ONCOLOGISCHE ZORG
IN MULTICULTUREEL VLAANDEREN

ERVARINGEN VAN ZORGVERLENERS EN BELEVING VAN FAMILIELEDEN

Ineke van Eechoud
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YOU NEED BOTH LOVE AND ANGER

TO CHANGE THE WORLD

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INHOUD

HOOFDSTUK 1

INTRODUCTIE EN ONDERZOEKSVRAGEN

Dit proefschrift heeft de oncologische zorg in multicultureel Vlaanderen als thema, met een focus op de ervaring van zorgverleners en de beleving van familieleden. In deze introductie wordt allereerst de achtergrond van het doctoraatsonderzoek beschreven. Daarin komen een aantal thema's aan bod die van belang zijn voor de keuze van het doctoraatsonderwerp of die dienen als achtergrondinformatie bij de volgende hoofdstukken in dit proefschrift. Achtereenvolgens wordt stilgestaan bij de diversiteit in de samenleving en in de gezondheidszorg, de oncologische context, het belang van communicatie, het principe 'zorg op maat' en de opvatting van cultuur. Vervolgens wordt het belang van het bestuderen van het perspectief van zorgverleners en zorgvragers beschreven. De specifieke keuze voor een focus op familieleden komt daarin ook aan bod. Na deze beschrijving van de achtergrond wordt de doelstelling van dit doctoraatsonderzoek weergegeven. Tenslotte worden de onderzoeksvragen vermeld en de gebruikte methoden toegelicht.

ACHTERGROND

Verschillende decennia van wereldwijde migratie hebben onze samenlevingen in toenemende mate etnisch en cultureel divers gemaakt (WHO, 2010). In 2013 was in het Vlaamse Gewest ruim 18% van de inwoners van buitenlandse herkomst (Noppe, 2015). Het aandeel jonge kinderen van buitenlandse herkomst ligt veel hoger (Noppe, 2015), waardoor volgens sommige prognoses tegen 2060 tussen de 30% en 50% van de Belgische bevolking een buitenlandse herkomst zal hebben (Hanseeuw, 2012). Als wordt gekeken naar de landen waar de meeste personen van 'vreemde origine' van afkomstig zijn, blijkt de grootste groep een Nederlandse achtergrond te hebben, gevolgd door personen van Marokkaanse origine, van Oost-Europa en Turkije (Noppe & Lodewijckx, 2012). In totaal is ongeveer de helft van de mensen met een migratieachtergrond, of een van hun ouders, afkomstig uit landen binnen de Europese Unie (SVR, 2014). Een veel grotere mate van 'diversiteit binnen deze diversiteit', blijkt onder andere uit de meer dan 160 verschillende landen waar inwoners van Vlaanderen uit afkomstig zijn (Verhaeghe, Zemni & Meulenman, 2012; WWR, 2015).

Gezondheidszorginstellingen hebben ook in toenemende mate te maken met zorgvragers van uiteenlopende etnische en culturele origine (Devillé et al., 2011) en het komt steeds meer voor dat zorgverleners en patiënten een andere etnische en culturele herkomst hebben (Kai, Beavan, & Faull, 2011). Verschillen in gezondheid tussen etnische groepen en culturele invloeden op gezondheidszorgpraktijken zijn veelvuldig aangetoond (Kleinman & Benson, 2006a). Tevens blijken tussen zorgverleners en patiënten van een etnische minderheidsgroep meer problemen in communicatie en ten aanzien van wederzijds begrip voor te komen dan bij patiënten van 'autochtone' origine (Van Wieringen, Harmsen, & Bruijnzeels, 2012).

Het Belgische gezondheidszorgsysteem wordt wereldwijd erkend als één van de meest rechtvaardige (Derluyn, Lorant, Dauvrin, Coune, & Verrept, 2011) en discriminatie is verboden bij de wet. Gezondheidszorginstellingen in België hebben echter geen formele verplichting om aandacht te besteden aan diversiteit en om ongelijkheden weg te werken (Dauvrin, Derluyn, Coune, Verrept, & Lorant, 2012; Lorant & Bhopal, 2010). In het Belgisch beleid lijkt er vanuit te worden gegaan dat discriminatie niet bestaat in de gezondheidszorg en dat de noden onder etnische minderheidsgroepen niet verschillen (Lorant & Bhopal, 2010). In de Migrant Integration Policy Index (MIPEX, 2015), een instrument waarmee wordt gemeten wat vanuit beleidswegen wordt ondernomen om de integratie van migranten te bevorderen, scoort België in vergelijking met de andere domeinen het minst goed op gezondheid. De index toont dat de rechten en toegankelijkheid van de gezondheidszorg in België gunstig zijn, maar dat de voorzieningen en het gezondheidszorgbeleid weinig gevoelig zijn voor de specifieke noden van migranten (MIPEX, 2015). Het belang van een gevoeligheid voor specifieke noden van migranten blijkt onder andere uit de vier topprioriteiten die de Wereldgezondheidsorganisatie voorop heeft gesteld ten aanzien van de gezondheid van migranten. Eén van de topprioriteiten betreft namelijk 'migrant sensitive health systems' (WHO, 2010). Deze 'migrant sensitive health systems' dienen onder meer te verzekeren dat gezondheidszorg geleverd wordt op cultureel en taalkundig passende wijze (WHO, 2010).

Oncologie

Dit doctoraatsonderzoek kadert binnen de oncologische zorg in Vlaanderen. De aansluiting met zorgvragers van andere etnische origine is namelijk ook voor de oncologische zorgverlening in Vlaanderen een actuele uitdaging. Kanker is een van de hoofdoorzaken van morbiditeit en mortaliteit wereldwijd (WHO, 2015b). Bovendien kan een kankerdiagnose zeer belastend zijn en raakt kanker zowel patiënten als familieleden emotioneel en fysiek

(Bultz & Carlson, 2006). Voor patiënten en hun naasten gaat kanker in eerste instantie altijd over leven en dood, waardoor de oncologische zorg een existentiële betekenis heeft. Kanker raakt dus de fundamenten van het leven. Een ziekte als kanker is altijd een diepe morele ervaring, aangezien de betrokkenen zaken van grote persoonlijke en gezamenlijke waarde te verliezen hebben (Kleinman & Benson 2006a).

Communicatie

Rekening houdend met het existentiële karakter van de oncologische zorg hoeft het niet te verbazen dat communicatie al geruime tijd is erkend als een essentiële klinische vaardigheid van oncologische zorgverleners (Fallowfield & Jenkins, 1999). Ook in de zorgverlening aan etnische minderheden is communicatie van groot belang (de Graaff, Francke, Muijsenbergh, & van der Geest, 2012a; Fallowfield & Jenkins, 1999; Kai et al., 2011; Owens & Randhawa, 2004; Pergert, Ekblad, Enskär, & Björk, 2007). Er wordt in dat verlengde wel gesproken van interculturele communicatie, waarmee het vermogen van mensen wordt bedoeld om elkaar met begrip voor de eigen culturele achtergrond te verstaan en te begrijpen (May, 2002). Respect, onbevooroordeeldheid en inlevingsvermogen zijn daarbij van bijzonder belang (May, 2002). In de existentiële context van de oncologie ligt bruuskeren extra gevoelig, waardoor oncologische zorg vraagt om genuanceerde communicatie. In essentie gaat het er om als zorgverlener te verstaan wat er werkelijk op het spel staat (Kleinman & Benson, 2006a; 2006b).

Zorg op maat

In de gezondheidszorg wordt in principe gestreefd naar kwaliteitsvolle zorg voor iedereen die daar een beroep op wenst te doen, zonder enig onderscheid. Gezien de multiculturele samenstelling van de Belgische bevolking, betekent dit dat deze kwaliteitsvolle zorg voor iedere inwoner van België moet gelden, ongeacht etnische, religieuze, culturele en andere achtergrond. Volgens Ingleby (2002) is het in interculturele zorg vooral van belang dat aansluiting wordt gevonden bij de leefwereld en de cultuur van de doelgroep. De WHO heeft recent een wereldwijde strategie uitgewerkt voor mensgerichte en geïntegreerde gezondheidszorg (WHO, 2015a). Onder mensgerichte gezondheidszorg verstaat de WHO een benadering van zorg waarin de perspectieven van individuen, families en gemeenschappen weloverwogen worden meegenomen en zorg wordt geleverd die op humane en holistische wijze beantwoordt aan hun noden en voorkeuren (WHO, 2015a).

Opvatting van cultuur

Voor de wijze waarop interculturele zorg wordt opgevat, is de interpretatie van het concept cultuur van groot belang (Bartels, 2004; Kleinman & Benson, 2006a; 2006b; Taylor, 2003). Het inzicht dat cultuur ook een menselijk product is en dus dat menselijk gedrag ook cultuurproductie is, is essentieel voor interculturele zorgverlening (Bartels, 2004). In de zorgsector wordt echter veelal een meer statische opvatting van cultuur gehanteerd (Bartels, 2004; Kleinman & Benson, 2006a; 2006b; Taylor, 2003), waarin cultuur eerder wordt gezien als een objectieve realiteit (Bartels, 2004). De mens wordt daarmee gezien als een product van zijn cultuur (Bartels, 2004).

Uit het voorgaande komen twee veelbesproken opvattingen van het cultuurbegrip naar voren, grofweg de essentialistische en de constructivistische opvatting (vgl. Eriksen, 1993; Baumann, 1999; Carens, 2000; Benhabib, 2002). De essentialistische opvatting gaat uit van cultuur als een statisch, homogeen, afgebakend geheel welke gerelateerd is aan een groep en een territorium (Baumann, 2002; Benhabib, 2002; Eriksen 2002; Kleinman & Benson, 2006a; 2006b). Cultuur wordt daarin eerder gezien als een gegeven pakket van normen en waarden die door alle groepsleden identiek worden gehanteerd (Oude Breuil, 2001). Voor de gezondheidszorg wordt culturele competentie dan ook veelal opgevat als een reeks “do’s en don’ts” waarin wordt aangegeven wat men wel en niet moet doen bij de zorg aan een patiënt met een specifieke etnische achtergrond (Kleinman & Benson, 2006b). Hoewel goed bedoeld, leidt een dergelijke opvatting van cultuur gemakkelijk tot gevaarlijke stereotypering (Kleinman & Benson, 2006b). Met betrekking tot de hulpverlening wordt cultuur vanuit deze essentialistische opvatting eerder beperkt tot het gezichtspunt van de hulpverlener over de cliënt. De cliënt wordt daardoor als ‘de ander’ beschouwd, terwijl de hulpverleningsrelatie zelf buiten beschouwing blijft (Bartels, 2004, vgl. Oude Breuil, 2005; Kleinman & Benson, 2006b).

Door de opkomst van etnische studies en de begrippen ‘etniciteit’ en ‘identiteit’ is vanaf de jaren zeventig in de antropologie de opvatting veranderd in de richting van een meer dynamisch cultuurconcept (Bartels, 2004; vgl. Eriksen 2002; Baumann, 2002). Cultuur is volgens deze opvatting niet een enkele variabele, maar omvat verschillende variabelen die van invloed zijn op alle aspecten van de beleving (Kleinman en Benson, 2006b). Het is onlosmakelijk verbonden met economische, politieke, religieuze, psychologische en biologische omstandigheden (Kleinman & Benson, 2006b). Binnen deze constructivistische opvatting wordt wel rekening gehouden met de dynamiek van culturen, dus dat culturen aan verandering en verschuiving onderhevig zijn (Benhabib, 2002). Individuen construeren hun eigen verhalen over hun toebehoren tot de groep, waardoor er juist sprake is van veel diversiteit binnen een cultuur (Benhabib, 2002).

In aansluiting met de hedendaagse antropologie, wordt in dit proefschrift cultuur benaderd vanuit de onderstaande constructivistische opvatting van Kleinman en Benson (2006a):

> “Culture is a process through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants (…) Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity, and even personality (Kleinman & Benson, 2006b, p. 1674).”

Als we deze definitie toepassen op de oncologische zorg, is het te verwachten dat de existentiële context van de oncologie ‘de emotionele lading en de morele betekenis’ van de ‘alledaagse activiteiten en omstandigheden’ nog versterkt en verdiept.

In het verlengde van deze opvatting van cultuur dient culturele competentie niet opgevat te worden als een technische vaardigheid, maar eerder als een ‘mini-etnografie’ waarin een zorgverlener probeert te begrijpen wat er werkelijk voor patiënten en hun naaste omgeving op het spel staat (Kleinman & Benson, 2006b). Deze benadering kan samengevat worden in één activiteit: Aan de patiënt en (wanneer gepast) aan zijn familieleden vragen wat voor hen het meeste van belang is ten aanzien van de ziekte en de behandeling (Kleinman & Benson, 2006b). Zorgverleners kunnen deze essentiële informatie vervolgens gebruiken in het zorgtraject (Kleinman & Benson, 2006b).

Verschillende perspectieven: zorgverleners en zorgvragers

> “Rather than understand culture as a “timeless” ethnic stereotype applied to patients—which is a common but dangerous practice—physicians need to understand how culture influences doctors as much as patients (Kleinman and Benson, 2006a, p. 834).”

In het verlengde van een eerder statische opvatting van cultuur, wordt bij de aandacht voor aansluitingsproblemen met de cultureel diverse patiëntenpopulatie vaak voorbijgegaan aan de (sub)culturele kenmerken van de zorgverlenende instanties zelf (Bartels, 2004; Kleinman & Benson, 2006a; 2006b; Oliemeulen & Thung, 2007; Oude Breuil, 2005; Taylor, 2003). Verschillende studies hebben echter aangetoond dat inzicht in de veelal relatief homogene cultuur van een instelling van groot belang is in de aansluiting met een cultureel heterogene cliëntpopulatie (Oude Breuil, 2005; Oliemeulen & Thung, 2007; van der Haar, 2007). Om in de huidige multiculturele samenleving aan iedere patiënt en zijn/haar familie kwaliteitsvolle zorg op maat te kunnen geven is het van belang om inzicht te hebben in de ervaringen van zorgvragers en van zorgverleners.

Hoewel er een groeiend bewijs is van ongelijke toegang tot kwaliteitsvolle kankerzorg tussen etnische minderheids- en meerderheidsgroepen, is weinig onderzoek gedaan vanuit het perspectief van gebruikers van etnische minderheidsgroepen zelf (Elkan et al., 2007). Er is eveneens weinig gekend over het perspectief van professionele zorgverleners in de zorg aan mensen van diverse etnische en culturele origine, ondanks de tendens voor het verbeteren van interculturele zorg (Kai et al., 2007). Binnen de niet-preventieve oncologische zorg hebben er tussen 2000 en 2013 wereldwijd slechts vijf studies plaatsgevonden met een primaire focus op de ervaringen en percepties van zorgverleners in de zorg aan patiënten van een etnische minderheid (Hoofdstuk 3).

Het perspectief van oncologische zorgverleners

Zoals hierboven beschreven, is naast het verkrijgen van inzicht in de beleving van zorgvragers ook inzicht in het perspectief van zorgverleners van bijzonder belang. Uit de beperkte literatuur over de ervaringen van oncologische zorgverleners in de zorg aan patiënten van andere etnische origine, blijkt dat barrières en moeilijkheden op de voorgrond staan (hoofdstuk 2). Tevens is bekend dat oncologische zorgverleners veel met familieleden te maken hebben in de zorg aan patiënten van andere etnische origine. Dit komt onder meer door de prominente rol die familieleden veelal opnemen en doordat familieleden vaak optreden als tolk wanneer er sprake is van een taalbarrière tussen de patiënt en de zorgverlener (hoofdstuk 2).

Zorgverleners ervaren onder andere culturele verschillen ten aanzien van de rollen die familieleden opnemen en ethische dilemma's wanneer familieleden vragen om geen waarheidsmededelingen te doen of om informatie te verzwijgen naar de patiënt (Huang, Yates, & Prior, 2009; Pergert et al., 2007). Eén studie toont expliciet aan dat oncologische zorgverleners een spanning ervaren tussen hun eigen focus op autonomie van de individuele patiënt en patiëntgerichte zorg enerzijds en meer familiegerichte benaderingen ten aanzien van informatie en besluitvorming anderzijds (Kai et al., 2011). Niet kunnen spreken in een taal die de patiënt machtig is, vormt de voornaamste bezorgdheid van oncologische zorgverleners (Pergert et al., 2007; Owens & Randhawa, 2004). Ze zijn ongerust of en hoe informatie over diagnose en prognose wordt meegedeeld aan de patiënt als naasten de boodschap overbrengen (Huang et al., 2009; Kai et al., 2011; Lanceley & Cox, 2007; Richardson, Thomas, & Richardson, 2006). Tegelijkertijd werken oncologische zorgverleners veel vaker met familieleden die vertalen dan met professionele tolken (de Graaff et al., 2012a; Kai et al., 2011; Owens & Randhawa, 2004). Uit de literatuur blijkt dat professionele vertalers (of tweetalige zorgverleners) de beste garantie bieden voor kwaliteitsvolle gezondheidszorg in het geval van een taalbarrière (Flores, 2005; vgl. Bischoff, 2012; Verrept, 2012).

Het perspectief van familieleden

Naast het perspectief van zorgverleners, ligt de focus in dit doctoraatsonderzoek op het perspectief van familieleden. Hoewel in de zorg aan patiënten van andere etnische origine de zorg aan patiënten centraal staat, staan voor oncologische zorgverleners ervaringen met familieleden veelal op de voorgrond. De focus van dit proefschrift, op het perspectief van zorgverleners en familieleden, lijkt dan ook een waardevolle combinatie in het streven de aansluiting te verbeteren tussen oncologische zorgverleners en de diverse patiëntenpopulatie.

Een ziekte wordt altijd beleefd in een sociale context (Kleinman & Benson, 2006a). Het is bekend dat familieleden vaak dubbel lijden, doordat ze met de patiënt mee lijden en hun eigen verlies lijden (Grypdonck, 1996). Uit onderzoek blijkt ook dat ondersteuning van familieleden niet alleen van belang is voor henzelf, maar ook van betekenis is voor de patiënt (Verhaeghe, 2007). De patiënt heeft er namelijk alle voordeel bij dat familieleden de situatie kunnen hanteren en overzien (Verhaeghe, 2007). Uit de literatuur komt bovendien naar voren dat familieleden vaak een essentiële rol opnemen in de zorg aan mensen met kanker, dit wordt in de volgende paragraaf toegelicht.

De keuze voor een focus op familieleden volgt ook uit een taakverdeling binnen een samenwerkingsverband tussen de vakgroep Huisartsgeneeskunde en Eerstelijnsgezondheidszorg van de UGent, de Dienst Geriatrie van het UZ Gent en het Universitair Centrum voor Verpleegkunde en Vroedkunde van de UGent. Parallel met het onderzoek naar familieleden liep vanuit de vakgroep Huisartsgeneeskunde en Eerstelijnsgezondheidszorg een onderzoek naar de perceptie en beleving van zorg door niet-westerse oncologische patiënten na migratie (Aelbrecht, Vos, & Deveugele, 2014). Mede aangezien het bestuderen van ‘familieleden in de zorg’ behoort tot een van de onderzoekslijnen van het Universitair Centrum voor Verpleegkunde en Vroedkunde, is gekozen voor deze focus in dit doctoraatsonderzoek.

De rol van familieleden in de zorg aan patiënten met kanker

Uit de literatuur is reeds veel bekend over de rol van familieleden in de zorg aan patiënten met kanker, maar veel minder is geweten over familieleden van etnische minderheden. Algemeen wordt erkend dat kanker zowel effect heeft op de patiënt als op de familie (Harden, 2005; Kristjanson & Ashcroft, 1994; Nijboer et al., 1998;). Familieleden nemen veelal een essentiële rol op in het kankertraject (Haley, 2003; Ponto & Barton, 2008) en vaak geven ze zowel emotionele als praktische ondersteuning (Blindheim, Thorsnes, Brataas, & Dahl, 2013; McIlfatrick, Sullivan, & McKenna, 2006; Pusa, Persson, & Sundin, 2012; Röing, Hirsch, & Holmström, 2008; Teschendorf et al., 2007). In veel studies ligt de focus op de lasten, noden en coping strategieën van familieleden en wordt aangetoond dat zorg dragen leidt tot veel emotionele, gezondheidsgerelateerde, sociale en financiële druk (Amir, Wilson, Hennings, & Young, 2012; Clemmer, Ward-Griffin, & Forbes, 2008; Doumit, Huijer, Kelley, & Nassar, 2008; McConigley, Halkett, Lobb, & Nowak, 2010; Proot, et al., 2003). Aan de andere kant, blijkt zorg dragen ook een positieve invloed te hebben op familieleden, zoals het herzien van levensprioriteiten, een verbeterde relatie met de patiënt en gevoelens van voldoening (Bruun, Pedersen, Osther, & Wagner, 2011; Clemmer et al., 2008; Haley, 2003; Levesque & Mayberry, 2012; Sand, Olsson, & Strang, 2010; Teschendorf et al., 2007; Williams & Bakitas, 2012).

Er heeft relatief weinig onderzoek plaatsgevonden naar familieleden van oncologische patiënten van een etnische minderheid (Dilworth-Anderson, Williams, & Gibson, 2002; Dilworth-Anderson et al., 2005; Kristjanson & Ashcroft, 1994; Mosher & Danoff-Burg, 2005). Uit studies (de meeste) buiten de oncologische context, die zich richten op familieleden van patiënten van een etnische minderheid, blijkt dat normatieve culturele waarden een groot gewicht hebben in de wijze waarop mensen zorg dragen voor familieleden (Anngela-Cole & Busch, 2011; Dilworth-Anderson, 2002; Doumit et al., 2008; Goodman, Zarit, & Steiner, 1997; Knight & Sayegh, 2010). De systematische literatuurstudie van Dilworth-Anderson en collega’s (2002) geeft meer inzicht in de normatieve waarden door aan te tonen dat er binnen culturele groepen waarden worden gehanteerd ten aanzien van reciprociteit, filiale plicht en een verantwoordelijkheidsgevoel voor het zorg dragen voor oudere familieleden. Meer recent bracht een systematische review over de zorg en communicatie van familieleden met ongeneeslijk zieke Turkse of Marokkaanse patiënten naar voren dat familieleden cruciale zorgverleners zijn voor deze patiëntengroep en dat veel patiënten verwachten dat hun kinderen en aangetrouwde kinderen voor hen zorg dragen (de Graaff, Mistiaen, Devillé, & Francke, 2012b). Twee kwantitatieve Nederlandse studies bevestigen dat volwassen kinderen en hun oudere ouders van Turkse of Marokkaanse herkomst veel meer belang hechten aan filiale verantwoordelijkheid in vergelijking met mensen van Nederlandse origine (de Valk & Schans, 2008; Schans & Komter, 2010). Wanneer echter gekeken wordt naar het effectief verlenen van zorg, worden de patronen meer complex (Schans & Komter, 2010), en blijkt het zorg dragen voor oudere ouders niet meer zo vanzelfsprekend als het van oudsher was (Yerden, 2013).

Uit het voorgaande blijkt het belang van het verkrijgen van inzicht in de beleving van familieleden, waarschijnlijk veelal volwassen kinderen, van oudere volwassenen met kanker van andere etnische origine in Vlaanderen. In deze studie is ervoor gekozen om de onderzoekspopulatie te beperken tot familieleden van oudere volwassenen van Turkse of noordwest Afrikaanse herkomst met kanker. Mensen van Turkse en noordwest Afrikaanse origine behoren namelijk tot de twee grootste groepen van personen ouder dan 55 jaar met van niet-Europese herkomst in Vlaanderen (Lodewijckx, 2007). Hoewel zij uit verschillende landen afkomstig zijn, delen zij een gelijkaardige immigratiegeschiedenis. De meeste van hen zijn namelijk naar België gekomen als gastarbeiders in de jaren 60 en 70 van de vorige eeuw (Lodewijckx, 2007). Tevens maken beide groepen deel uit van de Islamitische religieuze minderheidsgroep in België. Door de diversiteit in afkomst in de studie te beperken tot deze twee groepen, is het beter mogelijk om recht te doen aan de heterogeniteit binnen deze groepen en om beter te contextualiseren.

DOELSTELLING

Deze doctoraatsstudie geeft inzicht in de perceptie en ervaringen van oncologische zorgverleners ten aanzien van de zorg aan etnische minderheden en in de beleving van familieleden van oudere volwassen patiënten met kanker en van Turkse of noordwest Afrikaanse origine. In de discussie worden beide inzichten samengebracht. Met dit proefschrift wordt geprobeerd om de beperkte wetenschappelijke kennis over dit onderwerp uit te breiden, maar bovenal wordt hiermee getracht bij te dragen aan een goede aansluiting tussen de oncologische zorg in Vlaanderen en de diverse patiëntenpopulatie.

ONDERZOEKSVRAGEN EN METHODE

In dit proefschrift worden de ervaringen van zorgverleners en de beleving van familieleden bestudeerd binnen de context van de oncologische zorg in multicultureel Vlaanderen. Hieronder staat beschreven welke onderzoeksvragen werden beantwoord.

- Wat is wereldwijd uit eerder wetenschappelijk onderzoek bekend over de opvattingen en ervaringen van oncologische zorgverleners in de zorg aan patiënten van een etnische minderheid?
    - Met de term ‘etnische minderheid’ wordt verwezen naar alle personen van buitenlandse herkomst die behoren, of worden gerekend, tot een minderheidsgroep. Zoals in de sociale antropologie, verwijst de term etniciteit naar aspecten van

    relaties tussen groepen die zichzelf rekenen tot, of door anderen worden gepercipieerd als, onderscheidend (Eriksen, 2002, p. 4).

- Hoe percipiëren en ervaren oncologische zorgverleners in België de zorg aan patiënten van niet-westerse origine?
    - Met de term ‘niet-westerse origine’ wordt door de onderzoekers verwezen naar personen die zelf, of een van hun ouders, zijn geboren in landen buiten EU -15 [1], de VS, Canada of Japan (vgl. Lodewijckx, 2007).
- Hoe beleven familieleden de zorg aan mensen ouder dan 50 jaar met kanker en van Turkse of noordwest Afrikaanse origine, in België?
    - De term Turkse of noordwest Afrikaanse origine verwijst hier naar personen die zijn geboren in Turkije of noordwest Afrika (Marokko, Algerije of Tunesië).

De eerste onderzoeksvraag werd beantwoord door middel van een systematische literatuurstudie. Daarvoor werden vier databanken systematisch doorzocht op empirische studies, zowel met een kwalitatief als een kwantitatief onderzoeksdesign, en systematische reviews (gepubliceerd tussen januari 2000 en december 2013). Tevens werden referentielijsten gescreend op bijkomende publicaties. De overige onderzoeksvragen werden onderzocht door middel van een kwalitatieve onderzoeksmethode, gebaseerd op de constructivistische grounded theory (Charmaz, 2006). De analyse van de data over de beleving van familieleden gaf ook inzicht in een proces waarin familieleden openheid over ziekte afwegen wanneer zij een rol opnemen als vertaler of contactpersoon. Deze bevindingen worden apart besproken in dit proefschrift. Er is gekozen voor een kwalitatieve benadering omdat deze zeer geschikt is voor het krijgen van inzicht in de percepties, ervaringen en beleving van participanten. Ze laat beter dan andere onderzoeksstrategieën toe om recht te doen aan de beleving en betekenisgeving van de familieleden en de zorgverleners (Verhaeghe, 2007).

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[1] Europese Unie: 15 landen (EU-15): De samenstelling van de Europese Unie per 1 januari 1995: België, Duitsland, Denemarken, Finland, Frankrijk, Griekenland, Ierland, Italië, Luxemburg, Nederland, Oostenrijk, Portugal, Spanje, Verenigd Koninkrijk en Zweden. (Bron: Centraal Bureau voor de Statistiek, http://www.cbs.nl/nl-NL/menu/methoden/begrippen/default.htm?ConceptID=2980, opgehaald op 4 september 2015)

Constructivistische grounded theory gaat uit van een relativistische positie en veronderstelt dat kennis wordt geconstrueerd in een interactief proces tussen de onderzoeker en de participant (Mills, Bonner, & Francis, 2008). Voor de verschillende onderzoeksvragen werd de methode aangepast. Een meer uitgebreide beschrijving van de specifieke onderzoeksstrategieën wordt gegeven in de afzonderlijke hoofdstukken.

Voor het onderzoek naar zorgverleners werden data verzameld door middel van vijf focusgroepinterviews in drie ziekenhuizen uit een uiteenlopende demografische context. Er hebben in totaal 23 oncologische zorgverleners van verscheidene disciplines deelgenomen: verpleegkundigen, artsen, sociaal werkers, psychologen en diëtisten. Voor het onderzoek naar familieleden werden 28 individuele interviews met 32 familieleden afgenomen. Die familieleden werden gerekruteerd via uiteenlopende locaties en kanalen in Vlaanderen. Alle interviews werden afgenomen door de doctoranda. Dataverzameling en data-analyse werden met elkaar afgewisseld in een cyclisch proces. De data werden uitgewerkt en geanalyseerd door middel van 'constante vergelijking', een van de hoofdcomponenten van de constructivistische grounded theory methode (Boeije, 2005; Charmaz, 2006). De analyseprocessen waren vergelijkbaar met de ‘Qualitative Analysis Guide of Leuven’ (QUAGOL) (de Casterlé, Gastmans, Bryon, & Denier, 2012). Voor de validiteit van de studie werd in alle onderdelen gebruik gemaakt van onderzoekerstriangulatie: meerdere onderzoekers uit diverse disciplines lazen (een gedeelte van) de data en hebben elkaars interpretaties van de data bediscussieerd (Boeije, 2005).

Na deze introductie komen in de volgende drie hoofdstukken de verschillende studies aan bod. Deze hoofdstukken zijn opgebouwd uit vier Engelstalige artikels. In hoofdstuk 2 wordt de systematische literatuurstudie besproken, gevolgd door de empirische studie over het perspectief van oncologische zorgverleners in Vlaanderen in de zorg aan patiënten van niet-westerse origine. Hoofdstuk vier brengt vervolgens de beleving van familieleden naar voren en de wijze waarop zij openheid over ziekte afwegen in het opnemen van een rol als vertaler of contactpersoon. In de discussie, hoofdstuk 5, wordt een verbinding gelegd tussen het perspectief van de zorgverleners en dat van de familieleden om vervolgens te komen tot implicaties en aanbevelingen voor de zorgpraktijk.

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HOOFDSTUK 2

ONCOLOGISCHE ZORG IN MULTICULTURELE CONTEXT: ERVARINGEN VAN ZORGVERLENERS WERELDWIJD

ARTIKEL 1. - P. 35

Gebaseerd op het artikel van: van Eechoud, I., Grypdonck, M., Beeckman, D., Van Lancker, A., Van Hecke, A., & Verhaeghe, S. Oncology health workers' views and experiences on caring for ethnic minority patients: a mixed method systematic review. *International Journal of Nursing Studies*. In Press. DOI: 10.1016/j.ijnurstu.2015.09.007.

ONCOLOGY HEALTH WORKERS' VIEWS AND EXPERIENCES ON CARING FOR ETHNIC MINORITY PATIENTS: A MIXED METHOD SYSTEMATIC REVIEW

ABSTRACT

Objectives: To investigate what published research reveals about the views and experiences of oncology health workers when caring for ethnic minority patients.

Design: Systematic review of qualitative and quantitative studies.

Data sources: The following databases were systematically screened: PubMed, CINAHL, Web of Science, and AnthroSource. Reference lists were checked for additional articles.

Review methods: Empirical studies or systematic reviews (1/2000 to 12/2013) were included if they concerned the oncology setting and the views or experiences of healthcare workers and care users belonging to an ethnic or cultural minority group. The methodological quality of each individual study was assessed using the Critical Appraisal Skills Programme for Qualitative Studies and the Quality Assessment Tool for Quantitative Studies.

Results: Eighteen publications met the inclusion criteria. Thirteen articles had a qualitative, four a quantitative, and one a mixed methods design. The results in the individual studies were heterogeneous.

Most studies reported challenges or barriers when caring for ethnic minority patients, whereas fewer than half of the articles discussed facilitating factors and opportunities. Oncology health workers participating in the included studies sought to provide professional standards of care and tried to adapt care to the needs of ethnic minority patients. However, they experienced formidable communication barriers and they feared doing things that might be considered culturally insensitive. The organizational aspects of care for the oncology patient appeared to have a significant influence on how healthcare providers view and experience oncology care for ethnic minority patients.

Conclusions: Views and experiences of participating oncology health workers were characterized by a willingness to provide proper care for ethnic minority patients, but this was hampered by a tangle of interrelated issues such as linguistic barriers, fear and uncertainty, and assumptions about cultural matters. Organizational aspects were shown to be a strong influence on healthcare workers caring for ethnic minority patients. Due to methodological limitations of the included studies, conclusions should be viewed with caution.

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What is already known about the topic?

- Healthcare has to deal with an increasing population of ethnic and culturally diverse care recipients.
- In culturally competent care, the culture of both care recipients and healthcare providers are of great significance.

What this paper adds:

- Oncology health workers participating in the included studies sought to provide professional standards of care and tried to adapt care to the needs of ethnic minority patients. However, they experienced formidable communication barriers and they feared ‘doing the wrong thing.’
- Many interrelated issues such as linguistic barriers, experienced fear and uncertainty, and assumptions about cultural matters have an impact on how healthcare workers perceive care for the ethnic minority oncology patient.
- Current knowledge on this topic is largely limited to the way healthcare professionals perceive themselves in caring for ethnic minority patients, as none of the qualitative studies on this topic used observational methods.

INTRODUCTION

Several decades of global immigration have made our societies increasingly multi-ethnic (WHO, 2010). For instance, in Flanders, the Dutch-speaking part of Belgium, approximately 15% of the population is of foreign descent (Noppe and Lodewijckx, 2012). Worldwide, healthcare services must deal with the growth of ethnic and cultural diversity in their populations (Devillé et al., 2011). In developed countries, care involving healthcare workers and patients with different cultural backgrounds and ethnicity is increasingly the norm (Kai et al., 2011). One of the four key priorities of the World Health Organization (WHO, 2010) regarding the health of immigrants concerns 'migrant sensitive health systems.' These systems should, among other things, ensure that health services are delivered to immigrants in a culturally and linguistically appropriate way (WHO, 2010).

Cancer is a leading cause of morbidity and mortality worldwide (WHO, 2015). A cancer diagnosis can be challenging, cancer is a disease that affects patients and their families emotionally and physically (Bultz & Carlson, 2006). Communication within oncology practice has been recognized as a core clinical skill (Fallowfield & Jenkins, 1999). To do justice to these specific aspects of oncology practice, this review focuses on cancer care services.

A critical review of the views and experiences of care users from ethnic minority groups who have received cancer services in Britain reveals the importance of gaining insight in the perspective of healthcare workers (Elkan et al., 2007). The review reported significant issues and challenges: comprehension and communication barriers, a lack of awareness of the existence of services, a perceived failure by providers to accommodate religious and cultural diversity, health beliefs, and diversity of views and experiences. The authors conclude that "*although direct or overt racism was identified as a problem in some studies, the greatest challenges appeared to result from institutional racism, from a failure of the NHS [National Health Service] to respond adequately to the information, language, religious and other cultural needs of people from minority ethnic groups* (Elkan et al., 2007, pp. 119)."

Both the culture of care recipients and healthcare providers are important in attuned connections between professional caregivers and care users of foreign descent (Kleinman & Benson, 2006; Oliemeulen & Thung, 2007). Hence, it is also beneficial to gain insight into the views of healthcare providers in caring for people with culturally diverse backgrounds. Kai et al.

(2007) point out that despite a tendency for improving intercultural care, surprisingly little is known about how health professionals themselves experience and perceive their work with care users of diverse ethnic origins. In this review we chose the term 'ethnic minority patients', to refer to all persons of foreign descent belonging to a minority group. As in social anthropology, the term ethnicity refers *"to aspects of relationships between groups which consider themselves, and are regarded by others, as distinctive* (Eriksen, 2002, pp. 4).

To our knowledge, no systematic literature review has been undertaken to investigate what is known from previous research about the views and experiences of oncology healthcare providers in caring for ethnic minority patients.

Aim

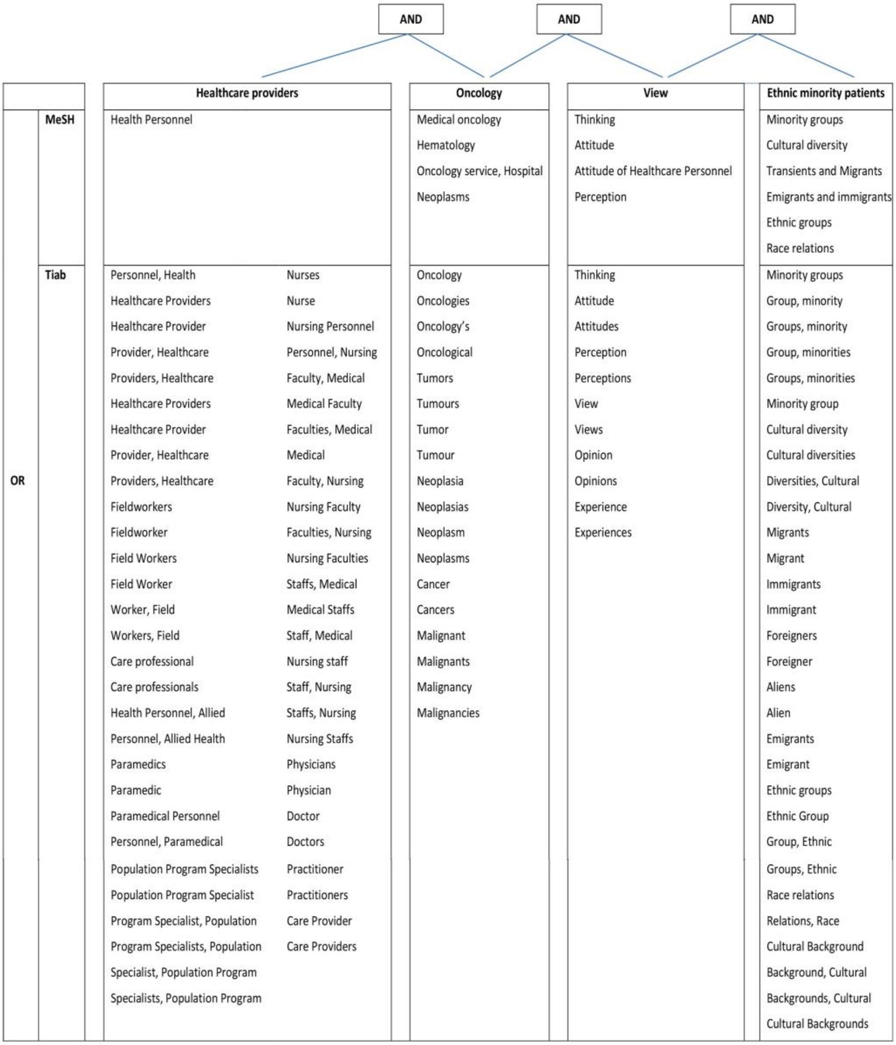
The aim of this review was to bring together and comprehensively summarize previous research reporting on the views and experiences of oncology healthcare providers when caring for ethnic minority patients.

METHOD

Search Strategy

A systematic mixed method review was conducted. Four electronic databases were systematically searched for relevant qualitative and quantitative studies: PubMed, CINAHL, Web of Science, and AnthroSource. Four groups of search terms were combined: healthcare provider and oncology and view/experience and ethnic minority. View was understood to mean "*a particular way of considering or regarding something; an attitude or opinion*" (Oxford Dictionaries, 2014). The search filter in Table 1 was used for PubMed. Searches in the other databases were based on this search strategy and adapted where needed. Reference lists of the included articles were screened for additional articles.

Table 1. Search Filter



		AND		AND	AND	AND
		Healthcare providers		**Oncology**	**View**	**Ethnic minority patients**
OR	**MeSH**	Health Personnel		Medical oncology	Thinking	Minority groups
				Hematology	Attitude	Cultural diversity
				Oncology service, Hospital	Attitude of Healthcare Personnel	Transients and Migrants
				Neoplasms	Perception	Emigrants and immigrants
						Ethnic groups
						Race relations
	Tiab	Personnel, Health	Nurses	Oncology	Thinking	Minority groups
		Healthcare Providers	Nurse	Oncologies	Attitude	Group, minority
		Healthcare Provider	Nursing Personnel	Oncology's	Attitudes	Groups, minority
		Provider, Healthcare	Personnel, Nursing	Oncological	Perception	Group, minorities
		Providers, Healthcare	Faculty, Medical	Tumors	Perceptions	Groups, minorities
		Healthcare Providers	Medical Faculty	Tumours	View	Minority group
		Healthcare Provider	Faculties, Medical	Tumor	Views	Cultural diversity
		Provider, Healthcare	Medical	Tumour	Opinion	Cultural diversities
		Providers, Healthcare	Faculty, Nursing	Neoplasia	Opinions	Diversities, Cultural
		Fieldworkers	Nursing Faculty	Neoplasias	Experience	Diversity, Cultural
		Fieldworker	Faculties, Nursing	Neoplasm	Experiences	Migrants
		Field Workers	Nursing Faculties	Neoplasms		Migrant
		Field Worker	Staffs, Medical	Cancer		Immigrants
		Worker, Field	Medical Staffs	Cancers		Immigrant
		Workers, Field	Staff, Medical	Malignant		Foreigners
		Care professional	Nursing staff	Malignants		Foreigner
		Care professionals	Staff, Nursing	Malignancy		Aliens
		Health Personnel, Allied	Staffs, Nursing	Malignancies		Alien
		Personnel, Allied Health	Nursing Staffs			Emigrants
		Paramedics	Physicians			Emigrant
		Paramedic	Physician			Ethnic groups
		Paramedical Personnel	Doctor			Ethnic Group
		Personnel, Paramedical	Doctors			Group, Ethnic
		Population Program Specialists	Practitioner			Groups, Ethnic
		Population Program Specialist	Practitioners			Race relations
		Program Specialist, Population	Care Provider			Relations, Race
		Program Specialists, Population	Care Providers			Cultural Background
		Specialist, Population Program				Background, Cultural
		Specialists, Population Program				Backgrounds, Cultural
						Cultural Backgrounds

Selection Criteria

Studies were included if they met following inclusion criteria:
- Empirical research or systematic review article.
- Article written in English, Dutch, French, or German.

- The study concerns each of these elements: an oncology setting; views/experiences of healthcare workers; care users belonging to an ethnic/cultural minority group.

Exclusion criteria were studies concerning:

- Cancer prevention: general prevention; (genetic) screening; vaccination.
- Participation in clinical trials or research.
- Cancer education.
- Treatment referral/recommendations.
- Articles published before January 2000.

Articles published before the year 2000 were excluded because of the recent rapid demographic changes in many parts of the worlds with regard to ethnic and cultural diversity. Furthermore, perceptions, attitudes, and policies towards inhabitants belonging to ethnic minority groups now are very different from 15 to 20 years ago.

Two reviewers independently screened all titles and abstracts. Disagreement or doubt about inclusion or exclusion were discussed between the reviewers. If doubt remained or if the abstract did not provide enough information, the paper was included for full text screening. One reviewer screened all full-text articles. In case of doubt, an additional screening was performed by a second reviewer. Studies also focusing on other participant groups besides healthcare providers, like patients, were included if the differing perspectives were discussed separately in the results section. The same criterion was used for studies not exclusively concerning oncology care settings; articles were included if the findings on different settings were clearly distinguishable in the results section.

Quality Assessment

For assessing the methodological quality of qualitative studies the Critical Appraisal Skills Programme (CASP) instrument was used (Milton Keynes Primary Care Trust, 2002) and for quantitative studies the Quality Assessment Tool (Vyncke et al., 2013). The assessments were done on full-text articles before data extraction.

The CASP comprises 10 questions to determine the rigour, credibility, and relevance of the study. The questions are designed to assist the reviewer in the evaluation by addressing the aim, methodology, design, sampling, data collection, reflexivity, ethical issues, data analysis, findings, and the value of the research.

The Quality Assessment Tool for quantitative studies was a modified version of an instrument developed by the Effective Public Health Practice Project (Thomas et al., 2004) and used in several other systematic reviews (Verbrugghe et al., 2013; Goossens et al., 2013). The instrument evaluates the overall quality of each study design and analysis by addressing the following items: selection and allocation bias, confounders, data collection methods, withdrawal and drop-outs, and comments on analysis.

The methodological quality of each included article was checked by one or two researchers. The evaluation process started with pilot testing the application of the tools in two articles with a qualitative design and two with a quantitative design by two reviewers. After piloting, 25% of the articles were independently evaluated by two researchers. Disagreements between the reviewers were discussed until consent was reached. The remaining articles were evaluated by one reviewer.

Data Extraction and Synthesis

Data were extracted by one reviewer and checked by two other reviewers. Data extraction tables (Tables 2 and 3) were designed to systematically extract the following data: primary aim of the study, methods (design, sample, and data collection method), study population, and results which were relevant for the purpose of this review. The data extraction tables present relevant findings literally, without the interpretation of the authors. An analysis of the extracted data showed several main topics. Due to heterogeneity of the results, meta synthesis of the qualitative studies and meta analysis of the quantitative studies was not possible. Therefore, the synthesis of the results was reported narratively.

Table 2. Supplementary Data: Overview of the Findings of the Included Studies with a Qualitative Research Design

Reference	Primary aim	Methodology		Study population	Results
		Setting	Design and Data-collection method		
Qualitative research design					
De Graaff et al., 2010	To answer the following questions: 1) What do cancer patients originating from Turkey or Morocco understand by 'good palliative care'? 2) How do Dutch care providers deal with ideas that diverge from the dominant values within palliative care?	The Netherlands	Design not specified Semi-structured in-depth interviews	33 cases of incurable cancer patients of Turkish or Moroccan decent 6 patients, 30 relatives, 47 care providers	The views of Turkish and Moroccan cancer patients and relatives on 'good palliative care' diverge on several points with Dutch care professionals. The main contradictory values for aims and means at the end-of-life are: - "Striving for cure up to the end" versus "Improving quality of life" - "Keeping patients' hope alive, therefore the family decides how much information can be given to a patient" versus "Fully informing the patient to reach shared decision making and to realize advance care planning" - "Ensuring that the patient dies with a clear mind" versus "Giving sufficient pain and symptom relief" - "Using opportunities for care in the Netherlands as well as in the country of origin" versus "Giving optimal care in the Netherlands"
De Graaff et al., 2012a	To gain insight into the factors that influence communication between health professionals and Turkish and Moroccan immigrants in the palliative phase of cancer.	The Netherlands	Design not specified Semi-structured in-depth interviews	33 cases of incurable cancer patients of Turkish or Moroccan decent 6 patients, 30 relatives, 47 care providers	"Few care providers made use of professional interpreters, as they considered this a time-consuming practice that needed planning and, moreover, one that most relatives did not appreciate." **Views on language differences and involvement interpreting family members:** - By some care providers as an impediment to providing good care - Others were well satisfied (especially those who adopted an open, inquiring attitude and who took plenty of time) despite experiencing restricted communication **Different expectations of communication** To many care providers it was "self-evident that patients, for whom further curative treatment is unavailable, should be discharged (...) Many patients and family members, however, continued to hope for a cure and hence wished to stay in hospital." **Different ideas about the role division in communication** A great deal of communication occurred via relatives. Patients and family regarded this generally as normal. In the view of care providers the patients should decide about treatment or care. **Responses of care providers to conflicting opinions and wishes regarding communication** - Resignation or blaming the family - Recognising differences and complying with the wishes of patient and family - Acknowledging differences yet proceeding on the basis of their own opinions and wishes -Acknowledging differences and jointly seeking the middle ground
De Graaff et al., 2012b	To explore how communication and decision-making in palliative care among Turkish and Moroccan patients is influenced by different styles of care management between Turkish and Moroccan families and Dutch professional care providers.	The Netherlands	Design not specified Semi-structured in-depth interviews	33 cases of incurable cancer patients of Turkish or Moroccan decent 6 patients, 30 relatives, 47 care providers	Concept 'care management group' used as key analytical tool Reasons for hampered communication and joint decision making: **- Different ethnic-cultural views on 'good care'**: focus of care providers on quality of life, while families tend to insist on cure **- Conflicting views on the role of the 'care management group'**: care providers see the patient as their primary discussion partner, while in the families relatives play a major part
Huang et al., 2009a	To explore the social construction of cultural issues in palliative care	Australia	Grounded theory Semi-structured interviews	7 oncology nurses in palliative care	The core category was **'accommodating cultural needs'**. This meant that nurses attempted to meet patients' specific requirements. They actively found ways to accommodate the needs of patients and their families. The process included compromise and negotiation, whereby limits were set. Nurses described cultural care in a palliative setting as being especially important and they described a high level of awareness on the importance of understanding cultural needs, such as: - Cultural-religious practice: "Cultural awareness and sensitivity and understanding of cultural mores helped nurses to actively recognize and meet their patients' cultural needs." Nurses adapt a variety of ways to respond to and respect the cultural and religious beliefs patients and their families. - Health practices: "Nurses sometimes compromise and even go beyond the boundary of routine or standard care practices to accommodate patients' cultural needs as expressed in religious practice" (e.g. alternative therapies). - Daily living practices: "Nurses accommodated culturally diverse daily living practices in several ways." - Responding to the challenges of cultural diversity: compromising and negotiating. "Despite many examples of nursing care being adapted to the cultural requirements of patients, most nurses noted (...) that they often encountered challenges when responding to such cultural diversity." They occasionally encountered ethical dilemmas regarding information disclosure and medical treatment choices. This was often presented as a conflict of values and often led to ambivalent feelings about the care they provided. There were some limits to the extent to which cultural needs were accommodated: the process of compromise and negotiation was often used when facing environmental barriers to the provision of culturally appropriate care (e.g., burning oil and candles). **The utilization of cross-cultural communication strategies** To provide appropriate cultural care, nurses often actively sought ways to effectively communicate and to understand cultural mores and needs. - The use of nonverbal communication techniques - Learning new languages and teaching patients: nonverbal communication, translated materials, and impromptu interpreters and communication techniques - The use of family members and key informants - The use of staff from other cultural background: as a resource for communication - Checking the level of understanding

Huang et al., 2009b	To understand the social construction of cultural care by oncology nurses providing palliative care	Australia	Grounded theory Semi-structured interviews	7 oncology nurses in palliative care	Following contributory factors influenced the way nurses **'accommodate cultural needs'** (described in previous article: Huang et al 2009 A): - **Views and understandings of culture and cultural mores:** a tendency to generalize about cultural characteristics of particular groups, however most nurses recognized that culture was not a fixed or static concept. Nurses often held well established views about the cultural mores of different groups. - **Philosophy of cultural care**: being culturally aware and sensitive; being respectful; being proactive; being competent with communication skills. - **Previous experiences with people from other cultures** had an important role in shaping nurses' approach to care. Experiences in caring as well as in personal life. Majority noted positive experiences in caring. - **Organisational approaches to culture and cultural care** influenced the nurses' approaches to accommodating cultural needs: organisational philosophy (culture and training); caring environment; available and accessible support services and resources (included social workers, cultural support services, interpreting services; information and materials about cultural needs). The environment appeared an important factor in the quality of cultural care by nurses.
Kai et al., 2007	To explore how practising health professionals experience and perceive their work with patients of ethnicity different from their own to inform interventions to enhance quality of care (using cancer care as a clinical context)	United Kingdom Cancer care settings	Constant comparison Focus groups	106 health professionals of differing disciplines	Respondents sought to provide professional standards of care for patients from diverse ethnic background, but they wrestled with a range of challenges. Including: communication, language, and working with patients in the context of their families. **Uncertainty and disempowerment** - Health professionals working with patients of differing ethnicity to their own experience considerable uncertainty. This was most often driven by a fear of doing the wrong thing. -The uncertainty had disempowering effects, which was characterized by anxiety and stress in cross-cultural interactions and inertia in the clinical approach. - Uncertainty and disempowerment had the potential to be self-perpetuating, to the detriment of patients care **Focus on cultural expertise** - Most professionals emphasize on factual knowledge about cultural difference in order to act and feel more confident. - There was incongruity between, on the one hand, a desire for and application of a knowledge-based cultural expertise approach and, on the other, a continuing experience of uncertainty with patients despite this approach. - Some professionals identified the risk of engendering stereotypical expectations of patients.
Kai et al., 2011	To explore health professionals' experiences of caring for patients with cancer from diverse ethnic communities to inform practice and quality of care interventions. This paper reports data on the contemporary practical challenges of communication, disclosure and patient autonomy faced by professionals in providing cross-cultural cancer care.	United Kingdom Cancer care settings	Constant comparison Focus groups	106 health professionals of differing disciplines	Health professionals perceived patients' needs generally similar across ethnic groups. **Opportunities** Respondents gave examples of how they experienced caring for patients of differing ethnicity to their own to be positive, stimulating and rewarding. **Challenges: Compromise of communication** Respondents experienced a range of challenges, particularly in encounters with a third party interpreting. When others acted as interpreter, communication often remained unsatisfactory. Some respondents were familiar with professional interpreters, but experience with family interpreters was much more common. Working with trained bilingual professionals: respondents usually valued the benefit, but still posed difficulties: -planning, resource and practical issues (lack of budget, need to anticipate patients' language needs, book in advance) - lack of confidence in skills of interpreter or uncertainty about precise role - sense of changes in power - Some participants found relatives were not willing to have a professional interpreter Disclosure, patient autonomy, and relationship with patient: respondents had concerns about whether and how information was disclosed to the patient when relatives mediated communication. -They experienced tension between their regard for individual patient autonomy and patient-centeredness on the one hand, and some families' approaches to ownership of information and decision making about care on the other
Lanceley and Cox, 2007	Identifying the: - educational and support needs of statutory and voluntary health and social care workers involved in meeting the cancer information needs of black minority ethnic (BME) communities living in a multiracial London borough; and - cancer information and support needs of people from BME communities living in a multiracial London borough.	London, statutory and voluntary sectors	Design not specified Semi-structured one-to-one interviews (with care workers) and focus groups (with patients and carers)	33 health and social care workers, 7 patients, and 3 carers	**Educational and support needs in working with people from ethnically diverse communities:** - Operate in challenging contexts. Distress in relation to work circumstances - Primarily function to make existing health and cancer information systems and procedures work better **Perceptions of current services:** - Role of general practitioners as gatekeeper problematic - General practitioners and medical colleagues recognized shortcomings in their services **Contributing factors:** Lack of understanding of available services and sometimes few avenues to talk about distress of cancer within the family (no common vocabulary; stigma)

Owens and Randhawa, 2004	To explore the ways in which professionals address the difficulties, problems and ambiguities of culturally competent practice.	Luton, United Kingdom Home and community-based palliative care settings	Phenomenology Semi-structured in-depth interviews	10 palliative care workers	**Cultural difference and practiced philosophies of palliative care:** The idea and philosophy of palliative care not seems exclusionary in itself. However staff expressed the view that it was sometimes difficult to put it into practice without there being discriminatory effects: 1."Staff seemed concerned that they frequently did not have the linguistic skills or sufficient understanding of a patient's cultural background to 'make them comfortable'." "The inability to provide the personal and emotional commitment seen as intrinsic to the job undermines the more professional notion of providing a service." 2."Palliative care involved 'standing back', and letting individual patients take the lead in requesting help and care." Some respondents recognized that 'cultural competence' may require a more interventionist and persistent approach to the provision of services than philosophies of palliative care usually allow. However, "anxieties raised by staff not just arise from concerns about linguistic proficiency, but also stemmed from ambivalence and uncertainty about how to bring together a system of care marked by a particular cultural tradition with the needs of patients whose cultural position was seen as being fundamentally different." **Caring for South Asian patients: encountering difference** Respondents sensed that they were dealing with patients who had ways of life which, in most cases, felt distinctively from their own. Overall, "a tension is detectable in the way in which service providers conceptualise cultural differences. On the one hand, clear distinctions are routinely drawn between the cultural position of service providers and that of South Asian patients, particularly when they become readily visible in the context of home and community. On the other, professional notions of fairness, equality and understanding needs on an individual basis work to undermine the significance attached to cultural difference in everyday practice." **Working across difference: communicating with patients, family and community** "While respondents recognised that effective communication went beyond language to include an ability to understand and empathise with a variety of cultural practices and beliefs, the difficulties of caring for those who do not speak fluent English lay at the heart of their concerns." Many respondents preferred using family members to communicate than a professional interpreter or link worker.
Pergert et al., 2007	To explore the caring situation of families with an immigrant background within the context of paediatric oncology care.	Sweden Paediatric oncology	Grounded theory Focus groups and individual interviews	- Focus group participants: 25 healthcare staff members - Individual interviews: 5 registered nurses	A main concern of healthcare staff: **obstacles** to communication and consequently to development of the **"transcultural caring relationship"**. Obstacles may lead to: misunderstandings; perhaps damage; a full stop to the transcultural care relationship. The obstacles were divided into 4 main categories: 1. Linguistic obstacles: the greater the inability to speak the same language, the higher the linguistic diversity. A primary obstacle. Consequences include: - lack of nursing communication; - lack of caring conversation and chatting; - interpreter dependency (consequences: triadic relationships, loss of information control, information compacting) 2. Cultural and religious obstacles: include different views and practices (regarding social codes; social roles; social space) that may influence communication and social interaction. Most relevant consequences: - Differences in emotional expression: can lead to misunderstandings if differences are great - Truth-telling differences: healthcare staff are favourable to truth-telling, they believe it is a prerequisite for honesty and trustworthiness. They are put in an ethical dilemma when families ask them not to tell the truth or omit some information. 3. Social obstacles: includes differences in social situation, identities and status that will influence the social interaction. A consequence is: Racism and prejudice (can exist on both sides) 4. Organizational obstacles: unadjusted policies and routines (inflexible policies, routines, and practices that are not adjusted to suit transcultural care situations). "The healthcare staff carry out their jobs according to policies and routines on the ward, and when reflection is missing they will continue even with routines that are obviously obstructing the development of transcultural caring relationships." Consequence is a lack of time: it takes longer to develop a caring relationship with someone when there are many obstacles. Inequity in Care: "When healthcare staff fail to recognize obstacles to the transcultural caring relationship, the consequence will be inequity in the care of families with an immigrant background, because they often experience more obstacles in the caring relationship and thus receive less qualitative care"

Pergert et al., 2008	To gain knowledge about how health-care staff continuously resolve "obstacles to transcultural caring relationships" as they care for families with an immigrant background within the context of paediatric oncology care.	Sweden Paediatric oncology	Constant comparative method Focus groups and individual interviews	- Focus group participants: 25 healthcare staff members - Individual interviews: 5 registered nurses	Through **"bridging"** health-care staff deal with **obstacles** to transcultural caring relationships. Bridging is a process in which following tools may be used and combined: **Communication tools** - Non-verbal communicating : Signs and 'charades'; Caring touch; Providing printed information - Interpreter reliance Transcultural tools - Transcultural learning (continuous process including theoretical knowledge and awareness of one's own culture) - Transcultural reflecting (reflective approach including trying to understand other people, cultures and looking at oneself and one's own culture) - Transcultural linking (other person's functioning as a transcultural link) Organizational tools Organizational possibilities and responsibilities for bridging obstacles: to adjust policies and routines and to provide necessary resources and conditions. - Time allocating (e.g., extra time for interpreting-relying consultations) - Transcultural training (opportunities for transcultural learning and reflecting) "The degree of success in bridging varies. Using only one tool or using tools inappropriately can lead to failure in bridging. If several tools are combined and bridging is successful, the transcultural caring relationship will continue with various degrees of quality, depth, and intensity"
Richardson et al., 2006	To explore the views of professionals caring for people with cancer from black and ethnic minority groups currently working in health and social care and to consider their needs for training.	London, Birmingham, Manchester - United Kingdom	Design not specified Focus groups	28 professionals working with cancer patients	Following issues arose from the analysis: **Language and achieving understanding** Professionals were deeply concerned about patients' lack of understanding of a diagnosis or the complexities of treatment. They were keen for their patients to have a full understanding. Solution: some find non-verbal means of communicating. Written information was often not a satisfactory solution (lack of availability in different languages; illiterate patients) **The process and outcome of working with interpreters** Some professionals had very good experiences with specialist medical interpreters, but serious problems were experienced with generic interpreters: Unobtainable of interpreters; to busy; often unclear what was actually translated Unable to convey the same underlying message: breach cultural norms; Concerns about the impact of the work for interpreters Family interpreters: unfair for translating relatives (children); relationship mediated by someone else **Dealing with cultural difference at both a practical and philosophical level** Many enjoyed learning about different cultures, but being confronted with many new ways of coping with illness, dying or death could cause some anxiety. Some tried to learn key cultural issues, but many stressed the importance of not making assumptions about any one patient. Concerns about breaching cultural norms of patients and families unknowingly. Fear of antagonizing a patient and losing trust, while at the same time a concern to be true to their caring principles **Issues of racial bias** "Most participants were certain that there was no element of racial bias in their work, a small number admitted that they did feel differently towards some groups in their day-to-day life, but hoped that this did not impinge on their work" Racism amongst patients towards staff or other patients was widely acknowledged and could be difficult to handle **Desire for training and support** - Few lacked support - Most felt they lacked training in responding to ethnic, religious , and cultural diversity and sought better skills for engaging openly with all patients. - Training to help reflecting on their own feelings, attitudes and assumptions (no 'fact file' training); some suggested training in working with interpreters
Vadaparampil et al., 2008	To better understand factors that may influence the discussion of fertility preservation issues with paediatric cancer patients and their families	Florida, 13 out of 15 paediatric cancer centres	Design not specified Semi-structured telephone interviews	24 paediatric oncologists	**Barriers in discussing fertility preservation:** According to one-third of the respondents: issues of culture and cultural differences (of parents). Description often touched religious values or cultural views of masturbation. Although respondents answered "no" when they were asked if religion was an issue (or culture or non-English speaking parents)

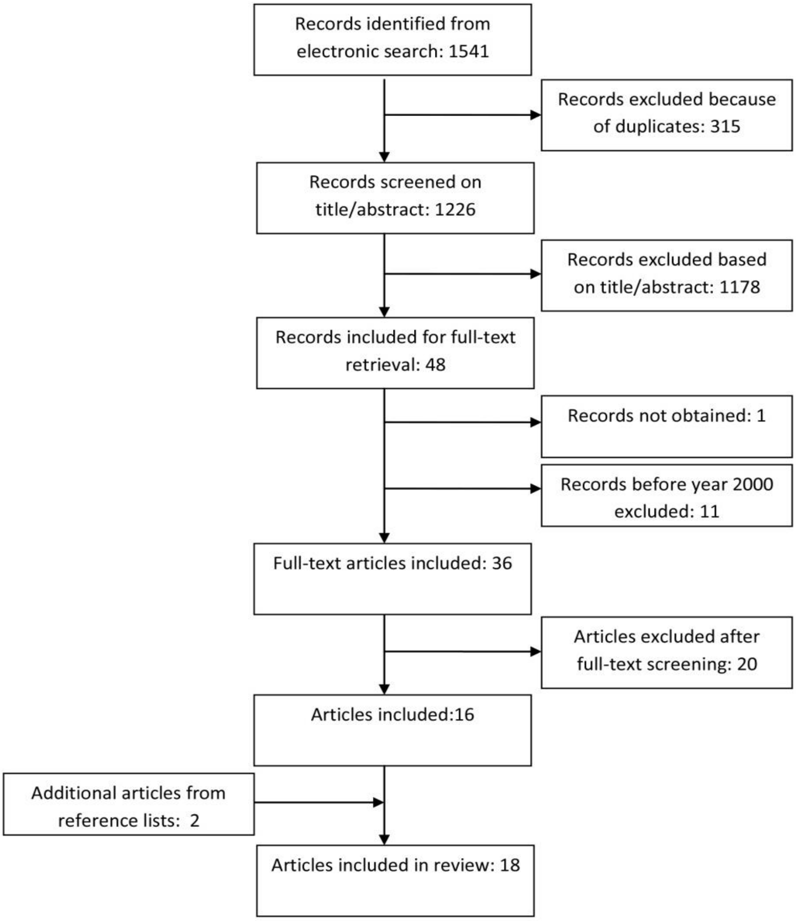
Table 3. Supplementary Data: Overview of the Findings of the Included Studies with Quantitative and Mixed Methods Design

Reference	Primary aim	Methodology		Study population	Results
		Setting	Design and Data-collection method		
Quantitative and mixed method researchs design					
Abbe et al., 2006	To determine the attitudes and perspectives of a sample of paediatric oncologists, trained, professional interpreters, and Spanish-speaking parents on the topic of language barriers in paediatric oncology.	Washington DC and Los Angeles, United States Two private non-profit hospitals	Mixed method Cross-sectional	37 paediatric oncologists 17 trained professional interpreters 17 Spanish speaking parents	**Most important element of interpretation** - accurate, word-for-word interpretation (52%) - level of experience oncologists and interpreters at working together (28%) - oncologist's choice of words and sentence length (15%) -family's level of comfort as the most important (6%) **Confidence working with interpreters** - 46% very confident - 51% fairly confident **Sense of control working with interpreters** - 38% less in control - 8% more in control - 51% no effect on sense of control **Most significant obstacle in communicating through an interpreter** - complexity of information (52%) - inability to know whether information has been accurately interpreted (36%) - extra time (9%) - the stop and start nature (3%) **Benefits of an interpreter** According to several oncologists: could improve communication process in ways other than providing accurate and complete interpretations **Oncologists' suggestions for improving interpreted consultations:** - learn Spanish themselves (33%) - use of videos and other handouts in the patient's language(27%) - work with one specific interpreter who was familiar with oncology/ haematology (17%) - increase number of interpreters: less "wait time" and less fatigue interpreters (13%)
Anderlik et al., 2000	To seek information concerning: 1) The frequency with which physicians encounter family requests to withhold information from patients 2) the manner in which physicians respond to such requests 3) the influence of cultural norms on physicians' decisions 4) the range of factors that motivate physicians to withhold information 5) the extent to which physicians employ euphemisms to communicate a cancer diagnosis	Texas, United States of America M.D. Anderson Cancer Centre	Cross-sectional Questionnaire	124 physicians	63% of physicians answered yes when they were asked "are you more likely to abide by a family request if you believe that informing the patients would violate their cultural norms" Most frequently selected motivating reason for withholding information were: - sensitivity to patient's/family cultural norms (37 respondents) - patient's fragile emotional state (34 respondents) - respect for patient's expressed wishes (34 respondents) - concern that information would destroy hope (24 respondents) - respect for family's expressed wishes (22 respondents)
Butow et al., 2011	Comparing the content and process of communication between oncologists and Anglo-Australians vs immigrants with and without an interpreter, in audio-taped Oncology consultations.	New South Wales, Australia 10 medical oncologists in 9 hospitals	Cross-sectional Observational study	Consultations with 78 patients with incurable cancer (31 Anglo-Australian and 37 immigrants) and 115 family members (38 Anglo-Australian and 77 immigrants)	- Consultation length with immigrants vs Anglo-Australians (with or without interpreter) were not significantly different Results were mostly not significantly different for immigrants without interpreters vs Anglo-Australians - Doctors spoke less to immigrants with interpreters than to Anglo-Australians ($p < 0.0001$); - Doctors spent proportionally less time on: cancer related issues ($p = 0.005$), summarizing and informing ($p \leq 0.003$); - Doctors spent proportionally more time on: other medical issues ($p = 0.0008$), and directly advising ($p = 0.0008$) and asking questions ($P = 0.002$)
Butow et al., 2013	To compare communication about poor prognosis between oncologists and Australian-born patients versus immigrants with and without interpreters, in audio-taped oncology consultations.	New South Wales, Australia 10 medical oncologists in 9 hospitals	Cross-sectional Observational study	Consultations with 78 patients with incurable cancer (31 Anglo-Australian and 37 immigrants) and 115 family members (38 Anglo-Australian and 77 immigrants)	- Few differences were detected in the content or style of oncologists' discussion of prognosis with immigrants versus Anglo-Australian born patients. -The use of hope giving by oncologists was substantially less when an interpreter was present ($p = 0.004$) - Oncologists less commonly used some medical jargon with immigrants without interpreters ($p = 0.009$)
Zebrack et al., 2008	To assess oncology social workers' roles, functions, scope of practice, and level of competence in key areas of practice, as well as their perceptions of professional development and training needs	United States	Cross-sectional Survey	622 members of the Association of Oncology Social Work	Members spent an average of 9.8% on non-English-speaking populations. They indicated their level of competence in working with non-English-speaking populations as: -11% none -39 % little (50% little to none) -35% some -15% a lot

RESULTS

The search revealed a total of 1541 records: 872 in PubMed, 317 in Web of Science, 294 in CINAHL, and 58 in Anthrosource. After removal of duplicates, records were screened for relevance by applying the inclusion and exclusion criteria. Most records were excluded based on title and abstract. Eighteen articles were retained, reporting 14 different studies. One record retained in the abstract selection was an unpublished PhD dissertation. It could not be obtained, even after attempts to contact the author and the University Department, therefore the record was excluded. The process of identifying relevant publications is depicted in Figure 1.

Figure 1. Decision Flowchart for Indentified Studies



Characteristics

All articles were written in English and each study was undertaken in a 'western' country.

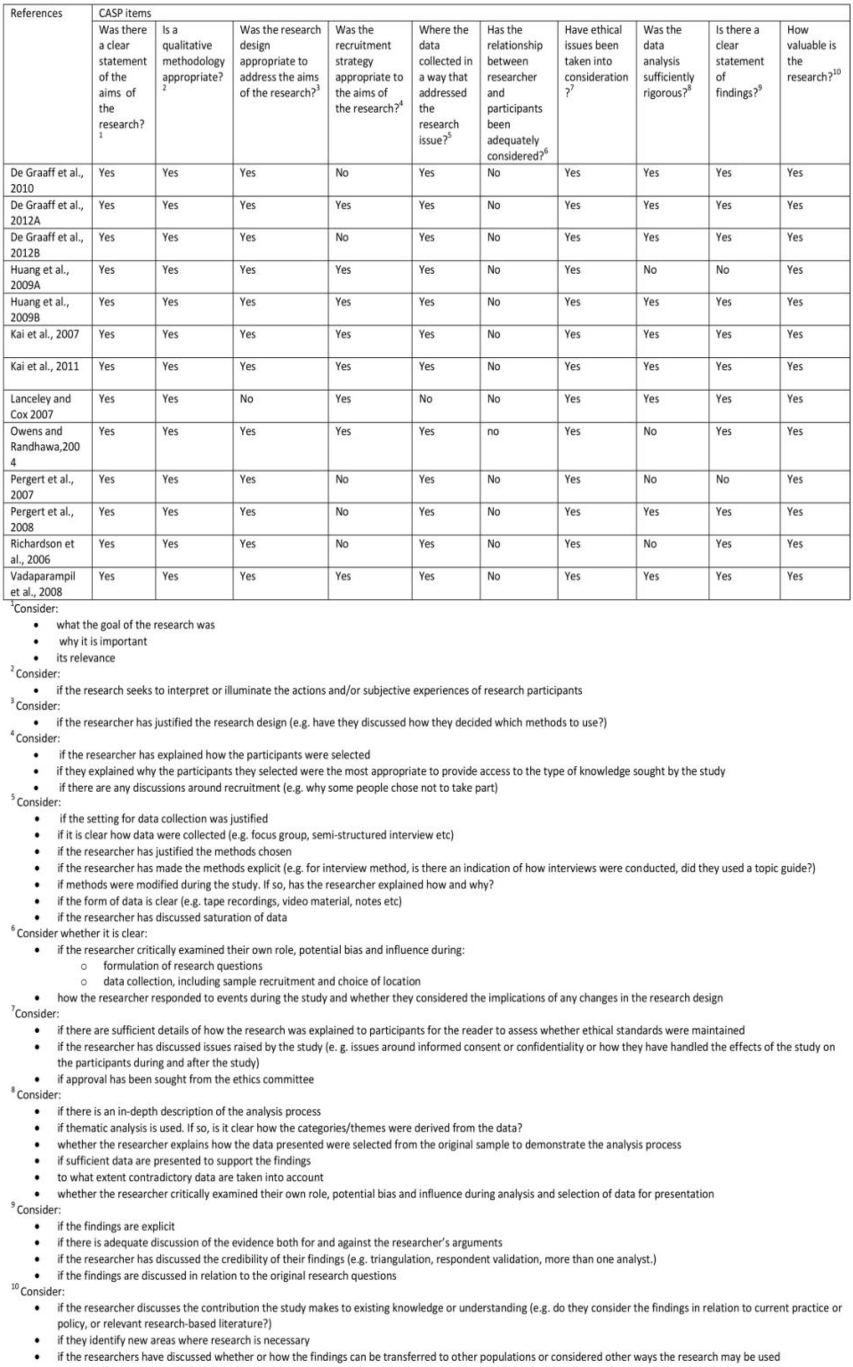
Eight studies (13 articles) with a qualitative design were included. Four qualitative studies (five articles), were conducted in the United Kingdom. One of the four remaining studies (three articles) was conducted in the Netherlands, one in Sweden (two articles), one in Australia (two articles), and one in the United States (one article). Two studies (three articles) used a grounded theory design, two studies (three articles) used constant comparison method, and one study (one article) used a phenomenological design. In four studies (six articles) the design was not further specified beyond being qualitative. Semi-structured interviews (mostly face-to-face) were conducted in five studies (eight articles), focus groups in two studies (three articles), one study (two articles) used both data-collection methods. All but two studies (two articles) concerned health care providers of diverse disciplines, in which nurses and physicians were most frequently represented. One study represented nurses alone, and one study focused only on paediatric oncologists.

Three studies (four articles) with a quantitative design and one mixed method study were retained. Three of these studies (three articles) were conducted in the United States, and one study (two articles) was conducted in Australia. A cross-sectional design was used in all studies. Three studies (four articles) represented oncologists or physicians, and one study (one article) concerned members of the Association of Oncology Social Work.

Methodological Quality

The results of the quality assessment (CASP) for the selected qualitative articles are presented in Table 4. In none of the articles was the relationship between the researcher and participants adequately described. An average of 26% of the CASP items of the articles were evaluated negatively (range 10% to 40%). The representativeness of the participants within the qualitative studies is doubtful, as some authors have pointed out. No article was excluded because of methodological quality, as the limitations observed were not the type that would invalidate the findings.

Table 4. Quality Assessment of Qualitative Studies Using the Critical Appraisal Programme (CASP) (Milton Keynes Primary Care Trust, 2002)



References	CASP items									
	Was there a clear statement of the aims of the research? [1]	Is a qualitative methodology appropriate? [2]	Was the research design appropriate to address the aims of the research? [3]	Was the recruitment strategy appropriate to the aims of the research? [4]	Where the data collected in a way that addressed the research issue? [5]	Has the relationship between researcher and participants been adequately considered? [6]	Have ethical issues been taken into consideration? [7]	Was the data analysis sufficiently rigorous? [8]	Is there a clear statement of findings? [9]	How valuable is the research? [10]
De Graaff et al., 2010	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
De Graaff et al., 2012A	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
De Graaff et al., 2012B	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Huang et al., 2009A	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes
Huang et al., 2009B	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Kai et al., 2007	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Kai et al., 2011	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Lanceley and Cox 2007	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes
Owens and Randhawa,2004	Yes	Yes	Yes	Yes	Yes	no	Yes	No	Yes	Yes
Pergert et al., 2007	Yes	Yes	Yes	No	Yes	No	Yes	No	No	Yes
Pergert et al., 2008	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Richardson et al., 2006	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes
Vadaparampil et al., 2008	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

[1] Consider:
- what the goal of the research was
- why it is important
- its relevance

[2] Consider:
- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

[3] Consider:
- if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

[4] Consider:
- if the researcher has explained how the participants were selected
- if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- if there are any discussions around recruitment (e.g. why some people chose not to take part)

[5] Consider:
- if the setting for data collection was justified
- if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
- if the researcher has justified the methods chosen
- if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?)
- if methods were modified during the study. If so, has the researcher explained how and why?
- if the form of data is clear (e.g. tape recordings, video material, notes etc)
- if the researcher has discussed saturation of data

[6] Consider whether it is clear:
- if the researcher critically examined their own role, potential bias and influence during:
    - formulation of research questions
    - data collection, including sample recruitment and choice of location
- how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

[7] Consider:
- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- if approval has been sought from the ethics committee

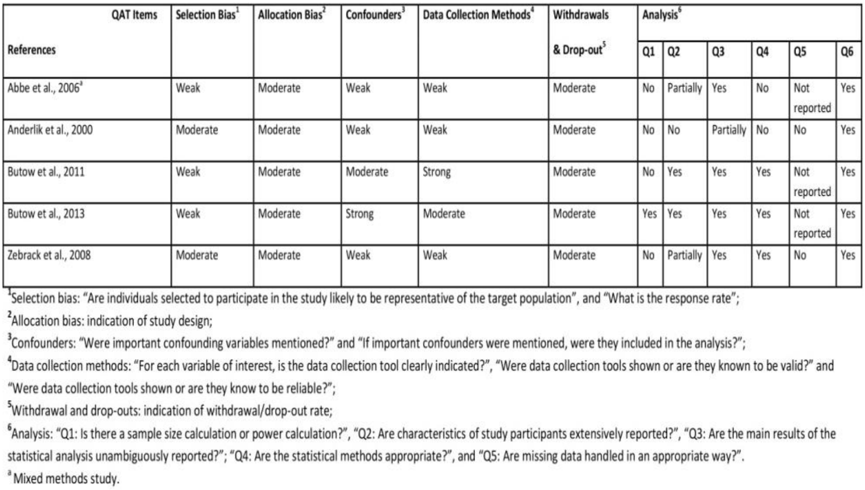
[8] Consider:
- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

[9] Consider:
- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
- if the findings are discussed in relation to the original research questions

[10] Consider:
- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

The results of the quality assessment tool for quantitative studies (Vincke et al., 2013) are presented in Table 5. The quality of the selection of participants within most quantitative studies was evaluated as weak. No article was excluded because of methodological quality. In one case in which the results were ambiguously reported, the first author was contacted for further information.

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



QAT Items References	Selection Bias[1]	Allocation Bias[2]	Confounders[3]	Data Collection Methods[4]	Withdrawals & Drop-out[5]	Analysis[6]					
						Q1	Q2	Q3	Q4	Q5	Q6
Abbe et al., 2006[a]	Weak	Moderate	Weak	Weak	Moderate	No	Partially	Yes	No	Not reported	Yes
Anderlik et al., 2000	Moderate	Moderate	Weak	Weak	Moderate	No	No	Partially	No	No	Yes
Butow et al., 2011	Weak	Moderate	Moderate	Strong	Moderate	No	Yes	Yes	Yes	Not reported	Yes
Butow et al., 2013	Weak	Moderate	Strong	Moderate	Moderate	Yes	Yes	Yes	Yes	Not reported	Yes
Zebrack et al., 2008	Moderate	Moderate	Weak	Weak	Moderate	No	Partially	Yes	Yes	No	Yes

[1] Selection bias: "Are individuals selected to participate in the study likely to be representative of the target population", and "What is the response rate";

[2] Allocation bias: indication of study design;

[3] Confounders: "Were important confounding variables mentioned?" and "If important confounders were mentioned, were they included in the analysis?";

[4] 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?";

[5] Withdrawal and drop-outs: indication of withdrawal/drop-out rate;

[6] 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?", and "Q5: Are missing data handled in an appropriate way?".

[a] Mixed methods study.

Study Aims and Outcomes

The included articles dealt with a wide variety of research questions, hence the results of the articles were heterogeneous. A detailed description of the study aims, characteristics, and outcomes is shown in Tables 2 and 3. The primary aim of five qualitative research articles was on views or experiences of healthcare providers in caring for ethnic minority groups in a cancer setting (Kai et al., 2007; Kai et al., 2011; Pergert et al., 2007; Pergert et al., 2008; Richardson et al., 2006). The primary aim of six other articles with a qualitative research design indirectly concerned the experiences or views (De Graaff et al., 2010; 2012a; 2012b; Huang et al., 2009a; 2009b; Owens and Randhawa, 2004). The other seven articles, mostly quantitative, had a different primary focus. As already mentioned, data extraction of the results was limited to findings relevant for the aim of this review. An analysis of the extracted data revealed following main topics: general views of oncology health workers caring for ethnic minority patients, challenges or barriers, and opportunities or contributory factors. The results were synthesized on the basis of these main topics. The following discussion presents the details of the findings.

General Views of Oncology Health Workers Caring for Ethnic Minority Patients

Oncology health care providers sought to meet professional standards and tried to adapt care to the needs of ethnic minority patients (Huang et al., 2009a; Kai et al., 2007; Pergert et al., 2008). This process has been either described as ‘accommodating cultural needs’ (Huang et al., 2009a) or as ‘bridging obstacles’ (Pergert et al., 2008). The process of ‘accommodating cultural needs’ included the use of compromise and negotiation strategies, whereby limits are set to the extent to which cultural needs are accommodated (Huang et al., 2009a). By ‘bridging obstacles’ healthcare staff tried to deal with obstacles to transcultural caring relationships (Pergert et al., 2008). Obstacles to communication and consequently to the development of the transcultural caring relationship were the main concerns of healthcare staff (Pergert et al., 2007). Healthcare workers used and combined communication, transcultural, and organizational tools to overcome obstacles (Pergert et al., 2008). To provide appropriate cultural care, nurses often actively sought ways to effectively communicate and to understand cultural mores and needs (Huang et al., 2009a).

Kai et al. (2007) showed that healthcare professionals fear doing the wrong thing when working with patients of a different ethnicity. This causes uncertainty with disempowering effects in caring for these patients (Kai et al., 2007). Many healthcare professionals focus on expertise and factual knowledge about cultural differences to act and to feel more confident (Kai et al., 2007).

Challenges and Barriers When Caring for Ethnic Minority Patients

Most studies showed that oncology healthcare providers are faced with challenges or barriers when caring for ethnic minority patients (Abbe et al., 2006; Anderlik et al., 2000; Butow et al., 2011; 2013; De Graaff et al., 2010; 2012a; 2012b; Huang et al., 2009a; Kai 2007; 2011; Lanceley & Cox, 2007; Owens & Randhawa, 2004; Pergert et al., 2007; Richardson et al., 2006;

Vadaparampil et al., 2008; Zebrack et al., 2008). One study pointed out the general importance of recognizing obstacles to the transcultural caring relationship as otherwise ethnic minority patients would receive lower quality care (Kai et al., 2007). Since perceived challenges and barriers are mostly related to communication, cultural matters, or organizational aspects, the details of these issues are presented in the following paragraphs.

Communication

Issues related to communication were the most extensively described challenge in the studies, and were often perceived as a primary barrier when caring for ethnic minority patients. Barriers concerning interpreters and barriers regarding disclosure were most frequently mentioned, and are discussed in the next section.

Interpreters: Relatives and Professionals

Being unable to speak the patient's language lies at the heart of the concern of oncology healthcare workers (Owens & Randhawa, 2004; Pergert et al., 2007). Consequences are, among others, a lack of caring conversation and chatting and dependence on the interpreter (Pergert et al., 2007). Communication often was unsatisfactory in patient encounters when there was a third party interpreting (Kai et al., 2011). Although most healthcare professionals do have some experience with professional interpreters, it is much more common to work with family interpreters (De Graaff et al., 2012a; Kai et al., 2011; Owens & Randhawa, 2004). Working with professional interpreters posed several difficulties, including being time consuming (Abbe et al., 2006; De Graaff et al., 2012a; Kai et al., 2011), practical issues (budgetary, needs planning, unobtainable) (De Graaff et al., 2012a; Kai et al., 2011; Richardson et al., 2006), sense of less control (Abbe et al., 2006; Kai et al., 2011), not knowing what is translated (Kai et al., 2011; Richardson et al., 2006), and relatives not willing to have a professional interpreter (De Graaff et al., 2012a; Kai et al., 2011). Abbe et al. (2006) showed that a majority of pediatric oncologists perceive accurate word-to-word translation as the most important element of interpreting.

Working with relatives who interpreted was much more common than professional interpreters. One study showed that some care providers viewed family interpreters as an impediment to providing good care, while other care providers were satisfied despite experiencing restricted communication (De Graaff et al., 2012a). Concerns were related to the triadic relationship between the patient, the family interpreter, and themselves (Pergert et al., 2007; Richardson et al., 2006), and some care providers felt it was unfair to the family members to ask them to translate, especially in case of children translating for their parents (Richardson et al., 2006). In a quantitative study the process of communication was observed between oncologists and Anglo-Australian patients versus immigrants with and without interpreters (Butow et al., 2011). This study showed that the consultation length for immigrants (with or without interpreter) versus Anglo-Australians was not significantly different. The following differences between consultations with immigrants using an interpreter and consultations with Anglo-Australians were found: the number of words doctors spoke to immigrants was lower; they spent proportionally less time on cancer related issues, summarizing and informing; and spent proportionally more time on other medical issues, directly advising, and asking questions.

Disclosure of Diagnosis and Prognosis

The literature shows that oncology healthcare professionals are concerned about whether and how information about diagnosis and prognosis is disclosed to the patient when relatives mediate the communication (Kai et al., 2011; Richardson et al., 2006; Huang et al., 2009a; Lancely & Cox, 2007). Healthcare staff believe that it is important for their patients to have a full understanding of the diagnosis and prognosis (Richardson et al., 2006; Pergert et al., 2007; De Graaff et al., 2012a) and they experience an ethical dilemma when a family asks them not to tell the truth or omit some information (Pergert et al., 2007; Huang et al., 2009a). De Graaff et al. (2012a) bring to light the different expectations of communication between Dutch care providers and cancer care users of Turkish and Moroccan descent: for many care providers it is self-evident that patients should be discharged when further curative treatment is unavailable, while many patients and family members wish to stay in hospital as they continue to hope for cure. Although Butow et al. (2013) detected few differences in the content or style of oncologists' discussion of prognosis with immigrants versus Anglo-Australian born patients, the practice of giving hope by oncologists was substantially less when an interpreter was present.

A quantitative study with a contrasting outcome demonstrated that 63% of physicians answered yes when they were asked "Are you more likely to abide by a family request if you believe that informing the patients would violate their cultural norms?” (Anderlik et al., 2000).

Cultural Matters

Another challenge in oncology care practice for ethnic minority patients is attributed to cultural matters. In most articles cultural matters refer to differing views between healthcare professionals and patients of other descent, mostly concerning the role of family or issues relating to truth telling and hope (De Graaff et al., 2010; 2012a; 2012b; Huang et al., 2009a; Kai et al., 2007; 2011; Lanceley & Cox, 2007; Owens & Randhawa, 2004; Pergert et al., 2007; 2008; Richardson et al., 2006; Anderlik et al., 2000).

Pergert et al. (2007) discussed cultural and religious obstacles which include different views and practices regarding social codes, roles, and space. Richardson et al. (2006) found that healthcare professionals have concerns about breaching the cultural norms of patients and families without realizing it is happening. Professionals fear antagonizing a patient and losing trust, but are simultaneously concerned about adhering to their principles of care. De Graaff et al. (2010; 2012a; 2012b) point out differing views between Dutch oncology care providers and Turkish or Moroccan cancer care users on ‘good care’ at the end-of-life and ‘care management groups’ (a concept that visualizes the diversity of interests and tasks among those involved in care activities). Healthcare professionals views on ‘good care’ are characterized by a focus on quality of life and they see the patient as the primary discussion partner, while families insist on cure and relatives play a major part (De Graaff et al., 2010; 2012b). A great deal of communication occurred via relatives. Patients and family regarded this generally as normal, while in the view of healthcare providers, patients should decide about treatment or care (De Graaff et al., 2012b). Respondents in the study of Kai et al. (2011) experienced tension between their regard for individual patient autonomy and patient-centeredness on the one hand, and some families’ approaches to ownership of information and decision making about care on the other.

A quantitative study on discussing fertility preservation with patients found that, according to one-third of the paediatric oncologists, issues of culture and cultural differences are perceived as a barrier in discussing this issue, although they answered “no” when they were asked if religion (or culture or non-English speaking parents) was an issue (Vadaparampil et al., 2008).

Organizational Aspects

Organizational aspects also represent a barrier in oncology care for ethnic minority patients.

Pergert et al. (2007, pp. 323) highlighted the general importance of organizational obstacles in oncology care for ethnic minorities, as their study showed that *"healthcare staff carry out their jobs according to policies and routines on the ward, and when reflection is missing they will continue even with routines that are obviously obstructing the development of transcultural caring* relationships."

One study points out that, although few healthcare workers lacked support, most were in need of training in responding to ethnic, religious, and cultural diversity and sought better skills for engaging openly with all patients (Richardson et al., 2006). They desired training to reflect on their own feelings and attitudes and assumptions.

Healthcare and social workers working with black minority ethnic communities in London experienced distress in relation to work circumstances and perceived the work context as challenging (Lanceley & Cox, 2007). A quantitative study on members of the Association of Oncology Social Work in the US found that respondents spent an average of 9.8% of their time on non-English-speaking populations, while half of them indicated their level of competence in working with non-English-speaking populations as 'little to none' (Zebrack et al., 2008). However, a study on paediatric oncologists reported a somewhat different finding with regard to working with interpreters, as 46% felt very confident and 51% felt fairly confident (Abbe et al.,2006).

With regard to the provision of palliative cancer care, a few studies point out more specific organizational barriers (De Graaff et al., 2010; Owens & Randhawa, 2004). Palliative care is perceived as a western-care model that does not always correspond with the views and values of care users of non-western origin (De Graaff et al., 2010; Owens & Randhawa, 2004). Owens and Randhawa (2004) found that the idea and philosophy of palliative care does not seem exclusionary in itself, but staff reported that it was sometimes difficult to put the idea and philosophy into practice without there being discriminatory effects. Among other things, staff seemed concerned about being unable to make ethnic minority patients comfortable. They perceived personal and emotional commitment as intrinsic to their job, but experienced an inability to provide it. Therefore, they believed the professional mission of providing service was undermined.

Facilitating Factors and Opportunities When Caring for Ethnic Minority Patients

Whereas most studies reported the challenges or barriers in caring for ethnic minority patients, fewer than half of the articles also discussed facilitating factors and opportunities (Huang et al., 2009a; 2009b; Kai et al., 2007; 2011; Pergert et al., 2008; Richardson et al., 2006; Owens & Randhawa, 2004). In most cases these factors and opportunities were related to positive experiences, cultural competence, and organizational aspects.

Positive Experiences

Two qualitative studies described positive experiences of oncology healthcare professionals in caring for ethnic minority patients (Huang et al., 2009b; Kai et al., 2011). Kai et al. (2011) reported healthcare provider examples of positive, stimulating, and rewarding experiences in caring for patients of a different ethnicity. Huang et al. (2009b) pointed out that previous experiences with people from other cultures have an important role in shaping nurses' approaches to care. In their study, a majority of the respondents noted positive experiences in caring for patients from other cultures.

Cultural Competence

Six articles, with a qualitative design, discussed competencies of healthcare professionals as a possible facilitating factor in caring for ethnic minority patients (Huang et al., 2009a; 2009b; Kai et al., 2007; Pergert et al., 2008; Owens & Randhawa, 2004; Richardson et al., 2006). Huang et al. (2009b) argued that nurses' philosophy of cultural care was a facilitating factor in accommodating cultural needs. According to the participants, this meant: being culturally aware and sensitive, respectful, proactive, and competent in communication. One study explicitly referred to cultural competence (Owens & Randhawa, 2004); in other articles authors used different terminology. In general, communication strategies and cultural knowledge or transcultural learning and reflection were clearly distinguished in these articles.

Communication strategies

Three articles discussed facilitating factors or opportunities in communication with ethnic minority patients (Huang et al., 2009a; Pergert et al., 2008; Richardson et al., 2006). Huang et al. (2009a) showed that nurses, among others, often actively seek ways to effectively communicate to provide appropriate cultural care. The use of non-verbal communication methods is mentioned most often, such as translated and printed information, and 'caring touch' or other non-verbal signs (Huang et al., 2009a; Pergert et al., 2008; Richardson et al., 2006). In addition, the use of interpreters (Huang et al., 2009a; Pergert et al., 2008), key informants such as family members, or staff of other descent, and checking to be sure of the patients' level of understanding have been described as facilitating factors (Huang et al., 2009a).

Cultural knowledge or transcultural learning and reflection

Some studies pointed out that healthcare professionals both emphasized the importance of cultural needs and factual knowledge about cultural differences and generalized cultural characteristics (Huang et al., 2009a; 2009b; Kai et al., 2007), and recognized that culture is not a fixed or static concept (Huang et al., 2009b), so that they were aware of the risk of engendering stereotypical expectations of patients (Kai et al., 2007). Two studies reported an incongruity or tension in the way in which health professionals conceptualized cultural differences (Kai et al., 2007; Owens & Randhawa, 2004).

Pergert et al. (2008) found that healthcare providers also use a static cultural concept as a dynamic conceptualization. Transcultural tools are one of the means used by professionals to bridge obstacles in transcultural caring. This implies a continuous process including theoretical knowledge and awareness of one's own culture (transcultural education), and a reflective approach including trying to understand other people, cultures and looking at oneself and one's own culture (transcultural reflection).

Organizational Aspects

Two studies described organizational aspects as one of the factors contributing to cancer care for ethnic minority patients, by 'accommodating cultural needs' (Huang et al., 2009b) or by 'bridging obstacles' (Pergert et al., 2008). Huang et al. (2009b) found that the environment appears to be an important factor in the quality of cultural care by nurses. Organizational approaches to culture and cultural care, including the organizational philosophy (culture and training), the caring environment, and available and accessible support services and resources (e.g., social workers, cultural support and interpreting services, and information and materials about cultural needs), influence the way nurses approach patients of different ethnicity. Pergert et al. (2008) reported that organizational tools involve the organizational possibilities and responsibilities to provide necessary resources and conditions and to adjust policies and routines. They include time allocation (e.g., extra time for consultations with the help of interpreters) and transcultural training (opportunities for transcultural education and reflection).

DISCUSSION

This review provides an overview of what is known from empirical research about the views and experiences of oncology healthcare professionals who provide care for ethnic minority patients.

In general, findings of qualitative studies included in the review show that oncology healthcare providers sought to meet professional standards and to adapt care to the needs of ethnic minority patients (Kai et al., 2007; Huang et al., 2009a; Pergert et al., 2008). However, this was difficult to achieve, as providers experienced formidable barriers and challenges in caring for ethnic minority patients. The primary challenges related to communication and provider fears of acting in ways that might be considered culturally insensitive.

Furthermore, the findings reveal that issues of experienced fear and uncertainty, linguistic barriers, and assumptions about cultural matters are interrelated. Participating oncology healthcare providers reported that they feared breaching cultural norms (Richardson et al., 2006) and doing the wrong thing (Kai et al., 2007), which caused considerable uncertainty (Kai et al., 2007). This personally felt uncertainty when caring for ethnic minority patients seems to be closely related to cancer care as, to our knowledge, this finding has not been identified within the non-oncology healthcare literature (Kai et al., 2007). The emotional character of oncology care (Bultz & Carlson, 2006) possibly reinforces the feelings of uncertainty in caregivers. Linguistic barriers were frequently experienced and working with relatives as interpreters was much more common than with professional interpreters (De Graaff et al., 2012a; Kai et al., 2011; Owens & Randhawa, 2004). This implies that the quality of communication with patients where shared language is lacking depends mostly on relatives, while communication has been recognized as a core clinical skill in oncology (Fallowfield & Jenkins, 1999). A systematic review on the impact of medical interpreter services shows that access to trained professional interpreters or bilingual providers are the best guarantee for quality of health care for patients where shared language is lacking (Flores, 2005). Participants reported that they experienced ethical dilemmas (Pergert et al., 2007; Huang et al., 2009a) and were concerned about adhering to their principles of care (Richardson et al., 2006). While they appeared to have internalized one of the principles of contemporary biomedical ethics, that is, ‘respect for autonomy’ (Westra et al., 2009), they were aware that patients and families from other ethnic backgrounds might place a higher value on families’ approaches to ownership of information and decision making (Kai et al., 2011). This struggle seems to be reinforced by linguistic barriers, including the common practice of working with family interpreters. The literature shows a risk of jeopardising what the principal of autonomy was meant to ensure: respect, integrity and human worth, and if so, this *“may damage any relationship of trust that may exist between patient and health care worker* (Hanssen, 2004, pp 277). Following from this, the importance of having conversations between healthcare providers and patients, together with immediate family, about desires and attitudes to sharing information and decision making has been pointed out (Betancourt et al., 2011; Kai et al., 2011). Participants conceptualized culture both in a static way and dynamically. They emphasized the importance of cultural needs and static factual knowledge about cultural differences (Huang et al., 2009a; 2009b; Kai et al., 2007), as well as the need for dynamic transcultural reflection (Pergert et al., 2008). The literature emphasizes the risk for stereotyping when culture is seen as static and an individual patient approach has been recommended as cultural diversity not only embraces ethnicity, but also influences such as gender, religion, social background, education, and even personality (Kleinman & Benson, 2006; Kai et al., 2007).

The findings also reveal that organizational aspects have a significant influence on culturally sensitive care, either as facilitating factors or as obstacles. A few studies indicated the general importance of organizational aspects for the quality of care for ethnic minority patients (Huang et al., 2009b; Kai et al., 2007; Pergert et al., 2008). Overall, findings on this subject are still somewhat fragmentary. Nevertheless, it can be concluded that, according to the healthcare providers, the following organizational aspects are perceived to be beneficial in providing proper care for ethnic minority patients: (1) a reflective organizational culture, in which necessary adjustments to policies and routines can be made (Huang et al., 2009b; Pergert et al., 2008); (2) providing training for healthcare professionals (e.g., transcultural education and reflection) (Huang et al., 2009b; Pergert et al., 2008; Richardson et al., 2006); and (3) availability and accessibility of support services and necessary resources (e.g., interpreting services; time allocation) (Huang et al., 2009b; Pergert et al., 2008).

Methodological Limitations of the Included Studies

Several methodological limitations of the included articles are noted. First, the included articles with a qualitative design collected data only through individual or focus group interviews. As none of the qualitative studies used observational methods, findings are to a large extent limited to the way healthcare providers are able to perceive themselves and their behaviour remained largely unexamined.

All studies took place in western countries. Most quantitative studies were performed in the United States and Australia, while most qualitative studies were undertaken in Europe. The qualitative studies provided the most relevant findings for the purpose of this review, because most of these studies had a primary or an indirect focus on views and experiences of healthcare providers. Most of the quantitative studies had a different primary focus, therefore providing less relevant findings for this review. Hence, the review mostly concerns perspectives of oncology healthcare providers caring for ethnic minority patients in west European countries.

Furthermore, representativeness of the participating oncology healthcare providers within the qualitative studies is doubtful, as earlier mentioned. It can be expected that the respondents who were willing to participate in the studies either think relatively positively about caring for ethnic minority patients or are concerned about care practices for these patient groups. The strong social desirability of the topic probably further decreases the representativeness. This limitation is inevitable in qualitative research, as participating in this type of research creates higher barriers compared with survey methods. Also, the quality of the selection of most quantitative studies was evaluated as weak. Consequently, the findings represent the views and experiences of a segment of oncology healthcare providers but not of *the* oncology healthcare provider. Hence, conclusions should be drawn carefully.

Strengths and Weaknesses of the Review

Some limitations of this review should be noted. The review focuses on scientific literature, without taking into account grey literature. Therefore, some data or results relevant to the purpose of this review might have been missed. Besides, this review addresses the broad category of oncology healthcare professionals, while some studies only included one specific group of professionals. As the findings of the included studies were already heterogeneous, the authors were not able to analyse the findings separately between these subgroups. Consequently, generalizations have been made with regard to the professions of the participants.

On the other hand, this review has several strengths. A comprehensive systematic search was performed with the use of a well-designed search filter. Three main scientific databases with regard to healthcare, and the main anthropological database were used. Reference lists of the included articles were screened for additional articles. Methodological quality of the included studies were assessed and taken into account in the discussion of the findings.

Implications for Clinical Practice and Research

The findings of the review illustrate ways to support oncology professionals in providing culturally sensitive care for ethnic minority patients. The organizational approaches to oncology care play an important role. The fears and uncertainties healthcare professionals experience in caring for ethnic minority patients must be considered. The usefulness of static knowledge on culture and cultural differences versus dynamic transcultural training and reflection must be examined carefully, with avoidance of stereotypical assumptions. The linguistic barriers healthcare professionals experience, as well as the common practice of working with family interpreters, must be considered as organizations plan for culturally sensitive care. The use of observational methods in future qualitative research will provide the possibility to gain new insights on this topic, specifically on the behaviour and attitudes of health professionals.

CONCLUSION

Most studies showed that oncology healthcare providers are faced with challenges or barriers when caring for ethnic minority patients, whereas fewer than half of the articles also discussed facilitating factors and opportunities. The views and experiences of oncology professionals are characterized by a willingness to provide proper care, which is hindered by challenges and barriers related to fear and uncertainty, linguistic barriers, and assumptions about cultural matters. Being unable to speak the patient's language lies at the heart of their concern, and working with relatives as interpreters is much more common than with professional interpreters. Participating oncology healthcare professionals struggle with the value attached to 'respecting patient autonomy', because care recipients of different ethnicity might attach higher value to family approaches. Participants both emphasized the importance of cultural needs and static factual knowledge about cultural, as well as the need for dynamic transcultural reflection. Organizational approaches have a significant influence on culturally sensitive oncology care, whether they facilitate or obstruct.

Due to methodological limitations of the included studies, these conclusions should be carefully considered.

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HOOFDSTUK 3

ONCOLOGISCHE ZORG IN MULTICULTUREEL VLAANDEREN: ERVARINGEN VAN ZORGVERLENERS

ARTIKEL 2. - P. 69

Gebaseerd op het artikel van: van Eechoud, I., Grypdonck, M., Leman, J., & Verhaeghe, S. Perspectives of Belgian Oncology Health Workers on Caring for Patients of non-Western Descent. Submitted.

PERSPECTIVES OF BELGIAN ONCOLOGY HEALTH WORKERS ON CARING FOR PATIENTS OF NON-WESTERN DESCENT

ABSTRACT

This study was undertaken to gain insight in the views and experiences of Belgian oncology healthcare providers in caring for patients of non-Western descent. Qualitative data were collected through five focus group interviews, with 23 oncology health workers as participants. Barriers and difficulties were paramount in the provision of care to patients of non-Western descent. Participants want to act according to their professional standards, which call for treating all patients equally and providing appropriate care. However ‘cure’ takes precedence over ‘care’ when participants were not willing or not fully able to overcome barriers. This results in feelings of inadequacy in those participants who equate professional standards to care of equal quality. Participants who interpreted their professional standard as equivalent care were irritated by ‘these’ patients who restrained them from providing appropriate care. The findings indicate that professional standards provide protection against possible discrimination that may result from personal beliefs. Extending professional standards from ‘treating all patients equally’ to ‘care attuned to each patient’ might be a way to prevent ‘cure’ taking precedence over ‘care’.

Key words: ethnic and cultural diversity; oncology health workers; focus group; professional standards; personal beliefs and attitudes

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INTRODUCTION

As in other West-European countries, Belgium is characterized by an increasing diversity in its population. Approximately 15% of the population in Flanders, the Dutch speaking part of Belgium, is of foreign descent (Noppe and Lodewijckx, 2012). In developed countries it is increasingly the norm that healthcare involves professionals and patients with different cultural backgrounds and ethnicity (Kai et al., 2011) According to the World Health Organization (WHO, 2010) health services should be delivered to immigrants in a cultural and linguistically appropriate way. The healthcare system in Belgium has been identified as one of the most equitable in the world (Derluyn et al., 2011) and discrimination is a legal offence. However, healthcare organizations in Belgium have no official obligation to pay attention to diversity, leading to the implicit denial that there may be discrimination in the provision of care (Dauvrin et al., 2012; Lorant and Bhopal, 2010). There are state-funded intercultural mediators within hospitals, but few interpreting services are available outside the hospital setting (Derluyn et al., 2011; Lorant and Bhopal, 2010).

Both in care provision for patients of foreign descent and oncology, communication is paramount (Fallowfield and Jenkins, 1999; Owens and Randhawa, 2004; Pergert et al., 2007; De Graaff et al., 2012; Kai et al., 2011). In care relations between professional caregivers and care users of foreign descent both (cultural) characteristics of care recipients and care providers are important (Kleinman and Benson, 2006; Oliemeulen and Thung, 2007). Therefore, it is important to understand the views of care providers who are caring for people of foreign descent. Surprisingly little is known about how healthcare providers experience and perceive their work with patients of diverse ethnic origins (Kai et al., 2007). A systematic review on views and experiences of oncology healthcare providers in caring for ethnic minority patients found only five studies published between 2000 and 2013 with this topic as a primary focus (van Eechoud et al., in press). There were no direct or indirect studies done in Belgium with this subject as a research focus. Oncology healthcare workers seek to meet professional standards of care and try to adapt the care they provide to the needs of ethnic minority patients. However, they experience formidable barriers in communication and they fear doing things that might be regarded as culturally insensitive (van Eechoud et al., in press).

This study was undertaken to gain insight in the views and experiences of Belgian oncology healthcare providers when caring for patients of non-Western descent.

METHODS

Design

In order to gain insight and understand the views and experiences of the participants, a qualitative design with the constant comparative method was chosen. For this study, view was defined as a particular way of considering or regarding something, or having an attitude or opinion.

Five focus groups were held wherein study data were collected (Kitzinger, 1995). Social interaction can be particularly fruitful in focus groups, as the thoughts of participants are stimulated by a dynamic interaction and answers build on comments of others in the group (Kitzinger, 1995; Holloway and Wheeler, 2002). The focus groups were held in one academic hospital and two regional hospitals in Flanders. The hospitals were located in different geographic locations with varying proportions of inhabitants with a non-Western background. Focus group interviews lasted about 90 to 120 minutes and took place in a meeting room in the participating hospitals. The focus group interviews were audio-taped and transcribed verbatim.

Recruitment of Participants

There were 23 participants, in five focus groups, each with two to six participants. All participants were oncology healthcare workers; characteristics are reported in Table 1.

Table 1. Descriptive Information about Oncology Health Workers (*N*=23)

Characteristic	*N*
Gender	
Male	3
Female	20
Age	
21-30	10
31-40	7
41-50	4
51-60	2
Years of experience	
1-5	11
6-10	2
11-20	7
21-30	3
Discipline	
Nurse	5
Clinical nurse specialist	2
Social worker	2
Psychologist	3
Dietician	3
Physician	8

To promote constructive group dynamics, healthcare providers in hierarchical positions relative to other participants were excluded. For the same reason, 'being a healthcare provider of non-Western descent' was also an exclusion criterion for participation in a focus group. The composition of the focus groups differed in order to maximise the variety of interaction effects. To promote equality of professional power and sharing of experiences (Kai et al., 2007), two focus groups were held exclusively with physicians in the field of oncology. Three focus groups were multidisciplinary, including one or two nurses, a clinical nurse specialist, a social worker, a psychologist, a dietician, and, in one focus group, an oncologist. Explorations of views from members of the same oncology care team were encouraged (Kai et al., 2007). Selection was partly defined by availability of potential participants. After permission was provided by the person in charge, potential participants were contacted via email with information about the study and its purpose and goals.

The ethical committees of the three hospitals involved approved the study protocol (B670201319414). Signed informed consent was obtained from all participants.

Data Collection

The first author moderated all focus groups, assisted by an observer. The moderator used an interview framework to stimulate and focus the discussion on the research topic (Pergert et al., 2007). Participants were asked to share their views and experiences. To begin, participants were asked to note a case of a patient of non-Western descent which made deep impression on them. Subsequently, they were asked to note which items in their case were and were not representative in caring for patients of non-Western-descent in general. The case reports were useful as a stimulating starting-point for group discussion. To gain insight in the general attitudes of the participants towards patient of non-Western descent, they were asked how they would feel if they were employed in a hospital without patients of non-Western descent. To conclude the group, participants were asked to share their main motto in caring for patients of non-Western origin. The focus of the discussions changed slightly as they progressed, as the data collection and analyses progressed concurrently.

Data Analysis

The analysis process in this study is comparable with the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterlé et al., 2012). The process started after the first focus group was conducted. In the first and second stage, transcribed focus groups interviews were thoroughly read and narrative interview reports were written. In a third phase, two researchers discussed all transcripts to further explore the meaning of the views and experiences of participants. In addition, selections of the transcripts were discussed with a third researcher. By continually comparing fragments within and among the focus groups in stage four, in-depth insight was gained in the views and experiences of participants. The transcripts were re-read and relevant fragments were linked to appropriate codes with the use of Nvivo 10 (QSR International, Australia). In the final phase, in-depth insights in the views and experiences and interrelated themes were further refined through confrontation with new data. All decisions were made by researcher triangulation, thus contributing to the credibility of the analysis (Coté and Turgeon, 2005).

The transcripts were analysed at the level of individual focus group participants, at the group level, and for interaction between participants. Group dynamics were taken into account in the analysis, as the researchers were attentive for indications and contra-indications of possible influences on the meaning following from the contributions of the participants.

To allow better understanding of the participants' narratives, the first author was a participant observer at an outpatient oncology centre for one morning. Preliminary results were discussed two times with the other authors. The authors provided alternative interpretations, which were used in confronting interpretations of the data.

All interviews were conducted in Dutch and the analysis of the data used Dutch language transcripts. Only after all data were analysed and finalized, were selected participant comments translated into English for this report.

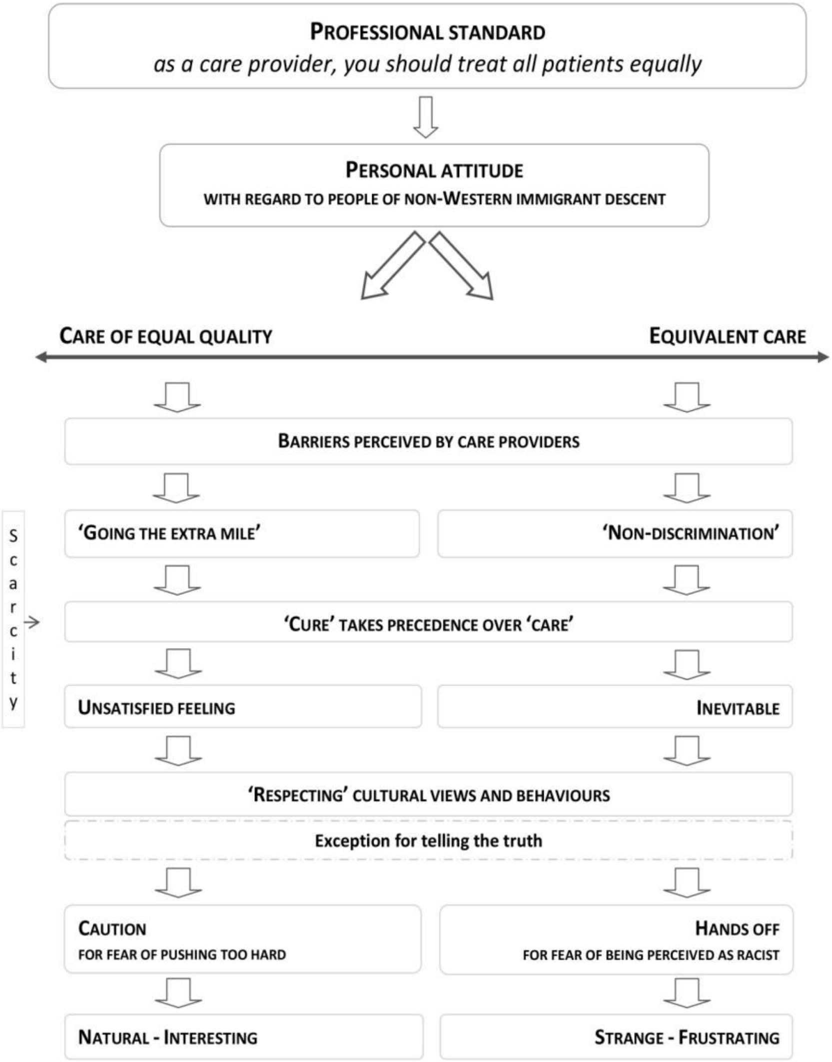
RESULTS

Group Dynamics and Case Histories Shared

The data analysis indicates that group dynamics were a significant influence on the contributions of some participants. The presence or absence of some participants influenced what was easily shared, or not. Participants also varied in terms of their persistence to contribute. The analysis also showed that being able to speak together provided the opportunity to exchange information and knowledge and think about ways to facilitate care for these patients. Most of the reported case histories concerned patients of Turkish or Moroccan descent, with wide variations in age and generation of migration. Several other cases concerned patients from countries in South, Eastern or Central Europe.

The analyses of the interviews revealed considerable variation but there were also similarities among participants. The reported behaviour of the healthcare providers differed less than their opinions did. The most important similarity was that all participants said they intended to act according to their professional standard of treating all patients equally. Differences were limited by this professional standard and, to a lesser extent, by a sense of political correctness. Although several participants explicitly mentioned that they perceived the experience of working with patients of non-Western descent as enriching and interesting, discussions generally focused on difficulties and problems. Despite the neutral formulation of the focus group questions, most of the cases that were shared involved situations that did not proceed smoothly. Participants were frustrated when the match between their professional standards and their personal attitudes were not congruent. Some were dissatisfied because they were unable to provide the quality of care that they wanted to provide. Others were irritated by the effort required to provide equal care and the few returns yielded by these efforts. Barriers perceived by participants led them to focus strictly on medical aspects of their interventions. 'Cure' thus seems to have taken precedence over 'care'. This insight can be elaborated further according to the schematic representation in Figure 1.

Figure 1. Schematic representation of the perceptions and attitudes of oncology healthcare providers in the care of patients of non-Western descent



Professional Standards

All patients must be treated equally and all are entitled to appropriate care

All participants believed every patient (including those of non-Western descent) is entitled to equal medical care. Each participant regarded this standard as an overarching principle that applied to oncology care. For some participants, this was a strongly internalised norm, while others saw it more as a duty inherent to their profession.

In two focus group interviews, however, the right to equal medical care was called into question for people with no residence status in Belgium and hence left out of the National Health Insurance. Some participants were very glad that they had not yet experienced any restrictions in treating such patients, and they feared a future in which they would have to choose those for whom oncology treatment would and would not be covered by state funding. In their perception, this would conflict with their professional ethics. These participants regarded the ability to provide standard oncology treatment regardless who the patient was *'as a major advantage of Belgium'*. A few other participants, however, expressed frustration regarding the provision and financing of 'cutting-edge Belgian care' to patients with no residence status in Belgium – people who make no effort or feel no commitment to 'our' society. They regarded this as the *'destruction'* of the Belgian healthcare system, and they blamed the government (and particularly the Public Centre for Social Welfare) for allowing this to happen.

Personal Attitudes

With regard to people of non-Western immigrant descent

The participants held diverse personal attitudes with regard to people of immigrant descent in Belgian society. In this context, the term 'personal attitude' is used to refer to the convictions, thoughts, and emotions of the participants. Tension can emerge if the professional standard is not consistent with the personal attitude. This was the case for one of the participants, who thought that allowing people who came from other countries for treatment was abusing the system to the point of destruction. At the same time, his professional standards were contradictory:

> *You just don't have a good feeling about it, because you think, 'Look, I've got this real, live patient whom I think should be treated, even*

> *though I actually think that this person should never have been allowed to be here in the first place'.*

Participants' personal attitudes were determined largely by the extent to which they had accepted the multicultural demographic reality of Belgian society. For some participants, this was obvious, while others found it disturbing and expressed dissatisfaction. Fear was expressed, particularly with regard to the possible loss of 'characteristically' Belgian standards and values, and in some cases with regard to negative financial consequences associated with the presence of people of foreign descent.

Care of equal quality or equivalent care

The diversity of personal attitudes resulted in a difference in interpretation of professional standards. These interpretations ranged from those who interpreted equal care as equivalent care that is, the same care for all patients, to care providers who interpreted equal care as being of equivalent quality, with an intention to provide all patients, regardless of who they are, the best care. For the former care providers, equivalent care meant that patients of non-Western descent should not receive more services than those provided to 'native' patients. If this were to result in less appropriate care, the provider did not regard it as their responsibility, but rather the responsibility of the patient. In contrast, some participants who intended to provide care of equal quality explicitly mentioned their efforts to achieve equal outcomes, even if it required additional effort and resources to do so. The various interpretations held by participants can be arranged along a continuum ranging from an intention to provide 'care of equal quality' to an intention to provide 'equivalent care'. The difference between the two interpretations is not absolute. Some participants interpreted equal care in a manner falling somewhere between 'care of equal quality' and 'equivalent care', while others alternated between the various interpretations.

The analysis indicates that such differences in interpretation among providers were at the root of other differences in perceptions and attitudes with regard to people of non-Western descent. At the same time, the care providers demonstrated many similarities in behaviour.

Perceived Barriers

All participants perceived various barriers in the provision of care, with the following at the forefront: language barriers, the presence and prominent role of many family members, limited openness about the illness, and the marked expression of emotions. With the exception of language, these barriers were largely regarded to be determined by culture. Many participants were inclined to accept barriers as they experienced them. Under the pressure of their daily activities, they did not think about long-term solutions. They were also limitedly aware of existing resources to overcome barriers. Several of the participants formed an exception, however, including the dieticians, who reported often searching for structural solutions for overcoming barriers, such as the use of pictograms or adapted diets.

Participants regarded the use of interpreters or intercultural mediators in cases involving language barriers as a solution of only moderate utility. Their perceived feeling of having no control over what they would like to communicate to the patient was a particularly important limitation. In addition, participants encountered many obstacles when using professional translators, including limited availability and flexibility, resistance from family members, a more succinct manner of transferring information, time investment required, and cost. Some participants found the use interpreters particularly difficult for conversations involving psycho-social issues or highly sensitive information. Participants sought a variety of ways to bridge language barriers including relying on relatives who could translate, the use of signs, body language, and digital translation websites.

‘Going the extra mile’ or ‘non-discrimination’

Participants who assigned priority to equivalent care were of the opinion that the provision of care to people of non-Western descent should not require much additional effort, particularly not at the expense of other (‘native’) patients. Following this view, they were also likely to limit their efforts to using the same resources that they used with other patients. This led them to focus their treatment primarily on medical issues, paying less attention to supporting patients and their families in the difficult situations they were experiencing.

> *In general, [...] I don’t have the kind of emotional chats with any of these patients that I do with other patients. You can’t just go up to them and say things like, even if they do understand Dutch, that’s always a… Yeah, is that culture or something else? I just don’t know. You can’t just… Whether they understand you or not… Yeah, they don’t say anything, or… Yeah, for me, it’s never quite the same.*

Participants who emphasised care of equal quality tried to bridge the barriers described above. In the case of language barriers, they tried to use professional interpreters or intercultural mediators. The use of pictograms and other visual aids was also mentioned, particularly by the dieticians. A factor that seems to have played a role is that care provided in the area of nutrition tends to be practically oriented. The care providers perceived a variety of obstacles when working with interpreters, however, which led them to use these resources primarily to communicate medical information. Proceeding from the conviction that these patients were entitled to the best of care, like all other patients, they were more likely to take it for granted that they should 'go the extra mile'. Due to the lack of time and limitations of the system, however, they nevertheless felt forced to focus their care on medical issues.

> Participant: *I know that when you're working with people of non-Western descent, it just takes more time. And the work pressure makes it more difficult to take the time that you really need… I have to see if it's being monitored – okay, not at the expense of others, but yeah, it's hard, you know?*
> Interviewer: *Monitoring of…?*
> Participant: *That there's still, well…That the quality doesn't suffer too much simply because the work pressure is greater.*
> *I've already said a lot about those communication problems. I can't just say, 'yeah, I treat them just like everybody else'. In my opinion, our motto – the same as what we're doing at the clinic – my motto just has to be, 'the best care possible' [...] Everyone is entitled to this, regardless of any differences in communication.*

'Cure' takes precedence over 'care': Unsatisfying or inevitable

As revealed in the preceding discussion, the provision of care to patients of non-Western descent tends to focus strictly on medical issues. 'Cure' thus seems to take precedence over 'care'. Within the oncological context, 'cure' is perceived as the primary responsibility, and it therefore receives the highest priority. This seems to be related to a general sense of scarcity in the area of finances and work pressure.

> *Yeah but you don't always have an interpreter, so you focus a bit on your part and everything that you want to say, as well as on their questions at that time. But if you're able to communicate with someone week after week, you obviously grow in certain areas. With them, it's often the case that you only have an interpreter every now and again. So then, you focus more on…*

For the participants who felt that these patients were entitled to care of equal quality, even if it requires more effort, the focus on medical issues left them feeling unsatisfied. They missed a more holistic approach to care, in which attention is paid to emotional and psycho-social aspects. Some participants also perceived the inability to reassure their patients as a major shortcoming. Limited communication due to language barriers was perceived as a major problem:

> *My general rule should actually be to approach them in the same way that I approach people of our own background. This brings me back to the point that was just mentioned – that we don't actually do this in practice, due to the language barriers that really do exist. For me, however, it's actually – if I'm honest – if I were to have my way, I'd be able to say, 'In fact, I visit that patient just as often as anyone else. The threshold is indeed just as low as it would be for anyone else'. For me, that would be, yeah, more satisfying.*

In contrast, participants who held the opinion that the (medical) care should be equivalent were more likely to perceive the focus on medical issues as inevitable, or as the responsibility or fault of the patient. It thus did not necessarily produce any bad feelings about their own working methods.

> *They should be treated equally in the provision of care, right? The medical and nursing care that they receive should be just as good as that any other patient would receive. After all, they're people in need of care too, aren't they? That's what we should be there for, but I think we are, aren't we?*

> *I think that there's a wide range of intercultural services. That's a good thing. It's a good thing as long as it's funded. If I happened to get sick in Turkey, I don't think that I'd get a Turkish interpreter who*

> *speaks Dutch. So again, this is goodwill on our part. This is a service that we provide. But it's not a must, right? What I'm trying to say is that these people are in need of help, aren't they? We can organise services, but we have to stay within reason, right?*

'Respecting' cultural views and behaviours

Many of the barriers perceived by the participants were understood as cultural behaviours or views. This applied largely to the prominent role played by many family members, limited openness with regard to illness, and the marked expression of emotions. Some participants also encountered what they assumed to be 'different' male-female patterns, eating habits, and boisterous behaviour. These behaviours often conflicted with the care providers' own standards or views. At any rate, they were behaviours to which the care providers were not accustomed. Many participants wanted to respect these behaviours or views. For some participants, this involved a certain level of caution for fear of damaging the relationship with the patient by pushing too hard or offending them. Other participants, however, felt that they should adopt a hands-off approach, for fear of being perceived as racist.

> *I think we are all walking on tiptoes to a certain extent. Something like, 'Oh no! A foreigner', right? And then we're all on high alert: what should we pay attention to and what should we ignore? For Western patients, we just do what we always do, it seems to me. We don't think things like, 'I have to be careful not to say or do the wrong thing'. But, yeah, I do feel like they're crossing my boundaries. How should I tell them? It's just that we…It's a bit like walking on tiptoes, isn't it?*

Several participants were an exception in this regard, stating explicitly that they did not present themselves any differently to 'foreign' patients than they did to 'native' patients. Nevertheless, their reasons differed. One of the participants said that he did not behave any differently because, '*that's just the way I am*', and he expected patients to respect and adjust to his way of working. In contrast, two participants stated that they considered it important not to make any distinctions, as these patients are simply people, just like those of Western descent. They coordinated the care in the same way that they did for every patient. For example, one of them expressed the conviction that, if 'you just act normally, just like with anyone else', it is just as easy to point out to them ‘things that are not acceptable’. These participants thus did not exhibit any ‘caution’ or ‘hands-off’ approach, as was the case with the other care providers.

Exception for telling the truth

For most of the participants, telling the truth constituted an exception to the practice of respecting cultural behaviours. Many care providers regard as unacceptable the seemingly frequent desire of family members for little or no openness towards the patient with regard to the illness. The patient’s right to medical information appears to have been an internalised standard for all of the care providers. Although a number of participants noted that other views had been common in Belgium not so long ago, many consider it an essential duty in medical treatment to communicate information to the patient regarding the diagnosis, prognosis, and treatment.

> *I think that the patient has a right to know the truth; this is relatively common in oncology, after all – telling the truth – we’ve worked so long and so hard to develop a good way of doing this. Second, [...] they will be receiving a serious treatment, and that has consequences as well. It’s not just some pill that you’re talking about. They could become seriously ill; they could run a fever. It could even cause a serious infection and put them in intensive care. They’re going to lose their hair. It’s important for this to be said.*

Although all participants tried to communicate the truth to their patients, some went much farther than others did in this regard. The type of treatment appeared to play a role. For example, one participant made a practice of telling the translating family members that the surgical procedure would not take place unless the patient had been informed.

Some care providers indicated that they did not want to go against the family when the family continued to refuse the use of an interpreter to communicate medical information, despite explanations of the importance of being open about the illness. In contrast, another care provider told about a case in which she tried to use signs to communicate the severity of the treatment to the patient.

> Participant 1: *When they're in a terminal phase, you know, it's sometimes hard for me, because I can't simply go along with all those stories, can I? They're just going to die within the week and...*
> Participant 2: *I absolutely do not go along with it. I don't go along, but I also don't add my own story, well….*
> *[…]*
> Participant 3: *If the family refuses to call in an interpreter, I think, yeah...*
> Participant 4: *Yes, it's really difficult.*
> B-green: *You try to work up to that, but you actually want to have the family's consent. You don't really want to go against the family.*

> *And then I noticed that he* [the patient's husband] *actually hadn't told her any of that. And then I think, at that point, the husband did become slightly angry when I said something like, 'Look, otherwise we'll bring in an interpreter who will relate it honestly' [...] But I ultimately cut off the communication and said, 'New appointment for the outpatient centre', or I don't know what else to do. And then I went to her alone once, and I tried to use signs to relate to her that it really was very serious, after all, and that we wanted to try a severe treatment with a good chance of a cure.*

'Caution' for fear of pushing too hard or 'hands off' for fear of being perceived as racist

For some participants, 'respecting' putative cultural behaviours and views entailed adopting a 'hands-off' approach to them. These participants felt obliged to consider the cultural behaviours and views, even in the case were they rather appeared to be stereotypes. Although several matters (e.g. the presence of many family members, boisterous behaviour, and eating habits) were a major source of irritation to some of the participants, they felt that they should not let this irritation show. They felt obliged to respect 'their culture', and some explicitly expressed fear of being considered racist. A few participants had experienced being called racist by family members. Many participants noted that they were much more likely to call people of Belgian descent to task for undesirable behaviour. They did not feel free to act unless the behaviour exceeded their own boundaries or if it was negatively affecting other patients. They appeared to attach considerable importance to 'their own boundaries', seemingly without reflecting on them or subjecting them to any critical questioning. Instead of engaging in dialogue, they acted by using their authority. As long as the behaviour did not cross their boundaries, they would accept or tolerate it, albeit reluctantly. If the behaviour crossed their own boundaries, they would forbid it, apparently without asking themselves what this might mean to the person in need of care. In this context, cultural behaviours were perceived in a highly static manner, such that many participants apparently regarded them as matters that were not to be discussed.

> *Participant 1:* *You have to show respect.*
> *Participant 2:* *Yes, otherwise, they might say something like, 'Yeah, but you don't respect us'. 'This is our culture'. 'That's what we do'. Right, but it also has something to do with the fear of appearing racist. That you, well, that's what I think.*
>
> *Although I do lean towards equivalent care for Western and non-Western patients, it should be a two-way street, don't you think? That would be nice. We shouldn't be bothered by things like, 'They'll think that we're racist because of something we said' and those who might ask us questions like, 'What are your values and standards here in the unit?' 'Which standards should we observe?'*

The stories recounted by the participants emphasising care of equal quality suggest that they are 'cautious' with regard to putative cultural behaviours for fear of pushing the patient or family members too hard or damaging the relationship by offending them. These participants attempted to understand the meaning of the putative cultural behaviours and to respond to these meanings.

> *I am simply open to what they, yeah … As I said in the beginning, I'm very open to that. They can tell me what, well yeah, how they perceive things, and that I won't judge them for it. I also try to look into their world and the issues that they are facing; taking that as a starting point. It's not like I have this agenda that I need to tick off. I proceed from the situation as it is, from what's going on.*

The participating dieticians had less to say about 'caution'.

Natural, interesting and enriching or strange, frustrating and irritating

Due to the situations described above, participants had differing perceptions regarding the provision of care to people of non-Western descent. Some regarded the care of this patient group as a natural, inherent part of multicultural society, and often found it enriching and interesting to care for them. With these participants, professional and personal attitudes were closely aligned. Professional standards directed them to provide each patient with the 'best' care, while personal attitudes led them to see people of non-Western descent as equal fellow citizens. These participants were not irritated by any additional effort for care that might be required, and when care did not proceed smoothly. They did tend to feel inadequate when they were unable to provide care of the same quality. These care providers appeared to be more aware of the patient's position and the influence that their own behaviour might have.

> *I don't know how that would be perceived. I think that, because we can also give the impression, that we are sometimes impatient or resentful because the situation is not very professional. […] Otherwise, you could say something. You could also explain the feeling: 'Look, it's not exactly how it should be, but it will be okay'. But those are things, yeah, these people see you coming in, going out; they see you with something else. So yeah, these are all impressions that you can give, even if you aren't able to say it exactly. […] You might want things to be different. You want to provide good care for these people.*

Some participants explicitly noted that it would *'bother'* them to work in a hospital that had no patients from other backgrounds. These participants had apparently accepted the multicultural reality of Belgian society. Many also mentioned the high level of diversity existing within the group of patients of non-Western descent (e.g. according to origin, length of residence, language skills), with little reference to stereotypes.

> *Because our population is large, we grow up in it and go along with it. We learn more about it, and I don't know, it just seems normal to me. […] and when I hear people from outside, I sometimes say things like, 'You shouldn't lump all of them together. You should look at each situation and realise that not everyone is the same'. There are*

> *many different stories within the group. […] But there are so many prejudices, yeah, particularly from outside. (…) Outside the hospital, in general.*
>
> *It's just more interesting to meet people from other cultures as well. And it's very interesting to me that some people from other backgrounds can also speak [the language] perfectly even if they have a different cultural background.*

Other participants were more likely to experience providing care to this patient group as frustrating or irritating. They felt that great efforts were made to care for patients from other backgrounds. In this regard, they wondered whether the same effort would be made for 'us' in 'their' countries of origin. Most did not think that this would be the case. They understood 'great efforts' to include using care providers to bridge language problems and offering the possibility of carrying out their 'own' mourning rituals. These participants experienced tension between their professional standards and personal attitudes. Although they allowed their behaviour to be directed by their professional standards, they did so reluctantly. They felt obliged to provide equal medical care, but they were irritated by the putative cultural behaviours of the patients. In most cases, this involved boisterous behaviour, failure to observe visiting hours, a large number of family members present, theatrical expressions of emotions, and behaviour ranging from forceful to aggressive. This type of behaviour led these participants to feel that the patients (and their loved ones) had no respect for them as care providers or for the Belgian healthcare system in general. They were irritated by the fact that, in their view, these patients did not adapt to the customs and practices of the Belgian healthcare system. Many of these participants spoke and acted strongly in terms of 'us' and 'them'. 'They' should be grateful that they are able to make use of 'our' Belgian healthcare system. These participants appeared to be somewhat afraid of and resistant to the multicultural demographic reality.

> *It sometimes bothers me that the standards that apply here, we can relax them a bit, but I think that they should also go along with them. That's simply the standard for us in a hospital, in a hospital environment. [...] They should also bend a little; I feel that we should be allowed to expect that. The way I see it, in terms of healthcare,*

> *they're being well cared for, assisted, received uhm….One time, I had to take my six-month-old son to an emergency room in Spain, and then you're just talking about Spain. I can assure you that they did not go to as much effort as we do here for our non-Western patients. I think this is a good thing. We shouldn't reduce our efforts, but I think that they ought to realise, uhm, that they're receiving extremely good services here in Belgium, right?*
>
> *In my opinion, we expect too little of them with regard to things like, 'Try to adapt a bit to the country to which you've come'. I truly hope that the conclusion* [of the study] *is not something like, uhm, '[the care providers] think that too little is being done for foreigners'. I think that a great deal is being done.*

DISCUSSION

Difficult Caregiving

Participants in this study remembered barriers and difficulties most vividly in the provision of care to patients of non-Western descent. This finding is in line with literature on this topic: "*Most studies showed that oncology healthcare providers are faced with challenges or barriers when caring for ethnic minority patients, whereas fewer than half of the articles also discussed facilitating factors and opportunities* (van Eechoud, in press)."

Professional Standards and Personal Attitudes

All participants regarded their professional standard as an overarching principle, according to which all patients should be treated equally and each patient is entitled to receive appropriate care. A few previous studies also found that oncology healthcare providers sought to meet professional standards of care when caring for ethnic minority patients (Huang et al., 2009; Kai et al., 2007; Pergert et al., 2008). The current study provides further insight behind this reasoning as it shows that care providers, influenced by their personal attitude regarding non-Western immigrants, interpret the meaning of their professional standard differently. While some interpret equal care as an intention to provide equivalent care, others interpret this as an intention to provide care of equal quality.

'Cure' Taking Precedence Over 'Care'

Barriers were challenges which made participants focus on ‘cure’ at the expense of ‘care’, both for healthcare providers who interpret equal care as equivalent care as for those who seek to provide care of equal quality. They could overcome barriers only to a limited extent, either because they believed care for patients of non-Western descent should not require much additional effort or because they felt themselves forced to continue with their daily activities. Some participants were frustrated with feeling irritated by not being able to provide adequate care, and they held the patient responsible for these feelings. Other participants were frustrated with feeling unsatisfied, as they perceived themselves being responsible for not being able to provide (holistic) care of the same quality for patients of non-Western descent. This profound understanding of the process wherein different perspectives and attitudes leads to different frustrations, has, to our knowledge, not been described in previous literature on this subject. Furthermore, the finding that ‘cure’ takes precedence over ‘care’ has also not been previously described in this context.

Professional interpreters are perceived as a solution of only moderate utility, and relying on family interpreters is the most common way to bridge language barriers. This finding is in accordance with previous studies (De Graaff et al., 2012; Kai et al., 2011; Owens & Randhawa, 2004). The literature notes, however, that the best guarantee for quality of healthcare for patients, where shared language is lacking, is access to trained professional interpreters or bilingual providers (Flores, 2005). Other barriers at the forefront were often perceived as cultural behaviours or views, such as the presence and prominent role of many family members, limited openness about the illness, and the marked expression of emotions. Many participants believe they should show ‘respect’, either by ‘being cautious’ or by adopting a ‘hands-off’ approach. A fear for doing ‘the wrong thing’ has been pointed out in a previous study (Kai et al., 2007). The participants who were dieticians had less to say about ‘respecting’ culturally perceived barriers and they often searched for structural solutions to overcome barriers. The type of care provided by these participants apparently generated less caution as it tends to be more practically oriented and is not emotionally charged. Therefore, miscommunication is less likely to result in offending a patient or family member.

Analysis of the focus group data shows that being able to speak together with care providers who seek to provide care of equal quality, provides the possibility to find a way out of the trap of experienced barriers.

Furthermore, as care providers are very limitedly aware of existing resources, and knowledge (such as pictograms, different kinds of professional interpreters, and so on) it would be beneficial to map out what is available, both within a healthcare institution as well as outside, and share this with colleagues.

Monocultural Oncology Care

Finally, this study shows that customs and standards of the Belgian healthcare system are often understood in a monocultural way, and some oncology healthcare providers are irritated that non-Western care users do not adapt to ‘our’ customs. They spoke and acted strongly in terms of ‘us’ and ‘them’. Among other things, some participants pointed out that ‘they’ (care users of non-Western descent) should be grateful that ‘they’ are able to make use of ‘our’ Belgian healthcare system. In their view, the healthcare system belongs to native Belgians, with the population segment of non-Western descent falling outside this group. Despite many references in the focus group interviews to patients belonging to the immigrant groups who came to Belgium in the 1960s and 1970s and their progeny, these participants did not see these people as part of the healthcare system. In contrast with other participants, these care providers did not seem to have accepted the multicultural reality of Belgian society. The risk of a monocultural healthcare system within a multicultural context has, among others, been highlighted by Ingleby (2000), who speaks of a monocultural tragedy, referring to the reluctance of the dominant culture to adapt to the current social reality.

In this regard, the participants have internalized the standard of ‘respect for autonomy’, one of the principles of contemporary biomedical ethics (Westra et al., 2009), as they consider communicating medical information to the patients as an essential duty. The literature however points out a risk of jeopardising what the principal of autonomy means to ensure: integrity, respect, and human worth, and if so, a relationship of trust may be damaged (Hanssen, 2004). It might be said that the participants interpreted autonomy from a principle ethics perspective instead of a care ethics perspective, as they do not subject the respect of the principle to the consideration of its consequences. Ethical provision of care is about acting in accordance with the *meaning* of the agreement and not only acting in accordance with the agreement. Following from this, the importance of conversations between oncology healthcare providers and patients, together with close relatives, about views and attitudes to sharing information should be pointed out (Betancourt et al., 2011; Kai et al., 2011).

The importance of a reflective attitude has been recognized as a cornerstone of qualitative intercultural care (Kleinman and Benson, 2006; Oude Breuil, 2005; Oliemeulen and Thung, 2007, Seeleman et al., 2009): "*Train clinicians to unpack the formative effect that culture of biomedicine has on the most routine clinical practices*" (Kleinman and Benson, 2006, p.1675). High quality care for patients of non-Western descent should be care attuned to the individual patient, in which a good healthcare provider-patient relation is essential. To fulfill this, it can be helpful "*to routinely ask patients and (where appropriate family members) what matters most to them in the experience of illness and treatment (…) then use that crucial information in thinking through treatment decisions and negotiating with patients*" (Kleinman and Benson, 2006, p. 1676).

It is important to note that in reporting the findings, we created a dichotomy in the perspectives of the care providers, while the reality was more complex. Some participants varied between different viewpoints and at times were somewhat neutral; it is important to emphasize that, instead of a dichotomy, the differences in perspectives should be considered as existing on a continuum.

Limitations

Some limitations of this study should be noted. By focussing on patients of non-Western descent, we created a distinction through ethnic-cultural lines, thus participants were possibly encouraged to reason in terms of differences rather than similarities.

Although we tried to select participants purposively, this did not happen in one hospital and selection was partly defined by availability of care providers. This might have caused a less diverse sample compared with the general population of oncology healthcare providers. However, the findings show a wide variety of perceptions and views of the care providers.

Analysis of the focus group interviews indicates that group dynamics had a significant influence on the contributions of some participants. We suspect that social acceptability of the subject had a strong influence on these participants. This research subject appears to be a topic in which contributions on views and experiences are influenced by the prevailing discourse. This has been taken into account in the analysis process.

Finally, as we used focus group interviews to collect data, the findings are mainly limited to the way participants were able to perceive themselves; their behaviour remained largely unexamined. However, by asking participants about experiences and patient cases we tried to counter this limitation and overcome social desirability in their discourse. Future ethnographic research could provide more insight in the way care providers act towards ethnic minority patients, besides their discourse on this topic.

Conclusion

Results of this study provide insight into the attitudes and perceptions of oncology healthcare providers in their care for patients of non-Western descent. All participants indicated that they try to act according to their professional standards, which call for treating all patients equally and each patient is entitled to appropriate care. However as oncology healthcare providers, influenced by their personal attitudes, they are either not willing or not fully able to overcome barriers that are present, so they focus on medical aspects wherein ‘cure’ takes precedence over ‘care’. This causes feelings of inadequacy for those care providers who believe they should provide care of equal quality for patients of non-Western descent. On the other hand, care providers who believe care for patients of non-Western descent should not require much additional effort become irritated, as ‘these’ patients restrain them from providing appropriate care. Professional standards provide powerful protection against possible discrimination, particularly when they derive from personal attitudes. Thus extending the professional standard from ‘treating all patients equally’ to ‘care attuned to each patient’ might be a way to prevent ‘cure’ taking precedence over ‘care’.

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HOOFDSTUK 4

ONCOLOGISCHE ZORG IN MULTICULTUREEL VLAANDEREN: BELEVING VAN FAMILIELEDEN

ARTIKEL 3. - P. 97

Gebaseerd op het artikel van: van Eechoud, I.J., Grypdonck, M., Leman, J., Van Den Noortgate, N., Deveugele, M., & Verhaeghe, S. (2015) Caring for Family Members Older than 50 of Turkish and Northwest African Descent: The Meaning of Caregiving. *Cancer Nursing*. 2015 Feb 27. [Epub ahead of print]

ARTIKEL 4. - P. 125

Gebaseerd op het artikel van: van Eechoud, I., Grypdonck, M., Leman, J., Van Den Noortgate, N., Deveugele, M., & Verhaeghe, S. Balancing truth-telling: relatives translating for cancer patients over 50 years of age of Turkish or Northwest African origin. Submitted.

CARING FOR FAMILY MEMBERS OLDER THAN 50 OF TURKISH AND NORTHWEST AFRICAN DESCENT: THE MEANING OF CAREGIVING

ABSTRACT

Background: The first generation of immigrants to Belgium from Turkey and Northwest Africa are aging and at risk for developing cancer. Family members play an important role in both illness and old age.

Objective: The objective of this study was to gain insight into experiences and perceptions of families with Turkish or Northwest African backgrounds who were caring for cancer patients older than 50 in Flanders, Belgium.

Methods: A qualitative research design with elements of constructivist grounded theory was used. Twenty-eight loosely structured interviews were conducted. Three researchers were involved in data analysis (researcher triangulation), and 6 conversations took place with experts.

Results: Cancer appeared to be a family matter. Caregiving had a strong moral meaning for all participants, particularly for children providing care to a parent. Caregiving could be described as “guiding”: family members led the patient through, or familiarized the patient with, the health care system. There were strong differences in the extent to which family members believed they should provide care, as well as the kind of professional care considered desirable.

Conclusions: Despite shared values of the importance of family and family caregiving, concrete ideas about caregiving differed considerably. The findings imply that shared cultural or religious normative values do not predict day-to-day care practices.

Implications for Practice: This study provides new insights into the moral and practical meaning of caregiving, which will help professionals understand the roles adopted by family members. Furthermore, individualized approaches to care appear to be essential, because concrete ideas about informal caregiving differ strongly despite shared values.

Key words: Adult children; cultural diversity; Family; Family caregivers;
Older adult; Oncology

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INTRODUCTION

Although Belgium is characterized by increasing diversity in its population, little is known about the experiences and perspectives of care users from ethnic minority groups. The Belgian healthcare system has been recognized as one of the most equitable in the world,[1] however, its commitment to diversity is rather weak.[2] Among other things, healthcare organizations in Belgium have no official obligation to pay attention to diversity, leading to implicit denial that there may be discrimination in the delivery of healthcare.[2,3] There are state-funded intercultural mediators, but their practice is limited to hospitals, and few interpreting services exist in outpatient settings.[1,2]

Moreover, the proportion of people from foreign countries in the ageing population of Flanders (the Dutch speaking part of Belgium) is rising, as in other Western European countries.[4] Given the higher incidence of cancer in older age groups,[5] it is expected that oncology health professionals will increasingly confront patients of diverse ethnic and cultural origins. The 2 largest Non-European immigrant groups of people older than 55 years in Flanders are of Turkish or Northwest African descent.[4] The ethnic roots of the 2 groups differ, but they share a similar immigrant history, as the majority came to Belgium as young labour immigrants between 1960 and 1975.[4] Furthermore, both groups live in Belgium as a Muslim minority.

It has widely been acknowledged that cancer affects both the patient and the family.[6-8] Family members play an essential role in the cancer trajectory[9,10] and often provide emotional and practical support.[11-15] Many studies have focused on the burdens, needs, and coping strategies of family caregivers; being a caregiver causes many emotional, health-related, social, and financial strains.[16-20] On the other hand, caregiving also appears to have positive effects on family members, such as revised life priorities, an improved relationship with the patient, and feelings of fulfillment.[9,13,18,21-24]

Relatively little research has been undertaken with regard to family members of ethnic minority cancer patients.[6,25-27] Among the studies about caregiving with specific attention to race, ethnicity, or culture, the 20-year review (1980-2000) of Dilworth-Anderson and colleagues[27] provides good insight. Although the included studies mainly concerned caregiving to patients with dementia/Alzheimer disease, and most were conducted in North America, the review makes the point that culture affects caregiving experiences and “cultural groups have values about reciprocity (giving back), filial obligation, and a sense of responsibility for providing care to older family members.”[27(pp266)] Similar conclusions about the importance of normative cultural values on family caregiving are also drawn in other studies.[19,28-30] More recently, an extensive systematic review of family members’ care and communication with incurably ill Turkish and Moroccan patients points out that family members are crucial care providers for incurably ill Turkish and Moroccan patients and that many patients expect their children and their children’s partners to care for them.[31] Two quantitative Dutch studies confirm that adult children and older parents with a Turkish or Moroccan background adhere far more strongly to norms of filial responsibility compared with native Dutch.[32,33] However, with regard to providing support, the patterns become more complex,[33] and care for older parents is no longer as self-evident as it traditionally was.[34]

Therefore, it is important to gain insight into the experiences and perspectives of family members, presumably adult children, of older adult cancer patients of Turkish or Northwest African descent who are living in Belgium. Through gaining this insight, this study could enhance the limited knowledge about the experiences of family members of ethnic minority patients in a Western European country. Understanding the experiences and perspectives of family caregivers allows healthcare professionals to tailor interventions and support, thereby improving outcomes.

METHODS

DESIGN

A qualitative methodology, with elements of the constructivist grounded theory,[35] was chosen because it is well suited to gather data on *how* family members experience and perceive the patient’s disease and the care situation. Although the study concerns a multicultural context, it is not an anthropological study. The aim is not to enrich anthropological theory but to use insights from several disciplines, including anthropology, to understand as far as possible the lived experience of a vulnerable group in healthcare.

DEFINITION OF CULTURE

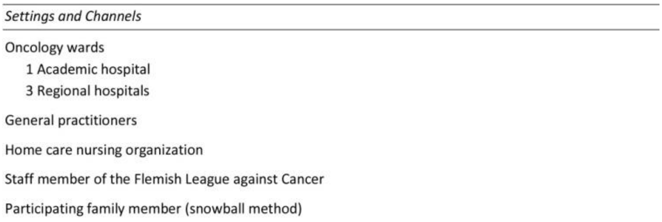
Culture is defined here as "a process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants."[36(pp1674)] This means that cultures are not fixed entities or things[37], culture is not static or homogeneous and "cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, ethnicity, and even personality."[36(pp1674)]

PARTICIPANTS

Participants included adult family members of patients who were 50 years or older, diagnosed with cancer or a severe haematological disease (with increased risk of developing leukaemia), and Turkish or Northwest African (Moroccan, Algerian, or Tunisian) by birth. The sample consisted of family members of patients who were in different stages of the illness trajectory. Participants were recruited from multiple settings and through different channels in Flanders (Table 1). Because it proved difficult to recruit participants, several attempts were made in new settings and different recruitment channels. Healthcare providers, and in one case a participating family member, asked permission for the researcher to contact family members and provide more information on study goals and the nature of the interview. Of 43 potential participants, 5 refused to be contacted when the healthcare providers asked permission, and 6 refused to participate when asked by the researcher. One interview took place unintentionally with 3 family members of a deceased patient whose death appeared to have been caused by kidney failure rather than cancer. The research team decided to include this interview as it enriched the constant comparative method. The differing diagnosis was taken into account in the analysis process.

The study protocol was approved by the ethical committees of the involved hospitals (B670201111438). Written informed consent was obtained for all interviews.

Table 1. Recruitment Settings and Channels in Flanders



Settings and Channels
Oncology wards
1 Academic hospital
3 Regional hospitals
General practitioners
Home care nursing organization
Staff member of the Flemish League against Cancer
Participating family member (snowball method)

DATA COLLECTION

Data were collected via 28 loosely structured interviews with 32 family members. All interviews were conducted by the same researcher. At the request of the participants, 2 interviews took place with 3 family members together. Twenty-three participants were adult children; 3 were daughters-in-law, and 6 were spouses. The mean ages of the family members and the patients was 37 and 64 years, respectively (Table 2).

Table 2. Descriptive Information About Family Members (*N* = 32 of 27 patients)

Characteristic	*N*
Gender of family member	
Male	10
Female	22
Gender of the patient	
Male	16
Female	16
Relationship	
Husband	2
Wife	4
Daughter	15
Son	8
Daughter-in-law	3
Diagnosis	
Cancer	26
Myelodysplastic syndrome/aplastic anaemia	3
Severe kidney failure (deceased)	3
Patients deceased by the time the interview took place	10
Age of the family member, y	
21-30	11
31-40	13
41-50	3
51-60	2
61-70	3
Age of the patient, y	
51-60	15
61-70	8
71-80	7
> 80	2
Country of birth patient	
Turkey	12
Morocco	16
Tunisia	2
Algeria	2
Origin of family member	
Turkish	11
Moroccan	17
Other: Belgian, Polish, Macedonian, Algerian-Moroccan	4

The interview framework was based on the literature and previous research[38-40] and was discussed with experts in medical and nursing care and intercultural care for older migrants. The interviewer attempted to elicit personal narratives from the interviewees on their experiences with and ideas about the patient's disease, the care situation, and their experiences and ideas about their role in caregiving and their experiences with professional caregivers and the medical care system. Basic demographic information was also collected. To invite participants to speak, each interview started with the following question: "I understand your family member is diagnosed with a severe illness/has died. Can you tell me something more about this?" As the interviews and analyses progressed, the focus of the interviews changed to pursue deeper understanding of central themes emerging from the data.

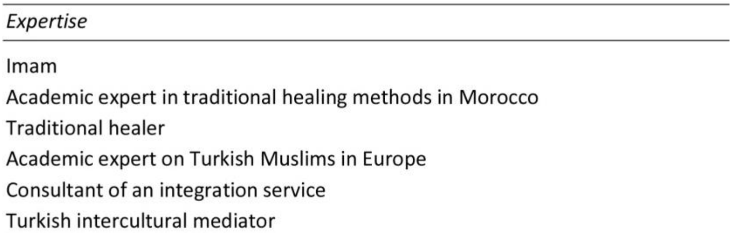
The interviews had a mean duration of 97 minutes (range, 32-185 minutes). According to participant preference, 20 interviews occurred in homes, 10 in a private room in the hospital, and 2 at the workplace. All interviews but one were audio-taped and transcribed verbatim. One participant refused tape recording of the interview. The interviewer took notes during that interview and wrote a detailed report the same day. Field notes were made about interactions with all family members, interview settings, and the atmosphere. Although the ability to speak Dutch was not required to participate in the study, all but one participant knew enough of the Dutch language for sufficient expression; a professional translator assisted in the interview with the excepted participant.

DATA ANALYSIS

Data collection and data analysis alternated in a cyclic process and continued until theoretical saturation.[41] Constant comparative analysis, one of the defining components of grounded theory, was conducted.[35] The process of analysis in this study is comparable with the Qualitative Analysis Guide of Leuven (QAGOL)[42] It is important to emphasize that the stages were not discrete and linear.[42] On the contrary, the analysis moved among the different stages, and the process of analyzing started after the first interview and continued until theoretical saturation.[42] The first stage in the analysis consisted of a thorough reading of the transcribed interviews. To further explore the meaning of the narrative, 2 researchers discussed the interviews together in a second stage of analysis. In addition, a quarter of the interviews were read and discussed with a third researcher who is an anthropologist specializing in interculturalism and Mediterranean cultures. In a third phase, themes were identified, and theoretical notions were developed by continually comparing fragments within and among the transcribed interviews. In stage 4, transcripts were reread, and relevant fragments were linked to appropriate codes[42] using the qualitative software program Nvivo 10 (QSR International, Australia). In the final phase, themes were refined through confrontation with new data. During the analysis, all decisions were made by researcher triangulation, thus contributing to the credibility of the analysis.[43]

To allow better understanding of specific themes and to consider the field of possible interpretations of the data, 6 experts or privileged witnesses involved in transcultural healthcare or religious matters (Table 3) were consulted. Topics for discussion included illness, healthcare, and family care in the respondent's culture and religion.

Table 3. Information About Experts



Expertise
Imam
Academic expert in traditional healing methods in Morocco
Traditional healer
Academic expert on Turkish Muslims in Europe
Consultant of an integration service
Turkish intercultural mediator

Preliminary results were discussed a total of 5 times with three different groups of experts: the steering committee of the research project, a group of 15 nurse consultants and clinical nurse specialists in oncology, and a group of experts in diversity and healthcare. The experts were asked to provide alternative interpretations, which were used to confront the data.

RESULTS

Two central themes and several subthemes resulted from the analysis of family member narratives. The first central theme, that cancer was a family matter in which the experiences and perceptions of the participants were embedded, enclosed the second central theme: caregiving had a strong meaning, both moral and practical, for all family members. The moral meaning encompassed a deeply felt moral obligation. The practical meaning of caregiving was divided into the following subthemes: a description of caregiving ("being a guide"), division of caregiving tasks, and the use of professional care. The following discussion presents the details of these findings.

CHARACTERISTICS OF THE FAMILIES

Many participants came from families with an average of 6 children. In almost all families, at least some of the adult children lived close to their parents. In most cases, parents came to Belgium as young adults, and the children were either born in Belgium or were brought to Belgium at a young age. A few of the patients had immigrated to Belgium as middle-aged or older adults. In some cases, adult children brought their parents to Belgium because of health problems, or they stayed on after a visit to Belgium. Most of the patients and their spouses had a poor command of the Dutch language, whereas most children spoke Dutch well. All but one family member referred to Islam as their religion. However, this varied among participants, some of whom stated religion was paramount in life, whereas others mentioned that they did not really practice their religion. Based on the demographic data collected during the interview and the interviewer's observations about the participants' appearances and their living conditions, the participants represented diverse social classes.

CENTRAL THEMES - CANCER: A FAMILY MATTER

The cancer diagnosis concerned the whole family. Family members described feeling responsible for making sure that what was needed would happen, and they played an active role in bringing it about. The role played by the patient differed. Sometimes the patient acted together with family members, and in other cases, the family members decided what should happen without consulting the patient. In several cases, the patient was left out of the decision making deliberately so that the family could do what they thought necessary.

> *We* [children and children-in-law] *dragged him to the hospital, because he doesn't understand it* [the Belgian healthcare]*, he is not familiar with it, and he doesn't want to know about it and about doctors. Not about the disease. It was already difficult for him to go there, he would rather prefer to stay home and die. He doesn't want to know anything about hospitals. He is not familiar with it, he*

> *doesn’t want to go there.* (Daughter - father with Moroccan background)

The following quote illustrates how in other families the patient participated more fully:

> *We discussed it* [treatment options]*. We are one family. We are.. He has 8 children; 7 were still alive. And everyone had his say in it.* […] *No one wants to let his father go too early, so… So everybody thought about it and took part in decision making. Useful or not. And at the same time gave him some freedom to make his own decision consciously.* (Daughter - father with Moroccan background)

THE MEANING OF CAREGIVING: MORAL AND PRACTICAL

THE MORAL MEANING OF CAREGIVING

Taking care of an older adult family member had a strong moral meaning for all the participants, particularly when it pertained to caring for a parent. The adult children experienced a deeply felt moral obligation (which is not the same as an imposed duty) toward a parent. Participants were both intrinsically and extrinsically motivated to take care of the patient. They mentioned that they felt ‘in their heart’ that caregiving was the right thing to do (intrinsically motivated), as well as that it was something they were “supposed to” or “obliged to” do (extrinsically motivated). Love and fear of losing the patient were intrinsic motivations to take good care of their mothers or fathers. The family members had internalized the idea that a parent needed to be taken care of and that this responsibility devolved first and foremost to the children. They maintained this standard by providing good care. The parent deserved it or had earned the right to it by having borne the burdens of parenthood.

Adult children often mentioned that caring for a parent diagnosed with cancer is the least they could do because “they brought you into the world and raised you.”

> *They* [parents] *took care of us too, so you need to take care of them in return, you see. That’s the way we think about it* […] *they took care of you. When they are in need of care, you must take care of them. It’s just the way it is.* (Daughter-in-law – father-in-law with Moroccan background)

> *They are still my parents. I won't say, you raised me, and that's it.* (Son – mother with Turkish background)

Some family members explained that taking care of a mother had an even stronger moral meaning than taking care of a father, as she is the one who "carried you for nine months."

> Daughter: *She took care of you for years. And for us that's how it is, your mother, your father, they are the most important persons in your life. I think for everybody, but for us in our religion, you need to be good to your parents. You need to be good to everyone, but certainly to your parents.* [...] *Certainly to your mother.*
> Interviewer: *Yes, certainly to your mother?*
> Daughter: *Yes, because it's a saying, you know, your mum carried you 9 months, it doesn't matter what you ever did, you will never be able to give enough in return. A mother to us, is highly valued in the family.* (Daughter - mother with Moroccan background)

The source of the deeply felt moral obligation to take care of family members was most often explained as a cultural or religious matter and sometimes as "natural." The participants often mentioned a difference between "their" way of taking care of older or ill family members and the way of native Belgians.

> *From Islamic perspective, you need to take care of your father, right, or of your mother* […] *I thought it was my duty as a Muslim to do this.* (Son - father with Moroccan background)

> *To us in, in Turkish families, I think so too in Tunisian and Moroccan, if, for example, one person in the family is ill, we all must help each other. You should not remain distant from it.* (Daughter-in-law – mother-in-law with Turkish background)

> *In my case, caring for parents is ingrained. It is ingrained in us, we sometimes do not understand, like "come on, why do they* [healthcare workers] *consider it special what we do?" And then you give it a moment's thought and start to realize, wait a second, I see,*

> *here* [in Belgium]*, it is not like that. We do not have old people's homes.* (Daughter - mother with Moroccan background)

Although taking care of the patient was often experienced as a difficult task, many family members described a feeling of satisfaction resulting from it or peace of mind, because taking good care of one's older adult family member with cancer was felt to be the right thing to do.

> *I think that we psychologically strongly supported her and that she was very satisfied with us emotionally. It made me feel good to be able to achieve this.* […] *That I was able to do something after all* […] *The right of mothers is beyond any value to us. And I believe I .. to her a little, you see, after everything she did for me, I was able to do something for her of significance and about which she was satisfied.* (Son - mother with Turkish background)

> *I am glad she permitted the assistance. For us it was a way to be there for her. She has always been there for us… And now we were able to give something in return* [cries]. (Daughter - mother with Moroccan background)

> *We didn't let her down; we take care of each other together. My mum and dad, we feel well when we lay our head down on bed, on our pillow, we sleep, we can sleep after all. Some people do not help their parents; I wonder, how can these people sleep?* (Daughter – father with Turkish background)

Some family members also referred to a possible benefit for themselves by taking good care of the patient, as they hoped they would be taken care of when needed.

> *It gives a good feeling, to be able to help someone. And you never know, in case I need help, it will be there too.* (Wife - husband with Moroccan background – with translator)

> *The only thing I can do is to take good care of her, always be polite and respectful. And I hope my children will do the same for me.* [...] *Allah, God wrote it also down for us that you should respect your*

> *parents. If you want respect, you should give respect to your parents first. And your children will do it for you in return. Insha'Allah, I hope so.* (Daughter – mother with Turkish background)

The general pattern, in which caregiving carried a strong moral meaning, was not evident in one case. This family member was the Belgian wife of a Northwest African man. She was the only participant who explicitly mentioned that she and her husband were not religious at all. She stated that their 2 children played only a minor role in the care for their father. She was the main family caregiver for her husband, and when the interviewer asked about the caregiving tasks of the children, she explained that they had already left the parents' home. Later she stated that the children "have a life of their own" and that her husband, influenced by the Northwest African mentality, would have liked the children to pay more attention to him, but "he can't compel them."

Family members who reported a loving relationship with the patient perceived caregiving tasks as less burdensome compared with family members who lacked a loving relationship. A few interviews also revealed that the intrinsic motivation for caregiving played a lesser role when there was a negative relationship between the patient and the family member. However, this was not always the situation. In one case where a reduced intrinsic motivation was strongly present, the family member, a daughter in-law who described a sequence of bad experiences with her father-in-law, chose to play a minor part in the caregiving for her father-in-law, even though she attached strong moral meaning to caregiving for older family members.

THE PRACTICAL MEANING OF CAREGIVING: WHAT DOES CAREGIVING ENTAIL?

Moral obligation in practical terms meant making sure that the older family member received the appropriate care. In most cases, family caregivers ensured that all the patient's needs received attention. Both emotional and practical care were provided, such as physical and domestic caregiving at home, acting as a contact person or a translator for healthcare providers, "being" with the patient, searching for a cure (via alternative treatment), mental support, and sharing the financial burden of illness (such as costs related to transport to and from the hospital or the country of origin, alternative medication, food, and professional care).

Subtheme 1: “Being a guide” through the Belgian healthcare system

Most participants considered their primary task to be ensuring that the patient received the most beneficial care possible. The role of family members varied, but can best be described as “guiding” the patient through the Belgian healthcare system. They helped the patient to navigate the healthcare system, provided advice on events and choices, and supported the patient in coping with the experiences of diagnosis and treatment. They made sure that, despite the patient’s unfamiliarity with the system and limited knowledge of the language, the appropriate care was provided.

The difference, mentioned above, between acting together with the patient or acting on behalf of the patient was also reflected in the “guiding style” of family members: some “guided” the patient by directing events and making choices, and others tried to empower the patient to understand what was happening and which decisions needed to be taken. The following quote is from a family member who attempted to empower the patient as a “guiding style”:

> *I was raised here, I have my own driver’s license, I know the language.* […] *My mommy depends on me actually. I go with her, I make the appointments, I talk to the doctors, I go to the emergency department, you know.* […] *I said to my mom a couple of times already, try to manage yourself a little, because I do not work for the moment, as I have a career break. Imagine that I had been working. You need to be able to go your own way a little, you know. Imagine that someday I can’t be there, for example. What will happen in case I am ill or I don’t know what, you don’t know what will happen then, right.* (Daughter - mother with Turkish background)

In contrast, family members sometimes took on a “directing guiding style,” as previously illustrated by the daughter who explained that she, together with her brothers and sisters, “dragged” their father to the hospital.

Subtheme 2: Division of caregiving tasks

Caregiving was often coordinated by one or a few of the children, who saw to it that all the patient’s needs were met to the fullest extent possible and who took responsibility for organizing support. Often, they were assisted by other family members who provided as much practical help as they could.

The participants described the division of care tasks as mainly pragmatic: a particular task is fulfilled by the person most suited or in the best circumstances. Circumstances considered good or bad in terms of caregiving tasks included: being employed (full- or part-time) or not, having a family of one's own (children to take care of) or not, being in good health or not, and the distance between the place of residence and the home of the patient.

> Interviewer: *What was your main reason to say: "I will do this* [taking care of your mother]*?"*
> Daughter: *Just because for me it was more easy.. I lived at home. And I simply had most time, didn't have children, I didn't have a family. So I was just able to do that, practically.* (Daughter - mother with Moroccan background)
>
> *I was with her always. But I left in the evening, to my own home, I had 3 children too, my husband had to go to work, and things like that. I had to be at home, right? And my brothers stayed there, with my dad and my mum.* (Daughter - mother with Turkish background)

Suitability to task pertained to contact with professional caregivers. Familiarity with the Belgian healthcare system (including general health literacy) and mastery of both the Dutch language and the patient's language were seen as key characteristics.

> Interviewer: *What is the reason that 1 of the 2 of them* [2 of 5 children who are nurses] *went along* [to consultations with the doctor]?
> Wife: *Well, because it was the most practical… how can I explain? It is their field, they are nurses. They will more easily understand something in case of terms related to treatment or something or another.* (Wife - husband with Algerian background)

Although caregiving tasks were usually divided among family members along pragmatic lines, some participants referred to the position of the "eldest son" or the role of responsibility within the family. When a family member didn't fulfill an expected caregiving task, the others took over. In most cases, this did not seem to cause relational issues between siblings. When others did less than was expected, the obligation to make sure parents received the care to which they were entitled was not diminished; it was increased for other family members.

In contrast, the division of tasks concerning intimate matters, such as personal hygiene and conversations with healthcare providers about issues related to sexuality, were mainly determined by gender. However, when needs could not be met according to these rules, needs prevailed, and rules were bent.

For a male patient, a spouse was preferred for the performance of intimate care tasks. The second preference was for a son, but this was sometimes perceived as unsuitable and emotionally difficult. A daughter was perceived as the most inappropriate choice for intimate caregiving; nevertheless some daughters did provide care when no one else was available. Similarly, for female patients, a daughter or the husband was perceived as the most suitable choice. Some sons provided this type of care for their mothers, but the experience was emotionally charged. None of the 3 daughters-in-law who participated in this study carried out intimate care tasks.

> *I have done that, changing diapers and things like that. But doing this for my mother, it was very painful, because I always.. my mother, as to say, she was really a kind of father figure at home.* (Son - mother with Turkish background)
>
> Daughter: *I have 2 other brothers and to the doctor he* [father] *goes with my brother. I go with my mum, my brother accompanies my dad.* […] *helping my father to the toilet, if my brother is in the room, I would rather not go.*
> Interviewer: *In that case, your brother goes?*
> Daughter: *Yes. In our religion, it is like that actually […] in case my brother is not in, I will go. But when my brother is in, I won't go. It depends […] rather girls with the mother.* [...] *Generally, it is like that; in Turkish culture, it is like that. Without, in case I wouldn't have a brother, I should give them both* [mother and father] *a bath. I never gave my father a bath* […], *my brother always gives my father a bath.* […] *once in every 2 days.*
> Interviewer: *Every 2 days, yes. What if your brother wouldn't manage it, would you do it?*

> Daughter: *Yes, we did that, but uhm.. I let him keep on his underwear, and afterwards I said, take it of yourself, and wash yourself down there. Not naked constantly, with my brother he is naked constantly, right? I did the toilet, but not underneath. Because my brother returned Monday, he returned from Mecca Monday last week* […] *He was away 2 weeks, 18 days and in the main time, I did the washing.* (Daughter - father with Turkish background)

Combining an extensive caring role with full-time employment and dependent children was especially demanding. This was most apparent when family members were unable to share care tasks with relatives.

Subtheme 3: Use of professional care

In general, professional caregivers were engaged only if family members believed they lacked the competencies required and that professional care would be superior. This concerned mostly medical care or technical nursing tasks. However, there was strong disagreement among participants as to how care should be organized and which professional care was desirable. For example, family members differed in their ideas about transport service to and from the hospital. One daughter mentioned that making use of this service was something that no one “among them” would ever do and something she could not think of doing. In contrast, other family members explained how useful this service was and how happy it made them and the patient.

Admission of patients to palliative care elicited similar responses. Two of the participants had chosen to have the patient admitted to a palliative care unit (one with and one without patient involvement). Both family members described very positive experiences with the care provided.

> *But at the palliative care unit, I thought it was very positive. The commitment of these people, the way they really create an atmosphere in which you are truly able to say goodbye to your loved one, and things like that.* (Daughter - mother with Moroccan background)

Some other participants were made aware of palliative care services and decided not to admit the patient, because they (or the patient) preferred the patient to die at home surrounded by relatives. A son and his mother and sister explicitly stated that admitting their father/husband to a palliative care unit went against their principles regarding fulfillment of the moral obligation of caregiving.

> Son: *We didn't want that* [admission to a palliative care unit]. [...] *It doesn't suit us, you see yes, it doesn't suit us.*
> Daughter: *In our Islam, it's…*
> Wife: *Islam.*
> Son: *For us, according to our religion and, uhm..., to honour your parents, or whom it may be. You see, it's impossible. It's out of the question.*
> Interviewer: *And what... Can you explain it a bit more, what is exactly out of the question?*
> Son: *Uhm.. Yes..., uhm, in case you have children, for us it is system, culture. If you have children, your children need to take care of you. In bad times. And if you don't do that, it is bad also. As to say, it is a bad example for society too. For us, it's something... yes, it is not allowed. It is not allowed. You have to take care of your parents.*
> Wife: *Yes.*
> Daughter: *Till death.*
> Son: *They took care of you. They took care of you, right, until this moment for example. And it's your turn now.* (Daughter, wife and son - patient with Turkish background)

All Belgian healthcare facilities were considered acceptable by some of the participants. Even admission to a nursing home, seen by most participants as beyond consideration, was still acceptable to some family members, provided the facility respected the religion, language, and culture of the parent.

There were discrepancies between family member and parent perceptions of the desirability of professional support. For example, some family members wanted to hire cleaning people, but as the patient thought this was the children's duty, the children did the chores.

Some family members reported doing more for their parents than they expected from their own children. They attributed lower expectations to familiarity with the Belgian heath care system and their ability to communicate with healthcare workers. Apparently they believed they would need less support than their parents did.

In summary, the narratives of the family members' experiences revealed that cancer was considered a family matter. Embedded within this context, caregiving had a strong meaning, both moral and practical, for all family members. Particularly, the adult children experienced a deeply felt moral obligation toward caring for the sick parent. Most participants considered their primary task to be make certain that the patient got the most beneficial care possible. An important characteristic of caregiving is providing the "guiding" role through the healthcare system. The division of care tasks within the family is pragmatic. However, more intimate care tasks are generally determined by the gendered position of a family member. Although in general, family members are considered to be the most appropriate caregivers, opinions differed as to how care should be organized and which professional care was desirable. While participants have strongly shared principles and values, their concrete ideas about daily care practices differed considerably.

DISCUSSION

For the participants in this study, when an older adult relative of Turkish or Northwest African descent had cancer, the disease was considered a family matter, and caregiving held strong moral meaning for all participants. As previously discussed, the importance of family for cancer patients has been widely acknowledged in the literature. However, the emphasis on patient autonomy in contemporary Western biomedicine[44] was not shared by the participants in this study, who perceived the family as the "principal actor" instead of the patient alone. The strong moral meaning caregiving had for all family members, in particular for adult children taking care of a parent, is in accordance with literature specifically concerned with the ethnic-cultural minority groups we studied.[31-34] Only a few qualitative studies on West-European family caregivers, mainly partners, point out the meaningfulness of supporting or taking responsibility in caregiving.[21-23] The current study provides further insight into the reasoning behind the value family members attached to caregiving, which they compared with persons of Belgian origin.

The intrinsic and extrinsic motivations for caregiving are similar to a Turkish study pointing out motives for caregiving, including responsibility and social obligation, and emotional and personal connectedness.[45] In the context of culture as defined in this study, the narratives show that culture is the process through which caregiving takes on an emotional tone and strong moral meaning for the family members.[36,37]

Despite the shared values of the importance of family and family caregiving in the illness trajectory, concrete ideas about how care should be organized and what type of professional care is desirable differed considerably among the family members. Understanding shared values can help nurses and other healthcare providers accommodate the roles family members adopt, for example, the presence of an adult child with an ill parent. However, the results also illustrate that shared cultural or religious normative values do not predict the daily care practices and preferences of family members. Reducing cultural competency to a list of "do's and don'ts" is useless and may be dangerous.[36]

The complexity of understanding family roles in caregiving is even more apparent when considering the division of caregiving tasks within these families. Although the division of more intimate tasks was determined by gender, [46] care tasks were generally assigned to family members on pragmatic grounds such as the life circumstances and capacities of each person. This finding is similar to the study on informal caregivers in Turkey.[45] The few West-European, mainly Dutch, studies on family caregiving in Turkish and Northwest African minority groups describe a somewhat more static picture of family care as an obligation in which mostly female relatives are heavily burdened.[31,47] The findings from this study are comparable to the conclusions of the anthropological study of Yerden[34] on care expectations and care practice (non-cancer-related) among 3 generations of Turkish immigrants in The Netherlands. Family care remains central, but traditional care is subject to change, and care practice has become a combination of traditional and new forms.[34] We might well speak of new forms of family care practices within "old" values of family care.

Characteristic of family caregiving is the "guiding" role that family members adopt. Often adult children, who have been raised in Belgium, led the patient through or familiarized the patient with the healthcare system. They made sure that the most beneficial care was provided despite the patient's unfamiliarity with the system and his/her limited knowledge of the language. Understanding the "guiding role" and the high level of responsibility this involves is useful for nurses and other healthcare providers. To our knowledge, this has not been explicitly identified elsewhere, although previous studies on cancer caregiving have shown that family members take on advocating,[48] sometimes leading,[49] and other active roles with regard to communication with healthcare providers.[15,20,50] One other study notes that Turkish family members in The Netherlands act as intermediaries between healthcare professionals and their mostly non-Dutch speaking parents.[47]

LIMITATIONS

This study had several limitations. Because of ethics committee requirements, no information could be obtained about potential participants who had not been approached by healthcare providers or potential participants who refused to be contacted by the researcher. It was difficult to recruit participants, and some healthcare providers reported reluctance to ask potential candidates permission for the researcher to contact them. This might have caused a less diverse sample compared with the general population of family members of these patient groups. However, out of the 43 potential participants who were asked to participate, only 11 refused.

This study provides insight into the experiences and expressed motives of family members involved in caregiving and only to a limited extent into motives for not being involved in caregiving. Hence, the findings might not be generalizable to family members of these immigrant groups in general.

Although the sample consisted of family members of patients in different stages of the illness trajectory, because of the cross-sectional study design, insight into the care experience is limited to the information obtained during a single interview with each family member.

REFLECTION

The researcher who conducted the interviews was a woman of approximately 30 years of age; therefore, she belonged roughly to the same age group of most participants. As she was of West European origin, the narratives were constructed from an interactive process between a West European researcher and family members of Turkish or Northwest African origin. This may have affected the results in the sense that participants explicitly explained cultural or religious values to the researcher of another cultural, ethnic, and religious group. Because the researcher was employed by the Faculty of Health and Medical Science, she might have been perceived as part of the Belgian healthcare system. In order to obtain valid data, the researcher tried to behave as free from value judgement as possible, by being well aware of her own background, characteristics, and opinions.

FUTURE RESEARCH

It would be beneficial to study the family member perspectives within a triad including the patient and professional caregiver perspectives. This would provide insight into perspectives of care users as well as a better understanding of the perspectives of healthcare providers caring for people with culturally diverse backgrounds. The current study provides a useful basis for future research on this subject.

Contrary to the static way culture is often defined in medicine,[36(pp1673)] the current study empirically confirms the dynamic definition of culture as "a process through which ordinary activities and conditions take on an emotional tone and moral meaning for participants."[36(pp1674)] In future studies on diversity in healthcare, researchers should be clear and thoughtful about the definition of culture they use.

CONCLUSION AND CLINICAL IMPLICATIONS

This study provides insights into the moral and practical meaning of caregiving for older adult cancer patients of Turkish or Northwest African descent, the 2 largest Non-European immigrant groups of people older than 55 years in Flanders.[4] These insights will help nurses and other professional healthcare workers understand the roles family members adopt.

Cancer affects the whole family.[6-8] This takes on particular form in Muslim immigrants from Turkey or Northwest African countries. Nurses, who have easy access to patients and their family members in the course of their activities, are well positioned to explore the role family members want to play and especially why they want to play that role. An open dialogue with family members exploring how to best provide care to the patient will best meet the needs of both patient and family members.

Cancer is considered a family matter, and caregiving has a strong moral meaning for all family members, particularly when providing care to a parent. Despite these shared principles and values, concrete ideas about how care should be organised and the type of professional care that is desirable differ considerably. This makes it essential that care is attuned to the individual. In fulfilling this, it can be helpful, to use Kleinman's and Benson's words,[36(pp1676)] "to routinely ask patients and (where appropriate) their family members what matters most to them in the experience of illness and treatment."

Family members adopt a “guiding” role to lead the patient through and/or familiarize the patient with the healthcare system. As a nurse or other healthcare provider, it is important to take this into account. Family members should be supported in adopting this role, without limiting the patient in the exercise of his/her rights. In addition, it is important to realize that performing certain intimate care tasks can be perceived as strongly inappropriate within particular (gendered) family relations.

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BALANCING TRUTH-TELLING: RELATIVES TRANSLATING FOR CANCER PATIENTS OVER 50 YEARS OF AGE OF TURKISH OR NORTHWEST AFRICAN ORIGIN

ABSTRACT

The first generation of Turkish and Northwest African immigrants in Belgium are aging and at risk for developing cancer. Relatives play an important role and provide both emotional and practical care, including mental support and acting as a contact person and/or a translator. The aim of this study was to provide insight into the process wherein relatives balance truth-telling in translating for an older family member diagnosed with cancer. This was a qualitative research study, with elements of constructivist grounded theory. Twenty-eight loosely structured interviews were conducted. Most relatives consider it their responsibility to contribute to a positive attitude of the patient. Based on several motives and embedded in their assessment of the patient's emotional strength, understanding, and need to be informed, relatives decided to what extent they inform the patient. What they decide influences the way they act as a translator and/or a contact person. Some considered it best to omit medical information while others considered it best to inform the patient fully. The results emphasize the importance for healthcare providers to take into account the complexity and unpredictable character of the process of balancing truth-telling when family members translate for their ill older relative.

Keywords: family, ethnic and cultural diversity, oncology, older adult, truth-telling

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INTRODUCTION

As in other West-European countries, Belgium is realizing increasing ethnic diversity in its population. Furthermore, the proportion of people from abroad is rising in the aging population (Lodewijckx, 2007). As the incidence of cancer is higher in older age groups (Anisimov *et al.*, 2009), it is expected that oncology healthcare providers will increasingly confront patients of foreign descent. People from Turkey or Northwest Africa account for the two largest Non-European immigrant groups of people older than 55 years in Flanders (the Dutch speaking part of Belgium) (Lodewijckx, 2007). The majority of both groups came to Belgium as young labour immigrants between 1960 and 1975 and live in Belgium as a Muslim minority (Lodewijckx, 2007).

It has been widely acknowledged that family members play a crucial role in the patient’s cancer trajectory (Haley, 2003, Ponto and Barton, 2008). Whereas much qualitative research has been undertaken exclusively with regard to family members of western origin, relatively few studies have focused on relatives of ethnic minority patients (Dilworth-Anderson *et al.*, 2002, Dilworth-Anderson *et al.*, 2005, Kristjanson and Ashcroft, 1994).

Family members of cancer patients often provide practical as well as emotional support (Blindheim *et al.*, 2013, Röing *et al.*, 2008, Teschendorf *et al.*, 2007, Pusa *et al.*, 2012, McIlfatrick *et al.*, 2006). Some studies explicitly point out that family members try to protect the patient from unpleasant information (Steinvall *et al.*, 2011), keep peace and maintain an upbeat atmosphere (Teschendorf *et al.*, 2007), and try to keep hope alive (Sand *et al.*, 2010). In addition, a few studies, mostly concerning non-western countries or populations, found that family members sometimes played a role in non-disclosure of the cancer diagnosis or prognosis (Balneaves *et al.*, 2007, Doumit *et al.*, 2008, Teschendorf *et al.*, 2007). A systematic review specifically focussing on incurably ill Turkish and Moroccan patients reported that “relatives often prevented disclosure as they felt this might upset their patient” (de Graaff *et al.*, 2012, p. 34). Studies concerning the perspective of oncology healthcare providers in caring for ethnic minority patients found that professionals experienced ethical dilemmas when the family asked not to tell the truth or to omit information when speaking to the patient (Pergert *et al.*, 2007, Huang *et al.*, 2009). Professionals believe it is important that their patients have full understanding of the diagnosis and prognosis (Richardson *et al.*, 2006, Pergert *et al.*, 2007, Graaff *et al.*, 2012, Butow *et al.*, 2013).

Furthermore, it is common for oncology healthcare providers to work with relatives as interpreters rather than professionals (Graaff *et al.*, 2012, Kai *et al.*, 2011, Owens and Randhawa, 2004).

We conducted a study to gain insight in the experiences and perspectives of family members of older adult cancer patients of Turkish or Northwest African descent who are living in Belgium. The current article is part of this larger study. In an earlier paper, concerning the meaning of caregiving, we discussed the two central themes and several subthemes resulting from the analysis of family member narratives (van Eechoud *et al.*, 2015). The paper reported that cancer is considered a family matter and caregiving had a strong meaning, both moral and practical, for all participants. In particular, adult children felt a deeply moral obligation toward caring for the sick parent. Moral obligation in practical terms meant making sure that older family members received the most beneficial care possible. Most participants ensured that all the patient's needs received attention. Characteristic of caregiving was the 'guiding' role that participants took on to help older family members navigate the healthcare system. Both emotional and practical care was provided, including mental support and acting as a contact person or a translator. The analysis of the family member narratives in the larger study also yielded in-depth understanding of a process wherein family members attempted to balance truth-telling in the role of translator. The aim of the current article is to provide understanding of the process of balancing truth-telling, thus allowing health care professionals to tailor interventions and support with regard to the exchange of medical information.

METHODS

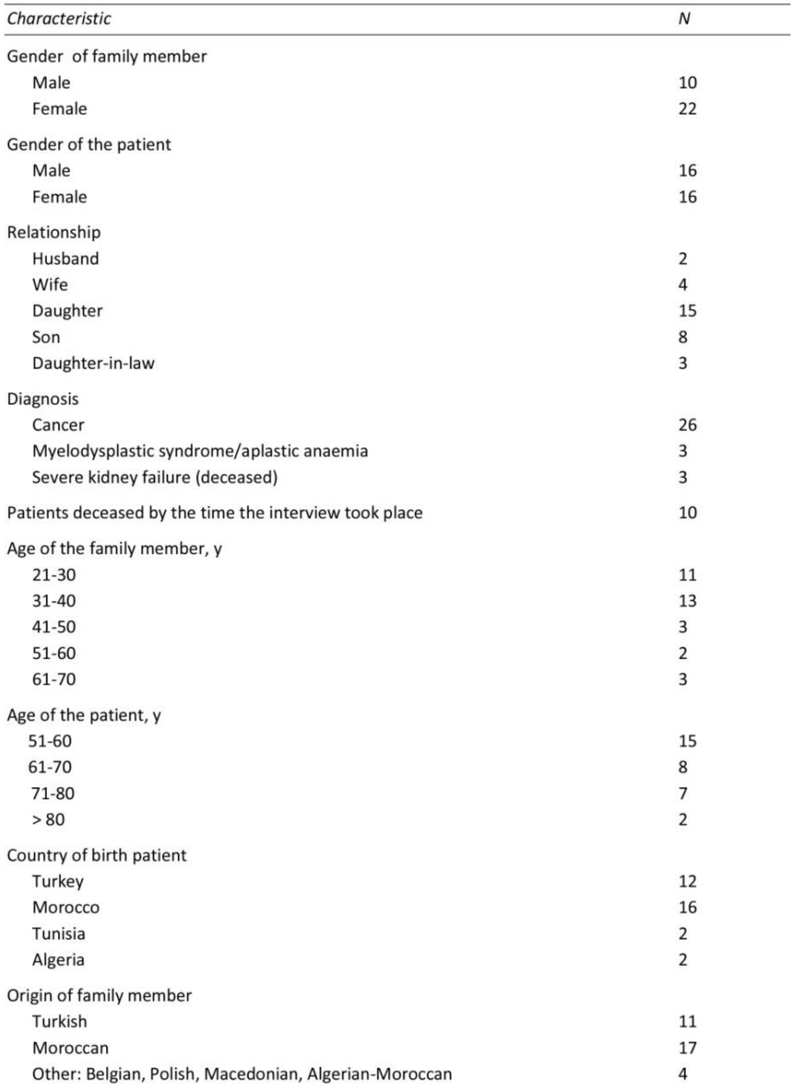
DESIGN

A qualitative methodology, with elements of the constructivist grounded theory (Charmaz, 2006), was used as it is well suited to gain an in-depth understanding of experiences and perceptions of participants. The technique of constant comparison analysis was used to analyse the data from the interviews, because it is one of the defining components of grounded theory (Charmaz, 2006).

PARTICIPANTS

Twenty-eight loosely structured interviews were conducted by the first author with 32 family members. Two interviews took place with three relatives together at their request. Twenty-three participants were adult children, six were spouses, and three were daughters-in-law. The mean age of the patients and the family members was 64 and 37 years, respectively. More demographic information is presented in Table 1.

Table 1. Descriptive Information About Family Members (N = 32 of 27 patients)



Characteristic	*N*
Gender of family member	
Male	10
Female	22
Gender of the patient	
Male	16
Female	16
Relationship	
Husband	2
Wife	4
Daughter	15
Son	8
Daughter-in-law	3
Diagnosis	
Cancer	26
Myelodysplastic syndrome/aplastic anaemia	3
Severe kidney failure (deceased)	3
Patients deceased by the time the interview took place	10
Age of the family member, y	
21-30	11
31-40	13
41-50	3
51-60	2
61-70	3
Age of the patient, y	
51-60	15
61-70	8
71-80	7
> 80	2
Country of birth patient	
Turkey	12
Morocco	16
Tunisia	2
Algeria	2
Origin of family member	
Turkish	11
Moroccan	17
Other: Belgian, Polish, Macedonian, Algerian-Moroccan	4

We intended to include family members of patients who were diagnosed with cancer or severe haematological disease, aged 50 years and older, who were Turkish or Northwest African (Moroccan, Tunisian, or Algerian) by birth. Participants were recruited from multiple settings and through several channels in Flanders (Table 2). Because it proved difficult to recruit relatives, several attempts were made in different recruitment channels and new settings. Permission for the researcher to contact family members and to provide more information on the study was sought by healthcare providers, and in one case a participating family member. One interview was conducted unintentionally with family members of a deceased patient whose death was caused by kidney failure rather than cancer. The authors decided to include the interview as it enriched the technique of constant comparison analysis. The differing disease was taken into account during the analysis.

Table 2. Recruitment Settings and Channels in Flanders

Settings and Channels
Oncology wards
1 Academic hospital
3 Regional hospitals
General practitioners
Home care nursing organization
Staff member of the Flemish League against Cancer
Participating family member (snowball method)

Ethical committees of the involved hospitals approved the study protocol (B670201111438). Written informed consent was obtained for all interviews.

DATA COLLECTION

Literature and previous research was used in developing the interview guide (van Eechoud *et al.*, 2014, Verhaeghe *et al.*, 2007a, Verhaeghe *et al.*, 2007b), which was evaluated by experts in nursing and medical care and intercultural care for older migrants. During interviews, personal narratives on the following subjects were recorded: participant experiences with and perspectives on the patient's disease; the care situation, and their experiences and perspectives on their role in caregiving; and their experiences with the medical care system and professional care providers. Basic demographic information also was collected. To seek deeper understanding of the process of balancing truth-telling, the focus of the interviews changed slightly as the data collection and analyses progressed.

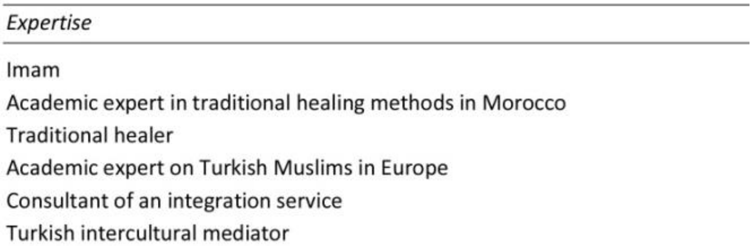
The interview recordings had a mean duration of 97 minutes (range 32 - 185 minutes). According to participant preference, 10 interviews were held in a private room in the hospital, 20 in the homes of family members, and two at the workplace. All interviews except one were audio-taped and fully transcribed; for the single participant who refused tape recording, the interviewer took notes during the interview and made a detailed report the same day. Field notes described interactions with the participants, the atmosphere, and interview settings. All but one participant had enough knowledge of the Dutch language for sufficient expression; a professional interpreter assisted in the interview with the excepted family member.

DATA ANALYSIS

A cyclic process, alternating data collection and data analysis, occurred until theoretical saturation was reached. The analysis process was comparable with the Qualitative Analysis Guide of Leuven (QUAGOL) (Dierckx de Casterlé *et al.*, 2012). The analysis moved among different stages, and the process started after the first interview was conducted and continued until theoretical saturation was reached (Dierckx de Casterlé *et al.*, 2012). In the first stage, transcribed interviews were thoroughly read. In a second phase in the analysis, two researchers discussed all the interviews to further explore narrative meaning. In addition, a quarter of the transcripts were discussed with a third researcher who is an expert in Mediterranean cultures and intercultural issues. By continually comparing fragments within and among the interviews in a third stage, the process of truth-telling and interrelated motives were identified as a major theme. In stage four, interviews were reread and relevant parts were linked to applicable codes using the qualitative software program Nvivo 10 (QSR International, Australia). In the final phase, the process of balancing truth-telling and interrelated themes were further refined through confrontation with new data. All decisions during the analysis were made by researcher triangulation, which contributed to the credibility of the analysis (Côté and Turgeon, 2005).

To consider the field of possible interpretations of the data and to allow better understanding of the process of balancing truth-telling, six experts or privileged witnesses were consulted (Table 3). In addition, preliminary results were presented for comments a total of five times to three different expert groups: a group of experts in diversity and healthcare; a group of 15 clinical nurse specialists and nurse consultants in oncology; and the steering committee of the research project. Alternative interpretations provided by these experts were used in testing the interpretations with the data.

Table 3. Information About Experts

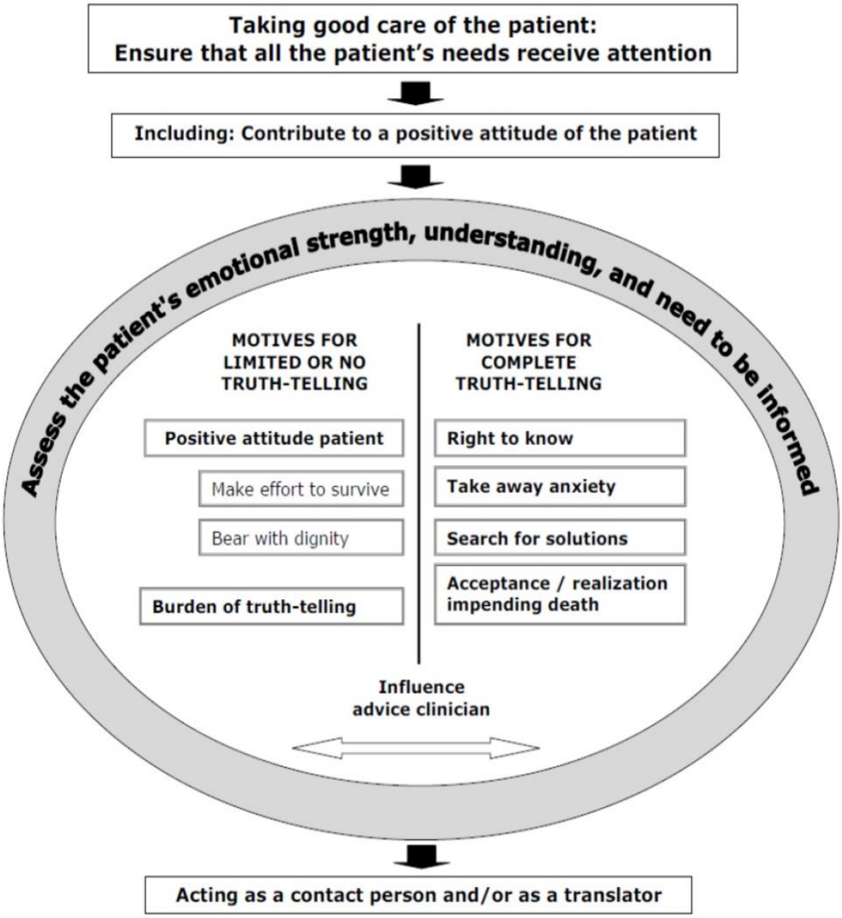


Expertise
Imam
Academic expert in traditional healing methods in Morocco
Traditional healer
Academic expert on Turkish Muslims in Europe
Consultant of an integration service
Turkish intercultural mediator

RESULTS

The narratives of participating relatives provided insight into the process of balancing truth-telling under the influence of certain factors (see Figure 1). Following from their self-perceived responsibility for ensuring that all of the patient’s needs received attention, family members felt that it was important to contribute to a positive attitude in the patient (Figure 1, second text box). Their decision about truth-telling was based on several motives (Figure 1, inner circle) and embedded in their assessment of the patient’s emotional strength, understanding, and need to be informed (Figure 1, outer circle). What relatives decided about truth-telling influenced the way they acted as a translator and/or a contact person (Figure 1, text box at the foot of the figure). Some participants considered it best to omit medical information while others considered it best to transmit all information to their ill older relatives. Details of this process are described in the following section.

Figure 1. Process of balancing truth-telling



CONTRIBUTING TO A POSITIVE ATTITUDE

Since most relatives felt a deeply moral obligation to take good care of their ill family members, many of them also considered it their responsibility to provide mental support to the patient. Contributing to a positive attitude was perceived as an important aspect of mental support. Some relatives imparted a psychological interpretation to the concept of positive attitude. They feared that patients would no longer do what was necessary to remain alive if they lost hope. Some could not face the fact that they might lose their loved ones and therefore wanted the patients to do anything that might extend life.

> *I tried to keep her as strong as possible on a psychological level.*

> *Because my mother, pardon me, didn't get that mental support from my father, I really tried to keep her spirits up* [...] *She really thought she was going to get better, and you know, I think that we were of real mental support to her and that she was very happy with us emotionally. I'm happy that I've been able to do that for her.* (Son – woman of Turkish origin)
>
> *My mom stayed positive. Whereas if you start to think in a negative way, this won't be alright, this and that, then it really won't get right because you stop fighting.* (Daughter – woman of Moroccan origin)
>
> <u>Daughter:</u> [...] *her psychological attitude is important as well. You know, she always has positive thoughts. I can do this, I am going to get my health back, by the doctors too, I mean the treatments they've given her* […]
> <u>Interviewer:</u> *Because if you don't, if you don't think positively, how do you think…?*
> *<u>Daughter:</u> Well then you don't feel like doing anything and she won't be taking her drugs on time, she won't be going to her check-ups. Basically, she wouldn't put in any effort, and if you don't put in an effort, you're not going to get very far either.* (Daughter – woman of Turkish origin)

For other family members the need for the patient to stay positive was rooted in religious convictions. According to these participants, a patient needed a positive attitude in order to behave in a 'dignified' way and thus show submission to God and the fate to which they were destined. To express this attitude, they used phrases such as 'behaving in a dignified way', 'calmness', 'gratitude', 'acceptance' and 'patience'. Some relatives explicitly voiced the belief that the patients could be forgiven for sins if they expressed submission and gratitude towards the fate willed by God, and they wanted to contribute what they could to make sure the patients did not miss this forgiveness.

> <u>Daughter:</u> *It is important to know that in our religion, that the perception of being ill, of illness, is, you know, different, it is perceived differently* […] *If you are grateful. In fact, you should, you know, you have to be grateful every day. For everything you receive and carry with you. But being ill is actually, is actually a, not everybody*

> *becomes ill. Not everybody has the opportunity to experience that. And if you carry your illness with dignity and still remain thankful to God, that erases your sins. To put it like that.*
> (Daughter – woman of Moroccan origin)

BALANCING TRUTH-TELLING

The interviews revealed that relatives held diverse views of what they did and did not tell the patient concerning the illness, varying from keeping silent about all bad news (and twisting information) to sharing all they knew. The extent to which relatives communicated information to the patient was embedded in their **assessment** of the patient's **emotional strength**, how much he/she **could understand** and of what he/she **wanted to know** about the illness. Reasons for the relatives to assess the patient's emotional strength as limited include advanced age, a vulnerable personality, and having gone through many difficult experiences. Some children indicated that the ill parent viewed cancer differently because he or she did not know that it could be treated, and did not know and possibly could not understand the possibilities of Belgian healthcare.

Motives for limited or no truth-telling

Taking into account the patient's emotional strength and his/her need to be informed, many relatives considered the extent to which they should be open about the diagnosis, prognosis, and treatment. The majority of relatives opted not to inform the patient fully, but for varying reasons. In an extreme case, a son made his mother believe that she was treated only for diabetes while in fact she received treatment for malignant liver tumours. Usually, however, cases were less extreme and only part of the information was withheld. This was the case, for instance, for a daughter who told her mother that she had 'the bad disease', but did not communicate her prognosis and the number of metastases.

The relatives who opted not to inform the patient fully were convinced that a **positive attitude** could be maintained only with partial, or no, information about the diagnosis, prognosis, or treatment. As mentioned earlier, some relatives thought it necessary for the patient to have a positive attitude to **continue with the treatment**, or in other words to make an effort to stay alive. Others believed that partial or no information was necessary so that the patient **continued to behave in a dignified way** and thus demonstrated submission to the fate willed by God. Relatives had various reasons for wanting the patient to continue with the treatment; some expressed the hope that the patient would ‘be able to stay with them for a longer time’ by continuing with the treatment. Other relatives, however, indicated that it was of the utmost importance for the patient to ‘remain in good shape’ because otherwise, care would become too difficult. Finally, some stated that it was important to continue treatment from an Islamic point of view. It was the patient’s duty to God to do everything in his/her power to heal, and they would not want to contribute to failure to conform to the requirements of religion.

One daughter informed her mother about the diagnosis, but did not tell her about the metastases and the terminal prognosis:

> *It is also our job to make sure that that message comes across as well as possible. Because doctors are not always the most communicative people. So actually, we are making it easier for them too. Because you can omit, not say certain things. For instance, in my case, I told her “look, this chemo, it’s all in God’s hands. The doctor is not God”.* (Daughter – mother of Moroccan origin)
>
> <u>Interviewer</u>: *Who decided to say “we are not going to tell”?*
> <u>Daughter</u>: *All of us, actually. All brothers and sisters* […] *All of us together said “no, no we’re not going to tell him that, he doesn’t understand that and he won’t understand, and he’ll panic and you know he doesn’t like hospitals, it’s hard enough as it is, we’re glad he agreed to come in the first place, we’ve been able to bring him there.” So you know.* (Daughter – father of Moroccan origin)
>
> *It hurts to know that you’re going to lose someone, doesn’t it ... But you know, it did give us a bit of strength. The fact that we, well … that she carried the burden of her disease with so much dignity. She never actually, this might be important, she never heard the actual diagnosis* […] *That was difficult for me, at first. Because that’s not how I am, because I think that, you know, you should know what’s going on inside your body, you know, you’re entitled to that, you know, you should know.* […] *And then we* [brothers and sisters] *really started thinking, look, does our mother need that? Who is our*

> *mother? And then we really started talking in those terms. And then I thought, no, we shouldn't do that* […] *I'm happy now that I didn't.* (Daughter – woman of Moroccan origin)

It was also apparent from the interviews that apart from wanting to prevent the patient from losing his/her positive attitude, some relatives did not inform the patient of the full seriousness of the illness because of the **emotional burden** of telling the truth.

Of course, none of the reasons above can be disconnected from the relatives' ability to cope with the illness and the negative prognosis, the hope they attempted to maintain, their ability to let go, or their need to control the situation. It might be easier for the relative to deal with the situation by not confronting the patient with the seriousness of the illness.

<u>Motives for complete truth-telling:</u>

Although a majority of the participants were not completely open about how seriously ill the patient was in the hope of preserving a positive attitude, there were also family members who believed that information should be fully shared, even though they too considered it their duty to contribute to a positive attitude for the patient.

Approximately one third of the family members interviewed believed that the patient should be fully informed. They felt that the patient was **entitled to know,** or that they did not have the right to omit certain things or lie, and that the patient's **anxiety** would be **relieved** by full information. Relatives who expected that the illness might be beyond cure also described a **search for solutions**, such as alternative treatments, and **acceptance or realization of an impending death** as reasons why patients should know. Realization or acceptance of the possibility that the end of a person's life is near enables one to prepare one for death, for instance by saying goodbye, forgiving and asking for forgiveness, and taking care of practical matters.

> *Well I know that he always wants to be informed of everything. I can tell* […] *When you're ill, you just want to know everything. So I don't think it's nice not to be informed of anything, so* […] *Because at the beginning, my mother was like "we're not going to say that". But I said no I'm sorry, I mean, we don't have the right to do that, we don't have the right to hide things like that from him. It's about his life and he needs to know everything* […] *So I tell him everything. How hard it*

> *may be, because you know, it is hard. But it has to be said, hasn't it.* (Daughter – father of Northwest African origin)
>
> Interviewer: *What mattered most to you during this period, within the period of illness? What was important?*
> Daughter: *Well that he actually, that he knew. And that he, if possible, could say goodbye to people. That I thought, was most important. You know, my brothers thought it didn't matter, but I believe if my time has come and you realize in advance, you want to straighten things out. That's the way I saw it.* (Daughter – father of Moroccan origin)

Most family members tried other ways of providing mental support to the patient in order to contribute to a positive attitude. The belief that, in the end, the decision of life or death is in God's hands could give them the strength to maintain a positive attitude. However, this strength could also be found through trust in medical treatment or a search for alternative treatments.

As the narratives of these relatives show, there are often various opinions within a single family, and individual members who do not want the patient to be fully informed of the illness. The above also reveals that the same religious views can lead to varying conclusions, as the same religion-based arguments were made both by those who wished to tell the complete truth and those who wished to divulge part of the truth.

Influence of healthcare providers

The stories of some relatives show that their 'choice' to inform the patient of the illness was influenced by a physician's advice. One daughter, for instance, reported that she and her brothers chose not to inform their father of his diagnosis of lung cancer partly on the physician's advice. In other situations, advice from a physician led to increased openness concerning the illness. In these cases, the relatives perceived the physician as sharing the same concerns. The following quote, for instance, is from a daughter who was advised by physicians to tell her mother that she would undergo a stem cell transplant, even though she (and her father) did not want to do that. The physicians explained that her mother would be "*really scared*" if she is not told the truth, and the daughter, who wanted to prevent that, assumed the physicians were right. She believed that they had the experience and thus the knowledge to make a person less anxious and fully accept the advice.

> *We always said, well my father said 'we're not going to tell her anything'. Not even about the transplant but the doctors said, if you're not going to tell her, she's going to be really scared about what we're going to do* […] *she'll be even more frightened so the best way is to tell her, look this is what you've got, this is what they're going to do, and she'll be more at ease. So we just, you know, explained it to her* […] *They're seeing so many patients so we thought, you know, the doctor knows better than we do.* (Daughter – woman of Turkish origin)

TAKING ON THE ROLE OF TRANSLATOR AND/OR CONTACT PERSON

The flow of medical information from healthcare providers to patients is often in the hands of relatives, since they, either voluntarily or without an alternative available, take on the role of translator and/or contact person. The adult children, who are second-generation immigrants, predominantly take on this role. They often have a good command of Dutch, while most patients and their spouses have only a limited command of the language. Only a few relatives reported that conversations occurred with the help of a professional interpreter or intercultural mediator.

Family members who acted as translators held the key to the degree of disclosure, and healthcare providers had little or no control. As previously discussed, complex considerations guided their decisions, and similar considerations appear to lead to very different decisions. In some situations, family members provided only translation between the patient and the healthcare providers, while in other cases the patient was practically excluded from the conversation. Some participants considered it best to omit medical information while others considered it best to fully inform their ill older relatives.

In addition, preferences as to how to solve the language issue were divergent. Some relatives preferred the presence of an interpreter or an intercultural mediator, or a healthcare provider who spoke the same language. Other participants felt that they, as a member of the patient's family, were the best choice of translator, because it prevented a 'stranger' being involved in the situation, and/or because it provided them with control over the information reaching the patient.

> *But that doesn't make sense to us, a complete stranger* [translator]*. (…) I mean come on, it's the least you can do if you have the time of course, and possibility to take your mum to the doctor's, to tell the doctor about your mum's issues, problems or complaints. I don't want a third party to do that, to be honest.* (Daughter – woman of Turkish origin)

> *I didn't need an interpreter. And that wouldn't have been okay for my mother either. No, she wouldn't like to hear that from a stranger, or she wouldn't like a stranger to know about her current medical situation.* (Daughter – woman of Moroccan origin)

Being asked or assumed by healthcare providers to act as a translator gave them the responsibility to decide what to tell and how. Relatives experienced this process of translating differently; some thought it normal to do that if you care for your parent, while others felt that it was too difficult and burdensome to deliver such news to your parent. Regarding diagnosis and bad prognosis it was often very difficult for family members to decide what to tell and what not to tell the patient.

> Daughter: *You know, you stay positive until they say that there is absolutely nothing left to do, and then you have to start explaining that, don't you.*
> Interviewer: *What was it like for you to explain that?*
> Daughter: *It was very hard. I said 'father there isn't anything they can do for you, chemo isn't going to help, radiation isn't going to help'.* […] *And that is a shame, it all becomes the family's burden.*
> Interviewer: *What do you mean, it all becomes the family's burden?*
> Daughter: *Well, the nurses, the doctors, they all come to you: 'Can you tell your father this? Can you tell your father that? We are going to do this or we are no longer going to be able to do that'. Maybe I didn't want to do that. I had had it too, you know. I need to pour my heart out too.* (Daughter – man of Moroccan origin)

DISCUSSION

As part of relatives' self-perceived responsibility to ensure that all the patient's needs received attention, they wanted to contribute to a positive attitude in the patient. Based on several motives and embedded in their assessment of the patient's emotional strength, understanding, and need to be informed, relatives decided how much information to give the patient about his or her medical situation. What relatives decided about truth-telling influenced the way they acted as a translator and/or a contact person. A majority of the participants considered it best to omit some medical information, while others decided to fully inform their ill older relatives about the illness, diagnosis, and prognosis. Although many previous studies have discussed the more general topic of truth-telling or disclosure of cancer diagnosis, to our knowledge this is the first study providing a thorough understanding of this process from the perspective of relatives.

Whereas the current study provides insight in a complex process of balancing truth-telling – ultimately resulting in a majority of these relatives not fully informing the patient – previous literature often focuses on the non-disclosure itself, thus often ignoring the decision-making process. A quantitative study conducted in Turkey showed, similar to our findings, that two-thirds of family members did not want the cancer diagnosis to be disclosed (Ozdogan *et al.*, 2004). The authors of the extensive systematic review 'Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals' conclude that *"relatives often prevented disclosure as they felt this might upset their patient* (de Graaff et al., 2012, pp. 34)". The current study provides insight into the process behind this reasoning. In addition, trying to contribute to a positive attitude of the patient has also been shown by research concerning 'western' populations (Blindheim *et al.*, 2013, McIlfatrick *et al.*, 2006, Pusa *et al.*, 2012, Röing *et al.*, 2008, Sand *et al.*, 2010, Steinvall *et al.*, 2011). The current study shows that the same intention can lead to differing actions. While participants shared their desire to contribute to a positive attitude in the patient, some considered it necessary, in this respect, to omit medical information, while others believed it best to provide full information to their ill older relatives. To this end, the same religious arguments are made both by those who wished to tell the complete truth and by those who wished to divulge only part of the truth.

Few studies have been conducted on the perspective of family members of first-generation immigrants who have cancer and who may not speak the language of the country where they live, and little has been written about family members acting as translator and/or contact person for them. Nevertheless, the topic is of importance to oncology care professionals in western societies, as language issues lie at the heart of their concern in caring for ethnic minority patients (Owens and Randhawa, 2004, Pergert *et al.*, 2007) and the use of family interpreters is much more common than professionals interpreting (Graaff *et al.*, 2012, Kai *et al.*, 2011, Owens and Randhawa, 2004).

Finally, the findings of this study demonstrate that about a third of the relatives decide to fully inform the patient about his/her medical situation and many others divulge parts of the information. Only in extreme cases did family members decide to hide all information about the illness, diagnosis, and prognosis. This is an important finding in light of the risk for an oversimplified expectation that people of non-western descent all prevent disclosure to their ill relatives. The study of Van den Brink, for example, points out that "A*mong Turkish families, it is not acceptable for adult family members to inform their elders about their negative physical state. This is contrary to the religious tenet of showing respect for the elder and acceptance of the will of Allah (van den Brink, 2003) (pp.152)."* Aside from the value judgment based on simplistic interpretations such as these, stereotypes are counterproductive to provision of healthcare to patients with diverse backgrounds. As Knight and Sayegh (Knight and Sayegh, 2009) point out: *"To date, theory development and empirical research indicate that the role of culture in influencing caregiving outcomes is more nuanced and complex than imagined a decade ago. Cross-cultural research and evidence-based practice should meet this complexity head on rather than retreating to the use of stereotypes and simplistic categorical assumptions* (Knight and Sayegh, 2009, pp. 7)."

LIMITATIONS

Because of ethics committee requirements, no information could be obtained about potential candidates who had not been approached by healthcare workers or potential candidates who refused to be contacted by the researcher. It was difficult to recruit participants, and some healthcare workers reported they were reluctant to ask potential participants for permission for the researcher to contact them. This might have resulted in a less diverse sample compared with the general population of relatives of these patient groups. This limitation is inevitable in qualitative research, which faces higher barriers in recruitment compared with survey methods. However, only 11 out of 43 potential participants who were asked to participate refused.

Although the sample consisted of relatives of patients in different stages of the illness trajectory, because of the cross-sectional study design, insight into the process of truth-telling is limited to the information obtained during a single interview with each family member.

FUTURE RESEARCH

It would be beneficial to study both patient and health provider perspectives on the role of family members who act as interpreters, and the process of truth-telling. It might be interesting to approach this topic from a legal perspective on patient rights as well as from an ethical care perspective. Such research might also provide further understanding of the experience of family members in taking on a role as translator. The current study can be used as a starting point for future research on these topics.

This study shows that differing approaches of family members in balancing truth-telling stem from the same intention and from the same religious arguments. This is in line with the contemporary dynamic definition of culture in social sciences, but contrary to the static way culture is often defined in medicine (Kleinman and Benson, 2006). In future research on diversity in healthcare, researchers should be thoughtful about the way they, implicitly and/or explicitly, define culture.

CONCLUSIONS AND CLINICAL IMPLICATIONS

This study provides insight into a complex process of balancing truth-telling by relatives, mostly adult children, of older adult cancer patients of Turkish of Northwest African descent. These relatives attach great value to taking good care of the patient, and from that point of view they want to contribute to a positive attitude of the patient. Based on several motives and embedded in their assessment of the patient’s emotional strength, understanding, and need to be informed, relatives decide to what extent they provided information to the patient about his/her medical situation. Motives for no or little truth-telling include maintaining a positive attitude and the burden of truth-telling. The right to know, relieving anxiety, finding solutions and accepting an impending death are reasons for relatives to be completely open towards the patient regarding the seriousness of his/her illness. This complicated and unpredictable complex of considerations often leads to family members making different decisions in taking on a role a translator and/or a contact person, even when family members have the same considerations. In some situations, the relatives’ role is mainly limited to providing translation between the patient and the healthcare providers, while in other cases the patient is practically excluded from the conversation. Some relatives considered it best to omit medical information while others considered it best to fully inform their ill older relatives. Subsequently, it is important for healthcare providers to take into account the complexity and the unpredictable character of this process. Furthermore, it is essential for healthcare providers to be aware of the influence they might have in this process, most certainly when they share and recognize the concerns of the relatives.

Healthcare providers must try to have conversations with the patient, together with immediate family, about designating the most appropriate person(s) with whom to discuss diagnosis, prognosis, and treatment information. Discussions should occur as soon as possible and repeatedly, and are only possible with the help of a professional interpreter. After all, according to the Belgian Law on Patient’s Rights (2002) a patient has the right to be informed about his/her health condition, as well as the right not to be informed. Ethical provision of care, however, is not about acting in accordance with the agreement, but acting in accordance with the *meaning* of the agreement.

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DISCUSSIE

De algemene doelstelling van dit doctoraatsonderzoek was het verkrijgen van inzicht in de wijze waarop oncologische zorgverleners de zorg aan etnische minderheden ervaren en de wijze waarop familieleden de zorg aan oudere volwassen patiënten van Turkse of Noordwest Afrikaanse origine met kanker beleven[2]. Met deze inzichten wordt getracht bij te dragen aan een goede aansluiting tussen de oncologische zorg en de diverse patiëntenpopulatie in Vlaanderen.

Niettegenstaande het doctoraatsonderzoek was gericht op twee verschillende doelgroepen, zijn er een aantal thema's die in beide perspectieven een prominente plaats innemen. De beleving van de familieleden geeft namelijk inzicht in de processen en de betekenis die zij toekennen aan gedrag dat door de oncologische zorgverleners wordt ervaren als de voornaamste barrières in de zorg.

In deze discussie ligt de focus vooral, maar niet uitsluitend, op de thema's die in beide perspectieven naar voren komen. Resultaten uit de vorige hoofdstukken dienen als vertrekpunt, waarbij sommige bevindingen verder worden uitgewerkt. De discussies en conclusies uit de voorgaande hoofdstukken worden in deze discussie niet op eenzelfde wijze aangebracht, zodat onnodige herhaling wordt vermeden. Implicaties en aanbevelingen voor de oncologische zorgpraktijk worden apart aangeduid, maar vormen een geïntegreerd onderdeel van de discussie. De meest essentiële aanbevelingen voor de oncologische zorgpraktijk worden weergegeven in een tabel op pagina 167. Tot slot worden in deze discussie aanbevelingen gegeven voor toekomstig onderzoek.

Een eerste thema dat in beide perspectieven naar voren komt, betreft de prominente rol en aanwezigheid van familieleden. Vanuit het perspectief van familieleden blijkt zorg dragen voor een ouder familielid met kanker een diepe morele betekenis en waarde te hebben. Door zorgverleners wordt een prominente rol en de aanwezigheid van familieleden opgemerkt en frequent ervaren als een barrière in de zorg aan patiënten van niet-westerse origine. Een tweede thema heeft te maken met het opnemen van een rol als vertaler of contactpersoon door een familielid. In het opnemen van deze rol blijkt zich een complex proces af te spelen waarin familieleden een afweging maken over openheid over ziekte. Een meerderheid besluit in beperkte mate open

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[2] Daarmee is niet gezegd dat de bevindingen uit dit doctoraatsonderzoek exclusief gelden voor de onderzochte populatie.

te zijn over de ziekte. Bij alle zorgverleners lijkt daarentegen het recht van de patiënt op medische informatie een geïnternaliseerde norm te zijn. Zij streven er dan ook naar om waarheidsmededelingen over te brengen naar de patiënt.

Dat deze thema’s ook naar voren komen in het perspectief van zorgverleners, heeft waarschijnlijk te maken met het feit dat de meeste casussen die de oncologische zorgverleners aanbrachten in de empirische studie handelden over patiënten van Turkse of Marokkaanse origine, weliswaar van uiteenlopende leeftijden en behorend tot verschillende generaties migranten (hoofdstuk 3). In hoeverre dit te verklaren is doordat zorg aan deze patiëntengroepen zorgverleners het meest bijblijft of doordat deze groepen het grootste aandeel vormen van patiënten van niet-westerse origine, kunnen we niet met zekerheid zeggen.

PROMINENTE ROL EN AANWEZIGHEID VAN FAMILIELEDEN

Oncologische zorgverleners lopen in de zorg voor patiënten van andere etnische origine aan tegen de aanwezigheid van vele familieleden en een prominente rol die familieleden veelal opnemen. Dit kwam zowel naar voren in de empirische studie (hoofdstuk 3) als in de systematische literatuurstudie (hoofdstuk 2). Het verkregen inzicht in de betekenis van het zorg dragen vanuit het perspectief van familieleden (hoofdstuk 4) biedt inzicht in de betekenis van het gedrag waarmee zorgverleners veelal geconfronteerd worden in de zorg aan patiënten van andere etnische origine. Het is gedrag dat door zorgverleners veelal als een barrière wordt ervaren.

Vanuit het perspectief van oncologische zorgverleners (hoofdstuk 2 en 3) wordt de aanwezigheid en de prominente rol van (vele) familieleden ervaren als een van de barrières in de zorg aan patiënten van een etnische minderheid (hoofdstuk 2 en 3; de Graaff, Francke, van den Muijsenbergh, & van der Geest, 2012a; 2012b; Kai et al., 2007; Kai, Beavan, & Faul, 2011; Lanceley & Cox, 2007; Pergert, Ekblad, Enskär, & Björk, 2007; 2008). Deze aanwezigheid van familieleden wordt door zorgverleners veelal cultureel geduid (hoofdstuk 2 en 3). Ze heeft voor veel zorgverleners niet zozeer een positieve betekenis. Integendeel, ze maakt voor hen vaak een wezenlijk onderdeel uit van de problemen en moeilijkheden die voor velen van hen vooraan staan in de zorg aan patiënten van andere etnische origine. Door sommige zorgverleners worden de aanwezigheid en de prominente rol van familieleden als echt storend ervaren.

Onderzoek naar de beleving van familieleden bevestigt dat familieleden een prominente rol spelen en het laat zien welke diepe betekenis dit voor hen heeft (hoofdstuk 4, artikel 3). Kanker blijkt een familieaangelegenheid te zijn en zorg dragen heeft een grote morele betekenis en waarde, in het bijzonder wanneer het over de zorg voor een ouder gaat (hoofdstuk 4, artikel 3; vgl. de Graaff, Mistiaen, Devillé, & Francke, 2012c; de Valk, & Schans, 2008; Schans, & Komter, 2010; Yerden, 2013). Familieleden hebben zowel interne als externe motivaties om goed te zorgen voor de patiënt (vgl. Kuşçu, Dural, Yaşa, Kiziltoprak, & Oenen, 2009). Aan de ene kant voelen ze 'in hun hart' dat zorg dragen het juiste is om te doen en aan de andere kant geven ze aan dat het iets is wat je 'hoort' te doen of 'moet' doen. Ze lijken de norm te hebben geïnternaliseerd dat voor een ouder (met kanker) goed zorg dient te worden gedragen en dat deze verantwoordelijkheid in de eerste plaats bij de volwassen kinderen ligt. Door zelf goed zorg te dragen houden ze deze norm tegelijkertijd in stand en dragen ze deze uit. De ouder heeft recht op deze zorg of heeft het recht daarop verworven door de lasten van het ouderschap te hebben gedragen. De volwassen kinderen benoemen vaak dat zorg dragen voor een ouder die gediagnosticeerd is met kanker het minste is wat je kan doen, aangezien "*zij jou ter wereld hebben gebracht en voor jou hebben gezorgd*".

Sommige ziekenhuizen lijken werkwijzen te hebben ontwikkeld waarin de grote betekenis van aanwezigheid van familieleden is meegenomen, zonder afbreuk te doen aan de hoofddoelstelling: de gezondheid van de patiënten.

Het inzicht in de beleving van de familieleden is een empirische bevestiging van Kleinman en Benson's definitie van cultuur (2006a; 2006b; Kleinman, 2004), namelijk dat cultuur het proces is waardoor alledaagse activiteiten en omstandigheden, in dit geval het zorg dragen, een [sterke] emotionele lading en [diepe] morele betekenis krijgen. Het existentiële karakter van kanker maakt waarschijnlijk dat het hier gaat over een 'sterke emotionele lading' en een 'diepe morele betekenis' van het zorg dragen.

> ***Aanbeveling voor de oncologische zorgpraktijk***
> *Het verkregen inzicht in de beleving van de familieleden, biedt zorgverleners de mogelijkheid om te begrijpen waarom familieleden aanwezig zijn en waarom zij een prominente rol opnemen. Namelijk omdat het zorg dragen voor hen een zeer diepe morele betekenis en waarde heeft. Op goede wijze zorg dragen is 'het juiste' om te doen,*

> *wat maakt dat ze als zoon of dochter tekort zouden schieten als dit niet zou gebeuren. Als zorgverlener besef hebben van deze diepe betekenis is van grote waarde. Dit besef kan namelijk voorkomen dat met de aanwezigheid van familieleden, wat veelal als een moeilijkheid wordt ervaren, lichtzinnig wordt omgesprongen.*
>
> *In navolging van sommige ziekenhuizen, lijkt het waardevol om werkwijzen te ontwikkelen waarin de grote betekenis van de aanwezigheid van familieleden is meegenomen, zonder afbreuk te doen aan de hoofddoelstelling: de gezondheid van patiënten. Een voorbeeld daarvan is het voorzien van vele zitruimtes doorheen een ziekenhuis terwijl het aantal bezoekers in de kamers van patiënten wordt beperkt tot het aantal aanwezige stoelen.*

Vanuit het perspectief van familieleden komt naar voren dat zowel op praktisch als op emotioneel vlak door de familie zorg wordt gegeven. Zorgtaken zijn onder meer fysieke en huishoudelijke zorg, contactpersoon of vertaler zijn, ‘er zijn’ voor de patiënt, zoeken naar (alternatieve) geneeswijzen en het bieden van mentale en financiële ondersteuning. In de meeste situaties voelen ze er zich voor verantwoordelijk dat aan alle noden van de patiënt aandacht wordt besteed.

Ten aanzien van de gezondheidszorg, wordt het zorg dragen gekenmerkt door het opnemen van een ‘gidsende’ rol. Familieleden leiden of maken de patiënt wegwijs door de Belgische gezondheidszorg, ze geven advies over gebeurtenissen en keuzes en steunen de patiënt in het omgaan met de ervaringen van de diagnose en de behandeling. Ze zorgen ervoor dat de patiënt de gepaste zorg krijgt ondanks zijn/haar onbekendheid met het zorgsysteem en de beperkte kennis van de Nederlandse taal. Veelal fungeren de volwassen kinderen als deze verbinding tussen de patiënt en het Belgische zorgsysteem, een zorgsysteem waar zij vaak meer mee vertrouwd zijn en waarin zij vaak beter hun weg vinden door te zijn opgegroeid in Vlaanderen met het Nederlands als taal.

Een flexibele houding van zorgverleners, onder andere ten aanzien van bezoekuren en de momenten waarop afspraken worden vastgelegd, wordt door sommige familieleden expliciet benoemd als iets dat ze erg waarderen (van Eechoud, et al., 2013). Deze flexibiliteit is voor hen namelijk helpend in het opnemen van een gidsende rol.

> ***Aanbeveling voor de oncologische zorgpraktijk***
> *Het is van grote waarde als oncologische zorgverleners (h)erkennen wanneer familieleden, veelal volwassen kinderen, een gidsende rol*

> *opnemen voor hun oudere zieke familielid en de grote verantwoordelijkheid waarmee deze rol gepaard gaat. Familieleden worden het best ondersteund in het opnemen van deze rol, zonder de patiënt te beperken in het uitoefenen van zijn/haar rechten. Een zekere flexibiliteit vanuit de oncologische zorg kan daarin helpend zijn, bijvoorbeeld ten aanzien van bezoekuren en de momenten waarop afspraken worden vastgelegd.*
>
> *Gezien de grote betekenis die familie kan hebben, bevinden oncologische zorgverleners zich veelal in een driehoeksverhouding tussen de patiënt, familie en zichzelf. Aandachtig zijn voor en verbinding maken met de patiënt en zijn/haar naasten is daarin heel belangrijk.*

Hoewel bovenstaande inzichten een prominente rol van familieleden verklaren en de diepe betekenis ervan blootleggen, laat de studie tegelijkertijd zien dat ondanks de gedeelde waarden familieleden zeer uiteenlopende ideeën hebben over de wijze waarop ze zorg dienen op te nemen en welke professionele zorg gewenst is (hoofdstuk 4, artikel 3). Zo hebben familieleden bijvoorbeeld zeer verschillende opvattingen over het gebruik van ziekenvervoer of de opname op een palliatieve eenheid. Waar het ene familielid dit als zeer mooie en waardevolle vormen van professionele zorg beschouwt, vindt een andere familielid dat de inzet van dergelijke professionele zorg niet in overeenstemming is met zijn/haar opvatting van goed zorg dragen. Wanneer alle vormen van professionele zorg in België bij elkaar worden genomen, blijkt dat iedere vorm door sommige familieleden als passend wordt beschouwd binnen de zorgwaarden. Een opname in een woon- en zorgcentrum lijkt het meest vergaand te worden ervaren, maar is voor enkele kinderen aanvaardbaar (of zelfs wenselijk) mits deze voorziening aangepast wordt aan het geloof, de taal en de cultuur van hun ouder.

Bij de verdeling van de zorg tussen de familieleden wordt veelal op pragmatische wijze te werk gegaan. Zorg wordt opgenomen door diegene die het meest geschikt is en wiens situatie zich er het best toe leent. Met betrekking tot intieme zorgtaken daarentegen wordt de verdeling sterk bepaald wordt door man-vrouw verhoudingen binnen het gezin (hoofdstuk 4, artikel 3). Maar voor alle zorgtaken geldt dat als het ene familielid een zorgtaak niet opneemt, de volgende het doet die daarvoor het meest geschikt is en in de beste situatie verkeert. Overstijgend blijkt dus dat de gedeelde waarden niet de praktische invulling van het zorg dragen en de (dagelijkse) zorgpraktijk laten voorspellen. Er kan gesproken worden van nieuwe vormen van familiezorgpraktijken binnen 'oude' waarden van familiezorg (vgl. Yerden, 2013).

Inzicht in het perspectief van oncologische zorgverleners in Vlaanderen (hoofdstuk 3) toont dat sommige zorgverleners sterk in stereotypen redeneren en nauwelijks oog hebben voor verschillen tussen mensen van niet-westerse origine, terwijl andere zorgverleners zich sterk bewust tonen van de diversiteit binnen deze patiëntengroepen en nauwelijks in stereotypen spreken. Ook uit de literatuurstudie (hoofdstuk 2) kwam naar voren dat zorgverleners cultuur zowel statisch als dynamisch opvatten. Ze benadrukken zowel het belang van culturele noden en statische feitelijke kennis over culturele verschillen (Huang, Yates, & Prior, 2009a; 2009b; Kai et al., 2007) als de nood voor dynamische transculturele reflectie (Pergert et al., 2008).

Implicatie en aanbeveling voor de oncologische zorgpraktijk

Begrip van de gedeelde waarden die familieleden toekennen aan het zorg dragen, kan oncologische zorgverleners helpen om aansluiting te vinden bij prominente rollen die familieleden opnemen. Doordat deze gedeelde waarden echter niet de dagelijkse zorgpraktijk en de voorkeuren van familieleden voorspellen, is het van groot belang om de cultuursensitieve zorg niet te beperken tot een reeks "do's en dont's" waarin staat wat men wel en niet moet doen bij de zorg aan een patiënt met een specifieke etnische-culturele achtergrond (Kleinman & Benson, 2006a). Culturele diversiteit omvat namelijk niet alleen etniciteit, maar ook invloeden zoals gender, religie, sociale achtergrond, opleiding, en zelfs persoonlijkheid (Kleinman & Benson, 2006a; Kai et al., 2007). Verkennen en afstemmen van de oncologische zorg op de specifieke opvattingen en behoeften van patiënten en hun naasten is dan ook essentieel.

Als zorgverlener is het zinvol om rekening te houden met de rolverdeling van families ten aanzien van zorgtaken, door ernaar te vragen, en in het verlengde daarvan na te gaan welke rol familieleden willen opnemen en waarom ze die rol willen opnemen. De rolverdeling kan voortkomen vanuit traditionele familiezorgpraktijken, maar kan ook zijn ingegeven door pragmatiek. Het kan daarbij helpend zijn om familieleden erkenning te geven voor de waarde die het zorg dragen voor hen heeft en van daaruit samen te zoeken naar een oplossing indien zich problemen lijken voor te doen. Een open dialoog samen met patiënt en familieleden over hoe het best zorg verleend kan worden zal het best voldoen aan de noden van de patiënt en familieleden (hoofdstuk 4, artikel 3).

Hoewel in algemene zin de prominente rol en aanwezigheid van vele familieleden als een barrière wordt ervaren door oncologische zorgverleners, geven sommige zorgverleners aan dat ze het ook mooi vinden om te zien dat familieleden zo veel doen voor een patiënt. Dit werd soms vergeleken met 'autochtone' patiënten die veelal minder omringd zijn door familieleden. Een aantal andere zorgverleners waren geïrriteerd door de prominente rol en de aanwezigheid van vele familieleden. Meer specifiek spreken zorgverleners bijvoorbeeld over de moeilijkheid van een groot aantal familieleden bij consultaties en op meerpersoonskamers en de luidruchtigheid en de veeleisendheid waarmee dat volgens sommigen gepaard gaat. Ook de aanwezigheid van familieleden buiten de bezoekuren en het meebrengen van eten voor de patiënt wordt door sommige zorgverleners als hinderlijk ervaren. Het zijn gedragingen van familieleden die zorgverleners niet gewoon zijn en soms ook tegen hun eigen normen of opvattingen ingaan. Volgens zorgverleners dient men zich in een (Vlaams) ziekenhuis onder meer rustig en ingetogen te gedragen en respect te tonen voor zorgverleners. Sommige zorgverleners storen zich eraan dat mensen van niet-westerse origine zich niet aan de normen aanpassen. Tegelijkertijd geven enkele zorgverleners aan dat zij van patiënten van andere origine soms een grote vorm van dankbaarheid ervaren die zij (nog) weinig zien bij patiënten van Vlaamse herkomst.

Aanbeveling voor de oncologische zorgpraktijk

Een eenzijdig 'westers' perspectief in de gezondheidszorg kan belemmerend werken voor een kwaliteitsvolle aansluiting van zorg (vgl. Ingebly, 2000; Kortmann, 2002; RVZ, 2000b). Een reflectieve attitude wordt erkend als een van de belangrijkste pijlers in kwaliteitsvolle cultuursensitieve hulpverlening (Kleinman & Benson, 2006a; Oude Breuil, 2005; Oliemeulen & Thung, 2007, Seeleman, Suurmond, & Stronks, 2009), waarbij het bijzonder zinvol is om als zorgverlener te leren loskomen van het vormende effect dat de biomedische cultuur heeft op de dagelijkse zorgpraktijken (Kleinman & Benson, 2006a).

Vanuit het beleid is het belangrijk om in het licht van de hoofddoelstelling van de zorg, de gezondheid van patiënten, enerzijds grenzen duidelijk te stellen én goed uit te leggen. Anderzijds is het van bijzonder belang om grenzen te verleggen door bestaande werkwijzen, regels en methodieken in vraag te durven stellen en aan te passen aan de nieuwe situatie. De (sub)cultuur van een zorginstelling evolueert namelijk bij voorkeur naar een cultuur

> *waarin haar patiëntenpopulatie zich kan herkennen* (vgl. Boukhriss, s.d.; Ingelby, 2000; 2002).
>
> *Een gedegen divers personeelsbeleid waarin zorgverleners zoveel mogelijk een afspiegeling vormen van de zeer diverse samenstelling van de bevolking (RVZ, 2000a; Thung & Demiralay, 2002) kan bijdragen aan een reflectieve attitude, doordat het de mogelijkheid geeft de eigen (sub)culturele kenmerken van de oncologische zorg zichtbaar te maken. Tevens kan het helpend zijn de 'handelingsverlegenheid' in de zorg aan patiënten van andere origine te verminderen, doordat 'het vreemde' minder vreemd wordt.*
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> *In het kader van patiëntparticipatie is het ook van belang te letten op een zo volledig mogelijke afspiegeling van de samenstelling van de patiëntenpopulatie, dus ook naar etnische, culturele en religieuze herkomst (vgl. RVZ, 2000a).*

De grootste moeilijkheid waar zorgverleners mee geconfronteerd worden, heeft te maken met een verschil tussen hun eigen norm van 'respect voor autonomie' en meer familiegerichte benaderingen omtrent het recht op informatie en besluitvorming waar patiënten en familieleden van niet-westerse herkomst meer waarde aan kunnen hechten (hoofdstuk 2 en 3, Kai, et al., 2010). Vanuit het inzicht in de beleving van familieleden worden deze ervaren verschillen in normen bevestigd en verduidelijkt. Zoals hierboven al benoemd, wordt kanker als een familieaangelegenheid beschouwd. De kankerdiagnose gaat de hele familie aan: de familie als geheel voelt zich verantwoordelijk dat er gebeurt wat nodig is en neemt een actieve rol op om te zorgen dat het daadwerkelijk wordt gerealiseerd. De patiënt is daarin niet altijd de voornaamste actor, maar de familie als geheel of een aantal familieleden. Soms handelen familieleden samen met de patiënt en in andere situaties is de patiënt niet actief betrokken. In de wijze waarop familieleden een 'gidsende' rol opnemen is ook een dergelijk verschil te zien in de mate waarin de patiënt een actieve rol opneemt of niet. Sommige familieleden 'gidsen' de patiënt namelijk op een leidende manier door gebeurtenissen te sturen en beslissingen te nemen zonder actieve betrokkenheid van de patiënt. Andere familieleden 'gidsen' de patiënt door hem/haar wegwijs te maken. Zij proberen de patiënt zelf in staat te stellen om te begrijpen wat er gebeurt en welke beslissingen genomen dienen te worden.

Nauw verbonden met deze verschillen in opvattingen was het proces waarin familieleden, in de rol van vertaler, openheid over ziekte afwegen terwijl zorgverleners waarheidsmededelingen nastreven. Dit tweede thema dat in beide perspectieven naar voren komt, wordt in de volgende paragraaf besproken.

FAMILIELEDEN IN DE ROL VAN VERTALER EN OPENHEID VAN ZIEKTE

Vanuit het perspectief van zorgverleners blijkt dat velen cultureel geduide gedragingen van patiënten en familieleden van niet-westerse origine willen ‘respecteren’, ofwel door er ‘vanaf te blijven’ of door een zekere ‘voorzichtigheid’ te tonen (hoofdstuk 3, vgl. hoofdstuk 2; Richardson, Thomas, & Richardson, 2006; Kai et al., 2007). Een uitzondering op het ‘respecteren’ van culturele gedragingen geldt voor de meeste zorgverleners omtrent het doen van waarheidsmededelingen. De in hun ogen vrij frequent voorkomende wens van familieleden voor geen of beperkte openheid over de ziekte naar de patiënt, is voor veel zorgverleners onacceptabel en kan spanningen bij hen oproepen. Het recht van de patiënt op medische informatie, lijkt bij alle zorgverleners een geïnternaliseerde norm te zijn. Het overdragen van informatie over diagnose, prognose en behandeling aan de patiënt is voor veel zorgverleners een essentiële taak in de medische behandeling. Hoewel alle zorgverleners proberen waarheidsmededelingen aan de patiënt over te brengen, gaat de ene zorgverlener daar veel verder in dan de andere. Tegelijkertijd blijkt in het geval van taalbarrières, het veel gebruikelijker voor zorgverleners om te werken met familieleden die vertalen dan gebruik te maken van professionele taalbijstand en/of intercultureel bemiddelaars (hoofdstuk 2 en 3). Zij zien professionele taalbijstand en/of intercultureel bemiddelaars maar in beperkte mate als een zinvolle oplossing omwille van vele hindernissen die het met zich meebrengt. Hieruit blijkt een zekere paradox. Zorgverleners beschouwen namelijk het overdragen van medische informatie aan de patiënt als een essentiële taak, ondanks dat ze ervaren dat familieleden daar een andere visie op kunnen hebben. Tegelijkertijd maken ze voor het overbruggen van taalbarrières gebruik van die personen (familieleden) bij wie ze opmerken dat informatie frequent niet wordt overgebracht. Hierin is, net als bij het overbruggen van andere barrières, een zekere ‘handelingsverlegenheid’ te zien, waardoor zorgverleners in de waan van de dag maar in beperkte mate barrières overwinnen.

Vanuit het perspectief van familieleden blijkt ook dat er maar weinig gesprekken hebben plaatsgevonden met behulp van professionele taalbijstand en/of intercultureel bemiddelaars. De doorstroom van (medische) informatie van zorgverleners naar de patiënt ligt vaak in handen van familieleden. Sommige familieleden die gevraagd worden het slechte nieuws te 'vertalen' vonden dit een onmogelijke of quasi onmogelijke opdracht. Anderen waren tevreden dat ze op deze manier konden bepalen wat de patiënt wel en niet te horen kreeg.

In het opnemen van een rol als vertaler, blijkt zich een complex proces af te spelen waarin familieleden een afweging maken over openheid over ziekte naar de patiënt (hoofdstuk 4, artikel 4). Vanuit de grote morele betekenis die het zorg dragen voor hen heeft, willen zij onder meer bijdragen aan een positieve ingesteldheid van de patiënt. Gebaseerd op verschillende motieven en ingebed in hun inschatting van wat de patiënt aankan, kan begrijpen en wat hij/zij wil weten over de ziekte, beslissen familieleden in welke mate zij de patiënt op de hoogte stellen van de medische situatie. Redenen voor geen of weinig openheid over ziekte zijn het behoud van een positieve ingesteldheid bij de patiënt en de emotionele belasting van het overbrengen van het slechte nieuws. Recht om te weten, wegnemen van onzekerheid, zoeken naar oplossingen en aanvaarden of besef van een naderend overlijden, zijn redenen voor familieleden om volledig open te zijn naar de patiënt over de ernst van de ziekte. Dit complexe en onvoorspelbare geheel van afwegingen leidt ertoe dat familieleden uiteenlopende keuzes maken in het opnemen van een rol als vertaler of als contactpersoon, zelfs als zij gelijkaardige intenties hebben en gelijkaardige religieuze argumenten hanteren. In sommige situaties is de rol van de familieleden beperkt tot het vertalen tussen de patiënt en de zorgverlener, terwijl in andere situaties de patiënt volledig is uitgesloten uit de communicatie. Sommige familieleden vinden dat zij het best medische informatie verzwijgen voor de patiënt, terwijl andere vinden dat zij hun oudere familielid het best volledig informeren. Uit de verhalen van een aantal familieleden komt naar voren dat hun 'keuze' voor openheid over de ziekte beïnvloed is door het advies van een arts. Meestal leidde dit tot meer openheid over de ziekte. Deze familieleden beschrijven de arts als iemand die aansluiting vindt bij de overwegingen en de zorgwaarde die zijzelf hanteren.

> ***Aanbeveling voor de oncologische zorgpraktijk***
> *Als oncologische zorgverlener aan familieleden de rol van vertaler geven, kan sommige familieleden een gevoel van controle geven: zij hebben de dingen meer in de hand. Maar het kan familieleden ook voor een bijna onvervulbare opdracht stellen: aan de persoon waar je nauw verwant mee bent zijn doodvonnis meedelen. Wat het beste*

> *is om te doen, zal in iedere situatie afgewogen moeten worden. Hoe beter de zorgverlener inzicht heeft in het complexe geheel van overwegingen van het familielid en wat de situatie voor de betrokkenen betekent, hoe beter de afweging kan gebeuren. Bovendien is het essentieel om als zorgverlener bewust te zijn van de eigen invloed op de afwegingen die familieleden maken, zeker als aansluiting wordt gevonden bij de overwegingen en de waarden van familieleden.*
>
> *Probeer als oncologische zorgverlener vroegtijdig en met enige regelmaat in dialoog te gaan, met behulp van professionele taalbijstand en/of intercultureel bemiddelaars, met de patiënt en familielid/leden over wie de gewenste persoon/personen zijn om diagnose-, prognose- en behandelingsinformatie mee te bespreken. Een patiënt heeft immers het recht om geïnformeerd te worden over zijn gezondheidstoestand, maar hij heeft evengoed het recht om die informatie niet te vernemen (wet op patiëntenrechten, 2002) (hoofdstuk 4, artikel 4; vgl. hoofdstuk 2 en 3; Betancourt & Renfrew, 2011; Kai et al., 2011).*

Uit het voorgaande blijkt dat oncologische zorgverleners ‘respect voor autonomie’ (Westra, Willems, & Smit, 2009), een van de principes van de hedendaagse biomedische ethiek, hebben geïnternaliseerd als norm (hoofdstuk 2 en 3). In de literatuur wordt echter gewezen op het risico voor het in gevaar brengen van datgene wat het principe van autonomie moest beschermen: integriteit, respect en menselijke waardigheid (Hanssen, 2004). Indien dit gebeurt, kan het leiden tot een beschadigde vertrouwensrelatie (Hanssen, 2004).

> ***Implicatie en aanbeveling voor de oncologische zorgpraktijk***
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> *Een relationele benadering van autonomie lijkt beter passend dan een individuele interpretatie van autonomie (vgl. Surbone, 2006): “In a diverse society where many clinicians are unfamiliar with their patients’ family backgrounds and values, respect for autonomous agency requires that clinicians trust and abide by their patients’ own analyses of their familial situation and expressed preferences (Ho, 2008, p. 134).”*
>
> *Het voeren van gesprekken als oncologische zorgverlener met patiënten en hun naasten over de opvattingen en zienswijzen ten aanzien van het uitwisselen van informatie is van groot belang (Betancourt & Renfrew, 2011; Kai et al., 2011).*
>
> *In principe wordt professionele taalbijstand en/of intercultureel bemiddelaars het best beschouwd als een standaard*

instrument voor oncologische zorgverleners. Net zoals het vanzelfsprekend is om gebruik te maken van bijvoorbeeld technische hulpmiddelen, mag een zorgverlener verlangen dat hij/zij ondersteund wordt in zoiets essentieels als het kunnen spreken met een patiënt. Dit neemt voorgaande zaken omtrent het belang van familie en relationele autonomie echter niet weg. In het geval van een taalbarrière bieden professionele vertalers (of tweetalige zorgverleners) de beste garantie voor kwaliteitsvolle gezondheidszorg (Flores, 2005; vgl. Bischoff, 2012; Verrept, 2012). Tevens kan verondersteld worden dat het gebruik van professionele vertalers een escalatie van kosten op lange termijn voorkomt, ondanks dat de initiële kosten hoger liggen (Bischof, & Denhaerynck, 2010). Inherent aan de inzet van professionele taalbijstand en/of intercultureel bemiddelaars als standaard instrument, is uiteraard een flexibel inzetbaar en uitgebreid aanbod van taalbijstand en/of intercultureel bemiddelaars (vgl. Dauvrin, Derluyn, Coune, Verrept, & Lorant, 2012). Daarnaast is het essentieel dat oncologische zorgverleners meer vertrouwd raken in het werken met verschillende vormen van professionele taalbijstand en/of intercultureel bemiddelaars, waarvoor (praktijkgerichte) vorming aangewezen is.

TOT SLOT – DE PROFESSIONELE STANDAARD ALS OVERSTIJGEND PRINCIPE

> “De patiënt heeft, met eerbiediging van zijn menselijke waardigheid en zijn zelfbeschikking en zonder enig onderscheid op welke grond ook, tegenover de beroepsbeoefenaar recht op kwaliteitsvolle dienstverstrekking die beantwoordt aan zijn behoeften.”
> (Artikel 5, Wet betreffende de rechten van de patiënt, 2002)

Het perspectief van oncologische zorgverleners laat zien dat zij allemaal vertrekken vanuit een professionele standaard waarin iedere patiënt gelijk hoort te worden behandeld en recht heeft op adequate zorg (hoofdstuk 3; vgl. Huang et al., 2009a; Kai et al., 2007; Pergert et al., 2008). Zorgverleners zijn echter, onder invloed van hun persoonlijke attitude, niet bereid of niet in staat om barrières (volledig) te overwinnen. De zorg aan patiënten van niet westerse origine wordt daardoor gefocust op strikt medische zaken. De ‘cure’ lijkt het dus te winnen van de ‘care’ (hoofdstuk 3). Een algemeen gevoel van schaarste op het gebied van financiën en werkdruk lijkt hierop van invloed te zijn. Zorgverleners die de intentie hebben even kwaliteitsvolle zorg te geven, voelen zich verantwoordelijk voor het tekort schieten in het geven van holistische zorg. Zorgverleners die van mening zijn dat de zorg aan patiënten van andere origine niet (veel) meer tijd en middelen mag vragen, leggen de verantwoordelijkheid daarentegen bij de patiënt en nemen het hen kwalijk niet de adequate zorg te kunnen geven.

Familieleden geven globaal genomen aan vrij positief te zijn over het Belgische zorgsysteem en de oncologische zorg in het bijzonder (van Eechoud, et al., 2013). Sommige familieleden zeggen dat zij zich realiseren dat de gezondheidszorg in België tot een van de beste van de wereld behoort. Ze vergelijken met andere landen en soms ook met hun land van herkomst. Dit neemt niet weg dat bijna ieder familielid wel zijn eigen specifieke positieve en negatieve ervaringen met de zorg en zorgverleners heeft. Een van de negatieve ervaringen die door sommige familieleden wordt benoemd, is het aanreiken van minder zorg aan patiënten van andere origine. Soms bestaat de indruk bij familieleden dat er minder wordt langsgegaan aan het bed van de patiënt dan bij ‘autochtone’ patiënten. Het gaat soms om relatief kleine zaken, zoals het aanbieden van koffie of thee en in andere gevallen om meer essentiële zaken zoals de tijd die voor de patiënt wordt genomen tijdens de dagelijkse ronde van artsen. Het aanbieden van psychosociale zorg lijkt soms ook minder te gebeuren. Meerdere familieleden geven aan dat zij een gebrek aan steun of ‘warme’ zorg van zorgverleners hebben ervaren, vooral tijdens of kort na de diagnose. In zeker zin bevestigen deze familieleden de bevinding vanuit het perspectief van zorgverleners dat ‘cure’ het wint boven ‘care’, namelijk dat zij aandacht voor emotionele en psychosociale aspecten hebben gemist waar een meer holistische benadering van zorg voor staat.

> ***Kernaanbeveling: uitbreiden van de professionele standaard***
> ***Van ‘gelijke zorg voor iedere patiënt’ naar ‘zorg op maat voor iedere patiënt[3]’***
> *Het perspectief van oncologische zorgverleners toont dat hun professionele standaard als een alles overstijgend principe fungeert in de zorg aan iedere patiënt, waaronder ook patiënten van niet-westerse herkomst. De professionele standaard biedt een krachtige bescherming tegen eventuele discriminatie voortkomend uit een persoonlijke attitude. De waarde die zorgverleners aan hun beroepsethiek toekennen overstijgt dus hun persoonlijke opvattingen. De huidige opvatting van professionele standaard laat echter nog vrij veel ruimte voor interpretatie. Gelijke zorg wordt, onder invloed van de persoonlijke attitude, ofwel opgevat als even kwaliteitsvolle zorg ofwel als (medische) zorg die gelijkwaardig moet*

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[3] In de betekenis van ‘afgestemde zorg’ (Baart & Grypdonck, 2008).

> *zijn en zeker niet meer middelen, inspanning en tijd mag vragen dan voor ('autochtone') andere patiënten. Uit de tweede interpretatie blijkt een zeker denken in standaarden, namelijk dat er een 'gemiddelde' duur en aanbod bestaat van zorg dat gebaseerd is op het zorgaanbod aan de 'gemiddelde' patiënt (vgl. Ingleby, 2002). Dat is echter in strijd met het principe van 'zorg op maat', voor iedere patiënt zonder enig onderscheid. Het lijkt tevens sterk verband te houden met groepsdenken, waarin de specifieke patiënt vooral wordt gezien als representant van 'zijn groep'. Hij/zij behoort in de ogen van de zorgverleners in de eerste plaats tot de groep van personen van niet-westerse origine. Bovendien behoort de Belgische gezondheidszorg in de ogen van deze zorgverleners niet toe aan de groep van personen van niet-westerse origine.*
>
> *Als zorg op maat voor ieder patiënt, zonder enig onderscheid op welke grond ook, de alles overstijgende professionele standaard wordt, kan het een buffer vormen voor persoonlijke opvattingen ten aanzien van specifieke patiëntengroepen. Een buffer voor opvattingen die ertoe leiden dat individuen die tot een specifieke groep worden gerekend minder kwaliteitsvolle zorg krijgen. Tevens kan het oncologische zorgverleners die even kwaliteitsvolle (holistische) zorg nastreven, ondersteunen en motiveren om barrières te overwinnen en om aan langetermijnoplossingen te werken. Zij kunnen zich onder invloed van deze meer uitgebreide professionele standaard gelegitimeerd voelen om niet altijd de 'waan van de dag' voor te laten gaan en om beperkingen van het zorgsysteem aan te pakken. Een dergelijke professionele standaard zou bovendien de zorg aan alle patiënten (en zijn/haar naasten) verbeteren, omdat iedere patiënt eigen individuele noden heeft die zorg op maat vragen.*
>
> *Het gaat om inzicht krijgen in hetgeen werkelijk voor de patiënt en zijn/haar naasten op het spel staat (Kleinman & Benson, 2006a;2006b). Om dit te bereiken kan het helpend zijn om regelmatig aan de patiënt en (wanneer gepast) aan zijn familieleden te vragen wat voor hen het meeste van belang is ten aanzien van de ziekte en behandeling. Zorgverleners kunnen deze essentiële informatie vervolgens gebruiken in het zorgtraject (Kleinman & Benson, 2006a).*

We kunnen besluiten met de volgende woorden van Kleinman en Benson (2006b, p. 839):

> "If culture is about what is at stake for patients, families, and [care providers], then [care providers] need to be trained to inquire about

> what is at stake in illness and treatment, and to respond to what they learn about patients in their local worlds. Whether the patient is Russian, Haitian, or Dominican, or the [care provider] is Arab, Chinese, or Indian, the focus needs to be on the vital cultural condition that connects their moral experiences, which in truth is our human condition, and therefore the basis for humane care."

TOEKOMSTIG ONDERZOEK

Dit doctoraatsonderzoek bevestigt op empirische wijze de dynamische definitie van cultuur als een proces waardoor alledaagse activiteiten en omstandigheden een emotionele lading en morele betekenis krijgen voor participanten (Kleinman & Benson, 2006a). Cultuur gaat over wisselende morele ervaringen van patiënten, families en zorgverleners en de wijze waarop deze morele ervaringen de zorgverlener-patiënt relatie sterk beïnvloeden (Kleinman & Benson, 2006b). In toekomstig onderzoek omtrent diversiteit in de gezondheidszorg waarbij onderzoekers impliciet of expliciet spreken over cultuur is het van belang dat een weloverwogen definitie van cultuur helder wordt gemaakt. Eveneens is het van belang zich als onderzoeker te hoeden voor homogeniserende en essentialistische definities van religie, aangezien religie als culturele uiting ook divers wordt ervaren door gelovigen.

Onderzoek naar de wijze waarop de patiënten aankijken tegen de rol die familieleden opnemen, is een belangrijk onderwerp voor een volgend onderzoek. De huidige studie naar de beleving van familieleden kan daarvoor dienen als een vertrekpunt.

Een uitgebreid etnografisch onderzoek binnen de Vlaamse oncologische zorgsetting, waarin het perspectief van patiënten, familieleden, zorgverleners en het beleid op geïntegreerde wijze wordt onderzocht zou een waardevolle volgende stap zijn in het verkrijgen van inzicht in de aansluiting tussen de oncologische zorg en de diverse patiëntenpopulatie. Etnografisch onderzoek kenmerkt zich door uitgebreide data- en methodetriangulatie waarin naast intensieve participerende observatie onder meer gebruik wordt gemaakt van interviews en documentanalyse. Dit laat toe om naast een gesproken en geschreven vertoog ook het handelen van de onderzoekspopulatie te onderzoeken, waardoor het onderzoek niet beperkt blijft door de wijze waarop personen in staat zijn zichzelf te zien. Bovendien kan hierdoor de interactie tussen patiënt, familieleden en zorgverleners bestudeerd worden. Het beleid van de instelling zou daarin bij voorkeur ook meegenomen worden, onder meer door het bestuderen van beleidsdocumenten, afnemen van interviews met verantwoordelijken en beleidsmedewerkers en deelname aan overlegmomenten.

In toekomstig onderzoek is het van bijzonder groot belang dat de populatie de etnische diversiteit binnen de onderzochte groep weerspiegelt. Om ervoor te zorgen dat, in elk geval, toekomstig ontwikkelde theorieën en methodieken gebaseerd zijn op de werkelijke diverse samenstelling van de bevolking of patiëntenpopulatie (vgl. Ingleby, 2002). Grote voorzichtigheid is dan ook geboden met exclusie langs etnische lijnen. Daarnaast wordt ook exclusie op basis van taal het best vermeden door het overbruggen van eventuele taalbarrières met de inzet van professionele taalbijstand. In het geval van moeilijkheden bij het rekruteren van specifieke groepen, kan het zinvol zijn om gebruik te maken van personen of organisaties die deel uit maken van, kennis hebben over en/of contacten hebben binnen de specifieke groep. Uitkijken naar andere tussenpersonen dan zorgverleners voor de rekrutering kan ook helpend zijn. Hoewel een probleem van selectiviteit zich zal voordoen, kunnen verschillende vormen van selectiviteit elkaar deels opheffen. Het is tevens van belang voldoende tijd te voorzien voor de rekrutering, zodat er tijd is om de procedure aan te passen of uit te breiden wanneer onvoldoende participanten gevonden worden. Voor de financiering van onderzoek kan het zinvol zijn om als voorwaarde te stellen dat de onderzoekspopulatie een afspiegeling dient te zijn van de multiculturele samenleving (vgl. van Dijk, R., Boedjarath, I., de Jong, J., May R., & Wesenbeek, R., 2000). Dit geldt zeker voor kwantitatief onderzoek, waarin representativiteit een belangrijk kwaliteitscriterium is, maar ook in kwalitatief onderzoek is dit van belang. Dat in kwalitatief onderzoek gezocht wordt naar een evenwicht tussen heterogeniteit en homogeniteit in de steekproef, lijkt geen legitimatie te zijn voor het excluderen van participanten enkel langs etnische, culturele of religieuze lijnen. Ook voor- en nadelen van een exclusiecriterium op basis van taalbarrières worden bij voorkeur goed overwogen en eventueel meegenomen in de beoordeling van onderzoeksaanvragen.

Tabel 1. Beknopt overzicht van de meest essentiële aanbevelingen voor de oncologische zorg

	ZORGVERLENERS NIVEAU	**ORGANISATORISCH NIVEAU**
REFLECTIE	Een reflectieve attitude aannemen - waarbij het bijzonder zinvol is om te leren loskomen van het vormende effect dat de biomedische cultuur heeft op alledaagse zorgpraktijken (Kleinman & Benson, 2006a)	Faciliteren van een reflectieve zorgpraktijk - De (sub)cultuur van een zorginstelling evolueert bij voorkeur naar een cultuur waarin haar patiëntenpopulatie zich kan herkennen - In het licht van de hoofddoelstelling van de zorg, de gezondheid van de patiënten: grenzen duidelijk stellen en goed uitleggen & grenzen verleggen door bestaande werkwijzen, regels en methodieken in vraag te durven stellen en aan te passen aan de nieuwe situatie (vgl. Boukhriss, s.d.; Ingelby, 2000) - Een gedegen divers personeelsbeleid, waarin zorgverleners zoveel mogelijk een afspiegeling vormen van de diverse samenstelling van de bevolking - In het kader van patiëntparticipatie: zo'n volledig mogelijke afspiegeling van de diverse samenstelling van de patiëntpopulatie
RELATIONELE BENADERING VAN AUTONOMIE	In de divers samengestelde samenleving is een relationele benadering van autonomie beter passend dan een individuele benadering (vgl. Surbone, 2006), bijvoorbeeld door: - een open dialoog aan te gaan met de patiënt en naasten over hoe het best zorg verleend kan worden - verkennen en afstemmen van de oncologische zorg op de specifieke opvattingen en behoeften van patiënten en hun naasten - vroegtijdig en met enige regelmaat in dialoog gaan, met behulp van taalbijstand, met de patiënt en zijn naasten over wie de gewenste persoon/personen zijn om diagnose-, prognose- en behandelingsinformatie mee te bespreken	Ondersteunen en uitdragen van een relationele benadering van autonomie
TAALBIJSTAND EN/OF INTERCULTURELE BEMIDDELING	In principe wordt professionele taalbijstand en/of interculturele bemiddeling het best beschouwd als een standaard instrument	Faciliteren van taalbijstand en/of interculturele bemiddeling - Taalbijstand en/of interculturele bemiddeling wordt het best beschouwd als een standaard instrument - Flexibele inzetbaarheid en uitgebreid aanbod - (Praktijkgerichte) vorming voor zorgverleners
ZORG OP MAAT ZONDER ONDERSCHEID	Zorg op maat geven aan iedere patiënt, zonder enig onderscheid en dit beschouwen als de alles overstijgende professionele standaard - Het gaat om het krijgen van inzicht in hetgeen werkelijk voor de patiënt en zijn naasten op het spel staat	Ondersteunen en uitdragen van een visie waarin de alles overstijgende professionele standaard zorg op maat is voor iedere patiënt, zonder enig onderscheid

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SAMENVATTING

Demografisch gezien kenmerkt Vlaanderen zich door een toenemend diverse samenstelling van de bevolking. Binnen gezondheidszorginstellingen komt het steeds meer voor dat zorgverleners en patiënten een andere etnisch en culturele achtergrond hebben. Voor een goede aansluiting van de zorg is het van belang om inzicht te hebben in het perspectief van zorgverleners en in de ervaring en beleving van zorgvragers. Gezien de existentiële betekenis van oncologische zorg, geldt dit zeker binnen de oncologische context. Onderzoek naar de wijze waarop oncologische zorgverleners de zorg aan patiënten met een migratieachtergrond ervaren is echter eerder beperkt. Er is ook relatief weinig bekend over de beleving van familieleden van oncologische patiënten met een migratieachtergrond.

Deze doctoraatsstudie heeft als doel inzicht te geven in de wijze waarop oncologische zorgverleners de zorg aan patiënten van andere origine ervaren en de wijze waarop familieleden de zorg aan oudere volwassen patiënten van Turkse of noordwest Afrikaanse origine met kanker beleven. Het is bekend dat familieleden veelal een essentiële rol opnemen in het kankertraject, waardoor het waardevol is om inzicht te verkrijgen in hun beleving. De inzichten worden verkregen door middel van een systematische literatuurstudie en empirisch kwalitatief onderzoek, gebaseerd op de constructivistische grounded theory.

Eerst wordt onderzocht wat bekend is uit de literatuur over de ervaringen en percepties van oncologische zorgverleners wereldwijd in de zorg aan patiënten van etnische minderheidsgroepen. De beperkte literatuur over dit thema brengt vooral moeilijkheden en barrières naar voren die oncologische zorgverleners ervaren. De ervaringen en percepties worden gekenmerkt door een bereidwilligheid om gepaste zorg te verlenen. Dit wordt echter belemmerd door een kluwen van zaken, zoals taalbarrières, angst en onzekerheid en veronderstellingen over culturele geduide kwesties. Organisatorische aspecten blijken daarnaast een aanzienlijke invloed te hebben op oncologische zorgverleners wanneer zij zorg dragen voor deze patiëntenpopulatie.

In een kwalitatief onderzoek, met behulp van focusgroepinterviews, worden de ervaringen en percepties bestudeerd van oncologische zorgverleners in

Vlaanderen ten aanzien van de zorg aan patiënten van niet-westerse origine. Barrières en moeilijkheden blijven zorgverleners het meest bij. Alle zorgverleners vertrekken vanuit een professionele standaard waarin iedere patiënt gelijk hoort te worden behandeld en recht heeft op adequate zorg. Zorgverleners zijn echter, onder invloed van hun persoonlijke attitude, niet bereid of niet bij machte om barrières (volledig) te overwinnen. De zorg aan patiënten van niet-westerse origine wordt daardoor ingeperkt als het niet om strikt medische zaken gaat. De 'cure' lijkt het dus te winnen van de 'care'. Zorgverleners die de intentie hebben even kwaliteitsvolle zorg te geven, voelen zich verantwoordelijk voor het tekort schieten in het geven van holistische zorg. Zorgverleners die van mening zijn dat de zorg aan patiënten van niet-westerse origine niet (veel) meer tijd en middelen mag vragen dan die van 'autochtone' patiënten, leggen de verantwoordelijkheid daarentegen bij de patiënt en nemen het hen kwalijk niet de adequate zorg te kunnen geven. De bevindingen tonen dat de professionele standaard een bescherming biedt tegen eventuele discriminatie voortkomend uit een persoonlijke attitude. Een uitbreiding van de professionele standaard van 'alle patiënten dienen gelijk te worden behandeld' naar 'zorg op maat voor alle patiënten', kan mogelijks voorkomen dat 'cure' het wint op 'care'.

De beleving van familieleden van oudere volwassenen van Turkse of noordwest Afrikaanse origine met kanker wordt onderzocht in een volgende kwalitatieve studie. De analyses van de individuele interviews geven inzicht in de grote betekenis die het zorg dragen heeft en de wijze waarop familieleden openheid over ziekte afwegen in het opnemen van een rol als vertaler of contactpersoon.

Kanker is een familieaangelegenheid en zorg dragen heeft een diepe morele betekenis voor alle familieleden, in het bijzonder voor volwassen kinderen die zorg dragen voor hun ouder. Het zorg dragen wordt gekenmerkt door het opnemen van een 'gidsende' rol: familieleden leiden of maken de patiënt wegwijs door de Belgische gezondheidszorg. Ondanks de gedeelde waarden, hebben familieleden zeer uiteenlopende opvattingen over de mate waarin zij zelf zorg dienen op te nemen en welke professionele zorg gewenst is. De gedeelde culturele of religieuze waarden laten dus niet de dagelijkse zorgpraktijken voorspellen. Verkennen en afstemmen van de oncologische zorg op de specifieke opvattingen en behoeften van patiënten en hun naasten is dan ook essentieel.

Vanuit de grote morele betekenis die het zorg dragen heeft, willen familieleden onder meer bijdragen aan een positieve ingesteldheid van de patiënt. Gebaseerd op verschillende motieven en ingebed in hun inschatting van wat de patiënt aankan, kan begrijpen en wat hij/zij wil weten over de ziekte, beslissen familieleden in welke mate zij de patiënt op de hoogte stellen. Sommige familieleden vinden dat zij het best medische informatie verzwijgen voor de patiënt, terwijl andere vinden dat zij hun oudere familielid het best volledig informeren. Wat ze beslissen beïnvloedt de wijze waarop ze een rol als vertaler of contactpersoon opnemen. Het is van belang als zorgverlener rekening te houden met het complexe en onvoorspelbare proces waarin familieleden openheid over ziekte afwegen wanneer zij vertalen voor een ouder familielid. In dat verlengde is het voeren van gesprekken met patiënten en hun naasten over de opvattingen en zienswijzen ten aanzien van het uitwisselen van informatie bijzonder waardevol.

De bevindingen in deze doctoraatsstudie wijzen erop dat een alles overstijgende professionele standaard van zorg op maat voor iedere patiënt, zonder enig onderscheid, kan voorkomen dat individuen die tot een specifieke groep worden gerekend minder kwaliteitsvolle zorg krijgen. Het gaat er om inzicht te krijgen in hetgeen werkelijk voor de patiënt en zijn naasten op het spel staat en de zorg daarop af te stemmen. Een dergelijke professionele standaard kan de oncologische zorg verbeteren voor *alle* zorgvragers.

SUMMARY

As in other West-European countries, Belgium is characterized by an increasing diversity in its population. Care in which provider and patient have a different cultural background is more and more common. For care to be well attuned to patients of foreign descent, gaining insight in the perspective of the provider and that of the care receiver is important. Considering the existential meaning of oncology care, these insights are certainly a matter of importance within the context of oncology. However, little is known about how health professionals experience and perceive their work with care users of diverse ethnic origins. With regard to family members of ethnic minority cancer patients also relatively little research has been undertaken.

This dissertation aims to provide insight in both the experiences of oncology health workers in caring for ethnic minority care users and in the experiences of family members of older adult cancer patients of Turkish or Northwest African descent. As family members play an essential role in the cancer trajectory, insight in their perspective is valuable. The insights were gained by means of a systematic literature review and qualitative empirical research, based on constructivist grounded theory.

First it is investigated what published research reveals about the views and experiences of oncology health workers when caring for ethnic minority patients. The limited literature reports mostly about challenges or barriers when caring for these patient groups. Views and experiences of participating oncology health workers are characterized by a willingness to provide proper care, but providing such care is hampered by a tangle of interrelated issues such as linguistic barriers, fear and uncertainty, and assumptions about cultural matters. Organizational aspects were shown to have a strong influence on healthcare workers caring for ethnic minority patients.

Experiences and perceptions of oncology health providers in caring for patients of non-Western descent in Flanders are studied in a qualitative research, using focus group interviews. Barriers and difficulties appear to be paramount in the provision of care to patients of non-Western descent. Participants want to act according to their professional standards, which call for treating all patients equally and providing appropriate care. However ‘cure’ takes precedence over ‘care’ when participants are not willing or not

fully able to overcome barriers. This results in feelings of inadequacy in those participants who equate professional standards to care of equal quality. Participants who interpret the professional standard as calling for equivalent care are irritated by 'these' patients who restrain them from providing appropriate care. The findings indicate that professional standards provide protection against possible discrimination that may result from personal beliefs. Extending professional standards from 'treating all patients equally' to 'care attuned to each patient' might be a way to prevent 'cure' taking precedence over 'care'.

Insight in the experiences of family members of older adult cancer patients of Turkish or northwest African descent is provided in a subsequent study. Analysis of the individual interviews yields insight in the strong moral meaning of care giving and in the way family members balance truth-telling when translating for their older relative.

Cancer appears to be a family matter. Care giving has a strong moral meaning for all participants, particularly for children providing care to a parent. Care giving can be described as "guiding": family members lead the patient through, or familiarize the patient with, the health care system. Despite shared values of the importance of family and family care giving, there are strong differences in the extent to which family members believe they should provide care, as well as the kind of professional care considered desirable. Hence shared cultural or religious normative values do not predict day-to-day care practices. Therefore, individualized approaches of care are essential.

Following from the strong moral meaning care giving has, most relatives consider it their responsibility to contribute to a positive attitude of the patient. Based on several motives and embedded in their assessment of the patient's emotional strength, understanding, and need to be informed, relatives decide to what extent they inform the patient. Some consider it best to omit medical information while others consider it best to inform the patient fully. What they decide influences the way they act as a translator or a contact person. The results emphasize the importance for healthcare providers to take into account the complexity and unpredictable character of the process of balancing truth-telling when family members translate for their ill older relative. Furthermore, it shows the importance of conversations between oncology healthcare providers and patients, together with close relatives, about views and attitudes to sharing information.

Taken together, this dissertation indicates that an overarching professional standard of ‘care attuned to each patient’, indiscriminately, might prevent individuals receiving less qualitative care when being counted among a specific group. Attuned care requires gaining insight in what is really at stake for patients and their loved ones and to attune care to that information. Such a professional standard might improve oncology care for *all* care users.

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GEVOLGDE CURSUSSEN

Academic English writing skills, Universitair Centrum voor Talenonderwijs, 02/12 - 05/12

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4de symposium kwalitatief sterk, Cello en Universiteit Antwerpen, 02/12

Palliatieve zorg bij allochtonen, 1ste Sharaf medisch congres, 11/11

Kwalitatieve analyse, Kwalon - Universiteit voor Humanistiek, 11/10

Euthanasie, pijnbestrijding en levensmoeheid: Juridische en sociologische aspecten, Universiteit Antwerpen,12/09

Kind van diversiteit. Over opvoeden binnen verschillende familie culturen, Kind en Gezin Academie Brussel, 05/08

Werken met tolken in de hulpverlening, Tolk- & Vertaalservice Gent, 04/08

Zorg tussen twee werelden. Interculturele communicatie binnen de (geestelijke) gezondheidszorg, Medilex, 04/07

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Medisch Maatschappelijk Werk – Conflicthantering, AMC, 01/07

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