Corine Nierop-van Baalen

Hoop en positief denken bij mensen met kanker

Een exploratie naar de betekenis, beïnvloedende factoren en strategieën

Promotoren:
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HOOP EN POSITIEF DENKEN BIJ MENSEN MET KANKER

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Inhoud

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Introductie en onderzoeksvragen

Algehele inleiding proefschrift

Hoop en positief denken zijn begrippen die in het dagelijks taalgebruik van mensen met kanker veelvuldig worden gebruikt. Alleen al om deze reden verdienen de begrippen hoop en positief denken bij mensen met kanker een grondige exploratie. Het oorspronkelijke plan van dit proefschrift was om studies te verrichten naar hoop bij mensen met kanker in de verschillende fasen van het ziekteproces. Tijdens de data-analyse van mensen met kanker die met opzet curatief (genezend) worden behandeld bleek dat voor wat mensen in de dagelijkse taal gemakkelijk hoop zouden kunnen noemen, door hen de term positief denken gebruikt werd. Om deze reden focust dit proefschrift zich op hoop én positief denken bij mensen met kanker in de verschillende fasen van het ziekteproces.

Dit proefschrift wil bijdragen aan meer kennis over en inzicht op het gebied van hoop en positief denken bij mensen met kanker in verschillende stadia van de ziekte én vanuit het perspectief van hulpverleners. Door deze processen te begrijpen kan dit proefschrift een bijdrage leveren aan zorg die beter wordt afgestemd op de behoefte van mensen met kanker en die recht doet aan de worsteling en de moeite die het kost om te leven in het vooruitzicht van een (beperkte) toekomst. Dit proefschrift wil handvatten bieden aan hulpverleners die moeilijkheden kunnen ervaren in het omgaan met hoopvolle palliatieve patiënten.

Deze introductie beschrijft achtergrondinformatie van mensen met kanker en de verschillende fasen van behandeling als ook de impact daarvan. De concepten hoop en positief denken worden geëxploreerd. We verkennen het perspectief van mensen met kanker en van hulpverleners. Na deze beschrijving van de achtergrondinformatie wordt de doelstelling van dit proefschrift weergegeven. Tenslotte worden de onderzoeksvragen vermeld en de gebruikte methoden toegelicht.

De ziekte kanker, curatieve, niet-curatieve behandelingen en de palliatieve fase

In 2018 kregen 18,1 miljoen mensen, wereldwijd, de diagnose kanker en overleden 9,6 miljoen mensen aan de ziekte (Bray et al. 2018). In de Westerse landen krijgt een op drie mensen ooit de diagnose kanker (Beleidsvisie KWF Kankerbestrijding 2015 tot 2019). De verwachting is dat de komende jaren de incidentiecijfers zullen toenemen. Dit heeft met drie factoren te maken: het aantal mensen op aarde stijgt, de wereldbevolking vergrijst en de leefstijl is ongezonder geworden, waardoor het risico op het krijgen van kanker is vergroot (Bray et al. 2018). Naast de toename van het aantal nieuwe diagnoses is ook de levensverwachting gestegen, door eerdere ontdekking van de ziekte en door betere behandelmogelijkheden (Siegel et al. 2019).

In de oncologie worden meestal twee termen gebruikt om de therapiedoelen te beschrijven: curatieve en palliatieve behandelingen. Curatieve behandelingen zijn behandelingen gericht op het genezen van de ziekte, wat betekent dat de overleving van de patiënt niet wordt beperkt door hun huidige kankerdiagnose (Neugut & Prigerson, 2017). Palliatieve of levensverlengende behandelingen zijn behandelingen waarbij het doel is om het leven zo lang mogelijk te verlengen, hoewel de patiënt uiteindelijk waarschijnlijk aan de ziekte zal sterven. Deze benaming wordt in de oncologie ook gebruikt als het niet meer mogelijk is dat een patiënt zal genezen, maar de ziekte wel kan evolueren naar een chronische fase. Onder palliatieve behandelingen verstaan wij in dit proefschrift niet wat in de internationale literatuur palliatieve zorg wordt genoemd. Met palliatieve zorg wordt bedoeld: de zorg die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening of kwetsbaarheid, door het voorkomen en verlichten van lijden, door middel van vroegtijdige signalering en zorgvuldige beoordeling en behandeling van problemen van fysieke, psychische, sociale en spirituele aard. Gedurende het beloop van de ziekte of kwetsbaarheid heeft palliatieve zorg oog voor het behoud van autonomie, toegang tot informatie en keuzemogelijkheden (kwaliteitskader palliatieve zorg Nederland, IKNL/ Palliactief, 2017).

Naast de therapiedoelen wordt ook het begrip palliatieve fase veel gebruikt. In de artikelen van dit proefschrift gebruiken we de volgende definitie van palliatieve fase: De palliatieve fase van de ziekte betekent dat het voor hulpverleners duidelijk is dat er geen curatieve opties (opties gericht op genezing) meer zijn. Met palliatieve fase bedoelen we dus de niet-curatieve fase, zonder daarbij iets te zeggen over de ernst van de situatie, over de mate en de aard van de zorg die nodig is, of over de duur van de levensverwachting. Patiënten zijn alleen geïncludeerd in de studie als er duidelijk met patiënten gesproken is, dat er geen curatieve opties meer zijn. Voor de term palliatieve fase is gekozen omdat dit in de internationale oncologisch-medische literatuur, de meest gangbare term is om het onderscheid te maken tussen de behandeldoelen. Curatieve of palliatieve behandeling of fase zijn termen die vooral door hulpverleners werkzaam in ziekenhuizen worden gebruikt. Patiënten zelf gebruiken deze termen niet en spreken over een behandeling die genezing tot doel heeft of zeggen dat ze niet meer kunnen genezen. De term palliatief roept bij hen op zijn minst de associatie op met het levenseinde, en die associatie willen ze vermijden.

Impact van de ziekte kanker

De ziekte kanker heeft grote impact op iemands leven en van degenen om hem heen. Kanker raakt ons allemaal, is dan ook de slogan van de KWF kankerbestrijding (Beleidsvisie KWF Kankerbestrijding 2015 tot 2019). De ziekte kanker kan tegenwoordig beter en langer behandeld worden en meer behandelingen zijn ook mogelijk voor oudere mensen met kanker. Vaak ondergaan mensen meerdere behandelingen (operatie en/of chemotherapie en/of radiotherapie en/of hormonale therapie) die over het algemeen intensief van aard zijn en maanden kunnen duren. Naast lichamelijke gevolgen en ongemakken van de ziekte en behandeling heeft kanker ook grote impact op het psychisch welbevinden van mensen, zoals chronische vermoeidheid, relationele en seksuele problemen, depressie, de angst voor terugkeer van de ziekte, problemen bij de terugkeer naar werk en sociale isolatie (Kankerzorg in beeld over leven met en na kanker.pdf, 2019).

Hoewel mensen met de ziekte kanker betere overlevingskansen hebben dan vroeger, slaat een diagnose kanker nog steeds hard toe. De ziekte kanker tast het leven in zijn fundamenten, in zijn wortels aan. Het verandert het leven totaal. Het oude leven is in puin gevallen. Op die puinhopen moeten de patiënt en zijn familie een nieuw leven opbouwen. Het besef van de eindigheid van het leven en de onzekerheid die daarvan het gevolg is brengt een existentiële crisis teweeg (Grypdonck, 2005). Op deze existentiële crisis reageren veel mensen met kanker met het koesteren van hoop. Hoop dat het zo’n vaart niet zal lopen. Hoop dat het niet zo erg is; dat ze aan een goed behandelbare variant zullen lijden; dat de kanker niet is uitgezaaid; dat ze geen chemotherapie hoeven te krijgen. En vooral hoop op volledige genezing (Grypdonck, 2005).

De hoop van mensen met kanker is vaak prominent aanwezig en kan haaks staan op medische feiten en prognose. Veel hulpverleners vinden het lastig om te gaan met deze hoop, zeker als de hoop (veel) sterker is dan op grond van medische feiten verwacht kan worden. Hulpverleners kunnen denken dat mensen onvoldoende zijn geïnformeerd over hun prognose, of dat ze de situatie ontkennen. Hulpverleners weten dan vaak niet wat ze ermee moeten en zetten soms acties in, zoals opnieuw de prognose vertellen, die door de patiënten slecht ontvangen worden en niet aansluiten bij hun behoeften. Dit is een van de redenen waarom wij onderzoek naar hoop willen doen bij mensen met kanker en de hulpverleners.

Dit proefschrift behandelt, zoals gezegd, hoop en positief denken. Hoop en positief denken zijn twee verschillende concepten die dicht bij elkaar liggen, tegen elkaar aan schuren en elkaar deels overlappen. De data dwingen ons echter om hoop en positief denken als afzonderlijke concepten te beschrijven. De data laten zien dat positief denken moeilijk opgevat kan worden als een strategie van hoop. In de discussie zal dieper ingegaan worden op de overeenkomsten en verschillen tussen deze twee concepten.

Hoop bij mensen met kanker

Onderzoek naar hoop in de afgelopen jaren

Sinds langere tijd wordt onderzoek naar hoop bij mensen met kanker verricht. De eerste studies verschenen in de jaren 70, aangegeven door Herth (1992). Een eerste definitie van hoop die dan wordt gegeven is een vrij smalle conceptualisatie van hoop: hoop wordt gezien als een verwachting van het bereiken van doelen (Stotland's, 1969 In: Herth 1992). Begin jaren 80 worden er al kwalitatieve studies verricht naar dimensies van hoop (Miller 1983; Raleigh, 1980 In: Herth 1992). Deze studies beschreven aanvullende elementen over de ervaring van hoop en leggen de fundamenten van de multidimensionele dimensies van hoop. Deze dimensies gaan over: oriëntatie in de tijd, toekomstgerichte focus van hoop en de verwachting om doelen te bereiken. Deze toevoeging van de dimensies hebben geresulteerd in de ontwikkeling van verschillende meetinstrumenten o.a. de The Miller Hope Scale (Miller & Powers, 1988) en de Nowotny Hope Scales (Nowotny, 1989). Studies die halverwege de 80- jaren en begin jaren 90 zijn afgerond (Dufault & Martocchio, 1985, Herth 1990, Hinds & Martin, 1988, Owen 1989) beschrijven een aantal conceptuele issues die nog niet eerder waren beschreven en in dan gebruikte hoopinstrumenten waren opgenomen. Deze issues zijn: een meer algemene niet tijdgeoriënteerde gevoel van hoop, hoop ondanks verminderde of afwezige interpersoonlijke relaties, hoop als een gevoel van wederkerigheid in onderlinge relatie (iets doen voor jezelf en voor anderen) en de potentie van hoop om gedrag en emoties te kunnen beheersen om op die manier tegenover ervaringen en gebeurtenissen te zetten (Herth, 1992). De studies in de jaren 90 tot 2000 zijn vooral interventiestudies over het vermeerderen van hoop bij patiënten die pas zijn gediagnosticeerd met kanker (Rustøen, et al. 1998) en mensen met recidief bij kanker (Herth, 1995). Beide studies laten een significante toename zien van hoop na de interventie (Butt, 2011). Vanaf 2000 zien we een toename van studies over hoop bij mensen met kanker aan het einde van het leven (Benzein et al. 2001, Eliott & Olver, 2002, 2009; Johnson, 2009; Kylmä et al, 2009; McClement & Chochinov, 2008). Benzein et al. (2001) concludeerden in hun fenomenologisch-hermeneutisch onderzoek bij 11 mensen met kanker in de palliatieve fase, dat er twee soorten hoop kunnen worden onderscheiden: Hopen op iets, zoals hoop op genezing en in hoop leven, wat wil zeggen verzoening met het leven en de dood. Benzein et al. (2001) beschrijven dat er tussen beide dimensies van hoop een spanning is en welke dimensie prominent aanwezig is varieert gedurende de tijd. In het algemeen wordt hoop gezien als een effectieve copingstrategie voor mensen met kanker, het helpt hen door moeilijke situaties heen en geeft hen kracht om zich aan te passen aan de nieuwe situatie en om gewenste doelen te bereiken (Ebright & Lyon, 2002; Herth & Cutcliff, 2002). Opvallend genoeg lijkt de interesse in onderzoek naar hoop de laatste tien jaar weer te zijn afgenomen.

Definities van hoop

Hoop wordt gezien als een complex begrip. Ondanks vele studies is het niet duidelijk wat precies onder hoop wordt verstaan. In de literatuur wordt hoop wordt vaak gedefinieerd als: “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a good future which, to the hoping person, is realistically possible and personally significant (Dufault & Martocchio, 1985). Snyder (2002) omschrijft hoop als ‘one’s belief in the capability to achieve goals, particularly in situations where one can influence outcomes through the use of personal abilities of strengths’. In de medische context omvatten alle definities het concept van een gewenste toekomstige gebeurtenis, die, wanneer ze in het heden wordt verwoord, een positieve invloed op het welzijn kan hebben of op zijn minst een positieve toestand kan weerspiegelen (Olver, 2012). Hoop verschilt van optimisme omdat optimisme wordt gezien als een algemene verwachting op een goede uitkomst, ongeacht hoe beheersbaar deze is (Bryant & Cvengros, 2004; Rand et al. 2012).

Een andere manifestatie van het complexe karakter van hoop is het verschil in gebruik van het woord hoop als zelfstandig naamwoord of als een werkwoord. Uit discourse analyses bij mensen met kanker in de terminale fase (Eliott & Olver, 2002) blijkt dat als hoop gebruikt wordt als zelfstandig naamwoord die gezien wordt als een losstaande entiteit, zoals deze gegeven is door het medisch team. Vaak gebruikt als “geen hoop”. Als hoop daarentegen ingezet wordt als een werkwoord dan gaat deze hoop over de persoonlijke wensen en uitkomsten die belangrijk voor de patiënt zelf, zoals het bereiken van comfort of het kunnen meemaken van een belangrijke gebeurtenis in de toekomst.

Uit de gangbare definities van hoop blijkt dat (Dufault & Martocchio, 1985; Olver, 2012; Snyder, 2002) hoop een dynamisch proces is, dat door patiënten op verschillende manieren, op hetzelfde moment gebruikt kan worden. Dit maakt het moeilijk om de verschillende betekenissen van hoop te onderscheiden en kan ook leiden tot miscommunicatie tussen patiënten en hulpverleners, bijvoorbeeld wanneer artsen een bepaalde sterkte van de hoop verwachten op grond van de prognose, maar dit slechts gebaseerd is, op een dimensie van hoop, terwijl de patiënt meer een persoonlijker hoop heeft (Olver, 2005).

Positief denken

Twee andere termen die erg belangrijk zijn voor mensen met kanker is positief denken of positief zijn. In de algemene opinie heerst het beeld dat iemands mentale houding in reactie op de diagnose kanker van invloed kan zijn op zijn of haar overlevingskansen (Jouret, 2010). Petticrew et al. (2002) hebben een systematische review gedaan naar het effect van psychologische coping stijlen (zoals, vechtlust, hopeloosheid, ontkenning en vermijding) op overleving en op het krijgen van een recidief bij mensen met kanker. Zij vonden weinig overtuigend bewijs dat een van deze copingstijlen een klinisch belangrijke rol spelen bij het overleven van kanker of het voorkomen van een recidief. De studies die een positieve relatie tussen overleving en coping vonden betroffen kleine studies of methodologische gebrekkige studies, aldus Petticrew et al. (2002).

Positief zijn is een algemene term die gebruikt wordt voor zowel positief denken als een positieve attitude (O'Baugh et al. 2003). Volgens De Raeve (1997) wordt een positieve attitude gezien als een state of mind om met een positief gevoel zaken te bekijken. Positief denken gaat over cognitieve technieken en strategieën om onaangename gemoedstoestanden te overwinnen (De Raeve, 1997). Tod et al. (2011) omschrijven positief denken als een complex concept welke een range van waarden, attitudes en activiteiten omvat. Positief denken verschilt ook van optimisme omdat optimisme verankerd zit in het karakter en niet object gebonden is. Positief denken daarentegen kun je ook aanleren en is gericht op een specifiek object.

Positief willen zijn is enerzijds iets dat vanuit mensen met kanker zelf ontstaat, anderzijds kan positief moeten denken ook een reactie zijn op druk van anderen of van 'de wereld waarin we leven' (Wilkinson & Kietzinger, 2000). Volgens de Raeve (1997) kan zeggen dat je positief bent, een manier zijn om sociaal wenselijk te reageren. Deze druk kan ook vanuit de nabije omgeving (naaste, familie) komen (Youll & Meckosh, 2011). Hulpverleners en met name verpleegkundigen kunnen ook druk uitoefenen op patiënten door hen aan te moedigen om positief te zijn (O'Baugh et al. 2008; Tod et al. 2011). Er lijkt dus een verschil te zijn tussen enerzijds positief willen zijn en anderzijds positief moeten zijn.

Uitdagingen en problemen in de huidige praktijkvoering

Ondanks belangrijke inzichten die zijn voortgekomen uit bestaand onderzoek naar hoop en positief denken bij mensen met kanker, zijn sommige problemen met betrekking tot hoop en positief denken onduidelijk gebleven of is er nog weinig onderzoek naar gedaan. Deze problemen veroorzaken uitdagingen in de praktijk bij het begrijpen van hoop en positief denken bij mensen met kanker. Deze problemen betreffen vaak een gebrek aan inzicht in het perspectief en de betekenis van hoop en positief denken van patiënten, een beperkt tot geen inzicht in percepties van hulpverleners ten aanzien van hoopvolle patiënten en een gebrek aan inzicht in factoren die met hoop geassocieerd worden. Deze kwesties worden hieronder uitgewerkt.

Betekenis van hoop vanuit patiëntenperspectief

Ook al is er veel onderzoek naar hoop gedaan, verrassend weinig is bekend over de betekenis van hoop bij mensen met kanker. Hoop is belangrijk voor mensen met kanker in alle fasen van de ziekte, maar vooral in de palliatieve fase (Davis et al. 2017; Kylmä et al. 2009) en aan het einde van het leven (Clayton et al. 2005; Elliot en Olver, 2007). De meeste studies beschrijven het belang van hoop (Acquaye et al. 2016, Davis et al 2017, Elliot and Olver, 2002, Seibaeck et al. 2012). Slechts een enkele studie focust zich op de betekenis van hoop (Benzein et al. 2001). Exploratie vanuit het perspectief van de patiënt is belangrijk om de behoeften van de patiënten te leren kennen en om zorg te kunnen bieden die afgestemd is op de behoeften van de patiënten. Daarnaast maakt exploratie van het patiëntenperspectief zichtbaar dat hulpverleners andere visies op hoop kunnen hebben dan patiënten (Mok et al. 2010; Olsman et al. 2014). Dit maakt dat patiënten zich onbegrepen kunnen voelen en dat hoop bij patiënten niet altijd wordt herkend en soms verward wordt met ontkenning (Kersten et al. 2011; Van Laarhoven et al. 2011). Daarom is het belangrijk om inzicht te verkrijgen in de betekenis van hoop vanuit het perspectief van mensen met kanker, maar ook vanuit het perspectief van hulpverleners.

Hoop vanuit hulpverlenersperspectief

Als we naar hoop bij mensen met kanker vanuit hulpverlenersperspectief kijken dan valt op dat hoe hulpverleners omgaan met hoopvolle mensen met kanker per land kan verschillen. In de Noord-Amerikaanse en Aziatische literatuur, wordt hoop gezien als een positieve kracht (Herth & Cutcliff, 2002; Mok et al. 2010). In deze landen wordt van hulpverleners verwacht dat ze de hoop van mensen met kanker bevestigen en aanwakkeren. In de Noord-Amerikaanse landen zijn ook hoopinterventieprogramma's ontwikkeld, met dat doel (Duggleby et al. 2007; Herth, 2001). In de West-Europese oncologische literatuur wordt hoop, die verder gaat dan de medische verwachting, eerder gezien als een probleem. In die landen wordt van hulpverleners verwacht dat ze patiënten helpen om de realistische situatie onder ogen te zien (Dupuis, 1998, The et al. 2000; Van Laarhoven et al. 2011). Mok et al. (2010) laten in hun review zien dat hulpverleners in staat zijn om de hoop van patiënten te behouden, te versterken maar ook kunnen vernietigen door hun gedrag en manier van communicatie. Tot nu toe zijn er weinig initiatieven ondernomen om te focussen op het perspectief van hulpverleners in West-Europese landen en is er, op dit moment, geen evidence over het perspectief van hulpverleners t.a.v. omgaan met hoopvolle palliatieve patiënten.

Factoren geassocieerd met hoop

Meerdere studies zijn gedaan naar factoren die hoop beïnvloeden, de studies hebben zich gefocust op demografische factoren (Vellone et al. 2006), psychologische factoren, zoals angst, depressie en stress (Rustoen et al. 2010), coping (Vellone et al. 2006), sociale steun (Mattioli et al. 2008) en spiritualiteit (Benzein & Berg, 2005). Deze studies zijn vaak gebaseerd op een kleine steekproef of op een specifieke patiëntencategorie of focussen zich op enkele variabelen. Wat mist is een overzicht welke factoren wel en niet geassocieerd met hoop zijn. De laatste jaren is vooral onderzoek gedaan naar hoop en palliatieve patiënten (Clayton et al. 2005; Eliott & Olver, 2009; Kylmä et al. 2009; Olsson et al, 2011). Echter het blijft onduidelijk welke factoren hoop beïnvloeden bij mensen met kanker gedurende behandeling. Het aantal mensen met kanker neemt toe, meer behandelingen zijn beschikbaar, mensen kunnen langer worden behandeld doordat behandelingen minder toxisch zijn en mensen leven langer met kanker. Om deze redenen is het belangrijk om uit te zoeken welke factoren hoop beïnvloeden bij mensen die bezig zijn met behandelingen.

Betekenis van positief denken bij mensen die curatief worden behandeld

De afgelopen jaren zijn slechts enkele studies gedaan naar positief denken bij mensen met kanker. Vaak betroffen dit studies die geen onderscheid hebben gemaakt in of mensen behandeld worden met een palliatief dan wel curatief behandelingsdoel (Caprara et al 2016; O'Baugh et al. 2003). De studies (Caprara et al 2016; O'Baugh et al. 2003) laten zien dat positief denken positieve effecten oplevert. Positief denken is geassocieerd met een betere kwaliteit van leven bij mensen met kanker (Caprara et al. 2016). En mensen die positief denken rapporteren, volgens de studie van Caprara et al. (2016), minder symptomen als angst en moedeloosheid. Ook stelt het mensen in staat om om te kunnen gaan met de ziekte en behandelingen (O'Baugh et al. 2003). Het helpt patiënten die curatief zijn behandeld (Drageset et al. 2018) om door te gaan met leven en dit leven invulling te geven. Heel weinig studies zijn gedaan naar positief denken bij mensen met kanker die met curatieve intentie worden behandeld. Daardoor is er momenteel weinig inzicht in de betekenis van positief denken van mensen met kanker gedurende of na curatieve behandeling. Zoals eerder genoemd zijn steeds meer mensen met kanker bezig met behandeling en steeds vaker kan een behandeling met curatieve intentie gegeven worden. De literatuur en de praktijk laten zien dat er verwarring bij hulpverleners kan zijn of het positieve denken van mensen zelf komt, of dat patiënten 'moeten' positief denken vanuit hun omgeving. Om deze redenen is het nodig om inzicht te verkrijgen in het perspectief van mensen met kanker ten aanzien van positief denken.

Onderzoeksvragen en opbouw proefschrift

Dit proefschrift is samengesteld uit verschillende hoofdstukken. Deze hoofdstukken zijn opgebouwd uit vier Engelstalige artikelen, die gepubliceerd zijn of ingediend zijn voor publicatie in een internationaal, peer reviewed tijdschrift.

Om inzicht te krijgen in de betekenis van hoop, focust het eerste deel van het proefschrift (hoofdstuk 2 en 3) zich op de palliatieve fase. Uit eerdere studies bij mensen met kanker in de palliatieve fase blijkt hoop een prominent thema te zijn, terwijl hoop daarbij vaak geen onderdeel van de studie en de interviewvragen was. Om die reden is ervoor gekozen om een secundaire analyse te verrichten van data die eerder zijn verkregen uit zes kleinere kwalitatieve studies die gedaan zijn bij Nederlandse en Vlaamse mensen met kanker in de palliatieve fase van hun ziekte (n=76). Deze data zijn onder te verdelen in twee groepen. In de ene groep data was hoop het thema dat vooraf aan de interviews meegedeeld was. In de andere groep data was hoop geen onderdeel van de onderzoeksvraag en werd hoop zelf door de geïnterviewden ingebracht. Ons doel was om de betekenis van hoop bij mensen met kanker in de palliatieve fase inzichtelijk te krijgen. De onderzoeksvraag van de studie in hoofdstuk 2 luidt:

- Wat is de betekenis van hoop voor mensen met kanker in de palliatieve fase?

Om inzicht te krijgen in het perspectief van hulpverleners en in de moeilijkheden die ze daarbij kunnen ervaren bij het omgaan met hoopvolle palliatieve patiënten is een kwalitatieve studie vormgegeven met 3 focusgroep interviews met Nederlandse hulpverleners. Deze focusgroepen bestonden uit een multidisciplinaire groep met o.a. artsen, verpleegkundig specialisten, (wijk)verpleegkundigen, psycholoog en geestelijk verzorgers, een groep verpleegkundigen, werkzaam in het ziekenhuis en een groep met wijkverpleegkundigen. Alleen hulpverleners zijn geïncludeerd, die dagelijks werken met mensen met kanker in de palliatieve fase, in een regionaal ziekenhuis of in de thuiszorg.

Voor deze studie is de volgende onderzoeksvraag geformuleerd:

- Hoe gaan hulpverleners om met palliatieve patiënten die hopen op zo lang mogelijk leven?

In hoofdstuk 4 van het proefschrift is gezocht naar factoren die hoop beïnvloeden bij mensen met kanker die met curatieve intentie worden behandeld. Een systematische review is vormgegeven met dit doel. Echter, bij studies met mensen met kanker in de literatuur werd veelal de behandelintentie, palliatief of curatief niet weergegeven. En als deze behandeldoelen wel werden beschreven zijn de data niet apart, per behandeldoel geanalyseerd. Om die reden is de onderzoeksvraag verruimd naar mensen met kanker bezig met een behandeling, om te weten te komen welke factoren invloed hebben op hoop. De volgende onderzoeksvraag is geformuleerd:

- Welke factoren worden geassocieerd met hoop bij mensen met kanker die bezig zijn met behandelingen?

De literatuur van de laatste 10 jaar is onderzocht om hier antwoorden op te vinden, omdat specifiek gezocht is naar factoren geassocieerd met hoop zijn alleen de empirische kwantitatieve studies geïncludeerd. Hoofdstuk 4 geeft deze bevindingen weer.

Om inzicht te krijgen in hoop bij mensen met kanker die met curatieve intentie zijn of worden behandeld is een secundaire analyse verricht van eerdere – en andere data dan geanalyseerd in hoofdstuk 2 - data die verkregen zijn uit eerdere kwalitatieve data (5 studies) in Nederland en in Vlaanderen bij mensen met kanker (n=74) die curatief zijn of worden behandeld. Gedurende de data-analyse bleek dat voor deze respondenten positief denken meer dan hoop belangrijk voor hen was. Om die reden is de volgende onderzoeksvraag geformuleerd:

- Welke betekenis heeft positief denken voor mensen met kanker die met curatieve intentie zijn of worden behandeld.

Hoofdstuk 5 geeft hiervan de resultaten weer.

In de discussie, hoofdstuk 6, wordt een verbinding gelegd tussen de betekenissen van mensen met kanker in verschillende fasen van de ziekte, de perspectieven van hulpverleners en de huidige literatuur, om zo te komen tot aanbevelingen en implicaties voor de praktijk.

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2

Betekenis van hoop bij mensen met kanker in de palliatieve fase

Based on the article of Nierop-van Baalen, C., Grypdonck, M., Van Hecke, A., & Verhaeghe, S. (2016). Hope dies last… A qualitative study into the meaning of hope for cancer patients in the palliative phase. *European Journal of Cancer Care, 25,* 570–579. doi:10.1111/ecc.12500

Hope Dies Last…

A Qualitative Study of the Meaning of Hope for People with Cancer in the Palliative Phase

Palliative patients may have strong hope, even hope for a cure, despite knowing their prognosis. Health professionals do not always understand patients who have this kind of hope. The aim of this article is to explore the meaning of hope among patients with cancer in the palliative phase. A secondary analysis was conducted including a constant comparative analysis to uncover the processes underlying the maintenance of hope, of previously collected interview data (n=76). The meaning of hope is related to the importance of the object it is attached to, rather than to a real chance of achieving this object. Hope has a dual function: patients hope because they cannot forsake it and because they benefit so much from it. Hope can spring from many sources and is influenced by various factors. If there are fewer potent sources to tap into, people create hope themselves and this type of self-created hope takes more effort to maintain. Patients use different strategies to increase their hope, described as the “the work of hope”. A better understanding of the work of hope can lead to better psychosocial support by health professionals. Health professionals convey many messages that affect the work of hope.

Keywords: cancer, oncology, hope, palliative care, meaning, qualitative research

Introduction

Hope plays an important role in the lives of cancer patients. This is the case in all stages of the illness. Palliative cancer patients can have strong hope despite their awareness of the negative prognosis they have received (Ballard et al,1997; Felder, 2004).

Hope has been investigated in several studies. Quantitative research (Ballard et al,1997; Felder, 2004) has demonstrated firstly that palliative patients can have hope that is just as strong as that of curative patients, and secondly that hope produces positive effects (Benzein & Berg, 2005; Vellone et al, 2006), such as less anxiety, pain and depression and a better quality of life. Qualitative research has described hope as a complex and dynamic phenomenon (Benzein & Saveman 1998; Eliott & Olver, 2002; Hammer et al, 2009; Miller, 2007; Morse & Doberneck, 1995; Yates, 1993). Despite this extensive research, it is still unclear what is precisely meant by hope: different definitions, models and conceptual frameworks exist (Eliott & Olver, 2002, Wiles, 2008, McClement & Chochinov,2008) which are not always interchangeable (Eliott & Olver, 2002).

In an integrative review, Kylmä et al. (2009) described the current status of research on hope in palliative care. The reviewed studies deal with palliative care in a broad sense, not only limited to cancer patients. They describe two overarching themes relating to patients' hope and its specific characteristics. The first theme is "living with hope", i.e. existential hope, such as living with hope in spite of multiple losses (Duggleby & Wright, 2005), interconnectedness with others (Benzein & Saveman, 1998), reconciliation with and comfort with life and death (Benzein et al, 2001). The second theme is "hoping for something": the action of hope, such as hope as a future-oriented and goal-oriented phenomenon (Benzein et al, 2001; Flemming, 1997). This kind of hope implies patients' hope that they will be able to live a normal life as long as possible (Benzein et al, 2001), that they will live longer than expected (Clayton et al, 2005), that they will be able to live at home as long as possible (Appelin & Berterö, 2004) and will live life to the fullest in the time left to them (Duggleby & Wright, 2004).

Many professionals feel uneasy when a patient expresses hope that goes (far) beyond the prognosis that has been communicated to them. They feel they should help the patient to come to terms with reality. In other professional cultures, hope is seen as beneficial and something that should be fostered or sustained, and for which professionals should use interventions (Clayton et al, 2005; Herth, 1995; Reinke et al, 2010). In both contexts, however, little is written about the meaning of hope and the reasons why patients maintain hope despite their infaust prognosis. Since, health professionals have different views and beliefs about hope, it is important for medical professionals to recognize the meaning of hope in palliative care (Olsson et al, 2011).

The aim of this study is, therefore, to elucidate the meaning of hope for cancer patients in the palliative phase.

Methods

This study contains a secondary analysis of data obtained in a series of small studies in the Netherlands and Flanders (De Beer et al, 2009; Demarré, 2003; Mulder, 2006; Nierop-van Baalen & Grypdonck, 2008; Rensen et al, 2003; Steenhaut, 2008) on living with cancer with a short life expectancy (between 3 and 12 months). Two types of data from the interviews were available: data from interviews in which hope was the theme announced before the interview took place, and data from interviews that treated broader illness experience, during which hope was discussed at the initiative of the interviewee.

Recruitment and data collection

All patients meeting the inclusion criteria of the specific study were recruited by their own health professionals. The data were collected through open interviews. Each study had its own specific interview protocol, consistent with the aim of the study. Hope was discussed in all interviews. All interviews were audio-recorded and transcribed verbatim. The interviews took 45- 90 minutes each. A total of 76 interviews were analysed concerning the experiences of palliative cancer patients. Most patients were under palliative treatment (primarily chemotherapy) at the time they were interviewed. The palliative phase of the illness means that to health professionals it was clear that no curative options were left. Patients were only included after it had been clearly discussed with them that no curative options were left. In one of the studies, the patients interviewed were no longer being treated or could no longer be treated. Table 1 demonstrates the demographic variables of the respondents and inclusion criteria of the studies. None of the interviewers provided care to the patients concerned. Informed consent was obtained in each of the studies and the patient data were processed confidentially and all personal identifiers had been removed. The research protocol was approved by the ethics committee of each hospital involved. For the secondary analysis, a central ethics committee gave approval.

Table 1: Demographical characteristics of the respondents

Object of the study	Number of participants	Selection criteria*	Setting	Average Interview time (min)	Age range of participants	Data collection period
Role of hope in cancer patients participating in phase 1 trial	6 women and 4 men	Participating in phase 1 clinical trial, for first or several times	Hospital	75	38-67 years, average age 55	2000-2002
Experiences of patients who opted for palliative chemotherapy	13 women and 2 men	Patients who consciously chose palliative chemotherapy.	Hospital	90	35-68 years, average age 55	2000-2001
Experiences of incurable cancer patients no longer receiving chemotherapy	7 women and 6 men	No therapy (patient's own decision, no treatment available, expectation of too much toxicity)	At home	45	33-84 years, average age 69	2002-2003
Significance of complementary care/ therapy in addition to regular therapy for cancer patients	8 women and 4 men	Palliative cancer patients receiving complementary care/therapy and regular therapy (4 of 12 women received curative treatment, they were excluded)	At home	60	33-58 years, average age 50	2004-2005
The meaning of hope for palliative cancer patients	12 women and 3 men	Participation with palliative chemotherapy and advanced cancer	Hospital	90	37-80 years, average age 56	2006-2008
The significance of holding onto hope for cancer patients living with an unfavourable prognosis	11 women	Recurrence of cancer or metastatic cancer in women receiving palliative treatment	Hospital	60	49-74 years, average age 60	2007

*All patients who participated in these studies were diagnosed with cancer, age ≥ 18 years, and Dutch or Flemish speaking.

Data analysis

The aim of the secondary data analysis was theory development using the approach of 'amplified sampling' (Thorne in: Heaton, 2004). This approach involves the comparison of several distinct and theoretically representative data sets. First all, of the interviews were read in their entirety. Analysis was begun with the studies that explicitly dealt with hope, after which the other data were analysed. The data were searched for the term 'hope' in order to identify the passages in which the respondents used this term. Thereafter, we searched those fragments in which they used synonyms for hope, with the provision that the meaning would not change if those synonyms were replaced by the word hope. The researchers did not proceed from a definition of hope, because the aim was to understand hope from the perspective of the patients. Moreover, the different definitions of hope in the literature were not entirely congruent with one another and also not congruent with the outcomes of the first analyses of the interviews. Proceeding from a fixed definition of hope would have predetermined the meaning of the term hope. Instead, we intended to explore what meaning the patients had in mind when they used the term hope. Only those fragments which were related to hope were coded. After having grasped the meaning of the interview as a whole, we assigned a code to fragments reflecting the relevance of the fragment for the research question. Codes were assigned inductively by Boeije (2010, 2002). After this open coding, we integrated the codes around categories through axial coding. We explored the meaning of the categories and the way they are connected and distinguished. Finally, in the third phase of the coding procedure - selective coding - the findings were integrated by relating them to other categories and by filling in the categories that need further refinement and development. Data saturation was achieved. One of the authors was the main researcher in all the original studies and was as such involved in the analysis of the secondary data. Researcher triangulation was used to improve the quality of analysis. Two researchers [MG, CN] read all the interviews and each other's analysis notes, commented on them, and discussed each other's interpretations. The consistency and congruence of the findings from the analysis were critically examined. The first researcher subsequently consulted the data again in order to verify the preliminary interpretations against the data. The prominence of hope in the interviews allowed for a cogent discussion of this phenomenon.

Results

This section discusses the meaning of hope for respondents. The constituting categories of the meaning of hope are discussed in different sections: function, the object of the hope, the work of hoping, its sources and influencing factors, and finally a description of the nature of hope from the patients' perspectives.

Meaning of Hope for the Respondents

The meaning of hope for patients is related to their interest in the object it is attached to (e.g. being able to watch their children grow up). The object is often so important to patients that it seems they cannot live with the idea that it is unattainable. The intensity of this desire for a positive outcome is not related to the chance of their actually achieving this goal. They cling to the idea that this goal is not completely unattainable.

> "Two children, a 14 year old daughter and one who's 16. Yes, they're still so young, aren't they.. [cries]. I would so much like to be with them until they're really fully grown. But I'll just have to wait and see, won't I. I hope that I can stay alive for a while. I know can't be cured, but I hope that they can keep it under control and that I might still have some years."
> *(42-year-old female, metastasized breast cancer, palliative chemotherapy)*

People have hope in uncertain situations, in which at least two outcomes are possible: one is positive and the other is negative. Patients mostly use the word 'hope' in an active form as a verb. Patients use the word 'hope' as a noun only to indicate a static situation as in 'I have lost all hope'.

> "I have courage, but no hope."
> *(54-year-old female, metastasized pancreatic cancer, no therapy)*

Function of Hope

People hope because they have no other choice. Without hope life would have no quality or would be unbearable. That people hope because they have no other choice does not mean hope is readily available. To hope takes effort. Hope reduces stress and is felt to be necessary in order to be able to cope with the situation. Moreover, only hope can prevent people from giving up on treatment or sliding into a depression. Patients feel beaten down, but not broken; hope gives them resilience. By not blocking the future they can enjoy the present. Hope incites people to action and prevents them from passivity.

> "Yes, I want to live a long life. I don't think I have reached the end of my life. I didn't come here thinking they're going to extend my life. I came here because I'm ill and because… - how can I put this - because I hope for recovery, that that's a distinct possibility. Yes, I hope so, because otherwise I probably would not sit here so quietly."
> *(52-year-old female, metastasized breast cancer, palliative chemotherapy)*

Objects of Hope

Most respondents hope for a full recovery. Also, they hope for prolongation of life, improvement, quality of life and peaceful death. These various objects of hope are viewed by medical professionals as mutually exclusive categories with a certain hierarchy (Nierop-van Baalen and Grypdonck, 2012). However, respondents may have different objects of hope at the same time (e.g. hope for a peaceful death as well as for recovery), where one of the objects may be dominant. The various objects with their specific characteristics are described below.

Despite knowing their infaust prognosis, most respondents are still hoping for a cure. Patients experience this as a strong hope that gives them the energy to deal with all the hardship that falls upon them. Actions that would further this goal, such as taking treatments, eating healthily, visiting alternative therapists, etc. keep them among the living.

> "I hope they can stabilize the situation, so I can go on living. Deep within, I still hope sometimes that one day they will say it has disappeared. And that I'll recover. I know that's impossible, but you keep your hopes up." *(42-year-old female, metastasized breast cancer, palliative chemotherapy)*

Hope for improvement has to do with the desire of patients to get back to their old life. It may seem that this hope is geared toward minor goals, but the implications are far reaching. If their tumour shrinks or does not grow, patients can go on with their lives. When a physician tells them that the tumour has remained the same, or that they need to live with it, some people compare it with living with a chronic illness such as diabetes. In other words, they can go on with their daily life.

> "And now he [the doctor] said recovery is a strong word, and that recovery isn't possible, so it's best to learn to live with it. I think that means there is still hope. After all, people with diabetes or some other chronic illness also manage to live with what they got, don't they?" *(47-year-old female, metastasized breast cancer, palliative chemotherapy)*

Hope for prolongation of life relates to continuation, to staying in the game and grasping every opportunity for further treatment. 'Doing something is better than doing nothing,' is often the motto here. Patients count on rapid advances in medicine, so that what is impossible today may well be possible tomorrow.

> "I have good hope that here… that at least… that it will stop, that it won't become any bigger. Of course I'd like to see it shrink and go away. We'll have to wait and see. As long as it stops and doesn't become bigger. And if this therapy doesn't help… well, there are still other options." *(58-year-old female, metastasized rectal cancer, participant in a phase-1 trial)*

Hope for good quality of life is only mentioned when prolongation of life is definitely no longer possible in the eyes of the patients. Hope for good quality of life on the part of the patient means that the limited prognosis has to some extent been accepted. However, some people still leave a window of opportunity open by saying that they hope for a miracle and by convincing themselves that miracles do happen.

> "I have hope, not so much for recovery, but for some quality of life, just for a few more years." *(65-year-old female, metastasized breast cancer, palliative chemotherapy)*

Hope for a peaceful death is only mentioned by very few and only if death is imminent. Some hope for a painless death; some refer to the situation after death.

> "I hope my children will become good people." *(54-year-old female, metastasized pancreatic cancer, no therapy)*

'My hope' is a special category of the types of hope mentioned above. The respondents used the term 'my hope' when there is a great discrepancy between the likelihood of that which they are hoping for and the value they derive from hope. The chance that what they are hoping for will become true is very slim and most of the respondents do know that. That is why they refer to this hope as 'my hope'. 'My hope' as private hope reflects someone's deepest desires. It is a very personal hope that can barely be communicated and is cherished in silence. 'My hope' is hope for which no justification can be given other than that this object is so important that it neither has nor requires external legitimization. My hope is also used to refer to hope for recovery. Of all the types of hope, 'my hope' is most discordant with the medical facts.

> "I've placed all my hope on that. I don't ask to be cured; I just want it to stabilize. It would be wonderful if I could add ten more years to my life." *(42-year-old female, metastasized breast cancer, palliative chemotherapy)*

The Work of Hoping

Hope gives energy, but also takes energy. The patients demonstrate that it takes effort to keep hope alive or to raise hope. One way to do so is to test hope by consulting their doctor. This test is meant to confirm hope. If the hope is not confirmed, the patients themselves will need to make an extra effort to maintain or strengthen hope. Patients need strong sources of hope to accomplish their work of hope, such as positive feedback from doctors. If they do not have these strong sources, they will invent sources themselves, such as the conviction that their children still need them. Such self-created hope takes much more effort than hope resting on a sound foundation, because this hope needs to be built up, maintained and defended. Patients can use a number of strategies to increase hope: they can fight, remain positive, create uncertainty, play with possibilities or place their trust in doctors (see below). The respondents often refer to fighting which comes down to participating in therapy and, of course, compliance with therapy. In the interviews, patients frequently say "I go for it" which also refers to keeping fit by being active and eating healthy food. Remaining positive is also a targeted strategy to optimize the chance of a positive outcome. Patients convince themselves that they can influence fate by being and remaining positive.

> “He told me I had broken my hip, and that I needed a hip replacement. Otherwise I would spend the rest of my life in a wheelchair. I also asked him if it was still worth my while to have that hip replacement, because, if I have come to the end of my life now, it may perhaps not be necessary to undergo such an operation. One of the doctors said I also had problems elsewhere in my body. That really hurt me, because I didn’t expect that. I told them ‘I don’t feel really sick, I only have pain’. I don’t know what the doctors think about it and what they discuss with each other. I hope they wouldn’t do such an operation…. I mean replace an entire hip, without knowing whether I still have a chance. That’s what I think.” *(52-year-old female, metastasized breast cancer, palliative chemotherapy)*

Another strategy chosen by patients is to create uncertainty, even when everything is certain in the medical context. Even if the doctor’s message is: ‘Unfortunately, we cannot cure you’, patients can still create an uncertain situation, for example, by saying that medical science focuses on substantial groups of people and that little is known about individual effects. Playing with possibilities is a remarkable strategy and patients make creative use of the information obtained. For example when a doctor told them that there is a 30% chance that the treatment will succeed, they say in the same interview that they told their family: “I have a 50% chance: the treatment will either succeed or fail”. Placing their trust in doctors also helps them. They know they are in good hands with their doctor and they take that to mean that, therefore, the doctor will succeed.

Sources of Hope and factors influencing hope

As described before, the intensity of hope depends on the desirability of the object it is attached to. The true source of hope is the desire to live. Hope, as a verb, becomes stronger if the outcome is more important. Hope, as a noun, increases if the results get better. A strong factor influencing hope is the reporting done by physicians. If a physician communicates a positive message, for example that the tumour has shrunk, this will strengthen the hope of patients. Trust in healthcare practitioners is generally a source of hope as well. The respondents place their trust in the positive messages from the specialist and, if there are none, in the specialist’s competence.

> “I hope it’s going to be alright. Always hope for recovery, that’s all. Yes, I hope for the best. I have faith in the doctor… he assured me that something can be done about it, so I have hope. […] I only hope it’s going to be alright, that’s all…” *(73-year-old female, metastasized breast cancer with carcinomatous meningitis, palliative chemotherapy)*

Treatment is another factor influencing hope in that all treatments generate hope. Patients even derive hope from participation in phase 1 experimental studies, while they know they should not expect benefit for themselves. The fact that they are being treated means there is still a chance that the unlikely might happen and that their course towards death might be altered.

> "If you're in phase 1, you have little to no choice. You hold on to that tiny glimmer of hope. I know at the back of my mind that I also do it because it might help me in the future. It may also very well be that it doesn't work for me, that's what I more or less expect. But on the other hand, even if it only helps a bit, well… Yes, that's the main reason why I decided to take part in it." *(55-year-old female, metastasized lung cancer, participant in a phase-1 trial)*

Treatment also means there is a chance they will survive until a new effective medicine comes on the market. Treatment leading to amelioration of the symptoms is also a strong influencing factor. Reduction of pain or other symptoms strengthens the patients' hope. They regard the reduction of symptoms as proof of the success of the treatment.

> "After a few chemotherapy sessions, the pain had gone. So I stopped taking painkillers I don't need them anymore. I hope chemotherapy will enable me to live with it a little bit longer." *(58-year-old male, metastasized bronchial cancer, palliative chemotherapy)*

People also derive hope from previous experiences with the disease; for example, if they survived an early stage of the disease or felt a lot worse during a previous treatment.

> "And that's now… yes, I'm beginning to have more and more hope now…I've been alright for quite a while in the past, so why shouldn't that happen again?" *(47-year-old female, metastasized breast cancer, palliative chemotherapy)*

Social comparison is also a source of hope that is often mentioned. Three variants can be distinguished. The first variant is: 'Thank God I am better off than they are'. This refers to a situation in which other patients' illnesses are more serious or patients did not survive their illness. Through this comparison people classify themselves among the 'better' group and think that they have a better chance of survival statistically speaking. Another form of social comparison is 'If they can do it, I can do it too'. This refers to a situation in which people survived the disease. It proves that recovery is possible and legitimizes hope. 'They survived, and so can I'. The third variant is: 'If they can do it, then I certainly can'. This refers to a situation in which another patient with a "worse" illness survived. 'If they can survive, I certainly will, because I'm not as ill as they are/I'm younger/my condition is a lot better'.

> "And now to hope and fight, that's the only thing we can do. So many people have been cured." *(48-year-old female, breast cancer and brain metastases, palliative chemotherapy)*

Other sources of hope are nature, faith and social support. These are more general sources of hope to tap into, and they are less sensitive to external influences.

The nature of hope

Looking at how cancer patients speak about hope in the palliative phase of the illness, the following description can be given: hope, as seen in palliative cancer patients, is a verbal phenomenon and solely exists when expressed either to oneself or to others. Hope is subjective: it expresses a stance of the person towards future events that concern him/her. Hope is always focused on a positive goal. The likelihood of an object of hope to become reality can vary, but that does not determine the strength of hope. Hope can vary in strength, and that strength is not determined by circumstance, but by need. One of the functions of hope is to escape the unbearable. For all these reasons hope should be distinguished from denial, because in their thoughts and actions patients remain rooted in reality, which is not true of denial. Hope is not an emotion because it does not arise spontaneously, but needs to be created or strengthened. Hope is a thought construct which is cherished, nurtured and protected against threats. Hope needs a basis in reality, although what is possible can be rethought for the benefit of hope (for example a miracle). Hope can evolve over time in reaction to the disease or as a result of influencing internal or external factors. Hope is threatened when the probability of a negative outcome increases. Hope needs to be defended against that threat: this is the work presupposed by hope.

Discussion

This study has attempted to investigate the meaning of hope to cancer patients in the palliative phase of their disease by demonstrating where patients hope, what the function of hope is, its sources and influencing factors, the work of hope to build, foster en defend this hope. This study provides new insights into regarding, thinking about and dealing with hopeful palliative patients.

Below we describe the main results in relation to the recent literature. An important result is that the hope of the palliative patients primarily emerges from themselves and is fed and nurtured by themselves. In ‘my hope’ this is primarily present. “My hope” stresses that this hope is really theirs, it is their deepest desire, with the potential for a powerful influence on quality of life regardless of logic and reason. Although reports of doctors can strongly influence this hope by discussing the scan results and information about patient prognosis, patients react to these reports by rebuilding their hope again. To our knowledge, this is the first study that demonstrates which strategies patients use to build up their hope when the medical facts offer little reason for hope.

Our findings cast some doubt on the decisiveness of the role that some professionals and researchers have regarding the hope of patients. The et al. (2000) described that doctors provide false hope. In her study on the unrealistic optimism of lung cancer patients, The et al. (2000) described that ‘false optimism about recovery’ is caused by vague communications by physicians and by patients themselves who refrain from asking further questions about their prognosis. Koedoot et al. (2003) demonstrated earlier in her study that when patients choose palliative chemotherapy, the role of physicians in that process seems to be overestimated. Koedoot’s study demonstrated that when patients have to decide whether to opt for palliative chemotherapy, they made this choice before consulting their doctor. Therefore, Koedoot’s finding contradicted the assumption that it makes a difference how doctors discuss the decision regarding treatment with the patient. Our findings also enable us to look differently at decision making studies and training programmes for physicians.

This research study is a unique contribution to describing and explaining the interplay between the work of hope and factors influencing hope.

Positive effects of hope have been examined in several earlier studies such as a reduction of anxiety, pain and depression and a better quality of life (Benzein & Berg, 2005; Vellone et al, 2006). Often these are separate factors that were studied in a quantitative manner. This study adds a contribution by describing and explaining the function of hope. Patients hope because of its positive effects. It helps them to deal with physical deterioration caused by their illness and to carry on treatments. And hope prevents them from falling into depression and passivity. This study also demonstrate that hope gives energy and that is a valuable insight when energy is scarce at the end of life.

When we discuss the meaning of hope, then, an important result is that the meaning of hope differs for patients when compared to health professionals. From the perspective of the patient, hope is more related to the importance of its object than the real chance of achieving this object. From the perspective of medical caregivers, as is evident from the statements of the patients, hope has to do with facts and chances, for example: “you have a 30% chance that the treatment will be effective.” This could be an explanation as to why communication in the palliative phase can be difficult. The same word is used, hope, but the meanings are divergent (Nierop-van Baalen & Grypdonck, 2012). This is most visible in the case of patients’ use of “my hope”.

This study also demonstrates that hope is not the same as denial. Patients hope despite their knowledge of their prognosis and their awareness of their precarious situation. These results differ from Dupuis (1998). She stated that people would not be willing to participate in phase-1 trials if they are clearly told and understand what these studies involve. This proved not to be the case in our study. Respondents know they should not expect any personal benefit from participation, but they do nonetheless hope that their participation in these trials will prolong their live. Another contradictory result is seen by Johnson (2007) who demonstrates how goals of hope can change during terminal illness. Patients’ hopes focus less on themselves and more on other people’s futures. Our respondents had a life expectancy of 3-12 month and were mostly in palliative treatment. This explains why on the whole we did not see changes in objects of hope. The hope for a longer life is constantly mentioned in the interviews. The third contradictory result is seen by The et al. (2000). The fact that hope is geared towards unattainable goals is seen by some health professionals as denial or labelled as false hope (Eliott & Olver, 2009, Dubbleby et al, 2010). Also, healthcare professionals who define hope as related to cure or disease remission often view hope in terminally ill patients as a form of denial or false reality (Hall, 1990, Yates, 1993 in Johnson, 2007). Verhaeghe et al. (2007) found that family members of patients who hope for something that is important but unlikely to happen do not consider such hope ill-founded or illegitimate. They contrast such hope with false hope for example hope rest on an erroneous or inadequate representation of the facts by professionals. False hope, in their view, is to be avoided and is never beneficial. Our study foregrounds similar ideas relevant to cancer patients in the palliative phase. Healthcare practitioners often see hope as an information problem;

for example, as a sign that the patient has misunderstood the message from the doctor. Health professionals ideally prefer unrealistic hope to evolve into hope for realistic objects (Nierop-van Baalen & Grypdonck, 2012). Hence, healthcare professionals' perspective on what palliative care patients hope for affects communication (Olsman et al, 2014). Also, our study shows that doctors who constantly repeat the 'truth' hinder the coping of patients.

The patient strategy to create uncertainty is a remarkable finding. Clinicians often think it is crucial to enable patients to have certainty or at least the feeling of control. This insight from our study reveals quite the opposite: sometimes it is important for patients to have uncertainty, because it accommodates the possibility of cure or quality of life or whatever goal is important for the patient. Thus, this type of inverted form of control is very functional to the patient and has remained underestimated until now. This study does confirm some of the results found by other studies. Other authors have also seen that it is important for patients to continue their treatments and, thus, stay in the race (Benzein et al, 2001; Eliott & Olver, 2009; Herth, 1990). This study also supports the findings of Eliott & Olver (2007) about patients' use of the word hope in active and passive forms. Previous studies also found that people think they can influence fate through positive thinking (Stewart et al, 2001; Thorne et al, 2008). Other studies (Duggleby & Wright, 2004; Johnson, 2007) also mentioned the importance of setting and achieving (short-term) goals as a significant attribute to hoping in terminal illness. It provides meaning and value to patients' lives.

Limitations

This study has several limitations. First, there are limitations in doing a secondary analysis. The patients were interviewed by multiple interviewers and in different contexts. All the interviews in the original studies were analysed by one of the researchers in this study thereby limiting the impact of the fact that the data were not collected for this study. A more important limitation is that data collection and data analysis could not take place intertwined. However, the richness and variety of the data enabled in-depth analyses despite this limitation. Data saturation was achieved. The interviewees were native speakers of Dutch (the common language in Flanders and the Netherlands). Consequently, people with other cultural backgrounds are underrepresented in this study. An even more important but uncontrollable source of bias is patients' motivation to take part in the study. Indeed, their attitude towards hope will play a role in this; for more than one reason depressed patients are unlikely to participate. This study does comprise a secondary analysis, the original data of which dates back several years. This may be a limitation because the opinions of patients can change over time. However, the data we used were collected and analysed over a period of six years, during which we did not observe any difference in the ways in which patients expressed and talked about hope. We also compared this data with recent data (Verbrugghe et al, 2016), and this comparison also did not reveal any differences. This can be explained by the fact that the data relate to existential experiences and will, thus, be less influenced by environmental changes.

The strength of this study is that it examined the use of hope in the everyday language and lives of 76 palliative patients. The scope of this qualitative study and the different settings of the original studies (participation in experimental chemotherapy, non-treatment, participation in alternative treatments and regular palliative treatments) enabled the researchers to collect a wealth of data that clearly demonstrate the dynamics, influencing factors and efforts for hope on the part of the patient. The substantial number of participants produced a balance between the variety resulting from the different studies and the richness of the data, which enabled sufficient depth of analysis.

Implications for practice

The results of this study provide many tools for daily practice. For health professionals who already work to foster hope in palliative patients, this study offers many insights that confirm and strengthens their practice. Health professionals who adjudicate hope as denial or false hope can learn from the underlying processes at work, the factors influencing hope and the work of hope for cancer patients in the palliative phase. Patients do not give up hope for a longer life, contrary to what some professionals think and they do not redirect their hope to more realistic objects as some professionals think they should do. We have demonstrated that this process of hope cannot be labelled as denial, as patients are simultaneously aware of the precarious nature of their hope. Patients appreciate honesty about medical facts on the part of health professionals; however, patients also need scope for building up their hope. Health professionals could consolidate hope as hope, for example by responding: “I hope so too, to you”.

Conclusions

Our analysis of 76 interviews with palliative cancer patients reveals the logic underpinning the types of hopes which patients cherish and which do not run parallel with medical expectations. Health professionals already knew that advanced cancer patients may still hope for a cure or for a prolongation of life. This paper adds an explanation of why and how these patients maintain and build up their hope. That is what we have called the work of hoping. Patients need hope to live their lives. Supporting this hope, without enticing patients to undergo useless therapies, is a special challenge for professionals, including nurses who, in their daily contacts with patients, convey many messages that affect the work of hope. How this support should be organized, and the areas where this support of hope produces more negative than positive effects, will need to be further investigated.

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3

Ervaringen van hulpverleners in het omgaan met hoopvolle palliatieve patiënten

Based on the article of Nierop-van Baalen, C., Grypdonck, M., Van Hecke, A., & Verhaeghe, S. (2019). Health professionals' dealing with hope in palliative patients with cancer, an explorative qualitative research. *European Journal of Cancer Care.* doi:10.1111/ecc.12889

Health professionals' dealing with hope in palliative patients with cancer, an explorative qualitative research

Hope is important for individuals with cancer in palliative care. Health professionals' perspective on hope affects the communication with palliative patients. The aim of this study is to explore how Dutch health professionals deal with palliative patients with cancer who hope for prolongation of life. Focus group discussions (FGD) were conducted. An interpretive description approach was used to understand the interpretation of and reaction to hopefulness in palliative patients with cancer by health professionals. Three FGD's were held, each consisting of five to ten health professionals working with palliative patients recruited in a general Dutch hospital and homecare organization. The ways in which the participating health professionals interpret hope in palliative individuals with cancer and their behaviour towards these hopeful palliative patients are shaped by their reliance on their own normative ideas. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. Hope that does not correspond with the medical facts is experienced as problematic by Dutch health professionals who therefore believe they should intervene and do something about it. Health professionals are challenged to face and address patients' and families' perceptions of hope, especially when those perceptions might differ from their own as professionals.

Keywords: cancer, health professionals, hope, oncology, palliative care, qualitative research

Introduction

Hope is important for individuals with cancer in all illness phases, also or perhaps especially for individuals in a palliative phase. Several studies (Acquaye et al, 2016, Davis et al, 2017, Eliott & Olver, 2002, 2009, Kylma et al, 2009, Loneus et al, 2003, Seibaek et al, 2012, 2016) describe the importance and sometimes the need of hope for palliative patients. The meaning of hope was addressed in the study of Benzein et al. (2001), and Nierop-van Baalen et al. (2016). Nierop-van Baalen et al. (2016) conclude that there are three reasons why patients hope: because they cannot forsake it, because they greatly benefit from it in terms of reduced anxiety and depression, and because it helps them to cope with the situation.

Quantitative research describes the positive effects of hope, for instance on patients' mood (Benzein & Berg, 2005, Duggal et al, 2016, Kavradim et al, 2013, Rustoen et al, 2011, Vellone et al. 2006). It has long been established that hope is an important factor that improves the quality of life of patients with a short life expectancy (< 3 months) (Conrad, 1985, Macleod & Carter, 1999, Owen, 1989, Stoner & Keampfer, 1985). In a systematic review of hope and cancer covering studies from 2005- 2009, Olver (2012) found that hope and optimism negatively correlate with depression and anxiety. Davis, et al. (2017) also described in their empirical study that hope inversely correlated with anxiety and depression.

Although hope has been studied extensively, it is still not clear what exactly is meant by hope given that many definitions and concepts of the term exist (Eliott & Olver, 2009). Eliott & Olver (2002) searched for a generally accepted definition of hope, which they did not find. They were searching for a definition of hope within an empirical/realistic paradigm, which presupposes that reality exists independently from the observer, to be discovered by an objective researcher, unfettered by culturally or historically situated subjectivity. One frequently used definition in the literature is given by Dufault & Martocchio (1985), who describe hope as "a multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant". Among the many definitions of hope, two concepts of hope in palliative care can be distinguished, as described in an integrative review by Kylmä et al. (2009): living with hope as a mental state, originating in the feeling that life can take a more favourable turn, without it being linked to a specific object; and hoping for something as the wish to see something happening that is uncertain, but still can be achieved or that at least is not impossible. However, in daily speech and even in scientific literature the two concepts are not always distinguished and not easily distinguishable. Both of them are often covered by the same term: hope.

The way in which hope is treated in the professional oncology literature differs from country to country. In the North-American and Asian oncology literature hope is seen as a positive force (Herth, 1990, Herth & Cutcliff 2002, Itzhaky & Lipschitz-Elhawi, 2004, Mok et al. 2010). In these countries, health professionals are taught to encourage hope (Duggleby et al. 2007a, Buckley & Herth, 2004, Herth, 1990, 1995). Much of the West-European oncology literature, however, describes hope which transcends medical expectations as a problem and doctors are urged to help patients come to a more realistic assessment of their situation (Dupuis, 1998, Kersten et al. 2012, The et al. 2000, Van Laarhoven et al. 2011).

Health professionals' perspective on hope in palliative care affects the communication with these patients (Werner & Steihaug, 2017, Olsman et al. 2014). Health professionals are able to enhance, maintain or destroy hope in patients through their attitudes, behaviour, and ways of communicating (Mok et al., 2010). At present there is a discrepancy between the need for support of individuals with advanced cancer and the ways in which Dutch health professionals often deal with the hope of these patients.

Research has brought to light that health professionals experience difficulties in dealing with hope in palliative patients (Clayton et al. 2005, De Haes, & Teunissen, 2005, Eliott & Olver, 2009, Hancock et al. 2007, Shinall et al. 2018). However, little is known about the origin and nature of these difficulties. Such information is essential for improving both patients' and professionals' experiences and professionals' behaviour.

The aim of the study, therefore, was to explore how Dutch health professionals deal with palliative patients with cancer who hope for prolongation of life.

Methods

For this study an interpretive description approach was used. Data were collected by focus group discussions. Interpretive description (Hunt, 2009) is a qualitative research methodology aligned with a constructivist and naturalistic orientation to inquiry. This approach was chosen because it generates knowledge in a form that is clinically relevant and applicable, by theoretically orienting the data collection, analysis, and interpretation process toward the inductive articulation of thematic patterns that reflect commonalities and diversities within populations (Thorne, 1997, Thorne, 2006).

Focus groups discussions were chosen because they yield data through the interaction of individuals and have a synergistic nature (Cyr, 2016). This means firstly that the data collected by the group are greater than the sum of its parts and secondly that rich experiential information is generated. This gives focus groups a comparative advantage over other data collection methods. In addition, the participants were used to discuss their feelings and difficulties regarding these patients with colleagues. Focus group discussions offer insight into how moral discourses become visible within this interactional setting, and how participants position themselves in relation to those discourses (Murdoch et al. 2010). When the themes include moral practices, interactive focus group discussions can reduce socially desirable bias more than is the case in one-to-one interviews, because participants know each other and each other's way of working, and they are discussing themes among themselves instead of with the researcher.

Recruitment and data collection

Health professionals who daily work with palliative patients were asked, by mail, to participate in focus group discussions about the ways in which they deal with hopeful palliative patients, what they experience as going well, and what they experience as difficult. The palliative phase of the illness was understood to have the following characteristics: health professionals knew that no curative options were left and this fact was clearly discussed with the patients. The recruitment procedure was designed to collect experiences from different disciplines. Therefore, we conducted three focus groups, a multidisciplinary group, a nursing group, and a group of community nurses, each consisting of five to ten health professionals. These professionals were recruited at a general Dutch hospital with a specialized oncology department and in a large home care organization. The choice of the organizations was made by convenience. Participants had to meet two criteria: they were Dutch-speaking and they were daily working with palliative cancer patients. The participants from the general hospital received an open invitation by mail and could register for an arranged day/ time (self-selecting sample). They had two weeks to respond to the invitation. The mail explained that the data were collected for research purposes and how the data would be handled. Health professionals involved with the hospital multidisciplinary palliative care consultation group were invited and the team leaders of 3 wards were asked to send the email to the nursing team. In total 76 hospital health professionals received the invitation. Of these, 25 health professionals replied to the open invitation. Two health professionals were unable to come on the arranged day and one nurse was ill on the day of the focus group discussion. Twenty-two health professionals finally took part in one of the three focus group discussions. Their characteristics are given in Table 1. Nurses could choose to enrol in either a multidisciplinary group or a group of nurses. The community nurses (n=9) were also invited by mail; they preferred to have their focus group discussion as part of a regular knowledge exchange meeting. They all agreed to participate knowing that the focus group discussions was held for research purposes and informed about how the data would be analysed. The three focus groups discussions took place in January 2012.

Table 1: Participants' characteristics

Focus group	N	Profession	sex	Age	Number of years of work experiences
Multidisciplinary	8	Internist, Chaplains (2), Psychologist, Nurses (2), Nurse practitioner, Ward doctor in training.	4 men and 4 women	Average 40 years Range 26-56 years	Average 13 years Range 1- 26 years
Hospital nurses	5	Nurses from different wards, oncology, pulmonary disease, out patients clinic and Nurse practitioners (2)	5 women	Average 48 years Range 40-57 years	Average 17 years Range 9-30 years
Community nurses	9	Community nurses	9 women	Average 40 years Range 21-53 years	Average 14 years Range 1-34 years

According to Dutch law, this study did not require approval from the Medical Ethics Committee. The participants were free to register and participate in the study. Their willingness to participate in the focus group discussions was considered to constitute informed consent. All focus group discussions were conducted by the same researcher (the first author); a clinical nurse specialist in oncology acted as a second moderator in the multidisciplinary and hospital nurses groups. Each focus group discussion lasted 90 minutes. The focus group discussions were not structured. A topic guide, see table 2, was used to check whether all relevant topics were discussed; if a topic was not discussed, the moderator introduced the topic. All focus group discussions started with the same question: what are difficult situations for you in dealing with hopeful palliative care patients? The primary role of the moderator was to ask further questions if necessary. We did not explain beforehand what we meant with the concept hope or the meaning of hope as we wanted to uncover what the health professional themselves understood by hopeful patients. All the interviews were audio-recorded, fully transcribed, and anonymized to guarantee the privacy of the participants. To the second researcher only the pseudonyms and their professions were known. Each participant's contribution was highlighted in a separate colour (Blomberg et al. 2011). In this way it was easy to follow the different opinions of each participant in the interview.

Table 2: Topic guide

Areas to explore within the context of dealing with hopeful palliative patients
1. Perceptions and beliefs about hope For example, what are their opinions about hope in palliative care?
2. Situations that healthcare professionals experience as difficult For example, What are the difficult situations and how they experience and deal with these?
3. Situations in dealing with hopeful patients which go well For example, why they experience these situations as good and how do they feel about this?
4. Hope interventions For example, which interventions do health professionals use en when do they use them?
5. Factors that influence or might influence their hope intervention For example, what are the underlying processes or thought about this?

Data analysis

After each interview, the whole interview was read to see if adaptations were needed to the topic guide. It was not necessary to make adjustments to the topic guide. Every focus group interview was first read in full to acquire an overall picture of what had been discussed, and subsequently read through again to grasp in more detail what had been said about hope and hopeful patients. The meaning participants give to the word hope was derived from their discourse. In the analysis process we have carefully checked and analysed what meaning the participants had in mind each time they used the term hope. The interviews were analyzed employing constant comparative analysis as adapted by Boeije (2002, 2010). Each passage in the interviews was assigned a code which represents its content and the initial coding was fully inductive. After this open coding, we integrated the codes around themes through axial coding. Emerging themes were identified and developed by studying the transcripts and the codes and by considering possible meanings and the way they are connected and distinguished. Finally, by selective coding, the themes were verified, further refined, and developed.

Rigour

Although this is an explorative study, several measures were taken to increase rigour. To address trustworthiness, we used Lincoln's and Guba's (1989) criteria: credibility, dependability, confirmability, transferability, and authenticity which was added later (Lincoln and Guba, 1994 in: Cope 2014). Concerning credibility, the analyses were facilitated by the first author's familiarity with the field. However, as this large involvement can also lead to distortions, it was corrected by triangulation to enhance dependability and confirmability. Two researchers [MG, CN] read all the focus group interviews and analyzed the interviews separately. After they had read each other's analysis notes, they commented on them, and discussed each other's interpretations. The findings from the analysis were critically examined regarding their consistency and congruencies. The first researcher subsequently consulted the data again in order to verify the interpretations against the data. Authenticity also was enhanced by researcher triangulation and by taking into account the social context in which the participants work. The participants knew and respected each other and each other's work and felt safe to speak freely.

The resulting themes are presented below and are illustrated through quotes from the participants, using only the focus group in which they participated, to ensure anonymity and confidentiality.

Results

Health professionals' experiences, attitudes and behaviours are shaped by normative ideas about how the final phase of live should proceed. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. The framework that follows consists of eight normative concepts that health professionals tend to ascribe to regarding palliative patients. They have been derived from the focus group data, i.e. they were not mentioned explicitly but come to light when interpretatively reading the discourse. The health professionals cherish one or more of the following interrelated ideas. Each of these is entertained by a majority of the participants.

The truth must be told

Participants are of the opinion that the truth needs to be told, because they do not wish to tell their patients any lies. They also want to counter the hope for unachievable goals in order to save their patients from having to face the consequences of decisions taken on the basis of patients' wrong assessment of their situation (e.g. the decision to buy a house).

> *"I would like a bit more openness, or honesty [about themselves]. I don't want to give them any false hope." (focus group of nurses)*

Participants also insist that the prognosis be clear to the patients because they want to enable their patients and the latter's loved ones to prepare for the unavoidable end and take leave properly. Participants see patients' hope for unachievable goals as an information problem (the patient in question has not understood the information properly). Telling the truth about the prognosis once more will counter false hope in patients or so the participants believe. Participants do not distinguish between hope and denial. Denial is seen as something negative, as something that needs to be corrected, and participants assume that denial is based on a lack of understanding of the information. Therefore, they believe that what they interpret as denial can be corrected by informing the patient properly.

> *“Hope is also very useful, certainly when they’re still being treated. On the other hand, however, if it becomes an ongoing denial of reality, you need to do something about it as a caregiver.” (multidisciplinary focus group)*

Death must be faced

As described above, participants and especially nurses, including community nurses, want patients and their loved ones to face approaching death, so that they will be able to take leave of each other properly. If they are able to do so, this means they have accepted that the end is near, and this is what they feel should happen.

> *“ […] you wish they would accept the fact. It’s no use, and instead of wasting time on denying the fact, they would do better to spend the time they still have on taking proper leave” (multidisciplinary focus group)*

According to the participants, ideally patients should give up hope for prolongation of life and instead hope for a good death. Hope for prolongation of life begs for intervention or for asking others to intervene, for example by arranging an appointment with the physician to discuss the prognosis once again. Participants consider it important that patients face the unavoidable fact that death is near.

Needless suffering should be avoided

By preparing patients for their approaching death, participants also want to avoid a situation in which patients make choices that would prevent this resignation, such as opting for experimental treatment, causing them to suffer needlessly, that is: without any medical benefit.

> *“These people travel to Germany for useless treatment while they’re critically ill and spend the time they still have on driving back and forth to Germany, vomiting. It’s terrible.” (multidisciplinary focus group)*

To die fighting should be prevented

Health professionals try to prevent patients from ‘going down fighting’ because they are aware that friends and family of the patient may feel discomfort about this after the death of the patient. This is not in line with the values of the health professionals themselves (especially in the case of two participants, both of them physicians). Health professionals sometimes find themselves in a situation in which their “professional values” (i.e. when there are available treatments, you need to offer them) clash with their personal values (i.e. patients and family members should be able to accept death and take proper leave).

> *"Well, the main value I adhere to is, of course, that I want to give someone the opportunity to take proper leave and, yes, to spend time on this. Perhaps they'll be able to accept the fact that they're dying and their friends and family may then come to terms with it. Yes, that's the value I adhere to. But that doesn't happen if such patients continually want new chemotherapy, or another scan." (multidisciplinary focus group)*

These physicians say that patients often want to negotiate about further treatment, especially when the physician has already advised them to refrain from undergoing it. They feel that patients want to stay in the game as it were and grasp every opportunity for further treatment. These physicians, however, know that treatment can also actually reduce patients' quality of life and sometimes even shorten the period of time they have left. They sometimes feel in a bind of the patient's making as some patients leave their attending physician to be treated somewhere else.

> *"There are always doctors who go on at all cost. If you can't find them here, you can find them in Belgium or Germany, or wherever." (multidisciplinary focus group)*

A few participants - a psychologist and chaplains - feel less need to distance themselves from their patients' thoughts. They do not have to take decisions regarding treatment, of course. However, they also set clear boundaries.

> "*In that sense we, as psychologists or chaplains, have a freer role. I think it's essential that, in that capacity, we stay close to the patients' inner life. That is to say up to a certain point, because this should not turn into an unhealthy situation". (multidisciplinary focus group)*

Significant others must be able to go on with their lives

Health professionals are of the opinion that when the dying process goes well, the mourning process of the surviving friends and family will also go better. Therefore, it is better for everybody concerned that the patient accepts death. In their opinion, keeping up hope implies a greater risk of problematic mourning. For all health professionals, a good death implies that no avoidable problems are being created for the survivors. They are the ones being left behind; how they will get on with their lives is a matter of primary concern.

> *"Yes, that's a difficult situation, for the friends and family, for the patients themselves, and also for the caregiver, when people continue to fight and keep denying that they are dying. That's... years later, the survivors may still have problems to come to terms with that." (multidisciplinary focus group)*

Health professionals, and especially nurses and community nurses, want to play a more active role in guiding patients and their family and friends towards the end. They like the idea of having contributed to a good death. Nurses take the initiative to talk with the patient about his or her approaching death based on their own assumptions about what is good for patients in general. That is, the actions of the health professionals are driven by their own assumptions about what a good death consists of, and consequently they do not engage in an open dialogue with the patient.

The family and the patient must be united until the end

Health professionals attach great importance to the patient's relationship with family and friends. To the participating health professionals, a good relationship with family and friends means that all the people concerned think and feel the same about important matters, such as whether or not treatment should be continued. When patients and family and friends think differently about the latter, health professionals experience this as a problem that requires intervention. Furthermore, health professionals place family and friends in a strong position; the focus of guidance is on family and friends. As they are, after all, the ones who need to get on with their lives.

> *"It's also such a pity to see that they can't complete the process in a good way together. That's such a pity. You see it happening and you can't do anything about it." (nurses focus group)*

Although several health professionals did point to the positive effects of hope - hope can be seen as a positive force, and can give energy - they emphasize the negative effects, such as loneliness, which especially occurs in situations in which the patients and their family and friends think differently about the continuation of treatment.

Unrealistic goals must be exchanged for achievable goals

If patients' behaviour does not correspond with the normative ideas of professionals about a good death, the latter feel the need to intervene. They try to exchange unrealistic hope for what they regard as more realistic hope. In doing so, health professionals tend to focus on the object of the hope of patients, and much less on hope itself. First of all, they weigh the object of this hope to see whether it is realistic, and if in their view it is not, they intervene, for example, by asking family and friends to move up family weekends or parties. Another intervention consists of providing the patient once more with prognostic information. The citation below shows the shared opinion of the different health professions and the way they interact with each other.

> *"They [the patients] live in such a different world. Say, for example, a holiday. You might say, all right, let them pay for a trip they will never make. Or buy a new house. But that has all kinds of consequences. Such a holiday is relatively harmless, so why not just let them book it? (participant 1). But that goes against your own values. If you know better, I think it goes too far (participant 2). If they ask me, I tell them to book it a bit earlier (participant 3). Yes, why wait when you're still in a relatively good condition? (participant 4). Yes, in that way you don't discourage them, you just ask them to be more realistic (participant 5). (multidisciplinary focus group)*

Unrealistic hope requires intervention, unless....

Sometimes health professionals do not contradict the hope of patients, mainly in order to maintain a good care relationship or limit negative reactions of patients. They often do so after having experienced negative reactions from patients indicating serious damage to the relationship. However, health professionals are only inclined to do so if it does not jeopardize their own norms. Nurses and community nurses for instance are willing to go along with the hope of their patients as long as they do not need to belie their own nature and when their responses do not create too much ambivalence.

> *"I don't want to have to entirely fool myself. That's where I draw the line. If I don't feel good about it, something will have to be done about it. In such a case I let them know that I don't go along with their hope, because I don't want to come into conflict with myself." (focus group of community nurses)*

Some health professionals know from experience that trying to influence patients' hope does not help.

> *"Hope seems to be some sort of strategy, and you usually have little influence over it". (multidisciplinary focus group)*

Although they indicate that it is no use trying to adjust this hope, they do not intend this to mean that this hope *should* not be adjusted, demonstrating that they have no positive appreciation of hope.

> "*And when you have seen this frequently, you eventually begin to think it's no use going against it, and to take away this hope and make them face reality […] So I sometimes go along with it although not always." (focus group of community nurses)*

One participant, however, saw the hope of patients also as a way of coping, as a wish that does not need to be corrected. According to this participant, hope enables a patient to deal with a difficult situation, and everyone goes through this hope process at their own pace.

> *"What I do often see is that this hope takes other forms. Initially, they hope to make it until next year, and then they hope they will at least survive until their grandchild gets born, and then they hope to make it until spring. People do adjust their hope, but perhaps not always as fast as we would like them to. But eventually many people do" (multidisciplinary focus group)*

The same participant also pointed to the function of hope.

> *"It's often very ambivalent. They want to accept the situation, but they're not yet ready to accept everything. They still need a reason to get up in the morning, to enjoy the visits of family and friends. I think everyone goes through the process of acceptance at their own pace." (multidisciplinary focus group)*

Discussion

Main results

This study has attempted to explore and understand the difficulties experienced by health professionals in dealing with hope in palliative patients. The results show that the health professionals' conduct is based on normative ideas. These normative ideas seem to be judged as valid for all patients and have the following in common: the concept of a good death: a death that takes leave-taking from beloved ones into account, so they can go on with their lives. This requires acceptation of and resignation to the truth on the part of the patient, expressed in stopping treatment when the doctor proposes it. Consequently, when a patient does not want to stop the treatment a problematic discrepancy arises between what is and what ought to be. This discrepancy requires interventions by health professionals, even when there are circumstances that make it unlikely for the intervention to be successful. Health professionals believe that it is their professional role to guide patients to a good death. As a result, their care is not attuned to the needs of the patients as much as it could be.

The study gives insight into the perspectives from which different health professionals deal with hopeful palliative care patients in their daily practice. The focus group discussions were led by the same researcher, who was well acquainted with the practice of palliative care. The health professionals felt sufficiently comfortable to speak freely about dealing with these vulnerable patients and what it meant to them. The themes were, therefore, discussed in ample detail, which enhances the validity of the study. This study also has several limitations. First, it is a small-scale study, and therefore each professional group was represented by only a small number of participants. Second, the sample was self selecting and only a small percentage of those invited participated. We do not know to what extent the ideas represented in the study are shared by those who did not participate. However, we have noticed that the degree to which the ideas were similar among the participating professionals - a single exception notwithstanding - indicates that the findings are not exceptional.

Despite the small scale of the study, the themes were clearly expressed. Six of the seven themes were cogently presented in all three focus group interviews. Only the theme: 'To die fighting should be prevented' was not given much attention in the focus group of community nurses. An explanation for this could be that community nurses work in a different setting, in which most of the patients were not being treated anymore.

As described before, the study is based on a small self-selected convenience sample and its members are not representative of all the different organizations, and not all the opinions and practices were represented. However, this study reveals that the participating health professionals show strong consensus in their normative ideas, and they present these ideas as rooted in their professional norms. Therefore, we believe it is likely that our findings can be transferred to a broad segment of health professionals, at least in the Netherlands.

That health professionals think differently about the meaning of hope than individuals with cancer do has also been discussed in the literature (Nierop-van Baalen et al. 2016, Skevington et al. 1997). MacLeod & Carter (1999) also have shown that health professionals relate hope mainly to a cure or a stable illness, while the literature also describes other dimensions such as social, spiritual and existential dimensions of hope. We carefully examined in the interviews what the professionals referred to when talking about hope. The professionals focused on the (false) hope of their patients and their hope to live longer than medically possible. The professionals did not mention any existential and spiritual dimensions of hope. Other studies (Leung et al. 2009, Nierop-van Baalen et al. 2016, Verhaeghe et al. 2006, Wiles et al. 2008) have described that hope and expectations are different constructs. The differentiation between them may help health professionals in communicating about illness-related expectations while maintaining the integrity of patients' hope. The health professionals, in our study, do not distinguish between hope and expectations.

The participating health professionals give precedence to family and friends' needs rather than to the patients' needs and consequently, the participants give little or no attention to the meaning of the patient's existential suffering in dealing with a short life expectancy. This may be related to a tendency to avoid difficult conversations with dying patients. It may also be the case that the precedence given to family and friends is caused by the phenomenon of self-comfort in health professionals (Baart, 1996). They badly want to consider the care they give as good and useful and when their care for the individual with cancer does not allow this, they displace this wish on to their care for the patient's family and friends. Especially when family members share the same values as the health professionals, this form of care is probably easier and a more obvious choice. As a result, health professionals are able to avoid feeling powerless.

The findings of the study show that professionals in the Netherlands deal with hope quite differently from what has been reported in the literature about North-American professionals and similarly to what has been reported about West-European countries. In West-European countries many professionals feel uneasy when a patient expresses hope that goes (far) beyond the communicated prognosis. In other professional cultures hope is seen as an asset that should be fostered or sustained (Nierop-van Baalen et al. 2016). The present results also differ from the (North-American) study of Herth (2001) about cherishing hope and hope interventions, and from the results of the Canadian study of Duggleby and Wright (2007b); they studied, with a mixed method design and thematic analysis, the perceptions of 113 professional palliative caregivers attending a palliative care conference. These caregivers valued hope as a positive power and described hope in palliative patients as hope for peace, for a better future, spirituality (finding meaning and purpose), and making a difference. Hope helped them to foster positive relationships and communication with palliative patients and families, to provide comfort, and to offer hope.

The health professionals who participated in this study want to see the hope for a cure evolve into hope for a proper death. The resistance to "unrealistic" hope has been part of the palliative discourse for a long time (Kübler-Ross, 1969). However, in the countries under discussion understanding among health professionals is changing (Cannaerts et al. 2004, Loneus et al. 2003, Van Laarhoven et al. 2011). At the same time a recent study (Oosterveld-Vlug, et al. 2017) shows that health professionals still think that physicians could support patients' transition from "hope for a cure" to "hope for a good death". A qualitative Australian study (Johnson et al. 2017) about autonomy and advanced care planning found that medical norms and professional boundaries surrounding 'good deaths' have a greater influence on care than patient preferences. To the participants (consultant oncologists and palliative medicine doctors), there was a broad consensus that helping patients to achieve a 'good death' was a critical part of duty of care. Consequently, patients whose preferences were seen to go against these norms, were often perceived as being 'difficult', or even 'irrational'. However, in their study on the meaning of hope for people with cancer in the palliative phase, Nierop-van Baalen et al. (2016) found that physicians who constantly repeat the 'truth' hinder the coping of individuals with cancer.

In the literature little is known about the differences between health professionals when it comes to interpreting the expression of hope of palliative individuals with cancer as a sign of not knowing, not understanding or not accepting the situation. Whether the differences in practices situated in different countries are due to cultural differences has never been investigated. Anthropologic research is needed to fill these gaps.

An explanation as to why the Dutch health professionals persist in repeating and enforcing the truth to hopeful palliative individuals with cancer has been provided by The et al. (2000). This observational ethnographic study has attracted extraordinary attention and has been incorporated into education programmes. Profound regret features large in their description of the factors that result in "false optimism about recovery" in individuals with small cell lung cancer. The et al. (2000) suggested that this false optimism can be attributed to the unclear prognostic information given by the doctors which hindered individuals with cancer in making well-informed treatment decisions. Relatives expressed regret about this. It should be noted, however, that the bereaved relatives were interviewed within three months after the death of their loved ones. Moreover, the reproachful manner in which some social scientists (Dupuis 1998, The et al. 2000) speak about physicians who are not clear enough about the truth enforce these ideas and this behaviour. However, those studies that attempt to really understand the patients' perspective (Benzein et al. 2001, Loneus, et al. 2003, Nierop-van Baalen et al, 2016) suggest that the most helpful approach would be not to explain once more what the medical problem is, but to confirm the patient in his hope, as hope, and distinguish it from rendering expectations: i.e. I hope with you.

Implications

Implications for practice and policy

It is important for health professionals to realize that hope can be looked at from different perspectives and that the patients' perspective may be different from their own. They should be aware of the risk of imposing their own norms onto the individuals with cancer. Currently, scant attention is given to hope as such and the meaning of this hope for the individual with cancer.

If health professionals are able to see that a patient's hope may be connected to his or her deepest desire, instead of an actual expectation that the object of hope will be achieved, they may feel less need to intervene to correct the hope. It might help to enter into a dialogue on hope with the individual with cancer rather than give advice to the patient. More insight into the meaning of hope from the patients' perspective may contribute to this. A better understanding of the process of hope and more nuanced ideas about denial will help health professionals to attune their care. Professional education could also prepare professionals to deal with hope in a more nuanced way. Nurses can learn to work contextually rather than base their work on principles as such.

Implications for further research

More research is necessary to examine to what extent these findings can be completed or refined. Our analysis has shown that some health professionals have opinions about dealing with hopeful palliative patients that differ from those of their peers within the same team. Therefore, a study of the differences among health professionals, within their practice setting, may throw light on the processes and factors underlying these differences. It is also important to explore the positive and negative effects of hope on patients to better distinguish when the negative effects overshadow the positive effects. This study has demonstrated that there are differences between countries in dealing with hopeful palliative individuals with cancer. These differences within can be further investigated. It is also interesting to study why and how these differences persist. The respondents framework was that of Western patients. That is in part explicable by the location of the participating health care agencies, which are in an area with a relatively low concentration of people from a non-Western background. Studying perceptions of health professionals who regularly give care to patients with a non-Western origin of health professionals which such an origin may complete the picture.

Conclusion

Our analysis of three focus group discussions reveals the use of normative concepts by health professionals in dealing with hopeful palliative cancer patients. Health professionals mainly focus on the object of hope and feel the need to intervene when they think that this object is unrealistic. This study shows that in those cases they would rather repeat the true prognostic information to enable the individual with cancer to face and prepare for death than think about and proceed from the meaning that hope has for these individuals. Health professionals could be more aware of the possibility that facing impending death, and hoping for better times can go hand in hand.

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4

Beïnvloedende factoren van hoop bij mensen met kanker gedurende behandelingen

Based on the article of Nierop- Van baalen, C., Grypdonck, M., Van Hecke, A., & Verhaeghe, S. (2020). Associated factors of hope in cancer patients during treatment: a systematic literature review. *Journal of Advanced Nursing.* https://doi.org/10.1111/jan.14344

Associated factors of hope in cancer patients during treatment: a systematic literature review

Abstract

Aim: to identify the associated factors of hope during treatment in cancer patients.

Background: Hope is very important to cancer patients at all stages of the disease process. Hope is seen as an important coping mechanism. Most research about hope in cancer patients considered the end of life or in palliative care. Several and different factors are associated with hope. It is not yet sufficiently clear which factors are associated with hope during the treatment.

Design: a systematic literature review of quantitative empirical studies on hope in cancer patients during treatment.
Data Sources: Search in MEDLINE (PubMed interface), CINAHL (EBSCO interface), Psychinfo and Cochrane (January 2009-December 2018).
Review Methods: Empirical quantitative studies were included regardless of the disease stage, written in English or Dutch, measuring hope from the perspective of cancer patients. Two authors independently screened all the studies and assessed their quality.

Results: Thirty three studies were included. Positive relationship has been established between hope and quality of life, social support, spiritual and existential well-being. Hope appears to be negatively associated with symptom burden, psychological distress and depression. There appears to be no relationship between hope and demographic and clinical variables. The relationship between anxiety and hope remains unclear.
Conclusions: Hope primarily seems to be a process that takes place in a person's inner being rather than being determined from outside.

Impact: Health professionals may want to focus on the meaning of hope for cancer patients in relation to the associated factors. A better understanding of the meaning of hope during treatment can be of great value in supporting cancer patients with regard to treatment decisions, psychosocial support, the experienced quality of life and symptom burden and any wishes they may have with regard to advanced care planning.

Keywords: associated factors, cancer patients, cancer treatment, hope, literature review, neoplasms, nursing, patients perspective, quantitative research, systematic review

Introduction

Hope is important for patients with cancer in all illness phases (Nierop-van Baalen et al. 2019). Although hope has been studied extensively, it is still not clear what exactly is meant by hope given that many definitions and concepts of the term exits (Elliot & Olver, 2009). In the literature, one frequently used definition is given by Dufault and Martocchio (1985), who describe hope as "a multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant". Hope is also defined as one's belief in the capability to achieve goals, particularly in situations where one can influence outcomes through the use of personal abilities of strengths (Snyder, 2002). Hope differs from optimism because optimism is seen as a generalized expectancy for positive future outcomes, regardless of how controllable they are (Rand et al. 2012; Bryant & Cvengros, 2004).

Hope is a complex and multi-faceted phenomenon. Existing literature does not provide a clear explanation of factors associated with hope. This paper focus on associated factors of hope during treatment. A better understanding of these related factors will help health professionals to attune their care.

Background

Worldwide, over 43 million patients are living with cancer (WHO, 2018). Most patients in this group receive some form of treatment. Two concepts are generally used to describe the treatment goals: curative and palliative treatments. Curative treatments are treatments aimed at curing the disease, which means that the patient's survival will not be limited by their current cancer diagnosis. Palliative or life-extending treatments are treatments in which the intention is to prolong life as long as possible, although the patient is likely to die from the disease in the end. Palliative treatment also means that the treatment is aimed at improving the patient's comfort and thus improving their quality of life (Neugut & Prigerson, 2017). Both meanings of palliative treatment will be used in this paper.

A cancer diagnosis has an enormous impact. The awareness of the finiteness of life and the uncertainty that results from it can cause an existential crisis (Grypdonck, 2005). Many cancer patients respond to this existential crisis by nurturing hope. The hope is prominent and is also noticed by health professionals (Grypdonck, 2005). Many professionals feel uneasy when a patient expresses hope that goes (far) beyond the prognosis that has been communicated to them (Nierop-van Baalen, 2019).

In the study on the meaning of hope for patients with cancer in the palliative phase (n=76), Nierop-van Baalen et al. (2016) found that most patients hope because they feel they have no other choice, and they experience that life without hope would have no quality or would be unbearable. Hope is seen as an important coping mechanism (Folkman, 2010; Felder, 2004; Ebright & Lyon, 2002). Patients feel beaten down, but not broken. Hope gives them resilience (Nierop-van Baalen et al. 2016). Hope has an important meaning for cancer patients and is associated with several factors. Qualitative literature also shows that patients can use a number of strategies to increase hope, especially when they do not have strong sources, such as positive feedback from doctors. Patients with cancer need hope to live their lives (Nierop-van Baalen, 2016; Salander, 2014; Chi, 2007).

Several studies provide insight into hope in cancer patients and show that hope can be influenced by sociodemographic factors (Vellone et al. 2006), psychological states (anxiety, depression, self-esteem) (Rustøen et al. 1998), social support (Mattioli & Chappy, 2008), spirituality/religiosity and symptoms (Benzein & Berg, 2005) In addition, hope has been found to enhance coping adjustment and well-being (Vellone et al. 2006). These studies, however, include only a small proportion of patients, or focus only on a few variables and specific patient groups. In recent years, much research has been done into hope near the end of life (Olsman et al. 2014; Olsson et al. 2011; Kylma et al. 2009; Eliott & Olver 2009, 2007, 2002; Clayton et al. 2005). Little is written about hope and cancer patients during treatment and currently, an overview of what factors associating with hope during treatment is lacking. This study will therefore answer the following question: what factors are associated with hope in cancer patients during treatment?

The review

Aims

The aim of this review is to provide an overview of what is known about the associating factors of hope during treatment of cancer patients.

Design

A systematic review of empirical quantitative studies was conducted according to the procedure of the Cochrane guidelines (Higgins et al. 2019). This systematic review was reported in accordance with the PRISMA statement (Moher et al. 2015) and the additional reporting guideline for synthesis without meta-analysis (SWiM) in systematic reviews (Campbell et al. 2020).

Search methods

Identification of studies for inclusion

We systematically searched the MEDLINE (PubMed interface), CINAHL (EBSCO interface), Psychinfo and Cochrane databases from 1 January 2009 to 31 December 2018. A coherent search strategy was designed in which MESH terms were combined with 'free text' terms: hope (e.g. hopeful, hoping, optimism) and cancer (e.g. neoplasm, tumour) and anticancer (e.g. chemotherapy, radiotherapy, anti-tumour). Search terms that represent the same concept were combined with the Bolean operator OR. The concepts were combined with the Bolean operator AND. The search strategy was designed for MEDLINE (PubMed interface), see Table 1, and subsequently adapted for the other databases. Also, the reference lists of the selected studies were manually searched to find additional relevant studies. No additional studies were added after this search.

Table 1. Search strategy MEDLINE (PubMed interface)

	Concept		Number of references
#1	Cancer	"Neoplasms"[Mesh] OR neoplas*[tiab] OR neo-plas*[tiab] OR cancer*[tiab] OR tumor*[ti] OR "tumor"[tiab] OR tumor'*[tiab] OR tumors*[tiab] OR tumour*[tiab] OR oncolog*[tiab] OR carcinoma*[-tiab] OR malignan*[tiab] OR metasta*[tiab] OR meta-stas*[tiab] OR meta-static*[tiab] OR lymphom*[tiab]	4046568
#2	Hope	"Hope"[mesh] OR "Optimism"[mesh] OR "Adaptation, Psychological"[mesh] OR "hope"[tiab] OR hope'*[tiab] OR hopes*[tiab] OR hopeful*[tiab] OR hoping*[tiab] OR hopeless*[tiab] OR optimis*[tiab] OR hhi[ti] OR meaning*[tiab] OR adaptation*[tiab] OR coping*[tiab]	533239
#3	Anti cancer	"Chemoradiotherapy, Adjuvant"[Mesh] OR "Radiotherapy, Adjuvant"[Mesh] OR "Chemotherapy, Adjuvant"[Mesh] OR ((adjuvant*[tiab] OR curativ*[tiab] OR during*[tiab] OR palliat*[tiab]) AND ("Antineoplastic Agents"[Mesh] OR chemotherap*[tiab] OR chemo-therap*[tiab] OR chemoradiat*[tiab] OR chemo-radiat*[tiab] OR chemoradio*[tiab] OR chemo-radio*[tiab] OR radiochemotherap*[tiab] OR radiochemo-therap*[tiab] OR antineoplastic*[tiab] OR anti-neoplastic*[tiab] OR antineo-plastic*[tiab] OR anti-neo-plastic*[tiab] OR anticancer*[tiab] OR anti-cancer*[tiab] OR antitumor*[tiab] OR anti-tumor*[tiab] OR antitumour*[tiab] OR anti-tumour*[tiab] OR oncolog*[tiab] OR "Surgical Procedures, Operative"[Mesh] OR surger*[tiab] OR surgical*[tiab] OR "surgeon"[-tiab] OR surgeon'*[tiab] OR surgeons*[tiab] OR operati*[tiab] OR "Radiotherapy"[Mesh] OR radiotherap*[tiab] OR radio-therap*[tiab] OR radiation*[tiab] OR irradiat*[tiab] OR radioimmunotherap*[tiab] OR radioimmuno-therap*[tiab] OR immunoradiotherap*[tiab] OR immunoradio-therap*[tiab] OR "Immunotherapy"[Mesh] OR immunotherap*[tiab] OR immuno-therap*[tiab] OR targeted*[tiab] OR "Therapeutics"[Mesh] OR therap*[tiab] OR thera-peutic*[tiab] OR treat*[tiab] OR intent*[tiab]))	256041
#4	Search	#1 AND #2 AND #3	4700

Eligibility criteria

We included empirical quantitative studies on hope in cancer patients during treatment regardless of the stage of the disease, written in English or Dutch, published over the past decade, considering patients of 18 years or older, and receiving some form of treatment (such as surgery, chemotherapy, targeted therapy, immunotherapy, radiotherapy and/or hormonal therapy). Relevant studies also concerned studies that measure hope from the perspective of cancer patients. We excluded cancer patients who did not or no longer received treatment (e.g. survivors or patients at the end-of-life). Our intention was to establish associations between hope and other variables. Therefore, studies with a qualitative design, have not been included in this study. Articles with a mixed methods design were included using only the quantitative results.

Study selection

Two reviewers [CN, MG] used a stepwise procedure to identify relevant papers. First, one of the reviewers [CN] designed the search strategy and made a first selection based on all of the titles. Second, the selection based on abstracts was started together for at least the first 60 abstracts, to gain agreement on the selection process and refinement of the inclusion criteria. Third, the other abstracts were independently assessed by two reviewers [CN, MG]. In case of uncertainty for inclusion based on abstracts, the full text of the articles was screened. For the assessment of the full text articles, all suitable abstracts from 1 January 2009 onwards were included on the basis of the selection criteria, as well as the ones for which it was not yet entirely clear whether they met the selection criteria. Subsequently, some of the full text articles that had previously been rejected by the first reviewer were also assessed by the second reviewer [MG] to see whether these articles were rejected in accordance with the exclusion criteria and for a substantiated reason. Eligibility assessment was performed independently by two reviewers [CN, MG] on 5% of the titles, 20% of the abstracts and 26% of the previously rejected full text articles. An interrater agreement of 95% on title screening, 95% on abstract screening and 89% on the (previously rejected) full texts was obtained.

Search outcome

The search resulted in 8649 records. Duplicates (n=2894) were excluded. Based on the selection criteria, 5752 abstracts were screened and 135 full texts were retrieved and reviewed. Figure 1 shows the flowchart of this selection. Of the 135 potentially suitable articles, 102 were excluded. Reasons for exclusion were: no more treatment or in the last stage of life (n=23), no empirical study (n=34), qualitative design (n=32), language other than English or Dutch (n=10) and different focus of the research theme (n=3).

Quality appraisal

The Quality Assessment Tool (Vyncke et al. 2013) was used to determine the quality of the quantitative studies. The assessments concerned the full text articles before data extraction took place. The Quality Assessment Tool is an adapted version of a tool developed by the Effective Public Health Practice Project (Thomas et al., 2004), which was used in several other systematic reviews (Verbrugghe et al. 2013, Goossens et al., 2014, Eechoud et al., 2016). This tool assesses the overall quality of study design and data analysis by looking at the following items: selection and allocation bias, confounders, data collection methods, withdrawal and drop-outs and comments on analysis. The methodological quality of all articles was assessed independently by 2 researchers [CN,MG]. Discrepancies in the assessments were discussed until consensus was reached.

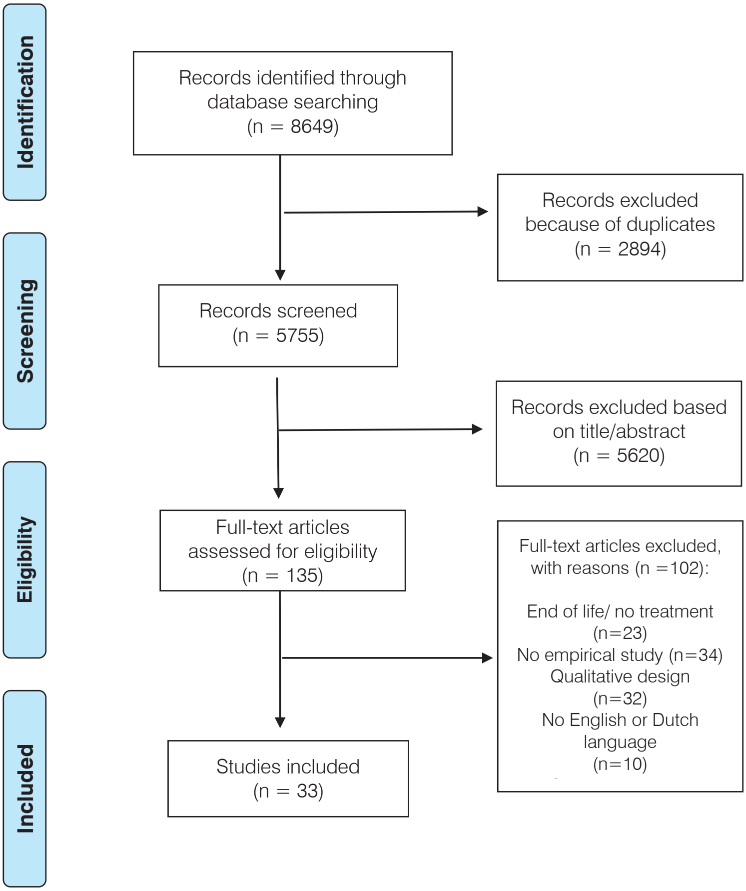

Figure 1: Flow chart

Data abstraction

One reviewer [CN] systematically extracted the key information related to hope in cancer patients. The data extraction tables (Table 2a, 2b) were designed to systematically show the following data: authors and publication date, primary aim, hope instrument, design/data collection/ data analyses/number of participants/ setting and country/ stages of disease or treatment goal/ percentage participants under treatment, and variables related to hope. Table 2a shows the main results of the studies. Table 2b shows all the results, de statistical tests, p-value and estimates of precision (Table 2b).

Table 2a: Summary of studies (n = 33)

No, authors and year of publication	Patient population	No. of patients Treatment intent Country	Hope instrument Design Data-analyses	Results: Positive associated with hope Negative associated with hope Other: relationships that cannot be interpreted as positive or negative
1. Bando et al. 2018	Lung cancer patients after surgery	82 Curative + Palliative Japan	HHI Cross-sectional Multivariate analyses	P: task-oriented coping and social diversion. N: dyspnea, a sore mouth, and chest pain. O: coping behaviors had greater influence on hope compared with treatment related symptoms
2. Bao et al. 2018	Central nervous system tumor patients after surgery	269 Not reported China	HHI Cross-sectional Multivariate analyses	P: social support N: depressive symptoms O: relationship social support – depressive symptoms mediated by hope
3, Beach & Dozier. 2015	New outpatients	44 Not reported USA	HHI Cross-sectional Only univariate analyses	O: patients with higher scores on the previsit hope index initiated more hopeful actions during the interview. Such hopeful actions were generally indirect rather than explicit
4. Biessen. Van der, et al. 2018a	Phase 1 trial patients	135 Palliative The Netherlands	HHI Cross-sectional Multivariate analyses	P: treatment motivation, psychological factors: tenacious and flexible coping, internal locus of control global quality of life N: external locus of control
5. Biessen. Van der, et al. 2018b	Phase 1 trial patients	135 Palliative The Netherlands	HHI prospective cohort study Only univariate analyses	O: in all patients (continuing vs stopping after first evaluation) hope diminished over time
6. Cao et al. 2017	Inpatients diagnosed within a year	192 Curative + Palliative China	HHI Cross-sectional Multivariate analyses	P: education, health, support from family, perceived emotional support from doctors Hope differs between disclosure (cancer diagnosis) by family > by doctors
7. Cripe et al. 2018	Advanced cancer patients	166 Palliative USA	SHS Cross-sectional Only univariate analyses	O: patient hope was consistently increased with more favorable patient and oncologist estimates of life expectancy for 6 and 12 months
8. DeMartini et al. 2018	Advanced cancer patients	265 Curative + Palliative USA	Other prospective cohort study Multivariate analyses	O: unqualified hopes for cure were more likely in younger patients (< 57 years) (OR 3.92; 95% CI 1.63-9.40, $p < .01$) and in those who did not endorse discussing their hopes with the primary care physicians

9. Duggleby et al. 2013	Newly diagnosed outpatients	310 Curative + Palliative Canada	HHI Cross-sectional Multivariate analyses	Hope differs between gender (men > women), age 18-64 years > ≥ 65 years
10. Fischer et al. 2018	Advanced cancer patients	84 Palliative USA	SHS Cross-sectional Multivariate analyses	N: severe depressive symptoms
11. Green et al. 2015	Advanced cancer inpatients	200 Palliative USA	HHI RCT Multivariate analyses	O: after engaging in ACP, there was no decline in hope neither in the control nor in the intervention group
12. Hasson-Ohayon et al. 2014	Women with breast-cancer and their spouses, outpatients	150 Curative + Palliative Israel	SHS Cross-sectional Multivariate analyses	P: social support: younger and older patients (≥ 55 years) N: depression by the older (≥ 55 years) patients O: relationship: social support - depression was mediated by hope
13. Hasson-Ohayon et al. 2009	Women with breast-cancer, outpatients	233 Curative + Palliative Israel	SHS Cross-sectional Multivariate analyses	P: fighting spirit N: fatalistic acceptance, anxiety/ preoccupation, helplessness/ hopelessness
14. Jafari et al. 2010	In- and outpatients	120 Not reported Iran	SHS Cross-sectional Multivariate analyses	P: life satisfaction, spiritual well-being = existential well-being (EWB) + religious well-being (RWB) O: EWB, hope and RWB explain 40% of changes in life satisfaction
15. Jimenez-Fonseca et al. 2018	Patients prior to adjuvant chemotherapy or chemoradiation	600 Curative Spain	MAC Cross-sectional Multivariate analyses	P: lower risk of anxiety and depression
16. Karami & Kahrazei. 2018	Patients with leukemia,	70 Not reported Iran	SHS Cross-sectional Multivariate analyses	P: feeling of God's presence, relationship with God, feeling responsible for others, the overall score of daily spiritual experiences O: Daily spiritual experiences explain 20% of variances in hope
17. Kavradim et al. 2012	Outpatients treated with chemotherapy at the Day unit	240 Curative + Palliative Turkey (Asian)	HHS Cross-sectional Multivariate analyses	P: net family income, the level of knowledge about the disease N: perception of satisfactory family support by the patient, mouth ulcers, feeling anxious or worried, fear, feeling of improvement

18. Khater & Alkwiese. 2013	Outpatients treated with chemotherapy or radiation therapy	170 Curative + Palliative Jordanian	HHI Cross-sectional Multivariate analyses	O: social support, perceived helpfulness of religious beliefs explain 22% of the variance in fostering hope. Presence of social support was the best predictor of a high level of hope
19. Li et al. 2017	Patients with cervical cancer during radiotherapy	480 Curative China	HHI Cross-sectional Only univariate analyses	P: household income. N: related factors of psychological distress and pain Hope differs between age: ≥ 45 years > < 45 years; being married > single; clinical stage I> III
20. Li et al. 2016	Patients with bladder cancer	78 Curative China	SHS Cross-sectional Multivariate analyses	O: social support, hope and resilience explain 30% of the variances in quality of life
21. Proserpio et al. 2015	In- and outpatients	320 Not reported Italy	Other Cross-sectional Multivariate analyses	P: **:** being able to share their experiences with others, having a positive perception of other people and trust in medical treatments
22. Rawdin et al. 2013	Outpatients	78 Curative + Palliative USA	HHI Cross-sectional Multivariate analyses	O: spiritual well-being (pos) and depression (neg) are predictors of hope
23. Ripamonti et al. 2015	Outpatients referred to supportive care unit for symptom management	276 Curative + Palliative Italy	HHI Cross-sectional Multivariate analyses	P: higher spirituality/religiousness N: Lower ESAS[1] scores, being referred to a psychologist previously, some of the informative, relational and some of the needs for psycho-emotional support
24.Rock et al. 2014	Breast cancer patient-partner dyads	56 Curative + Palliative USA	SHS Cross-sectional Multivariate analyses	O: higher patient hope predict greater patient marital satisfaction
25. Rustøen et al. 2010	Community-based sample of cancer patients	194 Not reported Norway	HHI Cross-sectional Multivariate analyses	P: self-reported health status, satisfaction with life N: psychological distress. O: Hope mediates between distress - health status and between psychological distress - life satisfaction

[1] ESAS = Edmonton Symptom Assessment System

26. Schjolberg et al. 2011	Women with breast cancer and fatigue, outpatients	160 Curative Norway	HHI Cross-sectional Multivariate analyses	O: total fatigue and living alone explained 13% of the variance of hope
27. Schofield et al. 2016	People with metastatic colorectal cancer	429 Palliative Australia	SHS RCT Multivariate analyses	O: hope is NOT related to progression free survival or overall survival
28. Shun et al. 2011	Outpatients chemotherapy or chemoradiation	182 Curative + Palliative Taiwan	HHI Cross-sectional Only univariate analyses	N: fatigue duration: total perceived interference of fatigue, perceived interference with functioning, interference of fatigue with relations with others, mood status
29. Soylu et al. 2016	Advanced breast cancer outpatients	55 Palliative Turkey (Asian)	SHS Cross-sectional Only univariate analyses	P: quality of life, optimism O: patients with “unrealistic” expectations had higher hope score than patients with “realistic” expectations
30. Steffen et al. 2018	lung cancer outpatients	50 Curative + Palliative Mexico	SHS Cross-sectional Multivariate analyses	O: hope is associated with functioning in lung cancer patients, regardless of physical symptoms from disease and treatment
31. Wakiuchi et al. 2015	Outpatients first cycle chemotherapy	60 Curative + Palliative Brazilian	HHI Longitudinal Only univariate analyses	P: education (more than eight years). Hope differs between: Occurrence of metastasis no> yes; Therapy purpose: curative>palliative; Pain: mild> moderate to strong pain
32. Wnuk et al. 2012	Inpatients with breast or lung cancer	50 Not reported Poland	HHI Cross-sectional Only univariate analyses	P: purpose in life, happiness in recent days, evaluation of life up to now, past satisfaction with life, current satisfaction with life, anticipated satisfaction with life, feeling of being loved
33. Ye et al. 2018	Women with breast cancer 1 week before treatment	342 Curative + Palliative China	SHS Cross-sectional Multivariate analyses	O: emotional distress, physical distress, self-efficacy explain 53% of the variance in hope for the future and is associated with resilience and transcendence

Data synthesis

Given to the heterogeneous nature of the results, it was not possible for us to perform a meta-analysis. In general, hope was measured with the same instruments. However, the other variables are often measured in different ways. For this reason, the data synthesis is presented in a narrative way. In the studies with both univariate and multivariate analyses we have seen that significant relationships with hope in the univariate analyses often demonstrated to be no longer significant in the multivariate analyses. Eight studies (3, 5, 7, 15, 19, 28, 29, 32) only involved univariate analysis, so it is uncertain what determines the relationships between hope and other variables. For these reasons in this results section only the results from the multivariate analyses are described. The results from the studies with multivariate analyses and only univariate analyses can be found in table 2a and 2b. We included the results from a significant level of p ≤ .05.

Results

Description of included studies

A total of 33 quantitative studies were included. Table 3 shows the characteristics of the studies. Most studies were cross-sectional, originated in Asia (n=14), America (n=10), Europe (n=8), and focused on curative and palliative treatment (n=16) or solely palliative treatment (n=7) of solely curative treatment (n=3). Seven studies did not mention the treatment goal (curative or palliative). Sample size varied from 44 to 600 participants. Most studies (n=25) included multivariate analyses. Some studies involved only univariate analyses (n=8).

Table 3: Characteristics of the included studies (n=33)

Study characteristics		**N**
Type of study	Cross-sectional	28
	Prospective cohort	2
	Randomized controlled trial	2
	Longitudinal	1
Data-analyses	Multivariate	25
	Only univariate	8
Treatment intent	Curative	3
	Palliative	7
	Curative and palliative	16
	Not reported	7
Continent	Asia	14
	America	10
	Europe	8
	Australia	1
Hope instrument	Herth hope index	17
	Herth Hope Scale	1
	State Hope Scale	12
	Other	3
Number of patients in study	0 – 100	11
	101 – 200	11
	201 – 300	5
	> 300	6

Definitions and assessments of hope

Several measuring tools were used to measure hope. Most studies measured hope using the Hope Herth Index (HHI) (n=17), the State Hope Scale (SHS) (n= 12), or the Herth Hope Scale (HHS) (n=1). One study used the Mini Mental Adjustment to Cancer scale (MAC) and two a self-designed questionnaire (Table 4 for the detail information about the hope instruments).

Table 4: Measuring hope as integrated in the included studies

Hope scales	Score ranges	Definition
Herth hope scale (HHS)	30 items, 4 point Likert scale ('never applies to me', 'rarely applies to me', 'sometimes applies to me' and 'always applies to me', scored as 0, 1, 2 and 3 respectively). 3 subscales ('future', 'positive readiness and hope' and 'connection with surroundings'). Total hope score between 0–90, total score of each subscale between 0–30. Higher scores indicate higher level of hope.	Dufault and Martocchio (1985): hope is "a multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant"
Herth hope index (HHI)	12 items, 4 point Likert scale ('strongly disagree' (1 point) to 'strongly agree' (4 points). 3 subscales: (a) cognitive-temporal (the perception that a positive, desired outcome is realistically probable in the near or distant future); (b) affective-behavioral (a feeling of confidence with initiation of plans to affect the desired outcome); (c) affiliative-contextual (the recognition of the interdependence and interconnectedness between self and others and between self and spirit). Total HHI scores range from 12 to 48 (higher scores indicate higher levels of hope).	Dufault and Martocchio (1985)
Modified HHI	Modified HHI: 12-items, 4 point Likert scale. 3 factors of hope: temporality and future, positive readiness and expectancy, and interconnectedness. Total scores range from 12 to 24 (higher score indicate higher hope)	
State hope scale (SHS)	6 items, 8 point Likert scale ('definitely false' (0 points) to 'definitely true' (8 points). 2 subscales: pathway and agency (3 items each). Total score between 0 (least hopefulness) to 8 (greatest hopefulness).	Snyder (2002): 'Pathways thinking' signifies one's perceived capabilities at generating workable routes to desired goals. 'Agency thinking' is the perceived capacity for initiating and maintaining the actions necessary to reach a goal.
Mini mental adjustment to cancer (MAC)	8 items, 4-point Likert scale. 4 subscales: fighting spirit, positive redefinition, helplessness-hopelessness, and anxious preoccupation. Total scores between 8 to 32; higher scores indicate greater hope.	-

Methodological quality of the included studies

Details of the assessment of the quality of the included studies are presented in Table 5. In general, the quality of the quantitative and mixed methods articles was assessed as medium to strong. None of the studies were excluded on the basis of their quality.
Table 5: Quality Assessment of Quantitative Studies and Mixed Methods Study Using the Qualitative Assessment Tool (QAT) (Vyncke et al., 2013)

Table 5: Quality Assessment of Quantitative Studies and Mixed Methods Study Using the Qualitative Assessment Tool (QAT) (Vyncke et al., 2013)

QAT item	Selection Bias (a)	Allocation Bias (b)	Confounders (c)	Data Collection Methods (d)	Withdrawals & Drop-out (e)	Analysis (f)					
						Q1	Q2	Q3	Q4	Q5	Q6
References											
Bando et al, 2018	Strong	NA	Strong	Strong	Strong	No	Yes	No	Yes	NR	Yes
Bao et al, 2019	Strong	NA	Strong	Strong	Strong	P	Yes	Yes	Yes	P	Yes
Beach and Dozier 2015	Strong	NA	NA	Strong	NR	No	Yes	Yes	Yes	NR	No
Van der Biessen et al, 2018a	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Van der Biessen et al, 2018b	Strong	NA	Strong	Strong	Strong	Yes	Yes	Yes	Yes	Yes	Yes
Cao et al, 2017	Strong	NA	Strong	Moderate	Strong	No	Yes	Yes	Yes	Yes	Yes
Cripe et al, 2018	Moderate	NA	Moderate	Strong	Strong	No	P	Yes	Yes	NR	Yes
DeMartini et al, 2019	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Duggleby et al. 2013	Strong	Strong	Moderate	Strong	Strong	P	Yes	Yes	Yes	Yes	Yes
Fischer et al. 2018	Strong	NA	Strong	Strong	Strong	No	P	Yes	Yes	Yes	Yes
Green et al. 2015	Weak	Strong	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Hasson-Ohayon et al. 2009	Strong	Strong	Strong	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Hasson-Ohayon et al. 2014	Strong	Strong	Strong	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Jafari et al. 2010	Moderate	NA	Moderate	Moderate	NR	No	No	Yes	Yes	NR	Yes
Jimenez-Fonseca et al, 2018	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Karami and Kahrazei, 2018	Moderate	NA	Strong	Strong	NR	No	No	Yes	Yes	NR	Yes
Kavradim et al, 2012	Strong	NA	Strong	Strong	Strong	Yes	Yes	Yes	Yes	NR	Yes

Khater and Alkwiese, 2013	Strong	NA	Strong	Moderate	Strong	No	Yes	Yes	Yes	Yes	Yes
Li et al. 2016	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Li et al. 2017	Strong	NA	Strong	Moderate	Strong	No	Yes	Yes	Yes	NR	Yes
Proserpio, et al. 2015	Strong	NA	NR	Weak	NR	No	Yes	No	P	No	NA
Rawdin et al. 2013	Strong	NA	Strong	Strong	Strong	Yes	Yes	Yes	Yes	P	Yes
Ripamonti et al. 2015	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Rock et al. 2014	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Rustoen et. al. (2010)	Moderate	NA	Strong	Strong	Strong	NA	Yes	Yes	Yes	NA	Yes
Schjolberg et al. 2011	Strong	NA	Strong	Strong	NR	No	Yes	Yes	Yes	Yes	Yes
Schofield et al. 2016	Strong	Strong	Strong	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Shun et al. 2011	Strong	NA	Weak	Strong	NR	No	Yes	Yes	Yes	NR	Yes
Soylu et al, 2016	Strong	NA	Strong	Weak	NR	No	Yes	Yes	Yes	NR	Yes
Steffen et al. 2018	Strong	NA	Strong	Strong	Strong	No	Yes	Yes	Yes	Yes	Yes
Wakiuchi et al. 2015	Moderate	NA	NA	Strong	NR	P	P	Yes	Yes	NR	Yes
Wnuk et al. 2012	Strong	NA	Weak	Strong	Strong	No	Yes	Yes	Yes	NR	Yes
Ye et al, 2018	Strong	NA	Strong	Strong	Strong	Yes	Yes	Yes	Yes	Yes	Yes

Selection bias: “Are individuals selected to participate in the study likely to be representative of the target population”, and “What is the response rate”.

a. Allocation bias: indication of study design.
b. Confounders: “Were important confounding variables mentioned?” and “If important confounders were mentioned, were they included in the analysis?”.
c. Data collection methods: “For each variable of interest, is the data collection tool clearly indicated?”, “Were data collection tools shown or are they known to be valid?” and “Were data collection tools shown or are they know to be reliable?”.
d. Withdrawal and drop-outs: indication of withdrawal/drop-out rate.
e. Analysis: “Q1: Is there a sample size calculation or power calculation?”, “Q2: Are characteristics of study participants extensively reported?”, “Q3: Are the main results of the statistical analysis unambiguously reported?”; “Q4: Are the statistical methods appropriate?”, “Q5: Are missing data handled in an appropriate way?”, and “Q6: Are all outcome measures mentioned in the method section reported in the result section.
P= partial, NA= not applicable, NR= not reported

Synthesis of the results

This review shows that hope is associated with different factors. The factors associated with hope are described by means of the following clusters: hope and demographic data, clinical variables, depression, anxiety, social support, other psychological variables, spirituality, quality of life and physical symptom load. Table 6 presents an overview of the associated variables with hope in relation to the studies, based on the multivariate analyses.

Table 6: Overview of the variables associated with hope in relation to the studies, based on multivariate analyses

	Relation with hope			
Variable	**Positive** **Other**		**Negative**	**No relation**
Demographical: **Age**	-	-	Bando et al, 2018 Hasson-Ohayon et al, 2014 Kavradim et al, 2012 Khater & Alkwiese, 2013 Rawdin et al, 2013 Ripamonti et al, 2015 Rock et al, 2014 Rustøen et al, 2010 Schjolberg et al, 2011	**Duggleby et al, 2013**
Gender	-	-	Bando et al, 2018 Hasson-Ohayon et al, 2014 Kavradim et al, 2012 Khater & Alkwiese, 2013 Rawdin et al, 2013 Ripamonti et al, 2015 Rustøen et al, 2010	**Duggleby et al, 2013**
Education	Cao et al, 2017	Ripamonti et al, 2015	Kavradim et al, 2012 Khater & Alkwiese, 2013 Rawdin et al, 2013 Rustøen et al, 2010 Schjolberg et al, 2011	-
Being Married	Schjolberg et al, 2011	-	Bando et al, 2018 Duggleby et al, 2013 Kavradim et al, 2012 Khater & Alkwiese, 2013 Rawdin et al, 2013 Rustøen et al, 2010	**Rock et al, 2014**

Clinical: Type of cancer	-	-	Khater & Alkwiese, 2013 Ripamonti et al, 2015 Rustøen et al, 2010 Schjolberg et al, 2011	-
Type of treatment	-	-	Bando et al, 2018 Rustøen et al, 2010 Schjolberg et al, 2011	-
Stages of disease	-	-	Khater & Alkwiese, 2013 Rawdin et al, 2013 Ripamonti et al, 2015	-
Depression	-	Bao et al, 2018 Fischer et al, 2018 Hasson-Ohayon et al, 2014 Jimenez-Fonseca et al, 2018 Rawdin et al, 2013	Duggleby et al, 2013	-
Anxiety	-	Hasson-Ohayon et al, 2009 Jimenez-Fonseca et al, 2018 Kavradim et al, 2012	Duggleby et al, 2013 Fischer et al, 2018 Rawdin et al, 2013	-
Social support	Bando et al, 2018 Bao et al, 2018 Cao et al, 2017 Hasson-Ohayon et al, 2014 Kavradim et al, 2012 Khater & Alkwiese, 2013 Li et al, 2016 Proserpio et al, 2015	-	-	-
Other psychogical: Psychological distress	-	Ripamonti et al, 2015 Rustøen et al, 2010	-	-

Coping, courage related strategies, self-efficacy, resilience, adaptation or Positive thinking	Bando et al, 2018 Biessen, Van der, et al, 2018a Proserpio et al, 2015 Rock et al, 2014 Ye et al, 2018	-	-	-
Spirituality	Jafari et al, 2010 Karami & Kahrazei, 2018 Rawdin et al, 2013 Ripamonti et al, 2015	-	-	-
Religion	Jafari et al, 2010 Karami & Kahrazei, 2018 Khater & Alkwiese, 2013 Rawdin et al, 2013 Ripamonti et al, 2015	-	Hasson-Ohayon et al, 2009	Proserpio et al, 2015
Quality of life	Biessen, Van der, et al, 2018a Jafari et al, 2010 Li et al, 2016 Rustøen et al, 2010	-	-	-
Symptoms: Treatment related symptoms or physical complaints	-	Bando et al, 2018 Ripamonti et al, 2015	Rustøen et al, 2010 Steffen et al, 2018	-
Improvement of symptoms or higher physical functioning	Kavradim et al, 2012	-	-	-
Pain	-	-	Bando et al, 2018 Duggleby et al, 2013 Rawdin et al, 2013	-
Energy	-	-	Duggleby et al, 2013	-
Total fatigue	-	Schjolberg et al, 2011	-	-
Mouth ulcers	-	Kavradim et al, 2012	-	-

Hope and demographic data

No relationship was found between age and hope in nine studies (1,12,17,18,22-26). However, one study (9) noted that the total hope score had an inverse relationship to age. Newly diagnosed patients aged 18 to 64 reported higher scores than participants aged 65 or over. In seven studies (1,12,17,18,22,23,25) were no differences between hope among male and female patients. However, male patients scored higher on hope than female patients, in one study (9).

No relationship between hope and level of education was shown in five studies (17,18,22,25,26). However, one study (6) found a positive relationship between level of education and total hope scores and one study found a negative relation (23). Six studies (1,9,17,18,22,25) showed no relationship between hope and being married. One study (26) concluded that the total hope score was positively related to being married. One study (24) showed that higher hope scores of patients (with breast cancer) and their partners predict greater marriage satisfaction.

Hope and clinical variables

No relationship was found between hope and the type of cancer in four studies (18,23,25,26) or type of treatment in three studies (1,25,26). Three studies (18,22,23) did not show any relationship between hope and the different stages of the disease.

Hope and depression

Several measuring tools were used to measure depression. Two studies (10,22) used the Hospital anxiety and depression scale (HADS), another two studies (12,15) the brief symptom inventory (BSI), one study (2) the Center for Epidemiologic Studies Depression Scale (CES-D) and one study (9) asked patients if they feel depressed. Although, the different use of measuring tools, a negative relationship between hope and depression was demonstrated in five studies, using validated measuring tools. However, one study (12) found a negative relationship between hope and depression for the group of female patients of 55 years and older and not for the group of female patients aged 54 or younger. No relationship was found between hope and feeling depressed in newly diagnosed patients (9).

Hope and anxiety

Anxiety was measured by different measuring tools. Two studies (10,22) used the Hospital anxiety and depression scale (HADS), one study (15) the brief symptom inventory (BSI), one study (13) the mental adjustment to cancer scale which measuring anxious preoccupation, and two times patients were asked if they feel anxious or worried (9,17). Hope and anxiety were negatively related to the overall hope scores in three studies (13,15,17). However, no relationship was demonstrated in three studies (9,10,22), whereby anxiety was measured by HADS (two times) and asked patients if they feel anxious.

Hope and social support

However, social support was measured by different measuring tools, all the eight studies (1,2,6,12,17,18,20,21) found a positive relationship between hope and social support. The used measuring tools for social support were: Perceived social support scale (PSSS) (2,20); Cancer perceived agents of social support (CPASS) (12), Personal resource questionnaire (PRQ) (18) and the use of a self-developed questionnaire (1,6,17). One study (18) showed that social support was the most influential factor on the strength of hope found. Another study (21) showed that patients had a stronger sense of hope when they received treatment and care and were able to share their experiences with others.

Hope and other psychological factors

Patients with high hope scores scored lower on psychological distress (23,25). Hope having a buffering role in the relationship between health status and psychological distress (25).

Hope was positively related to courage related strategies, self-efficacy and resilience (33). A higher degree of psychological adaptation measured using the Mood State Standard Form appeared to be related to higher patient hope scores (24). One study (21) concluded that positive thinking about others was a factor that gave patients a stronger sense of hope. For patients participating in phase 1 trials (4), hope was related to tenacity, flexible coping and internal locus of control. Hope turned out to be negatively related to external locus of control (4). Hope was positively related to task-oriented coping and social diversion (1).

Hope and spirituality/ Religion

Spirituality was measured in the studies by the spiritual well-being scale (SWB) (14), daily spiritual experience scale (DSES) (16), the system of belief inventory (SBI) (23) and the Steinhauser Spiritual Concern Probe (SSCP) (22). Hope had a positive relationship with spiritual well-being (14,22,23). A positive relationship had also been established between hope and existential well-being (14). One study (16) showed a positive relationship between hope and the total score of daily spiritual experiences, the feeling of God's presence, the relationship with God and feeling responsible for others respectively. Religious support was the second most influential factor (after social support) on the strength of hope (18). Hope had a positive relationship with religious well-being (14), religiousness (23) and trust in religion (21). Hope as a mediator decreased the negative relationships between religious identity and anxiety (12). No relationship was found between hope and any religious affiliation (22).

Hope and quality of life

Several measuring tools were used to measure quality of life: European Organization for Research and Treatment for Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (4); Functional Assessment of Cancer Therapy – Bladder cancer (FACT-BI) (20); The Satisfaction with Life Scale (14,25). A positive relationship between hope and quality of life was evident from all the studies that investigated these aspects (4,14,20,25). Hope can be seen as a source that helped patients to deal (cope) with the psychological distress associated with the disease (25). Hope was studied (14) as an independent variable and life satisfaction as a dependent variable, they show that hope determined life satisfaction. A positive relationship was found between hope and perceived health (25).

Hope and physical symptom burden

General symptoms

The total symptom load score (Edmonton Symptom Assessment Scale (ESAS)) was compared with the total hope score (23) and showed that hope had a negative relationship with the total ESAS score. No relationship between hope and physical complaints was found (25). No difference between hope and disease-focused symptoms had been demonstrated in lung cancer patients receiving palliative treatment (30). A negative relationship between hope and three treatment-oriented symptoms (dyspnoea, coughing and sore mouth) was found (1). The other treatment-related symptoms appropriate to postoperative treatment of lung cancer (e.g. alopecia, pain in chest, peripheral neuropathy, dysphagia) appeared not to be related to hope (1). The feeling of symptom improvement was positively related to the total hope scores (17).

Specific symptoms

There appeared to be no relationship between the total hope scores and pain scores (1,9,22). No relationship had been demonstrated between total hope scores and energy scores in newly diagnosed patients (9). One study (26) showed a negative relationship between the total hope score and total fatigue, mental fatigue and chronic fatigue respectively. There appeared to be no relationship between hope and physical fatigue. Mouth ulcers were negatively related to the total hope scores (17). Other symptoms (sleep disturbance, shortness of breath, weakness) did not appear to be related to the total hope scores (17).

Discussion

This systematic review attempts to identify factors that are associated with hope during treatment of cancer patients. A total of 33 studies were included. Descriptive synthesis of the studies allows us to draw some conclusions.

Main findings

The results suggest that hope can be associated with different factors and that these factors may vary across the included studies. However, some relationships are highlighted. A positive relationship has been established between hope and quality of life, social support, spiritual and existential well-being respectively. Hope appears to have a negative relationship with symptom burden, psychological distress and depression. There appears to be no relationship between hope and demographic and clinical variables. The relationship between hope and anxiety remains unclear.

Taking these results into account, it seems that external factors (demographic data, clinical variables) are not associated with hope. However, intrinsic factors, i.e. factors that are experienced and assessed by the patients themselves, such as quality of life, psychological distress and social support are associated with hope. Hope seems to be a process that is determined by a person's inner being rather than influenced from the outside.

Davis et al. (2017) also studied factors associated with hope, but with a focus on cancer patients in a palliative care unit. These are people who are further in the disease process and generally no longer receive tumor-oriented treatment. This study shows almost the same results: it also finds no relationship between hope and demographic and clinical variables. In the multivariate analyses, only the negative relationship between hope and depression appears to be significant. There seems to be no difference between people with cancer in active treatment and those with a more advanced illness. More research is needed to examine to what extent the findings regarding to the different phases in the disease process can be completed or refined.

Whether symptoms have a relationship with hope seems to depend on the method by which the symptoms were measured. Davis et al. (2017) found a weak relationship between hope and symptom burden. A possible explanation offered by Davis et al. (2017) themselves pertains to the way the symptoms were assessed; the ESAS measures only the intensity of a symptom (e.g. fatigue) and does not make a distinction between mental or physical fatigue, tiredness, or weakness. An association may exist between a particular fatigue domain and hope as demonstrated by the study of Schjolberg et al. (2011), included in our systematic review. They showed an association between hope and total fatigue, mental fatigue and chronic fatigue, but not with physical fatigue. For patients who are only asked about the intensity of a symptom, for example fatigue, we do not know what type of symptom (mental fatigue, chronic fatigue or physical fatigue) they had in mind when completing this score.

Moreover, it seems to be important whether symptoms have been measured in curative or palliative patients. The studies that show a negative relationship with hope and general or specific symptoms are all studies that have been done in predominantly curative patients, as described in our systematic review (Bando et al, 2018; Ripamonti et al, 2016; Kavradim et al, 2016; Schjolberg et al, 2011). In all the studies, hope is measured with the HHI or HHS validated for their country. The studies that did not show a relationship with hope and symptoms were done mainly in palliative patients (Steffen et al. 2018) or did not mention the treatment goal (Rustøen et al. 2010). Symptoms may play a different role in cancer patients who mainly undergo curative treatment, who generally have fewer symptoms due to their better performance.

Berendes et al. (2010) and Utne et al. (2010) both studied palliative cancer patients, and also demonstrated that other pain domains (such as pain interference with daily activities, the meaning of pain, or the affective domain of pain) may influence hope to a greater extent than pain intensity. These studies argue that symptoms should not only be measured by their intensity, but also by their interference with daily activities and the meaning it have for the patients.

A review to psychometric properties of hope scales (Redlich-Amirav et al. 2018) shows that 18 hope scales exists. In the oncology, the hope scales HHI, HHS and SHS are used most frequently. Two other hope scales are developed for oncology patients, are the Miller Hope Scale and the Nowotny Hope Scale. These are mainly described in older literature (before 2000). Redlich-Amirav et al. (2018) concluded that no robust and valid scale exists for measuring hope; they agreed with Eliott and Olver (2002) that it is possible that hope is an entity that cannot be accurately quantified, given the extensive ways to define and understand it. Eliott and Olver (2002) suggested that hope should not be explained using only models or definitions, but that the meaning of hope should be left to the individuals themselves to determine.

Nierop - van Baalen et al. (2016) and Salander et al. (2014) explained the importance of the meaning of hope from the patients with cancer themselves. This process is described as "the work of hope" (Nierop-van Baalen et al. 2016) and Salander et al. (2014) describes this as "a creative process for psychological survival thus been initiated by patients". These both studies showed that patients created hope themselves and used different strategies to increase their hope or defend it against threat, when necessary. These studies confirm that hope seems to be a process that is determined by a person's inner being rather than influenced from the outside.

Strengths and limitations

This study has several limitations. Generalisations require caution as the included studies used different methods for assessing, for example depression, anxiety, social support and spirituality. Almost all of the studies in this review had a cross-sectional design, which does not allow us to identify the direction of the relationship between hope and the associated factors. Consequently, we can say very little about the course of hope over time. In addition, one study (Rock et al. 2014) have low statistical power, meaning that their results should be interpreted with caution. The included studies reflect a diverse range of countries and societies. This can be a strength but might also account for some of the differences e.g. strength of the influence of spirituality was seen in countries that may have a stronger religious basis (e.g. Iran and Israel) – these findings may be less generalizable. As described before, the study is based on quantitative studies with predominantly cross-sectional design. That is why we cannot say much about the course of hope over time, the process, meanings and its dynamics. Qualitative studies on hope over time can complete this picture.

The strength of this systematic review is demonstrated by the design allowing for a comprehensive systematic search with the use of a well-designed search filter. Four major health care databases were searched. Reference lists of the included articles were screened for additional articles and no additional studies were added after this search. Large numbers of abstracts and published articles were screened or read. The different steps of the selection process and the assessment of the quality of the articles were rigorously done by two independent reviewers. Most studies examined hope using the same measuring tools, i.e. Snyders' hope scale and the Herth Hope Index, which enhances the validity of the study. The HHI and the SHS are the two hope scales that have been evaluated the most (Redlich-Amirav et al. 2018). Another strength of this systematic review, is that it only describes the results of the multivariate analyses. This enables us to interpret the relationships between the variables and hope with more certainty.

Implication for practice and further research

An important finding of this review is that the related factors are very diverse. It seems that the factors associating with hope are mainly factors that are experienced and assessed by the patients with cancer themselves. These are factors such as social support, quality of life, existential and spiritual well-being, symptom burden, psychological distress and depression. These factors are typically given meaning by the patients themselves. Social support, for example, is not about how many patients experience support, but that this support has real meaning for them. This may become even clearer in the case of experienced symptom burdens and psychological distress, in which only the patients themselves can make clear to the health professionals what impact and meaning these symptoms have for them. For nurses who work with patients with cancer during treatments, it is important to know that psychological distress diminishes hope and that patients have or could develop their own strategies to increase the hope. Health professionals are challenged to face and address patients' perceptions of hope and discussing this with them to explore which strategies can be helpful for them. This can be a valuable intervention and this approach may lead to decreased psychological distress and better quality of life for cancer patients.

More research is needed to find out more about the meaning of hope, the process of hope, its dynamics and the related factors. At the moment we do not know sufficiently whether hope has a different meaning for patients in the palliative phase than for patients in the curative phase. Although there are specific studies on hope in the palliative phase, the studies that have included both patients with curative treatments and those with palliative treatments did not analyse the results separately. More insight into the differences between these two groups can help health professionals to provide tailored care. This also applies to specific treatment phases, around diagnosis, during treatment, upon completion of treatment, after stopping treatment, for the 'survivors' and for patients who experience a relapse. This knowledge can be of great value in supporting patients with regard to treatment decisions, psychosocial support, the experienced quality of life, symptom burden, and any wishes they may have with regard to advanced care planning. Future studies are needed to study the direction of causality between hope and the variables.

Conclusions

This literature review of associated factors of hope in cancer patients receiving treatment shows that hope seems to be positively related mainly by intrinsic factors, such as perceived health, quality of life, social support, and existential and spiritual wellbeing. Hope is negatively related by experienced symptoms, psychological distress and depression. Demographic and clinical factors are not related to hope. Health professionals may want to focus on the meaning of hope for cancer patients in relation to these factors.

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Table 2b: Summary of included studies N = 33 (supplementary file)

Refs	Primary aim	Variabelen in study[1]	Hope[2] instrument	Participants (N) setting (S), stages of disease (St) percentage participants under treatment (T)	Design (D), data collection (DC) and data analyses (DA)	Variables related to hope with p-value and estimates of precision[3] Other: relationships that cannot be interpreted as positive or negative
Bando et al, 2018	To identify the factors affecting hope to develop a care-oriented perspective that focuses on the levels of hope of postoperative patients with lung cancer.	Socio-demographic characteristics Treatment-related symptoms Support-	Herth Hope Index (HHI) (Validated Japanese version)	**N** = 82 **S:** postoperative (3- 6 months after surgery) lung cancer patients, Japan **St:** 82% curative, 18% palliative **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: hierarchical multiple regression model	**Hope positvely related to:** improvement in treatment-related symptoms, task-oriented coping and social diversion ($\beta = 0.57$, $P < .001$); coping behaviors had a greater influence on hope (estimated value = 0.57), compared with treatment related symptoms (estimated value = −0.36). **Hope negatively related to:** Dyspnea, a sore mouth, and chest pain ($\beta = -0.36$, $P < .004$).
Bao et al, 2018	To examine the association of social support with depressive symptoms in central nervous system tumor patients and to explore the extent to which hope mediates this relationship.	Social support Depressive symptoms	HHI (Chinese Translation)	**N** = 269 **S:** newly diagnosed CNS tumor patients weeks after surgery), P.R. China **St:** not reported **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: hierarchical multiple regression model	**Hope positively related to:** social support ($\beta = .60$, $p < .001$) **Hope negatively related to:** depressive symptoms ($\beta = -.39$, $p < .001$) **Other:** the relationship between social support and depressive symptoms is partially mediated by hope

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[1] If relevant for the research question

[2] HHI = Herth hope index, SHS = the State hope scale, HHS = Herth hope scale,

[3] If described in the original study

Beach and Dozier, 2015	To understand when and how patients raise their concerns, how doctors responded to these patient-initiated actions, and implications for communication satisfaction.	Concerns about hopes	HHI	**N =** 44 **S:** new outpatients, USA **St:** not reported **T:** not reported	**D:** cross-sectional mix methods **DC:** video recordings and structured questionnaires **DA:** only univariate analyses[4]: quantified conversation analyses	**Other:** patients with higher scores on the previsit hope index initiated more hopeful actions during the interview (r(37)= .32, p<.05). Such hopeful actions were generally indirect rather than explicit (230 out of 260= 88.5%). However infrequent, when patient-initiated actions about hope were direct (30 out of 260 = 2,8%), such actions were more likely to be posed as questions (r(260)= .24, p< .001).
Biessen, Van der, et al, 2018a	To understand how hope and motivation of patients considering phase I trial participation are affected by psychological factors.	Psychological factors Quality of life Treatment motivation	HHI (Validated Dutch Version)	**N =** 135 **S:** phase 1 trial patients, The Netherlands **St:** palliative **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: structural regression (equation) model	**Hope positively related to:** Treatment motivation (β= .30, p< .01) psychological factors: tenacious and flexible coping (β= .52, p< .01), internal locus of control (β= .28, p< .01), global quality of life (p< .01) **Hope negatively related to:** external locus of control (β= -.28, p< .05)
Biessen, Van der, et al, 2018b	To assess the potential relation of HRQoL to eligibility for phase I trial participation.	Continuing vs. Stopping phase-1 trial participation	HHI (Validated Dutch Version)	**N =** 135 **S:** phase 1 trial patients, The Netherlands **St:** palliative **T:** 100%	**D:** prospective cohort study **DC:** structured questionnaires **DA:** only univariate logistic regression analysis	**Other:** In all patients (continuing vs stopping after first evaluation) hope diminished over time (β= .42, p< .01)
Cao et al, 2017	To examine the relationships between perceived initial cancer disclosure communication with doctors, levels of hope, and levels of trust in doctors among cancer patients, prior to treatment in China.	Demographical factors Personalized Disclosure information and person	HHI (Chinese translation)	**N =** 192 **S:** cancer inpatients P.R. China **St:** diagnoses within a year, cancer stage: early, mid, late. **T:** not reported	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: hierarchical multiple regression model	**Hope positively related to:** education (β= .16, p= .04) health (β= .22, p< .001), support from family (β= .15, p=.03), perceived emotional support from doctors (β= .26, p< .001) **Other:** patients who were mainly disclosed (has been told the cancer diagnosis) by family members had higher levels of hope compared with patients who were mainly disclosed by doctors (β= .21, p= .02)

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[4] Studies with only univariate analyses are shaded in grey.

Cripe et al, 2018	To clarify the relationships among patient and oncologist estimates of life expectancy for 6 and 12 months, chemotherapy use, and psychological characteristics.	Estimates of life expectancy for 6 and 12 months	SHS	**N =** 166 **S:** advanced cancer patients, US **St:** palliative **T:** 64%	**D:** secondary analysis from two cross-sectional studies **DC:** structured questionnaires **DA:** only univariate logistic regression analysis	**Other:** Patient hope was consistently increased with more favorable patient and oncologist estimates of life expectancy for 6 and 12 months. For patient estimates the mean values were 52.5 vs. 50.9 (OR 1.04; 95% CI 1.00–1.08, p< .05) at 6 months and 53.8 vs.50.1 (OR 1.11; 95% C I1.06–1.15, p< .001) at 12 months.
DeMartini et al, 2018	To describe patient's hope for advanced cancer treatment, and factors associated with expressing specific hopes, and the persons with whom hopes are discussed.	Factors expressing specific hope Persons with whom hope are discussed	Open-ended question: "What are you hoping for? And five point Likert scale	**N =** 265 **S:** advanced cancer patients, US **St:** 50% aggressive tumors and 50% non aggressive tumors **T:** not reported	**D:** prospective cohort study, mix methods. They dichotomized patients'responses for how thoroughly they had discussed their hopes with confidants. **DC:** structured questionnaires at baseline and after 3 months **DA:** multivariate logistic regression analysis	**Other:** Unqualified hopes for cure were more likely in younger patients (< 57 years) (OR 3.92; 95% CI 1.63-9.40, p < .01) and in those who did not endorse discussing their hopes with the primary care physicians (OR 3.21; 95% CI 1.13-9.14, p < .05)
Duggleby et al, 2013	To examine the relationship of hope with pain, energy, and psychological and demographic characteristics in newly diagnosed adult oncology outpatients.	Pain, energy, clinical variables, demographic variables, psychosocial concern	Modified HHI (12 items, max score = 24)	**N =** 310 **S:** newly diagnosed oncology outpatients in their first six months after diagnosis, Canada **St:** stages I t/m IV **T:** not reported	**D:** cross-sectional **DC:** health records **DA:** multivariate lineaire regression analyses	**Hope differs between:** Gender (men > women) (p< .01). Total HHI scores for men average 19.69 (SD = 3.74) for women average 18.59 (SD =3.26). Age: 18-64 years > ≥ 65 years (p< .05). Total HHI score for 18-64 years: mean: 20.18 (SD = 2.7), ≥65 years, mean: 18.59, SD = 3.26)

Fischer et al, 2018	To examine the relationships between two goal-related expectancies and two of the most common symptoms of psychological distress in patients living with advanced cancer: anxiety and depressive symptoms.	Severe anxiety symptoms Severe depressive symptoms	SHS	**N =** 84 **S:** patients with advanced cancer undergoing treatment with predicted survival < 1 year, US **St:** palliative **T:** not reported	**D:** cross-sectional secondary analysis of a descriptive study **DC:** structured questionnaires **DA:** multivariate analyses: hierarchical multiple regression model	**Hope negatively related to:** severe depressive symptoms (= -.42, p< .01)
Green et al, 2015	To investigate whether engaging in advanced care planning (ACP) using online planning tools adversely affects hope, hopelessness, or anxiety among patients with advanced cancer.	ACP	HHI	**N =** 200 **S:** patients with advanced cancer undergoing treatment in an academic medical center, USA **St:** stage IV or other poor prognosis cancer (e.g. AML), **T:** not reported	**D:** randomized controlled trial to engage in ACP using an online decision aid ("Making Your Wishes Known") **DC:** structured questionnaires **DA:** multivariate analyses: linear mixed effects model	**Other:** After engaging in ACP, there was no decline in hope neither in the control nor in the intervention group. HHI score (higher = more hope, range 12-48). Intervention group had mean scores of 40.6 (95% CI= 39.7, 41.4) and 41.2 (95% CI= 40.3, 42.1)
Hasson-Ohayon et al, 2014	To compare the relationship between social support, hope and depression among different age groups of women with advanced breast cancer and their healthy spouses.	Age Gender Social support Depression	SHS (Hebrew translation)	**N =** 150 **S:** women with breast cancer and their spouses, outpatients, Israel **St:** stage III (68.7) or IV (31.3) **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: structural equation model	**Hope positively related to:** social support: younger patients (=.40, p< .01), older patients (≥ 55 years) (= .30, p< .03) **Hope negatively related to:** depression by the older (≥ 55 years) women (= -.28, p<.03) **Other:** the group of older patients: the negative relationship between social support and depression was mediated by hope

Hasson-Ohayon et al, 2009	To examine the mediating role of hope between religiosity and coping for women diagnosed with breast cancer.	Religiosity Coping	SHS (Hebrew translation)	**N =** 233 **S:** Jewish women with breast cancer, outpatients, Israel **St:** stage III (65.2%) or IV (34.3) **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: hierarchical multiple regression models	**Hope positively related to:** fighting spirit (β=.43, p< .001) **Hope negatively related to:** fatalistic acceptance (β=-.24, p< .001) anxiety/preoccupation (β=-.30, p <.001), helplessness/hopelessness (β=-.46, p< .001)
Jafari et al, 2010	To predict life satisfaction through spirituality well-being and hope in cancer patients.	Spirituality well-being Existential well-being Religious well-being Life satisfaction	SHS (Iranian translation)	**N =** 120 **S:** in- and outpatients, Iran **St:** not reported **T**: 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: stepwise regression analysis	**Hope positively related to:** life satisfaction (β=.53, p< .001), spiritual well-being (β=.57, p< .001), existential well-being (β=.48, p< .01) religious well-being (β=.56, p< .001) **Other:** EWB, hope and RWB explain 40% of changes in life satisfaction [F (1, 118)= 41.70, p <.001)
Jimenez-Fonseca et al, 2018	To determine the prevalence of anxiety and depression in oncology patients initiating adjuvant treatment.	Anxiety Depression	Mini mental adjustment to cancer (Spanish validated version)	**N =** 600 **S:** patients prior to adjuvant chemotherapy or chemoradiation, Spain **St:** I t/m III (curative) **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate logistic regression analysis	**Hope positively related to:** lower risk of anxiety 0.98 (95% CI= 0.96-0.99, p< .001) and depression 0.97 (95% CI= 0.96-0.99, p< .001)
Karami & Kahrazei, 2018	To investigate the role of daily spiritual experiences in hope among patients with leukemia.	Daily spiritual experiences	SHS (Iranian translation)	**N =** 70 **S:** patients with leukemia, Iran **St:** not reported **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses**:** stepwise regression analysis	**Hope positively related to:** feeling of God's presence (β=.39, p< .001), relationship with God (β= .26, p<.02), feeling responsible for others (β= .31, p<.01), the overall score of daily spiritual experiences (β=.45, p< .001) **Other:** Daily spiritual experiences explain 20% of variances in hope

Kavradim et al, 2012	To determine the hope levels of people with cancer and the variables affecting hope.	Demographical, clinical, psychological and social factors.	Herth Hope Scale (Validated Turkish version)	**N =** 240 **S:** outpatients treated with chemotherapy at the Day unit, Turkey (Asian) **St:** 37.1 % with metastases, 62.9 % without metastases **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses**:** stepwise regression analysis	**Hope positively related to:** net family income ($\beta = .17$, $p < .01$), the level of knowledge about the disease ($\beta = .19$, $p < .01$), **Hope negatively related to:** perception of satisfactory family support by the patient ($\beta = -.17$, $p < .02$), mouth ulcers ($\beta = .-13$, $p < .02$), feeling anxious or worried ($\beta = -.13$, $p < .04$), fear ($\beta = -.14$, $p < .03$), feeling of improvement ($\beta = -.17$, $p < .02$)
Khater and Alkwiese, 2013	To identify predictors that correspond to fostering hope among Jordanian patients with cancer.	Demographical, clinical, psychological and social factors.	HHI (Arabic translation)	**N =** 170 **S:** outpatients treated with chemotherapy or radiation therapy, Jordanian **St:** stage I t/m IV **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses**:** stepwise regression analysis	**Other:** The final model ($R^2 = 0.22$, $p < .05$) explain 22% of the variance in fostering hope. Social support ($\beta = .44$, $p < .001$) and perceived helpfulness of religious beliefs ($\beta = .14$, $p < .05$). Presence of social support was the best predictor of a high level of hope
Li et al, 2017	To explore the factors affecting the level of hope and psychological health status of patients with cervical cancer during radiotherapy.	Demographical factors, religion, physical exercise time	HHI (Chinese translation)	**N =** 480 **S:** patients with cervical cancer during radiotherapy, P.R. China **St:** stage I t/m III **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** only univariate analyses: ANOVA	**Hope positively related to:** household income (HHI score: 31.79 ± 3.00 high income vs low income: 27.30 ±2.63) $p < .001$) **Hope negatively related to:** related factors of psychological distress (30.51 ± 3.99 (practical problems), 38.16 ± 4.86 (spiritual problem), $p < .001$), pain (range 42.17 ± 2.32 (no pain), 21.78 ± 3.23 (extreme pain), $p < .001$) **Hope differs between:** gender: age ≥ 45 years (32.46 ± 3.83) > age younger then 45 years (30.18 ± 5.73) $p < .001$), marital status: married (32.5 ± 4.19) > single (32.5 ± 4.19, $p < .001$), clinical stage I> III (35.34 ± 3.65 (stage 1, 28.95 ± 3.74 (stage III), $p = .001$)

Li et al, 2016	To assess quality of life and the integrative effects of social support, hope and resilience on quality of life among Chinese bladder cancer patients.	Social support Resilience Quality of life	SHS (Chinese translation)	**N =** 78 **S:** patients with bladder cancer, P.R. China **St:** stage I (64%), II-III (36%) **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses**:** hierarchical lineair regression model	**Other:** Social support, hope and resilience explain 30% of the variances in quality of life
Proserpio et al, 2015	To explore the determinants of hope in patients with cancer.	Demographical, and religious variables	Questionnaire developed by an expert team	**N =** 320 **S:** in- and outpatients, Italy **St:** not reported **T:** not reported	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: Linear regression model	**Hope positively related to:** being able to share their experiences with others ($p < .001$), having a positive perception of other people ($p < .03$) trust in medical treatments ($p < .02$)
Rawdin et al, 2013	To investigate the relationship between hope and cancer pain, after accounting for key psychological, demographic, and clinical characteristics.	Pain Demographic Clinical and Psychological characteristics	HHI	**N =** 78 **S:** outpatients, USA **St:** 33% no metastatic disease, 67% metastatic disease **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: Linear regression model	**Other:** In the final model $R^2 = .38$, $p < .001$ spiritual well-being ($\beta = 1.55$, $p < .001$) and depression ($\beta = -.63$, $p < .001$) are predictors of hope
Ripamonti et al, 2015	To explore the relationship between hope, symptoms, needs, and spirituality/ religiosity in patients treated in a supportive care unit.	Demographic, clinical characteristics experienced symptoms Spiritual and religious needs	HHI (Validated Italian version)	**N =** 276 **S:** Outpatients referred to SCU for symptom management, Italy **St:** curative 62 %, palliative 9 % **T:** 71%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: linear regression model	**Hope positively related to:** higher spirituality/religiousness ($\beta = 1.7$, $p < .01$) **Hope negatively related to:** Lower ESAS[5] scores (15.5 versus 22.6, $p < .001$), being referred to a psychologist previously ($p = .01$), some of the informative needs, some of the relational needs to assistance and some of the needs for psycho-emotional support ($p < .05$)

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[5] ESAS = Edmonton Symptom Assessment System

Rock et al, 2014	To examine the differential and combined roles of hope and optimism among breast cancer patients and their partners on patient marital satisfaction.	Age Health Mood	SHS	**N** = 56 **S:** breast cancer patient-partner dyads, USA **St:** stage I t/m IV (92% stage III or IV) **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: stepwise regression analysis	**Other:** Higher patient hope predict greater patient marital satisfaction (□= .58, p< .05)
Rustøen et al, 2010	The purposes of this study were to evaluate the relationships between demographic and clinical characteristics, health status, hope, psychological distress, and life satisfaction.	Demographical, clinical factors and physical complaints	HHI (validated Norwegian version)	**N** = 194 **S:** community-based sample of cancer patients, Norway **St:** not reported **T:** 56%	**D:** cross-sectional **DC:** structured questionnaires before the hope intervention **DA:** multivariate analyses: structural regression (equation) model	**Hope positively related to:** self-reported health status (□= .37, p< .001), satisfaction with life (□= .36, p< .01) **Hope negatively related to:** psychological distress (□= .37, p< .01) **Other:** Hope mediates the relationship between distress and health status. Hope partially mediates the relation between psychological distress and life satisfaction. The model that included hope provided a slightly better fit with the x^2 test of model fit = 3.03, P = .39. The CFI was 1.00 (perfect fit), the RMSEA was 0.008 (with 0 indicating a perfect fit), and the RMSR was 0.022, again showing very little deviation on average between the observed and expected residuals. All path coefficients were significant at P < .01
Schjolberg et al, 2011	To describe the relationship between hope and fatigue; and to evaluate the effect of demographic and clinical characteristics and fatigue on hope.	Demographical, clinical factors and physical fatigue	HHI (validated Norwegian version)	**N** = 160 **S:** women with breast cancer and fatigue, outpatients, Norway **St:** stage I en II **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: stepwise regression analysis	**Other:** In the final model (R^2 = 13%) living alone explained 9% of the variance of hope. Total fatigue and living alone explained 13% of the variance of hope.

Schofield et al, 2016	To investigate whether hope, optimism, anxiety, depression, health utility influencing survival in patients starting first-line chemotherapy for metastatic colorectal cancer.	Progression-free survival, overall survival	SHS	**N =** 429 **S:** people with metastatic colorectal cancer, Australia **St:** stage IV **T**:100%	**D:** randomised controlled trial (to receive chemotherapy or chemotherapy and immunotherapy) **DC:** structured questionnaires **DA:** multivariate analyses: (not futher specified)	**Hope NOT related to:** Progression-free survival or overall survival
Shun et al, 2011	To examine the relationship between hope and fatigue (intensity, duration, and interference) in newly diagnosed patients with cancer receiving chemotherapy.	Fatigue intensity, duration interference	HHI (Taiwanese translation)	**N =** 182 **S:** outpatients chemotherapy or chemoradiation, Taiwan **St:** stage I t/m IV **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** only univariate analyses: Pearson's correlations	**Hope negatively related to:** fatigue duration: total perceived interference of fatigue (□ = -.16 to □- .18, p< .05), perceived interference with functioning (□ = -.19, p< .05), interference of fatigue with relations with others (□ = -.18, p< .005), mood status (□ = -.21, p< .05)
Soylu et al, 2016	To explore knowledge of treatment intent and expectation of illness course and to evaluate their relationship with optimism, hope, and quality of life.	Optimism Quality of life Awareness of treatment intent Expectation of prognosis	SHS (Validated Turkish version)	**N =** 55 **S:** advanced breast cancer outpatients, Turkey (Asian) **St:** stage IV **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires **DA:** only univariate analyses: Mann-Whitney U	**Hope positively related to:** quality of life (□=.28, p< .05), optimism (□=.50, p< .01) **Other:** patients with "unrealistic" expectations had higher hope score than patients with "realistic" expectations (□=-.33, p< .01). Patients with an "accurate" perception of treatment intent had a lower hoper hope score (□=-.49, p< .01)

Steffen et al, 2018	To examine how daily hope, defined as goal-directed effort and planning to meet goals, and daily stigma were related to same- and next-day functioning in lung cancer patients receiving cancer treatment.	Stigma Physical symptoms Treatment factors Functioning	SHS (Spanish translation)	**N =** 50 **S:** lung cancer outpatients, Mexico **St:** stage III-IV NSCLC and limited (27 %) and extensive (73 %) SCLC **T:** 100 %	**D:** cross-sectional **DC:** structured questionnaires and daily diaries **DA:** multivariate analyses**:** hierarchical multiple regression model	**Other:** Higher daily physical functioning was related to same-day hope (estimate = 0.004, SE = 0.001, 95% CI = 0.001, 0.006) but not next-day hope (p = .892). Patients who reported more daily hope reported higher social/role functioning in same- and next-day models (estimate = 0.05, SE = 0.01, 95% CI = 0.02, 0.07; estimate = 0.02, SE = 0.01, 95% CI = 0.01, 0.03, respectively). Higher daily social/role functioning was related to sameday hope (estimate = 0.01, SE = 0.002, 95% CI = 0.002, 0.01), but not next-day hope (estimate = 0.003, SE = 0.001, 95% CI = 0.001, 0.01).
Wakiuchi et al, 2015	To measure the level of hope in cancer patients at the beginning and at the end of chemotherapy treatment and verify the associated factors in the two moments.	Time of diagnosis Previous therapy Occurrence of metastases Therapy aim Pain	HHI (Brazilian Portuguese version)	**N =** 60 **S:** outpatients first cycle chemotherapy, Brazilian **St:** 35% with metastases, 65% without metastases **T:** 100 %	**D:** longitudinal **DC:** semi-structured interviews at the start of chemotherapy and after three/four months **DA:** only univariate analyses: Mann-Whitney U	**Hope positively related to:** schooling (more than eight years education) **Other:** presence of metastases (without metastases > with metastases in the second moment) (p< .01), treatment goals (curative treatment > palliative treatment in the second moment) (p< .01), presence of mild or severe pain (mild pain > moderate to severe pain in both moments) (p< .01)
Wnuk et al, 2012	To investigate the relationship of purpose of life, and hope in the happiness and life satisfaction of patients with cancer during cancer treatment.	Pupose in life Happiness Life satisfaction Age Education	HHI (Polish translation)	**N =** 50 **S:** inpatients with breast or lung cancer during treatment or follow-up visits, Poland **St:** not reported **T:** not reported	**D:** cross-sectional **DC:** structured questionnaires **DA:** only univariate analyses: Pearson's correlations	**Hope positively related to:** Purpose in life (β=.62, p< .01), happiness in recent days (β=.42, p< .01), evaluation of life up to now (β=.51, p< .01), past satisfaction with life (β=.34, p< .01), current satisfaction with life (β=.46, p< .01), anticipated satisfaction with life (β=.64, p< .01), feeling of being loved (β=.87, p< .01)

Ye et al, 2018	To increase our understanding of how resilience outcomes are positively and negatively affected by protective and risk factors.	Emotional Distress Physical distress Intrusive thoughts Social support Courage related strategies Self-efficacy Resilience Transcendence	SHS (Chinese version)	**N =** 342 **S:** women with breast cancer 1 week before treatment, P.R. China **St:** I - III: 93%, stage IV: 7% **T:** 100%	**D:** cross-sectional **DC:** structured questionnaires **DA:** multivariate analyses: structural regression (equation) model	**Other:** Fifty-three percent of the variance in hope for the future is directly accounted for by emotional distress, physical distress, self-efficacy and courage-related strategy and is associated with resilience ($\beta = .39$, $p < .01$) and transcendence ($\beta = .46$, $p < .01$)

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5

Betekenis van positief denken bij mensen met kanker tijdens of na een behandeling met curatieve intentie

Based on the article of Nierop-van Baalen, C., Grypdonck, M., Van Hecke, A., & Verhaeghe, S. (2020). Positive thinking to lift life above cancer A qualitative study into the meaning of positive thinking in people with cancer during or after treatment with curative intent. *Submitted*

Positive thinking to lift life above cancer

A qualitative study into the meaning of positive thinking in people with cancer during or after treatment with curative intent

Abstract

Purpose: To explore the meaning of positive thinking in people with cancer during or after treatment with curative intent.
Method: A secondary analysis was conducted including a constant comparative analysis of previously collected interview data (n=74) to uncover the processes underlying positive thinking, with a constructivist paradigm approach.
Results: Positive thinking has many aims for people with cancer. It enables them to live as if curing is a certainty, as if they have a future ahead of them. Positive thinking also makes it easier for them to enjoy life and lift it above illness. The latter means that, in the balance between positive and negative things, the positive side becomes more important. Positive thinking also helps people to temporarily park their negative thoughts. This reduces stress and creates room for life that can then be redefined in a more meaningful way. People have different ways of thinking positively. Some people feel they are obliged to think posivitely. For some it comes naturally, while for others it takes great effort. Being cured is the ultimate object of positive thinking and, at the same time, people with cancer are in very fragile situation in this respect because effort is always needed to keep negative thoughts at bay. People do not experience social pressure to think positively.
Conclusions: People need to live as if curing is a certainty. Only then can they enjoy life. Health professionals should see positive thinking as a positive value, which they do not have to contradict in patients.

Introduction

In their daily language, people with cancer often use the word ‘positive thinking’. Because of that, the concept of positive thinking deserves a thorough exploration. It is generally believed that a person’s mental attitude in response to the diagnosis of cancer can influence their chances of survival (Jouret, 2010). Petticrew et al. (2002) conducted a systematic review to summarise the evidence on the effect of psychological coping styles on survival and recurrence in patients with cancer. They found little convincing evidence that any of these coping styles play a clinically important role in cancer survival or the prevention of recurrence. The studies that found a positive relationship between survival and coping were small studies or methodologically deficient studies, according to Petticrew et al. (2002).

O’Baugh et al. (2003) show that being positive is a general term used for both positive thinking and positive attitude. According to De Raeve (1997), a positive attitude is seen as a state of mind in which people look at things with a positive feeling. Positive thinking is seen as a cognitive strategy aiming to override or put aside unpleasant thoughts and moods (De Raeve, 1997). Tod et al (2011) describe positive thinking as a complex concept that represents a range of beliefs, attitudes, and activities. Positive thinking differs from optimism in this respect because optimism is seen as a general expectation of positive outcomes, regardless of whether they can be influenced or not (Rand et al. 2012; Bryant & Cvengros, 2004). Optimism is anchored in a person’s character and is not object-bound. Positive thinking, on the other hand, can be learned and focuses on a specific object.

On the one hand, being positive is something that originates from people with cancer themselves; on the other hand, their positive thinking can also be a reaction to pressure from their loved ones (Youll & Meckosh, 2011) or from ‘the world we live in’ (Wilkinson & Kietzinger, 2000). Consequently, being positive can be a socially desirable way of acting, according to De Raeve (1997). Health professionals and nurses in particular can also put pressure on patients by encouraging them to be positive (Tod et al. 2011, O’Baugh et al. 2008). Thus, there seems to be a difference between wanting to be positive and having to be positive.

In recent years, only a few studies have been conducted on positive thinking in people with cancer. These are often studies that do not distinguish whether people are being treated with a palliative or curative treatment goal (Caprara et al 2016; O’Baugh et al. 2003). These studies (Caprara et al 2016; O’Baugh et al. 2003) show that positive thinking produces positive effects. Positive thinking is associated with a better quality of life in people with cancer (Caprara et al. 2016). People who think positively report fewer symptoms such as anxiety and despondency according to the study. At the same time, being positive also enables patients to cope with their disease and treatment (Drageset et al. 2018). Very few studies were conducted on positive thinking in people with cancer who are treated with curative intent. As a result, there is currently little insight into the meaning of positive thinking in people with cancer during or after curative treatment. More and more people with cancer survive and can be treated with curative intent. People who have been treated with curative intent are happy and relieved that their treatment has been completed. At the same time, however, they feel vulnerable and are aware that the disease may manifest itself again.

The literature and practice show that there can be confusion among health professionals whether positive thinking comes from people themselves, or whether the people around them assume that patients ‘should’ think positively. For these reasons, it is necessary to gain insight into the perspective on positive thinking of people with cancer.

Method

For this study, a descriptive approach within the paradigm of constructivist inquiry was used, which theorises that each of us constructs our own meaning of reality, which may be common with or different from that of others, depending on the nature of shared experiences (Lincoln & Guba, 1985). The study is a secondary analysis of data previously acquired from smaller studies conducted in the Netherlands (Van Hell- Cromwijk & Grypdonck, 2008) and Flanders (Ronse, 2008; Deryckere, 2008; Vieren, 2007; Leroux, 2006). All studies involved people with cancer who were being treated with curative intent. The Flemish studies concern experiences of people who were engaged in adjuvant therapy (Ronse, 2008) or had completed adjuvant treatments in different time periods: < 6 months (Leroux, 2006), 1-8 months after completing treatment (these patients were engaged in a rehabilitation programme) (Vieren, 2007) or 2-5 years after completing treatments (Deryckere, 2008). The Dutch study (Van Hell-Cromwijk & Grypdonck, 2008) involved people who had undergone surgery because of a relapse or metastasis. Positive thinking was not part of the research question in any of these studies.

Recruitment and data collection

All participants were asked to participate by their own health professionals. None of the interviewers was a health professional for the patient in question at the time. The data were collected by means of open face-to-face interviews. Each study had its own interview protocol, appropriate to the purpose of the study. Being positive and thinking positively was addressed by the participants in all interviews. All interviews were audio-recorded and transcribed verbatim. A total of 74 interviews of 66 unique patients were analysed about their experiences during and after curative treatments. By curative treatments we mean all treatments that are curative in nature, i.e. given with the intention of curing the patient. Table 1 shows the demographic variables of the respondents and the inclusion criteria of the studies. Informed consent was obtained for each of the studies and the patient data were anonymised. The research protocol of each individual study was approved by the ethics committees of the hospitals involved. A central ethics committee approved the secondary data analysis.

Table 1: Demographical characteristics of the respondents

Object of the study	Number of participants	Selection criteria*	Setting	Age range of participants	Data collection period
To evaluate the effect of an rehabilitation programme for cancer patients from the participants' point of view	9 women interviewed twice (before and 3 months after participation in rehabilitation programme)	Participating in rehabilitation programme after adjuvant cancer treatment (1-8 months ago, 5 months on average)	Hospital or at home, based on patients' preferences	38-62 years; average age 50 years	2007
To gain insight into how persons with cancer live their life in the period after the adjuvant treatment	13 women; 2 men	Patients < 6 months after finishing their adjuvant treatment	At home	30-66 years; average age 47 years	2006
To gain insight into the experiences of participation in a nursing education programme for women with breast cancer	15 women with breast cancer	Patients participated in the nursing education programme; 3-6 weeks after surgery and undergoing adjuvant treatment (Radiation and/or chemotherapy and/or hormonal treatment)	At home	45- 77 years; average age 59 years	2008
To gain insight into the meaning of cancer survivors	10 women; 4 men	Patients 2-5 years after adjuvant treatment (Radiation and/or chemotherapy and/or hormonal treatment)	At home	43-61 years; average age 51 years	2008
To gain insight into the meaning of a recurrence in cancer patients	9 women; 3 men	Patients after surgical treatment (1-3 months after surgery) because of metastasis or recurrence of their disease	At home	30-71 years; average age 49 years	2005

*All patients who participated in these studies were diagnosed with cancer, age ≥ 18 years, and Dutch or Flemish speaking.

Data analysis

First of all, the interviews were read in their entirety. Codes were subsequently assigned to text fragments if relevant to the research question. Codes were assigned inductively by Boeije (2010). After this open coding, we integrated the codes around categories through axial coding. We explored the meaning of the categories and the way they are connected and distinguished. Finally, in the third phase of the coding procedure – selective coding – the findings were integrated by relating them to other categories and by filling in the categories that need further refinement and development. Data saturation was achieved. One of the authors was researcher in all the original studies and was as such involved in the analysis of the secondary data. Researcher triangulation was used to improve the quality of analysis. Two researchers [XX, XX] read all the interviews and each other's analysis notes, commented on them, and discussed each other's interpretations. The consistency and congruence of the findings from the analysis were critically examined. The prominence of positive thinking in the interviews allowed for a cogent discussion of this phenomenon.

Results

The results show that the central themes in the interviews are 'positive thinking' and 'lifting life above cancer'. Respondents show that by thinking positively, they can lift life above illness and that this life needs to be redefined. For the respondents, lifting life above illness means that in the balance between positive and negative things, the positive side has to become more important. This process can be visualised by using the weighing scales metaphor (see Figure 1).

Figure 1: The weighingh scales metaphor

Sickness burden	**Lifting life above illness**
Experienced symptoms	Positive thinking
Uncertainty	Social support

Meaning and function of positive thinking

For the respondents, positive thinking means believing in a positive outcome. Positive thinking is an act of will, which means that people consciously want to think positively and take actions to think positively. It is not certain what the future will look like for these patients. This uncertainty is difficult to live with, which is why they have to think positively. They believe they are going to get through it, that the disease will not come back. And if this is the case, that it can be treated again. Positive thinking is about living as if curing is a certainty.

The meaning of positive thinking also involves being able to enjoy life. People can enjoy life when they do not think of the possibility of it ending differently i.e. badly. Respondents need that certainty and that is why they have to think positively. In doing so people push uncertainty behind the horizon, as it were. In front of the horizon, uncertainty has a paralysing effect. People think positively because they force themselves to do so. At the same time, there is a necessity underlying positive thinking: you cannot do otherwise. Without positive thinking, it is not possible to lift life above illness and to enjoy that life. This enjoyment is the goal, but also the legitimacy for thinking positively.

"Um, yes, I'm scared, yes. But I can't, well I can't let that affect me, you know. [...] I want

> *to be positive; my environment says so, too:*

People who are diagnosed with cancer are horrified, and positive thinking ensures that the balance is re-established. Positive thinking reduces stress by parking negative thoughts temporarily and, thus, creates room for life again. Positive thinking is a way to fight cancer, by showing that the disease will not conquer you. And if this proves less successful physically, positive thinking helps to keep you mentally strong. Positive thinking is also seen as a way to protect yourself. Many respondents have the idea that they thwart their destiny if they do not think positively. In this way, positive thinking also comes with an obligation.

> *"You have to be positive; we know so many and…" But still, it's cancer, isn't it? There are times when I'm afraid it might come back... […] Well, life becomes unbearable when you're constantly thinking about it..."*

Positive thinking strategies

People think positively in different ways. One of these ways is to consciously expel negative thoughts from their mind.

> *"Yes, I've been thinking more positively on purpose. I'm working on that a lot. Um, whenever I catch myself thinking negatively, I say: stop!... I get worried, I sometimes see doomsday scenarios, and then I think: I shouldn't do that. Erm, then I grab my eraser and delete it in my mind, like that's gone and that's gone (laughs). That's a trick you can use."*

Another way of thinking positively is to look ahead to positive things and not cast your mind back at what happened in the past. Looking ahead to negative things only makes the fear prominent again.

> *"I always look on the bright side, not on... That's history now. I want to talk about it when people talk about it, you know like: "Back in those days, with that and that and that." Let bygones be bygones. I look forward, not back, no, no. What if you think: "Maybe it'll come back." I don't want that. No, I don't want that. I'm afraid it'll come back. I'm still scared to death of it, really. If it comes back now, it will be the end of me, I guess. Then it's really time to go… "*

Seeking distraction, for example by continuing to work, is also seen as a way of thinking positively.

> *"Yes, that's what people often say to me, how much they admire me for fighting so hard and trying to keep a positive outlook on things and for continuing to work, but it's actually not admirable at all, I'm actually a bit of a coward because I can't just sit at home and think about everything, and work is just a distraction for me. So it's not so admirable at all that I stay positive, it's a way to protect myself."*

Social comparison is also a way, and often a strategy, to look at one’s own world in a more positive way.

> *“I tend to lean on people around me, I talk with people who are already further along in the disease process, and, funny enough, that makes me feel a bit better because, compared to them, I’m not doing so badly. Of course I’m kidding myself, because I very well know that it’s not easy for me either.”*

Factors that promote positive thinking

Different factors can facilitate or reinforce positive thinking. Contributing factors that can strongly influence positive thinking are positive results of scans and positive messages from doctors. Respondents also sometimes interpreted messages from doctors more positively than they were intended.

> *“He [the doctor] told me: I don’t think you will need surgery in the coming ten years. So that’s my starting point. It gives me ten more years.”*

Social support can be experienced as a contributing factor.

> *“A good chat and support... well, they help me a lot with my financial affairs and other things like that. “You shouldn’t worry about that, it’s going to be all right and this and that and you have to think positively.” That’s what they keep saying to me.”*

As stated above, patients think they should think positively, but this does not mean that positive thinking goes without saying. Positive thinking is much ‘easier’ for some than others. Patients who can ‘easily’ think positively refer to their optimistic nature and say: “That’s how I am”.

> *“Being positive, that’s right, that I can do. ...That’s how I am. I’ve never been really pessimistic.”*

People who call themselves ‘naturally positive’ say that it takes little to no effort to think positively.

> *“I didn’t have to make much effort. It wasn’t that I got up in the morning and said: I’m going to fight the cancer or, um, today I’m going to be positive for once. Yes, that really came naturally.”*

Factors hindering positive thinking

A number of factors can also threaten or complicate positive thinking. Respondents indicated that not being optimistic is such an impeding factor. Consequently, it takes much more effort to think positively and these efforts can even become a daily struggle.

> *"… I tell you, I'm a pessimist by nature, always have been, a brooder, a doubter, and that's why I really have to train myself to be positive. It's a struggle every day."*

The occurrence of symptoms threatens positive thinking because it makes patients become more aware of the facts, of reality. The occurrence of a relapse is the greatest fear patients have. Respondents try to control their fears by declaring them normal.

> *"Yes, fear, um, I guess that's normal. If I feel something now, yes, I'm not allowing myself to feel too much, because that might start me off thinking there's something wrong again. Um, I think that's normal, if you've had cancer, you're much more alert. I had it last week. I had pain in my belly for a day or two and that… then my mood goes directly below zero, that's very frightening."*

The proximity of possible bad news is a limiting factor. Positive thinking, by correcting negative thoughts, is almost impossible just before a check-up. Fears are uncontrollable at such a time.

> *"I went for a check-up yesterday, so I had a few sleepless nights before that, but otherwise no problems. Yes, I found myself back there and had to undergo those examinations again, reliving a bit of what I went through last year, when I was diagnosed with cancer. That's actually my worst period."*

The realisation that you do not have 100% certainty sometimes makes it more difficult to keep thinking positively.

> *"So, hoping for the best, you think you've been cured, but you're not really sure."*

Making long-term plans is difficult for most respondents, because that brings them to the realisation that the future may very well be different.

> *"I'm starting to make long-term plans now, but it keeps playing a role. I keep thinking: "Let's hope we're still here then." I'm starting to make long-term plans, but um, that's always on my mind."*

Lifting life above illness

One effect of positive thinking is that you can lift life above illness and the experience of illness. That does not happen by itself. Most respondents said they had to fight hard to achieve it. They had to fight this hard because otherwise they would not have a life (in a literal and figurative sense). Lifting life above illness is about being able to live and enjoy life. That enjoyment has a certain urgency. The life that is lifted above the experience of illness is not the old life, but a life that does justice to the values the respondents find important. This 'new' life is seen as "a second chance" or "a gift". Patients feel they have to make good use of this new life; they do not to waste it and start to revalue it. They become more selective and authentic and want to define this new life differently. Work is usually given a relative position. Respondents indicated they want to spend time on what they find really important.

> *“I could still do the housekeeping, physically speaking, but I told myself: “No, I’m going to spend more time on enjoying life now.”*

Respondents who managed to lift life above the experience of illness say they have grown as a result of this experience. It is not when patients do not think about their illness that life is lifted above illness, but when it does not interfere with their daily functioning. Lifting life above illness also involves dealing with stress and, thus, lifting life above the experience of pressure. Patients grasp every opportunity they get to keep a relapse at bay, such as the offer of adjuvant therapy. At the same time, they are able to accept the finiteness of their existence, at least as long as the end is still far away. Being cured is the ultimate object of positive thinking

> *“But first of all, I owe it to myself. From the beginning I have been positive about it, despite my fears, my great fears. I resumed my life feeling positive. I, therefore, try to avoid stressful situations.”*

and, at the same time, the situation remains very fragile because efforts are always needed to keep the negative thoughts at bay.

> *“Last year I thought: I’m packing away these Christmas decorations now, but will I unpack them again next year? And that same thought cropped up this year. You’re just working on it every day.”*

Discussion

This study focuses on the meaning of positive thinking for people with cancer during or after treatment with curative intent. The results show that positive thinking is necessary to lift life above the experience of illness. Positive thinking can help people to temporarily park their negative thoughts. This reduces stress and creates space to live and enjoy life. This life can then be defined in a more meaningful way. The findings of O’Baugh et al. (2003) that positive thinking helps to deal with illness and treatment and those of Caprara et al. (2016) and Naseem & Khalid (2010) that positive thinking helps to make fears manageable are confirmed in this study. This study adds that patients consciously use positive thinking and have to make an effort to do so, even when they also say that positive thinking is easy for them. Patients show the use of different strategies in the ways in which they think positively. This study also shows which factors promote or hinder positive thinking.

This study demonstrates that most people see positive thinking as a duty: they believe they thwart their destiny if they do not think positively. Respondents do not experience social pressure to think positively as described in the literature (Ruthig et al. 2012, Youll & Meckosh, 2011, Wilkinson & Kietzinger, 2000). Our study shows that encouragement of loved ones to think positively is not perceived negatively, but rather as supportive and encouraging. This could have to do with the fact that all respondents experience positive thinking as a virtue.

A possible negative effect of social pressure to think positively, as experienced by patients, is indicated in a study by Arman et al. (2002). They show that some patients find it difficult to talk about their negative feelings with health professionals. One of the reasons given is that patients are afraid to paint an unacceptable picture that is in contrast with the value attached to being positive. The question remains what attitude health professionals should take towards positive thinking. Wilkes et al. (2003) suggested that nurses should listen carefully to what patients say and allow them to talk about difficult and negative feelings. At the same time, nurses should be aware that they play an important role in supporting patients to feel positive in a way that makes sense. Forcing patients into both positions is likely to increase their emotional distress (O'Baugh et al 2003, Wilkes et al 2003).

Relation between positive thinking and hope

Positive thinking overlaps with hope, but there are also some differences (O'Baugh et al. 2008). Dufault & Martocchio (1985) describe hope as "a multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant." Nurses associate similarities between positive thinking and hope with 'fighting spirit', 'acceptance', and 'looking on the bright side' (O'Baugh et al. 2008). A difference between hope and positive thinking is especially seen in situations where there is a greater degree of uncertainty, as is the case with palliative treatments. Hope also requires a greater degree of effort on the part of the patients themselves, precisely because they are in such a vulnerable situation (Nierop-van Baalen et al. 2016). Our study and the study by Nierop-van Baalen et al. (2016), which both involved people with cancer in the palliative phase, show that positive thinking and hope provide an answer to uncertainty. People who hope do not know whether the future will be favourable. People who think positively assume it will be favourable, although they cannot be certain of this. In the palliative phase, patients try to focus on the positive aspects while simultaneously taking an unfavorable outcome into account (Nierop- van Baalen et al. 2016). If people can no longer rely on the certainties of a positive future, they can cherish hope. This shows that positive thinking is stronger than hope. More generally, this study shows that both positive thinking and hope help to allay the fears associated with the disease and the treatments people with cancer have to undergo.

Positive thinking differs from hope in the attitude people with cancer take to reality. In the case of positive thinking, the patient considers a negative outcome unlikely. With hope, this outcome is not necessarily unlikely, but no less undesirable. Patients hope when there is also a negative outcome possible, and people want to resist this possibility. Hope enables them to put this possibility behind a screen, as it were. The calming effect of hope is insufficient in the curative phase because then hope implies more uncertainty than people can bear. In fact, you could say that positive thinking is the superlative of hope. Positive thinking enables people to say: "I assume that it will be okay". With hope, people say: "it can also work out". Both hope and positive thinking are about “something” that is unbearable, but that “something” is different for both groups.

Most importantly, positive thinking differs from hope in the attitude people with cancer take to reality; in the case of positive thinking, a negative outcome is unlikely in the mind of the patient, and with hope, this outcome is not necessarily unlikely.

Limitations and strengths of the study

This study has several limitations. The first limitation concerns our choice of a secondary analysis. Patients were interviewed by multiple interviewers and within different contexts. All interviews of the original studies were, however, analysed by one of the researchers who conducted these studies. As a result, the original context could still be understood. A more important limitation is that data collection and analysis could not be performed alternately. However, the richness, size, and diversity of the data made it possible for us to conduct in-depth analyses despite this limitation. Data saturation was achieved. Our inclusion criterion determined that people were interviewed in their national language (Dutch), as a result of which people with a different cultural background are underrepresented in this study.

An important but less influential source of bias is the motivation of patients to participate in the study. There are numerous reasons why depressed patients are not likely to participate in a study. The original studies date from a few years ago. This could be a limitation because patients’ opinions may change over time. However, we compared our data with the data in the current literature and found no differences in how patients express their views on positive thinking and, more broadly, on having cancer. This might also be explained by the fact that the data concerns existential experiences of patients who are less influenced by environmental factors. Although the chance of survival has increased in recent years, this makes less of a difference to patients. The fear of reoccurrence of the disease remains ever present.

One of the strengths of this study is that it analysed how people talk about positive thinking, while we did not put this forward as a concept beforehand, so what patients say has been influenced less by the interviewers. The scope of the data and the fact that patients were interviewed in different settings at different points in time enabled the researchers to use this wealth of data to clarify the meaning, functions, modes, and influencing factors of positive thinking as experienced by patients.

Implications for practice

The results of this study provide several opportunities to improve practice. By gaining more insight into the function of positive thinking and ways in which patients shape positive thinking, health professionals will be better able to tailor their care to the needs of these patients. Awareness of the fact that positive thinking is experienced as necessary to lift life above illness (even though this takes great effort for some patients) and enables patients to suppress fears can offer health professionals tools to start a dialogue with patients. Health professionals could come to realise that what patients describe as positive thinking may differ from their own views on the subject. Talking to patients about what positive thinking means to them can be a valuable way of providing attuned care.

The literature shows considerable differences in how health professionals view patients' positive thinking and how they can best respond to it. On the one hand, health professionals find it difficult to understand patients who are positive about the future while they do not have a very favourable prognosis (Van Allen, 2011; Nierop-van Baalen et al. 2019). On the other hand, there are nurses (O'Baugh et al. 2008) who find they have great influence on the positive attitude of patients and usually feel obliged to support patients in this positive attitude. O'Baugh et al. (2003) furthermore state that nurses believe that patients who are being positive are also cooperative patients. According to them, positive patients are those who follow the advice and precepts of nurses and are consequently seen as 'good' patients.

For health professionals it is important to know that positive thinking does not have to be contradicted; it is a positive value for patients. Health professionals should not stand in the way of positive thinking too much, should not want to guard and protect patients too much. If patients think positively, this usually does not mean that they have not understood the information about possible negative developments given to them. By listening carefully to patients, health professionals can find out what their source of positive thinking is. If patients are their own source of positive thinking, health professionals can support patients. If patients' positive thinking seems to have been determined by others, health professionals can support patients in regaining their autonomy.

Implicaties for further research

More research is needed to investigate to what extent these results can be supplemented or refined. Many studies have been done in people with cancer, often not distinguishing between people in the curative phase and those in the palliative phase. Where this distinction is mentioned in the data, these studies have not included it in the analyses (Nierop- van Baalen, et al. 2020). At present there is little evidence for the group of people being treated curatively. As this group of people is increasing worldwide, research into their needs and the meaning of their illness, i.e. characteristics of the curative phase, seems essential to us.

Dealing with the threat of recurrence and positive thinking in response to that threat could be phenomena that manifest themselves differently in different cultures. Given the nature of the data (secondary analysis), in which different cultural backgrounds are not described separately, we cannot make any statements about this aspect of which there is still little evidence in the literature. Studies into cultural differences and positive thinking may supplement the scarce existing evidence.

Conclusion

Our analyses of 74 interviews of people with cancer during or after treatment with curative intent show that these people think they should think positively. They need positive thinking to live as if curing is a certainty. Only then can they enjoy life. Health professionals may also see positive thinking as a positive value, which does not have to be contradicted in patients.

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6 Discussie

Algehele discussie

De algemene doelstelling van de dit proefschrift was het verkrijgen van inzicht in (1) de betekenis van hoop bij mensen met kanker in de palliatieve fase, (2) de perspectieven van hulpverleners die omgaan met hoopvolle palliatieve patiënten, (3) de beïnvloedende factoren van hoop bij mensen met kanker gedurende de behandelingen die curatief of palliatief van aard waren en (4) de betekenis van positief denken bij mensen die met curatieve opzet zijn of werden behandeld. Met deze inzichten willen wij bijdragen aan zorg die meer afgestemd is op de behoeften van mensen met kanker in de verschillende fasen van hun ziekteproces. Daarnaast willen we handvatten bieden voor hulpverleners in het omgaan met hoopvolle palliatieve patiënten.

Deze discussie begint met een samenvatting en discussie van de belangrijkste resultaten. Daarna volgen de methodologische overwegingen en implicaties voor de praktijk en vervolgonderzoek. Bij de bespreking van de bevindingen gaan we in op thema's die zowel in het perspectief van mensen met kanker als in het perspectief van hulpverleners een prominente plaats innemen. Beide perspectieven ontmoeten elkaar in de praktijkvoering en daarin zullen gelijkenissen en verschillen directe gevolgen hebben voor de zorg. De resultaten uit de vorige hoofdstukken dienen als vertrekpunt, waarbij sommige bevindingen verder worden uitgewerkt. De discussies en conclusies uit de voorgaande hoofstukken worden in de deze discussie niet op eenzelfde wijze aangebracht, zodat onnodige herhaling wordt vermeden. De implicaties voor de praktijk en vervolgonderzoek, worden in een aparte paragraaf besproken, maar vormen een geïntegreerd onderdeel van de discussie.

Discussie van de bevindingen

Deze discussie begint met de bespreking van de beide concepten positief denken en hoop, om de onderlinge relatie, zoals deze uit onze studies naar voren komt, zo helder mogelijk weer te geven. Daarna zoomen we in op de specifieke karakteristieken en betekenis van positief denken en vervolgens op de eigenheid van hoop. Aansluitend komen de thema's rondom communicatie en autonomie met daarin de perspectieven van hulpverleners aan bod.

Positief denken versus hoop

Onze data dwingen ons om hoop en positief denken als afzonderlijke concepten te beschrijven, die dicht bij elkaar liggen en elkaar deels overlappen. In de twee groepen studies, die bij patienten in de curatieve fase, en die bij patiënten die niet meer curatief behandeld kunnen worden, komen de termen positief denken en hoop ook in heel verschillende frequenties voor. In de literatuur hebben we opvallend genoeg alleen studies gevonden die of over hoop of over positief denken schrijven. Geen enkele studie is gevonden die beide concepten bestudeerd heeft.

Onze studies laten zien dat dat voor mensen met kanker die met curatieve opzet behandeld worden of zijn, positief denken prominenter is dan hoop. Positief denken verschilt van hoop in de houding die mensen met kanker aannemen ten opzichte van de werkelijkheid. Positief denken houdt in een negatieve afloop onwaarschijnlijk achten. Dat onwaarschijnlijk achten is niet zonder meer (een) gegeven, maar moet verworven en in stand gehouden worden. Bij hoop is, in de ogen van wie hoopt, het bestaan van een negatieve afloop niet uit te sluiten maar daarom niet minder ongewenst. Hoop is er als ook een negatieve uitkomst mogelijk is, en tegen deze mogelijkheid willen mensen zich verzetten. Door te hopen zetten ze deze mogelijkheid als het ware achter een tochtscherm. In de curatieve fase brengt hoop geen rust wat ze met positief denken wel kunnen bewerkstelligen. Voor mensen in de curatieve fase levert hoop hen te weinig op. Hoop veronderstelt meer onzekerheid dan ze kunnen verdragen. De data laten zien dat positief denken beschouwd zou kunnen worden als een overtreffende trap is van hoop. Bij positief denken zegt men: “ik ga er vanuit dat het goed zal komen”, Bij hoop zegt men: “het kan ook goed komen”. Bij zowel hoop als positief denken gaat het over ‘iets’ wat ondraaglijk is, maar dat ‘iets’ is voor beide groepen wel iets anders. De interviews laten zien dat anders dan veel hulpverleners laten zien en de literatuur beschrijft, de positieve instelling die mensen met kanker hebben en hoe ze naar hun kansen kijken, ook als deze niet aan de werkelijkheid voldoet, niet alleen een probleem is, maar ook een kracht. Dat geldt zowel voor hoop als voor positief denken.

Beschrijving en betekenis positief denken

Onze studies laten zien dat positief denken betekent geloven in een goede afloop. Mensen zijn enorm geschrokken van de diagnose kanker en de toekomst is onzekerder geworden. Mensen vinden het moeilijk om te leven met deze onzekerheid en daarom moeten ze positief denken. Ze geloven dat ze er goed uit zullen komen, dat de ziekte niet terug zal komen. En als de ziekte terugkomt, dat deze dan opnieuw behandeld kan worden. Positief denken is leven alsof genezing een zekerheid is. De betekenis van positief denken gaat ook over van het leven kunnen genieten. Mensen kunnen van dit leven genieten als ze er niet aan denken dat het ook anders kan aflopen. Positief denken zorgt ervoor dat mensen zich mentaal sterk blijven voelen. De respondenten laten zien dat het idee leeft dat ze het lot, dat ze gunstig gezind is, onrecht aan zouden doen, door niet positief te denken. Op deze manier brengt positief denken ook een verplichting met zich mee. Mensen laten verschillende manieren zien om positief te denken. Een manier is bewust naar de toekomst te kijken en niet naar het verleden, een andere manier is door bewust negatieve gedachten uit het hoofd te zetten. Afleiding zoeken, door te (blijven) werken is een manier om positief te denken, net zoals sociale vergelijking helpt om de eigen wereld positiever te bekijken. Verschillende factoren kunnen het positief denken bevorderen of belemmeren. Opvallend is dat deze bevorderende en belemmerende factoren grotendeels overeenkomen met de beïnvloedende factoren en bronnen van hoop, zoals sociale steun, berichten van artsen, inspanningen die mensen verrichten om positief te blijven en het optreden van symptomen. Anders dan bij hoop zien we dat mensen die zeggen dat positief denken hen heel gemakkelijk afgaat, verwijzen naar hun optimistische karakter en zeggen dat ze geen/ nauwelijks moeite hoeven te doen om positief te denken. Genezen zijn is de bezegeling van het positief denken en tegelijkertijd blijft het zeer broos omdat er altijd inspanningen nodig blijken te zijn om de negatieve gedachten op afstand te houden.

In de literatuur over positief denken wordt veel geschreven over sociale druk die patiënten ervaren om positief te *moeten* denken (Ruthig et al. 2012, Youll & Meckosh, 2011, Wilkinson & Kietzinger, 2000). Onze respondenten laten zien dat aanmoedigingen van naasten om positief te denken niet nadelig worden ervaren, maar juist bemoedigend en ondersteunend. Een mogelijke verklaring hiervan kan zijn dat de respondenten positief denken als een deugd ervaren. De literatuur beschrijft ook een nadelig effect van positief denken, zoals deze aangegeven zijn door patiënten in de studie van Arman et al. (2000). Zij beschrijven dat patiënten het lastig kunnen vinden om over negatieve gevoelens te spreken met hulpverleners, vanwege de waarde die gehecht wordt aan positief zijn. Deze waarde, of externe norm, wordt daar ook beschreven vanuit hulpverlenersperspectief. Hoewel niet in onze studie onderzocht, maar wel geobserveerd vanuit het werken met hulpverleners, lijkt de externe norm om positief te moeten denken in Nederland en Vlaanderen niet zo zichtbaar te zijn. In tegenstelling tot de sterke reactie van hulpverleners op hoopvolle palliatieve patiënten lijkt positief denken voor deze hulpverleners geen issue te zijn, waarmee wordt bedoeld, geen reden om te interveniëren. Een mogelijke verklaring hiervoor zou kunnen zijn dat er bij positief denken bij curatieve patiënten geen discrepantie is tussen de gewenste en verwachte uitkomst, namelijk genezing. Een andere mogelijke verklaring wordt gegeven door O'Baugh et al. (2003) die stellen dat patiënten die positief denken gezien worden door verpleegkundigen als 'goede' patiënten, coöperatieve patiënten, die adviezen opvolgen.

Als mensen positief denken inzetten als copingmechanisme, willen ze hierin ondersteund worden. Hulpverleners kunnen dus mensen die positief denken ondersteunen.
O'Baugh et al. (2008) hebben onderzoek gedaan naar het perspectief van verpleegkundigen wat betreft de positieve attitude van mensen met kanker. Deze verpleegkundigen vonden dat hoop en een positieve attitude grote overeenkomsten vertonen en gebruikten drie thema's om het concept een positieve attitude te beschrijven: Acceptatie; vechtlust en de wereld vanuit de positieve kant bekijken. De verpleegkundigen gaven aan dat ze vonden een grote invloed te hebben op de positieve attitude van patiënten, waaruit die invloed bestaat wordt niet uitgebreid beschreven. Een verpleegkundige vertelde dat door ondersteunend te zijn naar patiënten en door zelf op een positieve manier patiënten te benaderden dat ze daarmee de positieve attitude kon ondersteunen. Ze vinden zelf vooral dat ze dit door ervaring hebben geleerd. Deze verpleegkundigen omschreven ook wat ze onder een negatieve attitude verstaan: gevoel van overvallen te zijn door wat er gebeurd is, "opgeven", weinig vertrouwen in de behandeling hebben, focus op wat er niet goed gaat, teruggetrokken en boos zijn.

Beschrijving en betekenis hoop

Uit onze studies hebben we een beschrijving van hoop geformuleerd, zoals deze door de ogen van 76 palliatieve patiënten met een levensverwachting tussen de 3 en 12 maanden, gezien wordt: hoop is een verbaal fenomeen en bestaat alleen wanneer het aan zichzelf of aan anderen wordt uitgedrukt. Hoop is subjectief: het drukt een houding van de persoon uit naar toekomstige gebeurtenissen die hem / haar aangaan. Hoop is altijd gericht op een positief doel. De kans dat een object van hoop werkelijkheid wordt, kan variëren, maar dat bepaalt niet de sterkte van hoop. Hoop kan variëren in sterkte, en die sterkte wordt niet bepaald door de omstandigheid, maar door de behoefte. Een van de functies van hoop is om te ontsnappen aan het ondraaglijke. Om al deze redenen moet hoop worden onderscheiden van ontkenning, omdat patiënten in hun gedachten en acties geworteld blijven in de realiteit, wat niet geldt voor ontkenning. Hoop is geen emotie omdat het niet spontaan ontstaat, maar moet worden gecreëerd of versterkt. Hoop is een gedachteconstructie die wordt gekoesterd, gevoed en beschermd tegen bedreigingen.

Hoop heeft een basis in de realiteit nodig, hoewel wat mogelijk is, kan worden heroverwogen ten gunste van hoop (bijvoorbeeld een wonder). Hoop kan in de loop van de tijd evolueren als reactie op de ziekte of als gevolg van beïnvloedende interne of externe factoren. De hoop wordt bedreigd wanneer de kans op een negatieve uitkomst groter wordt. Patiënten voelen dat ze deze hoop tegen die dreiging moeten verdedigen: dit is het werk dat hopen veronderstelt.

Dit proefschrift heeft de functie en het belang van hopen ondanks de matige prognose, aangetoond. Mensen hopen omdat ze niet anders kunnen. Hopen is nodig om te kunnen omgaan met de situatie waarin ze zitten, omgaan met de belastende behandeling en omgaan met de lichamelijke achteruitgang. Hopen voorkomt dat mensen met kanker overmand worden door depressieve gevoelens. Door de toekomst open te houden, door te (blijven) hopen op genezing of op langer leven, lukt het ze om te kunnen genieten in het heden.

Een opvallende bevinding van deze studie is dat mensen met kanker en hulpverleners verschillende betekenissen toekennen aan hetzelfde woord: hoop. Voor mensen met kanker is hoop gerelateerd aan het belang van de uitkomst, bijvoorbeeld het zien opgroeien van de kinderen. Deze uitkomst is voor hen zo belangrijk dat dit de sterkte van de hoop bepaalt. De hoop voor mensen met kanker kan worden vergeleken met hun diepste wens. Als hulpverleners spreken over hoop dan bedoelen ze hoop die gerelateerd is aan (medische) feiten en kansen, bijvoorbeeld dat iemand 30% kans heeft dat de behandeling zal aanslaan. De hoop van hulpverleners kan eerder vergeleken worden met een verwachting. Een verwachting dat iets daadwerkelijk zal gaan gebeuren. Mogelijk is dit een van de redenen waarom de communicatie met mensen met kanker in de palliatieve fase soms minder goed loopt (De Haes & Teunissen, 2005). Hulpverleners en patiënten gebruiken hetzelfde woord: hoop, maar bedoelen er iets anders mee.

Hoop is subjectief

Hoop is subjectief, dat wil zeggen dat alleen de patiënt kan zeggen wat deze hoop voor hem of haar betekent. In de oncologie zijn we gewend om met subjectieve concepten te werken, zoals bijvoorbeeld in het geval van oncologische pijn. Bij oncologische pijn wordt de volgende definitie gehanteerd: pijn is wat mensen zeggen dat pijn is. In de oncologische praktijk wordt met deze definitie veelvuldig gewerkt en met volle tevredenheid. Hoewel pijn en hoop uiteraard niet met elkaar te vergelijken zijn, is het op zijn minst opmerkelijk te noemen dat hulpverleners er niet van uitgaan dat hoop een subjectief begrip is. Een mogelijk verklaring hiervoor zou kunnen zijn, dat hulpverleners veel meer de feitelijke situatie als referentiekader gebruiken dan de beleving van patiënten.

De respondenten laten zien dat ze op meerdere objecten tegelijkertijd kunnen hopen, waarbij er meestal een object van hoop het meest dominant is. Zoals uit onze studie blijkt heeft ieder object van hoop eigen kenmerken en een eigen betekenis. Hopen op genezing, is erdoor gekenmerkt dat patiënten dit als een sterke hoop ervaren, die veel energie geeft en aanzet tot acties. Actie om deel te nemen aan behandelingen, gezond te eten, actief te blijven, etc. Hoop op verbetering gaat bijvoorbeeld over de wens van patiënten om terug te keren naar hun ‘oude leven’, het leven van voor de ziekte, waarin ze hun dagelijkse activiteiten weer kunnen oppakken. Hoop op zolang mogelijk leven gaat over zolang mogelijk ‘in de race blijven’, doorgaan met behandelen en net zolang in leven blijven, totdat er een medicijn wordt gevonden, waardoor ze wel kunnen genezen. Hoop op goede kwaliteit van leven is erdoor gekenmerkt dat patiënten pas spreken over goede kwaliteit van leven, wanneer voor hen duidelijk is, dat verlenging van het leven niet meer mogelijk is. Voor sommige patiënten betekent dit dat ze min of meer accepteren dat het leven vroegtijdig zal eindigen, andere patiënten zetten de deur op een kier, door te hopen op een wonder en door zichzelf te overtuigen dat wonderen gebeuren. Hoop op goed sterven wordt alleen genoemd als voor patiënten duidelijk is dat de dood niet lang op zich zal laten wachten. Als aparte categorie hebben we 'mijn hoop' onderscheiden. De respondenten gebruiken 'mijn hoop' wanneer er een grote discrepantie is tussen de kans dat hetgeen waar ze op hopen daadwerkelijk zal plaatsvinden en de sterkte van deze hoop. De kans dat hetgeen waar ze op hopen zal gebeuren is heel erg klein en dat weten de respondenten ook. Dat is waarom ze het 'mijn hoop' noemen. 'Mijn hoop' verwijst naar hun diepste verlangens. Het is een heel persoonlijke hoop die nauwelijks gecommuniceerd kan worden en in stilte wordt gekoesterd. Van alle categorieën van hoop is 'mijn hoop' degene die het minst parallel loopt met de medische feiten.

De dynamiek van de hoop

Naast het gelijktijdig hopen op verschillende objecten kan de hoop ook variëren onder invloed van verschillende factoren. De respondenten laten ons zien dat er verschillende bronnen zijn waar ze hoop uit putten. De ware bron van hoop is de wil om te leven. Een sterke beïnvloedende factor zijn berichtgevingen van artsen. Als artsen positieve berichten geven, zoals bijvoorbeeld dat de tumor geslonken is, versterkt dit hun hoop. Andere bronnen van hoop zijn deelnemen aan behandelingen, verbetering van symptomen, eerdere ervaringen met ziekte en behandelingen en sociale vergelijking. Met sociale vergelijking wordt bedoeld dat patiënten zich vergelijken met anderen met de bedoeling om daaruit af te leiden, dat ze er beter voorstaan dan de anderen. Naast deze bronnen van hoop, zijn er ook algemene bronnen van hoop, zoals het geloof, de natuur, sociale steun en vertrouwen in artsen, die veel minder beïnvloedbaar zijn door externe factoren. De respondenten vertrouwen op de positieve berichten van de artsen en, als die er niet zijn, op de competenties van de artsen.

Naast deze bronnen van hoop hebben patiënten ook strategieën ontwikkeld om hun hoop te vergroten. Een veelgenoemde strategie is: vechten, waarmee wordt bedoeld deelnemen aan behandelingen en 'ervoor gaan'; therapietrouw zijn, gezond eten, actief blijven, etc. Een andere vaak besproken strategie is positief blijven, waarbij ze er vanuit gaan dat ze met het koesteren van positieve gedachten hun kansen op positieve uitkomsten kunnen vergroten. Weer een andere strategie is het creëren van onzekerheid, zelfs wanneer de uitkomsten zeker zijn, in de medische context, zoals bijvoorbeeld wanneer patiënten hebben gehoord dat ze niet meer kunnen worden genezen. Mensen kunnen dan onzekerheid creëren bijvoorbeeld door te zeggen dat de medische wetenschap zich baseert op uitkomsten van grote groepen mensen en dat dat weinig zegt over de individuele effecten. Spelen met kansen is een andere opmerkelijke strategie, waarbij patiënten op creatieve wijze omgaan met de verkregen informatie. Bijvoorbeeld wanneer een arts heeft gezegd dat iemand 30% kans heeft dat een behandeling zal aanslaan, vertellen patiënten hun familie dat ze 50% kans hebben: "De behandeling slaat aan, of niet". Dit gehele proces hebben we 'the work of hope' genoemd. Hopen geeft energie, maar kost ook energie, vooral als er minder sterke bronnen zijn. Als patiënten minder sterke bronnen hebben om hun hoop op te bouwen, dan creëren mensen de hoop zelf, desnoods tegen de feiten in. Zelf gecreëerde hoop kost veel meer inspanningen dan hoop die op sterke bronnen kan leunen. De hoop moet worden opgebouwd en behouden zien te blijven en de hoop dient verdedigd te worden tegen bedreigingen, dat is het werk dat hopen veronderstelt. De 'work of hope' zo heeft onze studie gesteld, veronderstelt dat de hoop beschermd dient te worden tegen bedreigingen van buitenaf. Je zou kunnen zeggen dat de 'work of hope' de bedoeling heeft om de (minder positieve) berichten van buitenaf, meestal van artsen te neutraliseren. Dit kost veel energie, terwijl mensen liever hun beperkte energie ergens anders voor willen inzetten.

De systematische review van kwantitatieve studies naar factoren die geassocieerd zijn met hoop laten zien dat hoop een negatieve relatie heeft met depressie, psychologische disstress en ervaren symptoomlast. Hoop is positief gerelateerd aan kwaliteit van leven, sociale steun en spiritueel en existentieel welbevinden. Als we naar deze resultaten kijken, dan valt op dat de externe factoren, zoals demografische en klinische factoren niet geassocieerd zijn met hoop. Terwijl de intrinsieke factoren, waarmee factoren bedoeld worden die door de mensen zelf worden ervaren en vastgesteld, zoals kwaliteit van leven, sociale steun, spiritueel en existentieel welbevinden, ervaren symptoomlast, psychologische disstress en depressieve symptomen, wel geassocieerd zijn met hoop. Onze studie toont aan dat hoop vooral een proces lijkt te zijn wat zich in mensen afspeelt in plaats van dat de hoop door externe factoren wordt bepaald. Hoop ontstaat voornamelijk van binnenuit en wordt ook vooral van binnenuit gevoed. Bij 'mijn hoop' is dat het meest zichtbaar.

De dynamiek van hoop lijkt een complex geheel te zijn van enerzijds een krachtenveld van beïnvloedende factoren, zoals uitslagen van scans en het verloop van het ziekteproces, die een voortdurende druk, spanning en invloed op de hoop uitoefenen. Anderzijds lijkt een deel van de hoop constant aanwezig en nauwelijks beïnvloedbaar te zijn, zoals bij 'mijn hoop'. Daarnaast zijn er ook bronnen van hoop die weinig beïnvloedbaar zijn, zoals geloof, sociale steun en natuur. Als reactie op dit krachtenveld op de hoop, zijn er de strategieën van patiënten om de hoop weer, indien nodig, op te bouwen of te beschermen en dit alles in een context van leven met een levensbedreigende ziekte en bezig zijn met belastende behandelingen.

Perspectieven van hulpverleners

Onze studie laat zien dat de moeilijkheden die hulpverleners ervaren in het omgaan met hoopvolle palliatieve patiënten gebaseerd lijken te zijn op normatieve ideeën. Deze normatieve ideeen lijken gebaseerd te zijn op een gemeenschappelijk concept: een goede dood. Voor deze hulpverleners is een goede dood gebaseerd op goed afscheid kunnen nemen van hun dierbaren, zodat zij verder met hun leven kunnen. Goed afscheid kunnen nemen betekent dat de waarheid aanvaard dient te worden en dat men daarin berust. Hulpverleners zien het als hun professionele rol om patiënten te begeleiden naar de aanvaarding, berusting van het naderende einde. Hierdoor is de zorg niet altijd afgestemd op de wensen en behoeften van de patiënten. De studie van Cannaerts et al. (2000) bevestigt ook al dat zorgverleners het gevoel hebben geslaagd te zijn in hun doelstelling als de patiënt en zijn familie op een serene manier kunnen omgaan met de waarheid.

Volgens een review van Olsman et al. (2014) kunnen de perspectieven van hulpverleners ten aanzien van hoop grofweg in drie perspectieven worden onderverdeeld, ten eerste: het realistische perspectief, waarbij hoop gezien wordt als een verwachting die waarheidsgetrouw zou moeten zijn, de zorgverlener probeert de hoop dan aan te passen aan de waarheid. Ten tweede: het functionele perspectief waarbij hoop als een copingmechanisme wordt gezien en de zorgverlener de hoop probeert te ondersteunen. Als derde en laatste: het narratieve perspectief waarbij hoop als een vorm van zingeving wordt gezien en de zorgverlener probeert dan de hoop te interpreteren in het licht van het levensverhaal van de patiënt. Dit zijn de verschillen die genoemd worden in de review, in onze studie naar het hulpverleners perspectief hebben vooral het realistische perspectief gezien en een geestelijk verzorger benoemde ook het functionele en narratieve perspectief. In onze studie was het lastig om onderscheid in de perspectieven te maken, mede door de sociale interactie van de focusgroep.

In onze studie hebben we ook gezien dat de meeste van de participerende hulpverleners vinden dat hoop op genezing zou moeten evolueren naar hoop op een goede dood. Oosterveld-Vlug et al. (2017) hebben bij Nederlandse hulpverleners online focusgroepinterviews gehouden over patiënten met een Moslim achtergrond. In deze studie, waar hulpverleners, o.a. acht artsen aan deelgenomen hebben, wordt gesteld dat hulpverleners de transitie van hoop op genezing naar hoop op goed sterven moeten ondersteunen. Hierbij moet opgemerkt worden dat de vraag in het (online) focusgroepinterview niet zonder suggestiviteit gesteld was. Uit onze studies met mensen met kanker in de palliatieve fase blijkt dat de meeste mensen de eindigheid van hun leven niet goed kunnen aanvaarden als er dwingende redenen zijn om te blijven leven.

(Valse) hoop en informatievoorziening

Uit onze studies en uit praktijkobservaties blijkt dat hulpverleners vaak noemen dat ze patiënten geen valse hoop willen geven. Als hulpverleners het over valse hoop hebben, dan bedoelen ze daarmee dat ze geen hoop op mogen wekken die tegen de feiten ingaat. Geen valse hoop willen geven wordt vaak genoemd als reden om (opnieuw) de prognose-informatie te bespreken. Valse hoop dient echter onderscheiden te worden van de hoop die patiënten ondanks de kennis van de feiten koestert. Onze studie naar het perspectief van hulpverleners laat zien dat sterke hoop, sterker dan op basis van de medische feiten verwacht wordt, bij patiënten soms verward wordt met valse hoop. Een mogelijke verklaring hiervoor is dat hulpverleners zich soms eenzijdig focussen op het belang van een goede dood, waarin de mens tot zijn recht komt omdat hij zijn sterfelijkheid heeft geïntegreerd of op de zorg voor de naasten die achter zullen blijven, die verder moeten met hun leven en bij een goed afscheid gebaat zijn.

Een belangrijke bevinding van onze studie is dat patiënten meermalen aangegeven hebben eerlijke informatie te wensen, waarmee ze de feitelijke medische informatie bedoelen. Mensen hebben deze informatie nodig om hun hoop op te kunnen baseren. In de literatuur wordt ook bevestigd dat mensen eerlijke informatie wensen (Blakely et al. 2017; Hagerty et al. 2005; Kaplowitz et al. 2002; Smith et al. 2010).

Onze studies laten zien dat hulpverleners graag en vaak feitelijke medische informatie geven, juist ook om (de suggestie van) valse hoop tegen te gaan. Een mogelijke verklaring waarom Nederlandse artsen het als hun plicht zien om veelvuldig en uitvoerig prognoseinformatie te bespreken, wordt gegeven in de studie van The et al. (2000). De studie van The et al. (2000) had als titel: Het onterechte optimisme op herstel bij patiënten met kleincellig bronchuscarcinoom. In deze studie waarbij The gesprekken tussen longartsen en patiënten observeerde, concludeerde zij dat onterecht optimisme bij patiënten veroorzaakt werd door onduidelijke communicatie van artsen over de prognose. Volgens The et al. (2000) zorgde de vage communicatie ervoor dat patiënten geen adequate besluiten over hun behandeling konden nemen. Nabestaanden betreurden achteraf, hoe de laatste maanden waren verlopen. Hierbij dient echter opgemerkt te worden dat nabestaanden binnen 3 maanden na het overlijden van hun dierbaren zijn geïnterviewd. Onze studies en die van Koedoot et al. (2003) laten zien dat hulpverleners veel minder invloed, dan gedacht, hebben op het besluitvormingsproces van patiënten. Koedoot et al. (2003) zien in hun onderzoek naar kiezen voor palliatieve chemotherapie, dat patiënten vooraf aan het eerste consult al het besluit hebben genomen om wel of niet deel te nemen aan palliatieve chemotherapie en dat de manier waarop de artsen het gesprek voerden – zoals vooraf werd gedacht – geen/ nauwelijks invloed op had. Nierop- van Baalen & Grypdonck (2008) laten vergelijkbare resultaten zien in hun studie naar de betekenis van hoop bij mensen die deelnemen aan fase-1-onderzoek. Ook zij concludeerden dat patiënten hun keuze al hebben gemaakt, zodra artsen hun patiënten ‘aanbieden’ om deel te nemen aan experimentele chemotherapie. Deze studies laten hulpverleners op een andere manier naar besluitvormingsprocessen kijken.

Hoop en communicatie

Hoop is een verbaal fenomeen, zo hebben we gesteld. Hoop bestaat alleen wanneer deze wordt uitgedrukt, ofwel aan zichzelf ofwel aan anderen. Voor hulpverleners is dit een lastig aspect, hoop kan namelijk niet geobserveerd worden. Hulpverleners ‘zien’ hoop pas als mensen erover spreken of als hulpverleners ernaar vragen. Uit onze studies en uit observaties van de praktijk zien we dat mensen met kanker niet vaak hun hoop uiten naar hulpverleners en hulpverleners vragen meestal niet naar de hoop van patiënten. Het is dus niet verwonderlijk dat hulpverleners de communicatie en het omgaan met hoopvolle palliatieve patiënten lastig vinden. In de huidige gezondheidszorg en vooral in West-Europese landen (Van Laarhoven et al. 2011) zijn hulpverleners niet gewend om over hoop te spreken. Dit heeft een aantal redenen, hoop heeft momenteel zoals ook in het verleden maar een zeer beperkte plaats in de opleiding voor artsen en verpleegkundigen (Campbell et al. 2010).

Uit een review van Campbell et al. (2010) blijkt dat het oncologen die getraind zijn in het bespreken van de prognose-informatie, lukt om vertrouwen te bieden, de onderlinge relatie goed te houden en de patiënt hoopvol te laten zijn. Een manier om dit te doen is om tijd en mentale ruimte te bieden om de informatie te verwerken. Dan, zo stellen Campbell et al. (2010) kan de patiënt nieuwe hoop vinden door te spreken over wat voor hem of haar belangrijk is. In een studie van Thorne et al. (2007) geven mensen met kanker aan een duidelijke mening te hebben over prognostische communicatie die ze nodig hebben om zo goed als ze kunnen te leven met de ernstige gezondheidsuitdagingen waarmee ze worden geconfronteerd. Vanuit hun perspectief kan er veel worden gedaan in de context van deze communicatie om het subtiele evenwicht tussen hoop en eerlijkheid te waarborgen en het vermogen van de patiënt te vergroten om de hoop te behouden die voor het leven noodzakelijk is. (Thorne et al. 2007).

Methodologische overwegingen

Elke afzonderlijke studie heeft methodologische sterktes en beperkingen die in de vorige hoofdstukken beschreven en bediscussieerd zijn. In deze paragraaf worden meer algemene methodologische overwegingen besproken die betrekking op de studies hebben.

Secundaire data-analyse

Beide studies over de betekenis van hoop en positief denken zijn gedaan volgens de methode van secundaire analyses. Deze methode heeft voor- en nadelen. Een voordeel van deze methode is dat hoop en positief denken bestudeerd konden worden in een grotere hoeveelheid uitgewerkte interviews waarin het thema veelvuldig aan bod kwam. In de studie naar de betekenis van hoop waren er twee soorten data. Een soort data, betrof interviewdata waarin hoop het thema van het onderzoek was en het tweede soort data waren interviews waarin hoop geen onderdeel van de onderzoeksvragen van de oorspronkelijke studie was, wat wil zeggen dat hoop alleen op initiatief van de respondenten is bediscussieerd. In het onderzoek naar de betekenis van positief denken, was positief denken bij geen enkele van de oorspronkelijke studies het thema van onderzoek. Dit heeft het voordeel dat hetgeen de respondenten zeiden zo min mogelijk beïnvloed is door de interviewers. Een nadeel van secundaire data-analyse is dat de studies gedaan zijn in verschillende contexten en door verschillende interviewers, waardoor nooit de exacte context gekend kan worden. In onze studies was een van de onderzoekers ook betrokken als onderzoeker bij alle oorspronkelijke studies. Hierdoor kende ze de context waarin deze studies plaatsvonden goed en kon ze deze kennis inzetten bij de data-analyses, waardoor dit nadeel van de secundaire analyses kon worden verkleind.

Van den Berg (2011) verbaast zich dat er in kwalitatief onderzoek zo weinig gebruikt wordt gemaakt van hergebruik van kwalitatieve data ten behoeve van onder andere secundaire analyses. Hij stelt dat het gebruikelijk is dat de kwalitatieve onderzoeker zijn of haar data zelf verzamelt en analyseert ten behoeve van een specifiek onderzoeksdoel. Van den Berg (2008) vindt het pure onderbenutting dat kwalitatieve data nauwelijks hergebruikt worden of worden ingezet bij secundaire analyses en pleit voor hergebruik van deze data. Van den Berg (2011) noemt deze onderbenutting grootscheepse kapitaalvernietiging, zeker als men zich realiseert dat veldwerkkosten bij kwalitatief onderzoek in het algemeen aanzienlijk zijn. Kwalitatieve data kenmerken zich door een grote rijkdom aan informatie die dit onderzoek oplevert. Deze rijkdom van data leent zich daarom vrijwel altijd voor meerdere onderzoeksdoelen. Deze informatierijkdom wordt vrijwel nooit uitgeput door het primaire onderzoeksdoel waarvoor de data werden verzameld. Naast het kostenargument en het benutten van de informatierijkdom willen wij hieraan een derde en vierde argument toevoegen. Wij zijn van mening dat het ook vanuit ethisch perspectief gewenst en noodzakelijk is om data te hergebruiken. In zorgonderzoek worden veel interviews met patiënten uitgevoerd of zoals hier het geval is, met patiënten in de palliatieve fase. Voor alle patiënten kost het tijd en energie om deelnemen aan de interviews. Voor mensen die in de palliatieve fase zijn, kost dit extra energie, moeite en tijd. En juist tijd en energie is hetgeen wat ze al zo weinig hebben. We vinden het heel respectvol naar patiënten toe, om de interviewdata, waar ze zoveel moeite voor hebben gedaan, optimaal te benutten voor meer dan een onderzoeksvraag. Tenslotte laat secundaire data-analyse ook toe om een hoeveelheid data te verzamelen en te analyseren, die anders niet tot de mogelijkheden zou behoren.

Verloop van hoop gedurende de tijd

Alle hulpverleners en de meeste patiënten zijn slechts eenmalig geïnterviewd. Dit betekent dat we geen longitudinaal beeld hebben hoe hoop verloopt gedurende de tijd. Ook in de literatuur is nog heel weinig bekend van de dynamiek van hoop. Enkele kwantitatieve studies hebben hoop gemeten met meerdere meetmomenten gedurende de tijd (Green et al. 2015; Van der Biessen et al. 2018; Wakiuchi et al. 2015). Deze studies hebben vooral gekeken of hoop gelijk bleef, verminderde of toenam gedurende de tijd en na een interventie, zoals bijv. deelname aan fase-1-studie of na gesprekken over advanced care planning. Vaak betreffen dit kleine studies met een specifieke onderzoeksvraag. Deze specifieke studies waren ook onderdeel van onze systematische review naar factoren die geassocieerd met hoop zijn. Uit de review blijkt dat hoop, gedurende de tijd, als onderdeel van klinische factoren niet geassocieerd met hoop was. Slechts 1 kwalitatieve studie naar de dynamiek van hoop is ons bekend. Deze studie (Olsman et al. 2015) heeft met behulp van thematische analyses bij patiënten met kanker, COPD of hartfalen in de palliatief-terminale fase geprobeerd inzicht te krijgen in de dynamiek van hoop, wanhoop en hopeloosheid. Deze studie laat zien dat de dynamiek van hoop niet zozeer parallel loopt met het verloop in de tijd, maar dat patiënten de dynamiek van hoop relateren aan veranderingen in hun fysieke conditie. Meer onderzoek is nodig om inzichten te verdiepen, verbreden en om nieuwe inzichten te verkrijgen omtrent de dynamiek van hoop.

Patiëntenperspectief als uitgangspunt

In beide studies naar de betekenis van hoop en de betekenis van positief denken zijn we vooraf aan de data-analyse niet vertrokken vanuit een vaste definitie, omdat we het gebruik van hoop en positief denken wilden onderzoeken vanuit het perspectief van de patiënt zelf. Tijdens de data-analyse hebben we daarom gezocht naar het gebruik van het woord hoop en positief denken of positief zijn in de data. Het voordeel van deze methode is dat we de begrippen niet vooraf vastgelegd hebben, om zo met een open blik in de data te zoeken naar het gebruik en betekenis van de begrippen hoop en positief denken om daarmee aan te sluiten bij het perspectief van de patiënt. Deze methode heeft uiteraard ook nadelen, patiënten gebruiken de woorden niet altijd consistent in hun dagelijks taalgebruik, soms kunnen hierdoor data gemist worden, omdat patiënten soms ook andere woorden gebruiken bij dezelfde betekenissen. Daarnaast kunnen de data kan besmet zijn via protoprofessionalisering, wat wil zeggen dat patiënten geleerd hebben om hun ervaringen en problemen te verwoorden in professionele hulpverlenersterminologie. Ook in deze situatie, kon door de grote hoeveelheid data deze nadelen worden verkleind.

Implicaties en aanbevelingen voor de praktijk en opleiding

Wat met de bevindingen van deze studie gedaan wordt, hangt af van de externe validiteit of generaliseerbaarheid. In kwalitatief onderzoek wordt de externe validiteit niet gewaarborgd door de representativiteit van de steekproef. Guba & Lincoln (1989) stellen dat generaliseerbaarheid bepaald wordt door de mate van overeenkomst tussen de verschillende contexten. De context van het onderzoek en de context van de praktijk waarin toepassing beoogd wordt. Volgens Guba & Lincoln (1989) dient de onderzoeker vast te stellen of de uitkomsten generaliseerbaar zijn en dient de praktijkbeoefenaar vast te stellen of de context van de praktijk zich leent voor de overdraagbaarheid van de onderzoeksgegevens. In onze studie zijn wij van mening dat de resultaten van de betekenis van hoop bij mensen met kanker grotendeels generaliseerbaar zijn naar andere contexten zoals naar sommige andere ziekten. Dezelfde processen zullen ook teruggevonden kunnen worden bij andere mensen met kanker in vergelijkbare omstandigheden en bij andere aandoeningen met vergelijkbare consequenties voor de spanning tussen levensverwachting en levenswens (wat hoop betreft) of met eenzelfde spanning tussen de behoefte aan zekerheid en feitelijke onzekerheid (voor het positief denken). Die veronderstelling is gesteund op de reconstructie van die processen die we in ons onderzoek gemaakt hebben. Wat het onderzoek naar de perspectieven van hulpverleners betreft, hebben we gesteld dat naar onze mening de resultaten generaliseerbaar zijn voor tenminste de Nederlandse hulpverleners.

Mensen met kanker staan voor enorme uitdagingen, ze moeten dealen met het feit dat ze kanker hebben, ervaren over het algemeen meerdere symptomen tegelijkertijd ten gevolge van de ziekte en/of de behandelingen en moeten leven met een toekomst die onzeker is. Voor mensen met een ziekte in de palliatieve fase is dit nog moeilijker omdat zij samen met hun naasten moeten leven met een toekomst die beperkt is. Onze studie laat zien dat hopen op betere uitkomsten en positief denken mensen met kanker helpen in het omgaan met de ziekte, het omgaan met de lichamelijke achteruitgang en om ondanks de dreiging van het levenseinde te kunnen leven met een toekomst voor ogen.

Het uitgangspunt voor de zorg van mensen met kanker zou moeten zijn om mensen te ondersteunen en helpen om te gaan met de uitdagingen waar ze voor staan. Onze studie laat zien dat de zorg die mensen met kanker ontvangen, ondanks alle goede bedoelingen, niet altijd afgestemd is op de behoeften van mensen met kanker. Ook laat onze studie zien dat hulpverleners, het niet altijd gemakkelijk of vanzelfsprekend vinden om die zorg te bieden die als ondersteunend wordt ervaren. Een manier om zorg te bieden die afgestemd is op de wensen en behoeften van mensen met kanker, vereist in de eerste plaats dat hulpverleners weten wat deze wensen en behoeften zijn. Eenvoudige vragen als: “Wat is voor u belangrijk?” of “wat is, op dit moment, voor u belangrijk?” kunnen hierbij ondersteunend zijn.

Patiënten voelen zich ondersteund als ze mogen hopen of positief denken. Dat de hoop er mag zijn, ook als hetgeen waarop ze hopen, in de ogen van hulpverleners onrealistisch kan zijn. We hebben laten zien dat dit proces van hopen niet gelabeld kan worden als ontkenning, patiënten zijn zich er wel degelijk van bewust van het kwetsbare karakter van hun hoop. Patiënten waarderen eerlijkheid over de medische feiten zoals besproken door hulpverleners en hebben deze eerlijke informatie ook nodig. Patiënten willen immers geen valse hoop, patiënten willen weten hoe ze ervoor staan, alleen wel gecommuniceerd op een manier dat mensen hoop kunnen behouden (Butow et al. 2020). Hulpverleners kunnen hoop als hoop bevestigen door te zeggen: “Dat hoop ik ook, voor u”.

Zoals eerder genoemd geven hulpverleners regelmatig berichten die de hoop of het positief denken beïnvloeden en vaak op een negatieve wijze. Hulpverleners zijn zich er niet van bewust dat een opmerking een nadelig effect kan hebben op de patiënt en vaak zijn deze opmerkingen – interventies- juist met goede bedoelingen gegeven, om patiënten en naasten ruimte te geven om zich voor te kunnen bereiden op het naderende afscheid. Een methodiek die hulpverleners kan ondersteunen in het reflecteren op hun ervaringen is de methodiek van lerende gemeenschappen (Wenger 1998, Wenger et al. 2002). Lerende gemeenschappen wil zeggen dat professionals met een gemeenschappelijke interesse leren van elkaar door ervaringen uit te wisselen in een sfeer van onderling vertrouwen en steun.

Om hulpverleners te ondersteunen in het (laten) vertellen van de waarheid is het allereerst belangrijk om te benadrukken en zich te realiseren dat de meeste mensen met kanker zelf ook de waarheid willen weten. Het is daarbij echter niet nodig om deze boodschap vaak te herhalen. Een belangrijke vaststelling is, dat hetgeen er gezegd wordt, in de relatie tussen hulpverlener en patiënt moet passen. Als de boodschap in de relatie past, dan is deze ook beter te incasseren. Het probleem zit niet alleen in de waarheidsmededeling, het gaat er ook om wat ermee gedaan wordt. Welke betekenissen mensen hier aan toekennen en hoe men, hulpverleners, naasten hier mee om gaan. Een helpende benadering zou kunnen zijn dat hulpverleners goed luisteren met oprechte interesse naar mensen met kanker, door hetgeen wat ze zeggen proberen te begrijpen en hun boodschappen daar op af te stemmen, met eerbied voor de ambivalenties. Een persoonsgerichte benadering kan hierbij ondersteunend zijn. Mc Cormack & Dewing (2019) beschrijven person- centred practice als een benadering waarbij de relatie tussen hulpverlener en patiënt en naaste belangrijk is en de zorg is afgestemd op de persoonlijke waarden van de patiënt, autonomie en wederzijds respect en begrip.

Om ervaring op te doen in het communiceren over hoop, kunnen artsen, verpleegkundig specialisten en verpleegkundigen aan patiënten met kanker vragen: “waar hoopt u op?” En dan bijvoorbeeld, als vervolgvraag “wat betekent deze hoop voor u?” Of “vertel eens”? Dit zijn vragen die aan elke patiënt met kanker gesteld kunnen worden. Hulpverleners kunnen dan ook ervaren dat de meeste mensen het heel fijn vinden om over deze onderwerpen te spreken, het geeft patiënten ook het gevoel gehoord te worden. Een ander idee zou kunnen zijn om een richtlijn over communiceren met patiënten over hoop te ontwerpen naar het voorbeeld van de Australische richtlijn over het voeren van een slecht nieuws gesprek (Clayton et al. 2007). Deze richtlijn beschrijft naast inhoudelijk thema’s ook voorbeeldzinnen, die kunnen helpen om dit gesprek te kunnen voeren. Voor hulpverleners zou zo’n richtlijn erg behulpzaam kunnen zijn, omdat voorbeeldzinnen helpen een eerste stap, vaak de moeilijkste, te zetten. En dan los te laten. Immers, als uit de conversaties blijken dat patiënten positief reageren en daarna verloopt het gesprek gemakkelijker.

Een zorgethische benadering kan zorgverleners helpen om de goede toon te treffen. De zorgethiek, een stroming in de bredere ethiek van de zorg (Baart, 2007; Grypdonck & Vanlaere, 2018; Tronto, 1993; Van Heijst 2011) houdt zich bezig met de ethiek van de dagelijkse zorg. De zorgethiek gaat ervan uit dat voor goede zorg, zorg die deugd doet en oog heeft voor de mens achter de ziekte, de relatie essentieel is. Zorgethiek kijkt naar zorg met een bijzondere aandacht voor: het unieke en specifieke van situaties, het feit dat zorgbetrekkingen altijd afhankelijkheid en asymmetrie met zich meebrengen, het gegeven dat mensen kwetsbaar zijn op grond van hun lichamelijkheid en het belang om in relatie te gaan staan met iemand die zorgafhankelijk is om te ontdekken wat goed is voor hem of haar (Grypdonck & Vanlaere, 2018; “Zorgethiek... Wat is dat nu eigenlijk?”, 2019). Wanneer er in de zorgethiek wordt gesproken over goede zorg, wordt er gesproken over aansluiten en afstemmen bij de ervaring en behoefte van de unieke patiënt vanuit zijn/haar specifieke context (Van Heijst, 2011). De communicatie over hoop stemt de hulpverlener dan af op de behoefte van de patiënt en op wat deze communicatie met hem of haar teweegbrengt. De hulpverlener werkt niet vanuit een principiële instelling in verband met "onterechte hoop". Vanuit een zorgethisch kader gelden de volgende aanbevelingen voor de praktijk: Stel niet alleen het maken van besluiten centraal in de zorg voor de patiënt. Heb oog en aandacht voor de opgaven en strubbelingen waar de patiënt en zijn naasten binnen het ziek zijn tegenaan lopen. Chaos, vervreemding en hoop hoeven niet bestreden te worden, dit is de realiteit die er is. Binnen de realiteit van de patiënt kan er worden meegedacht met de patiënt. Oog hebben voor deze realiteit kan bijdragen aan de ervaring van het gezien en gesteund worden ("Zorgethiek... Wat is dat nu eigenlijk?", 2019). Als de zorg voor patiënten en naasten afgestemd is op hun behoeften, dan voelen mensen zich gehoord, begrepen en erkend in het lijden en strijden (Baart & Grypdonck, 2008; Cannaerts et al. 2000).

Wat het onderwijs betreft, geldt dat hoop en positief denken bij mensen met kanker, of bij mensen met een (mogelijk of waarschijnlijke) nefaste prognose in het algemeen, een thema moet zijn dat voldoende aandacht krijgt in de opleiding. Dat geldt voor de basisopleiding, maar a fortiori voor nascholingen aan zorgverleners en vrijwilligers werkzaam in de oncologische en palliatieve zorg. Eerlijke informatie geven, of eerlijk op uitspraken van patiënten reageren, en hoop niet wegnemen waar patiënten die koesteren, is niet vanzelfsprekend. Er is meer voor nodig dan vuistregels of communicatietechnieken. Onze ervaring met scholing in deze materie heeft ons geleerd dat positieve leereffecten bereikt kunnen worden door o.a. gebruik te maken van lesvormen waarin bestaande casuïstiek besproken kan worden en waarin de zorgverleners of vrijwilligers met elkaar in kleine groepjes kunnen discussiëren over deze casussen. In ziekenhuizen of andere zorginstellingen kan het ook helpen om deze thematiek te bespreken tijdens de patiëntenbespreking/ het multidisciplinair overleg of moreel beraad.

Meer in het algemeen is aandacht nodig voor het perspectief van patiënten (en familieleden) en hoe dat van het perspectief van zorgverleners kan verschillen. Hulpverleners moeten leren met de discrepantie tussen beide op een adequate manier om te gaan. Wat adequaat is, moet telkens in de concrete situatie bekeken worden. Daarom kan niet volstaan worden met generaliserende richtlijnen of eenvoudig toe te passen hulpmiddelen. Zorgethisch denken is een competentie die hiervoor, maar ook voor vele andere situaties nodig is. In het zorgethisch denken staat immers de leefwereld van de ander centraal en is afstemming daarop de regel. De methodiek van lerende gemeenschappen (Wenger, 1998; Wenger et al. 2002; Fingrut & Beck, 2018) kan in ziekenhuizen of in de thuiszorg ook ondersteunend hierbij zijn om op structurele wijze ervaringen tussen zorgverleners te delen en daarvan te leren.

Aanbevelingen voor verder onderzoek

In onze studies hebben we een aanzet gedaan om de relatie tussen de concepten hoop en positief te beschrijven, meer onderzoek naar de overeenkomsten en verschillen tussen beide concepten kan bijdragen aan een verdere conceptuele helderheid.

Uit de huidige studies weten we dat sociale steun erg belangrijk is voor mensen met kanker. Veel minder inzicht is er over ervaringen, impact en betekenis van naaste(n) van hoopvolle palliatieve patiënten en van patiënten die positief denken en curatief zijn of worden behandeld. Vanuit observaties vanuit de praktijk weten we dat hoop ook consequenties voor achtergebleven familieleden kan hebben. Na het overlijden van hun dierbare kunnen familieleden achterblijven met zorgen en twijfels, in sommige gevallen is het afscheid en het leven na het afscheid minder bespreekbaar geworden en daar moeten achterblijvers mee verder. Een vervolgonderzoeksvraag zou kunnen zijn: hoe kunnen familieleden ondersteund worden om tijdens en na de ziekte en de palliatieve fase met de behoefte aan hoop om te kunnen gaan? Een kwalitatief onderzoek naar deze ervaringen zou een waardevolle volgende stap zijn in het verkrijgen van inzicht in de beleving van naasten van mensen met kanker. In oncologische zorg en zeker in de palliatieve zorg - zoals ook omschreven in de huidige definitie van palliatieve zorg (Kwaliteitskader palliatieve zorg Nederland, IKNL/Palliactief, 2017) - kan de zorg van de mens met kanker niet los gezien worden van de naasten. Patiënt en naasten worden ook wel ‘de unit of care’ genoemd. Hulpverleners kunnen veel leren van de wensen en behoefte van naasten van mensen met kanker, zodat de zorg ook op hun behoeften meer kan worden afgestemd. Echter in de praktijk kan de ‘unit of care’ extra lastig zijn, wanneer er tegengestelde belangen zijn tussen patiënt en naaste(n). Hoe hulpverleners zowel patiënt als naaste(n) hierin kunnen ondersteunen kan ook een waardevol thema voor vervolgonderzoek zijn.

Mensen met kanker hebben hoop nodig om hun leven te kunnen leven. Een van de bronnen van hoop voor mensen met kanker in de palliatieve fase is deelnemen aan behandelingen, al dan niet experimenteel van aard. Hoe hulpverleners deze hoop kunnen ondersteunen, zonder mensen te verleiden om nutteloze behandelingen te ondergaan is een uitdaging voor hulpverleners. Hoe deze ondersteuning eruit kan zien kan een onderwerp voor toekomstig onderzoek zijn.

Een andere groep mensen waar nog heel weinig aandacht naar uitgaan zijn mensen ondanks uitgebreide gemetastaseerde ziekte, nog 10-15 jaar kunnen leven met deze ziekte, dankzij nieuwe behandelingen. Volgens de huidige definitie vallen zij onder de palliatieve zorg, ze kunnen immers niet genezen. Echter voor deze groep mensen met chronische kanker, zou een andere term meer passend kunnen zijn, aangezien palliatieve zorg nog steeds als einde van het leven gezien wordt. Enerzijds kenmerkt deze groep mensen zich doordat ze langdurig kunnen leven met uitgebreide ziekte en vaak met een goede kwaliteit van leven. Mensen leven soms (veel) langer dan de prognose die ze bij aanvang van de ziekte te horen hebben gekregen, dit vergt van de mensen zelf voortdurende aanpassingen op fysiek, emotioneel en psychosociaal gebied en dat geldt ook voor hun naasten. Werkgevers en overheidsinstanties weten hiermee niet altijd raad, waardoor mensen, op basis van hun eerste prognose, volledig worden afgekeurd voor hun werk, wat maakt dat ze zich ‘gedumpt’ en ‘waardeloos’ kunnen voelen. Anderzijds, weet men vooraf niet of ze bij de groep mensen zullen horen die met de nieuwe behandeling langdurig kunnen leven. En is elke controle, elke onderzoek opnieuw heel erg spannend, omdat de uitslagen ervan een directe invloed hebben op hun toekomstperspectief. Meer onderzoek naar deze specifieke groep mensen met kanker zal meer inzicht geven en ondersteunend zijn voor hulpverleners die met deze mensen werken.

Veel studies die gedaan zijn met mensen met kanker maken bij de analyses geen onderscheid in het behandeldoel: curatief of palliatief. Uit de verschillende studies weten we dat mensen met kanker verschillende behoeften en wensen kunnen hebben in de verschillende stadia van de ziekte (vlak na de diagnose, tijdens behandeling, na afronding van de behandeling, in de symptoomgerichte palliatieve fase en aan het einde van het leven). Wij pleiten ervoor om in de data-analyse een onderscheid te maken in de verschillende ziekte- en behandelstadia en apart voor de curatieve groep en de palliatieve groep. Het zal de informatie die beschikbaar komt preciezer maken en ertoe leiden dat er per specifieke situatie meer afstemde zorg gegeven kan worden.

De relatie tussen angst en hoop is, in de systematische review nog onduidelijk gebleven. Kwalitatief onderzoek naar angst en hoop kan meer inzicht geven in deze fenomenen en hoe ze met elkaar samen hangen.

Zoals eerder vermeld kan toekomstig onderzoek zich ook richten op het proces van hoop, de dynamiek en het verloop van hoop gedurende het ziekteproces. Meer onderzoek naar het perspectief van hulpverleners ten aanzien van hoop en positief denken kunnen bijdragen aan meer wederzijds begrip en respect en communicatie over de betekenis van hoop en positief denken bekeken vanuit de verschillende perspectieven. In toekomstig onderzoek kan de focus worden gelegd op de betekenis van hoop en positief denken bij mensen met een migratie achtergrond. De huidige studies naar de betekenis van hoop en positief denken kunnen daarvoor als vertrekpunt dienen.

Conclusie

Onze studies hebben laten zien dat patiënten de hoop op een lang(er) leven meestal niet opgeven, in tegenstelling tot wat sommige hulpverleners verwachten en patiënten buigen hun hoop meestal niet om naar meer realistische doelen, zoals sommige hulpverleners vinden dat zou moeten. Hoop is erg belangrijk voor mensen met kanker, vooral in de palliatieve fase van hun ziekte. Zonder hoop heeft het leven geen kwaliteit en voelt het als ondraaglijk. Hopen geeft veerkracht, mensen voelen zich geknakt, maar niet gebroken. De hoop moet worden gekoesterd en beschermd tegen bedreigingen, dat is het werk wat hopen veronderstelt. Voor mensen in de curatieve fase is positief denken erg belangrijk. Positief denken zorgt ervoor dat mensen van het leven kunnen genieten. Zonder positief te denken lukt het niet om het leven boven de ziekte uit te tillen, ook al zijn de diagnose kanker en de behandelingen al enkele jaren geleden. Mensen in de curatieve fase bezweren hun angsten met positief denken, mensen in de palliatieve fase doen dit met hoop. Hulpverleners kunnen naar hoop en positief denken kijken als een positieve waarde, die niet tegengesproken hoeft te worden.

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Achtergrond

Hoop en positief denken zijn erg belangrijk voor mensen met kanker in de verschillende stadia van ziekte en behandeling. In het dagelijks taalgebruik gebruiken mensen met kanker vaak de termen hoop en positief denken.

Steeds meer mensen krijgen de diagnose kanker en steeds meer mensen leven met kanker, onder andere door eerdere ontdekking van de ziekte en betere behandelmogelijkheden. Een behandeling kan curatief van opzet zijn of palliatief. Curatieve behandelingen zijn behandelingen die gericht zijn op het genezen van ziekte. Bij palliatieve behandeling is genezing niet meer mogelijk en is het doel om zo lang mogelijk het leven te verlengen en/of gericht op het comfort van de patiënt en dus op het verbeteren van de kwaliteit van het leven. Gekozen is om de medische indeling te hanteren, omdat het ook om een medische diagnose gaat en omdat de internationale literatuur deze indeling hanteert. Curatieve of palliatieve behandeling of fase zijn termen die vooral door hulpverleners worden gebruikt. Patiënten zelf spreken over dat een behandeling genezing tot doel heeft of dat ze niet meer kunnen genezen

De diagnose kanker heeft grote impact op iemands leven en van degenen om hem heen. Het besef van de eindigheid van het leven en de onzekerheid die daarvan het gevolg is brengt een existentiële crisis teweeg. Op deze existentiële crisis reageren veel mensen met kanker met het koesteren van hoop. Hoop dat ze aan een goed behandelbare variant zullen lijden; dat de kanker niet is uitgezaaid; dat ze geen chemotherapie hoeven te krijgen. En vooral hoop op volledige genezing.

De hoop van mensen met kanker is vaak prominent aanwezig en loopt vaak niet parallel met de medische feiten en prognose. Veel hulpverleners vinden het lastig om te gaan met deze hoop, zeker als de hoop (veel) sterker is dan op grond van medische feiten verwacht kan worden. Hulpverleners kunnen denken dat mensen onvoldoende zijn geïnformeerd over hun prognose, of dat ze de situatie ontkennen. Om deze reden en omdat mensen met kanker de termen hoop en positief denken zo vaak gebruiken verdienen de begrippen hoop en positief denken een grondige exploratie.

Het oorspronkelijke plan van dit proefschrift was om studies te verrichten naar hoop bij mensen met kanker in de verschillende fasen van het ziekteproces. Tijdens de data-analyse van mensen met kanker die met opzet curatief worden behandeld bleek dat wat mensen in de dagelijkse taal gemakkelijk hoop zouden kunnen noemen, door hen de term positief denken gebruikt werd. Om deze reden focust dit proefschrift zich op hoop én positief denken bij mensen met kanker in de verschillende fasen van het ziekteproces.

Doelstelling

Deze doctoraatsstudie heeft als doel een beter inzicht te geven in de betekenis van hoop en positief denken van mensen met kanker in de palliatieve of curatieve fase van hun ziekte. Tevens wil dit onderzoek inzicht geven in perspectieven van hulpverleners bij het omgaan met palliatieve patiënten die hopen op een zo lang mogelijk leven. Deze studie wil daarbij ook inzicht krijgen in de factoren geassocieerd met hoop bij mensen met kanker die bezig zijn met behandelingen.

Methodologie

Dit onderzoek betreffen twee secundaire analyses met een constructivistische grounded theory benadering. In de ene studie is gebruik gemaakt van eerder verworven interviews van mensen met kanker in de palliatieve fase van hun ziekte (n=76). De andere studie heeft gebruikt gemaakt van eerder verworven data van mensen met kanker die met curatieve opzet zijn of worden behandeld (N=74). In beide studies waren de data afkomstig van Nederlandse en Vlaamse studies. Alle interviews zijn geanalyseerd volgens de constante comparatieve methode.

De studie naar de perspectieven van hulpverleners is vormgegeven met 3 focusgroep interviews met Nederlandse hulpverleners. Deze focusgroepen bestonden uit een multidisciplinaire groep met o.a. artsen, verpleegkundig specialisten, (wijk)verpleegkundigen, psycholoog en geestelijk verzorgers, een groep verpleegkundigen, werkzaam in het ziekenhuis en een groep met wijkverpleegkundigen. Alle hulpverleners werken dagelijks met mensen met kanker in de palliatieve fase van de behandeling.

Een systematische review is vormgegeven met kwantitatieve empirische studies over hoop bij mensen met kanker die bezig zijn met behandelingen. Drieëndertig studies zijn geïncludeerd om factoren te vinden die geassocieerd zijn met hoop.

Resultaten

Eerst is onderzocht wat de betekenis van hoop is zoals mensen met kanker in de palliatieve fase van hun ziekte zelf zeggen over hoop. Het valt op dat de sterkte van de hoop vooral bepaald wordt door het belang van het object waarop ze hopen, bijvoorbeeld het willen zien opgroeien van de kinderen. De sterkte van de hoop wordt nauwelijks bepaald door de kans om het doel daadwerkelijk te kunnen bereiken. Ze houden vast aan het idee dat hun doel niet onbereikbaar hoeft te zijn. Zonder deze hoop zou hun leven waarschijnlijk ondraaglijk zijn. Met ondraaglijk bedoelen ze, dat mensen ervaren dat ze in de wachtkamer van de dood zitten, wetende dat de deur elk moment open kan gaan. Hopen wordt ervaren als stress reducerend en wordt gezien als noodzakelijk om te kunnen omgaan met hun situatie. Hopen geeft mensen met kanker veerkracht en maakt dat ze kunnen genieten in het heden. Hopen geeft energie, maar kost ook energie. Mensen putten hoop uit verschillende bronnen, zoals positieve berichten van artsen. Als ze de hoop niet uit krachtige bronnen kunnen putten, kunnen mensen deze hoop ook zelf creëren, daarvoor gebruiken ze verschillende strategieën, zoals “vechten” wat onder andere inhoudt, deelnemen aan behandelingen, positief blijven (wat iets anders is dan positief denken, zie verderop in de tekst), onzekerheden creëren, als alles zeker lijkt te zijn onder andere door op een andere manier, anders dan de statische wijze, naar kansen en uitkomsten te kijken en door vertrouwen in hun artsen te hebben. De hoop wordt bedreigd als de mogelijkheid op een negatieve uitkomst groter wordt. Het proces van het koesteren, voeden van de hoop en het verdedigen van de hoop, als deze wordt bedreigd hebben we ‘the work of hope’ genoemd.

Daarna hebben we het perspectief van hulpverleners onderzocht. Het viel op dat bij hulpverleners hun ervaringen, houding en gedrag gevormd leek te zijn door normatieve ideeën over hoe de laatste fase van het leven eruit zou moeten zien. De uitingen van hoop op langer leven of zelfs genezing van mensen met kanker in de palliatieve fase van hun ziekte, werden door de meeste hulpverleners gezien als niet passend binnen deze normen, waarvoor de hulpverleners vonden dat er interventies nodig waren. De resultaten zijn weergegeven als een raamwerk van acht normatieve ideeën; de waarheid moet verteld worden; de dood dient onder ogen te worden gezien; zinloos lijden moet worden voorkomen; "vechtend ten onder gaan" moet worden vermeden; naasten horen door te kunnen gaan met hun levens; patiënt en naaste dienen samen te gaan tot het einde; onrealistische doelen dienen vervangen te worden door haalbare doelen; onrealistische hoop vereist interventies. Deze resultaten laten zien dat de meeste hulpverleners het als hun professionele rol zien om de patiënt te begeleiden naar een goede dood. Een goede dood houdt voor hen in dat het naderende einde onder ogen gezien en aanvaard wordt. Een mogelijke consequentie vanuit werken vanuit deze professionele rol, kan zijn dat de geleverde zorg niet altijd aansluit bij de wensen en behoefte van de patiënt zelf.

Vervolgens is een systematische review vormgegeven naar factoren geassocieerd met hoop bij mensen met kanker die deelnemen aan een behandeling. Deze resultaten laten zien dat hoop positief geassocieerd is met kwaliteit van leven, sociale steun, spiritueel en existentieel welbevinden. Hoop lijkt negatief geassocieerd met symptoomlast, psychologische distress en depressie. Geen relatie werd aangetoond tussen hoop, demografische en klinische factoren. De rol tussen hoop en angst is onduidelijk gebleven. Deze resultaten laten ons zien dat externe factoren (zoals demografische en klinische factoren) niet geassocieerd zijn met hoop. Terwijl intrinsieke factoren, wat wil zeggen factoren die worden ervaren en vastgesteld door patiënten zelf, zoals kwaliteit van leven, symptoomlast, psychologische distress en sociale steun wel geassocieerd zijn met hoop. Hoop lijkt veel meer een cognitief proces te zijn van een persoon, en gestuurd wordt door welke betekenis mensen toekennen aan factoren, dat dat deze van buitenaf wordt beïnvloed. Met deze inzichten kunnen hulpverleners voorwaarden creëren om de inspanningen die mensen met kanker (moeten) doen om hoop te behouden te verlichten.

Tenslotte hebben we interviews geanalyseerd bij mensen met kanker die met curatieve opzet zijn of worden behandeld in Nederland en Vlaanderen. Uit deze studie blijkt niet hoop maar positief denken het centrale concept te zijn. Positief denken wil zeggen, leven alsof genezing een zekerheid is. Uit de resultaten blijkt dat positief denken een manier is om om te gaan met de onzekere toekomst. Mensen vinden dat ze positief moeten denken. Door positief denken lukt het ze om van het heden te genieten en om te leven met een toekomst in het vooruitzicht. Op deze manier kunnen ze ook de negatieve gedachten, die vaak aanwezig zijn, tijdelijk parkeren. Door dit tijdelijk parkeren van negatieve gedachten kan de stress gereduceerd worden en dit geeft ruimte om te leven. Dit leven kan dan op een meer betekenisvolle manier worden ingevuld. De mate waarin er inspanningen geleverd moeten worden om positief te denken kan per individu verschillen. Hoop en positief denken hebben een aantal gemeenschappelijke kenmerken. Positief denken verschilt van hoop in de houding die mensen met kanker aannemen ten opzichte van de werkelijkheid. Positief denken vereist dat een negatieve afloop onwaarschijnlijk is. Bij hoop is dit niet onwaarschijnlijk.

Conclusie

De resultaten van dit proefschrift tonen het belang aan van inzicht in de beleving, de betekenis en de noodzaak van hoop en positief denken bij mensen met kanker in de verschillende stadia van het ziekteproces. Daarnaast laten de perspectieven van zorgverleners zien dat omgaan met hoopvolle palliatieve patiënten geen gemakkelijke opgave is. Mensen in de curatieve fase bezweren hun angsten met positief denken, mensen in de palliatieve fase doen dit met hoop. Hulpverleners kunnen naar hoop en positief denken kijken als een positieve waarde, die niet tegengesproken hoeft te worden.

Summary

Background

Hope and positive thinking play an important role in the lives of people with cancer in all the different stages of the illness. In their daily language, people with cancer often use the words 'hope' or 'positive thinking'.

Nowadays, a growing number of people gets diagnosed with cancer, and lives with the disease. Amongst other reasons, this is because cancer is discovered sooner and can be treated more effectively. Two concepts that are generally used to describe ~~the~~ treatment goals, are curative and palliative treatments. Curative treatments are treatments aimed at curing the disease, whereas palliative or life-extending treatments are treatments aimed at prolonging life as long as possible, since the patient is not likely to survive, and at improving the patient's comfort and quality of life. We have used this medical classification of curative and palliative treatments, because we are also concerned with a medical diagnosis and because the international literature uses this classification. Curative or palliative treatments are terms mainly used by health professionals; patients themselves discuss that a treatment is either aimed to cure, or that they can no longer be cured.

A cancer diagnosis has a major impact on a person's life and on the lives of those around them. The awareness of the finiteness of life and the uncertainty this brings can cause an existential crisis. Many cancer patients respond to this existential crisis by nurturing hope: hope they will suffer from a treatable variant; that the cancer has not spread; that they do not need to receive chemotherapy. And above all, hope for a complete recovery.

The hope is prominent and often does not run parallel with the medical facts and prognosis. Many health professionals feel uneasy when a patient expresses hope that goes (far) beyond the prognosis that has been communicated to them. Health professionals may think that people are insufficiently informed about their prognosis, or that they deny the situation. For this reason, and because people with cancer so often use the words 'hope' and 'positive thinking', these concepts deserve a thorough exploration.

The original plan of this thesis was to investigate hope in people with cancer in all the different stages of the disease process. During the data analysis of the cancer patients who were treated with curative intent, it was found that they often used the term 'positive thinking' for what in daily life, we simply refer to as 'hope'. For this reason, this thesis focuses not just on hope, but also on positive thinking in people with cancer in all stages of the disease process.

Aim

This thesis aims to provide a better understanding of what hope and positive thinking means to people with cancer in the palliative or curative phase of their disease. It also aims to provide insight into the perspectives of health professionals in dealing with palliative patients who hope to live as long as possible, and to gain insight into the factors associated with hope in people during cancer treatment.

Methods

Two secondary analyses were conducted with a constructivist grounded theory approach. The data were obtained in a series of small studies in The Netherlands and Flanders. One study focused on interviews with people with cancer in the palliative phase of their disease (n = 76). The other study focused on interviews with cancer patients who are being treated with a curative intent (N = 74). De data were analysed according to the constant comparative method.

To explore how Dutch health professionals deal with palliative patients with cancer who hope for prolongation of life, focus group discussions (FGD) were conducted. To understand health professionals' interpretation of and reaction to the hopefulness in palliative patients with cancer, an interpretive description approach was used. Three FGD's were held, each consisting of five to ten health professionals working with palliative patients recruited in a general Dutch hospital and homecare organization.

A systematic review of empirical quantitative studies on hope in people with cancer during treatment was conducted. A total of 33 studies were included to explore factors associated with hope in cancer patients during treatment.

Results

First, we investigated what the meaning of hope is, from the perspective of the patients with cancer in the palliative phase of their disease. A striking outcome, is that the intensity of these patients' hope seems to be determined mainly by the importance of the object that their hope is fixed on, for example being able to watch their children grow up. The object is often so important to patients that it seems they cannot live with the idea that it is unattainable. The intensity of the desire for a positive outcome is not related to the chance of their actually achieving this goal, yet the patient still clings to the idea that this goal is not completely unattainable. Without hope, life would have no quality or would be unbearable. Patients compare the feeling of living an unbearable life to the idea of being in a waiting room of death, knowing that the door might open at any moment. Hope is perceived as reducing stress and is seen as necessary to deal with their situation. Patients feel beaten down, but not broken; hope gives them resilience. By not blocking the future, it enables them to enjoy the present. Hope gives energy, but it also takes energy. Patients need strong sources of hope, such as positive feedback from doctors. If they do not have these sources, they will invent some themselves. Such self-created hope takes much more effort than hope resting on a sound foundation, because this self-created hope needs to be built up, maintained and defended. Patients can use a number of strategies to increase hope: they can fight, remain positive, create uncertainty, play with possibilities or place their trust in doctors. Remaining positive is also a targeted strategy to optimize the chance of a positive outcome; patients convince themselves that they can influence fate by being and remaining positive. When the possibility of a negative outcome increases, a patient's hope becomes threatened. The process of nurturing, fostering hope, and defending hope when it is threatened has been called "the work of hope."

Thereafter, we have investigated the Dutch health professionals' perspective on hopeful palliative patients with cancer. Health professionals' experiences, attitudes and behaviours are shaped by normative ideas about how the final phase of life should proceed. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. The results are displayed in a framework of eight normative concepts that health professionals tend to ascribe to palliative patients: ‘the truth must be told’; ‘death must be faced’; ‘needless suffering should be avoided’; ‘to die fighting should be prevented’; ‘significant others must be able to go on with their lives’; ‘the family and the patient must be united until the end’; ‘unrealistic goals must be exchanged for achievable goals’; ‘unrealistic hope requires intervention’ Health professionals believe that it is their professional role to guide patients to a good death. A good death, to them, means that patients face the unavoidable fact that death is near. As a result, their care is not attuned to the needs of the patients as much as it could be.

Subsequently, a systematic review was conducted to identify the factors associated with hope in people who are going through cancer treatment. The results demonstrate a positive relation between hope, and quality of life, social support, and spiritual and existential well-being. Hope appears to relate negatively with symptom burden, psychological distress and depression. There appears to be no relationship between hope and demographic and clinical variables. The relationship between hope and anxiety remains unclear. Taking these results into account, it seems that external factors (demographic data, clinical variables) are not associated with hope. However, intrinsic factors (i.e. factors that are experienced and assessed by the patients themselves, such as quality of life, psychological distress and social support) are associated with hope. The work of hope seems to be a process that is determined by a person’s inner being rather than influenced from the outside. These insights can inspire health professionals to create conditions in which cancer patients can maintain their hopeful attitude, with as less effort as possible.

Finally, we analysed interviews with people with cancer during or after curative treatment. The analyses show that not hope but positive thinking was the central concept. Positive thinking means living as if curing is a certainty; for these patients, however, the future is uncertain. This uncertainty is difficult to live with, which is why they have to think positively. Positive thinking also involves being able to enjoy life; when full recovery is taken as a fact, people can enjoy the present life without this being crushed by worry for the future. People need the future to be a certainty, and that is why they have to think positively. The results show that positive thinking is necessary to elevate life above the experience of illness. Positive thinking can help people to temporarily park their negative thoughts. This reduces stress and creates space to live and enjoy life, so this life might be given more meaning. Although there is some overlap between positive thinking and hope, there are also some differences. Most importantly, positive thinking differs from hope in the attitude people with cancer take to reality; in the case of positive thinking, a negative outcome is unlikely in the mind of the patient, and with hope, this outcome is not necessarily unlikely.

Conclusion

The results of this thesis demonstrate the importance of understanding the meaning and function of hope and positive thinking in cancer patients in all the different stages of the illness. In addition, the perspectives of health professionals show that dealing with hopeful palliative patients is not an easy task. People with cancer in the curative phase allay their fears with positive thinking, people in the palliative phase allay their fears with hope. Health professionals may also see positive thinking as a positive value, which does not have to be contradicted.

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1998–1995	LUMC Hematologie verpleegkundige afdeling Beenmergtransplantatie	Leiden
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Opleidingen

2011–2012	Hogeschool Utrecht Master of Advanced Nursing Practice	Utrecht
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1988-1992	Hogeschool Leiden HBO-V	Leiden
1982-1988	Zandevelt College VWO	’s-Gravenzande

Cursussen

EONS (European Nursing Society)
1ste EONS research workshop for doctoral students
May 2016, University of Stirling, Scotland, UK

English for professionals by Christien Franken
Academic writing 2015- 2016

Motiverende Gespreksvoering
VenVN 2013

Prijzen

Best Poster in the category: Oncology Nursing research, EONS 2016
Nominatie Anna Reynvaan praktijkprijs 2014
Jeltje de Bosch Kemper Best Practice award 2013
Amgen Award of Excellence Oncology nursing 2007
Talma Eijkman prijs 2004

E-college

Hope in palliative patients (held in collaboration with EONS)
e-session 382 – 9 February 2017 – 18.30/19.00 CET
Expert: Corine Nierop, University Hospital, Ghent University, Ghent, Belgium
Discussant: Diane van der Biessen, Nurse practitioner, Erasmus MC Cancer Institute, Rotterdam, The Netherlands

Publicaties

Artikelen in internationale peer-reviewed tijdschriften

- Nierop-van Baalen, C., Grypdonck, M., Van Hecke, A., & Verhaeghe, S. (2016). Hope dies last… A qualitative study into the meaning of hope for cancer patients in the palliative phase. *European Journal of Cancer Care, 25,* 570–579. doi:10.1111/ecc.12500
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Overige publicaties

- Nierop-van Baalen, C., Grypdonck, M., Van Hecke, A. & Verhaeghe S. (2017). *Handreiking omgaan met hoop, voor hulpverleners die omgaan met hoopvolle mensen die een korte levensverwachting hebben.* Universitair Centrum voor Verpleegkunde en Vroedkunde, Vakgroep Maatschappelijke Gezondheidkunde Universiteit Gent.

Wetenschappelijke presentaties

- Nierop-van Baalen C, Grypdonck M, Van Hecke A, Verhaeghe S. Hope as a problem. A qualitative study exploring how health professionals interpret hopefulness in palliative patients. *The role of advanced nurse practitioners within changing healthcare landscape: 10th ICN NP/APN, 26-29 August 2018.*
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- Nierop-van Baalen C, Grypdonck M, Van Hecke A, Verhaeghe S. Why do they still hope? A qualitative study to explore how caregivers interpret hopefulness in palliative patients. *Reinforcing multidisciplinarity: 17th European Cancer Congress, 28 September-1 October 2013.*
- Nierop-van Baalen, C. & Grypdonck, M. Man lives by hope. *Vulnerable groups in society: a nursing issue. 3rd European Nursing Congress, 5-8 October 2003.*

Overige presentaties over hoop in de palliatieve fase

2019	‘Hoop en Hopeloosheid’ Netwerk palliatieve zorg	Almere
2018	Oncologiedagen	Ede
2018	Symposium complementaire zorg	Amersfoort
2017	‘Hoop en Hopeloosheid’ Netwerk palliatieve zorg	Hilversum
2017	‘Hoop doet leven’ Netwerk palliatieve zorg	Meppel
2016	Symposium ‘Dag van verpleging’	Ede
2016	Vlaamse oncologiedagen	Antwerpen
2015	Palliatieve zorg: Intuïtie, wijsheid of wetenschap?	Nijmegen
2015	Inloophuis Scarabee	Leiden
2014	Nursing experience dagen	Ede
2014	Café Doodgewoon	Hoorn

Lessen over hoop en palliatieve zorg

2018	Advanced nursing practice in de oncologie	Gent
2017	Scholing hematologie	Leiden
2017	Bijscholingsdagen kinderverpleegkundigen	Amsterdam
2016- 2018	Scholing palliatieve zorg voor gevorderden	Leiden
2015-2017	Scholing oncologie	Groningen
Vanaf 2015	Bijscholing MDL- oncologie	Utrecht
2015	Training consultatieteams palliatieve zorg	Breda
2014	Scholing longoncologie	Amsterdam
Vanaf 2013	Specialistische opleiding palliatieve zorg	Eindhoven/Rotterdam
2013- 2018	Masterclass Mamma/ Longoncologie	Amersfoort

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