde stappen in het proces van dataverzameling en –analyse worden in de desbetreffende hoofdstukken meer in detail beschreven.

6.2 Het perspectief van de AYA-overlevers

Om het perspectief van de AYA-overlevers te begrijpen, werden volgende onderzoeksvragen onderzocht:

1. Wat zijn de huidige ervaringen, noden en behoeften in het dagelijks leven van AYA(overlever)s tussen 15 en 25 jaar die op een leeftijd van 0-15 jaar een kankerbehandeling ondergingen? (Hoofdstuk vier)
2. Welke copingstrategieën hanteren AYA(overlever)s in het huidige leven in de omgang met lange termijn gevolgen van de ziekte en de behandeling? (Hoofdstuk vijf)

Om deze onderzoeksvragen te beantwoorden, werd gekozen voor het uitvoeren van een thematische analyse volgens Braun en Clark (2006)[175]. Deze methode, gelinkt aan fenomenologie, laat toe om data te organiseren, beschrijven en interpreteren. Op een inductieve manier kunnen thema’s of patronen in betekenis worden geïdentificeerd die de dataset gedetailleerd beschrijven. Hierbij kan een onderscheid worden gemaakt tussen manifeste thema’s die rechtstreeks uit de data komen en latente thema’s die het resultaat zijn van interpretatie van de data[176]. In tegenstelling tot de hierboven beschreven GTA worden thema’s geconstrueerd o.b.v. hun waarde voor het beantwoorden van de onderzoeksvraag[177]. In de benadering van Braun en Clark[175] wordt thematische analyse als een proces in zes stappen toegelicht: (1) het vertrouwd raken met de data,

(2) het genereren van initiële codes, (3) het zoeken naar thema's, (4) het beoordelen van de thema's, (5) het definiëren en benoemen van thema's en (6) het uitschrijven.

Voor deze studies werden 21 Individuele interviews afgenomen met AYA-overlevers van kinderkanker.

7. Keuze voor het Nederlands

We kozen er voor om de inleiding en de discussie in het Nederlands te schrijven. Enerzijds vanuit een hoop om de toegankelijkheid van het proefschrift voor zorgverleners te bevorderen, anderzijds vanuit een overtuiging dat bij de beschrijving van de perspectieven van AYA(overlever)s ook dicht bij hun taal hoort te worden gebleven. Deze keuze impliceert echter een bewust afwegen of bepaalde terminologie die in internationale literatuur of praktijkvoering courant wordt gebruikt even gangbaar is of eenzelfde betekenis heeft in onze taal en Vlaamse zorgpraktijk. Zo wordt in dit proefschrift het woord 'coping' gehanteerd omdat er in het Nederlands geen volwaardig alternatief voorhanden is en de term breed gekend is, zowel in de psychologie van waaruit de term afkomstig is, als in andere domeinen zoals pedagogiek, agogiek, verpleegkunde enz. Ook 'empowerment' en 'disclosure' werden om eenzelfde reden niet naar het Nederlands vertaald. Er werd echter wel geopteerd om als rechtstreekse vertaling van 'survivor' de term 'overlever' te gebruiken omdat deze in ons taalgebruik wel veelvoorkomend is. Er kunnen echter semantische verschillen in deze term worden onderscheiden. In de discussie van dit proefschrift wordt hier op ingegaan.

8. Inhoud van het proefschrift

Dit inleidende hoofdstuk wordt gevolgd door vier hoofdstukken gebaseerd op evenveel gepubliceerde Engelstalige artikels. Hoofdstuk twee en drie geven inzicht in de kankerervaring vanuit het perspectief van AYA's met kanker. Hoofdstuk vier en vijf beschrijven de ervaringen van AYA-overlevers van kinderkanker. Tenslotte wordt in hoofdstuk zes de verwantschap tussen beide perspectieven nader bekeken en worden inzichten uit dit doctoraatsonderzoek in de huidige literatuur gekaderd. Sterktes en zwaktes worden geduid en er wordt een vertaalslag gemaakt naar concrete aanbevelingen voor praktijk en verder onderzoek.

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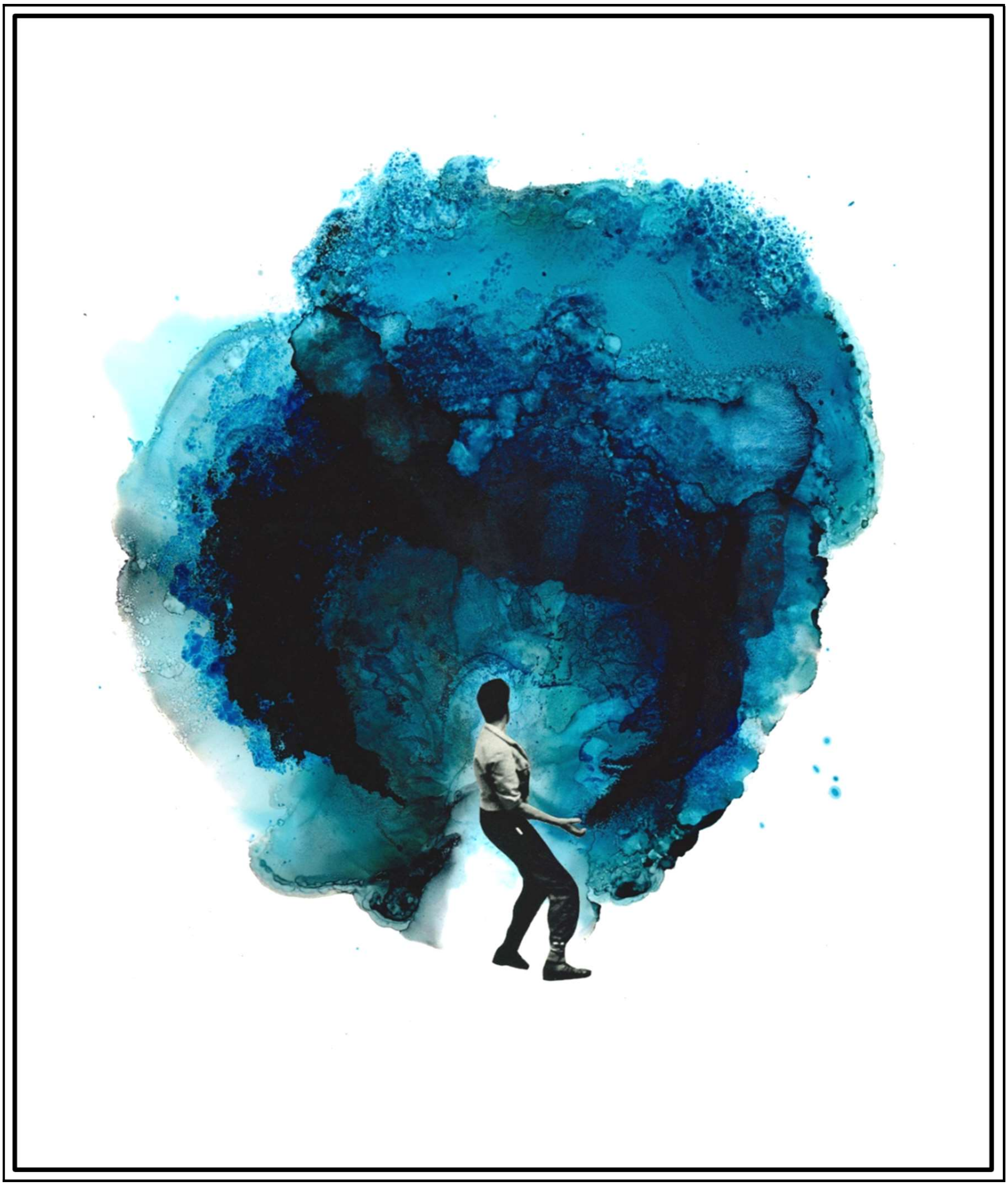
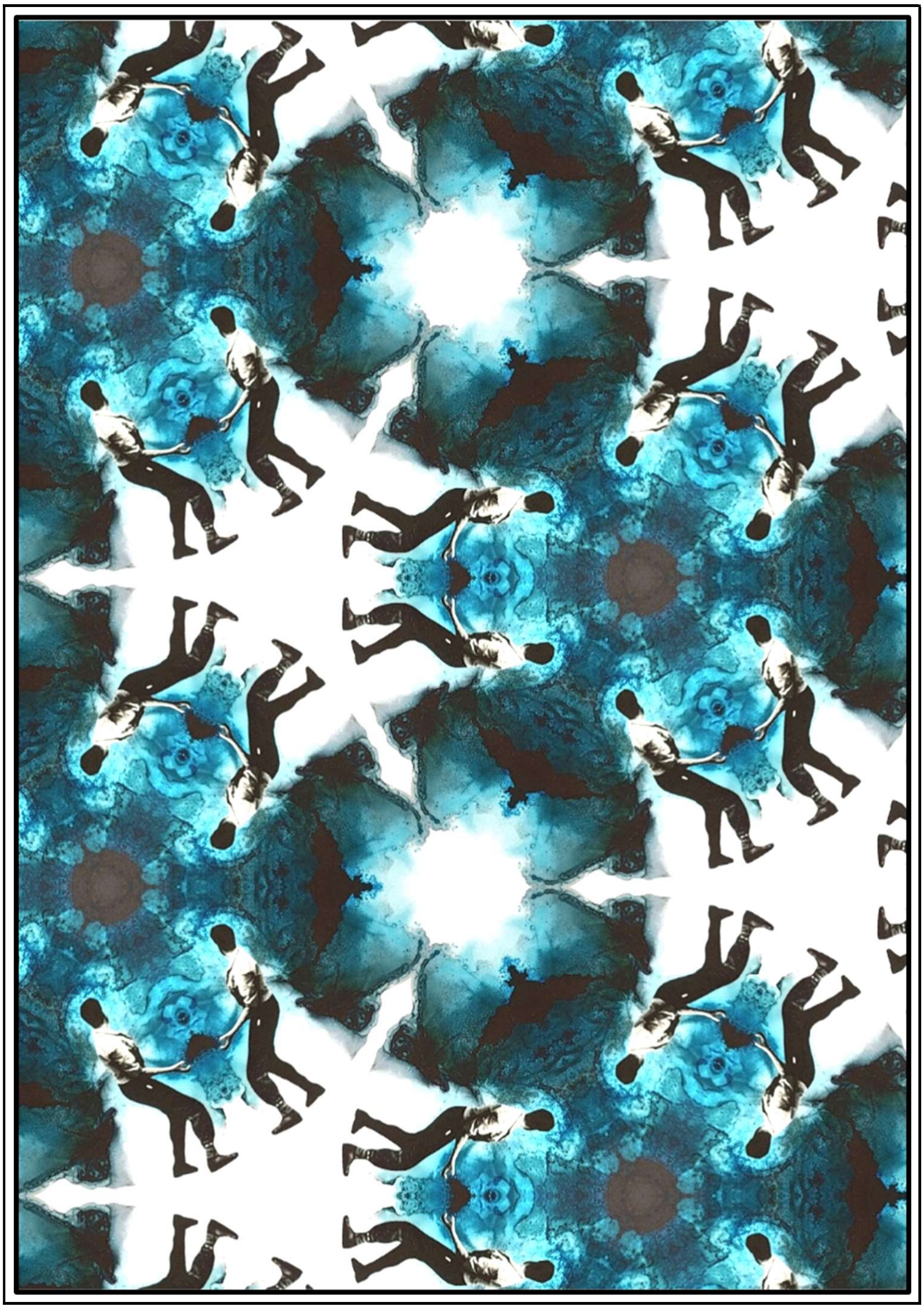
Deel 1

Het perspectief van de AYA’s



Hoofdstuk 2

‘‘The AYA Director’’: A synthesizing concept to understand psychosocial experiences of adolescents and young adults with cancer



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Gebaseerd op het artikel van Belpame N., Kars M.C., Beeckman D., Decoene E., Quaghebeur M., Van Hecke A., Verhaeghe S. (2016). “The AYA Director”: a synthesizing concept to understand psychosocial experiences of adolescents and young adults with cancer. Cancer nursing, 39(4), 292-302. DOI: 10.1097/NCC.0000000000000307

Category Nursing, 7/114, Q1, JIF Percentile 94,30

Abstract

Background

Adolescents and young adults with cancer face distinct psychosocial challenges because of the multiple developmental tasks associated with their age. Research on psychosocial care, directed to the unique needs and demands of this population, is limited.

Objective

The aim of this study was to describe the psychosocial experiences of adolescents and young adults with cancer to further broaden the understanding of the meanings they attribute to their experiences.

Methods

This study used a qualitative design in which individual semi-structured interviews were conducted with 23 participants aged 15 to 25 years.

Results

Physical consequences of the disease and its treatment, loss of independence, and being alone were significant challenges. Major coping strategies of the participants were to avoid the possible threats to life and maintain a positive attitude and normal life. Participants were ‘‘directors’’ who took control in order to manage their illness, maintain a sense of control, and master their lives to the fullest extent possible.

Conclusions

The concept of the ‘‘AYA (adolescent and young adult) director’’ provides insight for healthcare professionals to understand how adolescents and young adults experience cancer.

Implications for Practice

Throughout the cancer experience, participants wanted to be treated as individuals with specific needs and preferences. They preferred circumstances they are accustomed to; some found it difficult to accept restrictions imposed by the hospital. Adolescents and young adults with cancer want to be involved in the way healthcare professionals communicate with them and the information they are provided.

Keywords

Adolescents and young adults, AYAs, Cancer Nursing, Position in healthcare, Psychosocial experiences, Qualitative research

1. Introduction

A worldwide trend in the increasing prevalence of cancer in adolescents and young adults (AYAs) aged 15 to 25 years is evident. The prevalence holds true in Belgium, site of the research reported herein[1,2].

Previous studies have described the psychosocial challenges that AYAs with cancer face in view of the various developmental tasks associated with adolescence and young adulthood. Key developmental tasks are developing an identity of self, constructing a personal set of standards and values, establishing a positive body image, becoming independent from parents, gaining autonomy, establishing interpersonal and romantic relationships, attaining intimacy, achieving a sexual identity, and making decisions about studies, a profession, or starting a family[3-5]. The number of developmental tasks that must be accomplished makes adolescence and young adulthood a distinctive transitional stage.

A diagnosis of cancer during adolescence and young adulthood can jeopardize achieving these developmental milestones. During the cancer experience, the vulnerability of AYAs becomes apparent as they have to deal with specific difficulties associated with their illness. Besides confronting the life-threatening nature of cancer, AYAs face physical consequences and limitations caused by the disease and its treatment, such as alterations in appearance, disability, loss of fertility, delays in the development of autonomy, educational or professional repercussions, and disruptions in their social lives[4,6].

There is a growing awareness that the vulnerability of AYAs needs to be acknowledged and the psychosocial challenges they face, be properly managed. Some studies have shown what AYAs need to cope with during their cancer trajectory, but what has received less attention is how AYAs experience the cancer trajectory and what cancer really means to them[5,7]. The specific perspective of AYAs with cancer has been absent in literature. Research on psychosocial care, directed to the unique needs and demands of this population, is still limited[5,7]. Researchers such as Zebrack et al[5] stress the importance of patient-centeredness in cancer care and the need for research on healthcare interventions that involve AYAs, as they are important and at the center of their illness experience.

Building a culture of participation, it is necessary to listen and hear how AYAs experience cancer and its treatment and what their cancer trajectory means to them[8]. This sets the focus on their actual needs rather than on needs presumed by others, such as healthcare professionals[8]. Healthcare professionals often experience the behavior of AYAs with cancer as a mass of contradictions. They can be perceived as compliant and noncompliant, independent and vulnerable, or demanding as well as acquiescent[9]. Without understanding the origin of this behavior, tailored psychosocial care is difficult.

The objectives of this study were to describe the psychosocial experiences of AYAs with cancer and to understand the meanings that the AYAs give to their experiences. To study this in depth, a qualitative design was chosen, allowing the AYAs to describe their experiences in their own words.

The findings of this study were described in two articles. This first article focuses on the most essential concepts that were identified in the AYAs' psychosocial cancer experiences and the meanings AYAs attribute to their experiences.

In a second article, we will describe the processes AYAs go through, from their cancer diagnosis onward.

2. Methods

2.1 Design

A qualitative methodology, based on the principles of grounded theory[10], was used to investigate the experiences of AYAs with cancer and to detect and clarify the underlying meanings and processes.

2.2 Sample and Recruitment

Between February 2010 and April 2011, AYAs were recruited on four different wards in one university hospital: pediatrics, medical oncology, hematology, and orthopedics, to participate in the study. As the aim was to provide insight through the entire cancer illness trajectory, AYAs in the stage of diagnosis, active treatment, and follow-up care were recruited.

The following inclusion criteria were applied: male and female participants were required to be 15 years or older when diagnosed with cancer, not older than 25 years at the time of recruitment, and five years or less in follow-up. The number of years in follow-up was constrained because a person is regarded as a cancer survivor after five years.

Exclusion criteria were as follows: nonnative Dutch-speaking AYAs, participants whose treatment was not aimed at recovery, and AYAs with nonmalignant or benign tumors.

At the beginning of the study, initial sampling was based on a goal to achieve situational diversity. Variation was sought in age, gender, diagnosis, social context, education, and time since diagnosis. As the study and the analysis progressed, sampling was more driven by insights extracted from the data. For example, AYAs described that friends represented an important part in their network. To further explore if friendships (e.g. at school, at work) had different values for AYAs, subsequent participant recruitment was aimed at finding variation in the professional and educational status of the AYAs.

2.3 Ethical Review

The study was approved by the Ethics Review Committee of Ghent University Hospital (Belgian registration no. B67020096417). Participation in the study was voluntary. All participants signed an informed consent. For participants younger than 18 years, the permission of their parents was obtained as well.

Because of ethical considerations, the researcher did not consult the participants' patient records. During the recruitment procedure, the hospital staff member who approached the potential participant (based on inclusion criteria) only passed on age and diagnosis to the researcher. All further information about the participant was obtained in the interview.

2.4 Data Collection

During recruitment, participants who met the inclusion criteria were asked, during a telephone call by a member of the multidisciplinary team, if an independent researcher could introduce them to the study. This was the case for both AYAs in active treatment and AYAs in follow-up. All eligible AYAs who received a diagnosis in the recruitment period were asked to participate.

Prior to this contact, the potential participant received an informational letter about the study. If the participant agreed to take part, he/she was contacted by the researcher who provided more detail about the study and its procedures.

Data were collected through individual semistructured interviews, at the hospital or at home, depending on the preference of the participant. One interview was conducted with two participants together, at their request. The interviews lasted an average of 95 minutes (range, 26-185 minutes). Each interview was tape recorded and transcribed verbatim.

Interview questions were open-ended with an aim to invite the AYAs to respond in their own way and to facilitate extensive answers and rich data. Initial interviews were based on the input of the participants themselves. Throughout data collection, the interview guide was modified based on the analysis of the previous interviews, resulting in more structured interviews. However, the interview always began with open-ended questions. As the analysis progressed, the following topics on psychosocial experiences were discussed: perception of the diagnosis, impact of the disease on daily life, experiences in treatment and hospitalization, psychosocial needs in the cancer experience, the meaning of consequences of the disease and its treatment, ways of coping, experiences with healthcare professionals, expectations of care, and future visions of life. These topics were deepened as the interviews progressed and concepts appeared through analysis.

2.5 Data Analysis

The transcripts of the interviews were read and coded line by line[11]. Initially, open codes were used. As the data collection and the data analysis took place concurrently, new data were continuously examined using constant comparison. This resulted in reviewing, refining, and specifying the codes, whereby meaningful categories were defined. As the iterative process progressed, the researchers discussed and reflected on applied codes and categories until final concepts that were rooted in the data were identified, and data saturation was reached.

The data analysis led to findings that transcended individual experiences[12]. The second-order concepts and theories that were developed through the process of data analysis resulted in the description of the AYAs' experiences on a more abstract and theoretical level, which could go beyond the individual perspectives of the participants themselves. The qualitative data analysis program NVivo8 (NVivo qualitative data analysis software; Version 8, QSR International Pty Ltd, Australia) was used to manage the data and the coding process.

2.6 Quality of Data

In pursuing saturation of the concepts, quality was guarded by applying an audit trail, peer review, and researcher triangulation. Furthermore, a research committee was formed to serve as a guide throughout the research process.

An audit trail was set up in which contextual notes relating to the interviews, methodological decisions in the research process, and analytic reflections on the data were documented by the interviewer. In addition, personal responses and thoughts were noted. Three interviewers individually conducted all interviews. Each interviewer analyzed his/her own interviews and data. After this, the strategy of peer review was applied as the three interviewers reanalyzed the other interviews and corresponding data.

Researcher triangulation was achieved during the entire research process. The design of the study, the formulation of the research question, the interview guide, sampling, and data analysis were all discussed by researchers with scientific, practical, or methodological expertise. Researcher triangulation was enriching, because of the diverse backgrounds of the researchers (nursing and social work) and the variety of professionals present in the clinical setting. All researchers had been given permission by the participants to view the data.

Finally, the research process and the findings were discussed by members of the research committee. Different healthcare professionals took part in this committee: physicians, nurses, clinical nurse specialists, social workers, and psychologists.

3. Results

A total of 22 semi-structured interviews with 23 participants were conducted, including nine young men and 14 young women. Of this group, four participants had recently received a diagnosis of cancer; six were in the treatment phase; and 13 were in follow-up (Table).

From the data, five main categories were identified: ‘‘perceptions’’, ‘‘challenges’’, ‘‘focus’’, ‘‘coping’’, and ‘‘expectations’’. The category ‘‘perceptions’’ explained how AYAs viewed their diagnosis and understood their disease and treatment. The category ‘‘challenges’’ clarified the difficulties that AYAs experienced in living with their disease and treatment. The category ‘‘focus’’ explained how the experiences reinforced the AYAs’ focus toward self-centeredness and how this self-centeredness was needed to sustain them. ‘‘Coping’’ referred to the attempts of the AYAs to restrict the impact of the disease and treatment as much as possible, whereas the category ‘‘expectations’’ described what the AYAs expected of the people surrounding them, both in their formal and informal network.

Table: Demographic Characteristics of the Participants (N= 23)

Stage of Cancer Trajectory	Recently Diagnosed	On Treatment	In Follow-Up	Total
No. interviewees	4	6	13	23
Age, y				
15-19	2	1	7	10
20-25	2	5	6	13
Gender				
Female	2	3	9	14
Male	2	3	4	9
Relationship				
Yes (female AYA)	2	3	4	9
No (female AYA)			5	5
Yes (male AYA)		2	2	4
No (male AYA)	2	1	2	5
Studies/profession				
Secondary school	1	1	4	6
University college		1	5	6
University		2	2	4
Employed	2	1	1	4
Unemployed	1	1	1	3
Wards of recruitment				
Pediatrics	1		5	6
Medical oncology	1	2	3	6
Hematology	2	4	1	7
Orthopedics			4	4

Furthermore, the data revealed that the AYAs took a distinct role in their cancer trajectory. This was captured as the synthesizing concept the ‘‘AYA director’’ which embodies the essence of the AYA’s specific psychosocial role. This role demonstrated the position of the AYA throughout the cancer experience. In the following presentation of the results, the individual explanation of the five categories is followed by the description of the synthesizing AYA director role.

3.1 Perceptions on the Cancer Trajectory

The striking diagnosis

As they are young, the AYAs perceived their lives to be endless, in which disease, suffering, or death did not fit. The data demonstrate that, in general, participants were unfamiliar with life- threatening matters, and cancer was principally understood as a disease for adults and elders. Consequently, for most participants, the experience of being diagnosed with cancer was sudden and completely unexpected, like a verdict that struck from ‘‘out of the blue.’’ Some participants declared that they were in shock and not able to understand the situation, namely, ‘‘When the doctor told me that I had bone cancer, I didn’t really grasp this. But the moment I went out of the hospital, my clock just stopped. That was such a strange feeling. As for time and comprehension, everything suddenly froze.’’

Some participants were overwhelmed by the diagnosis, whereas others felt numb. Many felt that they were missing substantial amounts of information and could hardly process what was happening to them. At the time of diagnosis, most participants were not concerned about the possible impact of cancer on their future, because they felt that facing the ‘‘here and now’’ and getting a grip on this present crisis were already enough to deal with. Concerns expressed in response to their diagnosis were primarily related to the things they most valued that moment, such as school, activities, or their appearance. One AYA succinctly said, ‘‘Most of all, I was busy thinking ‘Oh no, I’m going to lose my hair!’’

The bewildering nature of the disease and its treatment

Being confronted with cancer was perplexing for participants. They found it rather strange and difficult to understand their new condition. For many participants, the disease itself was not significantly noticeable, to wit: ‘‘I did not absorb it [the diagnosis]. In fact, as long as you do not feel ill, you do not realize it.’’ Another participant said, ‘‘Hearing the diagnosis was strange because I just gave birth. So, initially, I thought it was not true. I thought they just made a mistake.’’ Only few participants suffered from severe cancer symptoms at the time of diagnosis; the majority did not feel noticeably ill. However, intensive and uncomfortable treatments could not be easily ignored. As one participant said, ‘‘Hodgkin [disease] is in my stomach, breasts, and throat, but I don’t suffer. That’s the strange thing about it: I don’t feel pain, no twinge, nothing. The only thing that makes me feel ill is the chemotherapy. Not the cancer. It seems to me that I wasn’t ill but that the medication makes me ill.’’ The interviews revealed that the concepts of ‘‘being ill’’ and ‘‘feeling ill’’ can both be experienced nonsimultaneously; AYAs did not necessarily feel the cancer, even though it was detected. This discrepancy was recognized only at the beginning of the cancer trajectory, shortly after diagnosis. Adolescents and young adults said that this confusing state disappeared with the first experience of physical discomfort or pain related to the disease or its treatment.

The AYAs often considered the treatment as a bewildering and peculiar experience. As one AYA said, “It [the brachytherapy] was so strange. Every hour, they send this little part through you. I felt like I was part of a science fiction movie.”

Perceiving cancer as temporary

When their first reactions and emotions subsided, participants dealt with the reality of their cancer diagnosis by thinking of it from a temporary point of view. Initially, they understood cancer as a transient occurrence, a certain episode in their lives they needed to get through, but once finished, everything would go back to normal. “It [the cancer experience] is only half a year. After that, I go back to school, and I can go out again.”

The severity of their condition was seldom considered with respect to long-term consequences. As one participant explained, “I knew it wasn’t good, but I knew I was going to make it because they had told me briefly what would happen and how long it would take. I didn’t really realize that it was so bad, but anyhow, everybody makes such a big deal of it. Being ill is being ill. I mean, it’s a little bit worse than having the flu, but actually, it’s not that bad.”

3.2 Challenges in the Cancer Experience

Physical consequences

During the cancer experience, participants felt limited by the physical consequences of their treatment, such as pain and nausea. In addition, the physical alterations were an emotional challenge. One participant noted that her hair loss was “the hardest thing of all!” Hair loss, weight change, scars, or other adverse effects: all influenced the participants’ body image and somewhat diminished their self-confidence. They noticed the impact of cancer on their gender identity. One participant stated that cancer “took away my femininity,” and “I do not feel attractive anymore.” Another participant said, “It [hair loss] makes me feel like a baby!” Physical changes were charged with emotions because they not only gave the AYA an altered and undesired appearance, but also made the AYAs aware that they looked different from others. This altered appearance made the fact that the AYAs had cancer apparent, which in turn accentuated what many described as their “abnormality.” Most AYAs were preoccupied with what people thought of them. A participant explained, “It was annoying because you could see that something just wasn’t right. Bald, OK, there are other bald men as well. But no eyebrows…then, you really see that something is wrong.” Furthermore, their concerns about physical alterations and body image influenced decisions made regarding treatment. One female participant said, “I decided to keep my leg because I am a girl of 16, and I like to wear shorts and skirts.” Another participant decided to have her breast removed and reconstructed because “As they use tissue from your belly for the reconstruction, you lose a part of your belly, which is an advantage. Then, you have two new breasts, and I used to have a very large bust. With the reconstruction, I could have the breasts that I wanted.”

Loss of independence

Participants faced a temporary or permanent loss of independence during their cancer experiences. It was frustrating to them that they needed to endure a loss of freedom and had to rely on parents, friends, or family for practical or financial support. One participant stated, “You feel so powerless. You would rather cry because of this powerlessness than from the cancer itself. You are less capable to do things yourself. You have to ask for help all the time, and you depend on others for a lot of things. It’s just like that. You can’t avoid it, you are a child again.”

Loneliness and being alone

Another significant threat for the participants, in their quest to maintain a normal life and positive attitude, was being lonely and feeling alone. Participants did not like being isolated from others in the hospital because that made their illness more apparent and harder to overcome. One participant stated, “Every morning, when I woke up, I felt this…void, like ‘Oh no, I’m all alone, and I don’t know what to do!’ Then I put on the TV, but that’s not helpful, nor were the nurses who came in the morning. I knew that my mother would come to visit me in one hour but that one hour would pass by sooooo slowly.” When they were alone, participants often had negative thoughts or frightening feelings. One participant said, “There are always a lot of people with me, I’m never alone: my mother, sister, boyfriend…So I don’t have the time to think about what’s happening to me.” Participants did not want to feel alone in their battle against cancer; they expressed needs for social connections.

3.3 Focus on the Cancer Trajectory

The salient place of self-centeredness

In dealing with the disease and its treatment, the experience of participants unfolded from themselves. From the interviews, it was learned that from the diagnosis on the AYAs took the central position in their cancer trajectories. The AYAs stressed that they were the patients; their identities and lives were at stake. They were primarily focused on their individual battles with cancer. Even so, they did not want to lose themselves to the cancer experience, nor did they want to be constantly present in the disease. It can be noted that while the AYAs were considerably self-conscious throughout the cancer experience, they also expressed an attitude of self-centeredness. The data show that they needed this self-centeredness to endure all the challenges related to the disease and its treatment. Because they were the ones that needed to undergo treatment, they found it essential that attention was paid to what they wanted and needed. As an example, ‘‘I was in the emergency department, waiting for someone to see me, like already ages; suddenly, they bring another patient in, on a stretcher, who was screaming and crying. They helped him first, and he left before me! I did not agree with this.’’ Another AYA said, ‘‘It gets on my nerves to wait. Look, there are elderly who cannot even walk anymore. Just leave them waiting, for them it doesn’t matter anymore.’’

In enduring the illness and treatment, the AYAs had no spare energy to consider what others may need. For example, ‘‘When my mother is angry, she often says, ‘You only think of yourself.’ Friends say this also. But you just become like this when you are ill.’’ Directing attention to significant others, on top of their demanding battles, was often hard for participants to accomplish. Self-centeredness could be fed by the cancer experience itself; some participants said that enduring the cancer experience made them more selfish. One AYA said he was encouraged by his doctors to do so: ‘‘The doctors were always telling me: ‘You should only do the things you feel like doing. You don’t need to consider other people’s interests.’ I can tell you, this mentality can take over.’’

3.4 Coping With the Cancer Experience

Avoiding the possible threat to life

The interviews revealed that most participants tried to avoid the confronting idea that cancer could be a life-limiting disease. One participant explained, ‘‘Sometimes I say to myself, ‘I could die of this.’

I mean, you’re just so busy with recovering that you suppress the idea.” Moreover, many participants said that they did not understand the threat to their life until later in their cancer trajectory. In the acute stages of the cancer trajectory, AYAs were focused on getting through the disease and its treatment. When the acute phase had ended, the data show that AYAs spent more time reflecting on what they had been experiencing: “I knew what my disease was, but I didn’t realize that it was life threatening. Only after a year or so I started to understand that there are people who don’t survive. After my therapy, a child on my unit passed away, and also another one whom I knew died. These things make you realize the life threat afterward but not during the experience.”

Maintaining a positive attitude

The data demonstrate that a positive attitude was essential for AYAs to cope with the cancer experience. Being able to maintain positive thoughts was encouraged by an optimistic network. Participants stressed the importance of humor, which helped them endure and put things in perspective. As one AYA said (about the loss of hair): “My mother and I, we were laughing: ‘Let’s wax my head like a bowling ball and paint some numbers on it!’ Like this, hard times were quickly rejected… just by trivializing and not thinking of possible negative aspects.”

The data reveal that the impact of the treatment was not the AYAs’ biggest concern. Sickness or pain was not the things that they wanted to dwell on. This does not mean that they did not experience their disease or treatment as a burden. Often, they stated, “The treatment was hard, and I do not want to experience it all over again.” Treatment was seen as a period the AYA needed to get through, and episodes of nausea and pain were not shared with a lot of other people. The AYAs emphasized that they needed people around them who were positive. Moreover, most participants avoided discussing matters that could hamper their positivity. For instance, the caregiving parent was often the person who spent the most time with the AYA and was most involved in the illness experience. Nevertheless, this did not mean that the AYAs reflected much about their personal state. For example, AYAs did not share negative thoughts with their parents. An AYA illustrated: “I would never talk with my mother about death.” This was reinforced by their wish to relieve their parents and to protect them from sorrow or despair. Some participants felt guilty for the pain they thought they were causing their parents.

Holding onto a normal life

Because the AYAs presumed the cancer experience would be temporary, they did not want it to dominate their daily life. Moreover, during treatment, participants held to what they were used to and what they valued the most. They attempted to keep their well-known normal life close by. One AYA, who really loved shopping, said that she always went shopping on the days she did not have to be in the hospital; other AYAs tried to continue music lessons or sports during their treatment. An AYA said, ‘‘I wanted to live as normal as possible. And everybody supported me in this as well. Yeah, in the end, they saw that this was not possible anymore, but they have always supported me in this. For instance, my friends, they called me and asked, ‘Do you want to come with us?’ Just knowing that you can still join them, that they think of you. That meant a lot.’’

To stay connected to themselves during the disease and treatment and to maintain feelings of belongingness, AYAs needed their friends. Friends were essential as they were mirrors for the AYA and reminded him/her of the person that he/she was before having received a diagnosis of with cancer. It was important for AYAs not to be different from others. The thought of losing a sense of compatibility with friends and thus losing the connection with a normal life frightened them. Likewise, friends represented a significant gate to a normal life, keeping participants informed about everything that was happening outside the hospital walls, the ins and outs of school or work, or the gossip that was currently ‘‘making the rounds.’’ One AYA explained: ‘‘A friend of mine sent me a text message: ‘I didn’t pass my exam,’ but 10 minutes later, she wrote, ‘That’s not important, what you are facing is worse.’ But the fact that she sends normal things to me makes me happy because she just acts normal with me.’’ Actions such as this made participants feel like they still belonged to their peer group.

Participants expressed equal expectations of their parents and families. They found it supportive, not only when their parents, friends, and family expressed positive attitudes, but also when they acted ‘‘normal.’’ ‘‘What really pulled me through is the fact that people were not down [depressed]. Everybody acted normal.’’

3.5 Expectations of the Network

What did the AYA expect of his/her informal network?

To Be Treated as Normal. The participants noticed that the people around them approached them differently during the cancer trajectory than before their illness. For example, many AYAs experienced pity from friends and family. The AYAs found this hard to handle because pity accentuated their condition and defined them as ‘‘ill.’’ As one AYA said, ‘‘If they [friends] act differently, I will tell them ‘You need to act like you did before!’ This annoys me, you really notice that people can be different, having pity and mothering you.” In the interviews, the participants expressed often that they wanted to be treated “normally.” In addition, they found it essential to have their personality and not their disease to be in the forefront.

To Direct the Support They Receive. The AYAs expected their network (parents, friends, and family) to be concerned and involved and providing the support they needed. Regarding the care and support they expected of their parents, the AYAs perceived these as obvious and found it quite normal that their parents were permanently present or immediately reachable. As one participant said, “I only have to give a quick sign, and my parents call me.” As for friends, the participants explained that during their disease and treatment, they got to know their “real friends”: friends who were always there for the AYAs but who were able and willing to support them like the AYAs needed. An important aspect was that AYAs wanted to determine who should visit them and when. For instance, when AYAs suffered from nausea or were enduring severe pain, they preferred to be left alone, accompanied only by a caregiving parent. At that moment, the AYAs did not feel like having fun or distraction. As one participant illustrated, “When I felt sick, I wanted to sleep, and I didn’t want to be bothered.” If friends were unable to visit, the AYAs expected telephone calls or messages through social media.

What did the AYA expect of healthcare professionals?

To Be Recognized as an Individual. In relation to healthcare professionals, AYAs expressed the need to be recognized as an individual, with particular needs and specific preferences. They did not want to be perceived as a “number,” nor as just one of many patients. They needed their identity to be acknowledged and appreciated a personal touch, which some described as a “human approach.” They wanted to be perceived as more than their illness. An AYA illustrated, “Maybe all patients are equal, but here, that doesn’t ring true to me. They [healthcare professionals] don’t treat me the same as a 9-year-old. You feel that they take into account that you’re older than the rest. Because you behave differently, you have other habits, customs, and standards. You want other things. You feel that they treat you as an adolescent instead of a toddler.” In approaching the AYA as an individual, the healthcare professional demonstrated interest in the person of the AYA and reinforced this involvement by taking time. The data demonstrate how the AYAs wanted their healthcare professionals to show their understanding for the state they were in, as one participant said, “One doctor was like a second mother. When I felt bad, she came to me and placed her hands on my forehead. She asked me, ‘Are you OK? Is this working for you?’ I told her things that I would never tell my parents and that were too personal for my friends.'' On the other hand, another participant described the following, using a very annoyed tone: ''The professor, I felt like he couldn't be bothered that I'm ill; it's just a fact for him. Other doctors entered my room with an apron and a mask, but he just stayed behind the window like it was just too much effort for him.''

To Be Supported in Maintaining Normalcy and to Experience Some Flexibility. The data reveal how the AYAs expected to pick up the threads of their lives rapidly, once the cancer experience was finished. It was crucial for them to stay connected to their normal lives. One strategy to maintain normalcy was to continue with familiar customs and habits. During hospitalization, participants wanted things to be consistent, such as having a permanent Internet connection, sleeping late, choosing what to eat, or being able to see friends without being bound to visiting hours. Some AYAs found it difficult to accept outlines imposed by the hospital that limited their freedom or their desire to stay connected to their lives. Adolescents and young adults appreciated accommodations that were made for them and were distressed when these were lacking. As one participant said, ''The biggest problem was the food. It was really annoying that I couldn't eat the things that I wanted.'' Another said, ''They don't respect your privacy enough. You close the door of your room, and they open it again because they want to see you all the time… I mean, I close it for a reason!''

To Have a Voice. The data demonstrate that AYAs wanted to be someone with a voice, who wants some control and who is capable of making his/her own decisions, based on what is important. For example, the AYAs' concerns about physical alternations and body image can have a greater influence on treatment decisions rather than the prognosis, as noted by the participant who decided to have her breasts removed as the reconstruction would enable her to give her the breast size she wanted. Another AYA said that he wished he could have chosen to be treated on a pediatric ward because on the adult ward the other patients ''got cancer through old age,'' whereas another participant said that he wanted to decide for himself if he would talk with a psychologist. In addition, AYAs wanted to be involved in the way healthcare professionals communicated with them or to be involved in the information they received. They needed information, in an amount they could control, and at a time they preferred. It was clear that the participants did not want extensive knowledge about their condition during their treatment. For instance, future implications such as possible sequelae of treatment often seemed to be too much information. The data demonstrate that information overload was overwhelming and had the potential to jeopardize the AYA's positive attitude. The AYAs also did not find it helpful if the information concerned a more distant future as most participants were more preoccupied with what was happening here and now. As one participant said, ''I didn't want to know much about my condition. Otherwise, I would perhaps be worried for no reason because not all things would happen to me.'' In addition, participants were concerned about the timing and the style of communication. They preferred information that was translated to their own way of living, not presented in an abrupt way or lacking nuance. As one participant said, ''They asked me in advance if I wanted to know everything. I really appreciated this. Otherwise, it could happen to you, that some doctor enters your room, bluntly telling everything, without you wanting all of that.'' Equally important was the AYAs' need for comprehensive information; they needed to understand the terminology of healthcare professionals. One participant commented, ''I received a brochure, but all these difficult words, you need a dictionary to understand them!''

Participants also appreciated participating in scheduling their treatments. They thought it was important that healthcare professionals understand the lives they led outside the hospital. In the interviews, it was often mentioned that the AYAs did not like to wait and preferred that their time be well managed. Time was precious, as one participant said, ''It gets on my nerves; I want to get out the hospital as quickly as possible. Like now, they already have had my results for one hour, but they didn't start yet... It annoys me because I know I won't be sick today, but tomorrow, I will, so today, I want to do things! Therefore, I think they need to help young people faster.'' Another participant said, ''I had to tell them not to plan my check-ups in the middle of my exams.''

3.6 The AYA Director Role

In the five categories or elements mentioned previously, the analysis revealed a distinction between the elements ''perceptions,'' and ''challenges'' on the one hand, and the elements ''focus,'' ''coping,'' and ''expectations'' on the other (Figure).

Perceptions and challenges

When confronting with their illness and treatment, the AYAs had certain perceptions, and they experienced specific challenges. The AYAs experienced their cancer diagnosis as sudden and bewildering. They perceived their disease and treatment as a temporary occurrence with an impact on their lives, mainly in the here and now. Physical consequences of the disease, loss of independence, and feelings of loneliness and being alone were experienced as major challenges.

Focus, coping, and expectations

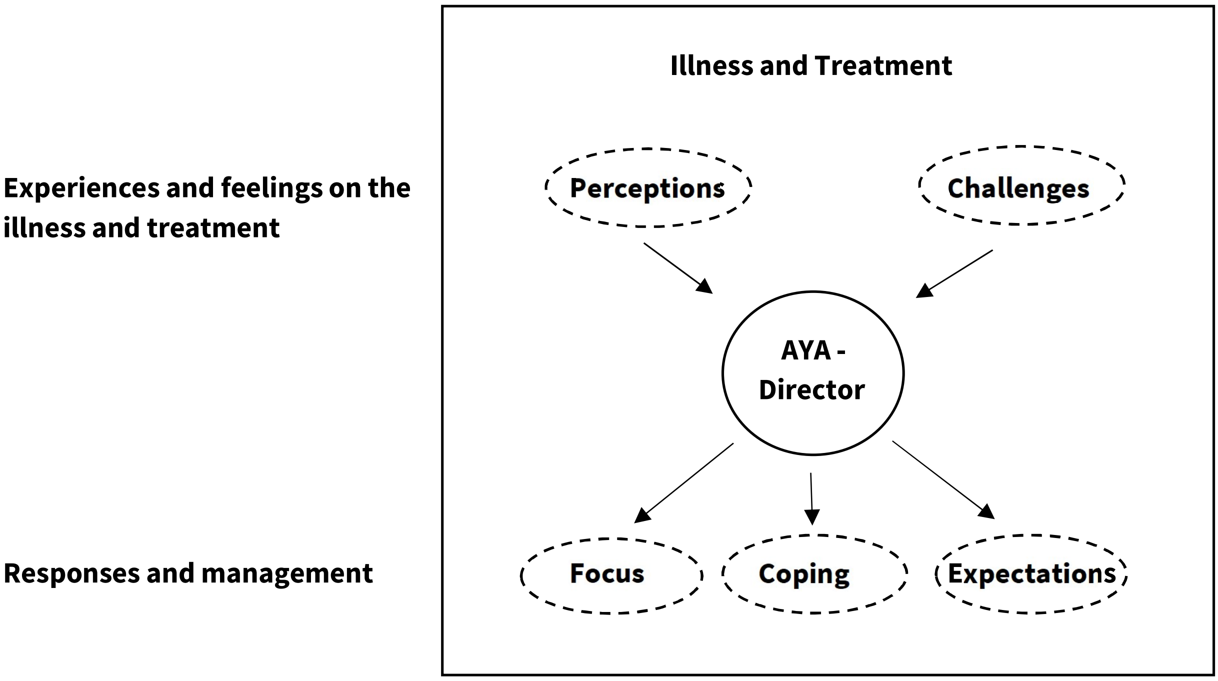
The AYAs responded to the cancer experience and attempted to manage their situation as much as possible, which became prominent in their focus, coping, and expectations toward their network. Throughout the cancer trajectory, the AYAs expressed an attitude of self-centeredness. Rather than thinking of this as a type of selfishness, self-centeredness emphasized the AYAs' concern to have their individuality protected. Aiming to safeguard the life they were used to and to get through the disease and treatment as efficiently as possible, they avoided confrontation, valued positive thinking, and attempted to hold on to their normal lives. If their coping strategies were challenged, the AYAs wanted support from their family and friends and expressed specific expectations.

The dynamics in and between the elements

The 5 elements should not be considered as isolated or static. Just as the AYAs' expectations were influenced by their self- centeredness, their coping strategies were affected by the challenges they faced, and all separate elements influenced each other. For example, AYAs who experienced being alone in the hospital as distressing (challenge) expected to have someone with them all the time, regardless of the visiting policy (expectations).

Dynamics could also be noticed in the elements themselves. For instance, the data demonstrate that the loss of independence was a less thorny issue shortly after diagnosis, while it became more an issue of concern for the AYAs later on in the trajectory. As one participant explained, ‘‘In the hospital, I was so tired of being dependent on others: from the nurses, my mother (I). And then I got my wheelchair. I drove around in the corridors; I loved experiencing the freedom of a wheelchair. That moment, I thought ‘Whoa! Once again, I can go wherever I want, do whatever I want!’ Once I had this wheelchair, I had a huge amount of freedom.’’

Figure: The framework of the AYA-director



The dynamics in and between the different elements are visualized by the open lines surrounding them

The AYA-director role

In their cancer experiences, the AYAs actively tried to manage and master their environment as well as the people who were in it. They wanted to be in control of their formal and informal care. As a result, they created a role for themselves, the AYA director. This role emerged from the data analysis process, as there were no participants who identified this role in the interviews. Thus, it should not be seen as a role that AYAs were fully conscious of, nor was it a role that was ‘‘played’’ by the participants. The AYA director is a more comprehensive and inherent aspect of their identity, pulling together their thoughts, feelings, meanings, drives, and actions. The AYA director was incorporated and included in their thinking and acting; as such, it should be understood as a way of being.

The role was apparent in the entire cancer trajectory, for AYAs treated on adult wards as well as on pediatric wards.

As AYA directors, participants could approach their situation in ways that best suited them. If things were going well or as they intended, then the actions and effects of their directorship were not overtly evident. Even though some AYAs were able to easily express what they wanted, compared with others, all AYAs assumed the director role in some fashion. For example, one AYA said, ‘‘My mother gave me everything what I wanted. I just had to do this [sound of a fillip], and I got it.'' This in contrast to situations that did not proceed as planned. If someone or something held them back, a lack of directorship of the participants became more noticeable. The AYAs expressed annoyance, frustration, uncertainty, or unease. An AYA explained, ''They wanted to help me as much as possible, but like, my grandmother was so worried that it really set me off. Every time she said 'No, leave it, I will do it,' 'I will do that.' It's like she wanted to eat my sandwich herself!'' Another AYA said, ''Sometimes in the hospital, I was in such a bad mood (I). If they asked me to repeat what I've asked, then I refused. I was sharp toned, angry and so stubborn.''

4. Discussion

The findings of this study reveal the specific experiences of the AYAs when faced with cancer, in particular the participants' genuine wish to be seen as individuals, who want a voice in the care and support they receive. This is explicated through the concept of the AYA director. As healthcare professionals, it is not enough to meet the needs of those AYAs who are assertive or articulate enough to express what they want. As presented in the findings, the AYA director is a role that belongs not only to the most communicative or outspoken AYAs; those who are less visible or quiet find it equally important that they are given the option to be AYA directors.

The findings clarify the perceptions, focus, coping strategies, and challenges experienced by the AYAs during their illness trajectory. Special attention should be paid to these dynamics as things change during the cancer experience. For instance, in the relationship the AYAs have with their parents, ''the law of double protection,''[13] needs to be considered; both AYAs and parents may not share everything with each other, aiming (unconsciously) to spare each other pain and grief.

Some of the findings from this study are consistent with prior research. Maintaining a positive attitude and having life get back to normal as soon as possible are primary coping strategies, affirmed by Kyngas et al.[14] The significance of a normal life was also emphasized by Zebrack et al.[6,7] Dyson et al[15] found that physical needs and needs of daily living were often unmet. Attending school and taking part in leisure activities are ''normal'' activities; not being able to do these causes distress. For this reason, a sense of normalcy needs to be maintained to enhance wellbeing. Emotional support for this can be provided by healthcare professionals or from the AYAs informal network[6]. Peer support is crucial for self-esteem and in their endeavors for ''normality''[16-18]. As for self-esteem, the findings indicate the significant value of appearance and body image for AYAs. This has been suggested in other studies as well[17,19,20]. Eiser and Kuperberg[21] confirm that changes in appearance and body image can have more impact than confronting the potential life-limiting nature of cancer.

Maintaining a normal life, particularly during hospitalization, is critical. The AYAs need to have the situation in their own hands and under their control. The salient concept of the ‘‘AYA director’’ is congruent with the findings of Zebrack et al[6] and Wallace et al[20], who stressed that regaining a sense of control is essential in the recovery process for the AYA. Likewise, Miedema et al[22] described the concept of ‘‘remaining in control’’ as a problem-focused coping strategy. As our data demonstrate, AYAs want to direct the information they are given and appreciate actions that support their sense of control. This can be done by offering the AYA choices and allowing individual decisions. This gives them the opportunity to ‘‘master’’ aspects of the disease and its treatment[23] and helps them to adjust to their care[19]. Moreover, providing AYAs with choices encourages them to cooperate and enhances treatment compliance[23]. Consulting the AYA about what he/she wants and needs can lead to individualized care, in the form of age-appropriate accommodations or policies that meet their specific needs, such as Internet access or flexibility in visiting hours[6,16,24].

As our findings indicate, communication is an essential concern for the AYA director. To improve a sense of control, AYAs prefer communication that includes them in the formulation of treatment plans[6]. In their conceptual model of communication roles and patterns, Gibson et al[25] proposed that an AYA shifts positions with his/her parents once autonomy has been gained. At that point, the AYA moves into the foreground while the parents place themselves in a supportive background role. Zebrack and Isaacson[4] further support this idea by stating that healthcare professionals need to ask AYAs directly how much information they want and to whom it should be directed: to themselves or to their parents. If information is given, our findings show that how it is presented is essential. This is affirmed by Zebrack et al[6] and Abrams et al.[16], who emphasized the communication style of healthcare professionals. They suggest that communication should meet, not only the AYAs’ developmental challenges but also their cognitive capabilities, leading to age-appropriate information[7]. Evan and Zeltzer[23] stated that cognitive ability needs to be taken into account when the emotional functioning of the AYA is evaluated. In this light, Eiser et al.[26] warn of the difficulties AYAs can have in anticipating how their decisions might impact their future lives. Our data illustrate this too. An AYA said that she based her decision to not have her leg amputated because of the fact that she likes to wear shorts and skirts. Some of the psychosocial concerns of AYAs with cancer, as explicated in this study, can be allocated to AYAs in general or may be extrapolated to the population of chronically ill AYAs. Nevertheless, these concerns are given an additional weight in the cancer experience. For instance, facing a changing appearance is without any doubt more challenging for an AYA with cancer than for a healthy peer.

4.1 Strengths and Limitations

This research has provided a deep understanding of the psychosocial experiences of AYAs who undergo a cancer treatment that is aimed at recovery. Valid findings were obtained and data saturation was accomplished. Nevertheless, some limitations can be noted.

In the recruitment procedure, a staff member was assigned to identify possible participants and introduce them to the study through an informational letter. Nothing is known about the AYAs who did not opt to be contacted by the researcher. This may distort the profile of the AYAs who did participate. In addition, participants were recruited in one university hospital. It is unclear whether the profile of the participants would be different in a non-university setting.

Cancer is a hard load to carry. How an AYA deals with cancer is determined by several things, such as the nature of the diagnosis and treatment, physical limitations, individual coping strategies, the network around the AYA, and the professional care that is provided. In this study, distinction in types of cancer was not made, and the concepts were generalized to the entire population of AYAs with cancer. However, one could assume that AYAs with a mental disability or who suffer from severe cognitive limitations as a consequence of the disease and its treatment experience additional challenges. The concept of the AYA director has perhaps a distinct dimension for these AYAs, because AYAs with more cognitive impairments are in general more dependent on their caregivers.

Finally, this research was focused on the psychosocial experiences of AYAs receiving curative treatment. It can be hypothesized that a cancer experience has a distinct meaning for AYAs in palliative care as well as for AYAs who received a diagnosis of cancer in childhood, but these AYAs were not part of this study; thus, findings cannot be generalized to them.

4.2 Research Implications

This research focused on the perspective of the AYA patient. However, cancer has a significant impact on the network around the AYA as well. In our interviews, participants did not mention siblings, which can be understood from their position of self-centredness. Hokkanen et al.[27] also noted that AYAs did not speak about their siblings. Further research might explore and investigate the experiences of the significant others of AYAs: their caregiving parents, brothers, sisters, or friends. Appropriate healthcare should also take their perspective and needs into account.

This study found no difference between the perceptions of AYAs who were treated on an adult ward and AYAs treated in pediatric settings. However, it could be an interesting objective in future research to compare the experiences of AYAs between adult- and pediatric-focused units.

Finally, future research could focus on the development and evaluation of interventions that support the AYA director role. Based on the findings of this research, ‘‘the AYA box’’ was developed. This instrument was developed to meet the AYA’s specific needs and to enhance the communication between the AYA and his/her informal network and healthcare professionals. It contains several components: a booklet with revealing stories of AYAs’ experiences, postcards, a unique AYA tag, stickers mentioning feelings or concerns, cards with information or instructions, a brief symptom scale, and smart aids for communication with relatives and healthcare professionals. Adolescents and young adults with a diagnosis of cancer are invited by healthcare professionals to actively work with the box, but the initiative to use the box is entirely left with the AYAs. The AYA box as an intervention has now been implemented into practice. Future research is needed to evaluate and assess its effectiveness.

5. Conclusion

This study has offered insight in the experiences of AYAs who are dealing with cancer and the meaning attributed to their experiences. Healthcare professionals should fully support the AYAs’ distinct attempts to sustain the impact of the disease and its treatment. By understanding what AYAs are facing, by helping them to put their needs into words, and providing anticipatory guidance, AYAs do not need to expend excess energy to claim their AYA director role.

It is hoped that this insight motivates healthcare professionals to alter their approach toward patient-centeredness by allowing AYAs the necessary space to become directors of their own care. These findings can help healthcare professionals to optimize their psychosocial care. This is important because the majority of AYAs are not treated in special adolescent units; this type of care is provided only in some hospitals in the United Kingdom and Denmark at present. Most AYAs are treated either on a pediatric or an adult ward. As a result, healthcare professionals in these settings often need to do more to provide care that meets the needs of AYAs. During the cancer trajectory, AYAs have a different view of the disease and its treatment as time progresses. In the interviews, many participants declared that they did not have a clue on what they were facing.

If cancer sweeps away the ground beneath their feet, people tend to hold on to everything that they can. It may increase an AYA's wellbeing to have the feeling that some aspects of their cancer experience can be mastered, even if these aspects seem insignificant to others, such as having a choice in food. It is essential that AYAs can have a voice in all aspects of the cancer experience, including choices in therapies or scheduling treatments.

Acknowledgments

The authors acknowledge the contribution of Stien Vandierendonck, MSC, RN, and Anneleen Raes, MSc, in the data collection and part of the data analysis. They also thank all AYAs who were willing to participate in this research, despite their intense struggles against cancer.

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Hoofdstuk 3

The 3-Phase Process in the cancer experience of adolescents and young adults

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Gebaseerd op het artikel van Belpame N., Kars M.C., Beeckman D., Decoene E., Quaghebeur M., Van Hecke A., Verhaeghe S. (2018). The 3-phase process in the cancer experience of adolescents and young adults. *Cancer Nursing*, *41*(3), E11-E20. DOI: 10.1097/NCC.0000000000000501

Category Nursing 17/115, Q1, JIF Percentile 85.65

Abstract

Background

When confronted with cancer, adolescents and young adults (AYAs) enter a psychosocial trajectory. Previous research has acknowledged the importance of care adjusted to the specific needs of AYAs. To develop AYA-focused care, in-depth knowledge about the experiences of AYAs with cancer is necessary.

Objective

The purposes of this study were to discover the psychosocial experiences of and their meanings for AYAs enduring cancer, as well as its treatment and follow-up, and to capture the basic social psychological process that shaped these experiences.

Methods

This was a qualitative study in which individual semi-structured interviews were conducted with 23 participants aged 15 to 25 years.

Results

A 3-phase process was identified, which demonstrated alterations in the AYAs' experiences and their underlying meanings: (1) maintaining normal life was essential, (2) normal life was slipping away, and (3) evolving toward a new normal life after treatment. Certain core dynamics were present in these three phases. Throughout the cancer trajectory, the AYAs attempted to maintain control, redefine the self, and incorporate their cancer experience to the long-term course of life and had varying expectations of their social networks.

Conclusions

Understanding the process that AYAs with cancer go through and taking into account their experiences can facilitate better psychosocial care for this emotionally vulnerable population.

Implications for Practice

Healthcare professionals need to take a patient-centered approach, with a focus on communication, to meet the needs of AYAs throughout the cancer trajectory.

Keywords

Adolescents and young adults, Cancer Nursing, Psychosocial experiences and needs, Qualitative research, The basic social psychological process

1. Introduction

All young people face a series of major developmental tasks in adolescence, leading them from childhood toward the next phase in life, adulthood. The developmental tasks that adolescents and young adults (AYAs) face are related to cognitive and emotional growth, such as forming identity, developing body image, initiating (intimate) relationships, separating from parents, and decision making to establish goals about future education, profession, or family planning[1,2]. In general, these developmental concerns can be distressing for AYAs. When, at the same time, an AYA is given a diagnosis of cancer, the significant transition between childhood and adulthood is jeopardized[3-5]. These AYAs experience life-threatening illness[6] and additional stressors such as increased dependence on their parents, changes in their physical appearance, isolation, and loss of social life[7]. The compromise between developmental needs for autonomy and independence and the demands of their illness such as dependence, vulnerability, and isolation is challenging[8].

Previous research has highlighted the importance of psychosocial support for this patient population, by determining the particular needs of AYAs in their cancer trajectory[9,10] and demonstrating that high levels of unmet service needs in this population were associated with poorer health-related quality of life[11].

Coping with cancer may include negative and positive experiences and outcomes[6,12,13], but in general, a cancer experience remains primarily distressing with ubiquitous challenges[2,14]. To what extent AYAs feel burdened by the cancer experience depends on how each one copes with the disease and treatment and is therefore partially individually defined. Although AYAs represent a group with disparate physical, emotional, and social needs[15,16], Grinyer[17(p153)] states that ‘‘there is more that unites young adults than divides them.’’ Despite their differences, AYAs share mutual experiences and have specific age-related needs.

Previous research on cancer in AYAs has categorized the negative experiences of AYAs as distress, related to physical concerns[3], an altered appearance[6,18], or fear of dying[6]. Positive experiences include emotional support of family[19], increased personal strength[20], or posttraumatic growth[21]. However, few qualitative studies have focused on AYAs' self-reported perceptions of their cancer experiences through individual interviews. Some studies have investigated support needs[22], healthcare needs[23], appearance- related concerns[20], or information needs[24] of AYAs, but there is still a lack of empirical research that studies the times across the continuum of cancer care that support is needed[2]. To improve psychosocial outcomes, the health-illness transitions of one phase in the illness to the next should be taken into account[25]. Furthermore, there is increasing consensus that the psychosocial care of AYAs should be age-appropriate[26] and meet their specific developmental needs[27,28]. The development of such tailored psychosocial care should be informed by evidence as to how AYAs experience their cancer trajectory. Yet, this kind of comprehensive research is rare.

The purposes of this qualitative study were to discover the psychosocial experiences of AYAs experiencing cancer, its treatment and follow-up, and the meanings they attributed to these experiences and to capture the processes that shaped their experiences.

2. Methods

2.1 Design

A qualitative research study, based on the principles of grounded theory[29] , was undertaken to gain holistic insight in the experiences of AYAs with cancer. This article focuses on the basic social psychological process[30] that AYAs underwent during the cancer experience and the meanings they attributed to this process. The AYAs' psychosocial cancer experiences and their meanings are described in the study of Belpame et al.[31]

2.2 Sample and Recruitment

For a period of one year, 23 participants, recently given a diagnosis of cancer (in the first month since diagnosis), in active treatment or during follow-up (after the end of the treatment), were recruited on four different wards in one university hospital - pediatrics, medical oncology, hematology, and orthopedics - because these were the settings where almost all AYAs with cancer are treated. Examples of diagnoses of AYAs treated on these wards include leukemia, osteosarcoma, testicular cancer, brain tumor, and Ewing sarcoma.

The following inclusion criteria were applied: male and female AYAs were required to be between 15 and 25 years old, 15 years or older when given a diagnosis of cancer, and no longer than five years in follow-up. After an event-free period of five years, one can be regarded as a cancer survivor, which possibly generates a distinct and different perception that is not relevant to this study. A 5-year event-free survival criterion has been used previously in several studies[32-35].

Excluded from recruitment were nonnative Dutch-speaking participants, AYAs in palliative care (i.e. whose treatment was not aimed at recovery), and participants with nonmalignant or benign tumors.

The initial purposeful sampling intended to achieve situational diversity by means of variation in age, gender, diagnosis, social context, education, and time since diagnosis. As the analytical process progressed, sampling was based on the preliminary findings (theoretical sampling). For example, the data revealed that friends represented an important part of the support network for AYAs. To increase insight into the value and meaning of friendship for AYAs, the study aimed to explore friendship in different situations, such as at school and work. Consequently, the participants recruited after preliminary results were assessed varied in professional and educational status. These participants were recruited on the same four wards.

2.3 Ethical Review

The study was approved by the ethics review committee of the Ghent University Hospital (Belgian registration number B67020096417). Participation in the study was voluntary. All participants signed an informed consent. For those younger than 18 years, parents gave their signed permission as well.

Because of ethical considerations, the hospital staff member who contacted potential participants, who matched inclusion criteria, gave only age, diagnosis, and telephone number of the AYA to the researcher. Additional information was provided by the participant during the interview. The researcher did not review each participant's medical record.

2.4 Data Procedure

Eligible participants in active treatment were asked in the hospital by a member of the multidisciplinary team whether an independent researcher could contact them within the context of a study. Eligible participants in follow-up were telephoned by a member of the multidisciplinary team with the same question. During the period of recruitment, all newly diagnosed AYAs were invited to participate. The member of the multidisciplinary team who approached the AYA only passed on to the researcher if the AYA was "newly diagnosed," "in active treatment," or in "follow-up." Detailed information on how far the AYA was into the cancer trajectory was not given.

All potential participants received an information letter about the study, and if they volunteered, the researcher contacted them with more detailed information about the interview structure and the study in general. The interviews were scheduled at the hospital or at home, depending on the participant's preference.

2.5 Data Collection

Three interviewers conducted an individual 1-time semistructured interview with each participant, with one exception: one interview was conducted with two participants together, at their request. On average, the interviews lasted 95 minutes (range, 26-185 minutes). All the interviews were audio-recorded and transcribed verbatim.

The initial interview guide included open-ended questions to stimulate the participants to respond in their own words, as well as elicit extensive answers and thick descriptions. The interview guide was developed by the researchers, in accordance with the objectives of the study. Questions from the initial interview guide were as follows: What does it mean to you to have cancer? How have you experienced your illness and treatment until now? Can you tell me more about what it means to be treated in the hospital? What have you experienced as helpful? The first interviews were based on the input of the participants themselves. The interview guide evolved throughout the research process, based on the analysis of earlier interviews. This resulted in more focused interviews; however, they always began with an open start, such as the following questions: What does it mean to you to be alone in the hospital? How do you experience the physical consequences of your illness and its treatment? How do you cope with the information provided? As the analysis progressed, different topics on psychosocial experiences were discussed: impact of the diagnosis, perceptions of the disease on daily life, experiences in treatment and hospitalization, the meaning of consequences of the disease and treatment, ways of coping, experiences with healthcare professionals, expectations of care, psychosocial needs in the cancer experience, and vision of future life. These topics were deepened as the data collection progressed and concepts emerged through data analysis.

2.6 Data Analysis

To start, the interviewers read three interview transcripts and coded them together, line by line, using open codes[36]. This coding was discussed in a meeting with the entire research group, which consisted of the three interviewers and six other researchers with different disciplinary backgrounds. The interviewers then coded three new interviews, using open codes, but this time individually. They compared and discussed each other’s coding. After this, they together coded the six interviews again, using axial codes. This was followed by a discussion on the coding with the entire research group. As the data were further collected and analyzed in the group in a cyclic process, the method of constant comparison was used to examine the new data, and codes were reviewed, refined, and made more specific, which resulted in the construction of meaningful categories (selective coding). As this iterative process progressed, the entire research group discussed and reflected on the applied codes and categories and worked toward major concepts extracted from the data. In this manner, data saturation was reached.

Through this process of data analysis, second-order concepts were obtained, and theories were developed. These findings transcended individual experiences[37] because the experiences of the participants were described on a more theoretical level. Data and coding were managed by using the qualitative analysis program NVivo 8 (QSR International, Victoria, Australia).

2.7 Quality

In this study, quality was ensured by executing an audit trail, peer review, and researcher triangulation. Contextual notes regarding the interviews, methodological decisions in the research process, analytical reflections on the data, and personal responses and thoughts were noted in an audit trail. The strategy of peer review was applied as the 3 interviewers reanalyzed all the other data, working toward consensus. During the entire research process, there was researcher triangulation. Using their scientific, practical, or methodological expertise, the researchers discussed the study design, formulation of the research question, interview guide, sampling, and data analysis. The varied backgrounds of the researchers (nursing and social work) contributed to the value of triangulation. In addition, a research committee consisting of different healthcare professionals (physicians, nurses, clinical nurse specialists, social workers, and psychologists) supervised the research process. They critically followed all steps in the research process and formulated their opinion on the findings and, in a later stage, on the AYA box. Participants gave their permission for all researchers to have access to their data.

3. Results

A total of 22 semi-structured interviews were conducted with 23 AYAs who were each interviewed once. Nine men and 14 women participated; four had been recently given a diagnosis of cancer, six were still in treatment, and 13 were in follow-up (Table).

Table Demographic Characteristics of the Participants (N= 23)

Stage of Cancer Trajectory	Recently Diagnosed	On Treatment	In Follow-Up	Total
No. interviewees	4	6	13	23
Age, y				
15-19	2	1	7	10
20-25	2	5	6	13
Gender				
Female	2	3	9	14
Male	2	3	4	9
Relationship				
Yes (female AYA)	2	3	4	9
No (female)			5	5
Yes (male AYA)		2	2	4
No (male AYA)	2	1	2	5
Studies/profession				
Secondary school	1	1	4	6
University college		1	5	6
University		2	2	4
Employed	2	1	1	4
Unemployed	1	1	1	3
Wards of recruitment				
Pediatrics	1		5	6
Medical oncology	1	2	3	6
Hematology	2	4	1	7
Orthopedics			4	4

The data analysis revealed that AYAs go through a specific process in the cancer trajectory, starting with the phase of diagnosis moving into the phase of active treatment until the phase of follow-up (Figure 1). Although this process was seen in every AYA, individual experiences were also needed for this to be understood. All AYAs went through this process in their own way, defined by their personal characteristics, specific diagnosis and treatment, and the particular informal networks surrounding them.

In the process, three phases were identified: (1) one in which maintaining normal life was obvious and essential for the AYA, followed by (2) a phase wherein the AYA felt that normal life was slipping away ineluctably, and finally, (3) the phase during which the AYA focused on evolving toward a new normal life. These phases should not be seen as delineated phases and as fixed periods determined in time. The transition of one phase to another was primarily induced by challenges the AYA needed to cope with, related to the disease and its treatment, instead of a specific moment in time.

As the cancer experience progressed and the AYA's endurance was tested, the AYA developed different views on the cancer experience and faced new challenges. Thus, throughout the three phases, certain dynamics were shaped, which demonstrated alteration in the AYA's experiences and the underlying meanings. As a consequence, the AYA experienced different psychosocial needs at the beginning of this trajectory compared with during it or at the end. The data revealed certain expectations that the AYAs had of their informal and professional networks, in which they were situated. These are described within every phase. From this point, the AYA is referred to in the masculine form to facilitate reading.

Figure 1: A 3-phase process in the cancer experiences of AYAs

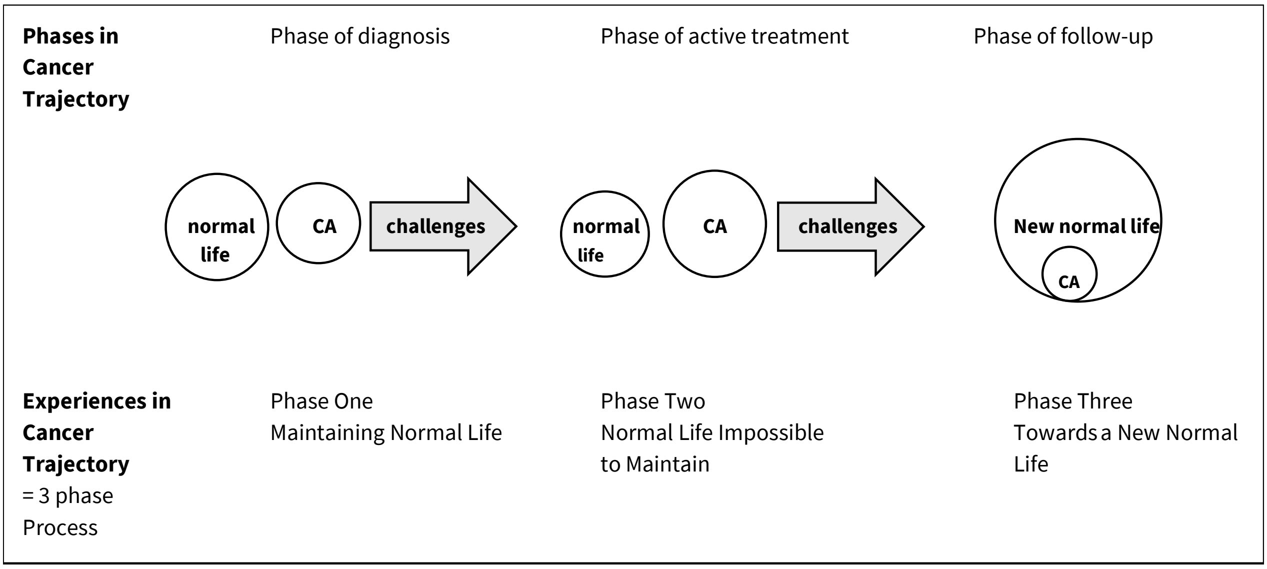

Figure legend: CA = cancer

3.1 The 3 Phases in the Process of AYAs Experiencing Cancer

PHASE 1: “Maintaining normal life”

As demonstrated in the data, living his endless life to the fullest, the AYA experienced the cancer diagnosis like a bomb going off. Seldom devoid of indication of symptoms and without any logic, the cancer struck the AYA suddenly, leaving him deprived of all his senses. To cope with this verdict, the AYA put it in a temporary perspective that understood his illness as a transient occurrence, after which everything would go back to the way it was before. As one AYA said, ‘‘As my treatment will be finished at the end of the summer, I will restart my life, and I will go back to school and start my studies. That is totally achievable.’’ Because everything happened quickly in this phase of the cancer trajectory, perceiving the cancer experience as a transient occurrence, limited in time, made it manageable and gave the AYA a sense of control. As a first expectation, the AYA needed everything outside the cancer experience to remain normal. As one AYA stated, ‘‘A friend of mine sent me a text message: ‘I didn’t pass my exam’ but 10 minutes later, she sent: ‘That’s not important, what you are facing is worse.’ But the fact that she sends normal things to me makes me happy because she just acts normal with me.’’

During hospitalization, the AYA wanted to continue his own way of living (e.g. diet, sleeping habits, use of Internet, etc.). Maintaining a normal life was as obvious as essential for the AYA because it did not occur to him that his life beyond the cancer experience could change. The conviction that the disease was a temporary condition without far reaching consequences strengthened the assumption that the AYA did not need to adapt to cancer. Cancer befell him without a particular reason so the AYA wanted to spend only the energy needed for a cure and found it important that his way of living remained the same. Therefore, he appreciated it if family and friends behaved normally as well. Having fun, being updated about all occurrences in daily life by his friends, was essential for the AYA. Thus, as a second expectation, the AYA needed everyone to behave normally and to treat him no differently than before. An AYA said, ‘‘I don’t want to be wrapped in cotton wool. I prefer not to be reminded of it [the cancer], I prefer that everybody behaves like I am just a normal person.’’ To cope with the cancer experience, a positive attitude was essential for the AYAs. The presence of friends encouraged them to maintain positive thoughts. The presence of parents prevented them from feeling alone so the AYAs wanted their parents with them at all times. At least one parent (mostly the mother) was practically permanently present or immediately reachable for the AYA, who considered this essential. Seeing the cancer experience as a bounded period encouraged the AYA to hold on to a positive attitude. To safeguard this, the AYA avoided challenging situations and confrontations.

Another expectation derived from the data was that the AYA did not want to get involved with other AYAs with cancer. In the interviews, many AYAs declared that support of family and friends was sufficient. One AYA explained, “I did not want to go on a holiday with other cancer patients, I rather go with my scouts. Activities, I want to do them with the people I know, with normal people. To have fun together and not to be confronted with diseases and so on.”

Major challenge In this initial phase, it appeared that it was extremely difficult for AYAs to cope with alterations in appearance, as a result of the disease and treatment. Physical consequences like alopecia or weight loss made the disease apparent and violated the identity of the AYA by demonstrating to him, as well as others, that there was something wrong. A changing appearance undermined the AYA’s state of mind completely. A deviant appearance emphasized the abnormal and the unknown which challenged the positive attitude of the AYA. An AYA said “I could not bear looking in the mirror, having no hair, wearing a scarf. I looked ill.”

PHASE 2: “Normal life slips away”

This second phase was characterized by the supremacy of the cancer over the AYA’s ability to maintain a normal life; the AYA could no longer evade the comprehensive impact of the disease and its treatment. He had to endure invasive therapies and surgical interventions, which left him with pain, sickness, and physical limitations. In this phase, the AYA focused on managing the illness and its treatment to get cured. Maintaining a normal life was no longer a priority. Besides, even if he wanted to, attempts to maintain a normal life were seldom successful; for example, studying was impossible when the AYA experienced chemotherapy adverse effects. Often, it was not until this phase that the AYA truly understood the life-threatening character of the disease. An AYA explained, “It was only then, after my first chemo’s, when I started to feel the pain, that I realized everything. That was the hardest time for me, then I felt really downhearted.”

At the same time, the AYA had less contact with friends. The AYA received a lot of visits, telephone calls, or messages in the beginning of his trajectory, but now, the AYA reported that he got to know his “real friends.” An AYA said, “Once you’re ill, then you see who your true friends are. I truly experienced this…some friends that I’ve expected to visit me just didn’t come. People you really could expect to visit me.” The AYA found that friends were afraid to contact him because they did not know how they should react or because they felt insecure about what they could do for the AYA.

With the decreasing frequency of visits and contacts with friends, the AYA was cut off from his normal life. The connection that the AYA used to feel with his friends was jeopardized because the normal lives of friends continued, whereas his life was frozen by the cancer experience. An AYA said, ‘‘There was a time that I did not want to see sunlight. If you are hospitalized in summer and you see everybody out there, while you are trapped inside… For sure, my curtains remained closed!’’ Some AYAs who felt like outsiders became interested in meeting other AYAs with cancer, in search of recognition or social acceptance.

An important finding was that the AYA wanted to direct the support he received. The AYA managed his remaining informal network so that friends were there for him, but only when he needed them. For instance, when the AYA experienced nausea or when he endured severe pain, he did not feel like having a lot of people around him. One AYA explained, ‘‘I indicated them [friends] that I rather preferred them not to visit me because when I was sick, I hardly could talk anymore. I just wanted to sleep and just…yeah, they had to leave me alone.’’ Real friends were those who supported the AYA in the way he preferred to be supported.

Major challenge In comparison with the initial phase, physical alterations such as alopecia were put in perspective. An AYA declared, ‘‘At first, I found it so terrible that my hair needed to be cut because it was so long. But now…that’s just something that really doesn’t matter if you have such a disease. It comes along with it and it will grow back. I definitely don’t upset myself about it anymore.’’ More challenging in this phase was the experience of overall loss and distress. The AYA lost control as cancer determined everything; he was bereft of personal freedom and autonomy because he became dependent (again) on others for personal care, financial aid, or practical support, both in and out of the hospital. An AYA reported, ‘‘The worst thing is that I lose my independence. It looks like I need to move back to my parent’s place. If it’s not necessary, I won’t do that. I’m really not looking forward to this!’’

PHASE 3: ‘‘Toward a new normal life’’

This phase began at the end of the treatment trajectory. The AYA was released from the hospital, the treatments were finished, and contact with healthcare professionals reduced. This was the moment the AYA had anticipated. Nevertheless, in contrast with his initial belief, the AYA declared that picking up the threads of his life was difficult. The world around him did not feel the same anymore; everything from his former world kept on evolving while his life was frozen during the entire cancer trajectory. This complicated the (re)connection with family and friends. An AYA said, ‘‘I had to go to this wedding and you know it’s going to be hard but still you want to do that. And then, you see your friends, still having fun and then you think ‘Why not me? Why can’t I just be normal, like all my friends…just dancing?’ That is the hardest thing for me.’’ Although the AYA’s life was put on hold, the development of his identity was not. All AYAs declared that, throughout the disease and its treatment, they had become different people. The AYAs felt that the cancer experience was not a temporary occurrence, as a first thought, but an experience that they would carry for the rest of their lives. An AYA said, ‘‘Cancer is something that is with me, every day. Not that I necessarily talk a lot about it but inside, I carry it with me, like in a backpack.’’ Besides possible permanent limitations (e.g. an amputation), the cancer experience seemed to have had a significant impact on their identities. The AYAs declared that they had developed a new view on life, which could be positive or rather negative. Some AYAs perceived the cancer experience as a distinct lesson in life, saying that the confrontation made them more mature or that it taught them to appreciate simple things. As one AYA said, ‘‘I’m not going to say that I have defeated death but it is something in the back of my head…It’s like, I know I was lucky and now I am truly going to make something out of my life.’’

Major challenge In this phase, many AYAs felt alienated and did not know how to manage all the challenges after treatment had ended. The AYAs stated that they struggled with finding a new direction in life, for instance, concerning studies or employment. They had to deal with a lot of insecurities or fears, such as fear of relapse, fear that others would appreciate them less because of their cancer histories, or the insecurity of not finding a partner. An AYA said, ‘‘I have the feeling that I am now, after the treatment, more at a loss to know what to do, than during treatment, especially psychologically it’s difficult.’’ Some AYAs explicitly expressed the need for professional guidance for the psychosocial challenges they faced.

3.2 The Dynamics in Transitioning the 3 Phases

Underpinning the three phases, the following core dynamics could be distinguished. These dynamics could not be attributed to specific moments in time.

From ‘‘Having the world in own hands’’ toward ‘‘Realizing the inability to have everything under control’’

Before the diagnosis of cancer, the AYA felt quasi-invincible and, as he was becoming more independent from his parents, experienced a growth in control over his own life. When he was subjected to an unpredictable disease and its treatment, the AYA lost this sense of mastering life and became more aware of his own vulnerability. This feeling of vulnerability was affirmed by the permanent physical limitations and the psychological changes due to the disease and treatment and the fear of relapse. An AYA explained, ‘‘Recently I had a sore throat and I felt a swollen gland. I became crazy! I called my physician immediately who took a blood sample. Fortunately, it was all okay, a weight off my shoulders, really. I think this fear will stay forever.’’

From ‘‘Having a familiar identity’’ toward ‘‘The quest for a new identity’’

During active treatment, the AYA lost the identity he had created before the diagnosis. The physical alterations changed his self-image and influenced the AYA’s feelings of personal freedom and independence. Things the AYA used to take for granted in life, such as finding a partner, having a family of his own, or entering a good profession, became uncertain. As one AYA said, ‘‘I’m afraid that in the future, a possible employer will choose someone else instead of me. Imagine that I become a very good educator and that an employer would prefer someone not that good as me just because this person does not have physical limitations… I really ask myself how this will turn out for me in the future.’’ The AYA felt forced to redefine his self and his capabilities.

From ‘‘Seeing cancer as something far away’’ toward ‘‘Living with cancer in a backpack’’

Before they became ill, most AYAs considered cancer as a disease of elderly people. The data demonstrated that they perceived cancer as something far away. At diagnosis, they perceived cancer as a temporary occurrence, in the here and now. In follow-up, some AYAs started to wonder what the impact of their cancer trajectory would be in the course of life. They realized that this experience would remain present somehow and that they would take it along with them forever. An AYA told, ‘‘It is a part of my life and it will stay a part of my life.’’

From ‘‘Living a normal life’’ toward ‘‘Creating a new normal life’’

Throughout the process, the normal life of the AYA crumbled away. Initially, he tried to maintain this normal life because he still saw cancer as a temporary, passing experience, but as time passed, he realized that this was not possible. When the treatment ended, the AYAs needed to construct a new normal life, which was challenging for many of them. An AYA stated, ‘‘I lost a part of my life and I found this really difficult. Every week, I trained [cycling], for hours. I lost all of this. Now, I need to find something to fill this gap.’’

From “Having a familiar network” toward “Identifying renewed meaningful relationships”

Initially, the AYAs were not interested in meeting other AYAs with cancer. They declared that the friends they had were all they needed. This changed throughout the illness trajectory. Because a considerable number of AYAs found that former friendships changed or faded away, they needed to find “new” connections and acceptance with peers. At that point, many of them wanted to contact other AYAs with cancer, because as one AYA explained, “If I talk to others who had cancer, I feel less of an outsider.”

The AYAs who had a partner before they became ill reported changed dynamics in their relationships. Some relationships came to an end. An AYA told, “My boyfriend became jealous and started to check me out. I had the feeling that he had lost control because he used to feel responsible about me. He took care of me but then, this wasn’t the case anymore. I felt him having difficulty with this. In the long run, he forbade me to see my friends any longer. That was the final straw.” One AYA, still together with her boyfriend, stated, “When we used to be together every day, I didn’t realize anymore how much I loved him. But now I see him like one or two hours a day, now I know again how it feels to miss him. Now I realize that I truly love him.”

The AYAs stated in the interviews that the cancer also had an impact on the relationship they had with their parents. Many AYAs declared that the relationship became more intense. The AYAs experienced an increased need for support from parents because it became too difficult to deal with the cancer experience alone. Often, AYAs stated that their parents had become more protective, which was sometimes difficult to handle once they needed to regain their independence in life after treatment ended. As one AYA said, “Towards my parents, it is more difficult. They are very well organized and well-structured and I prefer to do whatever I want now. If I want to travel to Africa, I will do that… I try to avoid stress as much as possible. I want to take it easy. Sometimes, my parents do not understand this. I have changed as a consequence of my experience.”

4. Discussion

Adolescents and young adults with cancer go through a distinct biopsychosocial process during their illness trajectory. This dynamic 3-phase process offers understanding in how AYAs, throughout the cancer trajectory, attempt to maintain in control, how they redefine the self, what their experiences add to their long-term course in life, and how their expectations of their social networks change.

Having a sense of control is of great importance for the AYA. When cancer has taken over the life of the AYA, regaining a sense of control is crucial for his recovery process[2]. The formation of a new identity and a new normal life in the process allows the AYA to regain control[3]. This can be facilitated by empowering the AYA to make his own decisions during treatment[27], which demands a certain flexibility from healthcare professionals[38]. To meet the changing needs of an AYA, it is crucial that the AYA's development is considered[39,40], and that psychosocial interventions are offered across the total disease trajectory[41]. For instance, Zebrack et al.[5] suggest that giving the AYA the opportunity to define how much information he wants and when should be a constant throughout the continuum of care[5]. They also found that AYAs ranked opportunities to meet other AYAs with cancer significantly higher later in the trajectory. This is similar to our finding that the need of AYAs for peer support increased as they went through the different phases.

Previous research indicated that, depending on the phase of the illness, certain views or expectations may differ[20,27,42]. The findings in this study emphasize the variation in the AYAs' needs throughout the cancer experience. What an AYA finds essential today may not be a priority tomorrow. For instance, an AYA can be very preoccupied with hair loss initially, which prompts wearing a wig or learning beauty techniques. However, this concern may assume less importance when the AYA needs to cope with a limb amputation. Our findings support Millar et al.[43] who argued that the needs of AYAs are phase sensitive, for example, on treatment, and that the needs for age-appropriate hospital care, food, and activities are often unmet. After treatment has ended, emotional and psychological needs, such as support in coping with identity changes and a new direction in life, become primary. Because cancer not only determines the life of AYAs during diagnosis and treatment but has a profound impact on their future lives as well, psychosocial interventions should be implemented across the entire disease trajectory and even into long-term survival[41,44,45].

The demonstrated importance of normality, as well as its changing nature, from losing the ‘‘old normal life'' toward the creation of a ‘‘new normal life,'' confirms previous research[17,20,42,46]. In this process, adjustment to the disease is an essential phase, which can consist of negative and positive aspects. Similar to our findings, in a study by Mattsson et al.[12], AYAs reported positive aspects, such as developing a more mature view on life, as well as negative aspects, including worries about relapse. How an AYA adjusts to the cancer experience translates into the development of a new identity. This is affirmed by Park et al.[47] who stated that the identification of the AYA with a ‘‘survivor’’ or with a ‘‘person who has had cancer’’ influences their well-being. As our findings show, after treatment ends, many AYAs feel alienated and somewhat confused about how to go on with life. This is similar to studies of Cantrell and Conte[48] and Thompson et al.[1] who pointed out that AYAs are often unprepared as they move out of an intense healthcare regimen toward follow-up care. For many AYAs, it is not until the follow-up phase that they start to process all the things that they have experienced[49]. It was clear in this study that AYAs had close relationships with their parents. The AYAs needed their parents ‘‘being there,’’[50] which is also identified as a parental need in pediatric oncology[51-53]. The AYAs considered the need for their unconditional presence and support to be self-evident. They found it essential to manage the support they would receive from them. Evidence is growing that psychosocial care from informal networks, as well as from healthcare professionals, is equally, if not more, important after than during treatment[54]. Psychosocial support should be made available as part of transitional services in a multidisciplinary approach[55].

4.1 Implications for Practice

By highlighting an underlying process, which includes three different transitional phases, this study demonstrates the importance of holistic care and patient-centered interventions throughout the cancer trajectory. Examples of these interventions may be multidisciplinary consultations during treatment and in follow-up, network meetings[56], promoting peer support in follow-up, and coaching parents in the process of balancing protection and facilitating independence for AYAs. Healthcare professionals are challenged to help AYAs in responding to the different challenges and needs they experience. Understanding the process the AYAs undergo can be the necessary first step. In a culture of increased development of clinical pathways and standardized care, the self-reported experiences of AYAs emphasize that an individual approach is still of value. Different from younger children, AYAs are growing into independence, which can be demonstrated in changing preferences or nonconforming behavior. Therefore, an open attitude and a willingness to communicate by healthcare professionals can improve patient outcomes.

Healthcare professionals should pay special attention to the dynamics underpinning the 3-phase process because these demonstrate how AYAs’ experiences and needs change during the cancer trajectory. Thus, our theory highlights the importance for healthcare professionals to strive for individualized and flexible care. This requires an open approach in which healthcare professionals are willing to start a dialogue with AYAs to discover their needs and wants.

Following our theory on the 3-phase process, the ‘‘AYA box’’ was developed, which was based on the experiences and needs of the AYAs with cancer that were revealed in this investigation. This patient-centered box was developed to meet the AYAs’ specific needs and to enhance the communication between the AYAs, their informal networks, and professional caregivers. The box and its contents were attractively designed and youth based. The box includes several tools, addressed to the AYAs, which can be of value throughout the three phases of the cancer experience. It contains a booklet with meaningful stories of AYAs’ experiences. We developed cards that express the AYAs’ preferences in phase 1, to continue his own, normal way of living during hospitalization. Other postcards aim at creating more openness in communication with the AYA’s network. These resources meet the AYAs’ needs to direct their own care and have a voice in decision making, which is of value in phase 2. For instance, there is a postcard on which the AYA can mark expectations of healthcare professionals: a ‘‘Code for Good Practice.’’ With this tool, the AYA can inform his physician that he prefers to receive all medical information in the presence of a loved one. A brief symptom scale is available on which the AYA can score his psychosocial concerns, such as loneliness, feelings of guilt, or tension. Other postcards can be used to let friends and parents know how the AYA feels about them. Inside the box, there is a unique AYA tag, the meaning of which is known only to other AYAs with cancer. With this tag, the AYA can mark his door during his stay at the hospital. In this subtle way, the AYA lets other AYAs with cancer know that he is there and willing to meet them. In addition, special stickers were developed to express feelings or concerns. These tools are in line with the AYAs’ psychosocial challenges that are faced in phase 3. Cards with information or instructions, for example, about how to deal with physical alterations or about where to find trustworthy advice on the Internet, are included in the box as well. We also designed cards that help the AYA to reflect on past experiences and encourage him to describe expectations for the future. This may help the AYAs express what kind of professional guidance they may need after the end of the treatment. Adolescents and young adults given a diagnosis of cancer receive this box and are often encouraged by healthcare professionals to use the tools. These tools can also be used by healthcare professionals in their counseling. The box was brought before several AYAs with cancer to elicit their opinions. On the basis of the first positive evaluations, it has been introduced into practice in several hospitals and will be evaluated in future research.

4.2 Strengths and Limitations

In this study, valid findings were obtained, and data saturation was achieved. Some limitations can be noted.

All participants were recruited in one setting. This may have consequences for external validity[57]. In addition, sampling was in the beginning heterogeneous and was later followed by more theoretical sampling[58], common in a grounded theory approach. Core concepts of meaning for all participants were identified, irrespective of the sampling. However, if the aim was to further deepen a specific theme, for example, physical alterations, then the sampling method could have been too variable. In that case, it would have been advisable to sample more homogenously on diagnosis or pathology, resulting in more insight in, for instance, the difference in meaning of physical alterations for an AYA with leukemia and for one with an osteosarcoma.

This study focused on the experiences of AYAs in curative cancer treatment. The findings cannot be generalized to AYAs who are in a palliative phase.

At the end of their cancer trajectory, AYAs have reached a different perspective on the disease and its impact than in the beginning. Moreover, the cancer experience has touched every aspect of their self, leaving traces on all domains of life. As mentioned previously[46,59], not all these changes can be attributed solely to the cancer experience. Adolescence is a distinct period, in which several life events change the ways maturing AYAs feel and think. It cannot be determined whether certain developmental aspects are related only to the cancer experience or are part of the ‘‘normal’’ development of adolescence.

4.3 Implications for Future Research

It may be that the cancer experience for an AYA who knows that he is in a palliative phase has other meanings than for the AYAs who were included in this study. This would be an interesting focus in future research.

Future research can also focus on support for AYAs and their parents during transition from active treatment into follow-up. Developing and evaluating psychosocial interventions that respond to the process that AYAs go through during this phase are needed to optimize care for AYAs.

5. Conclusions

This article reveals the dynamics in the experiences of AYAs with cancer. In this process, three phases are described: ‘‘maintaining a normal life’’, ‘‘normal life slips away’’ , and ‘‘toward a new normal life’’. In these phases, AYAs develop different views on the impact of the disease in their lives, and their identities are reformed. Furthermore, the process demonstrates distinct needs and expectations of AYAs toward their informal and professional networks throughout the cancer experience. Understanding and taking this into account can facilitate the development of psychosocial interventions for this distinct population. Healthcare professionals are specifically encouraged to take a patient-centered approach with a focus on open communication to explore the varying needs throughout the cancer trajectory.

Acknowledgment

The authors would like to thank all study participants for sharing their intense experiences.

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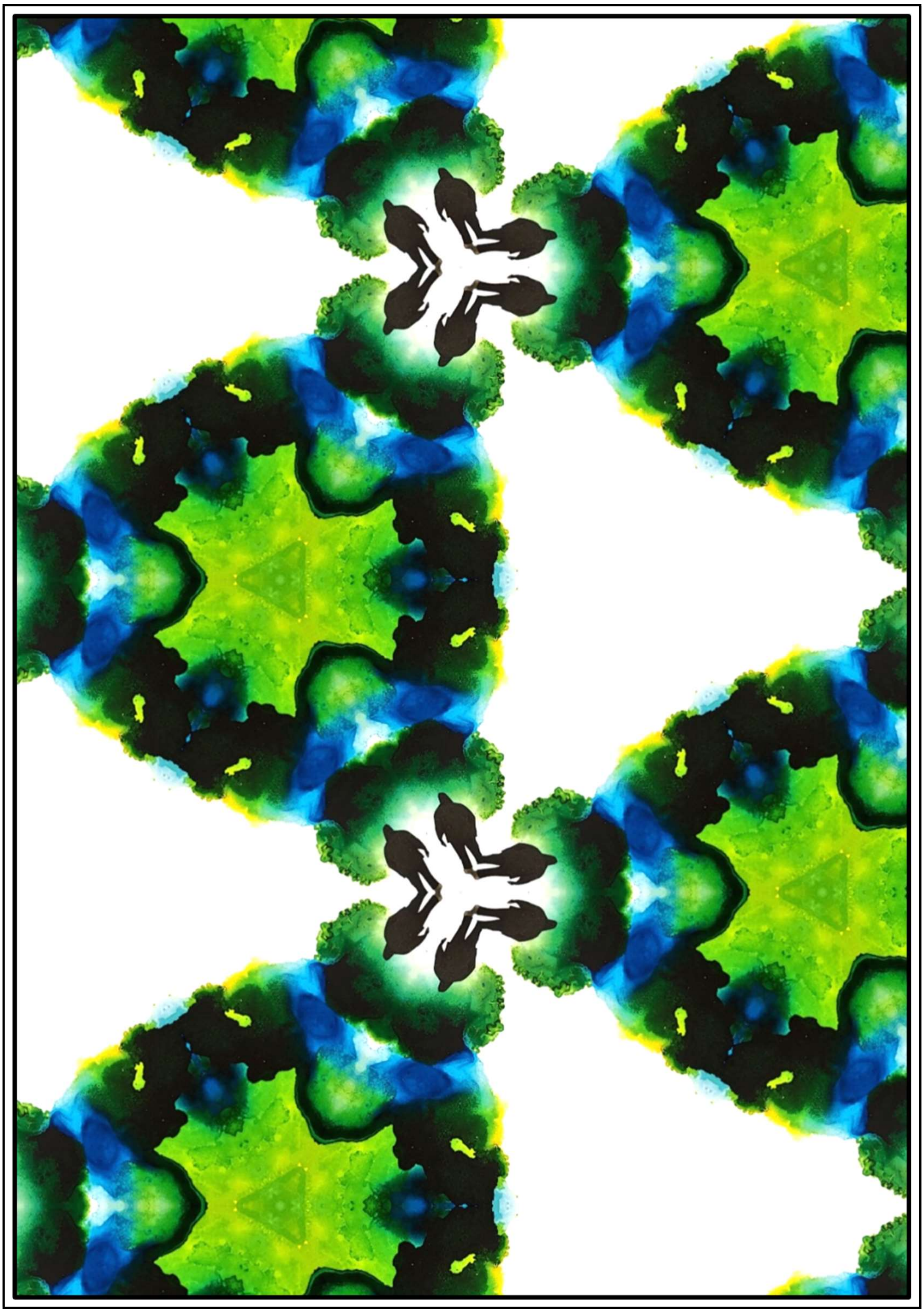
Deel 2

Het perspectief van de AYA-overlevers

Hoofdstuk 4

Living as a cancer survivor: a qualitative study on the experiences of Belgian adolescents and young adults (AYAs) after childhood cancer



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Gebaseerd op het artikel van Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., & Verhaeghe, S. (2019). Living as a cancer survivor: a qualitative study on the experiences of Belgian adolescents and young adults (AYAs) after childhood cancer. *Journal of Pediatric Nursing*, *49*, e29-e35. https://doi.org/10.1016/j.pedn.2019.07.015

Category Pediatrics, 28/177, Q1, JCI Percentile 84.46

Abstract

Purpose

Insight was sought in how a childhood cancer experience plays a role in daily life of adolescents and young adults (AYA) survivors.

Design and methods

A qualitative research in which semi-structured interviews were held with 21 AYA survivors of childhood cancer between the ages of 14 and 25. The AYA survivors were recruited from two pediatric oncology departments of two university hospitals in Belgium.

Results

The current situation and behavior of AYA-survivors who have been treated for childhood cancer are covered in five categories: The Feeling of Being Different while Aiming for Normalcy in Relationships, Living with Existential Uncertainty, The Conscious Protection of Health, The Attachment to the Parent(s) with Whom the Cancer Experience was Shared, and The Desire to Be Meaningful to Others.

Conclusions

The AYA survivors did not feel that their cancer experience dominated their current daily life, yet, the cancer experience had an important impact on their functioning.

Practice implications

The findings of the study can be used to optimize holistic psychosocial care of AYA survivors. By starting from the key elements in their current functioning, health care professionals can tailor their support to the way in which AYA survivors have integrated their cancer experience into their everyday lives.

Keywords

Qualitative research; Cancer survivors; Childhood cancer; Adolescent health; Nursing

1. Introduction

A large number of adolescents and young adults who have survived childhood cancer (referred to herein as: AYA survivors), experience, in one or more areas, late effects of their cancer and the related treatment[1,2]. These long-term consequences are often chronic in nature, causing the consequences of their survival to be ingrained into the entire course of their lives[3].

Earlier studies show that AYA survivors experience neuro-cognitive problems[4-6], behavioral problems[1,7], growth disorders[8], and/or a loss of mobility[9] as a result of their cancer and/or their treatment. At the same time, studies reveal that AYA survivors, in comparison to their healthy peers, more frequently suffer from post-traumatic stress symptoms[10,11]. In addition to such psychopathological conditions, AYA survivors can also experience psychosocial late effects, for instance in the areas of education[12], social behavior[13], or sexuality[14], which are sometimes less clear to define but, nevertheless, quite disruptive[13]. Besides negative consequences, a childhood cancer experience may also foster positive changes, as described in studies concerning post-traumatic growth, resilience or thriving[15-17].

While studies often focus on separate parts of the impact of cancer by studying the existence and significance of specific health problems, the reality is that its impact is very much interrelated in nature and that it can be felt on all life domains at the same time[18]. Physical long-term consequences for example always come along with a psychological, social and emotional impact, which makes it more complex to fully understand how these consequences affect the survivors' wellbeing or suffering. Especially, as it has been addressed before that the impact of cancer can be more determined by the survivor' subjective appraisal or individual perception of the cancer experience, than objective factors such as cancer characteristics or tumor biology[19]. Therefore, a more holistic view on how different mechanisms in a cancer experience impact the way survivors live their life, is needed. Yet, current literature seldom provides knowledge on the extent of the entire cancer experience[20,21].

Besides the challenges of cancer survivors in general, childhood cancer survivors have to cope with their cancer experience in a distinctive stage of development, namely adolescence. Certain psychosocial topics which can be rather latently subjected to the influence of cancer and its treatment during childhood, such as education orientation, physical appearance, starting a relationship, fertility etc. come explicitly to the foreground when transitioning into adulthood. For instance, the significance of having undergone fertility preservation can be primarily felt when AYAs start to explore their desire to have children[22]. At that point, some survivors realize that they don't have any recollection or much knowledge about the procedures they underwent as a child or are even unaware of their fertility status[23]. Dealing with this new perception of things can cause additional stressors in the AYA survivors' pursuit towards normalcy[17,21,24] and their attempts to reach full potential in life[12,25].

Even though long-term follow-up care is recommended for children with a cancer history, few attend regular follow-up[26,27]. The current conventional psychosocial care for children with cancer is frequently halted upon termination of the curative treatment, and only responds sporadically to the psychosocial needs of AYA survivors, or often in an insufficiently structured manner[1,28]. Many AYA survivors experience barriers to engage in survivorship care, such as practical or financial issues, reluctance for help or difficulty in transitioning from pediatrics to adult care[29-31].

Therefore, among policy makers and healthcare professionals, a strong call for appropriate and integrated psychosocial support remains highlighted[2,28]. An important first step in the determination of the different areas that need to be addressed in, for instance, survivorship care plans, screening tools or specific interventions for AYA survivors, is a thorough exploration of their perspective with a view on gaining insight into the influence of childhood cancer experience in daily life[21,24,32]. However, there is scant literature on how AYA survivors experience their life to be affected by their childhood cancer[20,33,34].

The aim of this study is to gain insight in the holistic impact of a childhood cancer experience by examining the perspective of AYA survivors firsthand, exploring in what way a childhood cancer experience plays a role in their current daily life and identifying their needs and resources.

2. Method

2.1 Design

A qualitative research design was chosen since this allows for the in-depth exploration of participants' perspectives, and facilitates the detailed description and understanding of experiences in terms of the meaning people bring to them[35]. As we intended to develop insight in the multiple layers of the experiences of AYA-survivors, semi-structured interviews with AYA-survivors were performed and thematically analysed[36].

2.2 Sample and Recruitment

From June 2014 to June 2015, AYA survivors were recruited from pediatric oncology departments of two university hospitals in Flanders, Belgium. In each setting, one member of the pediatric multidisciplinary team acted as reference persons and identified eligible participants from the electronic patient file from the first cancer episode. AYA survivors who had been between the ages of 0 and 14 when they started their first cancer treatment, who were between the ages of 14 and 25 when participating in the study, and who had terminated their curative treatment at least two years prior to inclusion in the study were purposefully selected. Participants who had a relapse after the age of 14 were excluded from the study. Participants who lacked sufficient proficiency in the Dutch language, and those whose contact details were no longer available, were excluded too.

To achieve diversity in the study population variation was sought with regard to age, sex, diagnosis, treatment, age at the time of diagnosis, level of education, marital status, and the amount of time that has passed since their treatment was completed. As data collection and analysis alternated, new participants were purposefully selected to pursue more comprehensively information regarding their experiences and to study if certain themes were shared. At a given moment, for instance, AYA survivors were selected who had become ill at an early stage in their childhood. In that way, we could study if the AYAs' recollections of their illness and treatment influenced the way they experienced their survivorship.

Of all selected AYA survivors (n=23), two refused to participate, one due to lack of energy (n=1) and one due to too many physical complaints (n=1). The reference persons acted as "gatekeepers"[37]: they deterred four eligible AYA survivors from participating because they considered recruitment as inappropriate because of severe mental disability, too limited interviewing capacity (autism spectrum disorder) and an emotional crisis situation (a problematic parental divorce and a recent parental cancer diagnosis).

2.3 Data Collection

One-time individual face-to-face interviews, with an average duration of 70 minutes (range 31-178 minutes) were conducted by two researchers (NB and ED). All interviews were audio recorded and transcribed verbatim.

An interview guide was used. Open-ended questions were posed, aiming to elicit extensive answers and expand on key components of the experiences under study[38]. The interview started with an open question to introduce the focus of the interview without stearing it towards a specific theme. The opening question was: “What does having experienced childhood cancer means to you?”. The following questions were based on what the participant talked about. If it was necessary to give extra input, themes derived from literature review were introduced. Each interview started open but in further interviews, themes that came to the fore in the analysis of earlier interviews were also introduced. Topics addressed included confrontation with the disease, experiences with the consequences of the disease and its treatment, and the requirements and needs experienced. Throughout the cyclic process of data collection and analysis, the interview guide was adapted to allow further exploration of specific themes that emerged during the analysis[39,40].

2.4 Data Analysis

The research group was composed of the two researchers charged with interviewing (NB and ED) and four researchers (MK, PR, AVH and SV), all of whom had different content-related and/or methodological expertise which gave breadth to the analysis[39,41]. Investigator triangulation was applied throughout the entire research process[42] and an audit trail was set up[43]. Data analysis was performed according to an inductive thematic analysis approach with an aim to identify data-driven themes[36].

All six researchers independently read and re-read the first four interviews. This enabled them to immerse themselves in the data and to identify patterns and meanings in the data. Supported by NVivo 10 software[44], manageable segments of text with similar meanings were given data-driven codes and integrated in a first code tree. New raw data were handled similarly. The open coding of the first eight interviews was followed by axial coding as codes in the code tree were carefully organized into (sub)categories, based on relationships within. Data were compared and reassembled which enabled the identification of patterns of meaning or themes[36]. All interviews went through this process of data analysis. The research group together worked out a framework of themes that with every new data, was adapted and thoroughly refined. Memoing helped in describing in detail interpretations, ideas, potential directions and conceptual thoughts[35,38]. Themes were theorized at a latent level, identifying underlying assumptions and meanings within the AYA survivors’ experiences. Data saturation was reached, meaning that gathering new data no longer gave rise to new theoretical insights regarding our overarching themes[38].

2.5 Ethical Review

The study was approved by the Ethics Committees of Ghent University Hospital and Leuven University Hospital.

All participants signed an Informed Consent Form. The written permission of parents of AYA survivors under the age of 18 was also obtained.

3. Findings

A total of 21 semi-structured interviews were conducted, with eight male and 13 female AYA survivors. The average duration between the end of the curative treatment and participation in the study was 11 years (range: 4-25 years). The analysis indicated that the AYA survivors could be divided into two analytically different groups. Those who received their diagnosis prior to attaining the age of seven comprised the group of participants diagnosed in “early childhood” (n=8). The remaining AYA survivors diagnosed in “late childhood”, namely between the ages of seven and 14, comprised the second group (n=13) (see Table 1). The decision to use the age of seven as a delineating factor was supported by theories taken from developmental psychology. Piaget, for example, describes how a person’s thought processes are more logical, more flexible and better organized in the concrete operational stage than in early childhood[45]. Erikson describes how social interaction becomes more important for primary school children[46]. Additionally, the manner in which children understand disease can be linked to a change in development from the age of seven onwards[47,48].

If a demonstrable difference in findings was found between both groups, this difference is made explicit. If not, the subjects are referred to more generally as “the AYA survivors”. The “cancer experience” refers to the AYA survivors’ experiences in their trajectory from diagnosis up to and including the follow-up phase.

In the following presentation of the findings, it is first explained in what way the AYA survivors reflected on the childhood cancer experience in their past and how they did not perceive it as a “halt” in their development. This is followed by what was learned, from the data, about the influence of the cancer experience on the AYA survivors’ existence and actions. Five categories were identified that demonstrate the role the childhood cancer experience still played in the current daily life of AYA survivors.

Table 1 Demographic Characteristics of the Participants (N = 21)

Time of the Cancer Diagnosis		Early Childhood (0-6y)	Late Childhood (7-14y)	Total
Age at diagnosis, y	0–3	4		4
	4–6	4		4
	7–10		3	3
	11–14		10	10
Type of cancer	Bone tumor		5	5
	Leukemia	2	6	8
	Lymphoma		1	1
	Soft tissue sarcoma	2		2
	Hepatic tumor	1		1
	Brain tumor	2	1	3
	Spinal tumor	1		1
Time since the end of the treatment, y	2–5		5	5
	6–9	1	7	8
	10–13	4		4
	14–17	2	1	3
	18–21			
	22–25	1		1
Sex	Female	5	8	13
	Male	3	5	8
In a romantic relationship	Yes (female AYA survivor)	1	6	7
	No (female AYA survivor)	4	2	6
	Yes (male AYA survivor)	1	2	3
	No (male AYA survivor)	2	3	5
Currently in school or (un)employed	Vocational school	2	5	7
	University college	2	2	4
	University		2	2
	Employed	2	1	3
	Unemployed	2	3	5

3.1 The cancer experience: part of a personal life history

To the interviewed AYA survivors, cancer was something that just happened to them during their childhood. They had no other alternative than to deal with it, as one AYA survivor said: “It was something that had to have happened” ; another AYA survivor described it as a twist of fate.

Similar to other significant events in their lives, such as a parental divorce, all AYA survivors considered their cancer experience as a crucial event in their life course. Those diagnosed in ‘late childhood’ created a clear demarcation between life before and after cancer. They had memories of life before as well as after cancer. Those who became ill in early childhood had no awareness of a life without the experience of having cancer. One AYA survivor explained: “The way I am today, I have always lived with it, so this is normal, it's a normal thing.”

Although described as an important life event, most AYA survivors did not give their cancer experience a prominent position in their present lives. The interviews revealed that AYA survivors saw the cancer experience above all as something that was past. They described their present lives to be active, full and the cancer experience was never construed as a “halt” in their development. Regardless of whether they were affected by cancer at an early or later stage in their lives, all said that they had learned, over time, to deal with the impact of the cancer experience on their lives. An AYA survivor said in the interview: “It is not something that has dominated my life. Rather, I have the idea that all the choices I have made were not connected to this experience (…) I have simply led my life. I simply went on.” After their cancer experience, all AYA survivors built up a new, normal life, in which they became used to dealing with the consequences of the cancer experience and the medical follow-up, as one AYA survivor illustrated: “You learn to deal with it, and after a while you are used to it (…) it is most difficult at first, but… the better your progress and the more frequently you have to do the same thing each day, over and over again, the more normal it becomes.”

Several AYA survivors, including the ones diagnosed in ‘late childhood’, explained that when they were children, they did not fully understand the significance of their cancer experience and had little understanding of the life-threatening nature of the disease or the seriousness of the situation. The full impact of the cancer experience was frequently only understood retrospectively, at a later age (e.g. when certain late effects became clear or when the survivors gained more insight into the full course of the treatment). An AYA survivor said: “Because you have fewer muscles, your movements are restricted. And, at certain times, it becomes important to you to not always lose [at sports]. You want to join in with the rest, at their level. This just wasn't possible at a certain point in time, and with this my understanding grew. […] Of course, I knew that something had happened to me but the concrete understanding that what had happened to me was something very serious only came to me in the second or third year [of primary school].”

3.2 The impact of the cancer experience on existence and actions

Both the past cancer experience and its consequences over time influenced the AYA survivors’ identity. Some survivors wondered which aspects of their personality could be attributed to their cancer experience, and which to their own character or disposition. An AYA survivor said: “I think that it changed me and I would like to know how things would have been if I had not had cancer. What would I be like then? (…) What would my personality be like, would I have been more sociable or… I don't know, more confident in life?” . These were considered rhetorical questions, as another explained: “I don't know what was there before the cancer (…) I don't know how it could have been different.”

In all cases, the cancer experience had an impact on the current functioning of the AYA survivors and their existence. From the analysis, the following elements that typified their current lives were identified.

The feeling of being different while aiming for normalcy in relationships

Regardless of whether AYA survivors became ill in early or late childhood, all AYA survivors said that their background gave them the feeling of being different compared to their peers. The AYA survivors distinguished themselves from the rest due to their experience with having had cancer, having undergone treatment and their current experience of the associated consequences. At the same time, it was crucial for them that others did not perceive them as different. An AYA survivor said: “I want to be just like everyone else and not that person with her leg and scars. That person who was ill, and so on.” Another AYA survivor explained: “You are different any way you look at it, but you don't want other people to see you as different. You want simply to be the person that you want to be, just like any other person.” Still, some AYA survivors expressed a need for recognition of who they were and acceptance of their ‘differentness’ by others and/or their environment. They expected people to treat them as normal while taking their special situation into account: “They have to simply take me as I am, with my pain, with my background. Interviewer: And if they can't? AYA: Then I don't need them to be a part of my life.” A distinctive example illustrating AYA survivors’ desire not to be different from others was the well-considered disclosure of the past cancer experience.

The announcement of the cancer experience, or “disclosure”, to people who had not been informed previously appeared to be a prominent detail in the social relationships and activities of AYA survivors. Firstly, several considered disclosure to be inevitable, as the consequences of the disease were often apparent; e.g. for those with a prominent physical disability. Secondly, some AYA survivors also experienced a need to inform other people of their past, considering that it was a significant part of their life and a formative element in their personality. Whenever avoidable, people who knew nothing about the cancer experience were not informed “casually”; disclosure was prompted more frequently than not by a particular situation or certain point in time. To many AYA survivors, this depended on the moment which prompted disclosure to occur “automatically” or not. They explained that disclosure never occurred “out of the blue”: they needed a reason to talk about their experiences; e.g. when they needed to clarify why there were certain things they could no longer do, or when they needed to explain their behavior. An AYA survivor illustrated: “…if they ask ‘why don't you want to eat that?’. I liked it before, but I don't anymore because of the cancer.” The presence of security and trust in the already existing relationship was believed to be essential. As one AYA survivor said: “I would never tell people immediately (…) When I start trusting a person more and think that this person is not likely to tell everyone else, I might”.

The majority of AYA survivors limited the information they shared with others in order to draw as little attention as possible to their cancer experience and to their “differentness”. Their focus remained always on safeguarding their normalcy. Some of them had experienced that people, once informed about their history of being a cancer survivor, distanced themselves from them or suddenly started treating them “differently”; e.g. with pity. To prevent these kind of responses, AYA survivors often shared only factual information about concrete matters, rather than their thoughts and emotions. One AYA survivor explained that she had a long and a short explanation, one more detailed than the other, but both a factual representation of occurrences, without further details about how she had felt.

Several AYA survivors made clear that when they talked about their cancer experience, their choice of words was well-considered, and that they often avoided the word “cancer”. For example, an AYA survivor with a visual impairment often told people that he had “something” as a child, without providing any further details. The interviews demonstrated that he was not the only AYA survivor to hardly ever mention the word ‘cancer’. The AYA survivors experienced that cancer has a specific connotation and emotional charge, with the implication that a generalized idea about cancer did not do justice to their individual and personal experience. Several AYA survivors pointed out in the interviews how they were confronted with prejudices and general preconceptions. One AYA survivor was told that he “didn’t look like someone who had had cancer”. Another experienced that people had doubts about his survivorship: “They say things like ‘You can always get it again’.”

Living with existential uncertainty

In the interviews, all AYA survivors expressed that their past cancer experience had confronted them with their own vulnerability. Once they had understood the seriousness of their experience, a significant time afterwards, an existential uncertainty arose. This became a permanent factor, forever ingrained in their lives. One AYA survivor said in the interview that every time he had to fill out a questionnaire, for instance regarding insurance, he felt the uncertainty of his health status: “It's like they [the questionnaires, e.g. regarding insurance] create the image that your health is more at stake.” Other AYA survivors mentioned this uncertainty in reflecting on the impact of the medication or in thinking about getting a loan. An AYA survivor stated: “I have an uncertain feeling about the effects. What are the effects of the medication I took, and so on, and the treatment truly? Those were extremely toxic substances.” while another one explained: “Not long ago in school, the teacher was telling the students that it is difficult for people who are very old or who have poor health to get a loan and I was thinking: ‘O, will that be a problem for me then?’. Normally, I shouldn't have a problem with that 'cause it [the cancer] is gone completely. Yeah, normally. I don't know how it will be for me exactly.” The AYA survivors mentioned that dealing with the consequences and impairments arising from their cancer experience was an everyday reality. They considered impairments as something that “they will have to deal with throughout their entire lives”. Most AYA survivors had learned over time that when growing older or entering a new phase in their lives, they continuously encountered situations which confronted them anew with the consequences of their cancer experience.

Digging deeper into the possibility of a future relapse, many AYA survivors mentioned that they had clearly been alerted to the possibility of a relapse in the early years following their cancer experience, but that their concern and fear of this had diminished with the passage of time. Although the uncertainty remained and although all assumed that a relapse could never be excluded, they experienced a certain degree of resignation; “If it happens, it will happen”. Furthermore, data revealed that a lot of survivors did not particularly consider a relapse as a risk, or renewed risk, of death. Rather, a relapse meant having to repeat the entire cancer experience again: the intensive treatment, the pain and discomfort. An AYA survivor told in the interview: “I don't think about the fact of dying; that you can die. Because, yes, you can always die and tomorrow, it's true, I could walk out the door and get run over by a car. So, that's not really what it's about. What's worse is that you would have to experience all of that once again, including the consequences (…). It genuinely is a coping process, and the period afterwards is the part I actually find hardest.”

The conscious protection of health

The interviews showed how the cancer experience also had an impact on the AYA survivors’ attitude towards health. The cancer experience had made all AYA survivors more conscious of their own health and vulnerability. Rather than ruling out or identifying a possible relapse, the check-ups for most AYA survivors every two years were particularly important with a view to assessing their health: “I have this list that they check every time: blood, kidneys, heart… I'm not scared of a relapse. It's rather the consequences of the chemo on my general health which can worry me sometimes.” Furthermore, several AYA survivors currently appeared to feel a great responsibility to protect their health and were careful to avoid any unnecessary health risks. The AYA survivors often emphasized that they would never smoke, drink or use drugs, and they often described themselves as not being hesitant to speak up when it came to their health. After all, their cancer experience had taught them that health was a priority issue, and that they had to act assertively if this was threatened. An AYA survivor said: “I have to drink a lot for my kidneys, and in the second year of secondary education I had a teacher who did not permit this. Well, I take my health seriously, so I drank during my classes. Then he said: ‘If you take one more sip, I will pour that bottle over your head!’ I became very angry, seriously, and the matter was brought to the attention of the school's directors. I mean, it wasn't a soft drink, you know, and it's for my health! I even had a note from my physician.”

The attachment to parent(s) with whom the cancer experience was shared

None of the AYA survivors interviewed had to undergo his or her illness trajectory and course of treatment alone. In all cases they had received support from one or both parent(s). The interviews revealed how the experienced togetherness in fighting the disease resulted in a strong sense of connection or attachment and loyalty towards the involved caregiving parents(s). These emotions appeared to be anchored in such a way that they would be felt by the AYA survivors throughout their lives. It also worked the other way around. When a parent, for example due to a divorce, was barely involved in the cancer experience, this also had left an indelible impression resulting in the AYA survivors feeling disconnected. An AYA survivor about his absent father: “Now, I can reasonably deal with it, but I will never forget who was there for me during that time and who was not.” Additionally, sharing the cancer experience had led to a reciprocity in which AYA survivors took care of the people who had taken care of them. An AYA survivor stated: “My mother herself says that there are few people who are as supportive and concerned about her as I am.”

Our data indicated that the close ties with the caregiving parent(s) did not stand in the way of the AYA survivors attaining independence as adults. While, for example, many of the AYA survivors interviewed did not feel any need to leave the parental home yet, others had already started taking steps towards adult independence. Based on our data, it seemed that the extent of independence mainly depended on the age of the AYA survivors. It appeared to be unrelated to the sense of connection the AYA survivors experienced with their parent(s). For example, an AYA survivor who currently had two children and had not lived with her mother for quite some time stated that she experienced her ties to her mother as more “crucial” to her than her relationship with her partner (who is also the father of her children).

The desire to be meaningful to others

As they were given so much care and attention because of their cancer experience, most AYA survivors tended to consider themselves as being able to demonstrate a lot of empathy and having a great desire to help others, which an AYA survivor illustrated in relation to his fellow cancer survivors “I try to be there for everyone, always, seven days a week.” Another said: An AYA survivor, called by her friends the “mother of the group”, explained: “You are aware of the problems and you want to prevent others from having them.” Their commitment towards others was also reflected in their academic choices. Many of the interviewed AYA survivors appeared to be interested in a career in healthcare. Nevertheless, as their own health had to always take precedence, some AYA survivors experienced feelings of guilt because they had not always been able to give priority to caring for somebody else. As an AYA survivor said: “I always have to think of myself first, before thinking of other people, but then I think: you know, in other ways I do think of other people. It's just that now my own needs have to take center stage. So, I need to be egoistical because otherwise I will not be able to make it through the week.”

4. Discussion

To gain understanding in the perspective of AYA survivors, research based on their self-reported findings is essential[49,50]. This study showed, that although the cancer experience is relegated to the background in their current lives, it exerts a significant impact on the AYA survivors’ functioning in daily life. A weighty issue is the importance the AYA survivors give to being normal. Their childhood cancer experience is a part of who they are and has been integrated in their daily life. Yet, it makes the AYA survivors feel different compared to their peers. In line with previous research[51-53], maintaining normalcy in social relationships can be a struggle. The interviewed AYA survivors appeared to sometimes communicate a contradictory message to the people surrounding them. Those who were closest to them were supposed to respond normally to them, while respecting their differentness at the same time. As such, this study uncovered a crucial balancing exercise for both AYA survivors and the people surrounding them, namely not feeling perceived (or perceiving) as different, while at the same time feeling acknowledged for (or acknowledging) what the AYA survivors had gone through.

For AYA survivors, finding this balance can also complicate the amount and manner of disclosure to people who are not yet informed about the AYA survivors' illness history. Literature confirms how self-disclosure is deemed necessary for building up an intimate relationship[54] or obtaining social support [55], yet it is hindered by difficulties such as uncertainty with regard to the way in which others might respond to the disclosure[56].

Consistent with other research[49,57], the AYA survivors in this study expressed that many years after their cancer experience they were doing fine from a psychosocial point of view. Even though they experienced adverse late effects, they felt that their past cancer experience did not necessarily interfere with their feeling of progression in life or their sense of normalcy. This should not be understood as a contradiction. Merely, it underlines that a childhood cancer experience can represent aspects both of burden and of benefit[58,59]. Moreover, despite the potential of a cancer experience to have a severe impact on future life, the cancer experience does not necessarily have to be regarded as overpowering, considering that in adolescence many different life events are experienced that lead to important changes in the lives of AYA survivors[52]. In a number of ways, the developmental milestones and expectations of AYA survivors in this study were similar to those of their peers (who have not had cancer), such as the search for a specific identity, the desire to be normal and to be accepted by others[60].

4.1 Implications for Nursing

Health care professionals could optimize psychosocial care by taking the experiences of childhood cancer survivors as a point of departure. It is important that individual support is tailored to the way in which AYA survivors have integrated their cancer experience into their everyday lives, and that support addresses the requirements and needs AYAs have in dealing with their survivorship issues. Although the AYA survivors in the interviews often indicated that their cancer experience was behind them, the analysis revealed that this life event had an existential significance to them which they will carry with them throughout their lives. An essential point for attention for health care professionals is that traces of this survival can often be read between the lines, so that it is recommended to be vigilant in this respect. Special attention could be given to the way AYA survivors communicate about their cancer experience. What do they share about their experiences? Concrete tension can arise between someone's desire to share an experience and his/her willingness to experience again the suffering in that experience by talking about it[61]. As shown in this study, some AYA survivors don't use the term 'cancer', when talking about their experiences. Health care professionals can try to reveal the meaning of the used terminology. For instance, avoiding the word 'cancer' could be a sign that the AYA survivor is worried of a possible negative attribution towards the disease[62]. It could also demonstrate AYA survivor's struggle with identity of being a cancer survivor, his/her sensitivity to social rejection or level of self-esteem[63]. It may reflect feelings of uncertainty regarding the seriousness of the past experience, its impact or possible future consequences. Yet, AYA survivors could just as well avoid the term 'cancer' because they do not want to be labeled, for instance because they do not want to dwell on the past and are focusing on the future[64]. Various explanations could be considered thus health care professionals should take the necessary time to gain understanding in the meaning that AYAs address to their survivorship.

4.2 Limitations

The study was marked by a number of limitations. The reference persons who selected the participants acted as gatekeepers. As a result, the participants in this study consisted primarily of AYA survivors who are doing relatively well in life and are not involved in an emotional crisis situation. It is possible that our sample therefore underrepresented AYA survivors who experienced more difficulty with their cancer experience or had other needs and requirements. As attendance of follow-up care was not an inclusion criterion, we have no information on the proportion of participants who are receiving regular follow-up care.

Despite the positive fact that so many AYA survivors could be recruited to participate in this study, AYA survivors with whom all contact was lost, could not be reached. Further research could explore if the AYA survivors who are lost to follow-up give other meaning to their experiences.

5. Conclusions

This study provided insight into what it means to be an AYA survivor of childhood cancer. The AYA survivors' concerns and how they integrated the consequences of their cancer experience in their current functioning, was explained. The AYA survivors did not feel that their past cancer experience predominated in their current normal life. Nevertheless, it was not possible for them to imagine a life without it; the cancer experience made them the way they are now and impacted their existence and actions. Psychosocial requirements and needs can be drawn from the experiences of AYA survivors which comprise the priority areas around which psychosocial support should be built up.

Acknowledgements

The researchers wish to thank all participants who were prepared to provide insight into the world as it is perceived by them.

This research was financed by the Flemish League against Cancer (KOTK), which had no influence in the design or output of this research.

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Hoofdstuk 5

Strategies of adolescent and young adult survivors of childhood cancer: a qualitative study

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Gebaseerd op het artikel van Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., en Verhaeghe, S. (2021). Coping strategies of adolescent and young adult survivors of childhood cancer: a qualitative study. Cancer Nursing, 44(6), E395-E403.

Category Nursing, 21/124, Q1, JIF Percentile 83.47

Abstract

Background

Many adolescent and young adult (AYA) survivors of childhood cancer are dealing with late effects of the cancer and its treatment.

Objective

The aim of this study was to explore how AYA survivors cope with their childhood cancer experience and its long-term consequences.

Methods

This is a descriptive qualitative study in which 21 semi-structured interviews with AYA survivors of childhood cancer were conducted. A thematic analysis was conducted by a multidisciplinary research team and supported by NVivo 10.

Results

Five coping strategies, which facilitated in living a normal life, of which some were developed during their cancer experience, were identified: (1) focusing on the “here and now,” (2) refraining from discussing the cancer experience, (3) recalling and preserving positive memories, (4) redefining the impact positively, and (5) consolidating and preserving a sense of togetherness.

Conclusions

Even long after completing treatment, the cancer experience remained deeply ingrained in AYA survivors' lives. Although they did not perceive their survivorship as a large problem in their current lives, coping with being a childhood cancer survivor did take effort. The deployment of specific coping strategies helped them to remain focused on the positive outlook in life and to deal with the long-term physical and psychosocial consequences of the cancer experience aimed at ultimately leading a normal life.

Implications for Practice

This study emphasizes the current individual frame of reference of the AYA survivor as the point of departure for psychosocial support. Healthcare professionals are advised to acknowledge and respect the value and function of the AYA survivors' coping strategies used.

Keywords

Adolescent health; AYA; Cancer survivors; Childhood cancer; Coping; Nursing; Qualitative research

1. Introduction

Survival of childhood cancer, an increasing trend, may be accompanied by morbidity later on[1,2]. Whereas childhood cancer itself is rarely defined as a chronic disease[3], it often causes threatening chronic health conditions[4]. Late effects of the cancer (treatment) such as developmental impairments, organ dysfunctions, and secondary cancers, as well as psychosocial adversities[5,6], manifest themselves during different periods of the survivors' lives. As a result, childhood cancer survivors need appropriate healthcare throughout their lifespan[7].

Adolescents and young adults (AYAs) who are survivors of childhood cancer may already have experienced various medical and psychosocial late effects[8,9]. To screen for and manage these late effects, guidelines have been developed by national and international organizations using the best available evidence[10–12]. However, to broaden the evidence, research addressing late effects is still needed[13]. Considering psychosocial late effects in AYA survivors of childhood cancer, opportunities to give voice to their specific experiences, needs, and requirements have not been as prevalent[14]. Nevertheless, the importance of focusing on the survivors' experiences and perceptions and how these impact the survivors' lives, rather than merely studying the actual existence of health problems, has been underlined previously[15,16]. Studying the perceptions of AYA survivors and assessing their specific needs are important steps in creating comprehensive care[13]. If healthcare professionals understand the impact of being a childhood cancer survivor and are more conscious of the ways how AYAs have adapted to the consequences of this experience, they can develop effective programs that promote the long-term wellbeing of survivors. Therefore, we aimed to explore how AYA survivors cope with their childhood cancer experience and its consequences in daily life.

2. Methods

2.1 Design

A large qualitative descriptive study using semi-structured interviews and a thematic analysis[17] into how AYA survivors and their parents experience life after childhood cancer was performed. The findings based on the semi-structured interviews with AYA survivors were described in two articles. The first article considers the overall experiences of AYA survivors and the meaning of their current concerns[18]. This second article presents the distinct coping strategies of AYA survivors that were particularly identified in the data.

2.2 Sample and recruitment

Between June 2014 and June 2015, adolescent and young adult survivors, who were between 0 and 14 years old when they were given their first cancer treatment and who had ended their curative treatment two years at the minimum, were purposefully selected for this study. Participants had to be between the ages of 14 and 25 years at the start of the study. Adolescent and young adult survivors who relapsed after the age of 14 years, who did not speak the Dutch language, and whose contact details were no longer accurate were excluded.

To ensure a wide range of experiences and multiple perspectives, maximum variation sampling was used[19]. Diversity on the following characteristics was sought: sex, age, age at diagnosis, diagnosis, education level, marital status, and the amount of time that had passed since the AYA survivors had terminated their treatment. Later on, iterative data collection and analysis allowed to purposefully select new participants guided by preliminary analysis[20]. For instance, after some interviews, it was noticed that recollection of the illness was an important issue because it seemed to have an influence on the way AYA survivors experienced their survivorship. At that point, most of the interviews were conducted with AYA survivors who were given a diagnosis in late childhood (LC). Thus, for the following interviews, participants who were given a diagnosis in early childhood (EC) were recruited.

The AYA survivors were recruited in the pediatric oncology departments of two Flemish university hospitals in Belgium. In both pediatric multidisciplinary teams, a reference person selected suitable participants from the electronic file of the first cancer episode and ascertained the AYA survivors' willingness to be contacted by a researcher. This was followed by an introduction to the study by the researcher and, after approval of the AYA survivor, the scheduling of the interview.

2.3 Data Collection

Individual, 1-time, and semi-structured interviews were held at a time and location of the participant's preference. Two researchers interviewed all the participants independently of one another (N.B. and E.D.). The interviews had an average duration of 70 minutes (range, 31–178 minutes) and were recorded and transcribed verbatim. An interview guide was used and modified during the iterative process of data collection and analysis[20,21]. In particular, insights and themes in early interviews caused the research group to want to explore these themes deeper; thus, the research group developed new enquiring questions for the subsequent interviews. Importance was attached to posing open-ended questions to receive comprehensive answers and to expand on key components of the experiences under study[22]. The interview began, for example, with the following question: “What does having experienced childhood cancer mean to you?” The following questions, posed by the researcher, would then be related to what the participant replied. For instance, when the participant told the researcher something about constantly experiencing fatigue, the researcher would ask: “How do you feel about this fatigue?” Topics addressed in the interviews were related to confrontation with the disease, experiences with the consequences of the disease and its treatment, and the requirements and needs experienced.

2.4 Data Analysis

The research group consisted of the two interviewing researchers (N.B. and E.D.) and four researchers (P.R., M.K., S.V., and A.V.H.) with content-related and/or methodological expertise. Data collection and data analysis were not performed consecutively but alternated in a cyclic process, enabling the development and refinement of themes. The data analysis was performed according to the thematic analysis approach[17].

To start with, the six researchers individually read and reread in an active way the first four transcribed interviews, allowing them to immerse themselves in the data and to identify patterns and meanings in the data. Furthermore, the entire research group reflected on the way researchers N.B. and E.D. introduced and formulated their questions and how they built up their interviews. Supported by NVivo 10[23] software, the two interviewing researchers (N.B. and E.D.) coded the four interviews into various units of text with a similar meaning, enabling the development of data-driven codes. These codes were checked for accuracy by the rest of the research team and became components of a first single code tree. After this, N.B. and E.D. performed the following interviews, and new raw data were managed similarly. After the first eight interviews were open coded, axial coding was performed through carefully organizing codes into (sub)categories. By comparing and reassembling the data, patterns of meaning or themes were identified[17]. A framework of themes was built, adjusted, and refined with every new data. The research group described interpretations, conceptual thoughts, and possible directions in memos[22,24]. Latent theorized themes captured underlying assumptions and meanings within the experiences of the AYA survivors. Inductive thematic data saturation was reached, meaning that themes were worked out in all their dimensions and variations and the mutual relations were clarified and validated[25].

In the process of data collection and analysis, the total research population was divided into two groups because it was seen that some experiences of AYA survivors were related to differences in age at diagnosis. Participants who were given a diagnosis before the age of seven years comprised the group of participants who were given a diagnosis in EC. Those who received their diagnosis after the age of seven years formed the group of participants who were given a diagnosis in LC. The delineation of both groups at the age of seven years can be confirmed on the basis of developmental psychology theories such as the work of Piaget and Inhelder[26], which defines a person's thought processes as more flexible, logical, and better organized in the concrete operational stage compared with EC, or Erikson[27], who discussed the importance of social interaction for primary school children. Furthermore, how children understand diseases can be associated with a change in development starting from the age of seven years[28,29].

2.5 Quality of data

The quality and trustworthiness of the study were enhanced by setting up an audit trail, organizing peer review, and implementing investigator triangulation and peer debriefing. The audit trail included a list of all the methodological steps taken in the research process, memos and notes on personal reflections and thoughts associated with the analysis process, and a description of the contextual data that applied when taking the interviews.

Each interview was coded by either N.B. or E.D., but they both reanalyzed the other's interviews as a means of peer review. During the entire research process, investigator triangulation was realized. All data were analyzed and discussed by all the researchers individually as well as collectively until there was consensus concerning the analysis[30]. The different backgrounds, professions, and perspectives of the researchers (social work, [pediatric] nursing, and psychology) gave breadth to the analysis[20,31]. The support and examining thoughts of the researchers who have considerable methodological expertise in qualitative research established peer debriefing[32].

A certified native-speaking translator translated all Flemish quotations of the AYA survivors into English. This translation was checked by members of the research team.

2.6 Ethical Review

The research ethics committees of the two participating university hospitals provided ethical approval of the study (B670201420572). Participation was voluntarily, and all AYA survivors signed an informed consent form. If the participant was younger than 18 years, the parents also gave their written informed consent.

3. Results

Of the 27 eligible participants, four were not invited on the recruiters' initiative. Reasons were either having severe mental disability, having limited interviewing capacity due to autism spectrum disorder, or currently being in an emotional crisis situation (a problematic parental divorce and a recent parental cancer diagnosis). Two participants refused participation for the following reasons: a lack of energy and too many physical complaints. In total, 21 participants were interviewed, of which eight were male and 13 female.

Adolescent and young adult survivors participated in the study, on average, 11 years after the end of their treatment (range, 4–25 years). The group of participants who were given a diagnosis in EC included eight AYA survivors. Thirteen AYA survivors received their diagnosis between the ages of seven and 14 years and comprised the group of AYA survivors who were given a diagnosis in LC (see Table). Certain differences in findings regarding the group of AYA survivors who were given a diagnosis in EC and those in LC are clearly described. If no difference can be demonstrated, we refer to the subjects more generally as "the AYA survivors." The "cancer experience" refers to the experiences related to the treatment trajectory that an AYA survivor has experienced, starting from the diagnosis period into the follow-up phase.

Table Demographic Characteristics of the Participants (N = 21)

Time of the Cancer Diagnosis		Early Childhood (0-6y)	Late Childhood (7-14y)	Total
Age at diagnosis, y	0–3	4		4
	4–6	4		4
	7–10		3	3
	11–14		10	10
Type of cancer	Bone tumor		5	5
	Leukemia	2	6	8
	Lymphoma		1	1
	Soft tissue sarcoma	2		2
	Hepatic tumor	1		1
	Brain tumor	2	1	3
	Spinal tumor	1		1
Time since the end of the treatment, y	2–5		5	5
	6–9	1	7	8
	10–13	4		4
	14–17	2	1	3
	18–21			
	22–25	1		1
Sex	Female	5	8	13
	Male	3	5	8
In a romantic relationship	Yes (female AYA survivor)	1	6	7
	No (female AYA survivor)	4	2	6
	Yes (male AYA survivor)	1	2	3
	No (male AYA survivor)	2	3	5
Currently in school or (un)employed	Vocational school	2	5	7
	University college	2	2	4
	University		2	2
	Employed	2	1	3
	Unemployed	2	3	5

3.1 Supportive Strategies for Living a Normal Life

The AYA survivors told the interviewers that, although their cancer experience was a thing of the past, it still had an important impact on their current functioning. The AYA survivors revealed that they became used to dealing with the consequences of the cancer experience and that they led their lives similarly to the way that their peers did. Yet, at the same time, they talked about the challenges they faced and explained how achieving and safeguarding normalcy took effort. Hereinafter, we present the strategies identified that helped them in living a life they described as normal. Some of these strategies were already developed during the cancer experience to deal with the challenges they had to face.

According to the AYAs, these strategies were often copied from the way in which their parents dealt with the cancer experience, as one AYA said in the interview: “When I was a child, my mother always talked with optimism about my situation and she really taught me how to look positive at it” (Q1, female, LC).

In addition, as another AYA explained: “My parents always fought for me (…) They never gave up, even though I was practically dead. If you grow up, surrounded by fighters, you start to possess this fighting spirit too” (Q2, female, LC).

In their current life, the AYA survivors used the following coping strategies.

Focusing on the “here and now”

The analysis revealed that the AYA survivors dealt with the consequences of the cancer experience by adopting the perspective of “here and now.” For some, this strategy was developed previously, during the cancer experience, and still adopted currently: “Personally, I thought the absolute worst part was chemotherapy. What I did was just think about the here and now. I think I still do that. Not thinking about tomorrow” (Q3, male, LC). The AYA survivors reported not to feel any need to extensively reflect on or speak about the past or to have any concerns about an unpredictable future. By considering the future as undetermined, they avoided the confrontation with possible consequences and learned to defer having to deal with it: “The future is still hazy (…) I know that there will be many times when things happen and I will say ‘That's not possible, that's not possible.’ We can try, of course, but the attempt will be unsuccessful, so we will have to try something else. So, yes, I will see that when the moment comes” (Q4, female, EC) and “If you cling to the possible consequences for later on now, this could be devastating” (Q5, male, LC).

Things that did not require an immediate response were postponed indefinitely: “I will know what to do when the time comes” (Q6, male, EC). It was apparent, for instance, that AYA survivors were generally well informed about the possible implications of their cancer experience on their fertility. However, as long as there was “no immediate cause to do so,” they did not feel the need to have their chances of conceiving a child assessed.

Refraining from discussing the cancer experience

The AYA survivors told the interviewers that they seldom spoke about their cancer experience, neither with close friends or relatives nor with persons they only have occasionally contact with and irrespective of whether these persons were involved during treatment. The analysis revealed that not talking about the cancer experience enabled the AYA survivors to safeguard normalcy, in which they found it crucial not to be seen differently by the people they know. However, being interviewed by an unfamiliar researcher, the AYA survivors managed to talk openly about their experiences. Several AYA survivors indicated they benefited from being able to disclose and tell their story differently from how they usually did: “You are an outsider, see? Imagine that I would do this in front of a friend (speak about everything like during the interview), this person would constantly think about what I told her because she sees me all the time, see, she might not be thinking about it constantly but she could remind me of it later, do you see? And you, yes, I will probably never see you again” (Q7, female, EC). Furthermore, the AYA survivors said in the interviews that they did not feel the need to put additional attention on their cancer experience in their current lives. Although AYA survivors indicated an ability to speak about their experiences, because “they have gotten over their cancer experience,” they saw no reason to do so. As an exception, the AYA survivors whose illness stemmed from EC and who had no memories of that period declared that they had wanted to talk to their parents about it. Because they wanted to reconstruct their past, they used to have questions about what it was like and what happened exactly. Once all their questions had been answered, they no longer felt any need to start a discussion about it.

The few moments in daily life in which the cancer experience was discussed with their parents, the AYA survivors said that they generally limited the conversation to practical and concrete matters that were of current importance: “Usually, the discussion is about the things that I am not allowed to do because I must be careful. That's about it. It's always about that, or about food; that there must not be too much salt in it because of my kidneys (...) Only about the present situation, always. About whether or not I should ride on a tandem bicycle, because my chances of falling off the bike are greater, and things like that” (Q8, male, LC). According to our participants, the experience and its consequences were discussed in a rational manner and emotions or experiences were not shared with one another in the family, because this could be confrontational and make it difficult for them to maintain their positive outlook. Adolescent and young adult survivors reported also that they refrained from sharing their emotions out of a desire to protect their parents and reduce their burden: “Yes, those emotions and everything that happened in the past, they make you think: ‘maybe it's better to just let that rest rather than bring it up all over again’” (Q9, male, LC).

Recalling and preserving positive memories

In the interviews, the AYA survivors who were given a diagnosis in LC often talked about negative and positive memories of their cancer experience and described how they dealt with them. Although the AYA survivors preferred to forget negative memories, they came to the fore. These memories frequently were associated with moments in which the AYA survivors had the feeling of having to cope with everything all alone: the idea that nobody understood them; that they were the only one who had to deal with the pain, nausea, or fear; that they felt themselves to be different from their contemporaries; and so on. An AYA survivor said that the negative memories “were haunting him” (Q8, male, LC). Adolescent and young adult survivors tried to defend themselves against the pain and sorrow associated with these memories by thinking back to this period as little as possible: “I have left all that behind me. Yes, I have a scar, but seeing it does not take me back to this period thinking: ‘this happened and the chemotherapy and everything.’ No. I do not want to dwell on it too much; I look towards the future and I want to get on with my life” (Q10, female, LC). Positive memories, on the other hand, were frequently associated with sharing the cancer experience and feeling connected to others, for example, feeling supported by others or playing games with friends who were trying to make you forget your disease: “I cherished the pleasant moments for longer, which is why I still remember them, as opposed to the unpleasant moments, which I have banned to the edges of my memory. I still have these memories, but they are hazier” (Q11, male, LC). These positive memories were recalled consciously, affirmed, preserved, and shared by the AYA survivors. Photos, stuffed animals, and gifts that helped to shape and keep the good memories alive were kept close. Preserving the positive memories and avoiding activating the negative ones helped them to soften the sharp edges of the cancer experiences.

Redefining the impact positively

Some AYA survivors placed the consequences or the impairments they had to deal within a perspective that enabled them to experience these not solely as problematic. They gave what happened to them another, less loaded definition: “My leg is in some way a handicap, but I do not look at it as a handicap. I look at it as a medical condition, an impairment. Of course, you can look at it from a negative perspective, but you can also look at it positively” (Q7, female, EC). Other AYA survivors considered their cancer experience as something that had contributed to their life in a positive way. Some of them placed the event in perspective by considering that things could have been worse or belittling their impairments by evaluating them positively within a perspective of life and death: “I would rather have these impairments than be lying in a grave” (Q12, female, LC).

Consolidating and preserving a sense of togetherness

The AYA survivors in this study went through their childhood cancer experience with the support of at least one of their parents. The AYA survivors told the interviewer how connected they felt with their parents as they had fought the disease together and often mentioned the positive frame of mind that they shared with their parent(s). From the interviews, it became apparent that, in their current everyday lives, AYA survivors tended to avoid conflicts with their caregiving parents. The close ties experienced in the past were maintained and affirmed as a positive consequence of the cancer experience. The AYA survivors were exceptionally tolerant of the “overly concerned” attitude adopted by their parents and spared their parents a lot of resistance, even if they did not always find this concern necessary or desirable. One of our participants said that he did not always speak out freely to avoid arguments: “I feel like I'm not allowed to have any arguments with them. I have to be able to get along with everyone” (Q13, female, LC). Another declared never starting smoking “out of respect for his parents” (Q14, male, LC).

Some AYA survivors reported that they also experienced a sense of attachment to the healthcare professionals with whom they shared the cancer experience at the time of their illness. Even AYA survivors who had been ill in EC and no longer had any memories of the disease and its treatment were able to discern a sense of warmth for the caregivers who provided them with follow-up treatment throughout the years. Our participants recounted that they reinforced their ties to specific healthcare professionals during each medical checkup. Here too, their focus on positive experiences was apparent; no attention was paid to negative experiences, and the warmth and connection with their caregivers was placed at the forefront.

4. Discussion

In this study, several coping strategies were identified that facilitated in living a normal life despite their cancer experience and its long-term consequences for daily life: focusing on the “here and now,” refraining from discussing the cancer experience, recalling and preserving positive memories, redefining the impact positively, and consolidating and preserving a sense of togetherness. These five coping strategies, of which some were developed during their cancer experience, helped the AYA survivors to integrate the cancer experience in everyday lives, to face the psychosocial challenges arising from it, and to enable them to live their lives as normally as possible and in a way that they did not necessarily have to be discerned as being different. Although the AYA survivors did not perceive their survivorship as a large problem in their current lives, coping with being a childhood cancer survivor did take effort to actively control the attention and significance that they and others attributed to the cancer experience. Some of our findings correspond with previous work, starting with our general statement that, although many AYA survivors have moved beyond their cancer experience, a lot still face psychosocial challenges[33]. Our research demonstrated that AYA survivors used several coping strategies to deal with these challenges. The strategy of AYA survivors toward the here and now has been described previously[34]. This present-centered time perspective can also be seen as a preference of adolescents not deviating from the norm[35,36]. Yet, in contrast to what often is understood as normal behavior in adolescence, namely, rebellion toward parents[37] , the AYA survivors in this study reported otherwise and did not seem to oppose the parents who supported them during the cancer experience[38].

Another coping strategy to come out this study is the AYA survivors' refraining from discussing the cancer experience. There is research on avoidance of cancer-related topics and the reasons why it occurs[39,40]; however, topic avoidance has not been studied in particular to AYAs in survival of childhood cancer. In a study on familial coping during lung cancer by examining the communication between ill parents and their adult children[41], it was found that family members can engage in open discussions, for instance, regarding treatments, while at the same time avoiding certain aspects such as emotions. This was seen in our study as well; AYA survivors experience that factual information can be shared easily but emotional issues are, in general, avoided. For AYA survivors, this strategy seems functional and helps them to protect themselves and others for unwanted confrontation and to remain focused on the positive outlook in life. As for the strategies “recalling and preserving positive memories” and “redefining the impact positively,” we can refer to earlier work on the attempts of AYAs to replace disruptive thoughts and the use of optimism as an important protective cognitive strategy[42,43]. This study revealed that AYA survivors experienced an attachment to those persons with whom they shared the cancer experience, which included parents as well as healthcare professionals. The special, close ties that many AYA survivors maintained with their parents[44] were, in many cases, characterized by the reluctance on the part of the AYA survivors to speak freely with a view to preserving a good relationship and protecting their parents[45], which is also referred to in professional literature as the "law of double protection"[46]. The finding that AYA survivors also build a bond of trust with their healthcare professionals has been confirmed in other research[47].

4.1 Implications for Practice

Our study demonstrates the positive outlook that AYA survivors hold in their current lives. This focus is in line with what the AYA survivors have learned during the cancer experience, mainly from their parents. Kars et al[48] describe how a similar approach is helpful for parents when dealing with a severely ill child. Parents focus on staying positive with an aim to help their child in keeping up with the intensive treatments. In accordance to that, children's hospitals often offer necessary services that give attention to positive experiences such as clown doctors or the fulfillment of the child's biggest wish. Our findings have shown that keeping up with a positive mindset is maintained in survivorship, because AYA survivors emphasized its importance not only for them but also for their parents. Nevertheless, our study also made clear that AYA survivors dealt with negative experiences. The coping strategies helped them not to activate these experiences, as was shown, for instance, by how AYA survivors and their parents never talked about emotions. So the question is raised to what extent the AYA survivors remain alone in their negative experiences, such as their experiences of enduring and suffering. Kars et al[49] describe the difficulty of acknowledging the child's perspective on his or her suffering. Therefore, we want to encourage healthcare professionals to consider as much as possible the voice of the child in their care by reframing their focus toward child-centered care[50] and implementing advance care planning approaches[51]. Accepting the capabilities of children and AYAs to reflect on their own situation and helping them engage in their own care by providing them the space to talk, at their level, about all the different emotions that can be felt are essential attitudes of healthcare professionals.

This study revealed that AYA survivors who became ill in EC had a need to reconstruct their history. During the active treatment phase, healthcare professionals could therefore encourage these patients' parents to keep a diary[52] and record other memories. We believe that it is important that these testimonials not only document the actual course of the cancer experience but also reflect the experiences and emotions that were part of this trajectory. A diary can be beneficial for the normalization and acknowledgment of these emotions. Furthermore, it can provide insight into the identity of the child having cancer and can help the AYA survivor to gain a clearer picture of who he or she was as a child.

Another essential finding was that refraining discussion about the cancer experience is a favorable coping strategy for AYA survivors. Taking into account the importance of directorship for AYAs who were given a diagnosis with cancer as adolescents[53], it may be equally important for AYA survivors of childhood cancer if healthcare professionals would improve communication skills by taking the specific preferences of AYA survivors into consideration. For instance, healthcare professionals can ask AYA survivors whether they want their parents to be present or whether they prefer individual consultations, which perhaps give more opportunities to talk freely about thoughts and emotions[39].

During the follow-up phase, some of the participants in this study actively reinforced their connection with trusted healthcare professionals. This finding ties well with previous research that demonstrates that, during the transition from pediatric to adult follow-up care, building a new bond of trust with unknown healthcare professionals is often experienced as a challenge[54,55]. Ensuring continuity in follow-up care is one of the goals that is set in guidelines for the transition of care for childhood cancer survivors[56], wherein the individual readiness for change is an essential requirement[57]. Discussing with AYA survivors which expectations they have in relation to new healthcare professionals enhances the transition process[58].

On the basis of these findings, it is also recommended to take the current individual frame of reference of the AYA survivor as the point of departure for psychosocial support. Asking an AYA survivor how he or she is currently experiencing his or her life will bring more space and openness to a discussion than only reflecting on the past cancer experience (which is remembered selectively) or looking ahead to the challenges that the AYA survivor might possibly have to face in the future. According to professional literature, healthcare professionals should adopt a relaxed and inviting attitude, in which positive communication and taking into account the pace of the AYA survivor are key elements[59].

In conclusion, we recommend that healthcare professionals acknowledge and respect the value and function of the coping strategies used by AYA survivors. Nevertheless, healthcare professionals should be alert to the moment at which concerns or problems surface, without emphasizing the pathos or problematic nature of concerns or problems. What initially had not taken a prominent position in the experience of an AYA survivor, such as the fertility issue, may gain significantly in importance at a later stage in the person's life[60]. Although the fertility issue may call specific questions to mind for an AYA survivor, it is nevertheless a part of normal adolescent development and can, as a result, also be defined and normalized in this manner. Healthcare professionals must make a thorough assessment of how they can sufficiently alleviate the condition of the AYA survivor, without causing this person additional stress by unnecessarily or undesirably making certain long-term consequences explicit[61]. After all, some AYA survivors may prefer a life marked by uncertainties rather than dealing with definite losses[62]. This should, however, not deter healthcare professionals from offering AYA survivors the opportunity to speak with them and to indicate to the AYA survivors that everything can be discussed openly.

4.2 Strengths and Limitations

In developing tailored psychosocial care, the perspectives from AYA survivors of childhood cancer are valuable and much needed. A major strength of this study is the number of interviewed AYA survivors, namely, 21, which provide profound insight in their perspectives. Nevertheless, our study has some limitations. Much attention was given to the selection and recruitment of the participants. Yet, appointing reference people to recruit AYA survivors may be seen as a limitation, because the researchers had to rely on them to act as "gatekeepers"[63]. In the case of those AYA survivors with mental disability, limited interviewing capacity, or experience of an emotional crisis situation, they considered that participation possibly would not be good for the participants. As a result, this study consisted primarily of AYA survivors who were doing relatively well in life, which may have influenced the findings of this study. Further research is recommended.

5. Conclusion

The findings from this study can offer healthcare professionals an interpretative framework with a view to optimization of the psychosocial care they provide. Specifically, attention should be given to the individual support provided to AYA survivors in maintaining their coping strategies, taking into consideration the importance for AYA survivors to safeguard their normalcy[64].

Acknowledgments

The researchers wish to thank all participants who were prepared to share their personal life stories and give insight into their current functioning.

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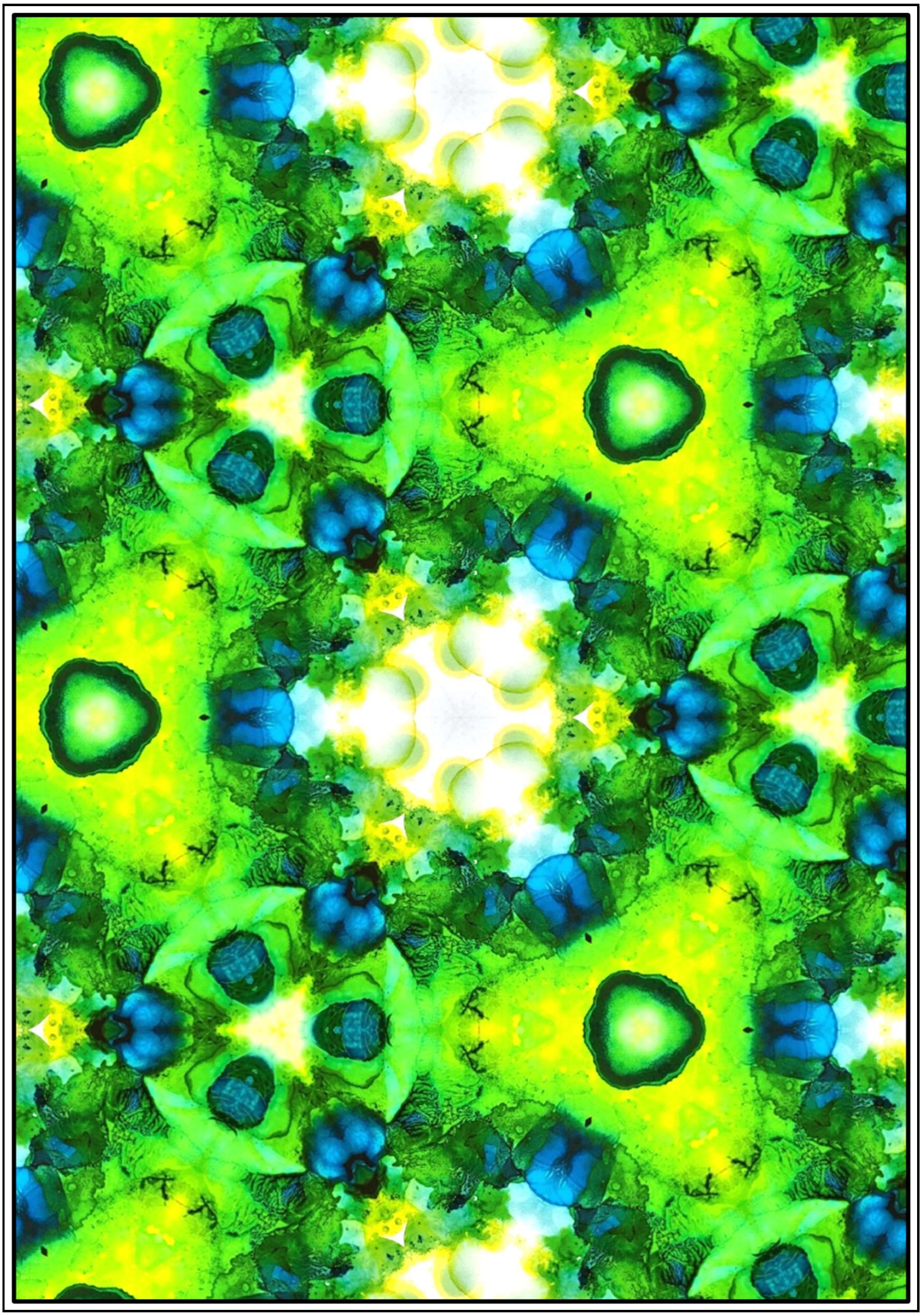
Hoofdstuk 6

Algemene Discussie



De perspectieven van AYA's met kanker en AYA-overlevers, beschreven in voorgaande hoofdstukken, maken zichtbaar wat het betekent om op jonge leeftijd het hoofd te moeten bieden aan een kankerervaring. Niettegenstaande de centrale onderzoeksvragen ruim werden opgesteld, brachten onze studies prominent aan het licht hoe de impact van een kankerervaring in het leven van AYA(overlever)s zich vooral laat voelen in het vormen van een eigen identiteit en het ontvouwen van een nieuw normaal. Het fysiek, psychisch, sociaal en spiritueel welzijn van AYA(overlever)s wordt bepaald door de wijze waarop ze zich adapteren aan de gevolgen van de ziekte en de behandeling. Onze studies tonen aan dat het opnemen van regie en het hanteren van specifieke copingstrategieën hen hierbij ondersteunen.

In dit doctoraatsonderzoek werden de belevingstrajecten van AYA's en van AYA-overlevers onafhankelijk van elkaar onderzocht. Bijgevolg geven de deelstudies de eigenheid van elk perspectief weer. Niettemin komen bepaalde belevingsaspecten zowel in het perspectief van de AYA's als in dat van de AYA-overlevers aan bod. In wat volgt, wordt gereflecteerd over de verbinding tussen beide perspectieven. Er wordt aandacht gegeven aan overeenkomsten maar ook geduid waar andere klemtonen in beleving worden gelegd.

Geïnspireerd door Mustard[1] (zie introductie) fungeert de caleidoscoop als metafoor om onze inhoudelijke reflecties te illustreren. Een caleidoscoop is een instrument dat met gebroken lichtvlakken verschillende constellaties van licht en kleur laat zien. Formaties zijn niet blijvend, na een draai van de caleidoscoop toont de werkelijkheid zich telkens op een andere manier. Hoewel het moeite kan kosten om na elke beweging een duidelijk beeld van het geheel te vormen, zijn er altijd patronen te ontwaren. De formaties zijn eindeloos.

1. Inhoudelijke reflecties

1.1 'Van gebroken vlakken tot een geheel van kleur': de integratie van de kankerervaring in de identiteitsvorming

Kenmerkend in de ervaring van AYA's die in hun adolescentiejaren worden gediagnosticeerd, is dat hun ziek-zijn hen overkomt in een fase waarin hun belangrijkste ontwikkelingstaak bestaat uit het verwerven van een eigen identiteit[2]. Zoals beschreven in hoofdstuk drie doorlopen AYA's een drie-fasen proces, met verschillende onderliggende dynamieken. Ondanks hun focus op zelfbehoud worden ze overspoeld door de kankerervaring, verliezen ze hun vertrouwde eigenheid en moeten ze noodgedwongen de kankerervaring in hun identiteit integreren. Illustratief hierbij zijn de moeilijkheden die AYA's ervaren wanneer uiterlijke veranderingen, zoals haarverlies of gewichtstoename, hen hun vertrouwde zelfbeeld ontnemen. Zij voelen zich in dit proces vrij eenzaam. Immers, waar interactie met leeftijdsgenoten voorheen een belangrijke rol speelde in hun identiteitsontwikkeling, beschreven we in hoofdstuk twee hoe het doorheen de kankerervaring voor AYA's steeds moeilijker wordt om met leeftijdsgenoten in contact te blijven of zich aan hen te spiegelen. AYA's merken op hoe het behouden van de connectie met gezonde leeftijdsgenoten uitdagender wordt[3]. Door het zich 'anders' voelen, dringt zich een nieuwe identiteitsverwerving op waarbinnen plaats is voor een integratie van de kankerervaring. Dit proces wordt door Charmaz[4] geduid binnen het concept ziekte-identiteit en is congruent aan eerdere bevindingen bij AYA's met kanker en andere pathologieën[5,6].

Anders dan AYA's, staan de AYA-overlevers op dit moment in een leven waar de kankerervaring van zijn acuutheid werd ontdaan. Zij hebben ervaren dat hun leven na de kankerervaring is verder gegaan; hun ontwikkeling stond niet stil waardoor zij de kankerervaring en de gevolgen reeds als kind in hun 'zijn' incorporeerden. Op deze basis krijgt hun identiteit in de adolescentie verder vorm. Ook al ervaren sommige AYA-overlevers nog dagelijks de gevolgen van de ziekte en de behandeling, de kankerervaring op zich hebben ze achter zich gelaten. Dit biedt hen de mogelijkheid om van op enige afstand te reflecteren over de persoon die zij sindsdien geworden zijn. In hoofdstuk vier wordt beschreven hoe de AYA-overlevers pas ver in de fase van follow-up bij de verregaande impact en het levensbedreigende karakter van hun ervaring konden stilstaan. Hierbij kan er in de identiteitsverwerving van AYA-overlevers geen differentiatie meer worden gemaakt tussen datgene wat gevormd werd door 'normale', leeftijdsgebonden groeiprocessen en wat voortgebracht werd door het omgaan met de kankerervaring.

Net als bij de AYA's is het zich identificeren met leeftijdsgenoten ook voor AYA-overlevers een onderdeel van hun identiteitsontwikkeling. Onze studie toonde echter de ambivalentie hierin aan: AYA-overlevers beschouwen hun ziekte-identiteit als normaal (dit is wie ze zijn), willen dus niet als anders worden beschouwd maar verwachten terzelfdertijd enige erkenning voor hun 'anders zijn'. Dit conflicteert met de blik van de buitenwereld waarin geen aandacht meer is voor de kankerervaring uit het verleden. Net zoals bij AYA's voelen AYA-overlevers zich hierin erg alleen staan[7,8].

De kankerervaring wordt echter niet alleen ontsloten in de manier waarop AYA(overlever)s er over denken maar ook hoe ze er over praten. Bij het integreren van de kankerervaring in de identiteitsvorming, blijkt hun aanpak van 'disclosure' of het kenbaar maken van deze nieuwe identiteit naar de buitenwereld, belangrijk. Vooral AYA-overlevers ervaren dit als een voorwaarde om met de ziekte en de behandeling om te gaan. Zo gaan AYA-overlevers over tot disclosure wanneer ze de behoefte of noodzaak voelen om hun fysieke beperkingen of littekens te kaderen of wanneer ze een relatie met iemand willen verdiepen of intensiveren. Onze studie beschrijft hoe AYA-overlevers bewust disclosure, en de mate van openheid en vertrouwen die dit vraagt, afwegen tegenover hun behoefte om net als de ander te kunnen zijn. Deze inspanningen worden eveneens onderschreven door eerdere studies waarin wordt gesteld dat AYA(overlever)s in het dagelijkse leven nooit zonder reden hun voorgeschiedenis onder de aandacht brengen[9-11].

Uit onze studie kwam ook naar voor dat AYA-overlevers zich niet de term ‘overlever’ toe-eigenen. Hoewel de term in vakliteratuur voorkomt wordt het in onze spreektaal weinig gebruikt, dit in tegenstelling tot ‘survivor’, courant in een Noord-Amerikaans discours. Zoals beschreven in de inleiding van dit proefschrift ontbreekt een generieke tijdsafbakening van “survivorship/survival” of overleving. Dit bracht doorheen de tijd ook verschillende semantische betekenissen met zich mee. Mullan (1985) was hierin bepalend door te stellen dat survivorship start bij het moment van diagnose, wanneer patiënten zich van meet af aan dienen aan te passen aan hun gewijzigde situatie[12] . Dit resulteerde in een denken waarin survivorship geassocieerd wordt met succesverhalen[2] , de mogelijkheid om met eigen kracht en vanuit actief verzet met de kankerervaring om te gaan[13]. Niet zelden werd en wordt nog steeds de kankerervaring omschreven als een ‘battle’[14]. Ook in ons taalgebruik wordt soms gesproken over het ‘strijden’ tegen kanker.

Literatuur beschrijft hoe taal vorm geeft aan de manier waarop er met de kankerervaring wordt omgegaan[15]. Door op een andere manier over de kankerervaring te denken en te praten, kunnen de emoties en de coping daaromtrent veranderen[13]. Als de kankerervaring niet wordt aanzien als een ‘battle’ maar wel als een ‘journey’ dan komt de focus op het proces te liggen[16], wat meer ruimte geeft voor het herbeoordelen van de kankerervaring en het bevorderen van positieve emoties[17]. In de hoofdstuk vier en vijf wordt ingegaan op het taalgebruik van de AYA-overlever en wordt beschreven hoe enkelen zich omfloerst uitdrukken wanneer het over hun voorgeschiedenis gaat; “Ik heb iets als kind meegemaakt”. Dergelijke uitdrukking vermijdt associaties en verdoezelt de emoties die met de ervaring gepaard gingen. Dit illustreert hoe de AYA-overlever(s) op dit moment in het leven staan: met een sterke blik vooruit en zonder behoefte om nog veel naar de kankerervaring te verwijzen. Ook in ander onderzoek wordt beschreven hoe overlevers bepaalde terminologie vermijden, om de confrontatie met en de focus op de kankerervaring uit de weg te gaan[18-20].

In onze studie naar AYA’s brachten participanten disclosure niet ter sprake. Wel wordt in hoofdstuk twee de sterke zelf-gerichtheid van AYA’s om zich staande te houden in de actieve behandeling, beschreven. Hun focus ligt op wat zij daarvoor nodig hebben. Het loslaten van hun identiteit waar kanker nog geen deel van uitmaakte, weerspiegelt de inspanningen van AYA's om zich verbonden te voelen met anderen en om zich begrepen te voelen. Wellicht is tijd hierbij ook een bepalende factor. Niet alleen is het verwerven van identiteit een dynamisch en stapsgewijs proces, het vraagt tijd voor een AYA om de kankerervaring te integreren in wie ze zijn, om vaardigheden te ontwikkelen die hen in staat stellen om over de kankerervaring te reflecteren en deze in context te zien. Ander onderzoek verduidelijkt hoe vooral in het begin van de fase van overleving AYA(overlever)s moeite hebben om de impact van de kankerervaring te plaatsen. Hoe verder in het traject, hoe meer ze er in slagen de kankerervaring in hun identiteit en normaal leven te integreren[21], wat een invloed uitoefent op het omgaan met disclosure[22].

In tegenstelling tot hun "gezonde" leeftijdsgenoten (i.e. zonder ziekte-ervaring) krijgen AYA(overlever)s te maken met onzekerheden, geïnduceerd door de kankerervaring, die hun psychosociaal welzijn compromitteren, gaande van de prognose, het succes van de behandeling, de gevolgen voor de toekomst enz. Dit staat in schril contrast met het beeld van "gezonde" AYA's die zich onoverwinnelijk of onbezonnen wanen[23] (een stereotypering die echter niet afdoende ondersteund wordt door literatuur[24]). Hoewel deze onzekerheden ook andere kankerpatiënten te beurt vallen, zowel kinderen als volwassenen[25-28], expliciteren onze studies specifiek dat AYA(overlever)s de intentie formuleren zich niet door deze onzekerheden en onvoorspelbaarheden te willen laten leiden. Uit de data maakten we op dat AYA(overlever)s problemen pas aandacht willen geven, wanneer deze zich zouden voordoen. AYA(overlever)s verwoordden dat ze "leven van dag tot dag". Deze strategie om noch vooruit, noch achteruit te kijken en geen energie te stoppen in het zorgen maken over een onzekere toekomst, wordt bevestigd in de literatuur[29,30].

Waldron et al.[31] beschreef hoe adolescenten na een harttransplantatie er in slaagden zich aan de gevolgen van hun ziekte-ervaring aan te passen maar terzelfdertijd wel voortdurend geconfronteerd werden met routines en handelingen die hen op hun ziekte en behandeling attendeerden. Dit kwam ook aan bod in onze studies. Hoewel AYA(overlever)s zich over het algemeen met succes kunnen afwenden van onzekerheid, zijn er omstandigheden of gebeurtenissen die hen opnieuw erg onzeker doen voelen. Zo gaven AYA-overlevers aan dat ze zich bij elk controle onderzoek opnieuw bewust werden van hun onzekere toekomst.

1.2 ‘Nieuw licht, nieuwe formatie’: de ontwikkeling van een nieuw normaal leven

Zowel in het perspectief van de AYA als van de AYA-overlever geeft het streven naar een ‘normaal leven’ prominent richting aan de integratie van de kankerervaring. In de ervaringen van AYA’s, wordt aan het concept ‘normaal leven’ in elke fase van het drie- fasen proces een andere betekenis toegedicht. In het begin van het traject willen de AYA’s heel erg het leven behouden dat ze tot dan toe leidden. Dit impliceert een uitgesproken verwachting van de AYA’s naar hun naasten: AYA’s willen dat sociale rollen in stand gehouden worden en dat ‘alles zo normaal mogelijk blijft’. Dit wordt bevestigd in de literatuur waar eveneens benadrukt wordt hoe de omgeving ingezet wordt om de normaliteit van het leven te behouden[32,33]. Onze bevindingen tonen echter aan dat de veranderingen die door de ziekte en de behandeling teweeg worden gebracht, niet kunnen worden afgewend. Het leven verliest zijn vertrouwde normaliteit en, aangestuurd door de kankerervaring, bewegen AYA’s zich in een proces naar het noodgedwongen installeren van een nieuw normaal leven. Een leven waarin ze zichzelf en hun omgeving herdefiniëren en waarin het omgaan met de gevolgen van hun ziekte en behandeling een nieuwe realiteit bepaalt. Met het aanpassen aan beperkingen en adapteren aan verlieservaringen, komt voor velen ook een inschatten van (nieuwe) mogelijkheden en het vooropstellen van nieuwe doelen. Hoewel sommige studies gewag maken van de ontwikkeling van AYA’s naar een nieuw normaal leven[34-36], beschrijft hoofdstuk drie, naar ons weten, voor het eerst de drie kernfasen die hierin kunnen worden onderscheiden.

Wat ons onderzoek naar AYA-overlevers leert is dat zij, zonder uitzondering, er allen in slagen zich doorheen hun kindertijd aan een nieuw normaal leven aan te passen. Wanneer zij in de adolescentie komen, ligt de kankerervaring achter hen en domineert het hun dagelijkse leven niet meer. Hoewel hun leven vanuit het perspectief van ‘gezonde’ leeftijdsgenoten wellicht niet geheel als normaal wordt aanzien, beschouwen AYA(overlevers) hun leven als normaal en geven ze aan goed te functioneren. Desalniettemin vragen de gevolgen van de kankerervaring van hen vaak een extra inspanning om aan het dagelijkse leven te participeren, zoals bij bv. uitgaan met vrienden, reizen, studeren enz. Hun overleving smaakt tegelijkertijd zowel bitter als zoet[37]. Desondanks de moeite die het AYA-overlevers kost om goed te functioneren[10,30,38,39], lijken zij daarin te slagen. Studies tonen aan dat zij slechts in beperkte mate psychopathologie ontwikkelen[7,40,41].

1.3 ‘Een eigen draai’: de betekenis van regie

In hoofdstuk twee wordt beschreven hoe het concept van de AYA-regisseur (‘AYA-director’) alle aspecten van het zijn en handelen van de AYA met kanker omvat. De rol van AYA-regisseur kan worden begrepen als het resultaat van alle gebundelde gedachten, gevoelens en drijfveren die tijdens het kankerproces worden ervaren. Het gedrag van AYA’s is gefocust op hun grote behoefte om regie in het traject op te nemen, afgestemd op hun eigen, individuele invulling van deze rol. Niettegenstaande het concept van de AYA-regisseur niet in de studie naar de AYA-overlevers aan bod kwam, tonen de copingstrategieën, beschreven in hoofdstuk vijf, aan wat zij zelf ondernemen om de impact van de kankerervaring hanteerbaar te maken. In hoeverre de AYA-overlevers als kind zelf regie opnamen tijdens hun actieve behandeling, was niet de scope van ons onderzoek en belet ons bijgevolg om hierover gegronde uitspraken te doen.

Algemeen kunnen we concluderen dat de AYA(overlever)s, door het zich toe-eigenen van regie, in staat worden gesteld om hun kankerervaring te benaderen op een manier die voor hen het meest passend is, in overeenstemming met hun eigen waarden, noden en strategieën. Identiteit en regie zijn dan ook onlosmakelijk met elkaar verbonden. Het opnemen van regie helpt de AYA’s om hun eigenheid te behouden, waardoor ze zich minder een nummer voelen[42,43].

In de literatuur wordt regie geassocieerd met betere psychologische uitkomsten[44,45]. Desalniettemin kan regie enkel op een betekenisvolle manier tot stand komen indien dit door naasten en zorgverleners wordt gerespecteerd en gefaciliteerd. De AYA(overlever) moet ruimte krijgen om regie op te nemen. Dit impliceert dat zij als actieve individuen worden gezien, als actoren die inspraak hebben in hun traject. Hierop komen we uitgebreid terug in het onderdeel ‘aanbevelingen voor zorgverleners’, verder in dit hoofdstuk.

1.4 ‘Ontwaren van patronen’ : de betekenis van de copingstrategieën voor AYA(overlever)s

In hoofdstuk drie en vijf worden de kenmerkende copingstrategieën beschreven die AYA(overlever)s in het dagelijkse leven gebruiken om met de uitdagingen en de gevolgen van de kankerervaring om te gaan. Hiermee wordt een bijdrage geleverd aan de bestaande coping literatuur die aangaande de AYA(overlever)-populatie nog steeds ontoereikend is[10].

In de literatuur omtrent coping is het werk van Lazarus en Folkman (1984) toonaangevend geweest. Zij omschreven coping als de voortdurend veranderende cognitieve en gedragsmatige inspanningen om de specifieke externe en/of interne eisen te beheren die als belastend worden beschouwd of die iemands mogelijkheden overschrijden[46]. Deze inspanningen maken deel uit van een dynamisch proces wat onderhevig is aan situationele en individuele factoren[47]. Copingstrategieën zijn bijgevolg een weerspiegeling van verzamelde percepties en acties[48].

Een essentiële copingstrategie die in onze studies werd aangetoond, is het aannemen van een positieve ingesteldheid. AYA(overlever)s beschouwen dit als een manier om zelf actief het hoofd te bieden aan negatieve gedachten, onzekerheden en angsten. Het 'leven in het nu', het koesteren van positieve ervaringen, het afwenden van negatieve herinneringen, het zoeken naar afleiding,.. ondersteunen AYA(overlever)s in het positief denken. Bovendien verwachten AYA(overlever)s van hun naasten dat zij hen positief benaderen, om hun situatie te verlichten en om vooruit te kunnen. Een positieve ingesteldheid beschermt niet enkel welzijn maar bevordert veerkracht, zijnde de mogelijkheid om zich staande te houden in onzekere of bedreigende gebeurtenissen[49-51].

Uit onze studies blijkt dat positieve ouderlijke steun de AYA(survivor)s helpen om constructief met de kankerervaring om te gaan. Ook blijkt dat de coping van AYA(overlever)s mede wordt bepaald door de manier waarop hun ouders met de kankerervaring omgaan. Zo vertelden de AYA(overlever)s in onze studies hoe de houding van hun ouders hen hielp om de normaliteit te behouden of hoe ze optimistisch waren doordat hun ouders zelf positief ingesteld bleven en bv. ruimte gaven aan humor. Dit is verwant aan het concept 'modelling', waarbij AYA(overlever)s een copingstijl overnemen van en ontwikkelen naar het model van hun ouders[52,53].

Algemeen wordt aangenomen dat positief denken een goede invloed heeft op een ervaring en wordt het meer geaccepteerd dan een negatieve ingesteldheid[54]. Dit blijkt uit onze studies waarin AYA(overlever)s het essentieel vonden dat iedereen positief ingesteld is/was. In de literatuur wordt beschreven dat een positieve ingesteldheid echter ook als een druk kan worden ervaren, waarbij men niet meer "mag" negatief zijn of waardoor men zich schuldig voelt als de dingen niet zo goed lopen[55,56]. Dit kwam ook aan bod in onze studies, waarbij AYA(overlever)s aangaven bepaalde thema's, zoals de dood, niet met hun ouders te bespreken. Uit schuldgevoel voor het verdriet dat de ziekte hun ouders brengt en uit bezorgdheid om hen zoveel mogelijk te ontzien. Dit zorgt er mogelijks voor dat de AYA(overlever)s zich alleen kunnen voelen met bepaalde gedachten en gevoelens. Rekening houdend met hun nadrukkelijke verwachting dat hun naasten normaal en positief blijven doen, dragen AYA(overlever)s zelf bij aan een klimaat waar minder ruimte is voor communicatie over negatief beladen thema's. Volgens het 'social-cognitive processing model' van Lepore (2001) kan het gebrek aan communicatie over negatieve gedachten een goede coping in de weg staan[57], maar Lahaye et al. stellen echter dat ‘niet praten’ ook helpend kan zijn om vooruit te kunnen in het leven[10]. Een mogelijke hypothese zou kunnen zijn dat sommige AYA(overlever)s weinig geneigd zijn om over hun beleving te praten, vanuit een overtuiging dat een “gezonde” ander toch nooit zal kunnen begrijpen wat ze doormaken; wat levert praten en zich blootstellen aan belastende gedachten hen dan op?

In hoofdstuk vijf wordt “de wet van de dubbele bescherming” beschreven. Dat het sparen tussen AYA(overlever)s en ouders twee richtingen kent en ouders ook zelf hun kind willen afschermen van potentiële moeilijke informatie wordt door eerder onderzoek bevestigd[58-60]. Niettemin wordt in Advance Care Planning literatuur beklemtoond dat verbinding tussen ouder en kind zich vaak net manifesteert in het delen van moeilijke boodschappen, omdat het beiden de kans geeft eigen ideeën maar ook deze van de ander te exploreren en verdiepen[61]. Onze AYA-overlever studie toonde eveneens aan dat de betekenisvolle, hechte band die AYA-overlevers ervaren met hun ouders vooral voortkomt uit hun gevoel dat ze samen met hun ouders hebben gestreden tegen de ziekte en hun ouders er altijd voor hen waren. Dit geldt ook voor ouders die ervaren dat de betekenis van hun ouderrol wordt verdiept en versterkt door het in alle omstandigheden beschermen van hun kind[62,63]. Er is veel literatuur voorhanden die aantoont hoe ouderlijke steun de ontwikkeling van veerkracht en posttraumatische groei bij AYA(overlever)s kan bevorderen[60,64-68] waaruit de belangrijke rol van ouders in het copingproces van de AYA(overlever)s blijkt. Belangrijk is dus om een dialoog van zorg mogelijk te maken met de AYA(overlever)s, het team en de ouders[69]. In onze studie naar AYA-overlevers kan worden opgemerkt dat alle participanten met minstens één ouder een steunende relatie hadden en dat de verbondenheid die zij tijdens hun ziek-zijn als kind hebben ervaren, zich in de follow-up fase en daarna onveranderd heeft voortgezet. Deze blijvende hechte ouder-kind relatie in de fase van overleving wordt eveneens bevestigd in de literatuur[70,71].

Tot slot; hoewel in dit doctoraatsonderzoek twee onderscheiden populaties werden bestudeerd, kan het als een belangrijke meerwaarde worden beschouwd dat fundamentele gelijkenissen tussen beiden werden vastgesteld. Dit inzicht geeft kracht aan de aanname dat de betekenis van kanker voor AYA’s in substantiële mate wordt gekleurd door de leeftijdsspecifieke ervaringen die breed worden gedeeld. AYA(overlever)s zijn in de eerste plaats gewoon jongeren; jongeren die kanker hebben (gehad)[72]. Deze vaststelling ondersteunt de veronderstelling dat de dynamieken beschreven in onze studies ook zouden kunnen gelden voor AYA’s met andere ernstige (chronische) gezondheidsproblemen.

2. Methodologische reflecties

De methodologische sterktes en beperkingen van de afzonderlijke studies werden beschreven in de voorgaande hoofdstukken en worden in dit deel niet herhaald. Wat volgt, is een overkoepelende reflectie over enkele methodologische keuzes die doorheen dit doctoraatsonderzoek werden gemaakt.

Onze studies hadden tot doel de ervaringen van AYA(overlever)s te begrijpen door hun binnenwereld te bestuderen. Om deze ervaringen vanuit hun binnenwereld of “emic perspective”[73] uit de eerste hand te verkrijgen, de gelaagdheid in beleving te ontrafelen, zonder vooraf bepaalde hypothese(s), werd een explorerende kwalitatieve onderzoeksbenadering gekozen. Enkele participanten gaven aan dat ze het interview fijn hadden gevonden omdat het hen de kans gaf hun verhaal te brengen. De open vraagstelling en het verdiepend ingaan op hetgeen de participanten in de interviews aanbrachten, zorgde ervoor dat zij de ruimte ervoeren om hun beleving breed te schetsen. Deze inductieve methodiek ondersteunde ons in het inzichtelijk maken van de betekenis van hun ervaringen alsook in het leggen van verbindingen tussen de verschillende thema’s. Dit zou onvoldoende mogelijk geweest zijn in een kwantitatief onderzoeksopzet[74].

Mede door de gehanteerde onderzoeksbenaderingen werd een holistische kijk op de omvang van de kankerervaring en de impact er van op belangrijke levensdomeinen bekomen. In de studies van AYA’s werden principes van grounded theory approach gevolgd, vanuit de benadering van Glaser & Straus[75]. In de studie naar AYA-overlevers werd gekozen voor thematische analyse volgens Braun en Clark (2006)[76]. In beide onderzoeksbenaderingen werden systematische en robuuste methodes uitgevoerd om data te verzamelen, te coderen en te analyseren wat heeft geleid tot valide en betrouwbare uitkomsten (‘Trustworthiness’[77]) en saturatie m.b.t. de belangrijke concepten.

Dit doctoraatsonderzoek kent ook enkele belangrijke beperkingen.

Een eerste beperking heeft betrekking op de rekrutering en het profiel van de participanten. In de studies werden participanten gerekruteerd door een lid van het multidisciplinair team die een behandelrelatie met de participant onderhield. Dit teamlid vroeg de toestemming van de participanten om hun contactgegevens door te geven aan de onderzoekers die op hun beurt de studie toelichtten en de participanten een informed consent lieten tekenen. Hoewel door de behandelende teamleden uitdrukkelijk werd gesteld dat de AYA(overlevers) volledig vrij waren om al dan niet akkoord te gaan met het delen van hun contactgegevens aan de onderzoekers, moet rekening gehouden worden met de mogelijke druk die participanten ervoeren om te participeren aan de studie. Tegelijkertijd kan de vertrouwensband die AYA(overlever)s met hun zorgverleners hebben ook als een positieve stimulans worden beschouwd voor een doeltreffende rekrutering[78].

In ons onderzoek naar de bevindingen van AYA-overlevers was er bij de meeste participanten veel tijd tussen de kankerervaring en het interview. Zoals Lahaye et al.[10] beschrijven, dienen we indachtig te zijn dat in de tijd tussen de kankerervaring en het interview, zorg en interventies kunnen zijn aangepast. Mogelijks ervaren kinderen die vandaag oncologisch worden behandeld in de toekomst andere psychosociale en fysieke late effecten, dan deze die in hoofdstukken vier en vijf worden beschreven. Desalniettemin lag de focus van het onderzoek op onderliggende dynamieken die tijdsgebonden elementen overstijgen.

In deze studies werden participanten eenmalig geïnterviewd, wat maakt dat de dataverzameling onderhevig is geweest aan de omstandigheden of de stemming van de participant op dat moment[79]. Om hieraan tegemoet te komen legden de onderzoekers een gevoeligheid aan de dag om bij elk interview een verslag te maken met details van het gesprek. Daarenboven werden achtereenvolgende interviews afgenomen totdat er geen nieuwe inzichten meer werden verkregen (i.e. data saturatie[80]) waardoor, naar ons inziens, de specifieke omstandigheden van het moment weinig impact of relevantie hadden.

Tenslotte werden er geen participanten geïncludeerd die een andere moedertaal hadden dan het Nederlands om zoveel mogelijk eventuele barrières die de nuancering in taal zouden kunnen bezwaren, uit te sluiten. Dit betekent dat we o.b.v. onze studies geen uitspraken kunnen doen over de ervaringen van bv. AYA(overlever)s met een migratieachtergrond. De onderzochte populaties zijn geen correcte afspiegeling van onze multiculturele maatschappij waardoor bepaalde thema's, bv. ontvangen steun uit het netwerk of disclosure wellicht in een te eenzijdig Westers, blank perspectief werden beschreven.

3. Aanbevelingen voor verder onderzoek

In onze studies werd van doelgerichte steekproeftrekking ('purposeful sampling') gebruik gemaakt. Daarbij stond generaliseerbaarheid niet centraal maar werd gezocht naar relevante diversiteit in het sample om rijke data en voldoende verdieping van het onderzoeksthema te bekomen[4]. Later werd in het proces van data-collectie en data-analyse theoretische steekproeftrekking toegepast waarbij participanten werden geselecteerd in functie van het verwerven van diepgaander inzicht in bepaalde concepten en van het verkrijgen van saturatie op facetten van de analyseresultaten. Dit houdt in dat in alle studies de sampling werd gestuurd aan de hand van preliminaire analyseresultaten en hun potentieel verband met bepaalde kenmerken van de participanten. Tijdens de analyses kwam niet naar voor dat kenmerken zoals leeftijd, ontwikkelingsniveau, type kanker of sociaal economische status resulteerden in andere analyse uitkomsten en werd, niettegenstaande onze studies een brede variatie aan kenmerken van participanten omvatten, geen verschil gezien in de uit de analyse voortkomende ervaringen en betekenisverlening o.b.v. bijvoorbeeld type kanker en leeftijd. Dit is wellicht het gevolg van de eigenheid van het hier beschreven kwalitatief onderzoek, wat gericht is op het genereren van inzichten op conceptueel niveau. Kenmerken van participanten, contexten en situaties zijn daarbij maar betekenisvol als ze de concepten en de conceptuele kaders beïnvloeden. En dit was in onze studies niet het geval. De beschreven dynamieken en processen en de betekenis van de kankerervaring op conceptueel niveau zijn gelijklopend ongeacht de specifieke kenmerken en contexten van de AYA(overlever)s. Op niveau van wat in kwalitatief onderzoek als exemplarisch wordt beschouwd en de concrete uiting is van wat conceptueel beschreven wordt, zijn er echter wel verschillen merkbaar. Welke verschillen dat zijn, in welke grootorde of in welke mate deze voorkomen, kan best via kwantitatief onderzoek verder worden verkend. Zo ging eerder onderzoek in op de variatie van gezondheidsgerelateerde kwaliteit van leven volgens ondermeer kanker type[81,82] maar zou kwantitatief onderzoek ook in kaart kunnen brengen of de copingstrategieën van AYA(overlever)s verschillen naargelang de ontwikkelingsfase, de leeftijdscategorie of de context waarin ze zich bevinden. Er zou ook nagegaan kunnen worden in welke mate zaken zoals een geïmpacteerde fertiliteit of zichtbare kankerletsels een invloed hebben op gevoelens van onzekerheid bij de AYA(overlever)s. Hierbij kan, zoals sommige onderzoekers suggereren[83,84], geopteerd worden om (sub)analyses uit te voeren met verschillende en nauwere leeftijdsgrenzen waardoor bijvoorbeeld zou kunnen worden onderzocht in hoeverre het sparen van de ouders anders is voor een AYA(overlever) tussen 15 en 18 jaar oud dan wel voor een AYA(overlever) tussen 18 en 25 jaar oud. Dergelijke onderzoeksvraag zou tevens a.d.h.v. hermeneutisch onderzoek kunnen worden gelinkt aan theoretische kaders binnen de ontwikkelingspsychologie waardoor eerdere inzichten met betrekking tot ontwikkelingsstadia zouden kunnen worden verbreed en verdiept.

Aanvullend op de eerder genoemde methodologische beperkingen, zou toekomstig onderzoek kunnen worden gedaan naar de ervaringen van AYA(overlever)s met een migratieachtergrond. Onze huidige multiculturele maatschappij weerspiegelt zich ook in de patiëntenpopulatie in de gezondheidszorg. Om leeftijdsspecifieke zorg voldoende cultuursensitief uit te bouwen, is het belangrijk dat participanten met diverse culturele achtergronden deelnemen aan onderzoek en interventieontwikkeling. Etnisch-culturele herkomst is echter slechts één van de vele onderliggende factoren die een belangrijke rol kunnen spelen in het leven van AYA(overlever)s[85]. In een pleidooi voor een holistisch zorgaanbod gaan kwalitatief onderzoek waarin de kaders geschept worden om afstemming op niveau van de individuele patiënt te bereiken en kwantitatief onderzoek naar diversiteit op vlak van gender, seksualiteit, samenlevingsvormen, gezinssystemen enz. binnen de populatie van AYA(overlever)s hand in hand. Hiermee onderschrijven we eveneens het belang om AYA(overlever)s meer te betrekken bij ontwikkeling van zorg en onderzoek[86], en dit met voldoende aandacht voor variatie[87] want “one size does not fit all” (Morgan et al. [72]).

4. Aanbevelingen voor de praktijk

In de literatuur wordt steeds gewezen op het belang van zorg op maat van AYA(overlever)s. Deze zorg, aangepast aan de noden en behoeften van de AYA(overlever)s, vertrekt vanuit een biopsychosociale benadering van gezondheid en impliceert een integrale kijk naar de AYA(overlever)s en hun context. Op basis van onze studies kunnen enkele criteria voor kwaliteitsvolle zorg worden voorgesteld: (1) Persoonsgerichte zorg), (2) Zorg met aandacht voor de specifieke copingstrategieën, (3) Zorg die regie faciliteert en (4) Zorg die voorziet in communicatie op maat. Hiermee worden zorgverleners uitgenodigd om AYA(overlever)s te ondersteunen in het draaien van de caleidoscoop opdat nieuw en overvloedig licht kan geworpen worden op wat voor AYA(overlever)s van betekenis is.

4.1 Persoonsgerichte zorg

Zoals blijkt uit voorgaande hoofdstukken, kunnen bepaalde ervaringen overkoepelend worden gethematiseerd. Niettemin beleven AYA(overlevers) hun kankerervaring op een unieke manier, binnen een eigen, individuele context. Eerder onderzoek wijst op het belang van persoonsgerichte zorg dat op een holistische manier tegemoet komt aan de voorkeuren, overtuigingen en behoeften van de AYA(overlever)s[88] waarbij holistisch vaak wordt omschreven vanuit vier dimensies, nl. een fysieke, psychologische, sociale en spirituele dimensie[89].

Dit impliceert dat zorgverleners voldoende begrijpen wat een kankerervaring in de unieke leefwereld van de AYA(overlever) betekent. In de literatuur zijn verschillende screeningsinstrumenten beschreven om in de verschillende levensdomeinen noden en bekommernissen te detecteren zoals bv. HEEADSSS[90], Canteen’s screeningtool[91], I-AM[92], RIM[93], enz.

Door een screening op meerdere tijdstippen in het traject uit te voeren, wordt niet enkel een inkijk gegeven in wat er speelt in de leefwereld van de AYA op dat moment maar worden ook veranderingen doorheen het traject kenbaar gemaakt[94,95]. Behalve het detecteren van moeilijkheden, signaleert een goede assessmenttool ook steunbronnen en beschermende factoren in de context van de AYA[95-97].

Zoals onze studies aantonen, wordt een positieve ingesteldheid soms door AYA(overlever)s afgedwongen wat hen mogelijks belet om over negatieve gedachten te praten. Ook een dynamiek van sparen werd beschreven. Zorgverleners kunnen AYA(overlever)s helpen om te communiceren over zorgen en bekommernissen. Essentieel hierbij is het opbouwen van een vertrouwensrelatie met de AYA(overlever). De AYA(survivors) in onze studies vonden het hinderlijk als zorgverleners hen louter als patiënt behandelden en geen interesse toonden in hen als persoon. Ook vonden ze het storend als zorgverleners geen empathie aan de dag legden of zich letterlijk en figuurlijk afzijdig hielden. Deze factoren die een vertrouwensrelatie bemoeilijken, worden bevestigd in andere studies[32,43,98,99].

Zorg gericht op de AYA(overlever) vraagt om een open blik en verbinding. Zorgverleners kunnen ruimte geven aan diversiteit in verwachtingen en voorkeuren door hun zorg niet af te stemmen op wat ‘normaal’ of ‘gangbaar’ is. Het is belangrijk om bekommernissen en vragen van AYA(overlever) zonder uitzondering te normaliseren[72,99].

4.2 Zorg met aandacht voor de specifieke copingstrategieën

Eerder werd beschreven dat het aanhouden van een positieve ingesteldheid een belangrijke copingstrategie is. Zorgverleners kunnen AYA(overlever)s moed geven en optimisme faciliteren door zelf een positieve houding aan te nemen. Toch moet dit in perspectief gezien worden. Andrade[100] waarschuwt voor een groeiende tendens waarbij aan positief denken zoveel waarde wordt toegedicht alsof het noodzakelijk zou zijn in het genezingsproces. O.b.v. onze studies onderstrepen we het belang om de AYA(overlevers) in hun coping te ondersteunen, doch terzelfdertijd hen de mogelijkheid aan te bieden negatieve gedachten en bekommernissen te bespreken. Zorgverleners kunnen AYA(overlever)s autonomie en vertrouwen bijbrengen dat alle gevoelens mogen worden ervaren en dat zorgverleners niet moeten worden ‘gespaard’.

Uit onze studies blijkt dat ouders een rol spelen bij het ontwikkelen en hanteren van copingstrategieën door de AYA(overlever)s. Studies tonen aan dat ouders deze strategieën bij hun kinderen kunnen promoten om posttraumatische groei te faciliteren. Ook hierin zijn zorgverleners goed geplaatst om ouders hierin te begeleiden[101-105].

Eerder beschreven we dat de behoeften en noden van AYA(overlever)s evolueren doorheen de tijd. Dit vraagt om een flexibele houding van zorgverleners[106]. In het bijzonder bevelen we zorgverleners aan zich in hun zorgaanbod te laten leiden door het proces dat de AYA(overlever)s doorlopen. Uit onze studies blijkt dat veel psychosociale noden zich stellen na de acute behandeling, terwijl uit literatuur blijkt dat interventies net vaak gericht zijn op de actieve behandelingsperiode[107]. In hoofdstuk drie werd beschreven dat vooral in de derde fase, waarin het uitbouwen van een nieuw normaal leven zich aandringt, AYA's nood hebben aan contact met lotgenoten om ervaringen te delen[72,107].

4.3 Zorg die regie faciliteert

Zoals eerder beschreven vormt regie als concept een rode draad doorheen het psychosociaal traject van AYA(overlever)s. Hun ervaringen zijn verweven met hun behoefte aan regie, soms uitdrukkelijk geëxpliciteerd maar vaak ook onderliggend aan de strategieën die ze hanteren. Het opnemen van regie vraagt in essentie om een context waarin AYA's zichzelf kunnen zijn, waarin ze zich uitgenodigd voelen om hun noden en verwachtingen kenbaar te maken en waarin ze navenant veiligheid ervaren om de situatie naar eigen wens aan te pakken. Zorgsystemen kunnen kansen geven aan AYA(overlever)s om met respect voor hun identiteit, zelf hun zorg richting te geven[43,108]. Voor zorgverleners is er een belangrijke taak weggelegd in het empoweren van de AYA(overlever)s om regie op te nemen, met respect voor hun wensen en voorkeuren. Ook dit is maatwerk; niet elke AYA(overlever) streeft er naar om uitdrukkelijk regie op te nemen.

Ook kan het bij sommige AYA(overlever)s op het eerste zicht lijken dat ze geen regie (willen) nemen. Verschillende redenen kunnen hieraan ten grondslag liggen. Een eerste bedenking is dat het nalaten van regie opnemen, ook een vorm is van regie. Zo kan bijvoorbeeld het overlaten van praktische zorg aan ouders, de AYA(overlever)s net een gevoel van controle geven. Daarenboven kan worden gesteld dat inzicht in een situatie, niet altijd voldoende is om over te gaan tot zelfeffectiviteit of het zich vaardig genoeg voelen om er naar te handelen[109]. Als AYA(overlever)s bijvoorbeeld onvoldoende zelfzeker zijn, zich niet goed geplaatst voelen, schaamte ervaren of de kankerervaring niet hebben geïntegreerd in hun identiteit, dan kunnen ze onvoldoende gemotiveerd zijn om iets in handen te nemen. Zorgverleners kunnen AYA(overlever)s empoweren door krachtgericht te werken, wat hen in de mogelijkheid stelt om eigen sterktes en zelfvertrouwen op te bouwen om regie op te nemen[110,111]. Het kan AYA(overlever)s helpen als zorgverleners heel gericht vragen naar wat zij als hun verantwoordelijkheden in het traject zien en welke verwachtingen naar ondersteuning zij hierbij hebben[65,112]. Het doorspreken van scenario's kan de AYA(overlever)s helpen in een situatie waarin ze hun weg nog moet vinden.

Onze studies tonen aan dat de kankerervaring een grote impact heeft op de identiteit van de AYA(overlever)s. Zorgverleners kunnen AYA(overlever)s ondersteunen in het behouden van hun identiteit en het opnemen van de copingstrategieën die ze hebben opgebouwd om met de kankerervaring om te gaan. Op die manier kunnen ze hun eigenheid in het verdere leven verder ontvouwen want ook in de fase van nazorg kunnen AYA(overlever)s gesteund worden om regie op te nemen, bv. in de uitbouw van een nieuw normaal leven of in het behoedzaam omgaan met de lange termijn gevolgen van de kankerervaring[113]. Psycho-educatie en aangepaste training kunnen AYA(overlever)s ondersteunen in het in handen nemen van hun leven na kanker. De participanten uit onze studies tonen zich erg bewust van gedrag dat hun gezondheid belast, zoals roken, en doen inspanningen om hun gezondheid niet nodeloos te hypothekeren. Deze bevinding verschilt van andere studies die aantonen dat AYA(overlever)s in gelijke mate experimenteren met roken, alcohol en andere middelen dan hun gezonde leeftijdsgenoten[40,72]. Mogelijks zijn de AYA(overlever)s in onze studie bewust met hun gezondheid bezig, onder invloed van de hechte relatie die ze er met hun ouders op nahouden.

4.4 Zorg die voorziet in communicatie op maat

Om regie te verwerven, is informatie noodzakelijk[32]. Bijgevolg moeten zorgverleners goede communicators zijn[114]. In hun communicatie en informatieverstrekking dienen ze niet enkel de leeftijd, de cognitieve capaciteiten en de emotionele ontwikkeling van de AYA(overlever)s in acht te nemen[99,112]. Onze studies tonen aan dat AYA(overlever)s het vooral belangrijk vinden dat hun persoonlijke voorkeuren worden gezien, erkend en gerespecteerd. Een voorbeeld is de hoeveelheid informatie die AYA(overlever)s werkbaar en wenselijk vinden. Ook kunnen zorgverleners bij de AYA(overlever) bevragen wie ze al dan niet bij zich willen hebben, wanneer zaken worden besproken. Indien gewenst, kan een gesprek worden opgedeeld in een deel in aanwezigheid van een naaste en een deel individueel met de AYA(overlever)[115].

5. Conclusie

AYA(overlever)s vormen een bijzondere groep binnen de oncologische zorg. De complexe combinatie van ontwikkelingstaken, eigen aan de levensfase, en de specifieke medische en psychosociale noden, gerelateerd aan de kankerervaring, onderschrijven hun kwetsbaarheid. Leeftijdsspecifieke ondersteuning vormt een uitdaging binnen de huidige organisatie van zorg die geënt is op een onderscheiden uitbouw van pediatrische zorg en volwassenenzorg. Veranderingsprocessen en zorginnovaties die recht doen aan de diverse noden van AYA(overlever)s beginnen bij bewustwording; een begrijpen van de betekenis die de kankerervaring in hun unieke leefwereld heeft en een erkennen van het belang om zorg hierop af te stemmen. Dit doctoraatsonderzoek wil deze bewustwording vergroten door een kader te scheppen waarbinnen de beleving van AYA(overlever)s beter kan worden begrepen.

Onze studies tonen aan dat het doormaken van de kankerervaring behelst dat de betekenis die AYA(overlever)s er aan geven, geïntegreerd wordt in wie ze zijn (‘identiteit’) en hoe ze hun (‘normaal’) leven leiden. Zorgverleners kunnen de processen die AYA(overlever)s doorlopen, ondersteunen door op een holistische manier aandacht te geven aan hun veranderende gedachten, gevoelens, drijfveren, coping en verwachtingen. Op grond van onze studies beklemtonen we het belang van empoweren van en ruimte bieden aan AYA(overlever)s om regie te nemen. Regie helpt AYA(overlever)s om zich aan de impact van de kankerervaring te adapteren en om op gevolgen in het verdere leven te anticiperen, opdat ze zich gesterkt voelen om bij elke draai aan de caleidoscoop, nieuwe formaties te ontwaren.

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Samenvatting

Adolescenten en jongvolwassenen, kortweg “AYA’s” vormen een bijzonder doelgroep in de oncologie. Naast de groep van AYA’s die in hun adolescentie de diagnose kanker krijgen, kan ook een groep AYA’s worden onderscheiden die in hun adolescentie worden geconfronteerd met de (chronische) gevolgen van een kankerervaring uit hun kindertijd. Deze groep wordt de AYA-overlevers genoemd. Voor beide groepen geldt dat een kankerervaring de normale ontwikkeling van kind naar volwassene doorbreekt en de verdere levensloop beïnvloedt. Internationaal wordt geijverd voor hoogkwalitatieve patiëntgerichte medische en psychosociale zorg die tegemoet komt aan een breed spectrum van acute en chronische noden van AYA(overlever)s. Om AYA(overlever)s zorg op maat te bieden, is inzicht nodig in hun ervaringen, behoeften en noden. Onderzoek daarnaar is tot op heden vrij beperkt **(hoofdstuk 1)**.

Dit doctoraatsonderzoek heeft tot doel de kennis over het belevingstraject van AYA(overlever)s uit te breiden, vertrekkende vanuit hun perspectief. Een eerste deel gaat in op de ervaringen van AYA’s met kanker en de betekenis die ze hieraan verlenen. In een tweede deel wordt de kankerervaring in het huidige leven van AYA-overlevers van kinderkanker onderzocht.

AYA’s die op een leeftijd tussen 15 en 25 jaar kanker krijgen, ervaren de diagnose als een bom die inslaat. Bijzonder confronterend zijn uiterlijke veranderingen ten gevolge van de ziekte en de behandeling, en het integreren van de kankerervaring in de identiteit. Andere uitdagingen omvatten het verlies aan zelfstandigheid en de eenzaamheid in de kankerervaring. AYA’s zijn zelfgericht en hanteren copingstrategieën, zoals het behouden van een positieve ingesteldheid, om zich staande te houden in de kankerervaring. Doorheen het traject willen ze de regie over hun leven zoveel mogelijk in handen houden. Daarom is het belangrijk dat ze door zorgverleners en behandelaars als regisseur worden gezien en dat ze als meesturende partner betrokken worden in hun behandeltraject. Dit stelt hen immers in staat om de kankerervaring te benaderen op een manier die het best bij hen past **(hoofdstuk 2).**

In de kankerervaring doorlopen AYA’s een proces dat bestaat uit drie fasen: (1) *Een fase waarin ze vasthouden aan het gewone leven.* In eerste instantie beschouwen AYA’s de kanker als van voorbijgaande aard; een tijdelijke halt, waarna het normale leven zal worden hervat zoals het was. (2) *Een fase waarin ze ervaren dat het normale leven niet kan worden behouden*. AYA’s ervaren hoe ze de connectie met het vertrouwde leven kwijtraken en bestaande relaties een andere invulling krijgen. (3) *Een fase waarin het vormgeven van een nieuw normaal leven zich aandringt.* AYA’s ervaren dat de kankerervaring hen als mens heeft veranderd en het leven van voorheen verdwenen is.

Onderliggend aan dit drie-fasen proces kunnen verschillende dynamieken worden opgemerkt in de betekenis die AYA's aan hun kankerervaring geven en de uitdagingen waarmee ze zich geconfronteerd zien. Zo ervaren AYA's hoe het gevoel van controle over het leven plaats maakt voor gevoelens van kwetsbaarheid. Dit heeft tot gevolg dat, doorheen het traject, noden van AYA's veranderen en zij andere verwachtingen van naasten en zorgverleners expliciteren **(hoofdstuk 3).**

AYA's die voor de leeftijd van 15 jaar een kankerbehandeling ondergingen, ervaren hiervan lange termijn gevolgen in het dagelijkse leven. In tegenstelling tot zij die in hun vroege kindertijd kanker kregen (<7 jaar), onderscheiden AYA-overlevers die in hun late kindertijd (7-14 jaar) werden gediagnosticeerd, een leven voor en na de kanker. Voor beiden betekent de kankerervaring dat: (1) ze zich anders voelen maar niet als anders willen worden aanzien, wat de manier waarop ze hun kankerervaring kenbaar maken aan anderen, beïnvloedt, (2) ze leven met existentiële onzekerheid, wat bij bepaalde situaties of gebeurtenissen in het leven steeds opnieuw tot uiting komt, (3) ze hun gezondheid bewust beschermen, (4) ze een hechte relatie hebben met ouders waarmee ze de kankerervaring deelden en (5) dat ze voor anderen van betekenis willen zijn (**hoofdstuk 4**).

Daarnaast hanteren AYA-overlevers specifieke copingstrategieën in de omgang met lange termijn gevolgen van hun ziekte en de behandeling, waarvan sommige strategieën hun oorsprong vinden in hun kindertijd. AYA-overlevers slagen er in zich doorheen hun kindertijd aan een nieuw normaal leven aan te passen doordat ze: (1) zich richten op het hier en nu, (2) vermijden om over de kankerervaring te praten, (3) positieve herinneringen levendig houden, (4) gevolgen positief herdefiniëren en (5) gevoelens van samenhorigheid consolideren **(hoofdstuk 5)**.

Dit doctoraatsonderzoek toont aan dat zowel AYA's als AYA-overlevers de betekenis van de kankerervaring integreren in hun identiteit en de opbouw van een nieuw normaal leven. Op grond van onze bevindingen kunnen enkele criteria voor leeftijdsspecifieke zorg worden voorgesteld: zorg dient (1) persoonsgericht te zijn, (2) aandacht te geven aan de specifieke copingstrategieën, (3) regie te faciliteren en (4) te voorzien in communicatie op maat van AYA(overlever)s. Door holistisch en met open blik aandacht te geven aan de veranderende behoeften en noden van AYA(overlever)s kunnen zorgverleners hen ondersteunen en versterken in de kracht die ze aan de dag leggen, van bij de diagnose tot ver na de behandeling (**hoofdstuk 6**).

Summary

Adolescents and young adults, or “AYAs", represent a specific population in oncology. Besides the group of AYAs who are diagnosed with cancer in their adolescence, a group of AYAs can also be distinguished who face in their adolescence the (chronic) consequences of a childhood cancer experience. This group is called the AYA survivors. For both groups, a cancer experience interrupts the normal development from child to adult and affects the further course of life. International literature emphasizes high-quality patient-centered medical and psychosocial care that addresses a broad spectrum of acute and chronic needs of AYAs. To provide tailored care for AYA(survivors), insight in the perceptions, experiences and needs of AYA(survivor)s is needed. To date, research is limited **(chapter 1)**.

This doctoral research aims to expand knowledge about the experience trajectory of AYA(survivors), starting from their perspective. The first part examines AYAs' experiences of cancer and the meaning they attribute to them. A second part explores the cancer experience in the current lives of AYA survivors of childhood cancer.

AYAs who are diagnosed with cancer between the ages of 15 and 25 experience the diagnosis like a bomb going off. Particularly confronting are physical consequences of the disease and its treatment, and the integration of the cancer experience into their identity. Other challenges include loss of independence and loneliness. AYAs are self-centered and adopt certain coping strategies, such as maintaining a positive attitude, to endure the cancer experience. Throughout the cancer trajectory, they want to master their lives as much as possible. Therefore, it is important that healthcare professionals allow AYAs the necessary space to become directors of their own care. After all, this enables them to approach the cancer experience in a way that suits them best **(chapter 2)**.

In the cancer experience, AYAs go through a three-phase process: (1) *A phase in which maintaining normal life is essential.* Initially, AYAs see the cancer as a transient occurrence, after which everything would go back the way it was before. (2) *A phase in which they experience that normal life slips away*. AYAs experience how they lose connection with familiar life and how existing relationships take on a different meaning. (3) *A phase in which a new normal life needs to be developed*. AYAs experience that the cancer experience has a significant impact on their identities and that their former life has disappeared. Underpinning these three phases, different dynamics can be distinguished in the meaning AYAs give to their cancer experience and the challenges they face. For instance, AYAs experience how they lose their sense of mastering life and become more aware of their own

vulnerability. As a result, the AYAs' needs change during their cancer trajectory and they express varying expectations of their social networks **(chapter 3)**.

AYAs who are diagnosed with cancer before the age of 15 experience in daily life the long-term consequences of the cancer and its treatment. Unlike those diagnosed in early childhood (<7 years), AYA survivors diagnosed in late childhood (7-14 years) distinguish a life before and after cancer. For both groups, the cancer experience means that: (1) they feel different but that they do not want to be perceived as different, which influences the way they communicate their cancer experience to others, (2) they live with existential uncertainty and encounter continuously new situations which confront them with the consequences of their cancer experience, (3) they consciously protect their health, (4) they have a close relationship with parents with whom they shared the cancer experience, and (5) they want to be meaningful to others **(chapter 4)**.

In addition, AYA survivors use specific coping strategies in dealing with the long-term consequences of their illness and treatment, some of which were already developed during the childhood cancer experience. AYA survivors facilitate in living a normal life by: (1) focusing on the here and now, (2) refraining from discussing the cancer experience, (3) recalling and preserving positive memories, (4) redefining the impact positively and (5) consolidating and preserving a sense of togetherness **(chapter 5)**.

This doctoral research demonstrates that both AYAs and AYA survivors integrate the meaning of the cancer experience into their identity and the construction of a new normal life. Based on our findings, some criteria for age-specific care can be proposed: care should (1) be person-centered, (2) pay attention to the specific coping strategies, (3) facilitate directorship and (4) provide tailored communication for AYA(survivors). By addressing the changing needs of AYA(survivor)s holistically and with an open mind, healthcare professionals can support and empower AYA(survivor)s in the strength they demonstrate, from diagnosis to well beyond treatment **(chapter 6)**.

Curriculum Vitae

Personalia

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Opleiding

2005 – 2007	Master Sociaal Werk – Universiteit Gent
2001 – 2004	Bachelor Sociaal Werk, optie maatschappelijk werk Arteveldehogeschool Campus St.Anna Gent
1994-2000	A.S.O. Latijn Moderne Talen - St.Jozefsinstituut Humaniora, Brugge

Bijkomende opleidingen

2022	(Residentiële) cursus "Leren implementeren": zorginnovaties en richtlijnen in de praktijk brengen" - AccentVV, KU Leuven
2020	Eindelevensverhaal schrijven - Amfora Vlaanderen
2020	Change Management - Amelior
2011	Academic English: Writing Skills in Life Sciences and Medicine - UCT, Universiteit Gent

Werkervaring

Bezoldigd

2022 – heden	AYA-zorgcoördinator UZ Gent (100%)
2016 – 2022	AYA-Project & Onderzoekscoördinator Kankercentrum UZ Gent (80%)
2013 – 2016	Doctoraatsbursaal UCVV, UGent (100%)

2012 – 2013	Wetenschappelijk medewerker, UCVV, UGent (75%) en Gastprofessor, Expertisecentrum Verpleegkunde en Vroedkunde, Katholieke Hogeschool Vives (25%)
2011 – 2012	Wetenschappelijk medewerker, Kankercentrum UZ Gent (100%)
2009 – 2011	Wetenschappelijk medewerker, Kankercentrum UZ Gent (50%) en Sociaal werker, Sociale Dienst Patiënten UZ Gent (50%)
2009	Sociaal consulente, Dienst Sociale Voorzieningen, Stad Gent (100%)

Onbezoldigd

2018 – heden	vzw Care4AYA, bestuurslid
2010 - 2020	vzw Daf-Dok, bestuurslid
2007 – 2023	vzw Bamboostic, bestuurslid
2007-2008	Coördinatie zuidwerking vzw Bamboostic in Camburi, Brazilië

Publicaties

Artikels in internationale peer-reviewed tijdschriften

Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., & Verhaeghe, S. (2021). Coping strategies of adolescent and young adult survivors of childhood cancer : a qualitative study. *CANCER NURSING*, *44*(6), E395–E403.https://doi.org/10.1097/ncc.0000000000000865

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Overige publicaties

Belpame, N., Decoene, E., Quaghebeur, M., Lapeire, L., Verhaeghe, S. (2018). *De liefdevolle manager. Ouders van een jongere met kanker vertellen hun verhaal.* ISBN 9789492944092 D/2018/3988/40. Gent: Care4AYA vzw.

Belpame, N., Decoene, E., Quaghebeur, M., & Verhaeghe, S. (2012). *Jong en kanker*. Gent: Oncologisch Centrum UZ Gent.

Mondelinge presentaties

Belpame N., Dedicated care for adolescents and young adults with cancer (2023) Young BSPHO symposium, *Young BSPHO*, Ghent.

Belpame N., AYA-zorg, in gesprek gaan met AYA's en naasten (2023) VVRO Jaarcongres, *VVRO*, Antwerpen.

Belpame N., Decoene E., Quaghebeur M., Neefs H., Lapeire L., Verhaeghe S. (2022) A tailored psychosocial support tool for parents of adolescents and young adults with cancer. 8th OncoPoint Symposium, *CRIG*, Gent.

Belpame N. Hoe ondersteun ik een AYA op mijn afdeling? (2022) VVRO Jaarcongres, *VVRO*, Blankenberge.

Belpame N. Psychosociale zorg op maat voor jonge patiënten met borstkanker (2022) Pfizer Oncology Workshop, *Pfizer*, Brussel.

Belpame N., Decoene E., Quaghebeur M., Lapeire L., Verhaeghe S. (2021) A tailored psychosocial support tool for parents of AYAs with cancer and AYA survivors. Global Adolescent and Young Adult Cancer Congress. *Global Aya Accord*, online.

Belpame N., Quaghebeur M., Decoene E., Neefs H., Verhaeghe S., Lapeire L. (2021) Zorg op maat van jongvolwassenen (AYA's) en fertiliteitspreservatie. Bereikbare oncologische zorg: een innovatief zorgmodel. *Kankercentrum UZ Gent*, Gent.

Belpame N., Decoene E., Quaghebeur M., Neefs H., Verhaeghe S., Lapeire L. (2021) Het AYA-kompas. Presentatie Jong en Kanker, symposium *Kom op tegen Kanker*, Mechelen.

Belpame N., Decoene, E., Quaghebeur, M., & Verhaeghe, S. (2019). Experiences of parents whose adolescent child has cancer, basis of a psychosocial support booklet "The Loving Manager." *CARE4-2019 Abstract Book*, 158–158.

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Belpame N., Kars, M. C., Beeckman, D., Decoene, E., Quaghebeur, M., Van Hecke, A., & Verhaeghe, S. (2017). Dynamics in the cancer experience of adolescents and young adults : the 3-phase process. *AYA Cancer, 2nd Global Congress, Abstracts*. Presented at the 2nd Global AYA (Adolescent & Young Adult) Cancer congress: Working together, achieving more, Atlanta, GA, USA.

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Belpame N., Decoene, E., Quaghebeur, M., & Verhaeghe, S. (2013). De beleving van de adolescent en jongvolwassene met kanker en van zijn mantelzorger. *Hiervoor Ben Je Te Jong!, Samenvattingen van Het Symposium*. Presented at the Symposium "Hiervoor ben je te jong!," Gent.

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Copromotorschap masterproeven

2022-2023	De ervaringen en noden van zorgverleners in de zorg voor adolescenten en jongvolwassenen met kanker (Willsens Tyra, UCVV)
2022-2023	De ontwikkeling en evaluatie van een psychosociale nazorgpas voor AYA's: een expertbevraging (Vancayseele Sharon, UCVV)

2021-2022	De ervaringen, beleving en noden van broers en zussen van overleden AYA’s met kanker (Meulemeester Laura,UCVV)
2019-2020	De ervaringen van jongvolwassenen in follow up na kanker (Peers Laura, UCVV)
2019-2020	Onderzoek naar de psychosociale noden van AYA’s met kanker en een migratieachtergrond (Mbonzololo La Perle, UCVV)
2019-2020	Psychosociale zorg voor jongeren en jongvolwassenen tussen 16-35 jaar met kanker in een palliatieve fase (De Langhe Paulien, CHI opleiding psycho-onco)
2018-2019	De ervaringen en psychosociale noden van jongvolwassenen met kanker (Huyghe Camille, UCVV)
2018-2019	De ervaringen en psychosociale noden van partners van jongvolwassenen en adolescenten met kanker (AYA’s) (Van Lerberghe Marc, UCVV)
2014-2015	Zorg dragen voor een adolescent of jongvolwassene met kanker. Een kwalitatief onderzoek naar de beleving van ouders (Dumortier Sofie, Master Sociaal Werk UGent)
2013-2014	Sturing van het sociaal netwerk van adolescenten met kanker. Onderzoek naar onderliggende mechanismen en processen (De Pree Marinus, UCVV)

Structurele lesopdrachten

CHi-opleiding Zorg op maat voor jongeren en jongvolwassenen met kanker (AYA's)

Verpleegkunde Postgraduaat onco Vives Kortrijk

Dankwoord

Dit doctoraat weerspiegelt een proces van ontmoeten, ontdekken en ontplooien, en werd mogelijk gemaakt dankzij de inspanningen van velen. Ik spreek dan ook graag mijn dank uit aan iedereen die mij in dit traject heeft begeleid, geïnspireerd en ondersteund.

Allereerst gaat mijn dank uit naar alle AYA's en AYA-overlevers die ondanks de uitdagingen waar ze voor stonden, de openheid en het vertrouwen aan de dag legden om een inkijk te bieden in hun ervaringen.

Daarnaast ben ik alle zorgverleners erkentelijk die betrokken waren bij de rekrutering van de participanten, het verzamelen van de data en het reflecteren over de inzichten. In het bijzonder, dank aan Stien Vandierendonck, Anneleen Raes, Marijke Quaghebeur, Elsie Decoene, Véronique Van de Velde†, Eva Deslypere en professor dr. Peter Rober.

Daarnaast wil ik mijn promotor en copromotoren bedanken voor hun aanhoudend engagement om dit traject mee vorm te geven. Jullie hebben van dichtbij gezien hoe dit doctoraat in vrije tijd doorvlochten was met alle verantwoordelijkheden die ik beroepshalve en familiaal wou opnemen. Bedankt om me niet onder druk te zetten. Het deed deugd om jullie gemeende aanmoediging te voelen bij het finaliseren van dit traject.

Professor dr. Verhaeghe, beste Sofie, jaren geleden polste je naar mijn interesse om te doctoreren. Op dat moment konden we niet inschatten hoe dit traject zich over de tijd heen zou ontvouwen rond de uitdagingen die we beiden in het leven zouden ervaren. Met jouw stielkennis, kundigheid in het reflecteren over de zorgpraktijk en in het analyseren over beleving en betekenisverlening, heb je mij niet alleen door de gezondheidszorg en het kwalitatief onderzoek geloodst maar heb je me ook verder reikende inzichten bijgebracht die me hielpen eigen levensgebeurtenissen in perspectief te plaatsen. Welgemeende dank daarvoor.

Professor dr. Van Hecke, beste Ann, je bent een gedreven onderzoeker en weet wat leeft binnen de praktijk. Bedankt dat ik beroep mocht doen op jouw knowhow. Je opmerkzaamheid en snelheid vertaalden zich steeds in waardevolle no-nonsense feedback en concrete oplossingen.

Professor dr. C. Kars, beste Marijke, bedankt dat ik ook van jou veel heb mogen leren. Met je breed gefundeerde visie en thematische expertise sloeg je in een analysebespreking vaak de nagel op de kop. Het gaf me steeds hernieuwde goesting om nog wat dieper in de data te graven. Ik heb je bemoedigende woorden in de momenten waarop ik die nodig had erg gewaardeerd.

Professor dr. Beeckman, beste Dimitri, bedankt voor jouw constructieve feedback als lid van de begeleidingscommissie.

Ook aan de leden van de examencommissie, professor dr. Stijn Blot, professor dr. Lore Lapeire, professor dr. Tina Vandecasteele, professor dr. Sarah De Pauw, professor dr. Leen Willems en dr. Danielle Zweers, wil ik mijn waardering uitspreken. Bedankt voor jullie tijd en expertise om mijn proefschrift te beoordelen en deze vanuit verschillende invalshoeken van feedback te voorzien. Jullie vragen en opmerkingen waren verrijkend.

Een woord van dank aan Kom op tegen Kanker die de studies hebben gefinancierd die aan de basis liggen van dit doctoraat.

Professor Verhaeghe, beste Rik, bedankt voor uw steun bij het voltooien en vieren van dit doctoraatstraject. Het is motiverend dat u, en bij uitbreiding het UZ Gent, gelooft en investeert in AYA-zorg.

Sinds de start van dit traject heb ik vele fijne en boeiende collega-onderzoekers en zorgverleners mogen leren kennen, zowel in het UCVV als in het UZ Gent als in Care4AYA vzw. Het is onmogelijk om iedereen te vermelden maar jullie weten wie jullie zijn; bedankt voor jullie betrokkenheid, de aangename samenwerking maar ook de luchtigheid die jullie brachten in de soms pittige periodes. In het bijzonder, dank aan Joline Goossens, Mathieu Verbrugghe en Ineke Van Eechoud; ik ben blij dat we na al die jaren het lachen nog niet zijn verleerd. Daarnaast prijs ik me erg gelukkig dat ik ook in mijn huidige functie als AYA-zorgcoördinator kan rekenen op vaste waarden Marijke Quaghebeur, Lore Lapeire, Veerle Sey en Elsie Decoene. Jullie ervaring met AYA's en voeling met de zorg geven AYA-interventies de nodige zuurstof. Elsie, met jouw eerste aanvraag voor projectfinanciering stak je het vuur aan de lont en gaf je me de kans om onder AYA-onderzoek en -praktijk mee de schouders te zetten. Sindsdien werken we al jarenlang samen en knettert het AYA-verhaal hoe langer hoe meer. Je bent een krak in je vak en hebt het vermogen om mensen te laten groeien. Dankjewel! Eva Pape en Isabel Vlerick, fijn dat ik met jullie van gedachten kon wisselen over de te nemen hordes in een doctoraatstraject. Eva, bedankt voor ons constructief schrijfweekend aan zee! Lies Buysse, Mieke Debrauwere en Michiel Daem, bedankt voor jullie hulp en onze humoristische intermezzo's met AYA-kwinkslagen. Heerlijk hoe jullie nog steeds mijn flauwe woordgrapjes gedogen.

Daarnaast ben ik ontzettend dankbaar voor mijn vele vrienden, stuk voor stuk talentvolle, inspirerende en vrije geesten; van kleine donkere musketiers tot grote (team) blonde en alles daartussenin. Het is een absoluut voorrecht om met jullie verbonden te zijn. Jullie zijn mijn gidsen in broze dagen en mijn partners in onstuimigheid. Bedankt voor jullie klankbord, humor en alle gelukzaligheid die jullie brengen.

Maïté, je hebt de gave om beeld te geven aan wat het hart en hoofd beweegt. Jouw illustraties vol betekenis zijn een constante in het AYA-verhaal en ook in dit proefschrift vormen ze de kers op de taart. Eeuwige dank.

Daarnaast heeft mijn schoonfamilie een speciaal plekje in mijn hart. Tamara en Bart, het doet goed jullie al zo lang in mijn leven te hebben. Lina, lieve schoonmama, bedankt voor jouw medeleven en goeie zorgen. Je bent een moemoet uit de duizend. Tinetch, zonder de schrijfretraites met sushi bij de stoof was dit werk nog lang niet afgeROND ; -)

Christine, Patrick, Johan, mijn lieve zus en broers, wat ben ik bevoorrecht dat jullie in het leven mijn langste compagnons de route zijn; een natuurlijke clan waarin ruimte is voor ieders eigenheid maar terzelfdertijd met een sterke bescherming en liefde voor elkaar. Ik besef maar al te goed dat dit niet iedereen is gegeven. Bedankt voor alles wat we delen.

Jan, mijn mooie man, zonder jou zou ik hier niet staan. Nooit heb je aan mij getwijfeld. Met jouw hartstocht en eigenzinnige creativiteit toon je me de schoonheid van ongebaande paden maar bied je me ook de vrijheid om mezelf te zijn. Je maakt oprecht een kunstwerk van het leven. Dank je wel voor de manier waarop je me door het leven draagt en er altijd vol overgave voor me bent. Ik heb je lief.

Robin en Tristan, jullie zijn mijn alles, mijn jongens vol puurheid, guitigheid en nieuwsgierigheid. In het schipperen tussen alle eisen die ik mezelf de afgelopen tijd heb opgelegd, heb ik jullie vaak om (te veel) geduld gevraagd. Jullie hebben zo jullie best gedaan en ik kreeg er nog eens ongevraagd en onverdiend zot veel zoentjes en knuffels bovenop! Ik ben dankbaar en trots op de prachtige kindjes die jullie zijn. Ik zie jullie graag.

Tenslotte, boven alles dank aan mijn ouders die ik mateloos bewonder; mijn papa voor zijn avontuurlijke, wijze en sociale aard en mijn mama voor haar integriteit, veerkracht en onvoorwaardelijke aandacht. Mama en papa, wat had ik jullie graag langer aan mijn zijde gehad. Ik troost me in de wetenschap dat ik jullie liefde intens heb mogen ervaren en dat wat we hadden tijd en ruimte overstijgt. Ik weet dat jullie vandaag met trots zouden kijken naar het behalen van dit doctoraat en ik draag dit werk dan ook met mijn volledig hart op aan jullie.