UNIVERSITEIT
GENT

Faculteit Geneeskunde en Gezondheidswetenschappen
Vakgroep Maatschappelijke Gezondheidkunde
Verplegingswetenschap

DE CONFRONTATIE
MET TRAUMATISCH COMA

Een onderzoek naar de beleving van familieleden

Proefschrift ingediend tot het behalen van de graad van Doctor in de Sociale Gezondheidswetenschappen: Medisch-sociale Wetenschappen

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Verhaeghe, Sofie

De confrontatie met traumatisch coma
Een onderzoek naar de beleving van familieleden
Doctoraatsthesis Universiteit Gent – met referenties – met samenvatting

Verschenen in de reeks monografieën van de Vakgroep Maatschappelijke Gezondheidkunde, Universiteit Gent

ISBN

Lay-out by Steven Six
Cover by Steven Six based on creative painting of Mathijs and Robrecht Vanhaverbeke

Printed by DCL Print & Sign | Leegstraat 15 | 9060 Zelzate | www.dclsigns.be

> **“In het extreme heeft het leven zijn waarde,**
> **in het gemiddelde zijn behoud”**
>
> Godfried Bomans
> (1913-1971)

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INHOUDSTAFEL

HOOFDSTUK 3:

HOOFDSTUK 4:

HOOFDSTUK 5:

INTRODUCTIE

Het onderzoek dat in dit proefschrift gerapporteerd wordt, heeft de beleving van familieleden van patiënten in traumatisch coma als thema. In deze introductie wordt na een korte situering en probleemstelling, beargumenteerd waarom belevingsgerichte zorg voor familieleden belangrijk is. Ook de redenen waarom we kiezen voor kwalitatief onderzoek worden aangegeven. Ten slotte wordt een overzicht gegeven van de verschillende hoofdstukken in dit proefschrift.

SITUERING EN PROBLEEMSTELLING

Beleving en ervaringen van familieleden van patiënten in een traumatisch coma, met name familieleden van patiënten in coma na een ongeval of een niet te voorziene intracraniële bloeding, staan centraal in dit onderzoek. Coma door medische verwikkelingen, terminaal coma en coma door een suïcidepoging worden buiten beschouwing gelaten omdat de omstandigheden waaronder het coma optreedt een ander karakter hebben en dit kan leiden tot een verschil in beleving. Deze familieleden in ons onderzoek includeren zou leiden tot een te grote heterogeniteit die de diepgang van de analyse in het gedrang zou brengen.

Incidentiecijfers over traumatisch coma zijn slechts in onvolledige mate voorhanden. Dit is te wijten aan verschillen in o.a. definiëring, diagnose en onderzoeksstrategieën (Van Balen 1992). Toch kunnen bepaalde cijfergegevens richting geven aan een schatting van de omvang van de problematiek. Cijfers voor België zijn echter moeilijk te achterhalen. De studie van Little (Brusselmans *et al.* 2000) uit Groot-Brittannië, is wellicht het meest informatief voor ons onderzoek omdat de gegevens het aantal ziekenhuisopnames weergeven gepaard gaand met een duidelijk opgestelde Glasgow Coma Scale (GCS). In de studie wordt een jaarlijkse incidentie van 6-12/100 000 voor diep coma (GCS 8 of minder) waarvan 4-8/100 000 overlijden, 12-14/100 000 voor matig coma (GCS tussen 9 en 12) en 170-180/100 000 voor mild coma (GCS 13 of meer) aangegeven. Op die manier komen de onderzoekers tot een incidentie van 200-250/100 000 comagevallen per jaar. Hierbij mag verondersteld worden dat in de meerderheid van de gevallen slechts een coma van korte duur vastgesteld werd. In hun eindrapport voor het Vlaams Fonds voor Sociale Integratie van Personen met een Handicap, extrapoleren Brusselmans *et al.* (2000) de cijfers van Little naar de Vlaamse situatie. Die extrapolatie geeft een jaarlijkse incidentie van 390-900, maar betreft enkel personen met een traumatisch hersenletsel met blijvende gevolgen waarvoor hulp van het Vlaams Fonds kan aangewezen zijn. Redelijkerwijs mag verondersteld worden dat het aantal gevallen van traumatisch coma in Vlaanderen hoger ligt.

De impact van traumatisch coma op de familie van de patiënt is verwoestend. Bij traumatisch coma worden familieleden geconfronteerd met een plotse, onverwachte en zware verandering in hun dagelijkse bestaan. Door de plotse en onverwachte aard van de situatie is geen anticipatorische coping mogelijk. Het coma en de ziekenhuisopname worden als overweldigend en bedreigend ervaren en geven aanleiding tot hevige emoties, variërend van shock en ontkenning, tot woede, wanhoop en schuldgevoel, angst voor verlies van het familielid en isolatie van andere familieleden en vrienden (Craft *et al.* 1993, Daley 1984, Freichels 1991, Jamerson *et al.* 1996, Kleiber *et al.* 1994, LaMontagne & Pawlak 1990, Leske 1986, O'Neill Norris 1986, Rukholm *et al.* 1991). Er bestaat grote onzekerheid over de evolutie van de toestand van de patiënt en communicatie met de getroffene is onmogelijk (Jacob 1998, Jillings 1990, Kleiber *et* *al.* 1994, Kleinpell 1991, Koller 1991, Mendonca & Warren 1998, Reider 1994, Schlump 1990). Familieleden komen in een onindenkbare wereld terecht. Door de onrealistische maatschappelijke beeldvorming, in de hand gewerkt door films en soapseries die een overwegend optimistisch idee over het bijkomen en het herstel portretteren, is de confrontatie met de harde realiteit vaak nog moeilijker (Casarett *et al*. 2005).

Zorg voor familieleden is noodzakelijk in een menselijke en menswaardige zorgverlening (Bouley *et al.* 1994, Duijnstee 1994). Ook vanuit het politiek beleid worden impulsen gegeven om familieleden een rechtmatige plaats te geven binnen de gezondheidszorg (Vogels 1999). In het eindrapport van een onderzoek van het Vlaams Fonds voor Sociale Integratie van Personen met een Handicap i.s.m. de Coma Vereniging België wordt vanuit de vastgestelde hiaten in de huidige situatie een oproep gedaan tot zorg voor familieleden van mensen met een traumatisch coma.

DE PLAATS VAN FAMILIELEDEN IN DE GEZONDHEIDSZORG

Gezondheid, ziekte en zorgbehoevendheid zijn contextspecifieke fenomenen. Ziek zijn is een gedeelde ervaring, de zorgvraag en het antwoord hierop worden binnen de kring van mensen waarmee de patiënt nauw verbonden leeft vastgesteld. Ook waar het om nieuwe samenlevingsvormen gaat, worden deze “naasten” in onderzoek en theorievorming nog steeds met de term familie aangeduid (Schnepp 2002). In ons onderzoek gebruiken we de term familie ook op deze wijze. Het gaat om de mensen die zichzelf als naaste van de patiënt beschouwen.

Familiezorg krijgt snel groeiende belangstelling in de gezondheidszorg. Het aantal publicaties over familieleden is de laatste jaren sterk gestegen. Toch is het idee van familiezorg nog niet algemeen aanwezig in de praktijk. Als familieleden genoemd worden, is dat meestal als mantelzorgers, met andere woorden vanuit de betekenis die ze hebben voor de hulpverlening aan de patiënt. In meer recent onderzoek is er eveneens aandacht voor het lijden van familieleden zelf. Onderzoek naar de beleving van familieleden laat zien dat veel psychologische processen die zich afspelen bij de patiënt, zich ook voordoen bij familieleden (Morse & Johnson 1991). Familieleden lijden vaak dubbel: ze lijden met de patiënt mee en ze lijden hun eigen verlies (Grypdonck 1996). Uit onderzoek blijkt verder dat ondersteuning van familieleden niet alleen voor familieleden nodig is, maar tegelijk ook van betekenis is voor de patiënt. De patiënt heeft er immers alle baat bij dat familieleden de situatie kunnen overzien en hanteren. De betekenis die ze geven aan hun ziekte kan er positief door beïnvloed worden en hun herstel kan vlotter verlopen. Familieleden die zelf ondersteund worden kunnen de patiënt ook beter tot steun zijn (Duijnstee 1993, Duijnstee *et al.* 1996). Familieleden brengen het dagdagelijkse leven binnen bij de patiënt en daarmee ook zijn verlangen om zo veel mogelijk aan dit leven deel te nemen (Stillwell 1984)

AANDACHT VOOR ZORG

In de gezondheidszorg is er de laatste jaren toegenomen aandacht voor zorg. Hoewel de mogelijkheden van de geneeskunde enorm zijn toegenomen, is echte genezing vaak niet mogelijk. Patiënten blijven in leven met restletsels, veel lijden blijft onoplosbaar en vraagt om zorg. In de verpleegkunde is “zorg” van oudsher een centraal begrip. Verplegen is (een bepaalde vorm van) zorg verlenen (McIlveen & Morse 1995). Het betekent: nagaan wat nodig is opdat de

ander, nu zijn gezondheid gehavend of bedreigd is, als mens tot zijn recht zou kunnen komen, en vervolgens doen wat daarvoor nodig is. Zorg verlenen begint met een cognitieve activiteit: nagaan, onderzoeken, beoordelen en besluiten. Of beter nog: het is de materialisatie van een relatie waarin de zorgverlener wakend aanwezig is bij diegene die zorg behoeft.

De laatste jaren heeft zich, quasi natuurlijkerwijs, een nieuwe ontwikkeling voorgedaan in de kijk op zorg. Waar vroeger, in het verlengde van cure, zorg vooral bekeken werd vanuit het perspectief van de hulpverlener, wordt er momenteel meer en meer van uitgegaan dat in zorg het perspectief van de cliënt een belangrijke rol moet spelen (Toombs 1992, Ricoeur 1992, Ricoeur 1986). Meer nog, zorg kan slechts effectief zijn als ze aansluit bij de ervaringen en beleving van de hulpvrager (Gamel *et al.* 2001). Wanneer het perspectief van de hulpvrager, met zijn of haar ervaringen en beleving het uitgangspunt vormt van zorg, wordt gesproken over belevingsgerichte zorg (Pool *et al.* 2003, Van Heijst 2005).

BELEVINGSGERICHTE ZORG EN HET PERSPECTIEF VAN DE FAMILIE

Het uitgangspunt van belevingsgerichte zorg is een andere visie op de werkelijkheid, een visie die in de eerste plaats haar oorsprong vindt in de fenomenologie. Voor de fenomenologie, ontwikkeld vanuit het intentionaliteitsconcept van Husserl, bestaat de menselijke werkelijkheid niet buiten de betekenis die de mens daaraan verleent (Ricoeur 1986). En zonder die betekenis kan de werkelijkheid niet benaderd worden. Ziekte is niet iets wat zich als objectief gebeuren, buiten de menselijke persoon om, in zijn lichaam voltrekt. Het is iets dat hij als persoon beleeft, en dat daardoor zijn specifieke vorm krijgt. Ziekte is voor de patiënt en zijn familie niet een wetenschappelijk objectief concept, geïnterpreteerd op basis van onder andere de kennis over fysiologie en anatomie en gedefinieerd in het licht van de geneeskunde: diagnose, behandeling en prognose. Ziekte is voor de patiënt en zijn familie een subjectieve ervaring waarbij de mens oog in oog staat met zijn eigen kwetsbaarheid. Ziekte heeft zijn voortdurende impact op het dagelijkse leven. De betekenis die de mens aan de confrontatie met de ziekte geeft, bepaalt hoe hij de ziekte beleeft.

Behalve de fenomenologie is ook het symbolisch interactionisme als stroming belangrijk voor belevingsgerichte zorg. Symbolisch interactionisme stelt dat de mens de werkelijkheid zin en betekenis geeft in interactie met zijn omgeving. De interactie met de omgeving is cruciaal in het proces van betekenisverlening. Ziekte is een gebeuren dat de patiënt en zijn omgeving in interactie betreft. Zowel de patiënt als de familie lijden onder de ziekte. De betekenis van het leven-met-de-ziekte is slechts te vatten als men de patiënt in interactie met zijn omgeving bestudeert en benadert.

Ook in de interactie met de hulpverleners wordt betekenis geconstrueerd. Hulpverleners en vooral verpleegkundigen hebben als opdracht de patiënten en hun familieleden te ondersteunen bij het leven met de ziekte: zo zorg te verlenen dat het leven zoveel mogelijk recht wordt gedaan. Ze hebben als opdracht de patiënt en zijn familie te ondersteunen als deze door de ziekte bedolven worden. Ze moeten ervoor helpen zorgen dat er weer aandacht en energie vrijkomt om te leven. Om dat te kunnen realiseren moet er inzicht zijn in de processen van ziek zijn en in de wijze waarop het leven-met-de-ziekte verloopt: wat de patiënt en zijn familie meemaakt als de diagnose gesteld wordt, hoe aan de diagnose en de consequenties ervan een plaats gegeven wordt, hoe aan het leven zin en vorm gegeven wordt in het licht van de (vaak in negatieve zin) veranderende perspectieven.

Kennis over de wijze waarop patiënten en familie hun leven zien en beleven is van groot belang in de zorgverlening. Problemen kunnen maar benoemd en vastgesteld worden tegen de achtergrond van het beeld van de wijze waarop de patiënt en zijn familie leven en willen leven. Patiëntgerichte zorgverlening vertrekt vanuit de visie van de patiënt en zijn familie op zijn situatie. Wat zin en betekenis verleent aan het leven en wat de beleving van zin verhindert, vragen prioritair aandacht.

Hoewel beleving individueel is, is het belangrijk dat een hulpverlener een kader van verwachtingen kan construeren, waartegen reacties van individuele patiënten en familieleden geplaatst kunnen worden. Dit is essentieel voor een goede communicatie tussen zorgverlener en hulpvrager. De communicatieboodschappen worden binnen dit kader gecodeerd. Als bij de decodering van de boodschap de context niet gekend is, of als de boodschap in een verkeerde context geplaatst wordt, gaat het met de communicatie verkeerd. Hoe meer kennis over de beleving en betekenisverlening, hoe kleiner het risico op verkeerde interpretatie of niet aansluitende communicatie.

Kennis bij hulpverleners over de beleving van de ziekte en de behandeling geeft de patiënt en zijn familie het gevoel begrepen te worden. De zorgverlener zal er veel sneller blijk kunnen van geven de situatie te begrijpen. Dat kan de patiënt of de familieleden vertrouwen geven in de zorg en de zorgverlener. Zich begrepen voelen leidt tot een positieve reactie. Omdat het voor mensen zeer belangrijk is in hun lijden begrepen te worden (Lindholm & Eriksson 1993), betekent deze herkenning door de zorgverlener veel voor hen. Het maakt het ondraaglijke of moeilijk te dragen lijden meer draaglijk.

Beleving en betekenisverlening zijn uiteraard individueel, en iedere zorgverlener zal telkens weer de situatie moeten verkennen. Kennis over patronen, over wat zich vaak voordoet of soms gebeurt, schept voor de zorgverlener echter wel een kader van verwachtingen. Dat voorkomt dat iedere situatie als een nieuwe situatie benaderd moet worden en vermijdt bovendien dat nieuwe situaties geïnterpreteerd worden op grond van eerdere, niet representatieve ervaringen.

Kennis over beleving en betekenis is niet alleen van belang voor de individuele zorgverlening, maar ook voor het beleid in de gezondheidszorg. Bij de planning en inrichting van zorgvoorzieningen zijn niet alleen de "objectieve zorgbehoeften" (beperkingen en handicaps) van belang, maar moet ook rekening gehouden worden met datgene wat de patiënten en hun familie nodig hebben om als mens tot hun recht te komen.

DE KEUZE VOOR KWALITATIEF ONDERZOEK

Om belevingsgerichte zorg wetenschappelijk te onderbouwen is kennis en onderzoek over ervaring en beleving van patiënten en familieleden noodzakelijk. Om ervaring en beleving op een genuanceerde wijze in beeld te brengen, is een kwalitatieve onderzoeksbenadering bijzonder geschikt (Maso 1989, Miles & Huberman 1984, Morse 1994, Morse & Field 1996, Strauss & Corbin 1990, Wester 1987, van Zuuren 1990, van Zuuren 1995, van Zuuren 2002). Kwalitatief onderzoek laat beter dan andere onderzoeksstrategieën toe de subjectieve aspecten van de werkelijkheid zichtbaar te maken. Het voorkomt dat beleving en betekenis te vlug gekanaliseerd worden in de gangbare psychologische verklaringsmodellen en daardoor moeilijker begrepen kunnen worden.

ONDERZOEK NAAR BELEVING VAN FAMILIELEDEN VAN PATIËNTEN IN TRAUMATISCH COMA

Zoals hoger reeds aangegeven, worden familieleden van patiënten in traumatisch coma geconfronteerd met een plotse, onverwachte en onvoorzienbare gebeurtenis die als overweldigend en bedreigend ervaren wordt. Familieleden kunnen zich niet voorbereiden op de situatie en anticipatorische coping is onmogelijk. Er bestaat onzekerheid over de evolutie, en communicatie met de getroffene is uitgesloten. Familieleden zijn voor de patiënt op de intensieve zorg afdeling van grote betekenis. Hun aanwezigheid en betrokkenheid heeft een positief effect op het welbevinden en herstel van de patiënt (Burr 1997, Morse & O'Brien 1995).

Uit literatuuronderzoek blijkt dat familieleden van comapatiënten grote behoefte hebben aan ondersteuning in de crisissituatie die ze meemaken. Ze balanceren op de rand van hun mogelijkheden. Het voor handen zijnde onderzoek naar familieleden van comapatiënten biedt te weinig houvast om adequate ondersteuning te bieden. Het wordt gedomineerd door kwantitatief onderzoek naar noden en behoeften van familieleden van intensieve zorg patiënten in het algemeen, waarbij gegevens zijn verzameld met één onderzoeksinstrument, de Critical Care Family Needs Inventory (CCFNI). De CCFNI bestaat uit een lijst van 45 noden, samengesteld op basis van de perceptie, de ideeën en de ervaring van enkele onderzoekers. Het instrument is gevalideerd en betrouwbaar bevonden (Bijttebier *et al.* 2000, Coutu-Wakulczyk & Chartier 1990, Harrington 1992, Leske 1991, Macey & Bouman 1991). Familieleden kunnen het belang van de verschillende noden aangeven op een vier-punten Likert schaal. Aan de hand van de CCFNI zijn noden van familieleden geïnventariseerd en getaxeerd op hun belangrijkheid. Deze inventarisatie biedt weinig inzicht omdat onduidelijk is hoe de scores tot stand komen en waarop ze wijzen. Bovendien is het niet mogelijk om de betekenis van de antwoorden te achterhalen en de processen die daarbij spelen in beeld te brengen. Daarbij komt dat de resultaten weinig specifiek zijn voor familieleden van comapatiënten. Bovendien werd in kwalitatief onderzoek (o.a. Burr 1998) aangetoond dat niet alle belangrijke noden van familieleden aan bod komen in de CCFNI en dat een inventarisatie van alleen veranderende noden tekort doet aan de processen die familieleden doormaken (o.a. Fulbrook *et al.* 1999).

Met onze keuze voor kwalitatief onderzoek hopen we de hiaten op te vullen. De onderzoeksvragen voor dit onderzoek concentreren zich rond de definiëring en beschrijving van het "basic psychological process" (Strauss & Corbin 1990) dat familieleden in de confrontatie met traumatisch coma doormaken. Welke betekenis geven familieleden aan het gebeuren? Welke rol(len) kennen ze zichzelf toe en welke rol(len) kunnen ze daadwerkelijk vervullen? Wat betekent het voor hen (te trachten) die rol te vervullen? Welke factoren beïnvloeden dit proces en wat biedt een verklaring voor strategieën, acties en inspanningen van familieleden? Welke omgevingsfactoren en reacties van hulpverleners en derden zijn voor familieleden ondersteunend en helpend, en welke zijn belastend, stresserend, pijnlijk?

Om de onderzoeksvragen te beantwoorden hebben we in twee algemene ziekenhuizen 24 interviews afgenomen met 22 familieleden. Deze interviews waren specifiek gericht op de beleving en ervaringen van familieleden van comapatiënten. Kenmerken van de interviews en de familieleden zijn in hoofdstuk 2, 3 en 4 vermeld. Op het ogenblik dat de analyse van de 24 interviews voltooid was en bleek dat voor de hoofdthema's theoretische saturatie (dit betekent dat nieuw materiaal geen nieuwe inzichten meer oplevert) bereikt was, is de inclusie afgesloten. Zeven interviews van een andere onderzoeker, uit een onderzoek naar de beleving van familieleden van orgaandonatiepatiënten (Stubbe, 2004), met een andere focus dus, maar verband houdend met coma zijn door middel van een secundaire analyse voor validering van de bevindingen gebruikt. Een gedetailleerde weergave van de onderzoeksopzet, de steekproef, de datacollectie en –analyse en de ethische aspecten van het onderzoek staat in hoofdstuk 3. Hieronder willen we de globale opzet van het onderzoek weergeven.

OPZET VAN DIT PROEFSCHRIFT

Dit proefschrift is opgebouwd uit vijf Engelstalige hoofdstukken, waarvan er vier in artikelvorm zijn verschenen of weldra zullen verschijnen en een binnenkort als manuscript aan een tijdschrift aangeboden wordt. Het eerste hoofdstuk bestaat uit een literatuurstudie over de noden en ervaringen van familieleden van volwassen patiënten op een intensieve zorg afdeling. Omdat er onvoldoende literatuur te vinden was over ervaringen van familieleden van comapatiënten in de acute periode is de uitbreiding gemaakt naar een literatuuronderzoek over familieleden van intensieve zorg patiënten. Dit leunt meest aan bij wat vooropgesteld was. Centraal in deze literatuur staan de resultaten op basis van de CCFNI. Daarnaast komen ook een aantal kwalitatieve onderzoeken aan bod. Vanuit de literatuurstudie werden de criteria voor sampling opgesteld en werd beslist om de thema's, die in de interviews aan bod zouden komen, zeer algemeen en belevingsgericht te houden met mogelijke verdiepingsthema's in de lijn van wat uit de literatuurstudie aan bod kwam.

In Hoofdstuk 2 wordt het proces beschreven van de taak die familieleden van coma-patiënten in de acute fase als hun belangrijkste opdracht ervaren. Centraal staat bescherming ("protecting"). Familieleden van comapatiënten zien het in de acute fase als hun belangrijkste taak om de patiënt, hun naaste familieleden en na enige tijd zichzelf te beschermen. Het uitvoeren van die taak is hun doel, het is de reden en hun motivatie om zich staande te houden in het lijden. Het beschermen evolueert en na de comaperiode wordt beschermen: leren leven met de gevolgen.

In Hoofdstuk 3 wordt het proces van "hoop" beschreven dat familieleden helpt om zich doorheen de comaperiode staande te houden. Er wordt vooral gefocust op het concept, het proces en de betekenis van hoop. Door hoop blijft het voor familieleden mogelijk om door te gaan. Dankzij hoop vinden ze de kracht om de zichzelf opgelegde taak te vervullen. In dit hoofdstuk worden de kenmerken en het verloop van hoop verhelderd. De individuele verschillen in hoop bij familieleden en de functies van hoop worden belicht. Omdat hoop van familieleden door hulpverleners vaak als ontkenning wordt aangezien, is een apart deel aan beide begrippen gewijd. In dit hoofdstuk is ook de methodologie het meest uitgebreid beschreven.

In Hoofdstuk 4 wordt de invloed van informatie op het ontstaan en op de inhoud van de hoop beschreven. Informatie en hoop zijn onlosmakelijk verweven. Het hoofdstuk biedt, anders dan Hoofdstuk 3, niet zozeer inzicht in het concept, het proces en de betekenis van hoop maar heeft als specifieke focus het proces van informatieverwerking en de invloed ervan op hoop. Omdat hulpverleners een cruciale rol spelen bij het geven van informatie en op die manier de hoop van familieleden sterk beïnvloeden, is een apart artikel aan dit onderwerp besteed.

Omdat het onderzoek zich beperkt tot de eerste periode in de "loopbaan" (Strauss *et al.* 1984) van familieleden van comapatiënten en we toch wilden melden wat er over de verdere "loopbaan" gekend is, bestaat Hoofdstuk 5 uit een literatuurstudie over stress en coping bij familieleden van comapatiënten in de post acute fase en de revalidatiefase. Patiënten zijn de comaperiode voorbij en familieleden worden geconfronteerd met de gevolgen van het hersenletsel. Dit literatuuronderzoek geeft weer met wat voor aspecten familieleden op langere termijn geconfronteerd worden en toont aan dat de confrontatie met het hersenletsel na traumatisch coma het leven van de familieleden voor altijd ingrijpend verandert. Onderzoeken over de beleving van familieleden in deze fase zijn vooral gebeurd in het licht van de stress-coping theorie en de systeemtheorie. Beide theorieën waren op het moment van de groeiende interesse voor familieleden van personen met een hersenletsel, de meest gangbare referentiekaders in de psychologie om psychologische reacties van mensen in beeld te brengen. Om de voor handen zijnde literatuur te kunnen ordenen en synthetiseren is gekozen om beide referentiekaders te gebruiken in de literatuurstudie.

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HOOFDSTUK 1

The needs and experiences of family members of adult patients in an intensive care unit: A review of the literature

ABSTRACT

Aims and objectives: Insight into the needs and experiences of family members is an initial but necessary step in providing appropriate care for both family members and the patient. This literature review aims to structure the available scientific knowledge on needs and experiences of family members of ICU patients with particular extension to coma patients. Qualitative as well as quantitative studies are discussed.

Method: literature review.

Results: Needs are divided into four categories: cognitive, emotional, social and practical needs. The need for accurate and comprehensible information that leaves room for hope is universal. Family members want to speak to a doctor every day about the condition of, and the prognosis for the patient, and want a nurse to explain to them about the care, the unit, the equipment and what they can do for the patient during visiting hours. Family members place great importance on being called at home if the condition of the patient changes. Emotional needs as hope, reassurance and being able to remain in the vicinity of the patient are crucial. Family members always give priority to the welfare of their relative. In their confused state, they often do not get around to paying attention to themselves. Caregivers underestimate all of the needs of family members and do not enough to meet these needs.

Relevance to clinical practice: Priority needs should be central in the nurses' approach of family members. The initiative for meeting the needs must be with the caregivers. Future, focused and well-designed qualitative research over a longer period of time could clarify the process that family members go through and explain the results of quantitative studies.

Keywords: experiences, needs, family, traumatic coma, intensive care, nursing

INTRODUCTION

This article originates in a literature search on experiences of adult family members of adult coma patients. Only a few references were found on this specific subject. Therefore, the literature search was broadened to experiences of family members of intensive care patients in general, providing the best approximation of what family members of coma patients experience.

Admission to an intensive care unit (ICU) and traumatic coma generate strong emotions, including shock, denial, anger, despair, guilt and fear for the loss of the family member. Family members may also close themselves off from the outside world. (Daley 1984, Engli & Kirsivali 1993, Johnson *et al*. 1995, Kleiber *et al*. 1994, Mendonca & Warren 1998, Neabel *et al*. 2000)

Concern for the family of the coma patient is necessary for humane and dignified care provision.

There does seem to be a general consensus that involving families in the care process is important and has a positive effect on both families and patients (Burr 1997). Research on health care practices has shown that family members do not receive the attention they need for reasons that are not entirely clear (Mendonca & Warren 1998, Daley 1984, Kleinpell & Powers 1992, Jacono *et al*. 1990, Warren 1993, Forrester *et al*. 1990, Hampe 1975, Lynn-McHale & Bellinger 1988). Several studies show that nurses often wrongly assess the needs of family members (Bijttebier *et al*. 2001, Molter 1979, O'Neill Norris 1986, Kleinpell & Powers 1992, O'Malley *et al*. 1991, Murphy *et al*. 1992, Forrester *et al*. 1990, Lynn-McHale & Bellinger 1988). Because knowledge of what family members undergo is an initial step in being able to provide appropriate care for both family members and the patient, this review of the literature examines the experiences and the needs of adult family members of patients (more specific traumatic coma patients) in an ICU.

METHODOLOGY AND CLASSIFICATION OF THE EXISTING RESEARCH

To collect the literature, we used the Medline, PsycInfo and CINAHL search systems and retrieved articles published between 1970 and January 2004. The focus of our review required a sensitive filter rather than a specific one. For our search in Medline we used the following MeSH-terms “coma” or “intensive care” or “critical care” and “family” combined with the more sensitive Entry-terms “trauma” or “critically ill” and “relative”. We also used these MeSH-terms or Entry-terms in combination with the following key words “needs”, “experience(s)”. Our search in Psychinfo and CINAHL was based on the combination of the following key words ”coma” or “trauma” or “intensive care” or “critically ill” or “critical care” and “family” or “relative” or “needs” or “experience(s)”. All studies or review articles containing elements relevant to the aim of the review were selected by two researchers who read the abstract or, in case of doubt or disagreement, the whole article. In total, 55 English language publications were assembled and studied. They were included in the review if the assessment of the full text, also made by two researchers, indicated that the content contributed to the understanding of the phenomena under study and the research methods warranted the “findings”. In case of limitations or doubt, the reasons for caution in the interpretation are reported in the result section.

Research on family members of the critically ill commenced in the middle of the 1970s. Most of the studies have been conducted to determine the experiences and particularly the resulting needs of family members of acute and critically ill patients. Quantitative descriptive studies predominate, focusing on inventorying family needs. Only a few studies focused on experiences in a broader sense. We will first summarize and categorize the quantitative research and then discuss the few qualitative studies we found on the experiences of family members in ICU.

Quantitative research into the needs of family members

Hampe (1975) was the first researcher to investigate the needs of grieving wives in the hospital. She interviewed wives of critically ill patients to determine what they needed and the extent to which these needs were met. She divided the needs of the grieving wives into two categories: needs related to the relationship with the patient and personal needs of the grieving wife. Among the former, she listed the need to be able to be with the dying person, the need to be able to help him and the need to know that he is physically and emotionally as comfortable as possible. Specific for a coma situation is that the wives indicated that they had no need to offer care to their partner as they could no longer do anything helpful after the coma commenced. In the category of personal needs of the grieving wife are the need for information, for ventilating feelings, for comfort and support of family members and for feeling accepted and supported by professional caregivers.

All of the needs were insufficiently met. The need to know that the patient was emotionally and physically as comfortable as possible was met in less than a third of the cases. The information given was satisfactory in fewer than half of the cases and in 40 to 45% of the cases the personal needs of the grieving spouse were met.

Hampe’s (1975) study strongly influenced further research on family members of the critically ill. On the basis of Hampe’s findings and her own practical experiences, Molter (1979) developed the Critical Care Family Needs Inventory (CCFNI) consisting of a list of 45 needs that family members could rate on 4-point Likert scales. The validity and reliability of this instrument has been found to be satisfactory, with internal consistencies (α) varying between 0.62 and 0.80 (Neabel *et al*. 2000, Bijttebier *et al*. 2000, Leske 1991).

The CCFNI has been used in many studies in several countries. We will discuss the results of these studies in some detail here. The literature offers several ways to classify the needs (Bijttebier *et al*. 2000, Leske 1991, O'Malley *et al*. 1991). For reasons of clarity and comprehensibility, however, we opted for a new division. We selected categories with which there is a certain degree of familiarity in health care, rather than using a classification based on factor analysis because factors are difficult to interpret theoretically and factor instability does occur.

We divided the 45 needs of the CCFNI into four categories: cognitive, emotional, social and practical. This categorization is not watertight, for some needs can be placed in more than one category. In classifying the needs, account is taken of where the needs could have a primary influence. Thus, the need for information is placed in the category of cognitive needs, although information can also serve emotional needs, for example, to reduce fear. However, one may assume that information will first of all alleviate cognitive needs. In the second phase, it can lead to a reassessment of the situation so as to reduce fear. Below, we summarize the most important findings for each category.

Cognitive needs

Although each of the needs included in the CCFNI was indicated as being very important by at least some family members in each study, the need for information and knowledge stands out. Information appears to be the greatest need of family members of the critically ill patient (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). This applies all the more for family members of coma patients (Kreutzer *et al*. 1994, Mathis 1984, Campbell 1988, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). Furthermore, it is important that the information is as accurate as possible and is provided in an understandable manner, but not without leaving room for hope (Freichels 1991, Molter 1979, Davis 1994).

Several studies are concerned with which professional can meet the information need of family members best (Molter 1979, Mendonca & Warren 1998, O'Neill Norris 1986, Daley 1984, Dockter *et al*. 1988). Family members state that first the doctor and then the nurse should be initiating the provision of information. Other potential sources such as a pastor or another family member appear to be considered less suitable candidates for satisfying cognitive needs

(Molter 1979). More specifically, family members state that they want specific information from the doctor about the condition, the prognosis and the precise treatment of the patient at least once a day. From nurses, they expect information about the daily care of the patient, about the reasons for particular treatments, about the ICU as such, the equipment and the various disciplines present in the unit, about what they can do at the bedside of the patient and about transfer plans if any. Family members need to be able to speak to the same nurse as much as possible and want to be called at home to be informed about any change in the condition of the patient (Mendonca & Warren 1998, O'Neill Norris 1986, Molter 1979, Daley 1984, Dockter *et al*. 1988).

Although the need for information is high, both shortly after admission and after one or two weeks, this need is not always met (Mendonca & Warren 1998, Molter 1979, Spatt *et al*. 1986, Warren 1993). This may be due to the fact that nurses, as well as doctors, do not always sufficiently appreciate the cognitive needs of family members. In general, they underestimate its importance (Bijttebier *et al*. 2001, Molter 1979, O'Neill Norris 1986, Kleinpell & Powers 1992, O'Malley *et al*. 1991, Murphy *et al*. 1992, Forrester *et al*. 1990, Lynn-McHale & Bellinger 1988). Moreover, nurses consider providing information primarily a task of the doctor (O'Neill Norris 1986). They underestimate their own role in providing specific information about such things as the daily care of the patient, the reasons for particular treatments, changes in the patient’s condition, the unit, the equipment and the staff, or they suppose that the information needs of the family have already been met (O'Neill Norris 1986, Molter 1979, Dockter *et al*. 1988, Kleinpell & Powers 1992). In the eyes of the family, doctors give information only sporadically, although their information is important for family members to make decisions (Mendonca & Warren 1998, Molter 1979, O'Neill Norris 1986, Kleinpell & Powers 1992, Warren 1993). When information is given, it is done primarily by nurses, that is, by several different nurses (Mendonca & Warren 1998, Molter 1979). However, family members strongly wish to talk to the same nurse (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993).

Emotional needs

In almost every study, several cognitive as well as emotional needs appeared among the ten most important ones (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). In some cases, the need for hope and reassurance seems even greater than the need for information (Freichels 1991, Molter 1979, Mathis 1984, Campbell 1988, Kreutzer *et al*. 1994, Davis 1994).

Rather nuanced data are available on the need for hope. The need for hope is great, even after one to two weeks (Davis 1994, Freichels 1991). Hope appears to be of greater importance in sudden, unexpected and serious changes in the condition of the traumatic-coma patient than in the case of chronically evolving illnesses (Freichels 1991, Mendonca & Warren 1998). A traumatic coma is clearly a sudden, unexpected and serious change in the state of health of a person, so it is reasonable to assume that the need for hope is particularly great in such cases. Still, the literature is somewhat unclear in this regard. In the large-scale study of Price *et al*. (1991), 213 family members of mostly trauma patients and neuropatients were interviewed in a specialized hospital within 24 to 72 hours after admission of the patient. In comparison with other studies, the need for hope was rated less great. The need to be certain that the patient was being cared for by competent and committed people, however, was scored higher by family members in this study than it was in other studies. The researchers attributed this difference to the nature of the illness of the intensive care patients: The patients in this study would all have died if it were not for the direct, massive, high-tech interventions. However, this is a post hoc explanation and, furthermore, the study was conducted in one hospital only. The differences could also be due to the policy of the hospital with respect to family members. The research report provided no clarity in this respect.

As for the need for reassurance, family members state that they certainly want to be called at home if the condition of the patient changes and that they want to be sure that the patient is receiving the best possible care and is as comfortable as possible (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). The need for reassurance continues even after a period of one to two weeks of intensive care (Davis 1994, Freichels 1991) and is present to a greater extent among family members of trauma patients and neuropatients than among family members of other intensive-care patients (Price *et al*. 1991, Freichels 1991, Molter 1979, Bijttebier *et al*. 2000, Kreutzer *et al*. 1994, Davis 1994, Engli & Kirsivali 1993).

Family members of trauma patients and neuropatients consider the need for spiritual support and the presence of a priest in the vicinity more important than do family members of other patient groups (Molter 1979, Freichels 1991). Feeling accepted by the staff of the ICU is also more important for this group of family members than for others (Bijttebier *et al*. 2001, Price *et al*. 1991, Freichels 1991, O'Neill Norris 1986, Molter 1979).

In general, emotional needs that are focused directly on one’s own dealing with the situation – for example, the need to speak about negative feelings, to talk about possible death, to be alone, and to be encouraged to cry – are ranked lower than other emotional needs (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). Emotional needs of family members focused on their own functioning are still scored rather highly, but have to give way, as it were, for other needs. The main concern of family members is clearly for the patient and not for themselves.

Research comparing scores on needs given by nurses and family members shows that nurses generally underestimate the emotional needs of family members (Bijttebier *et al*. 2001, Molter 1979, O'Neill Norris 1986, Kleinpell & Powers 1992, O'Malley *et al*. 1991, Murphy *et al*. 1992, Forrester *et al*. 1990, Lynn-McHale & Bellinger 1988). Consequently, they do little to meet these needs (Molter 1979, O'Neill Norris 1986). Doctors also seem to be insufficiently concerned about the emotional needs of family members (Molter 1979, Mendonca & Warren 1998, O'Neill Norris 1986, Kleinpell & Powers 1992, Warren 1993, Bijttebier *et al*. 2001). Family members do not rely on them to meet their emotional needs (Molter 1979).

Social needs

As social needs, we considered all the needs that concern relationships between people. This can be the relationship between the patient and his or her family members as well as the relationship between family members and friends.

In the studies reviewed, social needs are generally considered less important than other needs. The comment made in the preceding section also applies here: it is not that family members consider these needs unimportant, but they score them lower than the other needs. Here, too, the highest scores are given to items related to the patient's needs or to what benefits the patient.

Proximity, being able to be in the vicinity of the patient and being able to see the patient regularly, are important to family members (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993).This applies all the more to those who consider the condition of the patient to be critical (Stillwell 1984). Even after the most acute phase, the need to be near the patient is scored highly (Davis 1994, Freichels 1991). Restricted visiting hours and an inappropriate infrastructure, for example a waiting room and a telephone far from the unit, interfere with the attempts of family members to meet this need (Moseley & Jones 1991, Norris & Grove 1986, Marfell & Garcia 1995, Spatt *et al*. 1986, Hickey 1990).

The need of family members to have friends or other family members in the vicinity of the ICU and during the visit to the patient is unclear. Several studies show that this need is present to a large degree (Daley 1984, Kleinpell & Powers 1992, Spatt *et al*. 1986, Warren 1993). However, in the large-scale study by Price *et al*. with trauma patients and neuropatients it was found that family members considered the support of friends or other family members during a visit to the ICU of the least importance (Price *et al*. 1991). Having friends or family members nearby is often impeded by spread out and restricted visiting hours (Davis 1994, Kleinpell & Powers 1992).

Practical needs

In most of the studies the practical needs are considered the least important ones (Mendonca & Warren 1998, Leske 1986, Rukholm *et al*. 1991, O'Neill Norris 1986, Daley 1984, Davis 1994, Kleinpell & Powers 1992, Hickey 1990, Freichels 1991, Warren 1993, Spatt *et al*. 1986, Price *et al*. 1991, Bijttebier *et al*. 2001, Kreutzer *et al*. 1994, Testani-Dufour *et al*. 1992, Serio *et al*. 1997, Engli & Kirsivali 1993). However, here, too, one should be cautious in the interpretation of least important.

Practical needs generally concern the family member's feeling of comfort, in which both material and non-material matters can play a role. In the category of the non-material needs, flexible visiting hours are at the top, followed by help with financial or family problems and explanations of what family members can do at the bedside of the patient and how they can contribute to the patient's care. Material things include a waiting room with a telephone, comfortable furniture, blankets and a place to lie down, a cafeteria and a toilet and a bathroom near the ICU. The priorities assigned to these material-comfort needs vary. That family members find their own material needs least important shows, once again, that they give absolute priority to everything that concerns the patient.

The ranking of practical needs are similar shortly after admission and later on. The importance of material resources declines after one to two weeks (Davis 1994, Freichels 1991). At the initial visits, there is little need for privacy, which may be due to the fear of being alone with the patient in an unfamiliar and highly technological environment (Davis 1994, Freichels 1991).

Hospitals give low priority to meeting the practical needs of family members who, in turn, express the least amount of satisfaction with it (Mendonca & Warren 1998, Molter 1979, O'Neill Norris 1986, Spatt *et al*. 1986, Warren 1993). Restricted and inflexible visiting hours are particularly felt to be negative and burdensome. Family members note a lack of control, which results in a feeling of helplessness and powerlessness (Moseley & Jones 1991, Norris & Grove 1986, Marfell & Garcia 1995, Spatt *et al*. 1986, Hickey 1990). Individually adapted visiting hours could be a solution (Marfell & Garcia 1995, Moseley & Jones 1991, Norris & Grove 1986).

Factors that influence needs and their interrelations

A few studies examined whether there are demographic differences in the needs felt (Mendonca & Warren 1998, Bijttebier *et al*. 2000, Warren 1994, Price *et al*. 1991, Stillwell 1984, Kreutzer *et al*. 1994). With the exception of the need for information, women in general report more needs as being very important and more important than men do (Bijttebier *et al*. 2000, Kreutzer *et al*. 1994). More educated people have fewer needs than the less educated (Bijttebier *et al*. 2000). Age, sex, socio-economic status and educational level do not give rise to differences in the need for information (Bijttebier *et al*. 2000, Mendonca & Warren 1998, Stillwell 1984, Kreutzer *et al*. 1994). Apparently, the need for information is universal and extremely important for all family members (Bijttebier *et al*. 2000). The importance of the practical needs increases with the age of family members and the distance between their homes and the hospital (Bijttebier *et al*. 2000, Stillwell 1984). The need for support is significantly greater among the less educated than among the more educated (Bijttebier *et al*. 2000, Mendonca & Warren 1998, Warren 1994). Previous experiences with intensive care and the assessed condition of the patient do not influence the level of the scores nor does the kinship with the patient (Price *et al*. 1991).

Warren (1993) investigated correlations between the various needs and other variables. He found that there is a strong positive correlation between the need for social support and the need for comfort, which in turn shows a negative correlation with the need for information and with education. Two different explanations are possible. First, more social support gives rise to less need for information because the social network itself provides it already or supports the family member emotionally when uninformed decisions are to be made. Another explanation is that highly educated family members can make a well-informed decision in a more internally oriented and self-directive manner and so would have less need for social support (Warren 1993).

Ruckholm *et al*. (1991) examined the relationship between anxiety and the needs of family members. On the basis of an analysis of variance, they concluded that the need for information is strongly related to the level of state anxiety. Moreover, state anxiety seems to decline when information is provided. State anxiety is influenced primarily by trait anxiety, age, and spiritual and family needs.

Empathy and experience of nurses and their assessment of needs

A few studies set out to determine whether the empathy and length of experience of the nurses affect their assessment of the needs of family members (O'Malley *et al*. 1991, Murphy *et al*. 1992). The results are not easily explained. Nurses who score better on empathy have a better insight into only a few needs of family members than do nurses who are classified as being less empathetic. The former can better assess family members' needs related to access to the unit and to the caregivers. The researchers contend that it is possible that the restricted visiting hours may contribute to this last finding, as empathetic nurses have little opportunity to speak to family members. These nurses as well as family members may feel the restrictions in visiting hours to be a hindrance.

The amount of experience of the nurses also influences the accurateness of need prediction. Contrary to what might be expected, amount of experiences correlates negatively with the ability to assess the needs of family members. In other words, nurses who have worked longer in an ICU can assess the needs of family members less well than those who have worked there for a shorter period of time. This applies to all the needs covered by the study. O'Malley *et al*. (1991) cautiously suggest that training influences the assessment of family needs as well. More recently and better trained nurses are better able to assess the needs of family members. Further research is needed to clarify these cautious suggestions.

Qualitative research on the experiences of family members

The study we found most valuable for our focus of interest is that of Jamerson *et al*. (1996). Retrospective, open interviews were used to bring to light what family members of intensive care patients go through and experience. From the mass of information they obtained, the authors distilled four themes: hovering, searching for information, tracking and gathering resources. According to the authors, these can also be seen as four phases, in the beginning more or less in chronological sequence, and later on intermingled. We describe them briefly.

The first phase is "hovering": standing around, "floating", waiting. It is characterized by the uncertain tension, the stress and confusion that family members feel as they wait until they can gain access to the ICU, until they can speak to a doctor, until they can obtain information about the diagnosis and the prognosis. Family members feel uninformed. They often do not know where their relative is, where they can obtain information, how they have to act. They experience a variety of emotions. Furthermore their perception of time changes, and they are no longer aware of their own needs, such as the need to eat.

In the second phase, searching for information takes priority. Family members become more active in this phase and constantly accost caregivers with questions. If their questions are answered, they can move on to the next phase. Otherwise, they are frozen in this searching phase.

The third phase is the "tracking" phase. Family members observe, analyze, and evaluate the patient care. Being able to see things is comforting: they want to see their relative and observe the care being provided.

In the fourth phase, gathering resources, family members gather capabilities within themselves and from elsewhere, tapping resources to be able to provide for the needs of the patient and for their own needs. They seek social support, privacy and personal space. They may find strength in faith, and try to construct a safety net for themselves and for the patient. Furthermore, they try to satisfy their own physical needs as much as possible.

Other qualitative studies help to complete the contextual representation of needs and give a deeper understanding of what family members go through. Burr (1998) found that two major needs are not represented in the CCFNI: the need of family members to protect (others as well as the patient) and the need to provide reassurance and support to the patient. Her interviews also reveal why some items of the CCFNI are (very) important for family members. The different themes that emerged from the qualitative data are very alike to the themes of Fulbrook *et al*. (1999).

"Maintaining the vigil" embodies a strong need to be with or nearby the patient during the first few days of critical illness. It is very important for family members to be able to watch over the patient and to be there in case anything happens. They would never forgive themselves if something happened and they were not there. The patient has absolute priority over their personal comfort. It seems reasonable to conclude that this is one of the reasons why waiting is endured without resentment, waiting room discomfort is tolerated and knowing that one will be called in case anything happens is very important.

"The patient takes precedence" is a theme that reveals that all energy and attention is directed toward the patient. There is a strong need to interact with the patient through touch, talking or simply silent presence. Family members need to feel that they are doing some good. The majority of the participants were quite confident about how to interact with the patient at the time of the interview (48-72 hours after admission). Perhaps that explains why items as "having directions about what to do at the bedside" are ranked lower in the CCFNI.

"Not knowing was the worst part" is a theme that reveals the importance of information. Intense feelings of anxiety and distress remain until sufficient information was given or obtained. The obsession of a strong need to know is reflected in the quantitative score on similar needs on the CCFNI. Furthermore, most family members preferred to be told the truth even if it conflicted with their need for hope. Uncertainty and searching for meaning are the two major themes in the study of Plowfield (1999) on waiting following neurological crisis. Uncertainty due to a lack of information gives a feeling of helplessness and loss of situational control. Family members sought control by searching for (more) information in different ways such as asking for information, looking for signs on the faces of staff members and interpreting staffs' reactions. Diaries kept by nurses in an ICU can be helpful for family members, even after the critical period (Bergbom *et al*. 1999). The information in the diaries helps to fill the gap and makes the missing pieces fall into place. Therefore it makes it easier for family members to accept what happened and to understand the seriousness of the patient's injury or disease.

CONCLUSION AND DISCUSSION

This review gives an overview of what is known thus far about the needs and experiences of family members of patients admitted to an ICU. Most research in this field has been done with one validated and reliable instrument, the Critical Care Family Needs Inventory (Hampe 1975). Nurses and doctors often fail to appreciate the needs of family members. All studies show that family members give priority to the welfare of their relative. In their confused state, they often do not get around to paying attention to themselves, let alone to stand up for themselves. In the acute phase, family members are not even aware of their own needs. Personal needs are set aside, even when the patient remains in the ICU for a longer period of time. The need for accurate and comprehensible information that leaves room for hope is universal. Family members want to speak to a doctor every day about the condition of, and the prognosis for, the patient, and want a nurse – if possible the same nurse – to explain to them about the care, the unit, the equipment and what they can do for the patient during the visit. Family members place great importance on being called at home if the condition of the patient changes. Emotional needs are also prominently present. Hope, reassurance and being able to remain in the vicinity of the patient are crucial. For family members of trauma patients and neuropatients, it is important to know that the patient is receiving the best possible care and is as comfortable as possible. The strict visiting regimes of the ICU are felt very much to be an obstacle.

Furthermore, it is shown that all of the needs of family members are underestimated by the caregivers, and that not enough is done to meet them. Nurses underestimate their own role in satisfying the needs of family members, certainly with respect to the provision of information.

The studies show also that the initiative for meeting the needs must be with the caregivers. In the extreme circumstances with which they are confronted, family members expect that their needs will be met without them having to ask. Older family members and family members with less education require extra attention.

Some critical notes can be given. In the studies reviewed, insufficient distinction is made between different types of illness. It is to be expected that the kind of the patient's illness influences the experiences and perception of family members. Admission to an ICU after a generally successful surgery may be experienced differently than admission because of, for example, a severe traffic accident.

A gap in the research up till now is that no account is taken of family members who do not come or cannot come to the ICU. It could be the case that they have other needs than the ones mentioned before. Another gap is that the CCFNI is used primarily to assess individual needs. The results have only sporadically been compared with each other to determine, for example, differences in needs between partners and parents. Differences in perception among members of one family and the impact on the family network have also been given little attention.

Finally, research with the CCFNI only is too restricted in scope. It could be that relying almost exclusively on the CCFNI has prevented additional aspects of experiences from emerging. Qualitative studies can help to find items missing in the CCFNI. Furthermore, experience-oriented, qualitative research could provide a description of the experiences of family members and enable the process that family members go through to be understood. The results of the qualitative studies that have been conducted so far have shown this. If nurses and other staff members want to optimize family care and as a consequence patient care in ICU more focused and well-designed qualitative studies need to be conducted.

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HOOFDSTUK 2

Protecting: the focus of family members' functioning in the acute phase of traumatic coma

ABSTRACT

Aims: The identification and description of the basic psychological process linked with the focus of family members' functioning in the acute phase of traumatic coma.
Background: Earlier research learned that hope is crucial for relatives of traumatic coma patients. It seems to be the drive to keep going but also to fulfil a main duty. This duty is not yet described in literature.
Design: A qualitative approach according to the "grounded theory" method with constant comparison.
Method: We held 24 in-depth interviews with 22 family members of 16 patients with traumatic coma.
Results: Family members need to protect their relative in coma, other family members and themselves from suffering. They go through three phases. At first they concentrate on protecting the patient's life and their loved ones. They forget about themselves and live on their reserves. Later they put up a fight for their own survival and protect themselves, the patient and the family against unnecessary suffering. During the third phase their energy is directed at dealing with or learning to deal with the consequences.
Conclusions: These three phases are the same for all the relatives interviewed. Relatives who have already overcome previous setbacks get through the process slightly more quickly and experience less extreme emotions.
Relevance to clinical practice: Understanding the process of protecting may help health care professionals to do anything within their power to avoid unnecessary suffering, to ease the pain and to support family members in their task of protecting.

Keywords: protecting, protect, family members, coma, ICU, nursing

INTRODUCTION

Traumatic coma dramatically changes the lives of the patient and the family members confronted with it. A range of strong emotions, including shock, denial, anger, despair, guilt, and fear of the loss of a loved one overpower family members (Daley 1984, Engli & Kirsivali 1993, Johnson *et al.* 1995, Kleiber *et al.* 1994, Mendonca & Warren 1998, Neabel *et al.* 2000). Although it has been shown that addressing the needs of family members has a positive effect on the patient (Burr 1997, Morse & O'Brien 1995), family members do not always receive the attention they need, because their needs are often wrongly assessed (Daley 1984, Forrester *et al*. 1990, Hampe 1975, Jacono *et al*. 1990, Kleinpell & Powers 1992, Lynn-McHale & Bellinger 1988, Mendonca & Warren 1998, Warren 1993).
Up till now, research on the experiences and needs of family members in an ICU is not specifically

attuned to family members of coma patients and is limited to a rather superficial inventory of needs based on the Critical Care Family Needs Inventory (CCFNI) (Molter 1979). With this list of 45 needs, researchers repeatedly identified hope and information as the most important need of family members (Campbell 1988, Davis 1994, Freichels 1991, Gelling 1999 (a), Gelling 1999 (b), Jamerson *et al.* 1996, Kreutzer *et al.* 1994, Mathis 1984, Molter 1979, Verhaeghe *et al.* 2005(a)). However, the identification of the most important needs does not give insight in the reasons why family members find them most important and based on this inventory it is impossible to identify the processes that family members go through. Moreover, Burr (1998) found that two major needs are not represented in the CCFNI: the need of family members to protect (others as well as the patient) and the need to provide reassurance and support to the patient. In the qualitative study of Fulbrook *et al.* (1999) different themes emerged. One of these is "maintaining the vigil". This embodies a strong need to be with or nearby the patient during the first few days of critical illness. It is very important for family members to be able to watch over the patient and to be there in case anything happens. They would never forgive themselves if something happened while they were absent. Although protecting is not mentioned, family members indicate that watching over the patient is important to them. Focused and in-depth qualitative studies can give more insight in what family members experience.

The present study was undertaken to provide such in-depth material. The overall aim of the study was the identification and description of the basic psychological processes of family members confronted with traumatic coma. In this overall-analysis we found "hope" to be a central psychological process in coping with the unexpected, shocking situation. The results on the theme of hope are reported in a separate article (Verhaeghe *et al*. 2006(a)). A second central theme we found, is "protecting from suffering". Hope is not only the drive for family members to keep going, but also the drive or the force to fulfill what appears as their main duty, namely, protecting their relative in coma, other family members and themselves. In the present article we describe the results on the theme of protecting.

METHOD

A qualitative approach according to the "grounded theory" method with constant comparison (Glaser & Strauss 1967, Kuyper & Wester 1998, Wertz & van Zuuren 1987, Wester 1987) was chosen for studying experiences in relation to going through an experiential process (Morse & Field 1996). More details on methodology are given in the article discussing hope (Verhaeghe *et al.* 2006(a)).

Participants

We recruited family members of traumatic coma patients in two Belgian hospitals, a teaching hospital and a large general hospital. Family members of patients in a coma as a result of side-effects of medical treatment or a suicide attempt were excluded. Inclusion criteria were: native Dutch-speaking and a direct kinship with the hospitalized patient (partner, parent, child, brother or sister). All family members approached participated. In total, twenty-four semi-structured interviews were conducted with 22 family members of 16 coma patients.

Of these 16 patients nine were men and seven women, with ages varying between 17 and 85 years, fairly evenly spread. Twelve patients were admitted to hospital after an accident, four after intracranial bleeding. Two patients died between interviews, and on four occasions an interview was held after the death of the patient.

Of the 22 participating family members seven were men and 15 women with ages varying between 19 and 71 years old, more than half of these being between 35 and 45 years old. With regard to kinship, there were nine partners, five children, six parents, one brother and one sister. The study was approved by the ethics committees of both hospitals.

Data collection

The recruitment procedure and the interview time schedule were designed to lead to situational diversity in order to allow for the emergence of interactions between participant characteristics and time aspects. As a rule, members of one family were interviewed separately, but four interviews were conducted with two or three family members at a time. This was at their own request and such an interview still counts as one interview.

At the end of the first interview family members were asked whether they were prepared to be interviewed again later. All agreed and selection of participants for subsequent interviews was based on theoretical sampling. Of the 24 interviews held, five took place less than 72 hours after admission, seven between five and ten days, ten between 11 and 21 days, and two more than four weeks after admission.

All interviews were semi-structured. They lasted an average of 125 minutes (range 30-295 min). The following topics were discussed: reactions to the bad news; contact with the hospital, the patient and the professionals; responsibilities; coping; support; positive and negative experiences.

Twenty interviews were conducted by the researcher, four by a colleague with the same training, sex and age. Eleven interviews were held in an interview room at the hospital and thirteen at the homes of family members. All the interviews were tape-recorded and fully transcribed.

Data processing

Data processing and data analysis took place in a cyclic process wherein the induction of themes was alternated by confrontation with new material until saturation[1] was reached. All of the interviews were first read out in full to acquire an overall picture of the situation, and they were read again to grasp the details. The contents of the interviews were described and coded. The emerging themes were developed by studying the transcripts and the codes and by considering possible meanings and how these fitted in with the developing themes. Analyses were validated during the whole process by means of researcher triangulation. At the end of this process results were also validated by data triangulation. Apart from our own sample, seven interviews with family members of patients who were in a traumatic coma for at least 5 days were analyzed. These interviews were held by another researcher and were focused on the experiences of family members before and after consent for organ donation (Stubbe 2004). They were held between 3 months and one year after the patient died. This supplementary analysis not only validated our results, it also gave us an idea of how family members look back at the ICU period after a longer time.

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[1] Saturation means that the analysis of new cases does not provide new information that will further the analysis (Boeije, 2005, p.52) It is decided upon by the researcher, or, in case of researcher triangulation, by the researchers jointly)

RESULTS

Relatives describe the period after the confrontation with their relative in coma as a battle, a struggle. They find themselves in a strange, unfamiliar world and have no idea how to behave. Everything has suddenly changed, and anything that is still recognisable takes on a whole new meaning: time, everyday habits, sleep, work, relationships, need for food, etc. There is little or nothing to hold on to. They do not recognise their own emotions; the foundations on which their lives are built have been wrenched away. They fight just to keep going during this seemingly intolerable time. They wage a battle for the patient, their nearest and dearest and themselves. They also set themselves a task. They have to make sure that whatever they think needs to be done for the patient and for the family is actually done. They have to protect their loved ones in every possible way.

During the most acute period of the process relatives go through three phases. At first they concentrate on protecting the patient's life and their loved ones. They forget about themselves and live on their reserves. Later they put up a fight for their own survival and protect themselves, the patient and the family against unnecessary suffering. During the third phase their energy is directed at dealing with or learning to deal with the consequences. It is striking that these three phases are the same for all the relatives interviewed, suggesting a universal process that everyone goes through. Relatives who have already overcome previous setbacks get through the process slightly more quickly and experience less extreme emotions. They also take more care of themselves so that they do not exhaust their reserves to the same extent. The fact that they have managed to cope with a difficult situation once before gives them the confidence to do it again.

The one thing that keeps all the interviewees going is hope. Where there's life, there's hope. Here, relatives go through a process that shifts from absolute hope of the patient's survival to hope of an acceptable life. The hope process is described at length in Verhaeghe *et al.* (2006(a)).

The following is a detailed description of the three phases that relatives go through.

Phase 1: Protecting life

Protecting the patient's life

Once relatives have been apprised of the situation, their first priority is to be with the patient as soon as possible. They want to see what is happening with their own eyes, since as long as they have not yet seen the patient, anything is possible in their mind. They also think that perhaps they can do something useful for the patient. They want to be of value for the patient and try to get grip on a situation that they cannot control. It puts great strain on relatives to leave the patient in the hands of strangers in whom they must have blind faith. They need to protect the patient and check that he or she is receiving the appropriate care, but are only very indirectly able to do that. When they arrive at the hospital the care process is already under way. Relatives need information about how the patient is and what the medical staff can do for him or her immediately. It gives them confidence when that information is conveyed in an empathetic manner. During their long wait in hospital, relatives are plagued by hundreds of questions. They know little or nothing about the accident and about what happened between the time of the accident and their arrival at the hospital. They want answers but are reluctant to pester the health care professionals. The number one priority is the patient's survival.

> *"You sit there with a hundred questions that spook through your head. You can't do anything. ... The hundred questions soon become two or three hundred questions. What has happened, what are they doing, is he in pain, and so on. You want answers, you want them very much, but you can't, you don't disturb the people who try to save his life, you do not want to bother them, they have to concentrate on my son."*

Since relatives have little direct influence or control over the situation, initially they can only make sure not to hinder the professionals in their work or distract them from their main priority, which is to save the patient's life. Although their need for information is great, they refrain from asking questions and they see this as the sacrifice they have to make, as their contribution to the situation. They want to be assured that any contact they have with the staff does not in any way negatively affect the care provided.

> *"The doctor came to me and told me about the brain damage, the scan and the operation they had done. I was not able to listen, he was so friendly to take time to explain things to me and all I could think about was: Please don't stand here so long talking to me. Go and take care of my husband, go save my husband."*

This is why they do not bother the professional caregivers with questions, even though they are desperate for information, and do their best not to irritate the staff members by being too demanding or "difficult", e.g. too emotional.

Relatives are sustained by hope. During this phase there is the absolute hope of survival. Yet relatives do not want false hope, based on incomplete or incorrect information. For this reason, and because it is difficult for relatives to judge whether everything medically possible is being done to save the patient, they turn to friends and acquaintances who know the hospital system or the medical world. This has several consequences. At first, relatives get a better idea of the care the patient is receiving and therefore feel less helpless and dependent. They feel that there is more openness, that they are getting more information and, as a result, feel less insecure. They feel that their hope is based on something more tangible. Secondly, they ensure that the patient gets the best medical care because both he or she and the family are no longer just an anonymous number. Relatives seem to be convinced that the chance of getting the best care increases if the patient stands out for one reason or another and is not regarded as simply the next in a long line of cases to be dealt with. They only feel calmer once they know that the patient is in an environment where everything possible is being done to save his or her life.

During this initial phase relatives want to be with the patient all the time. They feel duty bound to do so. While they are with the patient, however, they realise that there is nothing they can do and find it exhausting to continue their vigil. They cannot communicate with the patient and are confronted with his or her suffering and with their own feelings of impotence, ignorance, dependence and uncertainty. Consequently, relatives cannot bear to be at the patient's bedside for very long and are often relieved when visiting time is over.

Protecting loved ones

Besides protecting the life of the patient, relatives also want to protect other members of their close family during the acute phase. They do this by breaking the bad news as gently as possible, giving them as much emotional support as possible and ensuring that family life goes on as normally as it can under the circumstances. They try to stick to the usual daily routine, especially where children are concerned. Since relatives themselves have very little energy in reserve to do this, practical help and support from third parties is particularly welcome at a time like this. Help from people outside the family in terms of providing emotional support for other members of the family is also very welcome. Relatives benefit most from knowing that their family is in good hands and yet close to them. Letting children stay somewhere else, for example, is not something that relatives choose to do. On the contrary, this is a time when family ties are strengthened; for example, a married daughter might move back in with her mother or a sister might come and stay with her family in order to provide practical help. Nevertheless, some members of the family, for reasons we were unable to discover, sometimes do not get the expected protection. It may have something to do with being unable to protect all family members and therefore having to choose between different members of the family in the heat of the crisis. Not everyone can count on getting the same level of care and attention. Children always come first.

There is little energy left for more distant relatives. For instance, the whole business of having to let them know what has happened and supporting them is too difficult. Yet relatives take on this task during this initial phase, because it is the obvious thing to do, as they are not strong or clear-headed enough to resist or try to find another solution.

Not getting around to protecting oneself

To enable relatives to fulfil what they see as their duty towards the patient, they need to keep going, to survive in an unfamiliar world, while being confronted with hitherto inconceivable emotions. Hope of the patient's survival is their anchor. Hope offers protection against emotions.

The effort of keeping themselves going and protecting the patient and their loved ones demands so much of relatives that they soon start to live on their reserves. Even when they become a physical and emotional wreck, a zombie, they carry on regardless. Only after several days the need to take care of themselves thrusts itself to the fore.

Relatives who have experienced previous setbacks do not let it come that far. They take better care of themselves. They pay some attention to their physical needs, eating and sleeping are two things that they know to be important.

Phase 2: Protecting from suffering

Relatives are worn out after an average of three days, so much so that this cannot go on. Without a reference point, a routine or self-protection mechanism, they simply cannot manage anymore.

> *"I've hardly eaten a thing the past three days. Just the odd drink and a couple of Mars bars to keep me going, but that's about it. And you can forget about a good night's sleep. You go to bed late and you think to yourself, "I can't fall into a deep sleep or I might not hear the phone if they ring from the hospital". So now I just sleep downstairs in an armchair (...) And then of course you need to look after your other child. He shouldn't have to suffer, he's been through enough already. But I can really feel it today, I'm completely exhausted. I just can't go on like this, something's got to change. I can't take it any longer. I'm just on my way to the doctor's to get some sleeping pills and while I'm out I'm going to pick up some food. Things just can't go on like this."*

Furthermore, their absolute hope of the patient's survival shifts somewhat as a result of receiving more information. The patient's future suffering comes more to the fore. Relatives start to focus on quality of life. They hope for a life with dignity, now and if he or she survives. They do not want the patient to feel trapped in his or her own body and to suffer to an unacceptable degree. A shift in perspective takes place. Relatives no longer think about the patient from their own perspective ("he or she must survive"). They start to think from the patient's point of view and in so doing they take the facts into account.

During this second phase, every effort is made to make their own suffering and that of the patient and their loved ones as bearable as possible. Anything that causes extra suffering is not tolerated, as described below.

Protecting the patient

Since communication with the patient is impossible, it is difficult for relatives to judge how he or she is feeling. Information is important in order to get an idea on that score. Contradictory information complicates things and upsets family members. On the one hand, relatives are told that the patient cannot feel any pain or discomfort and that he or she is not aware of his or her surroundings. On the other hand, they are encouraged to talk to the patient or bring in his or her favourite music. Moreover, relatives often notice that the patient's heart rate or blood pressure rises when they touch or speak to him or her. Some relatives see tears in the patient's eyes when they talk to him or her intensely. They look for signals and interpret their observations, not just to find out what they can do for the patient, but also because they want some realistic hope to cling to. As regards the patient's welfare, relatives feel that there is little they can do, except for small gestures to make the patient more comfortable, without even knowing whether these help. These gestures have more of a symbolic significance. They express solidarity with the patient that goes beyond all reason and make the relatives feel less helpless to some extent.

> *(a mother's story) "I looked at him lying there, white as a ghost, and thought to myself, "He'd be a lot more comfortable with his own pillow". I asked the nurses and they said it was OK to bring it in. It's better that way. He'll feel better, won't he? And perhaps I shouldn't say this, but I didn't wash the pillow slip. I thought it would smell a bit like home."*

Relatives appreciate and trust nurses who try to ease suffering and whose commitment and humanity is evident in the way they treat the patient, making it clear that he or she is not a lost cause.

> *"Yesterday one of the nurses surprised me by asking if there is a special ointment that my mother used. My mother suffers from psoriasis. I brought everything in and this morning when I came to visit her, she looked just great. They'd washed her hair with her special shampoo and put on the ointment. I could smell it. That really gets you. I really feel they're taking good care of her and that makes me feel a lot better. (...) It also makes it easier to go home afterwards, because you know she's in good hands."*

Self-protection

The emotional and physical exhaustion that relatives experience prompts them to take steps to protect themselves and to get their life on as normal a footing as possible. Otherwise they would not be able to endure the situation any further. They protect themselves from emotional highs and lows and from “intruders” into their lives, even if such people have the best intentions. They want emotional and physical peace and quietness to enable them to build up the strength to carry on. Time and space to reflect are important and relatives mention that while hope still keeps them going, they are less emotionally drained now by the ups and downs of hope and despair. Faith and spirituality help to give meaning to what has happened.

Communication with the outside world is taxing. It takes up a lot of time and disturbs relatives at times when they may be relaxing. Relatives also find it hard to repeatedly recount what is happening and report on the patient’s condition. They try to think of ways to keep people informed, but at less personal cost to themselves. For example, a website or an e-mail group might be set up where relatives can write a daily report on the patient’s condition, or it is agreed that just one person will call to find out how the patient is doing and that person will then pass on the news to others. The less relatives are disturbed, the more able they are to establish a daily routine as similar as possible to their normal one, but incorporating the visits to the hospital. They also force themselves not to ignore their own basic needs, such as rest, food and hygiene. The day is structured around visiting the patient in hospital. Relatives want to see the patient whenever they can. They cannot skip a visit because they see it as their duty to always be there for the patient. Inflexible visiting hours make it difficult to establish an optimum daily routine.

> *“We really have to get our skates on to get home in time to eat together at lunchtime and then after lunch we’ve just got time to clear everything away before we have to set off again for the hospital. It would do me good to be able to put my feet up for bit after lunch, but that’s just not possible. Then we have to hurry to be back for the kids coming home from school. And after the evening visit you have to wait nearly 16 hours before you can go in again. No, the visiting hours certainly don’t do us any favours.”*

Relatives find peace, security and distraction in the everyday things they used to do. They try to re-establish their former routine, get back to some sort of normality. That is difficult to accomplish, however, and is only possible with little tasks, such as cooking, cleaning and doing the shopping. These everyday activities are familiar and provide distraction to some extent. Yet it puts a lot of pressure on relatives to have to worry about all the practical aspects of daily life themselves. Particularly in a family with children, it is a demanding task. Practical help from others is very welcome.

> *“I came home and I thought, “It’s nice weather – I think I’ll clean the windows”. That did me good. For once I thought about something else and was busy doing something different. (...) Just for a while it was as if life was how it used to be. I used to clean when my husband was away too.”*

Relatives need a quiet moment to express their grief, both alone and with other members of their family. They describe their grief as something tangible, palpable, such as a lump in their throat, a heavy weight on their chest, something constricting. Subconsciously they introduce moments when they succumb to grief. They reminisce and talk about the patient. They bring the patient closer, for example by looking at photo albums, watching videos of the patient, listening to the patient’s favourite music, sitting in the patient’s bedroom or smelling an item of his or her clothing. They want to feel close to the patient. Expressing their grief gives them a sense of relief.

Expressions of grief from other people who hold the patient very dear can be a source of support to relatives. It conveys something positive, a regard for the patient, and gives relatives the feeling that they are not grieving alone. However, grief expressed by people who barely have any contact with the patient is viewed as bogus and is upsetting for relatives. Relations with more distant members or acquaintances become more aloof and people who do not treat the patient’s close relatives with empathy or respect are tackled about their conduct. Anyone who does not behave in a decent manner can no longer expect any sympathy and understanding.

> *“Some members of our family really bother me. His sister wants to muscle in on our visiting time to go and see him herself. That’s just not on, is it? I understand that she wants to come, but surely we’re most entitled to see him, aren’t we? I wasn’t going to say anything about it two days ago, but I will now. It’s not easy, but I’m not going to waste too much breath on it.”*

Hurtful comments from outsiders stir up powerful emotions. Relatives find them unacceptable and onerous. This adds to their suffering and relatives do not understand what prompts people to say such things. They put it down to stupidity, a thirst for sensation, a craving for attention. Relatives react to such comments, sometimes vehemently. They cannot help themselves, they have to defend and protect the patient and themselves against anything hurtful.

> *“You’re sitting in the waiting room and suddenly you hear them rabbiting on, those women who visit someone after an operation or something. (...) I heard one of them say, “That girl died, you know, and they had to drag her mother out”. I was livid. I said to them “She’s not dead yet and that mother they had to drag out was me” and I told them they shouldn’t gossip about things when they don’t know the whole story. I don’t know how I did it, but it all just came tumbling out. (...) The nurse told me later that the woman felt really bad about it. So she should. You shouldn’t go around talking about something if you don’t have all the facts. They don’t know the damage they’re causing. (...) I was completely exhausted. Probably also because I got so angry.”*

As time goes on, relatives feel more at ease with everything that goes on in hospital. They become more competent in their assessment of the patient’s care and condition. They feel that their hope is realistic and that gives them the strength to fulfil their task. They develop a certain familiarity with the hospital procedures and the health care professionals. Relatives make a distinction between “good” nurses and doctors whom they trust and “less good” staff in whom they do not have 100% confidence. They adjust their behaviour accordingly, for example by attaching more importance to the information they get from the health care professionals they trust or by seeking more contact with them. Relatives say that they are calmer and it is easier to leave the patient if “one of the good ones” will be taking care of the patient that day or over the next few days. Confidence in the health care professionals is not based on the technical skills or expertise that they may have. These are aspects that relatives find difficult to judge and in fact take for granted, particularly in an intensive care unit. They presume that nurses and doctors are doing their job properly, or they would not be allowed to work there. The criteria for trust that relatives apply are giving accurate information in an empathetic manner (Verhaeghe *et al.* 2006 (b)) and establishing human and personal contact with respect for the relatives and the patient (going the extra mile).

Protecting loved ones from unnecessary suffering

Every effort is made to make life as normal as possible for the loved ones that suffer most from the events, especially children and those who are very close to the patient. Relatives try to create a sense of stability and security by offering tangible support and establishing a predictable daily routine. They try to control their own emotions as much as possible or to express them in a controlled way when they are with other members of their family. They do not want to burden or worry them. They try to spare others and to support them by giving them space to express and talk about their emotions. They worry most about the children. Since relatives feel that they cannot offer enough support themselves, they look for other people who can help the children cope with their grief. They want to be sure that the children can also express their grief somewhere else than at home with them.

> *"I phoned the school. My son had told me that he had a good teacher. I asked for his number and rang him to ask if he'd talk to our son. (...) The next day my son said to me, "Mum, we (teacher and son) talked about my brother all during break and it really helped. (...) Teacher told me that if I wanted to talk about anything his door was always open". I feel a lot happier in my mind about it all now."*

Phase 3: Living in a new / an other world

As the patient's condition changes over time, so does the hope that relatives cling to as well. If the patient dies, there is hope that he or she did not greatly suffer and that his or her death still has some meaning. If the patient survives, there is hope of the best possible recovery. Protecting against suffering becomes a case of trying to accept what has happened and the consequences of it – out of sheer necessity, because there is no other choice. Whatever the outcome is, relatives feel duty bound to live with the consequences.

Once the patient is out of danger and has come out of the coma, the first emotion is joy and the feeling that everything is possible with a bit of patience and perseverance. Disillusionment sets in quite quickly as relatives are faced with the slowness of the recovery, the waiting and the unresolved uncertainty. If the patient dies, the relatives try to come to terms with death.

During this third phase differences between relatives emerge in the way they cope with grief and loss. In the interviews, the difference between men and women stands out particularly. After the acute period in intensive care, and sometimes even earlier, men typically want to resume their "normal" life. For men a normal life is very much associated with work. For various reasons they feel the need to get back to their job: for work reasons, as a means of distraction, as a way of escaping the unremitting confrontation with suffering and grief. They do not forget their grief, but the fact that their surroundings are not a constant reminder of it is a relief. Women, however, typically need peace and quietness to come to terms with their grief. The limited amount of energy they have left is used to build a life as normal as possible for their family. They seek distraction in looking after the home. Their family is where their responsibility lies.

The joy – however brief – of survival

When relatives are told that the patient's condition is stable enough to start gradually reducing sedation, they are cautiously relieved and happy that the patient has survived. There is no feeling of euphoria. By the time the patient regains consciousness, they are aware of the fact that they will have to consider the possibility of residual complications. Since the nature and seriousness of any such complications is difficult to predict, relatives feel very uncertain about what they can expect.

The interviews show that relatives are usually ill prepared for the sometimes slow and difficult process of easing the patient off sedatives and artificial respiration. They had imagined the patient waking up suddenly in the way often portrayed in films or soaps and find it difficult to cope with if the patient does not recognise them, or is confused or aggressive.

From the interviews held after the patient's stay in intensive care it is apparent that relatives formed a picture of possible physical problems, but not of possible behavioural and emotional problems. Relatives thought that once the patient had woken up, a bit of perseverance and courage is all it would take for his or her rehabilitation to get on the right track. But in fact, they are confronted with problems such as confusion, aggression, agitation, difficult communication, incontinence or loss of decorum. They soon start feeling that nothing has changed as regards the patient's condition. The ratio of fewer nurses to more patients is disappointing. They are desperate for information but get considerably less than they used to in intensive care. They feel unprepared for what is to come and find that there is nothing for them to do except waiting, endlessly waiting.

Relatives become more critical of health care professionals now. They are in a better position to assess some aspects of care and to see what goes wrong. Moreover, the patient's helplessness is more evident. Caregivers who do not show real commitment to or respect for the patient or his or her relatives are described as unreliable and irresponsible. If the nurses do not see to the basic needs of the patient, for example nourishment, relatives think this is scandalous. And yet they have to carry on dealing with these nurses. They may feel impotent, frustrated and angry.

> *"They've got time to stand around their office drinking coffee and chatting, but if you press the buzzer because mother needs to go to the toilet, it's 20 minutes before anyone appears. And what when I'm not there? That's just awful by anyone's standards. But what can one do? It's really irresponsible."*

> *"They don't dress him properly. He's got yesterday's dirty trousers on. That's not doing your job right, is it? They came in once to prop him up and were chatting away to each other and completely ignoring us. They always seem to be having a laugh about something or other and if you ask anything, they brush you off, saying "Yes, yes, we'll be with you in a minute...". That's no way to treat people, is it?"*

Family members realise that life will never be the same again. Being confronted with the possibility of the patient being permanently disabled is hard. It dawns on them that there is still a long way to go. They desperately need support at a time when support from family and friends is gradually drying up. The crisis is over. People who initially offered practical help now have their own family to look after. As for more distant relatives, acquaintances and neighbours, the whole subject gets relegated to the background. But for the family members, there is the difficult period of rehabilitation ahead (Verhaeghe *et al.* 2005 (b)).

The difficult task of coming to terms with the patient’s death

The interviews reveal that in case of death, this does not come as a complete surprise. Although there was still hope of survival and the relatives themselves expressed the longing that the patient would come round, even right up to the end, they report that they had time to let the idea of death sink in. They are grateful for the time the patient spent in intensive care. All the relatives interviewed say that coping with death would have been more difficult if the patient had died immediately. The spell in intensive care initiated the process of coming to terms with death and they got a chance to say goodbye to the patient.

As the inevitability of death dawns on them, it becomes more important for relatives to stay with the patient for longer periods, preferably outside the usual visiting hours to give them more privacy. They desperately need privacy to say farewell. If relatives give permission for organ donation, parting feels unreal. They feel they are abandoning the patient while he or she is still alive and that their goodbyes are not final. There is much more to say about learning to accept the death of the patient, but since our material seems not specific for traumatic coma anymore, we abstain from reporting this. After the death of the patient, the relatives are initially caught up with all the practical arrangements. When these are over, relatives are faced with the fact that life goes on. Particularly mothers who have lost a child say that they do not really want to go on, their life has little meaning now. The only thing that actually keeps them going is their other children. Mothers think that their surviving children are entitled to a normal life and sacrifice themselves in order to make this possible.

In quiet moments questions arise about why and how everything happened. Some relatives want to know every little detail. For example, they want to know if the patient was conscious at the scene of the accident, how he or she looked, what he or she was feeling, what the paramedics or bystanders did. They cannot come to terms with it as long as there is any lingering uncertainty. They picture what the patient went through, usually in gory detail. Perhaps more gory than it really was. Other relatives say that they do not need to know the details of what happened (or not yet). Nevertheless, all the relatives interviewed want to see where it all happened and, in the case of an accident, they want to see the wreckage of the car, bicycle or motorbike involved. This enables them to reconstruct the story of what has happened. As long as their questions remain, a search for answers impedes their ability to work through the situation.

Discussion

We described the process that family members of a patient in traumatic coma go through in fulfilling their most important task, protecting. Family members have to make sure that whatever in their opinion needs to be done for the patient and for their family is actually done. They want to protect their loved ones in every way possible. The need of family members of ICU patients to protect, is not mentioned extensively in the literature. It is not even included as a separate item in the CCFNI. In her study, Burr (1998), however, points to the need of family members to protect and remarks, as we do, that this need is not represented in the CCFNI. At the same time, results of the studies with the CCFNI reveal that needs indirectly linked to protecting the patient are scored by family members as very important. For example, the need for reassurance, being called at home if the condition of the patient changes and being certain that the patient is receiving the best possible care and is as comfortable as possible are ranked high (Bijttebier *et al*. 2001, Daley 1984, Davis 1994, Engli & Kirsivali 1993, Freichels 1991, Hickey 1990, Kleinpell & Powers 1992, Kreutzer *et al*. 1994, Leske 1986, Mendonca & Warren 1998, O'Neill Norris 1986, Price *et al*. 1991, Rukholm *et al*. 1991, Serio *et al*. 1997, Spatt *et al*. 1986, Testani-Dufour *et al*. 1992, Warren 1993). This is confirmed for family members of traumatic coma patients in the study of Price *et al.* (1991). The importance of proximity, being able to be in the vicinity of the patient and being able to see the patient regularly can also be linked to protecting and is confirmed by studies using the CCFNI (Bijttebier *et al*. 2001, Daley 1984, Davis 1994, Engli & Kirsivali 1993, Freichels 1991, Hickey 1990, Kleinpell & Powers 1992, Kreutzer *et al*. 1994, Leske 1986, Mendonca & Warren 1998, O'Neill Norris 1986, Price *et al*. 1991, Rukholm *et al*. 1991, Serio *et al*. 1997, Spatt *et al*. 1986, Testani-Dufour *et al*. 1992, Warren 1993). This applies all the more to those relatives who consider the condition of the patient to be critical (Stillwell 1984) and is all in accordance with our results. It could be that protecting is a more abstract concept that includes several concrete items from the CCFNI.

During the first phase family members solely concentrate on protecting the patient’s life and protecting their loved ones. The patient has absolute priority over their personal comfort. This finding is amply confirmed in the literature (Fulbrook *et al.* 1999, Verhaeghe *et al.* 2005(a)). In studies using the CCFNI, personal needs are also ranked lower than the needs related to the patient (Bijttebier *et al*. 2001, Daley 1984, Davis 1994, Engli & Kirsivali 1993, Freichels 1991, Hickey 1990, Kleinpell & Powers 1992, Kreutzer *et al*. 1994, Leske 1986, Mendonca & Warren 1998, O'Neill Norris 1986, Price *et al*. 1991, Rukholm *et al*. 1991, Serio *et al*. 1997, Spatt *et al*. 1986, Testani-Dufour *et al*. 1992, Warren 1993).

That family members are concerned about protecting their loved ones is found in studies focusing on less acute settings, e.g. parents of children with leukemia (Kars *et al.* 2003), family caregivers for chronically ill or geriatric patients (Duijnstee 1994, Duijnstee 1996, Schnepp 2003, Thorne & Robinson 1989) and family members of cancer and trauma patients (Morse & Johnson 1991). Especially protecting children is considered important (Titler *et al.* 1991). In a second phase they put up a fight for their own survival and protect themselves, the patient and their family against suffering. This is also confirmed in other studies (Kars *et al.* 2003, Thorne & Robinson 1989). During the third phase they have to learn to live in a new world, live with the consequences of what happened. Coming to terms with the patient’s death is difficult, but learning to live with the disabilities of a patient with traumatic brain injury seems even more difficult (DeMarle & Le Roux 2001, Kay & Cavallo 1994, Kreutzer *et al.* 1994, Romano 1974, Williams 1991). The life long period of rehabilitation is very stressful for relatives (Verhaeghe *et al.* 2005(b)).

Methodological considerations

With regard to protection, we more and more encountered the same themes and regularities in the material during analysis, suggesting that we reached a state of saturation here. In addition, coding and analyzing the interviews of the study on family members of organ donors did not lead to new categories or changes in the categories we already found and this can be considered as a positive indication of the validity of our results.

As none of the family members invited, refused to take part in the study and as theoretical saturation was reached, the suggested phases that family members go through seem to be universal and cannot be attributed to selection bias. There might exist a selection bias, however, in that we recruited in two large hospitals and that only native Dutch speaking family members who visited their relative in coma were invited. Therefore, we do not know whether the results can be generalized to not native Dutch speaking family members and family members who do not come to see the patient.

Implications for practice

The results described above lead to some suggestions for practical care. When family members arrive at the hospital, the life saving care for the patient is already under way. Family members have to make up the period of their absence. Although information is very important for them to understand the events and to complete the story of what happened, they will not easily ask the nurses or physicians for information. The reason is that they want to be sure that the time spent on giving them information is not at the cost of the patient. Therefore, nurses and physicians have to take the initiative for providing information and they have to reassure family members that the patient is in good hands and that nothing more can be done for the patient than is already done by the caretakers.

We also found that family members try to protect the patient by enlisting a trusted person, someone they know and who knows the medical system (Verhaeghe *et al.* 2006(a), Verhaeghe *et al.* 2006(b)). This person brings reassurance and makes the medical system less threatening. Family members also believe that he or she may make the patient less anonymous. Thus, by supporting this trusted person in his role, professionals may help family members to accomplish their task of protecting.

It is important to realize that family members will only leave the hospital when they are sure that the patient is in good hands. Professionals can thus make it easier for family members to leave the patient by establishing a respectful attitude, empathy and extras in the care for the patient. Furthermore, we plea for flexible visiting hours. This can help family members to establish a daily routine that is as similar as possible to the one they had before the coma, thus supporting their protecting task.

One of the tasks of health care professionals is to help relatives to avoid stressful and burdensome situations, especially during the first days, when family members do not get around to protecting themselves. Information on the process they go through could help them to understand what is happening and to avoid exhaustion. Offering a brochure including practical information and tips to handle problems could help. This brochure can be presented as an aid, composed by experiences of other family members in the same situation and the way in which they solved frequent problems. Relevant topics could be ways to organize care for the children, the process of giving information to other family members and friends, and the household.

The interviews show that family members are usually ill prepared for the sometimes lengthy and difficult process of reducing sedatives and artificial respiration. Films and soaps stimulate unrealistic ideas of fast and full recovery after the coma (Casarett *et al.* 2006). Family members need information, not only on the process of regaining consciousness, but also on the transfer to another hospital ward and the slow recovery and rehabilitation. They are faced with new and unknown events and feel uncertain. Now that they need extra attention, they are confronted with considerably less care than in the ICU. They experience shortcomings in the care of the professionals and become more critical. In other studies a similar process is described (Kars *et al.* 2003, Thorne & Robinson 1989). Preparing family members for this phase is important. Giving them extra support during the transfer period could help.

When the patient's death is inevitable, family members need privacy for their farewell. After the patient has died some family members cannot work through the situation as long as their questions remain unanswered. Therefore it could help those family members if a health care professional guides them in their search for answers. Several family members told us that a meeting with police, fire men, witnesses who saw the accident or other people involved in the first moments of care could help them reconstruct and cope with the events.

The suffering of family members confronted with traumatic coma is tremendous. Health care professionals should do anything within their power to avoid unnecessary suffering and to ease the pain. Supporting family members in their task of protecting is an important step to provide appropriate family care.

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The process and the meaning of hope for family members of traumatic coma patients in intensive care

ABSTRACT

In this study we examined the process that family members go through when they are confronted with traumatic coma. Twenty-four semi-structured interviews were conducted with 22 family members of 16 coma patients. We analyzed the data with the constant comparative method as proposed by “grounded theory”. “Hope” turned out to be the most prominent theme. It can be described as keeping a possible positive outcome in mind in an uncertain situation, knowing this outcome is unlikely to happen. Hope was found to evolve stepwise up and down, dependent on further events and information: big steps at first, smaller later on. Hope helps family members to keep going, and to manage the care for the patient and for each other. Family members were found to protect themselves against false or unjustified hope by seeking valid information. They alternate their moments of despair and in their interactions they respect each other’s hope.

Keywords: hope; traumatic coma; intensive care; experiences; family members

INTRODUCTION

When a patient lapses into traumatic coma, the everyday lives of family members are suddenly and unexpectedly ruptured. There has been no opportunity for anticipatory coping. How the situation will evolve is uncertain and communication with, or feedback from the patient is impossible. It is therefore not surprising that traumatic coma and admission to an intensive care unit (ICU) generate strong emotions in family members, including shock, denial, anger, despair, guilt, and fear of the loss of a loved one (Daley 1984, Engli & Kirsivali 1993, Johnson *et al.* 1995, Kleiber *et al.* 1994, Mendonca & Warren 1998, Neabel *et al.* 2000).
A review of the literature revealed that family members do not receive the attention they need and nurses often wrongly assess the needs of family members even though there seems to be a general consensus that involving families in the intensive care process is important and has a positive effect on families and patients (Bijttebier *et al.* 2001, Daley 1984, Forrester *et al.* 1990, Hampe 1975, Jacono *et al.* 1990, Kleinpell & Powers 1992, Lynn-McHale & Bellinger 1988, Mendonca & Warren 1998, Molter 1979, Morse & O’Brien 1995, Murphy *et al.* 1992, O'Malley *et al.* 1991, O'Neill Norris & Grove 1986, Verhaeghe *et al.* 2005(a), Warren 1993, Warren 1994). Research on the experiences and needs of adult family members of coma patients in an ICU is not specifically attuned to family members of coma patients and is limited to a rather superficial inventory of needs (Verhaeghe *et al.* 2005(a)). Focused and in-depth qualitative studies can give insight in what family members experience. This is important for health care professionals to optimize family care in ICU. The present study was undertaken to provide such in-depth material.
The aim of the study was the identification and description of the basic psychological processes of family members confronted with traumatic coma. Especially the processes that family members

go through in coping with the situation, the meanings they attribute to it, and the possible roles they play, were the focus of the study. We also wanted to assess what circumstances or reactions from professionals or other persons, are experienced as positive or supportive, and which ones as annoying, distressing, painful or unacceptable.

In the material we collected "hope" turned out to be the most prominent theme. It is crucial in the experience of family members and dominates the processes that they go through.

LITERATURE REVIEW

The concept of hope is complex, multifaceted, and multidimensional, so attempting a single definition is difficult (Gelling 1999(b), Kylmä & Vehviläinen-Julkunen 1997, Morse & Doberneck 1995, Stephenson 1991) and would lead to oversimplification (Yates 1993). Hope is described as an emotion, an experience, a need, a characteristic, a state or a dynamic process with affective, functional, contextual, temporal, and relational dimensions (Kylmä & Vehviläinen-Julkunen, 1997; Gelling, 1999(b)). Morse and Doberneck (1995) identified seven abstract and universal components of hope: a realistic initial assessment of the predicament of threat; the envisioning of alternatives and the setting of goals; a bracing for negative outcomes; a realistic assessment of personal resources; the solicitation of mutually supportive relationships; the continuous evaluation for signs that reinforce the selected goals; and a determination to endure. Stephenson (1991) described four attributes of hope: the object of hope is meaningful to the person; hope is a process involving thoughts, feelings, behaviors and relationships; there is an element of anticipation; there is a positive future orientation that is grounded in the present and linked with the past. The necessity and the dynamism of hope are emphasized as well as the dialectic between hope and despair.

Hope is a central concept in research to determine the experiences and particularly the resulting needs of family members of acute and critically ill patients. It is repeatedly identified as the most important need of family members (Campbell 1988, Davis 1994, Freichels 1991, Gelling 1999(a), Gelling 1999(b), Jamerson *et al.* 1996, Kreutzer *et al.* 1994, Mathis 1984, Molter 1979, Verhaeghe *et al.* 2005(a)). Even after two weeks the need for hope remains great (Davis 1994, Freichels 1991). Hope is ranked higher in sudden, unexpected, and serious changes in the condition of the traumatic-coma patient than in the case of chronically evolving critical illnesses (Freichels 1991, Mendonca & Warren 1998). In the study of Price *et al.* (1991), 213 family members of mostly trauma patients and neuro patients were interviewed in a specialized hospital within 24 to 72 hours after admission of the patient. The need to be certain that the patient was being cared for, by competent and committed people, was considered more important by family members in this study than it was in other studies. The researchers attributed this difference to the nature of the illness of the intensive-care patients: the patients in this study would all have died if it were not for the immediate, massive, and high-tech interventions. However, this is a post hoc explanation, and the study was conducted in only one hospital.

Hope is important as a coping strategy for relatives of critically ill patients because it helps family members to make sense of, and cope with, their current situation (Johnson & Roberts 1996). Family members want to hope, even if the prognosis is poor (Engström & Söderberg 2004, Jamerson *et al.* 1996). Only in one study family members of critically ill patients were described as having no hope, but they still looked for signs that the situation was not as bleak as it appeared (Rose 1995). In a review of the literature on hope for relatives of critically ill patients, ten key factors influencing hope were found: future orientation, time frameworks, cognitive restructuring, support, concomitant losses, energy, beliefs, disease, decision making and humor (Gelling 1999(b)). It is through relationships that relatives establish a firm foundation on which to build their hopes. The provision of accurate information without overloading helps relatives to formulate their hopes and set future goals. So do past experiences of family members. Loss of control has a negative impact on the ability of relatives to foster hope. (Gelling 1999(a))

METHOD

A qualitative approach according to the "grounded theory" method with constant comparison (Glaser & Strauss 1967, Kuyper & Wester 1998, Wertz & van Zuuren 1987, Wester 1987) was chosen for studying experiences in relation to going through an experiential process (Morse & Field 1996).

Recruitment of participants

Between September 2001 and February 2005 family members of traumatic coma patients were selected, recruited and interviewed. We selected family members in two Belgian hospitals, a teaching hospital and a large general hospital. The study was approved by the ethics committees of both hospitals. Only family members of patients in traumatic coma related to a sudden, unexpected event involving brain damage, as may be the case in a traffic or other accident or a rupture of a previously unknown aneurysm, could take part in the study. Family members of patients in a coma as a result of side-effects of medical treatment or a suicide attempt were excluded. Inclusion criteria were: native Dutch-speaking and a direct kinship with the hospitalized patient (partner, parent, child, brother or sister).

Upon admission of a patient with traumatic coma, a hospital staff member called the researcher (SV). Subsequently, and taking into account diversity and theoretical sampling[2] the researcher decided which family member(s) were to receive the information letter. Upon receiving the information letter, family members were given time to consider their participation. After half a day to a day, the staff member approached them again to ask whether the researcher was allowed to call them. All of those approached consented to this call. Thereupon, within twelve hours, the researcher called the family member in order to introduce herself, to explain the aim and the procedure of the research in more detail, to discuss possible practical implications, and to answer questions. Family members were asked to participate in one or more interviews and were free to choose the location. All of those so invited agreed to take part and signed the informed consent form.

Data collection

The recruitment procedure and the interview time schedule were designed to lead to situational diversity in order to allow for the emergence of interactions between participant characteristics and time aspects. In the beginning sampling was based on a review of the literature revealing that criteria such as family members' sex, age, type of kinship and period after hospital admission could be important for theory development. Later, the data collection process was influenced by

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[2] Theoretical sampling means that the sampling of additional units for data collection is directed by the evolving theoretical constructs. It requires and implies that sampling strategies are adapted in the course of the study (Schwandt, 1997, p.61)

the emerging analysis and sampling was based on criteria such as family members finding the patient themselves or being informed by a third party; family members already concerned about a possible accident before receiving the bad news; other persons involved in the accident; other doctors treating the patient. In total, twenty-four semi-structured interviews were conducted with 22 family members of 16 coma patients.

Of the 16 patients nine were men and seven women, with ages varying between 17 and 85 years, fairly evenly spread. Twelve patients were admitted to hospital after an accident, four after intracranial bleeding. Two patients died between interviews, and on four occasions an interview was held after the death of the patient.

Of the 22 participating family members seven were men and 15 women with ages varying between 19 and 71 years old, more than half of these being between 35 and 45 years old. With regard to kinship, there were nine partners, five children, six parents, one brother and one sister. Fourteen participants had children living at home. Sixteen family members were interviewed once, five twice, and one three times. As a rule, members of one family were interviewed separately, but four interviews were conducted with two or three family members at a time. This was at their own request and such an interview still counts as one interview.

At the end of the first interview family members were asked whether they would be prepared to be interviewed again later. All agreed and selection of participants for subsequent interviews was based on theoretical sampling. Interviews were held shortly after admission, and shortly after the patient had regained consciousness or shortly after his or her death. When the patient was in coma for more than ten days, an interview could be held in between. Of the 24 interviews held, five took place less than 72 hours after admission, seven between five and ten days, ten between 11 and 21 days, and two more than four weeks after admission.

All interviews were semi-structured. They lasted an average of 125 minutes (range 30-295; eighteen interviews between 100 and 140 minutes). The following topics were discussed: reactions to the bad news; contact with the hospital, the patient and the professionals; responsibilities; coping; support; positive and negative experiences. Usually family members started the conversation, often even before the tape recorder was switched on. Interviews at the beginning of the study were more open than the later ones as important themes emerged from the early analyses.

Twenty interviews were conducted by the researcher, four by a colleague. The colleague had the same training and instructions as the main interviewer. She had the same sex and was about the same age. Before the colleague started doing interviews, she was informed of the results of the analyses till then. The length of the interviews did not differ between the two interviewers.

Eleven interviews were held in an interview room at the hospital and thirteen at the homes of family members. All the interviews were tape-recorded and fully transcribed.

Data processing

Data processing and data analysis took place in a cyclic process wherein the induction of themes was alternated by confrontation with new material. All of the interviews were read out in full once to acquire an overall picture of the situation and were read again to grasp the details. The contents of the interviews were described and coded. The emerging themes were developed by studying the transcripts and the codes and by considering possible meanings and how these fitted in with the developing themes.

Analyses were validated during the whole process by means of researcher triangulation[3]. A second researcher (MG) followed the process closely, read most of the transcripts, checked the coding and meanings, and frequently discussed the themes that emerged from the analyses. A third researcher (FvZ) with a different background (psychology as opposed to nursing science) read part of the transcripts, made her own analyses, and discussed again the results. At regular times during the analysis process, discussions took place among two or three researchers. Every new insight emerging from the discussion was again checked against the data. All the transcripts were reread to find out exactly how the themes developed were represented in the interviews. Interviewing and analyzing alternated until we reached a state of saturation.

RESULTS

Hope was expressed in every interview. It is a crucial part of the experience of family members and is prominent in every story, regardless of the situation and how serious it is, the relationship with the patient or the personality of the family member. Hope is not only indicative of the emotional state of family members, it also determines the possibility of keeping going, continuing to function, and making sure that the necessary activities are undertaken to maintain the best care and the best prospects for the patient and to make life as livable as possible for the other family members.

> *"The only way to be able to go on is by hoping for the best. Loosing hope is paralyzing, you break down emotionally. (...)But you don't help anyone by letting yourself go. On the contrary: you have to go on (...) by keeping hope. Hope is what keeps us going."*

Definition and characteristics of hope

Hope can be defined as keeping a possible positive outcome in mind in an uncertain situation, even if one knows that this outcome is unlikely to happen. Hoping is a cognitive process in which the positive has a place. It starts at the moment the bad news of the accident or bleeding reaches the family members. If family members anticipate a possible accident or bad news, for example because their family member does not come home at the agreed time, hoping even begins before the bad news is reported.

> *"You start to get worried, normally he's never late or else he phones, and you hope that nothing has happened, you hope he's just bumped into someone and has lost track of the time."*

Hope is found to evolve, and what is hoped for seems to be strongly determined by information. Hope comes to the fore at moments of reflection, when family members receive no information and nothing is happening, when they are confronted with many uncertainties peculiar to the situation and the events surrounding the traumatic coma.

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[3] Researcher triangulation involves the involvement of multiple investigators in making inferences about the same subject matter based on the same data. Triangulation is a means of checking the integrity of the inferences one draws, and is used to increase the validity of these inferences (Schwandt, 1997, p.163).

> *"By then they've said and explained everything about this and that and the problems and so on, and you're sitting in the car and start thinking, everything is jumbled up in your head and it's like a cassette being played, and you hope that everything will go as well as possible, all you can hope is that they know what they're doing, and all we can do is hope, hope for the best."*

Uncertainty about the outcome is a precondition for hope. In general terms, what is hoped for is the best for the patient, and this evolves with changes in the patient's condition and the information the family members are given or actively seek. The object of the hope may differ from one individual to another in a similar situation or even in the same situation, but every family member needs "realistic, justified hope". Family members define this as hope based on information that is correct and as complete as possible.

The data show that family members do not, in any event, wish to cherish false hope. They describe false hope as hope based on incorrect or incomplete information, letting them hope for something impossible. Family members do not want to hold anything back from themselves or delude themselves, and they do not in any way wish to be spared or lied to by professionals.

> *"They have to say it like it is. You have to know. Hearing that you have been deceived or that they haven' t told you everything to spare you, is much harder. You have the right to know."*

They wish to protect themselves against the emotionally very difficult disillusionment false hope can lead to. This disillusionment is not to be confused with setbacks that occur as a result of having hoped for something very improbable that is not coming through. This is less painful because while hoping for the best, family members take into account the highly unlikely eventuality of the best outcome.

Another reason why family members detest incorrect information is because it forces them to work through the same situation twice, the first time through the horrific reality which the staff has presented in a more rose-tinted fashion than the true situation and the second time through the horrific reality it really is. Family members report that it is important to keep the truth in mind at all times and that it is better to know the truth from the beginning. If the full truth only emerges from beneath the water surface later, it is far more difficult to climb out of the well of despair.

> *"They told us straight out how it was, it's tough but that's best. They mustn't give wrong information or say things to spare you. You have to go through it, it's better to receive the hammer blow the first time than be hit twice. We knew straightaway what we were dealing with, and you can go on from there, otherwise you have to go through some of it all over again, that's the way it is."*

Working through the same events twice is very demanding for family members and leads to great disillusion and negative emotions. When family members come to the realization that their hope was not justified, they feel deceived by the professionals, which makes them distrust new information. After some time, family members then start to make a distinction between information from a professional who is to be trusted and information from one who is not to be trusted or is less trustworthy.

> *"First, they said it was bad, but that everything would turn out OK, nothing dramatic, the doctor said, it'll turn out fine, that's literally what he said. And then the next afternoon when I went to visit him (patient), I thought come on, it's not so bad, and they tell me that he's suffered severe brain injuries and that it will be a miracle if he pulls through. I said that can't be right, that's too much. First you're hit by the accident and then the next day there's another blow. They have to say it straightaway, not a bit here and a bit there, you never know where you stand, and you go to pieces, it can't be done that way, because in the end you don't know what to believe. (...) Now we know that that blond nurse just says something, she even mistook our son for that boy from the other accident. But that male nurse with long hair, he's good at explaining things. He tells us everything."*

For family members it is difficult not knowing whether their hope is justified or realistic. They consequently carry on looking for new information that can confirm or modify their hope. Particularly on the basis of doubt and uncertainty peculiar to the situation of traumatic coma, family members always remain on the look-out for new information, paying close attention to bad news or adverse events. In the interviews, expressions of hope are always linked back to the information obtained.

> *"When they tell you that there's considerable brain damage, you mustn't hope he'll be able to start the new school year next month."*

> *"Well, severe injuries to the brain, that can't be good, and I know it's a long-term thing and I know you never really recover, but I don't know if I can hope for a normal life. Will he still be able to live at home and so on, but they (the doctors) don't know that either, they say."*

> *"Well, he's lying there in a coma. You can see that it's bad, the machines, the tubes, there's a reason why they're there. And they tell you it's not good, he's hanging by a thread, we can hope that he survives, but you can't hope for anything more than that."*

Because family members want to protect themselves against excessive emotional ups and downs, they soon learn not to allow much emotion with regard to hope. Sharp fluctuations in hope are actively avoided after one such experience. Mentioning or putting into words what is hoped for is generally done in a way that is not very emotional, and concrete hope is formulated rather rationally. Emotions are mainly expressed in relation to the patient's present condition and the related suffering of the patient and other family members.

The process of stepped hope

Hope is almost constantly present, but what is hoped for changes as time goes by. We found that the evolution of hope is not streamlined, but moves stepwise: it remains at the same level for a certain period of time and relatively suddenly falls or rises in steps, depending in particular on events and information (Figure 1).

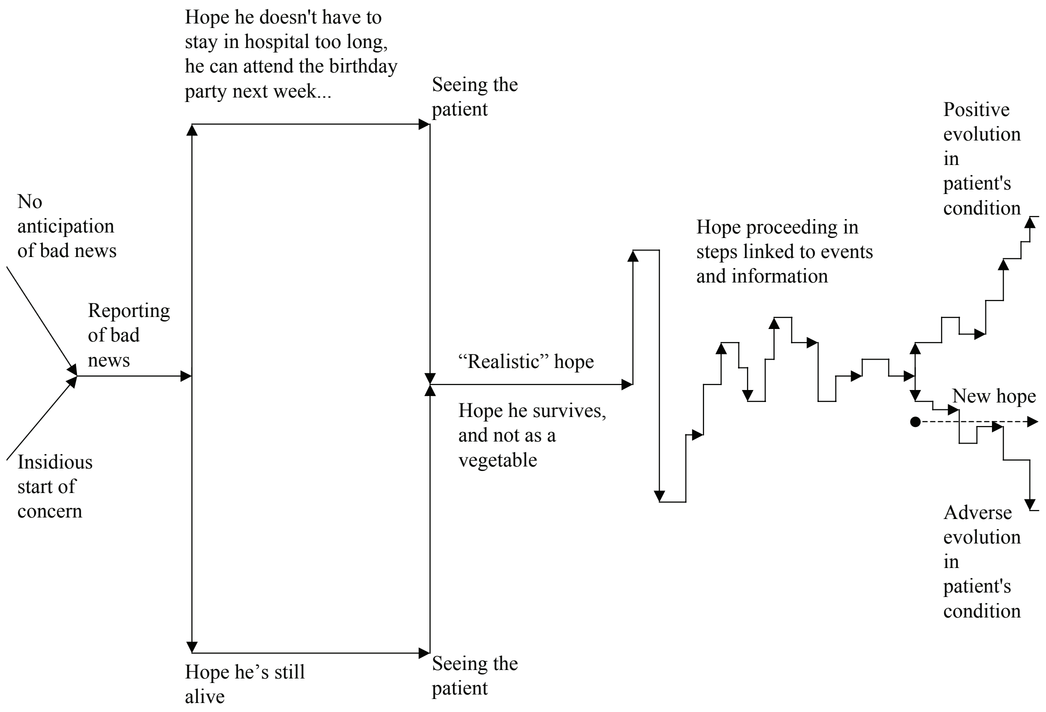

Figure 1: The process of hope

It is apparent from the interviews that each family member takes approximately two large steps in hope and then several smaller steps. There is the first hope after the report of the accident and the second hope after first seeing the patient in the intensive-care unit. After that hope changes further depending on the events, the information and how the patient's condition evolves (Figure 1).

Wide differences are noticeable in first hope among different family members. First hope ranges between two extremes: some family members hope that the patient only has slight injuries such as broken bones, and others hope that the patient has not yet died but that no one has yet dared to say so.

> *"When they said that it was a severe accident, I thought he would have broken both legs and an arm or something like that. I hoped he would be at home by the following weekend for the surprise party we arranged."*

> *"When his boss rang to tell that my husband had an accident I just hoped that I would be in the hospital before he would die."*

It has not become entirely clear from our interviews to what variables this initial difference is related. In any case the difference does not appear to be determined by the traumatic event itself. It is not related to the way in which the news is reported nor to whether an accident has been anticipated or not. Gender, age, and the level of education of the family member do not appear to be influencing factors, either. However, the data suggest that previous experience and personality make-up may make a difference. Family members who do not immediately think the worst often have a positive attitude that is apparent throughout the interview. They have confidence in themselves and in their approach to the situation. In particular they make reference to previous setbacks they have overcome. During the hospitalization of their family member in coma, they impose a stringent life pattern on themselves and oblige themselves to eat regularly, sleep, go out and so on.

A second crucial moment is the time at which family members "see" the patient in the intensive-care unit. At that time the seriousness of the situation comes home to them. Their first hope shifts, the hope of survival becoming the central hope now. Death is so far from daily life that family members cannot but hope that the patient survives. They do not set any limits on how survival is to be achieved.

And then comes the moment of truth. I will never forget it. All the hopes you had explode right in your face. You see him and you know, all you can hope for is that he survives.

> *"I was so glad to hear that he was still alive when I came into the hospital. The doctor told me about the injuries but I couldn't listen as I should have. I wanted to see him. (...) When I came into the ICU I was devastated. He was still alive, but for how long? (...) After seeing him my only hope was that he would survive."*

This absolute hope of survival is maintained for some time and is shaded according to particular events or information. As time passes family members become more aware of the fact that quality of life is important as well. This seems to be a form of cognitive coping in which a consoling thought is maintained. Rationally, family members then say that if the patient, for example, were to carry on living as a vegetable, no longer capable of communicating, then life might perhaps be not meaningful anymore. But the hope of survival is still present.

As the situation evolves and family members receive more information, new, but smaller steps are taken. Hope is then adjusted in an upward or downward direction. They hope, for example, that the patient does not suffer or that he feels that they support him and are close by his side. There is also hope for the best possible recovery. Family members dare not go too far in their hope in order to protect themselves against excessive disillusionment. They hope for minimum possibilities for the patients in the event of survival, such as recognizing intimate persons, showing signs of movement, fully regaining consciousness or being able to communicate. Later the hope is directed towards being able to look after oneself or being able to continue to live or work independently. There is often also hope that the patient will still be able to do things that are of special importance to him, such as being able to attend the first communion of a grandchild, being able to go to a weekly coffee circle with women who live in the neighborhood and so on.

Limits on hope do not only evolve when the patient's condition changes in a positive direction, but also when the patient's condition does not evolve, the coma period lasts more than a week and the brain damage becomes increasingly clear. Hope of survival diminishes and in the event that the patient dies, it disappears completely. New hope is established but we found that the hope that the patient has not suffered too much, has felt that the family members were with him or the hope that the death has had a meaning for others as a result of organ donation is not a real substitution for and not as strong as the hope that the patient will survive. It is more a comforting hope. Therefore we used a dotted line in Figure 1 to symbolize this comforting hope.

Because family members want as "realistic" hope as possible, they have a great need for professionals to give them clear, understandable information on the patient's condition and the possible prognosis. Information that traumatic coma is characterized by numerous uncertainties and unpredictable developments is particularly important. Family members can then focus on dealing with these uncertainties and unanswerable questions instead of becoming involved in a restless search for answers that do not exist. They work through the information obtained from professionals together with their own observations and the information of third parties. In this way they form a "realistic" picture of the patient's condition and feel they can make a proper assessment of the situation. On the basis of this assessment they hope for something concrete and set limits to the expectations for the patient's life and future.

> *"Now I think we know better what is going on. You learn to look at certain things and you know from experience that you have to be careful with things they (professionals) tell you. If they say something now, we see for ourselves if it is true. (...) I know we can't hope for full recovery. If he survives he will have handicaps. We have seen the son of our neighbor's sister who was in coma for two weeks. (...) I hope he (his son) is able to communicate if he survives. That would be important, otherwise life would not be meaningful."*

Events during the course of the coma and admission also have an impact on hope. An unexpected operation, very high intracranial pressure, a reaction by the patient, any event can bring family members to put their hope on a different level, a step higher or lower. They accomplish this step by step, not running ahead of the facts. For some family members hope evolves rapidly with the patient's condition, while other family members need more time to work through the events and to adjust their hope. And as the possibility of something becoming reality becomes more real, their hope is formulated as: the patient really ought to ... Hope gradually becomes a goal, and as a goal something that can be aimed for. This gives family members perspective again. They consequently give themselves (because they rarely receive one) a function, a reason to carry on. As a result, they take responsibility for the patient, become more demanding and less powerless.

From our data it appears that younger family members enter this active phase of the process sooner than older ones. Younger people accept less, want to intervene, to tackle, and try harder to get a grip on things. They want to take their lives in their hands, steer and control and preferably do so as quickly as possible. They find waiting terribly difficult and hard to accept. Action gives them a feeling of being useful. Whether the difference with older persons is due to experience, "wisdom", or to differences in values cannot be inferred from the data. The following quotation from the fiancée of a patient who was admitted after a road accident the day before they were due to move in together illustrates that it is not a matter of making vital or life-changing choices but of being able to shape their new life.

> *"You have to wait, be patient. I can't tell you how many times I've heard people say that. Well that doesn't work, waiting and waiting, waiting for what, I have to be able to do something, life doesn't come to a halt. I have to know where I stand, and I've now decided I'll carry on with him, he would have done that for me, so I've searched for everything on the Internet and created a website where everyone can set up something and I've recorded CDs for him with his music and made photo albums, and I've recorded and played back the voices of friends. I've also ordered special headphones so that he can hear even better."*

Individual differences in hope within one system

Interviews with family members from the same family show that they often have the same hope. When they find each other in identical hope, this creates a balance in support, understanding and trust. Hope that is expressed and shared with family members is helpful. It's like tugging the same rope. It is evident from the interviews, however, that family members do not always hope for the same thing and that they deal cautiously with each other's hope. This cautiousness is present because they know from experience how crucial hope is. If family members do not hope for the same thing, they are not on the same track in dealing with the situation. This creates an asymmetrical relationship and an attitude of responsibility. For example, a brother feels responsible for his sister who, he thinks, does not yet realize that her hope of full recovery for their mother is not realistic. Or: a wife feels responsible for her husband who, she believes, takes too gloomy a view and has abandoned all hope of a normal life for their son. Despite their respect for each other's hope, family members give each other information or they draw attention to particular things, so that hope can be adapted.

Sometimes, family members may seem to hope for different things, but the appearance of different hopes comes from the way they communicate about it. Particular thoughts or a particular hope may not be expressed because they then would become too real or because they would put too much strain on an other family member. A husband, for instance, thinks that his wife goes too far in her hope for the survival of their son, whereas his wife says that she does not talk to her husband about the possibility of death because this might perhaps not be good for him, as he already has so little hope.

Family members also feel responsible for other family members who for a time no longer see a way out or have temporarily lost all hope. It is striking that there is an alternation in family members who are in despair. A mother and father, for example, do not despair at the same time. When one of them finds it difficult and needs time to let himself go, the other one, as it were automatically, takes over tasks. At another time, the roles may be reversed. Collapsing and no longer being able to function, as it were, elicits a complementary reaction of support and taking over. Without designing it as such, a kind of system comes into effect, ensuring continuity in the performance of the functions that need to be fulfilled. There is always at least one family member available for the patient or for other family members.

Functions of hope

Hope dominates not only the feelings of family members, but also their thinking and actions, in brief their life. Life is not livable without hope. Family members set themselves the goal of continuing to hope. They have to do so. Otherwise they cannot move on and they have to be there for the patient and for other family members. This does not mean that there are not times when family members lose hope for a while.

> *"No hope, if you think no future, nothing. No, you have to get out of that as quickly as possible. It's unsupportable, and it does nothing to help anything or anybody, far from it, you feel really terrible and so do the others around you. That can't happen, that can't go on for long, that can't be done."*

Briefly losing hope, can also lead to a panic attack. Family members associate the feeling of panic with no longer being able to have an overview or to master the situation. They have the sense of not being able to handle a hopeless situation and briefly lose all control, even of themselves, their emotions and rationality.

> *"You see everything black, you no longer have any hope and it overcomes you, you can't deal with it, you can't live without him (the patient) and suddenly you can no longer breathe properly, you go into a complete panic."*

Usually, family members are capable of breaking through a panic attack by cognitive coping. Sometimes it is a third party, calmly responding to the family member, who helps them get a grip again. Because hope has a great impact on emotions and functioning, family members completely collapse if hope is lost. As mentioned above, it is striking that these moments do not occur at the same time in all family members. Relatively brief moments of hopelessness must not be confused with moments at which family members find it difficult to deal with the whole situation, moments at which it all becomes too much.

Hope and denial of reality

In our interviews, we did not encounter examples of denial, the stubborn and prolonged ignoring of reality and behaving accordingly, in any of the participants. Family members want a realistic picture of the facts. On the basis of their fear of false hope and their need to know where they stand, they look for as much information as possible, with extra sensitivity for negative information. This does not happen in denial. Family members in denial would refuse to accept negative information, or try to disprove it. This study shows that family members use negative information in their attempts to form a "realistic" picture of the situation. However, they cannot directly absorb or process all information and some specific forms of their behavior or statements could be misinterpreted as denial. Professionals often react to the behavior or statements of family members without questioning its background.

> *"Before I left my mum I said I'm off now, be brave and don't lose courage, don't give up and carry on, everything will be ok, we love you. There was a male nurse there (...) and he said: 'But madam it won't get any better, never, we've said that several times, can't you realize that's the situation?' (...) I said to him straight out: 'What should I say to her, maybe: Just let it go, you'll never again have any life, just give up?' As though I'm stupid. Of course I know that she'll never get as she was before, but I can't just tell her that, I have to keep up her spirits."*

Family members also "play" with hope. Sometimes they go further in their thoughts when, despite its low chance, they start putting the hope of survival, to the fore. On the basis of the need to evade the terrifying reality, family members make plans in their thoughts or together with other family members for a "good" outcome. This gives them some renewed energy to be able to tackle reality. In doing this, however, the reality always remains present, albeit temporarily more in the background.

> *"We were concerned yesterday with how we would take her (mother) along to the Christmas party in a wheelchair. My husband had already asked about the price of a van because we would certainly need one. We would also re-arrange our house and convert the garage to a living space and a bedroom for her. We had all that in mind, and suddenly you realize that you'd be happy just for her to make it through the night. (silence) And yet we found that it had helped us both, you can't say it, but it's a case of whether you see life again, you see a future again, you forget at that moment that it's so bad."*

This evading of reality by keeping a "good" outcome in mind is not to be defined as denial. It is also to be distinguished from putting reality in the background by seeking diversion in something different. Giving hope concrete form and talking about it increases the positive impact of the emotions without changing the assessment of the situation. The hope is revived and strengthened without altering the actual reality.

Family members also relate that they sometimes very much hope that something will happen which they really know cannot happen. This occurs particularly in the case of a more or less certainly impending death. Because the contrast is greatest there between what is hoped for (survival) and what is assumed (death), the behavior or statements of family members may be misinterpreted as denial. Family members themselves describe it as not yet allowing the thought that there is no longer any hope of survival, knowing but not being able to grasp, being unable to bring emotions in accordance with what is rationally registered. They have not yet been able to assimilate it, to integrate it into their thinking and functioning. They consequently continue to hope. What is about to happen is too far removed from life thus far, too strong, too sudden, it defies the imagination. Nevertheless, the necessary actions are taken and in the event of death family members say their goodbyes. There is, however, something unreal about it, it takes place without the family member in question really living through the condition.

> *"...well, as it gets worse and worse, the little remnants of hope get smaller and smaller. And yet they still remain. As long as she (daughter) is alive, the hope remains, even though I knew there were so many straight lines on the EEG. But, you realize, you know what it means, but it doesn't get through to you, you just don't want to allow it, that it's fatal or that it will prove to be fatal. It's more a wish you want to turn into reality. The feeling that you almost conjure up in yourself, the way it was when she came home and said hey."*

> *"It was just like in a film, a bad dream, when I was sitting with him (husband) to say goodbye. You hope, no you want really, really badly that he will open his eyes and say: 'just imagine'. But that doesn't happen, it can't happen and you know that really."*

CONCLUSION AND DISCUSSION

Conclusion

Hope is crucial for all family members of coma patients in ICU. Family members need realistic hope to be able to keep going. They absolutely do not wish to cherish false hope and need correct and complete information to avoid uncertainty. Concrete hope evolves stepwise: there is the wide range of first hope after the report of the accident and subsequently the hope of survival after seeing the patient. After that, smaller steps are taken depending on information and events. Family members work through the information obtained from professionals together with their own observations and information of third parties. As the possibility of something becoming reality increases, hope becomes a goal that gives perspective and reason to act. Hope that is shared with other family members creates understanding and trust. If family members have different hopes this creates cautiousness and an attitude of responsibility. Family members alternate their moments of despair, maintaining continuity in the performance of functions that need to be fulfilled. They help each other to get through panic attacks caused by hopelessness. Behavior or statements of family members and their need to temporarily evade reality could be misinterpreted as denial. In fact, it is a way of coping with a terrifying situation.

Methodological considerations

Hope emerges as a central theme in every interview. The prominent position and omnipresence of hope cannot be attributed to selection bias as none of the family members invited, refused to take part in the study. There might exist a selection bias, however, in that we recruited in two large hospitals and that only native Dutch speaking family members who visited their relative in coma were invited. We therefore do not know whether not native Dutch speaking family members and family members who do not come to see the patient experience hope in the same way.

With regard to hope, we more and more encountered the same themes and regularities in the material, suggesting that we reached a state of saturation here. This was the case notwithstanding the fact that we studied purposively a heterogeneous sample.

Hope in the health care literature

The importance of hope is amply confirmed in the literature on family members of ICU patients (Davis 1994, Engström & Söderberg 2004, Freichels 1991, Kreutzer *et al.* 1994, Mathis 1984, Mendoca & Warren 1998, Molter 1979, Verhaeghe *et al.* 2005(a)). In bad circumstances, life is not livable without hope. Hope is actively worked on and cultivated. We can also view hope as a positive force and springboard for action. This too is in agreement with the literature on families of critically ill patients (Engström & Söderberg 2004, Gelling 1999(a), Gelling 1999(b)) and with the literature on hope in patients after trauma, with a critical illness or with a terminal illness such as cancer or ALS (Centers 2001, Cutcliffe 1996, Cutcliffe & Herth 2002, Eliott & Olver 2002, Laskiewsky & Morse 1993, Morse & Doberneck 1995). Thanks to hope, family members are able to keep going and to act as the situation demands. Hope does not lead to inappropriate behavior, it does not prompt actions with consequences that are regretted afterwards.

We did not find examples of denial in this study. But we did encounter behavior that could be misinterpreted as denial. This concerns behavior by which family members briefly evade reality and by which hope is revived, or by which their deepest wish finds expression - a plea, so to speak. Family members in such situations remain aware of reality, however, they keep it out of their field of view temporarily. As in the literature, we found that family members have a great need for “realistic” hope, a realistic assessment of the predicament of threat (Morse & Doberneck 1995). Like health care professionals, family members make a distinction between false hope and justified hope, but they adopt different criteria. For family members false hope is hope based on an incorrect presentation of the facts. It is not hope that is disproportionate to the facts. A one percent chance, for example, means something different for family members than it does for professionals. Family members keep in mind the positive possibilities that still exist, whereas professionals act on the basis of the improbability of these minor chances to become reality.

Despite this positive story of hope, we also encountered moments of hopelessness and despair. These moments last for a short time, but take a lot of energy from family members. Hopelessness is described as no longer seeing any future or positive development for the patient. The patient's suffering prevails over everything. It is usually the family member himself or other family members who break through the circle of negative thoughts by emphasizing the possibilities that still exist and the negative experiences from the past they have been able to overcome. This same state of affairs has been reported to occur, for example, among parents of childhood cancer survivors (van Dongen *et al.* 1998) and children with leukemia (Kars *et al.* 2003). Family members also report that the stress and the need to keep going are great. Perhaps that is another reason why, in the acute situation, there is no opportunity for letting oneself go for a prolonged period.

Family members also allow each other space to deal with the situation differently. They accept this different coping. However, a literature study makes it clear that problems may emerge later. If family members are not on the same track after the acute situation with regard to hope and working through the situation, problems such as depression and marital breakdown are frequent (van Dongen *et al.* 1998, Verhaeghe *et al.* 2005(b)).

Practical implications

It is important that professionals understand the process and the function of hope in family members so that they can incorporate this in their approach. Strategies for dealing with hope have been described in the literature (Cutcliffe 1996, Cutcliffe & Herth 2002, Miller 1991, Miller 1989, Gelling 1999(a), Gelling 1999(b), Johnson *et al.* 1996, Johnson & Roberts 1996, Penrod & Morse 1997). In our interviews, the importance of good information emerged in particular. Appropriate information is information family members need in view of the events and the moment of time. Family members are very clear in affirming the need for truthful information, even if it is negative. They hate easy consolation that later appears to be given on false grounds.

The information given by professionals, however, is interpreted by the family members on the basis of their own background and perspective. Therefore, in order to avoid incorrect interpretation, professionals should be cautious in providing family members with information. Professionals must also look at what lies behind the questions family members ask. They must not answer the question as asked but the underlying question. For example, when family members ask how the patient is doing, they are often given answers in which intracranial pressure, the score on the Glasgow Coma Scale, and so on are mentioned. Because of their lack of professional knowledge, family members may not put these values in a correct context, with the result that they attribute greater absolute significance to values and measurements than these have in reality. Consequently, after some time, family members no longer ask how the patient is doing but, for example, what the patient's intracranial pressure is like, whereas this value is only marginally indicative of the patient's condition. In addition, it is important for professionals to realize that it is not just the events but the information as well that determine what can and what cannot be hoped for.

The content of the specific hope changes during the course of the process family members go through. At the start of the coma period, after having seen the patient, there is only hope of survival. Family members have so much to lose if the patient dies and death is so unthinkable that the hope of survival dominates everything. In the light of this it appears very difficult for family members, if not impossible, to take a decision on whether or not to continue the patient's therapy and this is best done by professionals in consultation with family members.

We also found that it is very important for family members to have a person they can trust who breaks through the anonymity of relations in the hospital. If family members do not have such a person, it is important that at least one of the professionals can give the family members the feeling that the patient is not just the umpteenth in a row. In the same vein, a mother testified that she had been able to calmly leave her son in the hands of a paramedic when he had told her that he would look after her son as though he was his own (Claeys *et al.* 2002). Furthermore, it seems helpful if family members have someone from and in the hospital who goes through the process with them. This person helps to gather and interpret information, and consequently is a constant factor in the verification of hope. On the basis of interviews, van Dalen *et al.* (1998) make the same recommendation for parents of children admitted to hospital with acute leukemia. However, up till now, in Belgium contacts with the emergency room stop after the patient has been transferred, and the contacts with ICU professionals do not start until after the patient has been admitted. Therefore, we would like to encourage the organization of emergency services to provide the service just mentioned.

Research implications

Many questions on the process and meaning of hope remain unanswered and the results of the study initiate suggestions for future research. Apart from non-Dutch speaking persons, a forgotten group of family members are family members who don't visit the patient in ICU. It would be interesting to study the meaning of hope for non-visiting family members. Does not visiting influence the process of hope that they go through? Or is the reason for not visiting linked with hope? Research on interactions of family members, linked with hope, could reveal more on the dynamics of hope within the family and in social context. The influence of characteristics or personality of health care professionals on interpreting and establishing hope could initiate the development of a support intervention for family members. One of the focuses could be information. Information seems to be intertwined with hope. Finding out more on how information is perceived by family members and how it influences hope, could help to get a clearer view on the possibilities for professionals to steer hope by giving information. This is what the researchers did and they reported this in another manuscript (Verhaeghe *et al.* 2006).

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How does information influence hope in family members of traumatic coma patients in ICU?

ABSTRACT

Aims: To assess the interplay between hope and the information provided by health care professionals.
Background: Earlier research learned that hope is crucial for relatives of traumatic coma patients. Also it has been reported that the need for information is extremely important for relatives of critically ill patients.
Design: A qualitative approach according to the “grounded theory” method with constant comparison was used.
Method: We held 24 in-depth interviews with 22 family members of 16 patients with traumatic coma. Data processing and data analysis took place in a cyclic process wherein the induction of themes was alternated by confrontation with new material.
Results: Family members of traumatic coma patients want information that is as accurate as possible, provided by doctors and nurses in an understandable manner and leaving room for hope. At first, family members can do no more than passively absorb the information they receive. After some time, they actively start working with information and learn what to build their hope on. In this way, concrete hope evolves and seems to be strongly determined by information. Information that is more positive than warranted is not appreciated at all. It leads to false hope, and once its real nature becomes apparent, to increased distress and loss of trust in the professionals.
Conclusion: The process of hope is crucial in coping with traumatic coma and information can facilitate this process.
Relevance to clinical practice: If professionals, especially nurses, keep the process in mind that family members go through in handling information, they can not only facilitate this process but also help them to establish realistic hope.

Keywords: information, hope, family members, coma, ICU, nursing

INTRODUCTION

Upon hearing the bad news about their relative, the lives of family members of traumatic coma patients completely change from one minute to another. Family members are overwhelmed with despair, anger, guilt, denial and fear for the loss of their relative (Daley 1984, Engli & Kirsivali 1993, Johnson *et al*. 1995, Kleiber *et al*. 1994, Mendonca & Warren 1998, Neabel *et al*. 2000). Professional care should take the needs of family members of coma patients into account because addressing the needs of families in the care process does not only have a positive effect on family members, but also on patients (Burr 1997, Morse & O’Brien 1995). Research shows, however, that family members do not always receive the attention they need (Daley

1984, Forrester *et al*. 1990, Hampe 1975, Jacono *et al*. 1990, Kleinpell & Powers 1992, Lynn-McHale & Bellinger 1988, Mendonca & Warren 1998, Warren 1993) because their needs are often wrongly assessed (Bijttebier *et al*. 2001, Forrester *et al*. 1990, Kleinpell & Powers 1992, Lynn-McHale & Bellinger 1988, Molter 1979, Murphy *et al*. 1992, O'Malley *et al*. 1991, O'Neill Norris 1986). Therefore, knowledge of the complex of mixed feelings and difficult to interpret behaviour of family members should be considered important for health care professionals.

Research on the experiences and needs of family members thus far is limited to a rather superficial inventory of needs (Verhaeghe *et al*. 2005). Focused and in-depth qualitative studies can give insight in what relatives experience. The present study was undertaken to provide such in-depth material. The overall aim of the study was the identification and description of the basic psychological processes and the “lived experience” of family members confronted with traumatic coma. In this overall-analysis we found “hope” to be a central psychological process in adaptation to the unexpected, shocking situation. The results of this study are reported in a separate article (Verhaeghe *et al*. 2006). From literature review on needs of family members of ICU patients, we learn that information is of crucial importance (Verhaeghe *et al*. 2005). Therefore, the purpose of this article is to explore the possibly intricate relationship between hope and information in family members of traumatic coma patients.

With regard to information, we focus on the role of professionals, especially nurses. Because of their frequent contact with relatives, it is the nurses who have a central function in providing information.

LITERATURE REVIEW

Research on needs and experiences of family members, is dominated by the Critical Care Family Needs Inventory (CCFNI) (Molter 1979). The CCFNI consists of a list of 45 needs that relatives can rate on four-point Likert scales. Research based on the CCFNI showed that the needs associated with information and knowledge are the greatest needs of family members of critically ill patients (Bijttebier *et al*. 2001, Daley 1984, Davis 1994, Engli & Kirsivali 1993, Freichels 1991, Hickey 1990, Kleinpell & Powers 1992, Kreutzer *et al*.1994, Leske 1986, Mendonca & Warren 1998, O'Neill Norris 1986, Price *et al*. 1991, Rukholm *et al*. 1991, Serio *et al*. 1997, Spatt *et al*. 1986, Testani-Dufour *et al*. 1992, Warren 1993). The same is true and even more so for family members of coma patients (Campbell 1988, Engli & Kirsivali 1993, Kreutzer *et al*. 1994, Mathis 1984, Serio *et al*. 1997, Testani-Dufour *et al*. 1992). The need for information is universal and extremely important for all family members regardless of age, gender, socio-economic status and educational level (Bijttebier *et al*. 2000, Kreutzer *et al*. 1994, Mendonca & Warren 1998, Stillwell 1984).

After the first shock and confusion, family members become more active and searching for information takes priority. They constantly accost caregivers with questions. If their questions are answered, they can move on. Otherwise, they are frozen in this search for answers. (Jamerson *et al.* 1996) Relatives find it important that the information is as accurate as possible and is provided in an understandable manner, but not without leaving room for hope (Coulter 1989, Davis 1994, Engström & Söderberg 2004, Freichels 1991, Molter 1979). However, most family members say they prefer to be told the truth even if it conflicts with their need for hope because “not knowing” is the worst (Fulbrook *et al*. 1999). Uncertainty due to a lack of information gives a feeling of helplessness and loss of situational control (Plowfield 1999). Intense feelings of anxiety and distress remain until sufficient information is given or obtained (Rukholm *et al.* 1991).

Family members state that first the doctor and then the nurse should be initiating the provision of information, without them having to ask (Daley 1984, Dockter *et al*. 1988, Mendonca & Warren 1998, Molter 1979, O'Neill Norris 1986). From the doctor they want information about the condition, the prognosis and the precise treatment of the patient at least once a day. From nurses, they expect information about the daily care of the patient, the unit, the equipment and what they can do for the patient during the visit. Family members need to be able to speak to the same nurse as much as possible and want to be called at home to be informed about any change in the condition of the patient (Daley 1984, Dockter *et al*. 1988 Mendonca & Warren 1998, Molter 1979, O'Neill Norris 1986). In the eyes of the family, doctors give information too sporadically (Kleinpell & Powers 1992, Mendonca & Warren 1998, Molter 1979, O'Neill Norris 1986, Warren 1993). When information is given, it is done primarily by nurses, that is, by several different nurses (Mendonca & Warren 1998, Molter 1979).

Nurses also underestimate the importance that relatives attach to obtaining information (Bijttebier *et al.* 2001, Forrester *et al*. 1990, Kleinpell & Powers 1992, Lynn-McHale & Bellinger 1988, Molter 1979, Murphy *et al.* 1992, O'Malley *et al*. 1991, O’Neill Norris & Grove 1986). They consider providing information as a task of the doctor (O’Neill Norris & Grove 1986).

METHOD

For the larger study we used a qualitative approach according to “grounded theory” (Glaser & Strauss 1967, Morse & Field 1996). To analyse the data relevant for this article we used the technique of constant comparison analyses (Kuyper & Wester 1998, Wertz & van Zuuren 1987, Wester 1987). This enabled us to study the process that family members go through in the reception and handling of information, and its relationship to hope.

Participants

Between September 2001 and February 2005 family members were recruited in two Belgian hospitals: a university hospital and a large regional hospital. Our sample consisted of native Dutch speaking parents, partners, children, brothers or sisters of patients in coma. Included were only family members of patients in a coma related to a sudden, unexpected event, involving brain damage, as may be the case in a (traffic-) accident or a rupture of an unknown aneurysm. Family members of patients in coma as a result of side-effects of medical treatment or a suicide attempt were excluded. In selecting family members, diversity with regard to for instance gender, age and type of kinship was taken into account and theoretical sampling was used. The recruitment procedure and time schedule were designed to lead to diversity in situations, allowing for the emergence of interactions between participant characteristics and time aspects.

All family members approached, participated. We held 24 interviews with 22 family members of 16 patients. Nine of the patients were men, seven women, with ages varying between 17 and 85 years. Twelve patients were admitted to hospital after an accident, four after intracranial bleeding. The characteristics of the interviews and the interviewees are described in Table 1.

Time after admission	<72h	5d-10d	11d-21d		>4weeks		
	1°int	1°int	1°int	2°int	1°int	3°int	**Total**
Number of interviews	5	7	5	5	1	1	**24**
Number of interviewees							**22**
1 pers	4	6	5	4	1	1	
2 pers	0	1	0	1	0	0	
3 pers	1	0	0	0	0	0	
Patient's condition							
Coma	5	4	1	1	0	0	**11**
Deceased	0	0	3	0	1	0	**4**
Regaining Consciousness	0	3	1	4	0	1	**9**
Interviewees' characteristics							
Male	4	1	1	3	0	0	**7**
Female	3	7	4	3	0	1	**15**
Interviewees' relation with the patient							
Parent	3	2	0	3	1	0	**6**
Child	2	1	1	3	1	0	**5**
Partner	2	3	4	0	0	0	**9**
Sibling	0	2	0	0	0	0	**2**
Average age of the interviewees (yrs)							**39 (19-71)**
Average duration of the interviews (min)							**125 (30-295)**

Table 1: Characteristics of the interviews and the interviewees

Data collection

The interviews were emotional intense for the interviewer as well as the interviewees and were semi-structured using a topic guide. The following topics were discussed: reactions to the news; contact with the hospital, the patient, the professionals; responsibilities; coping; support; positive and negative experiences. Interviews at the beginning of the study were more open than the later ones, where important themes that emerged from the early analyses were addressed more in-depth. All interviews were tape recorded and fully transcribed.

Ethical issues

The study was approved by the ethics committees of both hospitals. The aim of, and the procedure for, the study were explained in an information letter. In addition, the participants were informed that the researcher worked independently of the hospital, that anonymity was guaranteed, that the quality of patient care and the staff's attitude towards the family member was not influenced by participation, and that the participants could withdraw from the study at any time, including during an interview. All the participating family members signed the informed consent form.

Data processing and analysis

Data processing and data analysis took place in a cyclic process wherein the induction of themes was alternated by confrontation with new material. All of the interviews were read out in full once to acquire an overall picture of the situation and were read again to grasp the details. The contents of the interviews were described and coded. The emerging themes were developed by studying the transcripts and the codes and by considering possible meanings and how these fitted in with the developing themes.

Analyses were validated during the whole process by means of researcher triangulation. A second researcher followed the process closely, read most of the transcripts, checked the coding and meanings, and frequently discussed the themes that emerged from the analyses. A third researcher with a different background (psychology as opposed to nursing science) read part of the transcripts, made her own analyses, and discussed again the results. At regular times during the analysis process, discussions took place among two or three researchers. Every new insight emerging from the discussion was again checked against the data. All the transcripts were reread to find out exactly how the themes developed were represented in the interviews.

Hope was a central theme in every interview. Our analysis revealed the process of hope, its characteristics and variants (Verhaeghe *et al.*2006). As hope seemed to be so dependent on information, a second analysis was undertaken with specific attention to information in relation to the shaping of hope. With regard to hope and information we reached a state of theoretical saturation.

RESULTS

Hope and information turn out to be intertwined. Hope is a crucial part of the experience of family members, regardless of the seriousness of the situation, the relationship with the patient or the personality of the family member. Hope keeps family members going and helps them to make sure that the best care and the best prospects for the patient are maintained. It also enables them to make life as livable as possible for the other family members.

Based on our data, hope can be defined as keeping a possible positive outcome in mind in an uncertain situation, even if one knows that this outcome is unlikely to happen. In general terms, family members hope for the best for the patient. However, the concrete hope, that is hope for something defined e.g. that the patient will be able to speak again, evolves stepwise: it remains at the same level for a certain period of time and relatively suddenly falls or rises, depending on events and information. Because what is hoped for seems to be strongly determined by information, nurses and other health care professionals can optimize the process of hope by giving adequate information. Revealing the process that family members go through in the reception and handling of information, helps to describe characteristics of adequate information.

In the interviews, family members make it clear that they need information to understand what is happening and to have *realistic* hope. Realistic hope, to them, is hope based on information that is correct and as complete as possible. False hope, in contrast with realistic hope, is based on incomplete or incorrect information so that family members hope for something impossible. They want to protect themselves against the disillusionment false hope can lead to. This disillusionment is far more painful than the disillusionment of having hopes for something improbable that is not coming through. The need for information evolves, like hope, and is influenced by events and experiences of family members. Family members need different kinds of information on different moments in the process they go through. We discern four stages in how family members learn to handle information. All family members seem to go through these stages, regardless of their socio-demographic variables or their relationship with the patient. At first they passively absorb bits of the news that is brought to them. In a second stage, after seeing the patient, they try to get a grip on reality. In a third phase, as they are confronted with a completely unfamiliar world or negative experiences, they seek help to cope with information and to understand reality. And at last, they all learn to deal with information and develop a system of filtering and interpreting information to be able to establish realistic hope. Below, we will discuss these stages in detail.

The bad news: passively absorbing bits of information

Of the first information that family members receive they seem to absorb only the content of the most striking parts. For example: that an accident has happened and that there are severe injuries. Directly after receiving the bad news, the first hope is established too. It varies between two extremes: some family members hope that the patient only has injuries such as broken bones and others hope that the patient has not yet died but that no one has yet dared to say. It has not become entirely clear from our interviews to what variables this initial difference in hope is related. In any case it does not appear to be related to the person who brings the news or the way in which the news is reported.

Although the way the first information is given does not influence the first hope, it does influence the ability of family members to come to terms with the situation afterwards. Parts of the first events they are confronted with are clearly marked in their memory. The memories that remain, may either facilitate the coping of family members or become a black spot with a lot of negative emotions attached to. The way the message is given, should convey that the messenger is fully aware of the meaning of the message for the receiver, and is sympathetic with the suffering it generates. Telling family members the bad news should be done straight away, without them having to guess themselves. A lady of 61 years old, whose husband was admitted to the hospital after a severe traffic accident says:

> *"This policewoman came at the door and she said: 'Do you have children you can phone?' I asked her what was wrong. She answered: 'There is something with your husband. Perhaps you can change clothes and come with me to the hospital.' I did not want to change clothes, but she insisted and sent me upstairs. I listened at the stairs and saw her doing something at my telephone and she took my adress book. I went to her and asked what she wanted. She wanted the phonenumber of my son and then she said that she would take me to the hospital. I aksed her if she knew if it was bad. She didn't answer. I felt so terrible and was glad to be in the hospital and away from her. (...) Now it still puzzles me why she didn't want to say anything to me. It makes me angry. She made me feel like a stupid child, not to be taken seriously."*

Family members find it terrible if others are informed before they are. They want to be the first to be told about what has happened, otherwise they feel disrespected:

> *"My colleague rang to ask if everything was OK. I thought that was strange but did not pay any attention to it. (...) When she called again after half an hour I knew something was wrong. I asked her to tell me what it was. She did. She heard on the local radio that my husband had an accident at work and was severely injured. (...) I was devastated and felt really hurt. How can that happen? What am I? Just the wife? Do they not have any respect for the family? Do they not think that my husband could need me?"*

When family members arrive at the hospital, the medical condition of the patient is explained to them. The information family members receive at that time often does not penetrate. Family members understand what they are told, but do not comprehend the significance of the words. They do not realize how serious the situation is:

> *"It isn't Chinese they're talking, and you do understand the words, but you don't comprehend it, it doesn't really get through to you."*

Seeing the patient: trying to understand reality

As a result of seeing the patient, the significance of what happened becomes clear and family members are overwhelmed by emotions. Evidently, verbal information about the patient's condition is not found to say as much as one's own observations. Family members all say that despite the sometimes detailed explanation they have been given beforehand, it is not until they see the patient that the true seriousness of the situation comes home to them:

> *"They told us lots of things. I think we were there for half an hour listening to what was wrong. I tried very hard to grasp what was said, but it was only when I saw him (patient) lying there with all those tubes and machines that I realized how serious the situation was."*

After they have had some time to recover from the first shock of seeing the patient, family members feel completely ignorant in an alienating environment. They need further information to understand the situation. Concrete and detailed information given in understandable wording that is not broad or open to misinterpretation helps them to get a grip on what is happening. Family members want information on the condition and the treatment of the patient and the information has to reassure them that the best care is provided. They want to know where they stand and what to expect. One of the major concerns of all family members is truthful and complete information that allows building realistic hope. They report that it is important to keep the truth in mind at all times and that it is better to know the truth from the beginning:

> *"If they tell you straight out how it is, you know what you have to face up to. You can't imagine how hard it is, but it really is the best that they tell it like it is. You know where you stand and you don't have false hopes."*

Family members all want realistic and justified hope and this is not the same as what professionals have in mind. Family members define realistic, justified hope as hope based on information that is correct and as complete as possible. It takes the facts into consideration as they are. To family members, however, the intensity of hope and the likelihood of the thing to happen are not connected:

> *"If the chance is 1 in 1000, you can hope for that one little chance being fully aware that it's only one little chance."*

The data show that family members do not, in any event, wish to entertain false hope. They describe false hope as hope based on an incorrect or incomplete representation of the facts, letting them hope for something impossible. Hope proves false, not when it becomes clear that what was hoped for proves not to become reality, but when what was hoped for could in no way have become reality. In order to avoid disillusionment they do not want professionals to give information that makes things appear more positive than they are. The negative emotions associated with disillusionment are exhausting and difficult to cope with, apparently more difficult than negative messages per se:

> *"After he (patient) was admitted to the hospital the first doctor told us there was no severe damage to the brain. So we went home rather optimistic in our hopes. The next day when we arrived another doctor was there and he told us that his brain was severely damaged and that they were not sure that he would survive. If they tell you things like that you don't know where you stand and what to hope for and that is unbearable, you have nothing to hold onto anymore."*

When family members find out that they received false information, they distrust all new information and feel very insecure in establishing new hope. For family members it is like walking in darkness without any guidance. The father just cited continued:

> *"You feel like an idiot and you feel misled. Which doctor is telling the truth? Who can you believe? I tell you, you doubt everything they say."*

Seeking help/foothold

As a result of their experiences and the overwhelming situation family members feel very uncertain and have nothing to go by. They look for someone familiar to guide them in this unfamiliar and frightening situation. They need someone they know is worth being trusted blindly and whose judgment they consider to be very relevant. Such a trusted person is someone they know and who knows the medical system. This person brings reassurance to family members and makes the medical system becomes less threatening. Family members feel protected, less at the mercy of health care professionals, who they do not know but are forced to trust. The trusted person also takes over the management of the situation in the brief periods when family members are no longer able to do so. They help to gain an overview of the situation, translate the information received and confirm the reliability and completeness of this information. They give family members a rational basis for their trust in the professionals. They relieve the strain on family members and give them a feeling of control over the situation. Family members feel that there is more openness and that no information is being withheld from them. They have the feeling that they know more than the average family without acquaintances in the system would have known:

> *"I rang our friend (a doctor). He came immediately. He talked to the neurosurgeon. He knows him from their studies. You know, they always tell more to each other than to the family and what is important to us is that our friend then explains us everything in detail. We know he tells us the full truth as it is and because you know him you dare to ask him things that you wouldn't ask the surgeon. We are so lucky to have him. He helps us understand you know. (...) He also told us that this hospital is specialized and that the surgeon is one of the top surgeons in Flanders. We can leave him (patient) here in good hands."*

The trusted person appears to be particularly important in the beginning. As familiarity with the hospital and the situation increases, there is less need for intervention from the trusted person. After some time family members get to know the nursing staff within the system. Having received contradictory, incorrect or incomplete information from different nurses, they are increasingly able to make a distinction between nurses who provide adequate information and those who do not. They weigh information according to who gives it. Trust is based in particular on honesty and involvement:

> *"The nurse with the black hair always says 'we can't see the future, waiting is all we can do.' Yes, that is a big help!? But the other one is a good one, we always look for her. She tells things with so much feeling and she also tells what special things have happened, like when they brushed his teeth. What she says is always true."*

Learning to deal with information

Doubt and uncertainty are characteristic of the situation of traumatic coma. Family members are confronted with many unanswered and unanswerable questions. In their search for answers they are constantly on the look-out for new information. Family members report that such information can best be given by an expert who knows the patient. Each health care professional has, in the eyes of the family members, his own role in providing information. They want the doctor to tell them about the medical condition, the prognosis and the treatment of the patient. From the nurses they want to hear about the details on the daily care and the evolution in the condition of the patient.

Despite their problems in coping with uncertainty, family members understand that in many cases answers on evolution and outcome cannot be given. From the interviews it emerged that they can accept that the situation is unpredictable, if indeed they are clearly informed about the unpredictable nature of the coma. In that case, they can use their strength to cope with

uncertainty rather than to use it for continuous looking for answers that cannot be given.
Family members also find it important that the information on which medical and nursing staff base themselves to evaluate the patient's current condition, is shared with them. At the same time, they do not know how to interpret this information. Incorrect interpretation of such information can lead to unjustified panic or euphoria that put additional strain on family members once the true facts become apparent.
The incorrect interpretation of factual information is often the result of inadequate context information. When nursing staff provide facts only, the interpretation of these facts is left entirely to family members. It then often happens that, through ignorance, they hope for something they would never have hoped for if they had understood the information correctly. Various family members report that nurses give them medical parameters (intracranial pressure, blood pressure etc.) when they ask how the patient has been during the night. Family members interpret lowering of intracranial pressure as a sign of a stable positive development, which reinforces their hope of survival. If the intracranial pressure rises again later, there is great disillusionment and increased uncertainty:

> *"We asked how he was and the nurse told us that the intracranial pressure was lower. When we drove home we were so happy, life started again and I felt like standing on a hilltop and crying out loud that everything was going to be OK. The next morning when we rang to hear how he had been that night we got a cold shower. The pressure was higher than yesterday. Terrible, you feel like you fall down, like all hope is gone again."*

The initial hope of family members is not based on the same kind of information as the later hope. At first, because of their inexperience and the overwhelming nature of the situation, they cannot but react to the information as it is given. By experiencing the effect of other types of information than the verbal information given by professionals, family members develop their own system for evaluating information. It is remarkable how quickly family members learn the medical jargon. Getting to know the context in which to interpret information is more difficult. However, family members rarely get help from nurses or doctors to deal with this. So, by experience, they have to build their own system to actively seek their way through information. Therefore, family members use different kinds of information. They observe, listen, ask and almost constantly test the quality of the information they can obtain and the interpretations they make. Information from professionals, acquaintances or friends who are professionally familiar with the medical world and stories based on experience from people who have gone through the same situation are all valued. From the stories based on experience, family members pick out cues to which they attach more importance. The importance they attach to these stories is not based on the hoped-for outcome. It is the reliability they accord to the person telling the story and similarities with their own situation that increases the weight of the information. In contrast, stories that people tell about third parties who have been through a similar situation are generally regarded as irritating. Because they take no account of the perspectives of family members, these stories are classified in a category of less reliable information, containing false consolation, based on an urge for sensation and not bearing witness to empathy on the part of the person telling the story.
Thus, we found that, after some time, family members start trusting their own interpretation of the situation. They feel stronger to understand and interpret information and evaluate the situation based on multiple informational sources, including their own observations:

> *"We always want to see him first, before they (nurses) come to talk to us. We have experienced that this is better. Otherwise you are never sure that what they say is right. We see him twice a day and we know him. Sometimes there are nurses who see him for the first time. They can tell you the pressures and so, but how can they know whether things are moving in the right direction?"*

CONCLUSION AND DISCUSSION

Our study points to the central place of both information and hope in the experience of family members of ICU patients. These findings are amply confirmed in the literature. This study also reveals how hope and information are intertwined, that all family members have a need for hope and that concrete hope seems to be strongly determined by information. Hope and the need for information evolve by events and experiences of family members. Family members make it clear that they need information in order to understand what is happening and to have *realistic* hope. This is also confirmed in the literature (Azoulay & Sprung 2004, Gelling *et al. 2002,* Johnson *et al*. 1996, Johnson & Roberts 1996, Miller 1989, Miller 1991). In addition, our study shows that all relatives go through a learning process and become more active in collecting and interpreting information. At first, when they are confronted with a completely unfamiliar world and overwhelming emotions, they can do no more than passively absorb bits of the news that is brought to them and try to understand reality. After this first confrontation family members learn to deal with information. They develop a system of filtering and interpreting information to be able to establish realistic hope. Support from a person they know and trust, and who knows the medical system, helps to facilitate this process. These findings are completely in line with the findings of Jamerson et al. (1996) and can be considered as an elaboration of theirs. In the study of Jamerson et al. (1996) retrospective interviews are held with family members of intensive care patients. In the first two phases information is the central theme. The first phase is the phase of "hovering", standing around, waiting. Family members feel uninformed and uncertain. They wait until they can see the patient or speak to the doctor. They wait for information and are "floating". The second phase is the phase of searching information. Family members become more active in their search for information and they want answers to their questions. The third phase of analyzing and evaluating care and the fourth phase of gathering resources are directly linked with information. Family members evaluate care based on their knowledge and seek support and help e.g. to deal with information.

Relevance to clinical practice

It is important that professionals understand the role of information in establishing and maintaining hope that leads to positive coping, in order to incorporate this in their approach. Adequate information is described by family members as correct information adapted to the events and the moment of time and conveying that the nurse or doctor is fully aware of the meaning the information has for the receiver, and is sympathetic with the suffering it generates. Takman and Severinsson (2004) describe this as professionals who are sensitive when informing and listening to significant others. By giving such information, health care professionals, and in particular nurses, can facilitate the process of hope, because they help family members to understand what is happening, to establish realistic hope and to avoid unnecessary emotional fluctuations. Gelling (1999) concluded that honest, concise information is not always enough to enable family members to formulate realistic hopes. She found that the realistically bleak outlook and potentially poor outcome had to be continually reinforced. Taking into account our findings, we suppose that this may be due to the difference between family members and professionals in defining realistic hope. For family members realistic hope is based on information that is correct and as complete as possible. In contrast with professionals, relatives do not connect the intensity of hope and the likelihood of the event to happen. Our data also show instances in which professionals do not understand the meaning and expressions of hope in family members. They mistake the relatives' hope for denial or unawareness of the objective characteristics of the situation.

Professionals should not in any way lie to family members or try to spare them by presenting reality in a more rose tinted fashion. This only creates distrust in family members in a period of time when they need to be able to trust professionals blindly. In addition, it is important that relatives receive support from one specific person they trust, who relieves the strain by breaking through the anonymity of the hospital, by managing the different streams of information and by giving them a feeling of continuity and control. Moreover, this person may function as a constant factor in the verification of hope. Professionals should give such a person full support in accomplishing this role. If family members do not have such a person in their circle of acquaintances, it is important that at least one of the professionals accepts this role. Therefore, we would like to encourage the organization of emergency and intensive care services to take measures for the availability of such a person.

For nurses, it is important to know that the information they give, is interpreted by the family members on the basis of their own background and perspective. To avoid incorrect interpretation by family members, nurses should be cautious in providing information and should also look what lies behind the questions family members ask. When family members ask how the patient is doing, it is not sufficient to give them a report of the medical parameters. Family members have difficulty putting these values in a correct context. Nurses should give information on the condition of the patient and measurements can be part of that but not without a clarification of how to interpret them. Nurses should help family members to build a framework for interpretation of information so that they understand the information they receive in the correct way.

The design and methodology of the study do not leave room for the assessment of the process of giving information by professionals, doctors or nurses, as the reception of information as given and perceived cannot be disentangled. Our recommendations are based on family members' perspective. It is impossible to describe how nurses assess and evaluate the relative's need for information. Future research could focus on this and the combination of results based on perspectives of family members and perspectives of professionals could clarify what interventions can be appropriate to improve the process of giving information.

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HOOFDSTUK 5

Stress and coping among families of patients with traumatic brain injury: A review of the literature.

Abstract

Aims and objectives: This literature review aims to structure the available information on the psychological reactions of family members confronted with traumatic brain injury (TBI). The stress-coping theory and the systems theory provide the theoretical framework for this review.
Method: Literature review
Results: The level of stress experienced by the family members of patients who have TBI is such that professional intervention is appropriate, even after 10 to 15 years. Not the severity of the injury but the nature of the injuries determines the level of stress. Partners experience more stress than parents. Children have specific difficulties. Young families with little social support, financial, psychiatric and/or medical problems are the most vulnerable. Coping with TBI can be described in phases. The better family members can cope with the situation, the better the patient's recovery. There are functional and non-functional coping mechanisms and coping is influenced by such factors as gender, social and professional support and the possibility to have reciprocal communication or an affective relation with the patient.
Relevance to clinical practice: Support from professionals reduces the stress being experienced and encourages people to cope effectively. Conflicts with professional carers should be avoided. Every attempt should be made to develop models of long-term support and care that alleviate sources of burden on relatives. Further research is necessary to develop such models.

Keywords: stress, coping, family, relative, brain injury, support, trauma, nursing

Introduction

In this article, a literature review is presented on the consequences of traumatic brain injury (TBI) for the family members of patients suffering from such a condition. TBI often has serious consequences for patients and family members. This review is undertaken to help professionals understand what it means for families to be confronted with TBI. Understanding can be the first step to a better way of taking care for families.
The stress-coping theory and systems theory provide the theoretical framework for this review.

Background

TBI is an injury to the brain resulting from an externally applied mechanical force that affects the brain and leads to loss of consciousness or coma (Kay & Lezak 1990). Most cases of TBI are caused by an accident and result in changes that affect cognitive, emotional, communicative and social functions (Stratton & Gregory 1994). Depending on the severity of the injury, the presence of these changes may be either subtle or obvious. These changes cause problems of varying complexity for the individual concerned and for his or her social entourage. The brain injury suffered by the victim causes a different degree of permanent upheaval to the family system. Family members provide the primary support system for the patient and new patterns of living have to be developed by the family in order to achieve a balance in the altered situation (Florian *et al.* 1989, DeMarle & Le Roux 2001). The stress-coping theory can help to clarify and identify the steps a family has to undertake.

Aims and objectives

The needs and problems of family members of patients who have TBI have been discussed in the literature since the early 1970s. Initial reports were based on clinical experience, but subsequent reporting has taken a more systematic approach. The scientific literature on the topic, however, is poorly organised. General articles are rare. Furthermore, although several specific aspects of the impact of brain trauma on the family system were analysed, others were overlooked.

This literature study aims to organise the available information using a theoretical framework, and thus create an overview of what is known thus far which can be useful both for practice and further research.

METHODS AND FRAMEWORK

Existing search systems were used to collect the literature. Medline, Psyclit and CINAHL were consulted and articles were retrieved from 1970 until January 2004. The focus of our review required a sensitive filter rather than a specific one. For our search in Medline we used the following MeSH-terms "coma", "family", "stress" combined with the more sensitive Entry-terms "trauma", "brain injury", "head injury", "relative". We also used these MeSH-terms or Entry-terms in combination with the following key words "coping", "experience". Our search in Psychinfo and CINAHL was based on the combination of the following key words ”coma" or "trauma" or "brain injury" or "head injury" and "family" or "relative" and "stress" or "coping" or "experience*". All studies or review articles containing elements relevant to the aim of the review were selected by two researchers who read the abstract or, in case of doubt or disagreement, the whole article. In total, 94 English language publications were assembled and studied. They were included in the review if the assessment of the full text, also made by two researchers, indicated that the content contributed to the understanding of the phenomena under study and the research methods warranted the "findings". In case of limitations or doubt, the reasons for caution in the interpretation are reported in the result section.

The framework for the literature study comprises the stress-coping theory as described by Lazarus and co-workers and systems theory. These two theories are used in order to organise and interpret the literature. Before examining the specific survey results, the basic concepts of Lazarus's stress-coping theory and the pillars of systems theory will be discussed briefly.

STRESS-COPING AND SYSTEMS THEORY

Stress is conceptualised by Monat and Lazarus (1985) as a characteristic of the relation between the individual and his or her environment. A stressor is a stimulus that the individual perceives as threatening, because the person thinks or feels that he or she is inadequate in terms of being able to react to it. A stressor causes stress, even if the threat is unreal. The taxation of a situation is a two steps process. The primary taxation is the individual's registration of the meaning of the situation and its possible consequences. In the secondary taxation the individual assesses his or her own possibilities to response to or deal with the situation.

The response to the stressor is coping: the individual chooses a specific manner in which to deal with the stimulus. Coping is described as the constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. A coherent aggregate of varied coping behaviour is known as coping strategy. Coping strategies can fulfil two functions: on the one hand, they can focus efforts on the cause of stress (problem-oriented coping); on the other, they can reduce the individual's emotions resulting from the stress-inducing situation (emotion-oriented coping). Most people possess several coping strategies for dealing with stress-inducing situations, but have a preference for one type of coping strategy.

In this review TBI is conceptualised as the stressor and the way in which the family members react is conceptualised as coping.

Systems theory is based on four pillars: first, all components within a system are connected. Relationships run in several different ways between for example father and mother, child one and child two; the interactions are numerous. Second, the system develops over a life cycle. The system was not placed in a lifetime working order on the birth of the first child, or on the marriage of the mother and father. But, as each facet is added to the system, the system develops and evolves. Third, achange to one of the system's components implies change for all system components. If there is a disruption in the rules of the existing pattern within the family system, it does not disrupt just the identified person, it affects and disrupts all participants in the system. And finally, every system is unique. The system of one family is different from another family's system. Even though there may be the same number of children, they live in the same neighbourhood and go to the same schools, the system structure and order are different; thus, the roles are different and the disruption is different (Leaf 1993, Rosenthal & Young 1988). In this review the family is conceptualised as the system that is confronted with TBI and has to adapt to the new situation.

STRESS AND ITS DETERMINANTS

Researchers operationalise the impact of stress on the family members of patients in a variety of ways. Feelings of depression, psychosocial dysfunction, emotional and psychological distress, burden and the pressure experienced are measured using self-reporting scales. An assessment of global stress is made by adding up the scores on these scales.

The level of stress experienced by the family members of patients who have TBI is so high that professional intervention is appropriate (Rosenbaum & Najeson 1976, Lewin 1979, Brooks 1987, Livingston 1987, Gleckman & Brill 1995, Costello 1998, Kolakowsky & Kishore 1999, Siders 1999, Watanabe *et al*. 2001, Anderson *et al*. 2002, McHamer *et al*. 2002, Wade *et al*. 2002, Hawley *et al*. 2003). Moreover, scores remain very high even for as long as 10-15 years following the trauma (Panting & Merry 1970, Thomsen 1984, Oddy & Coughan 1985, Brooks & Campsie 1986, Brooks *et al*. 1987, Rappaport & Herero 1989, Minnes *et al*. 2000).

Severity and nature of the consequences of the injuries

In order to identify the sources of stress, the extent to which the severity of the injury determines the magnitude of stress reactions was systematically investigated. The relation between both is not unequivocal. No relation has been found between feelings of depression and injury severity (Oddy *et al*. 1978, McKinlay *et al*. 1981, McKinlay & Pentland 1987), but a relation is found between psychological strain experienced and injury severity (Livingston 1987, Groom *et al*. 1998).

The nature of the consequences of the victim's injuries clearly has a bearing on the degree of stress among family members. The victim's personality problems, behavioural problems, emotional and intellectual problems show a strong correlation with the extent to which family members experience pressure, anxiety and feelings of depression (Lezak 1978, Oddy *et al*. 1978, McKinlay *et al*. 1981, Brooks *et al*. 1983, Brooks *et al*. 1986, Lezak 1986, Lezak 1988, Hall 1994, Groom *et al*. 1998, Watanabe *et al*. 2000, Anderson *et al*. 2001, Anderson *et al*. 2002, Ergh *et al*. 2002, Ponsford *et al*. 2003, Swift *et al*. 2003). Even after 10-15 years, the primary physical problems that emerge are less stressful than the patient's cognitive, emotional and behavioural problems, which become more apparent over time (Thomsen 1974, Thomsen 1984, Koskinen 1998). Bidirectional influences between child behaviour and parent distress are found (Taylor *et al*. 2001).

Relationship to the patient

Parents and partners of patients experience other difficulties. A TBI has a greater impact on partners than on parents. The relation between partners becomes less stable and the stress experienced is greater (Panting & Merry 1970, Thomsen 1974, Mauss-Clum & Ryan 1981, Livingston *et al*. 1985(a), Lezak 1988, Cavallo *et al*. 1992, Hall 1994, Kreutzer *et al*. 1994(b), Siders 1999). Partners voice more health and psychological complaints, score higher on depression scales and face crisis situations more often than parents. Parental stress is greater when it involves children living at home rather than grown-up children living away from home. A difference is also observed between men and women, not only with regard to needs, but also with regard to depression and anxiety. Women always score higher on stress and depression scales than men (Kreutzer *et al*. 1994(b), Linn *et al*. 1994).

A degree of caution is necessary when drawing conclusions based on the former results. Usually, the score is calculated on the basis of self-reporting by the family member in question. What people say is not always valid in terms of what they are feeling. Social desirability plays a role and has a bearing on answers. The conviction within society, according to which parents carry on caring for their children and men do not discuss emotional matters as much as women, may be of influence here.

Children find it especially difficult in the event of parental trauma. Young children lose a parent and have to compete with the affected parent for the attention of the healthy parent. Older children living away from home are torn between their own family and that of their parents (Kay & Cavallo 1994).

Siblings have lower self concept, behaviour problems, symptoms of depression and their relationship with the child with TBI becomes more negative than before the injury (McMahon *et al*. 2001, Swift *et al*. 2003). Assistance from other family members and friends soon dries up. As little as one year after the trauma, the parents, partners and children are the only members of the brain trauma patient's social network (Oddy & Humphrey 1980, Kozloff 1987).

Characteristics of the family

Certain characteristics of family members appear to influence how stress and anxiety are experienced. When the family member providing care has a psychiatric and/or medical case history, stress and anxiety are greater. Previous contact with the judicial authorities is associated with greater psychosocial dysfunction. (Livingston 1987, Max *et al*. 1998, Minnes *et al*. 2000, Anderson *et al*. 2001, Sander *et al*. 2003)

Young families with several young children are the most vulnerable. If, in addition, there are financial problems and there is little social support, the stress is so great that it becomes impossible to function normally. Conflicts with the team of doctors, nurses and therapists also have a stress-inducing effect. (Moore *et al*. 1993, Hall 1994, Kreutzer *et al*. 1994(c), Leach *et al*. 1994, Linn *et al*. 1994)

TBI mostly affects young adult men. By implication, therefore, it chiefly affects young, fully-developing families often with one or more young children, and financial burden (Kalsbeck 1989, Wringley *et al*. 1994). TBI brings along more stress, greater dysfunction and more problems, which, in turn, give rise to more stress, greater conflict, etc. The problems, and interactions between each of them, mount up and attempts to break the circle usually result in failure.

COPING AMONG FAMILY MEMBERS OF PATIENTS WITH TBI

Every family develops its own equilibrium and its own means of coping in order to deal with family upheaval. A family crisis arises when this means of coping falls short of achieving a new equilibrium (Cope & Wolfan 1994). When a family member suffers a TBI, this adversely affects each individual and the system (family) as a whole. A TBI constitutes a major violation of (and challenge to) family homeostasis. It demands that all individuals within the family and the entire family as a system adapt so that it may grow and develop into a subsequent equilibrium phase. If the family becomes stuck in a specific stage, there is no growth and it is impossible to complete the development tasks that are necessary in order to allow the family to move on to a following stage (Leaf 1993).

Fewer publications are found on coping among the family members of patients with TBI than research into stress within this group. There is not much information available either, about the process whereby family members come to terms with having a brain injured patient in the family.

Phases in the coping process among family members

Coping among the family members of a person who has TBI has been conceptualised by different researchers in a variety of ways. Most researchers discuss phases that, although numbered as first, second and third phase, do not display an objective or universal sequence (Rape *et al*. 1992).

Most phase models developed for post-TBI application to families describe a similar evolution (Lezak 1986, Ridley 1989, Rape *et al*. 1992, Cope & Wolfan 1994, Kay & Cavallo 1994, Kwasnica & Heinemann 1994, Curtiss 2000, Degeneffe 2001). During the opening phase, the initial shock is lived through. Medical stabilisation and damage minimisation are absolute priorities. The family grows closer together and directs all its energy towards the injured person. Phase two involves emotional relief, denial and unrealistic expectations with regard to the evolution of the injury. It is likely that the euphoria of survival minimalizes problems and prolongs the expectation of subsequent full recovery. The ensuing third phase involves bewilderment, anxiety, dejection, depression, feelings of guilt, despair and the feeling of imprisonment. Some families eventually evolve into a final phase of sorrow and mourning, role reorganisation and role redistribution, the aim of which is to promote as much as possible the patient's recovery and integration. Not all families pass through every phase or display every characteristic of a particular phase.

Kübler-Ross's endopsychological model on coming to terms with death is often cited when discussing adaptation within families following brain trauma. However, key points of divergence should be taken into account (Romano 1974, Williams 1991, Kay & Cavallo 1994, DeMarle & Le Roux 2001). The fact that the person being grieved over is still alive interferes with the normal grieving process. Additionally, denial in the case of TBI may be viewed as a buffer against depression that should be respected by professional caregivers. Ultimately, achieving acceptance is neither realistic nor desired. Living with a person who has TBI demands a never-ending cycle of adaptation.

Research shows that the process of dealing with TBI is "less healthy" than that of dealing with a "normal" chronic condition like, for example, multiple sclerosis (Kreutzer *et al*. 1994(a)). Nevertheless, families of brain injury patients do function "more healthily" than families of psychiatric patients (Kreutzer *et al*. 1994(a)).

Importance of coping in the event of TBI

How family members cope with a person suffering from a brain injury has a huge bearing, not just on how the family member in question perceives stress, but also on the victim's outcome. The more adept family members are at dealing with the situation, the better the patient's recovery (Livingston 1987, Florian 1989, Laughlin & McCarey 1993, Pelletier & Alfano 2000, Sander *et al*. 2002). In these studies patient outcomes, measured by behavioural functional and psycho-social scales have a lower correlation with severity of the brain injury, measured by e.g. the GCS and duration of the post traumatic amnesia phase than with the scores of family members on coping, psychosocial functioning and family functioning questionnaires. Problem-oriented coping skills appear to be more effective than emotion-oriented coping skills (Leach *et al*. 1994, Linn *et al*. 1994).

Coping mechanisms may be divided into functional or adaptive coping mechanisms (like the search for new roles) and non-functional or maladaptive coping mechanisms (e.g. the ignoring of tasks, development of poor communication patterns, unrealistic thinking, projection of self-anger onto professional carers, and withdrawing from reality) (Cope & Wolfan 1994). Opinion is divided as regards the significance of denial. It is premature to regard denial during the opening period as nothing more than a dysfunctional coping mechanism. As a buffer against depression, it should be labelled as functional (Lezak 1986, Brooks 1987, Novack & Richards 1991). Post-TBI, professional caregivers are also very uncertain about the evolution and outcome (Bach-Y-Rita 1990). For that reason, it is inappropriate to describe an alternative "take" on recovery as denial (Novack & Richards 1991). The incidence of denial among family members of brain injury patients has never been established on a quantitative basis. To all intents and purposes, therefore, it is not safe to assume that it happens frequently. Furthermore, the term "denial" must be treated carefully on account of its pejorative significance. Nor is it improbable that carers will unjustly label hope and the voicing thereof as denial. If professional carers force family members to accept the unacceptable, family members describe these carers as insensitive and pessimistic. This puts at risk the therapeutic alliance that is so important for the patient's outcome (Laughlin & McCarey, 1993).

Factors that influence coping

The influence of brain injury severity on how family members cope is as yet unclear (Peters *et al*. 1990, Kreutzer *et al*. 1994(b)). Reciprocal communication and a reciprocal affective relation with the victim are important in order for family members to cope effectively (Florian 1989, Kreutzer *et al*. 1994(b), Kolakowsky & Kishore 1999, Anderson *et al*. 2002). Parents cope better than partners (Thomsen 1974, Thomsen 1984). Women tend to cope socially (seeking self-care groups) while men tend to do so individually (no wish to discuss matters) (Willer *et al*. 1991, Giles 1994, Kasowsky 1994, Kreutzer *et al*. 1994(b), Linn *et al*. 1994).

A psychiatric and/or medical disorder suffered by the family member before the trauma correlates strongly with non-functional coping afterwards. Personality and coping skills learned previously also play a role. (Livingston *et al*. 1985(b), Frank 1990, Klonoff & Prigatano 1990, Cope & Wolfan 1994)

The family members not involved in primary care distance themselves from the patient (Florian 1989). The ability of children to cope is influenced above all by the gender of the affected parent and signs of depression from the unaffected parent (Pressaro *et al*. 1993). If the father suffers the injury, they present more "acting out" behaviour. If, in addition, the mother displays symptoms of depression, behavioural problems among children rise significantly. The injury's severity has less of a bearing on how children behave.

Social and professional support constitute the development of effective coping mechanisms (Panting & Merry 1970, Uomoto & Brockway 1992, Cope & Wolfan 1994, Leach *et al*. 1994, Harris *et al*. 2001, Tyerman & Booth 2001, Albert *et al*. 2002, Armstrong & Kerns 2002, Ergh *et al*. 2002, Hibbard *et al*. 2002, Hawley *et al*. 2003) and, over time, family members learn to deal better with the situation even without intervention (Cope & Wolfan 1994, Kreutzer *et al*. 1994(c), Teyerman & Booth 2001). Concrete and written information (e.g. an information booklet), a social work liaison programme, long term follow-up and peer support are promising approaches to enhancing coping for families of TBI patients (Morris 2001, Albert *et al*. 2002, Armstrong & Kerns 2002, Hibbard *et al*. 2002, Ergh *et al*. 2003, Hawley *et al*. 2003). Surprisingly, family members cope better with out-patient rehabilitation than with residential treatment even when the severity of the injury is the same (Mintz *et al*. 1995).

Use of coping strategies by family members

In this literature study we use the most prevalent, yet artificial, division of "meta-coping strategies": problem-oriented and emotion-oriented coping. This division is considered to be artificial because specific coping strategies can fulfil both functions. Seeking social support, for example, may have a problem-oriented function (requesting specific advice) as well as an emotion-oriented function (seeking distraction). We use the division nonetheless because it constitutes to the clarity of the discussion.

The most frequent emotion-oriented coping mechanisms described in research are denial and escape or avoidance in the form of the use of alcohol and medication. The use of sleeping pills and tranquilisers by family members doubles over a period of two to three years following the injury (Panting & Merry 1970, Romano 1974, Mauss-Clum & Ryan 1981, Livingston 1987, Hall 1994).

Family members shut themselves off from the outside world and thus avoid unpleasant reactions from their entourage to, for example, the victim's socially inappropriate behaviour (Walker 1972, Lezak 1988). Moreover, the labour-intensiveness of patient care leaves little time for social contact (Lezak 1988).

A divorce may be considered as a means of escaping from the situation and therefore as an emotion-oriented coping mechanism. It may also be considered as a problem-oriented coping mechanism. The partner of the victim is getting to grips with the cause of stress. The decision to divorce goes hand in hand with severe guilt feelings and anxiety about social rejection. Memories of the pre-trauma period and the partner's dependency weigh heavily on the decision to divorce (Lezak 1988). Various surveys have established that some 30 to 50% of couples divorce within the 8 to 10 years following the trauma (Panting & Merry 1970, Walker 1972, Thomsen 1984).

Faith is a frequently used emotion-oriented coping mechanism that often provides the basis for effective coping (Livingston 1987, Kasowsky 1994, Minnes *et al*. 2000). A possible explanation could be that praying helps to find a state of emotional rest which enables family members to think more clearly about how to adapt to or solve their problems. In addition, the burden is lifted off one's shoulders and the self-efficacy of the person who believes that God will watch over the family and help wherever necessary.

Giving up work is, in the literature, discussed more as problem-oriented coping (Hall 1994). However, the effect of giving up work is to increase, rather than reduce, stress. The family member who gives up work becomes even more socially isolated and the financial situation deteriorates.

Seeking social support and taking on the victim's roles appear to be used frequently as problem-solving coping mechanisms (Rosenbaum & Najenson 1976, Livingston & Brooks 1985, Cope & Wolfan 1994, Hallet *et al*. 1994, Kasowsky 1994) that also have a positive impact on the stress being experienced (Minnes *et al*. 2000).

CONCLUSION

The research thus far conducted on the psychological reactions of family members of TBI-patients is valuable. The scale of the problems is now clear. The research indicates which family members are particularly vulnerable: partners, children, families with financial or medical problems. Interventions can be developed to give them attention by priority. Support from professionals reduces the stress being experienced and encourages people to cope effectively. Conflicts with professional carers should be avoided since they induce stress, make it more difficult to cope effectively and thus impair optimal patient recovery. Family intervention as part of the rehabilitation process is important. Models of long-term support and care that alleviate sources of burden on relatives are urgently needed.

Little is known, however, about a multitude of factors, and this is hampering the development of effective interventions. Future research might be directed at the reaction patterns of the family unit instead of addressing each individual family member. It is also worth investigating the typical ambivalence among the family members of brain trauma patients, e.g. how hope and despair interrelate and what are the influencing factors in this regard. Research on the evolution of the reactions of family members at the onset of trauma and at a later phase also appears needed. Certainly not all suggestions for further research are cited here. Clearly, further research is necessary so that more reliable support may be provided and in order to allow effective intervention programmes to be developed.

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Conclusie en discussie

In dit deel reflecteren we op het onderzoek naar de beleving van familieleden van patiënten in traumatisch coma als geheel. Om onnodige herhalingen te vermijden wordt hier niet geopteerd om elementen uit de conclusies en discussies van de afzonderlijke artikels opnieuw aan te brengen. We zullen ons beperken tot zaken die niet in de artikels aan bod kwamen of toch niet op de wijze zoals hier besproken. Dit deel bestaat uit drie onderdelen: de conclusie, methodologische overwegingen en suggesties voor verder onderzoek, en implicaties voor de praktijk.

CONCLUSIE

In het uitgevoerde onderzoek naar beleving en ervaring van familieleden van patiënten in traumatisch coma hebben we drie basisprocessen aan het licht gebracht: het proces van hoop, het proces van bescherming en het proces van informatieverwerking met zijn directe invloed op het proces van hoop. We stellen vast dat alle bevraagde familieleden deze processen doorlopen in hun confrontatie met traumatisch coma. We komen later terug op deze geringe variatie in de beleving.

Samengevat omschrijven familieleden hun leven na het ongeval of de intracraniële bloeding als onindenkbaar en onvoorstelbaar. Hun leven is als het ware geïmplodeerd, het is een puinhoop. Ze komen terecht in een vreemde onbekende wereld. Alles is op slag veranderd, en wat herkenbaar blijft, krijgt een andere betekenis, o.a. tijd, gewoonten, slaap, werk, relaties, behoefte aan voeding. Er is weinig tot geen houvast, familieleden zijn hun oriëntatie kwijt. Ze herkennen hun eigen emoties, reacties en gedragingen niet, de fundamenten van hun leven zijn onderuitgehaald. Het lijden van familieleden is groot. Hoewel we het lijden niet als apart hoofdstuk besproken hebben, ligt het aan de basis van de drie beschreven processen en hun wisselwerking. Zonder lijden zouden deze processen zich niet voordoen. De centrale plaats van hoop, bescherming en informatie is het gevolg van de intensiteit van het lijden. Tijdens de analyses werd snel duidelijk dat het verhaal van familieleden veel lijden in zich heeft maar daarmee stopt het niet. Het lijden van familieleden beschrijven zonder verder te gaan en de klemtoon te leggen op hoop, bescherming en informatie zou onrecht doen aan het verhaal en dus aan de beleving van familieleden. We hebben tijdens het analyseproces ook het lijden (suffering) in beeld gebracht. Opvallend is dat mensen niet lang in een toestand van lijden kunnen blijven. De momenten van lijden zijn te intens en te vernietigend. Zelfs op het moment van het interview geldt dat nog in zekere mate: ook dan kan men niet lang en niet uitvoerig bij het lijden stilstaan. Zoals we beschreven in de hoofdstukken vraagt lijden zeer veel energie, het is uitputtend. Familieleden richten zich daarom voortdurend op hoop en bescherming, en informatie die hen helpt om hun beleving en handelen te kanaliseren zodat het leven draaglijk blijft. We hebben daarom geopteerd om het lijden te beschrijven doorheen de processen. Het is er in de beleving van familieleden duidelijk mee verstrengeld maar overheerst hun verhaal niet. De drie beschreven processen domineren wel.
Familieleden vechten om zich in die quasi onleefbare periode staande te houden. Ze weten niet hoe zich te gedragen en zijn zich tegelijk bewust dat hun gedrag verstrekkende consequenties kan hebben. Ze voeren een strijd voor de patiënt, hun naaste familieleden en zichzelf. Bovendien leggen ze zichzelf een taak op. Ze moeten ervoor zorgen dat gebeurt wat moet gebeuren, voor de patiënt en voor hun eigen gezin. Ze moeten namelijk op elke mogelijke manier hun dierbaren

beschermen. Daarbij doorlopen ze drie fasen. Aanvankelijk richten familieleden zich volledig op het beschermen van het leven van de patiënt en hun dierbaren. Ze vergeten zichzelf en teren op hun reserves. Later leveren ze een strijd om zelf te (over)leven en beschermen ze de patiënt en hun gezinsleden tegen (onnodig) lijden. In een derde fase is de energie gericht op het (leren) omgaan met de gevolgen.

Wat alle familieleden staande houdt en kracht geeft om verder te strijden is hoop. Aan hoop trekken ze zich op. Zonder hoop geen leven, geen strijd. Ook in hun hoop doorlopen familieleden een proces evoluerend van absolute hoop op overleven naar "realistische", begrensde hoop op een aanvaardbaar leven. Als de patiënt bijkomt is er eerst een korte periode van vreugde om het overleven. Daarna volgt teleurstelling, niets gaat zoals ze zich voorstelden, nieuwe problemen steken de kop op en de confrontatie met de zorg op een verpleegafdeling is hard. Bij het overlijden van de patiënt ontwikkelen familieleden nieuwe hoop, bijvoorbeeld hoop dat uit het overlijden iets positiefs kan voortkomen.

Uit ons onderzoek is gebleken dat hoop niet gestroomlijnd evolueert, maar staps- of trapsgewijze, afhankelijk van de gebeurtenissen, maar voornamelijk gestuurd door informatie. Familieleden bepalen namelijk de inhoud van hun hoop op basis van de verkregen of gezochte informatie. De behoefte aan concrete, gedetailleerde en waarheidsgetrouwe informatie over de toestand van de patiënt is groot. Familieleden doorlopen een proces in de manier waarop ze informatie hanteren. In het begin gaat het enkel om passief absorberen van de informatie die ze krijgen. Na verloop van tijd leren familieleden dat niet alle informatie betrouwbaar is en ontwikkelen ze een systeem om informatie uit verschillende bronnen naar waarde te schatten en te integreren.

Familieleden die voordien andere tegenslagen te boven gekomen zijn, doorlopen de processen iets sneller en met minder extreme emoties. Ze zien overeenkomsten met eerdere tegenslagen en hoe ze zich toen voelden en gedroegen. Dat ze destijds de situatie te boven gekomen zijn, geeft hen vertrouwen de huidige beproeving eveneens aan te kunnen.

In antwoord op de onderzoeksvragen willen we in deze globale conclusie van het onderzoek een integratie van de deelresultaten op schematische wijze voorstellen (Figuur 1). We doen dit in het Engels omdat woorden en begrippen uit de artikels op die manier direct herkenbaar zijn. Wat in dit schema naar voor komt is opnieuw getoetst aan de oorspronkelijke data.

Figuur 1 stelt drie processen voor die familieleden doorlopen, en de onderlinge interactie tussen de processen. We beschrijven de beleving en ervaring van familieleden in drie processen en niet in één proces omdat dit het meest overeenstemt met de data. Wat familieleden meemaken is niet als één proces te reconstrueren zonder in conflict te komen met de data. Het schema geeft daarbij een vereenvoudigd, gereduceerd beeld van de complexiteit van beleving en ervaring van familieleden in hun confrontatie met traumatisch coma. Het is niet meer dan een hulpmiddel om een bepaald aspect, namelijk de samenhang van de drie processen te verhelderen en mag niet beschouwd worden als een volledige voorstelling van de complexe werkelijkheid.

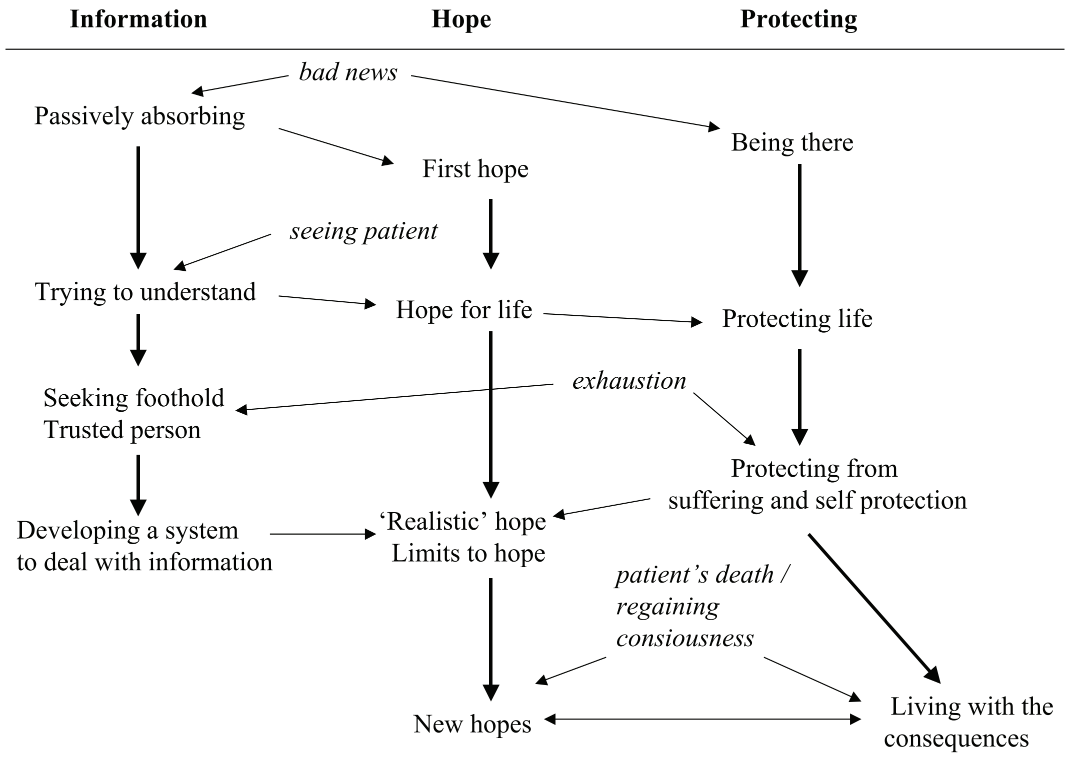

Figure 1: Integration of processes that influence family members' functioning linked with *events (in italics)*

Bovenstaande figuur geeft de dynamiek weer van wat familieleden doormaken. We geven hier een korte beschrijving. De processen starten bij het vernemen van het slechte nieuws ("*bad news*") en soms al voordien met insidieus beginnende ongerustheid. Wanneer familieleden het slechte nieuws over het ongeval of de intracraniële bloeding te horen krijgen, willen ze zo snel mogelijk bij de patiënt zijn. Ze absorberen de informatie die ze op dat moment krijgen op passieve wijze en vormen zich op basis van de informatie een eerste hoop.

Het zien van de patiënt in het ziekenhuis betekent voor familieleden een doordringende confrontatie met de werkelijkheid zoals ze feitelijk is. Met de informatie die familieleden vanaf dat moment krijgen en de flarden van de informatie die ze voordien kregen en onthouden hebben, proberen ze de gebeurtenissen en de situatie te begrijpen. Hun eerste hoop maakt plaats voor absolute hoop op overleven. Die hoop op overleven zorgt ervoor dat familieleden hun functioneren vooral richten op bescherming van het leven, zowel van de patiënt als van de naaste familieleden.

Bij het vervullen van hun quasi onmogelijke taak, het beschermen van het leven, vergeten familieleden zichzelf te beschermen. Ze raken uitgeput en voelen zich na enige tijd fysiek en emotioneel een wrak. Ze worden geconfronteerd met emotionele schommelingen, met het lijden van de patiënt dat steeds zichtbaarder wordt, met tegenstrijdige informatie of informatie die ze niet kunnen kaderen, en met "indringers" in hun leven. Deze laatste zijn mensen die ze niet zo goed kennen en vaak ongevraagd en met de beste bedoelingen in het dagelijkse gezinsleven binnen dringen. Na gemiddeld een drietal dagen zijn ze totaal uitgeput. Beschermen van het leven evolueert naar beschermen tegen lijden. Familieleden beschermen nu niet enkel de patiënt en de naaste familieleden tegen lijden, maar ook zichzelf. Alles wordt in het werk gesteld om het lijden zo draaglijk mogelijk te maken en (onnodig) lijden te vermijden. De uitputting en de ervaringen van de voorbije dagen zorgen ervoor dat familieleden ook anders kijken naar de informatie die ze krijgen. Ze hebben iemand nodig die houvast biedt bij het interpreteren van informatie, een vertrouwde persoon (zie Implicaties voor de praktijk). Mede dankzij de vertrouwde persoon ontwikkelen familieleden een systeem om met informatie om te gaan. Ze absorberen niet enkel passief de informatie die ze krijgen. Ze observeren, luisteren, vragen en testen bijna voortdurend de kwaliteit van de informatie. Familieleden leren aldus om de informatie actief te verwerken in functie van hun behoefte aan “realistische” hoop. Bovendien begrenzen ze hun hoop en koppelen, ter bescherming van zichzelf, minder hevige emoties aan veranderingen in hoop.

In een laatste fase ontwikkelen familieleden nieuwe hoop, afhankelijk van de evolutie van de patiënt en moeten ze noodgedwongen leren leven in de quasi totaal veranderde wereld, met of zonder de patiënt.

Hulpverleners kunnen familieleden doorheen deze processen begeleiden en ondersteunen. Ze kunnen echter onbedoeld het doorlopen van de verschillende fasen ook verhinderen of bemoeilijken. Vooral artsen en verpleegkundigen kunnen een belangrijke rol spelen. Door hun handelingen en hun keuzes beïnvloeden zij op elk moment de wijze waarop familieleden de drie geschetste processen doorlopen. Rekening houden met bovengenoemde inzichten over wat familieleden meemaken is de eerste stap in het voorzien van gepaste en menswaardige zorgverlening. In het licht van de lange lijdensweg die familieleden na de intensieve zorg periode nog voor de boeg hebben, is dit noodzakelijk.

Discussie

In de discussie zijn methodologische overwegingen, suggesties voor verder onderzoek en implicaties voor de praktijk opgenomen. De inzichten die in het laatste deel opgenomen zijn en in de voorgaande hoofdstukken niet aan bod kwamen, zijn afkomstig uit supplementaire analyses specifiek gericht op voor deze implicaties relevante thema’s.

Methodologische overwegingen

De gehanteerde strategieën om validiteit en betrouwbaarheid van de resultaten te bevorderen staan beschreven in de artikels. Er is gebruik gemaakt van theoretische sampling, theoretische saturatie, data- en onderzoekerstriangulatie, en aandacht voor de manier van benaderen van familieleden om aan de studie deel te nemen. Ook de wijze waarop de interviews verwerkt en geanalyseerd werden is uitvoerig beschreven. We zullen ons hier beperken tot enkele algemene vaststellingen en overwegingen die betrekking hebben op de validiteit van het onderzoek en die niet in de artikels aan bod kwamen.

Bij het bekijken van de onderzoeksbevindingen is het opvallend dat er in de beleving van familieleden bijzonder weinig verschillen naar voor komen. Er zijn wel verschillen in de observeerbare manifestaties van de beleving, maar de beleving op zich is sterk gelijklopend. De enige uitzondering hierop is de vaststelling dat familieleden die reeds serieuze tegenslagen meemaakten de processen sneller en met minder extremen doorlopen. Een mogelijke verklaring van de grote gelijkenis in beleving zou kunnen zijn een tekort in aantal bevraagden. Dit lijkt voor ons onderzoek echter niet het geval. Eenendertig interviews, waarvan zeven ingezet voor kruisvalidatie, werden geanalyseerd. Dit aantal zou voldoende moeten zijn om eventuele verschillen in beleving aan het licht te brengen (Miles & Huberman 1984). Bij de rekrutering is bovendien gestreefd naar voldoende heterogeniteit in kenmerken bij de geïnterviewde familieleden, onder andere wat betreft leeftijd, geslacht, oorzaak van het coma, type verwantschap met de patiënt, opleidingsniveau, werksituatie, gezinssituatie, vroegere ervaringen, leeftijd en geslacht van de patiënt, en overleven of overlijden na de comaperiode. Ook is er geen vertekening door weigeraars: alle aangezochte familieleden waren bereid aan het onderzoek deel te nemen. Een andere mogelijke oorzaak van beperkte verschillen kan liggen in het onvoldoende diepgaand of breed interviewen, of het teveel sturen in de interviews. Dit lijkt weinig waarschijnlijk. Bij aanvang verliepen de interviews zeer open. De interviewer diende quasi geen thema’s aan te brengen. Familieleden wilden hun verhaal brengen. De meeste vragen van de interviewer waren vragen naar verheldering. In latere interviews werden ook thema’s uit de literatuur aangebracht. Dit bracht weinig nieuwe inzichten. Belangrijk is ook te vermelden dat de interviews zijn afgenomen door twee verschillende interviewers. Er is geen verschil te merken in de resultaten tussen beiden. Onder andere omdat we zo weinig verschillen zagen zijn bovendien, na de 24 reeds geanalyseerde interviews, zeven interviews geanalyseerd die afgenomen werden in het kader van een onderzoek naar de beleving van familieleden van traumatisch comapatiënten in verband met orgaandonatie. Hoewel bij de analyse uitdrukkelijk gezocht werd naar verschillen en nieuwe zaken, bracht dit geen extra variatie in de beleving naar voor. We zien derhalve geen aanleiding om te veronderstellen dat de overeenkomst in beleving samenhangt met methodologische tekortkomingen. Wel kan het samenhangen met de vrij grote homogeniteit in de kenmerken van de geïnterviewde familieleden. Het gaat immers in alle gevallen om Nederlandstalige familieleden die ook feitelijk op bezoek komen bij de patiënt op de intensieve zorg afdeling. Wat het op bezoek komen betreft, kan verondersteld worden dat het gaat om familieleden die een goede relatie hebben met de patiënt, die in de fysieke gelegenheid zijn een bezoek te brengen en denken dit emotioneel aan te kunnen. Bovendien was geen enkel familielid getuige van het gebeuren en is niemand direct of indirect oorzaak of schuld van het gebeuren. Het ongeval of de bloeding kwam voor iedereen totaal onverwacht en geïnterviewde familieleden hadden daar op geen enkele wijze vat op. Overheersende schuldgevoelens of (mede)oorzaak zijn van het gebeuren zouden de beleving kunnen beïnvloeden. Het onderzoek kan daar geen uitsluitsel over geven.

Familieleden werden gerekruteerd in twee ziekenhuizen, een universitair ziekenhuis en een groot regionaal ziekenhuis. Dit aantal zou van invloed kunnen zijn op de variatie in de beleving, echter, beide ziekenhuizen zijn bewust zo geselecteerd omdat ze anders georganiseerd zijn wat betreft bezoekregeling en omgang met familieleden. Bovendien werken in de verschillende ziekenhuizen andere artsen en verpleegkundigen en binnen de ziekenhuizen werken meerdere artsen en verpleegkundigen, met andere communicatiestijlen. Er werden familieleden bevraagd van patiënten die door andere artsen behandeld werden en in periodes dat andere verpleegkundigen op de afdeling werkten. Er werden zowel familieleden bevraagd van patiënten die doorverwezen werden vanuit de periferie als patiënten die direct opgenomen werden in een van beide ziekenhuizen. Redelijkerwijze mag verondersteld worden dat de situaties voldoende verschillend zijn om variaties in de beleving aan het licht te brengen als die er zouden zijn.

Concluderend durven wij daarom ook stellen dat wat we in beeld gebracht hebben, kan gezien worden als een waarheidsgetrouwe weergave van de beleving van bezoekende familieleden in een betrokken relatie met de patiënt, zonder directe fout of schuld aan de gebeurtenissen. Dat de drie processen van beleving van familieleden zulke grote overeenkomsten vertonen, heeft volgens ons te maken met het feit dat traumatisch coma zeer fundamentele, existentiële ervaringen bij familieleden teweegbrengt. Onze conclusie dat het gebrek aan variatie geen artefact is van het onderzoek, wordt bevestigd door de resultaten van ander onderzoek bij familieleden van ICU patiënten en andere populaties (hoofdstuk 2, 3 en 4). Zoals in de literatuurstudie vermeld, is in diverse onderzoeken aan de hand van de CCFNI zelfs sprake van de universele behoeften hoop en informatie. Ook in ander kwalitatief onderzoek bij acuut kritisch zieken komen hoop en informatie naar voor. Onderzoeken waarin de behoefte om te beschermen bij familieleden van ICU patiënten expliciet naar voor komt zijn er echter weinig. Er is wel onderzoek waarin "er zijn", waakzaamheid, behoefte aan nabijheid, behoefte om te zorgen voor de patiënt op de voorgrond treden. En ook items van de CCFNI die gerelateerd kunnen worden aan bescherming zoals "weten dat de patiënt de beste zorgen krijgt" en "in de nabijheid van de patiënt kunnen zijn" worden gescoord als heel belangrijk door familieleden. Misschien is bescherming het beste op te vatten als een mantelbegrip, een begrip met een hoger abstractieniveau, waar verschillende concretere begrippen en items onder vallen.

De meerwaarde van dit onderzoek in verhouding tot de gepubliceerde andere studies ligt in het zichtbaar maken van drie centrale processen die familieleden doormaken in de confrontatie met traumatisch coma en als antwoord op het lijden dat ze in eerste instantie als vernietigend ervaren. Ook de coherentie tussen die processen is in beeld gebracht. Dit biedt de zorgverleners de mogelijkheid om familieleden te begrijpen in wat ze doormaken, hun gedrag beter te interpreteren en hun interactie met familieleden daarop af te stemmen.

Tot slot nog een overweging in verband met de ethische aspecten van het onderzoek. De weergegeven onderzoeksbevindingen zijn het resultaat van zeer rijke data. De interviews die afgenomen werden, leverden ons meer gegevens op dan we hier konden verwerken. Familieleden grepen de interviews aan om hun verhaal aan bod te laten komen. Bij aanvang van het onderzoek maakten we ons zorgen over de belasting die dergelijke interviews met zich zouden meebrengen voor familieleden. Dit was ook de bezorgdheid van de ethische commissie. Op de vraag aan familieleden of het interview voor hen een belasting betekende, gaven ze duidelijk aan dat dit niet het geval was, integendeel. De openheid en zelfs het verlangen van familieleden om over hun ervaringen te praten, versterkte ons idee dat de interviews voor familieleden een unieke kans bieden om in alle veiligheid hun ervaringen en emoties rond het gebeuren te ventileren, zonder zich zorgen te hoeven maken over het sparen van de gevoelens van anderen, gezichtsverlies te lijden of de zorg negatief te beïnvloeden. Er kan gesteld worden dat het ethisch juist wél verantwoord is om mensen voor dergelijk onderzoek uit te nodigen. Ze krijgen slechts zelden de kans om zo langdurig gehoord te worden en voor sommige mensen is het een troostende gedachte te weten dat hun lijden toch nog zin of nut heeft (Carpenter 1998, Hutchinson *et al.*1994). In elk geval leert de ervaring ons dat, wanneer een zorgvuldige rekruteringsprocedure (Hoofdstuk 2) gevolgd wordt, de gevoelsmatige drempel om familieleden in onderzoek te betrekken in crisismomenten, niet mag verhinderen dit toch te doen.

Aanbevelingen voor verder onderzoek

Het onderzoek verschaft geen inzicht in de beleving van niet bezoekende familieleden. Niet enkel in dit onderzoek, maar ook in de literatuur is weinig tot niets te vinden over familieleden die de patiënt niet bezoeken, die afstand nemen van de patiënt, die minder betrokken lijken te zijn of een slechte relatie hebben met de patiënt. Er is quasi geen kennis over het aantal familieleden dat de patiënt niet bezoekt, noch over mogelijke redenen van familieleden voor het niet brengen van een bezoek aan hun familielid op een intensieve zorg afdeling. Methodologisch en ethisch gezien is deze populatie familieleden moeilijk te contacteren en zij blijft misschien in de schaduw staan in onderzoek naar familieleden omdat ze niet direct tot de groep familieleden behoren waar hulpverleners in de gezondheidszorg mee in aanraking komen. Toch is de beleving van die groep familieleden niet onbelangrijk. De beleving van de meest kritieke periode in de ziekte van de patiënt kan voor de familieleden langdurige gevolgen hebben, en de relatie met de patiënt, als hij uit het coma ontwaakt, blijvend beïnvloeden. Toekomstig onderzoek kan daar meer klaarheid in brengen.

Het onderzoek beperkt zich tot de acute fase van coma op de intensieve zorg afdeling. Daardoor kan niets gezegd worden over de beleving van familieleden op langere termijn. De literatuurreview in hoofdstuk 5 toont aan dat de familieleden na de intensieve zorg periode nog lange tijd geconfronteerd worden met de gevolgen van het coma. De resultaten van de studies in hoofdstuk 5 tonen zelfs aan dat familieleden het misschien wel lastiger krijgen dan gedurende de intensieve zorg periode. De stress bij familieleden stijgt gedurende de eerste zes maanden en blijft dan zelfs tot 15 jaar na het trauma quasi even hoog (Verhaeghe et al. 2005(b)). In het licht van onze data over de post intensieve zorg periode hebben we een vermoeden dat na de comaperiode een aantal factoren spelen die dit in de hand werken zoals bijv. negatieve ervaringen met zorg en zorgverleners, uitputting, de confrontatie met blijvende letsels. Onze data zijn echter te beperkt om duidelijke lijnen te zien in het proces dat familieleden doormaken in het verder leven met de persoon met het hersenletsel.

De studies in de literatuurreview over de post acute periode brengen aan het licht hoe hoog de stress bij familieleden kan zijn, welke aspecten van het hersenletsel voor familieleden het moeilijkst zijn, welke familieleden bijzondere aandacht vragen en op welke wijze familieleden omgaan met het gebeuren. De studies in de literatuurreview bieden jammer genoeg weinig verklaring voor de hoge stress en de manier van coping. Ze zijn bovendien vooral gericht op stress in verband met de gevolgen van het letsel en minder op stress veroorzaakt door de confrontatie met zorg. Daardoor biedt de review weinig mogelijkheden om een adequate ondersteuningsinterventie op te bouwen. Om de variabelen en processen beter in beeld te brengen is verder onderzoek nodig waarmee de beleving na de comaperiode in beeld gebracht wordt. Enkele van de vragen die beantwoord zouden moeten worden zijn: Wat ervaren mensen na de intensieve zorg periode? Wat staat centraal in hun beleving als de patiënt op een verpleegafdeling verblijft? Evolueert hoop nog verder? Waarop richten familieleden zich in de post acute fase? Ons onderzoek geeft ook geen informatie over de invloed van de ervaringen van de intensieve zorg periode op de verwerking van familieleden nadien. Wat blijft bij en welke invloed heeft dit op de verdere betekenisverlening? Hoe kijken familieleden terug op hun ervaringen en welke invloed heeft dit op hun leven? Verder onderzoek kan daar meer over verhelderen. Het ligt in onze bedoeling de geïnterviewde familieleden opnieuw te contacteren om meer inzicht te krijgen in bovenstaande vragen. We willen begrijpen wat familieleden na de intensieve zorg periode nog meemaken en hoe ze achteraf op hun beleving tijdens de comaperiode terugkijken. Enerzijds geeft dit een longitudinaal zicht op beleving en betekenisverlening en anderzijds kan dit ons iets leren over de betrouwbaarheid van retrospectieve interviews.

Toekomstig onderzoek aan de hand van de CCFNI lijkt ons minder zinvol omdat het wellicht weinig nieuwe inzichten kan opleveren. Er is reeds behoorlijk wat onderzoek gebeurd aan de hand van de CCFNI. De in de CCFNI bevraagde noden en behoeften van familieleden zijn duidelijk in kaart gebracht. Er zijn ook grensoverschrijdende en patiëntengroepenoverschrijdende bevindingen die in dezelfde richting wijzen. Uit ons onderzoek en het onderzoek van Burr (1998) blijkt echter dat de CCFNI niet peilt naar alle behoeften en noden van familieleden. Bescherming bijv. ontbreekt. Ook over vertrouwen is eerder weinig terug te vinden. Bovendien biedt de CCFNI een inventarisatie van noden en slechts weinig inzicht in de processen waardoor de noden tot stand komen. Doordat de dynamiek van de noden niet verklaard wordt, biedt het onderzoek met de CCFNI minder handvaten voor een adequate begeleiding omdat minder kan ingespeeld worden op de processen die familieleden doormaken. In ons onderzoek is daar meer helderheid over gebracht.

Implicaties voor de praktijk

Studies over beleving en betekenisverlening van familieleden hebben in de eerste plaats consequenties voor het primaire proces, dat zich tussen de zorgverlener en de zorgvrager afspeelt. Het reconstrueren van de processen die familieleden doormaken geeft inzicht in hoe de interactie tussen de familieleden en de zorgverleners vorm kan gegeven worden en welke gevolgen daarvan te verwachten zijn. Uiteraard heeft zo een onderzoek ook beleidsimplicaties, voor zover het beleid het primaire proces moet ondersteunen. De afwezigheid van variatie in de beleving (zie hoger) verhoogt de generaliseerbaarheid van de bevindingen buiten de ziekenhuizen die aan het onderzoek hebben meegedaan. De aanbevelingen zijn dan ook geen aanbevelingen voor deze ziekenhuizen, maar voor de zorg voor familieleden van comapatiënten die op intensieve zorg afdelingen zijn opgenomen in het algemeen.

Om ook nu herhaling te vermijden worden de reeds in de afzonderlijke artikels gesuggereerde praktijkconsequenties niet samengevat.

Implicaties voor de praktijk, uit onderzoek naar beleving en ervaringen, laten zich niet vertalen in to-do lijstjes of richtlijnen. De kernopdracht voor de artsen en de verpleegkundigen in de ondersteuning van de familieleden is aan te sluiten bij hun beleving. Het onderzoek helpt hen de signalen van de familieleden te interpreteren en vooral ook te begrijpen. Echter, het mag ook niet tot vooroordelen leiden. Vanuit begrip voor de beleving zal de individuele hulpverlener moeten beslissen wat in het concrete geval aangewezen is of niet. Welke vorm de geschetste processen in een concreet geval krijgen, zal telkens verkend moeten worden om adequaat te kunnen reageren. (Communicatie)technieken worden door de betrokkenen snel als onecht ontmaskerd als het louter om technieken gaat. Daarom kiezen we ervoor de praktijkimplicaties eerder te formuleren als inzichten dan als handelingsvoorschriften.

Suggesties die de individuele hulpverlener kan aanwenden om de zorg voor familieleden beter af te stemmen op hun beleving, hebben we reeds besproken (Hoofdstuk 2, 3 en 4). In wat nu volgt willen we echter nog enkele in het oog springende mogelijkheden bespreken om de zorg voor familieleden te optimaliseren. Flexibele bezoekuren voor familieleden van patiënten op intensieve zorg afdelingen, in de literatuur reeds als “best practice” beschouwd (Gottlieb 2003, Ramsey *et al.* 1999, Sims & Miracle 2006), en op sommige eenheden in Vlaanderen al toegepast, zullen ook voor familieleden van comapatiënten een grote waarde hebben. Het vraagt weinig aanpassingen van de intensieve zorg afdelingen om familieleden de uren waarop ze bij de patiënt op bezoek komen in overleg met de hulpverleners te laten bepalen, en het geeft familieleden de kans hun nieuwe dagelijkse routine zo goed mogelijk af te stemmen op hun eigen noden en die van de overige gezinsleden. Bovendien heeft een pilootproject uitgewezen dat flexibele bezoekuren ook in Vlaanderen niet enkel familieleden ten goede komen maar ook de relatie tussen verpleegkundigen en familieleden bevordert en de ondersteuningsmogelijkheden vergroot (Wanseele *et al.* 2004).

Familieleden hebben behoefte aan iemand die ze volledig vertrouwen, die vertrouwd is met de ziekenhuiswereld en die kan optreden om de familie in de vreemde ziekenhuiswereld als gids te dienen. Het gaat dan om iemand die zowel met de familie als met het ziekenhuis of ten minste met de gezondheidszorg vertrouwd is. De houding die binnen een ziekenhuis best aangenomen wordt ten opzichte van deze vertrouwde persoon is reeds aangehaald in de artikels. Er kan echter verder gegaan worden dan het creëren van openheid voor de vertrouwde persoon die namens de familieleden contact opneemt met de arts of verpleegkundige. Familieleden kunnen in den beginne gevraagd worden of ze een familielid, vriend of kennis hebben die zij vertrouwen en die de gezondheidszorg kent. Ze kunnen aangemoedigd worden om die persoon te contacteren en de evolutie te laten meevolgen. Uiteraard mag de vertrouwde persoon niet aangesproken worden in plaats van de familieleden en geen taken in de schoenen geschoven krijgen die door de behandelende arts(en) of verpleegkundigen dienen opgenomen te worden. De vertrouwde persoon biedt supplementaire en broodnodige ondersteuning zoals in Hoofdstuk 2 en 3 aangegeven. Wanneer familieleden geen vertrouwde persoon kunnen aanspreken is extra aandacht en waakzaamheid aangewezen. De familieleden zijn dan immers meer kwetsbaar. Een aantal van de geïnterviewde familieleden heeft ervaring met een afdelingsoverschrijdende vertrouwenspersoon die door het ziekenhuis is aangesteld en hen ter zijde staat niet alleen tijdens maar ook na het ziekenhuisgebeuren. Hij blijkt voor hen van grote betekenis. Deze persoon heeft een andere functie dan de in sommige artikels genoemde zorgmanagers of case managers. Deze laatste hebben vooral een organisatorische functie, zorgen weliswaar voor een vlottere organisatie (Briones & Carlino 1998, Ebert 2001, Sohl-Kreiger *et al.* 1996) en soms ook een betere communicatie (Sohl-Kreiger *et al.* 1996). Ze moeten echter ook de belangen van de organisatie met die van de patiënt (of de familie) verzoenen (Padgett 1998), en kunnen daardoor niet het onvoorwaardelijk vertrouwen van de patiënt of de familieleden krijgen (Thorne & Robinson 1989, van Dalen *et al.* 1998). De vertrouwenspersoon die wij op het oog hebben heeft echter als opdracht de familieleden in hun opdracht (zie hoofdstuk 2) en in hun proces (hoofdstuk 2, 3 en 4) te ondersteunen.

We stelden vast dat familieleden in en na de acute periode van coma vaak erg in beslag genomen zijn door hun onbeantwoorde vragen. Familieleden kunnen niet verder als ze de gebeurtenissen niet kunnen reconstrueren. Vooral bij het overlijden van de patiënt hinderen deze onbeantwoorde vragen de verwerking. Wanneer familieleden aangeven dat ze vragen hebben over de voorbije gebeurtenissen die ze niet kunnen loslaten, is het belangrijk dat artsen of verpleegkundigen aangeven dat dit een normale reactie is. Daarna is het belangrijk om stappen te ondernemen om op die vragen een antwoord te vinden. Zo kan contact gelegd worden met de artsen en verpleegkundigen van de spoedopnameafdeling, er kan vanuit het ziekenhuis zelfs contact opgenomen worden met brandweer en politie. Vanuit het ziekenhuis kan aan familieleden de mogelijkheid geboden worden om, als ze dat wensen, een na-opname of na-overlijden overleg bij te wonen. Op die manier krijgen familieleden de kans om met diverse hulpverleners antwoorden op vragen te zoeken of onwetendheid te delen. Dit heeft een positief effect op de verwerking. Het brengt rust en is een essentiële voorwaarde om het gebeuren een plaats te kunnen geven.

Familieleden van comapatiënten spreken in de interviews regelmatig over goede artsen en goede verpleegkundigen. Ze vinden dat ze goede en minder goede hulpverleners duidelijk van elkaar kunnen onderscheiden, maar het is opvallend dat ze het moeilijk vinden om aan te geven wat hulpverleners goed en minder goed maakt. Ze gaven meestal voorbeelden van positieve of negatieve ervaringen met artsen en verpleegkundigen. In elk geval heeft het “goed” zijn van een hulpverlener vooral te maken met zijn of haar attitude ten opzichte van de patiënt en de familie. De technische vaardigheden en de kennis van artsen of verpleegkundigen is voor familieleden moeilijk in te schatten en wordt als vanzelfsprekend aangenomen. Voor familieleden zijn de artsen diegenen die macht hebben over leven en dood. Familieleden zijn volledig afhankelijk van de arts(en) voor het redden van het leven van de patiënt. Voor hen is een goede arts een arts die in woorden en daden duidelijk maakt dat hij “er voor gaat”, een arts die aan de zijde van familieleden staat in de strijd voor het leven van de patiënt. Wanneer familieleden oprecht engagement voelen van de kant van de arts zijn ze gerustgesteld en kunnen ze in volle vertrouwen de patiënt in zijn of haar handen achterlaten. De arts moet voor familieleden het leven van de patiënt redden. Verpleegkundigen moeten de waakzaamheid van familieleden overnemen op momenten dat zij er niet kunnen zijn. Ze moeten zorgen voor de patiënt zoals de familieleden dat zouden doen. Eerlijkheid, oprechte betrokkenheid en menselijk en persoonlijk contact met respect voor de patiënt en zijn familie zijn daarbij van belang. Het moet voor familieleden duidelijk zijn dat de verpleegkundige een relatie heeft met de patiënt als mens, niet enkel als lichaam. Goede verpleegkundigen hebben oog voor het draaglijker maken van het lijden en maken in hun handelingen duidelijk dat de patiënt nog niet verloren is.

Goede zorg heeft een prijs, en dat geldt ook voor goede zorg voor familieleden van comapatiënten. Toch zullen bij de implementatie van de hierboven gegeven suggesties de financiële consequenties eerder beperkt zijn. De invoering van flexibele bezoekuren bijvoorbeeld kan tegen een relatief lage kost gerealiseerd worden. Betere communicatie met de familieleden vraagt tijd, maar in de eerste plaats de juiste vorm van aandacht. Maatregelen zoals een afdelingsoverschrijdend vertrouwenspersoon, vormen een grotere kost.

Tenslotte willen we na deze schets van problemen en mogelijkheden om die aan te pakken, benadrukken dat de data tegelijkertijd op indrukwekkende wijze laten zien, hoe sterk mensen zijn in de confrontatie met een dramatische gebeurtenis zoals traumatisch coma. Alleen al deze vaststelling vraagt om een houding van bijzonder veel respect voor familieleden.

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Samenvatting

De confrontatie met traumatisch coma: een studie naar de beleving van familieleden

Beleving en ervaringen van familieleden van patiënten in een traumatisch coma na een ongeval of een intracraniële bloeding, staan centraal in dit onderzoek. Bij traumatisch coma worden familieleden geconfronteerd met een zware, plotse en onverwachte verandering in hun dagelijkse bestaan. De evolutie van de toestand van de patiënt is onzeker en communicatie met de getroffene is onmogelijk. Toch moeten familieleden als naaste van de patiënt optreden. Uit literatuuronderzoek blijkt dat familieleden van comapatiënten grote behoefte hebben aan ondersteuning en dat er weinig onderzoek is verricht dat hiertoe een leidraad biedt. Ondersteuning kan pas effectief zijn als ze aansluit op de beleving van degene die geholpen wordt. Om deze aansluiting mogelijk te maken richt onze studie zich op het belevingsproces dat familieleden doorlopen, hoe ze met de situatie omgaan, wat hen helpt en wat als negatief ervaren wordt.

Er is voor een kwalitatieve onderzoeksbenadering gekozen volgens de grounded theory methodologie. In twee algemene ziekenhuizen werden 24 los gestructureerde interviews afgenomen met 22 Nederlandstalige bezoekende partners, ouders, kinderen of broers/zussen van de patiënten in traumatisch coma op een intensieve zorg afdeling. Er werden interviews afgenomen binnen de 72 uur na aankomst van de patiënt in het ziekenhuis, nadat de patiënt gestorven of bijgekomen was en/of tussentijds. De dataverzameling en -analyse verliep in een cyclisch proces waarin de formulering van nieuwe thema's afgewisseld werd met de confrontatie met nieuw onderzoeksmateriaal. Er werd gebruikt gemaakt van de constante comparatieve methode en de analyse werd door middel van onderzoekerstriangulatie gevalideerd. Zeven interviews uit een onderzoek bij familieleden van "heart beating" orgaandonoren werden gebruikt voor kruisvalidering van de onderzoeksresultaten.

Onze resultaten wijzen drie basisprocessen aan: het proces van bescherming, het proces van hoop, en het proces van informatieverwerking dat een directe invloed heeft op het proces van hoop. Alle bevraagde familieleden blijken deze processen in hun confrontatie met traumatisch coma op een sterk vergelijkbare wijze te doorlopen.

Wat betreft het proces van bescherming, omschrijven familieleden hun situatie na het ongeval of de intracraniële bloeding als onindenkbaar en onvoorstelbaar. Er is geen houvast, ze zijn hun oriëntatie kwijt. Ze herkennen hun eigen emoties, reacties en gedragingen niet. Ze voeren een strijd voor de patiënt, hun naaste familieleden en zichzelf. Bovendien leggen ze zichzelf een taak op. Ze moeten ervoor zorgen dat gebeurt wat moet gebeuren voor de patiënt en voor hun eigen gezin. Ze voelen het als hun opdracht op elke mogelijke manier hun dierbaren te beschermen. Hierbij doorlopen ze drie fasen. Aanvankelijk richten familieleden zich volledig op het beschermen van het leven van de patiënt en hun dierbaren. Ze vergeten zichzelf en teren op hun reserves. Later leveren ze een strijd om zelf te (over)leven en beschermen ze de patiënt en hun gezinsleden tegen (onnodig) lijden. In een derde fase is de energie gericht op het (leren) omgaan met de blijvende gevolgen van het hersenletstel.

Wat alle familieleden staande houdt en kracht geeft om verder te strijden is hoop. Aan hoop trekken ze zich op. Zonder hoop geen leven, geen strijd. Ook in hun hoop doorlopen familieleden een proces evoluerend van hoop op overleven naar "realistische", begrensde hoop op een aanvaardbaar leven. Als de patiënt bijkomt is er eerst een korte periode van vreugde om het overleven. Daarna volgt teleurstelling, niets gaat zoals ze zich hadden voorgesteld, nieuwe problemen steken de kop op en de zorg op een verpleegafdeling valt hen tegen. Bij het overlijden

van de patiënt ontwikkelen familieleden nieuwe hoop, bijvoorbeeld hoop dat uit het overlijden toch iets positiefs kan voortkomen. Uit het onderzoek is gebleken dat hoop niet gestroomlijnd evolueert, maar staps- of trapsgewijze, afhankelijk van de gebeurtenissen, maar voornamelijk gestuurd door informatie. Familieleden hebben behoefte aan concrete, gedetailleerde en waarheidsgetrouwe informatie over de toestand van de patiënt. Dit helpt hen hun hoop in overeenstemming te brengen met de feitelijke stand van zaken. Ze wisselen hun momenten van hopeloosheid met elkaar af en respecteren in hun onderlinge interacties elkaars hoop.

Familieleden doorlopen een proces in de manier waarop ze informatie hanteren. In het begin zijn ze enkel in staat om informatie passief te absorberen. Na verloop van tijd leren familieleden dat niet alle informatie betrouwbaar is en ontwikkelen ze een systeem om informatie uit verschillende bronnen te waarderen en integreren.

Voor familieleden is het belangrijk dat hulpverleners oprecht, respectvol en menselijk zijn in hun contact en communicatie. Organisatorische maatregelen zoals flexibele bezoekuren (familieleden bepalen hun bezoekmoment in overleg met de hulpverleners) zijn helpend. Een flexibele bezoekurenregeling vraagt weinig aanpassingen van de intensieve zorg afdelingen en geeft familieleden de kans hun nieuwe dagelijkse routine zo goed mogelijk af te stemmen op de noden van de overige gezinsleden. Familieleden hebben behoefte aan iemand die ze volledig vertrouwen, die vertrouwd is met de ziekenhuiswereld en die kan optreden om de familie en de ziekenhuiswereld te verenigen. Een afdelingsoverschrijdende vertrouwenspersoon is van grote betekenis voor familieleden, niet alleen tijdens maar ook na het ziekenhuisgebeuren.

Dit onderzoek biedt hulpverleners de mogelijkheid om zich een concrete voostelling te maken van wat familieleden beleven. Gecombineerd met de bereidheid van hulpverleners om daar iets mee te doen, is zodoende een kwaliteitsverbetering van de zorg voor familieleden mogelijk.

Summary

The confrontation with traumatic coma: a study on the experience of family members

When a patient lapses into traumatic coma, the everyday life of family members is suddenly and unexpectedly ruptured. There has been no opportunity for anticipatory coping. How the situation will evolve is uncertain and communication with, or feedback from the patient is impossible. A review of the literature revealed that family members do not receive the attention they need, although attending their needs is important and has a positive effect on both families and patients. To optimize family care in ICU, insight in the experiences of family members is necessary. The present study was undertaken to provide in-depth material about this topic.

The aim of the study was the identification and description of the basic psychological processes of family members confronted with traumatic coma. Especially the processes that family members go through in coping with the situation, the meanings they attribute to it, and the possible roles they play were the focus of the study. We also wanted to assess what circumstances or reactions from professionals or other persons are experienced as positive or supportive, and which ones as annoying, distressing, painful or unacceptable.

A qualitative approach according to the grounded theory method with constant comparison was chosen for the study Twenty-four interviews were held with 22 native Dutch speaking partners, parents, children or brothers/sisters who visited the coma patient in ICU. Interviews were held within 72 hours after the patient's arrival at the hospital, after the patient's death or regaining consciousness, and/or in between. Data processing and data analysis took place in a cyclic process wherein the induction of themes was alternated by confrontation with new material. Analyses were validated during the whole process by means of researcher triangulation. Apart from the data collected for this study, seven interviews with family members of heart beating organ donors were analyzed. This supplementary analysis (cross) validated our results.

We found three processes that family members go through in their confrontation with traumatic coma: the process of protecting, the process of hope and the process of dealing with information that directly influences the process of hope. With regard to protecting, family members feel they need to protect their relative in coma as well as other family members and themselves from suffering. They go through three phases. At first they concentrate on protecting the patient's life and their loved ones. They forget about themselves and live on their reserves. Later they put up a fight for their own survival and protect themselves, the patient and the family against (unnecessary) suffering. During the third phase their energy is directed at dealing with or learning to deal with the consequences.

Hope was found to evolve stepwise up and down, dependent on further events and information: big steps at first, smaller later on. Hope helps family members to keep going, and to manage the care for the patient and for each other. Family members were found to protect themselves against false or unjustified hope by seeking valid information. They alternate their moments of despair and in their interactions they respect each other's hope.

With regard to information it turned out that family members of traumatic coma patients want information that is as accurate as possible, provided by doctors and nurses in an understandable manner and leaving room for hope. At first, family members can do no more than passively absorb the information they receive. After some time, they actively start working with information and learn what to build their hope on. In this way, concrete hope evolves and seems to be strongly determined by information. Information that is more positive than warranted is not appreciated at all. It leads to false hope, and once its real nature becomes apparent, to increased distress and loss of trust in the professionals.

With regard to practical implications, we found that it is important for family members that health care professionals are true, respectful and humane in their contact and communication. Flexible visiting hours (family members determine the visiting moments in consultation with professionals) can help family members to establish a daily routine that is as similar as possible to the one they had before the coma. It is also important for family members to have a person they can trust who breaks through the anonymity of relations in the hospital. Furthermore, it is helpful if family members have someone from and in the hospital who goes through the process with them. This person helps family members to gather and interpret information, and consequently is a constant factor in the verification of hope.

This research gives health care professionals insight in what family members experience in the confrontation with traumatic coma. When professionals use this insight they can support family members in ICU more adequately.

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Dankwoord

Een groot werk is afgerond. Dit volbrengen was enkel mogelijk dankzij vele mensen rondom mij. In de eerste plaats mijn promotoren. Weinigen hebben het geluk er twee op papier te hebben maar in werkelijkheid door drie omringd te worden. Drie promotoren die elkaar perfect aanvulden. Ik kon het niet beter treffen.

Prof. dr. T. Defloor wil ik bedanken voor zijn geduld en volhardend geloof in mijn kunnen. Tom, niettegenstaande ik gedurende de voorbije jaren voor de nodige druk(te) zorgde door kinderen te krijgen en vaak op cruciale momenten ziek te worden, hebt u me steeds vooruit doen kijken, steeds ondersteund en begeleid. U hebt me geïntroduceerd in de wereld van de computer, de universiteit, de congressen en het schrijven. U verruimde mijn blik en stimuleerde me om door te gaan. Zonder jou lag dit ‘boekje’ er niet.

Prof. dr. M. Grypdonck, Mieke, met uw naam ben ik in de verpleegkunde geïntroduceerd. Een wereld ging voor me open toen uw theorie over integrerende verpleegkunde mij vol geestdrift door de docenten van de opleiding verpleegkunde werd aangeleerd. U werd voor mij een ware legende. Toen ik na mijn opleiding verpleegkunde de licentie wilde starten, zag ik uw naam bij enkele vakken staan. Ervan overtuigd zijnde dat iemand die ‘verpleegkunde in Vlaanderen veranderde’, ongetwijfeld al overleden moest zijn, dacht ik dat het om een fout moest gaan. Maar de eerste les stapte u binnen. Iedereen werd er stil van, tot u bijna over het opstapje vooraan in het lokaal struikelde. Vanaf dat moment werd u een levende legende. En die bent u tot op heden voor mij nog steeds. Gedurende de jaren dat u me begeleidde heb ik met stijgende verbazing de ondoorgrondelijke rijkheid van uw ideeën en uw visie vastgesteld. U hebt een onvermoeibare werkkracht en gedrevenheid. De momenten van samen analyseren waren mijn motor om verder te gaan. Hoewel ik veel respect heb voor uw kennis en deskundigheid, wordt mijn respect voor u als mens steeds groter. U bent wat u doceert. Ik heb gevoeld dat u weet wat een zieke beleeft. Bedankt voor het doorgeven van een stukje van uw wijsheid.

Dr. F. Van Zuuren, Florence, een kwalitatief onderzoek nauwgezet uitwerken vraagt een grote inspanning. Minutieus hebt u het hele proces mee ontwikkeld en actief bewaakt. De methodologische keuzes die gemaakt werden, het interviewen, analyseren en schrijven, alles is uw kritische blik gepasseerd. U stelde in vraag, zette me aan het denken, bracht alternatieven. Bedankt voor uw tijd, geduld, begrip en betrokkenheid. Bedankt voor het zeer nauwgezet corrigeren van de artikels doorheen de diverse fasen. Bedankt ook voor uw tips en adviezen die buiten de directe wetenschappelijke ondersteuning vielen.

Prof . dr. M. Duijnstee, Prof. dr. G. De Backer en Prof. dr. F. Colardyn, wil ik bedanken als leden van de begeleidingscommissie. Ze waren steeds bereid tot het geven van opbouwende feedback.

Ook de leden van de jury Prof. dr. P. Boon, Prof. dr. B. Dierckx de Casterlé, Prof. dr. T. Van Achterberg, Prof. dr. W. Schnepp wil ik bedanken. Hun vragen waren soms lastig maar verrijkend.

Speciale dank gaat uit naar de familieleden die ik mocht interviewen. Dankzij hun openheid en de tijd die ze vrijmaakten in de zeer belastende situatie waarin ze verkeerden, konden we tot deze onderzoeksresultaten komen.

Mijn collega's van verplegingswetenschap en de vakgroep wil ik bedanken voor hun betrokkenheid en hun luisterend oor. Alexander, Ann, Dimitri, Els, Ginette en Katrien bedankt voor de ondersteuning, de motiverende babbels en het delen van leed.

Bedankt aan Maaike en Veerle voor de interviews die ik mocht gebruiken. Bedankt aan de nalezers, Marijke en Maurits voor hun oog voor detail en aan Roos, Griet, Leen, Joke en Julie die de interviews uittypten. Steven bedankt voor de professionele hand in kaft en lay-out.

Mijn ouders, familie, vrienden en vriendinnen wil ik bedanken voor de stille en luide interesse en aanmoediging in de loop van de jaren. Bedankt voor het begrip dat ik vaak afwezig en weinig sociaal was. Yesmien, Josefien, Diederik, Stijn, Maria bedankt voor jullie bijdrage in het overleven in de hectische periode.

Tot slot maar niet in het minst wil ik de drie mannen bedanken die me nauwst aan het hart liggen. Mathijs en Robrecht, bedankt om me met beide benen bij het echte leven te houden. Ik hoop dat, nu jullie me meer zullen zien overdag, de behoefte om me 's nachts wakker te houden snel wegebt. Johan, bedankt voor het in stilte dragen van ons gezin. Wat ik niet kon, nam jij altijd over. Ik hoop dat ik voor jou nu hetzelfde kan doen en dat we met meer rust onze weg samen kunnen verderzetten.

Curriculum vitea

Sofie Verhaeghe werd geboren op 15 mei 1971 te Roeselare. In 1993 behaalde ze het diploma van gegradueerde ziekenhuisverpleegkundige aan het Hoger Instituut voor Verpleegkunde H. Hart Roeselare. Aansluitend startte ze de opleiding licentiaat in de Medisch-Sociale Wetenschappen, optie Verplegingswetenschap aan de Universiteit Gent. Ze werkte ondertussen als verpleegkundige in het Universitair Ziekenhuis Gent op de afdeling revalidatie na hersentrauma. In 1996 behaalde ze haar diploma van licentiaat in de Medisch-Sociale Wetenschappen en in 1997 behaalde ze het diploma van de academische initiële lerarenopleiding. Gedurende een schooljaar werkte ze als stagebegeleidster in het Technisch Instituut voor Verpleegkunde Ic Dien in Roeselare. Van 1997 tot 1999 werkte ze in de Katho, departement Hoger Instituut voor Verpleegkunde en Biotechnologie. Ze was er lector en jaarcoördinator van het derde jaar ziekenhuisverpleegkunde. Sinds 1999 werkt ze als assistent aan de afdeling Verplegingswetenschap, Vakgroep Maatschappelijke Gezondheidkunde, Universiteit Gent.

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