Betekenis en Waarde van Patiëntperspectief en Patiëntdeskundigheid in de Zorg

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Kintsugi:

The Japanese art of repairing broken pottery with gold.

The mended piece is believed to be more beautiful,

more valuable, and stronger,

because it has transformed through suffering.

(author unknown)

Meaning and Value of Patient Perspective and Patient Expertise in Healthcare

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Lijst met afkortingen

Bv.	Bijvoorbeeld
CI	Confidence Interval
CHIME	Connectedness Hope Identity Meaning Empowerment
ED	Ervaringsdeskundige
ENSPa	Evaluation of Nursing Students by Patients instrument
GGZ	Geestelijke Gezondheidszorg
ICC	Intraclass Correlation Coefficient
R1, R2, etc.	Researcher 1, Researcher 2, etc.

Q1, Q2, etc.	Quote 1, Quote 2, etc.

Voorwoord

De basis van dit proefschrift werd in 2006 gelegd met de opstart van het masterproeftraject: Cliëntenparticipatie in stagefeedback van studenten psychiatrische verpleegkunde, een meerwaarde voor student én cliënt? (Debyser, Defloor, & Grypdonck, 2007). Op dat moment was het denken vanuit patiëntenparticipatie niet gangbaar, eerder bedreigend en in elk geval erg innovatief in Vlaanderen. Het was bij aanvang van dit traject dus absoluut geen evidentie om dit project op te zetten en het fiat te krijgen van de commissie medische ethiek om met deze studie aan de slag te gaan~~.~~ Maar ook enkele jaren later, wanneer er (mede onder impuls van de doctorandus) projectmatige en onderzoeksmatige patiënt-gestuurde initiatieven werden opgezet om de stem van de patiënt nadrukkelijk naar voor te brengen in de zorg, het verpleegkundig onderwijs én het onderwijs voor mensen die hun ervaringskennis als patiënt actief willen inzetten, was het telkens weer een uitdaging om collega's-zorgverleners en beleidsmensen te bewegen in de richting en de geest van waaruit dit proefschrift neergeschreven is. Projectfinanciering vinden bijv. was evenmin een gemakkelijke opdracht om vormingsinitiatieven op te starten voor mensen die hun ervaringen als (ex)-patiënt wensen in te zetten in de geestelijke gezondheidszorg. Zowel de focus van de onderzoeken en projecten als de methodiek waren voor de eerdere traditionele financieringskanalen wat bevreemdend. Gelukkig was er ook erkenning en werd de meerwaarde van dergelijk onderzoek doorheen het traject steeds meer gewaardeerd (Nominatie prijs humane psychiatrische zorg, 2012; reïntegration award, 2013; afstuderen eerste Vlaamse ervaringswerkers in de Geestelijke Gezondheidzorg, 2016).

Dit proefschrift kende een quasi organische groei. In heel nauwe samenwerking met ervaringsdeskundigen werden de projecten en onderzoeken uit dit proefschrift opgezet. De focus van de onderzoeken kwam voort uit hun ervaringen, uit wat zij als barrières en opportuniteiten zagen, uit hun gedrevenheid om de zorgpraktijk en de -opleidingen te veranderen. Er werden initiatieven opgezet en uitgewerkt waar de doctorandus een belangrijke partner was, een motor om te kunnen realiseren wat ervaringsdeskundigen nodig achtten. Nu zijn deze initiatieven een (eerder) normaal onderdeel van de zorgpraktijk geworden en wordt het uitbreiden en opnemen van dergelijke initiatieven gestimuleerd, ondersteund, gefaciliteerd. Waakzaamheid is echter geboden opdat een evolutie naar het eerder normatieve, het gestandaardiseerde en het vanuit de gezondheidszorg gereguleerde niet contraproductief kan werken op de waarde en de betekenis die het patiëntperspectief en ervaringsdeskundigheid kan hebben voor de zorg.

Hogerstaande illustreert hoe er in twee decennia veel veranderd is in de gezondheidszorg. Van patiënten die nauwelijks konden wegen op de zorgverlening tot de situatie nu, waarin patiëntenparticipatie en co-creatie meer en meer dé norm lijken te worden. Het proefschrift is doorheen de verschillende publicaties een illustratie van de veranderende context, het veranderende jargon, de inzichten die zich op erg korte termijn en soms nog wat beperkt onderzocht ‘op de markt’ lijken te zetten. Het illustreert ook hoe het hele discours van ‘de (ex-)patiënt zien als iemand die deskundigheid met zich meedraagt en de betekenis hiervan in de zorg’, in een korte tijdsperiode vorm kreeg. Een nadeel hiervan was dat het bijzonder lastig was om een coherent begrippenkader op te bouwen dat als rode draad gebruikt kan worden doorheen dit hele proefschrift. Begrippen als het patiëntperspectief, ervaringskennis, patiënt expertise, ervaringsdeskundigheid evolueerden immers mee op het ritme van nieuwe kennis die wereldwijd en in diverse domeinen rond deze topics gegenereerd werd. Maar je kan het ook positief bekijken: de snelheid van deze evolutie illustreert de kracht en de dynamiek die (ex-)patiënten in gang kunnen zetten.

.

Hoofdstuk 1

Patiëntperspectief en patiëntdeskundigheid in de zorg

1. Inleiding

Het actief betrekken van patiënten[1] in hun eigen zorg en in de zorgverlening algemeen staan vandaag hoog op de agenda. Enkele evoluties hebben hiertoe bijgedragen. Zo is er in de geestelijke gezondheidszorg (GGZ) een shift van een eerder paternalistische, institutionele psychiatrie met een sterke medische benadering naar een samenlevingsgerichte zorg met focus op empowerment en patiëntenparticipatie (Mancini & Lawson 2011; Nelson et al. 1998). In de GGZ heeft vooral de herstelvisie (Anthony, 1993) het besef versterkt dat patiënten zelf een actieve rol spelen in het omgaan met hun ziekte of problematiek (Higgins et al. 2016). In de herstelvisie staat het valoriseren van de ervaringsdeskundigheid van de patiënt en naastbetrokkenen bij het herstelproces centraal (Debyser, Deproost, Verhaeghe & Verkest 2014). Gevolg hiervan is dat er in de geestelijke gezondheidzorg een steeds groter wordende behoefte ontstaat aan participatie van personen die beschikken over ervarings- en hersteldeskundigheid (Geraghty et al. 2011). Deze ervaringsdeskundigen (ED) benutten hun doorleefde ervaring met opname, zorg, behandeling, ontslag, ziekte, herstel, enz. om zeer gevarieerde rollen op te nemen binnen diverse domeinen van de gezondheids- en welzijnszorg. Het zijn rollen die zowel op micro-, meso- en macroniveau ingevuld en uitgebouwd kunnen worden (Wallcraft, 2012).

Maar ook in de algemene gezondheidszorg zien we diezelfde beweging richting het actief betrekken van patiënten in zorg en zorgverlening. Onder impuls van het chronisch zorgmodel (Wagner et al. 2001) is zelfmanagement een belangrijk aandachtsgebied geworden bij mensen met chronische aandoeningen (Duprez 2018). Het versterken van het zelfmanagement is erop gericht de persoon te leren omgaan met zijn ziekte of beperking zodat hij of zij de aandoening optimaal kan inpassen in zijn

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[1] We opteren om in deze dissertatie te spreken over ‘patiënt’ om redenen van eenvoud en om niet voorbij te gaan aan het lijden dat inherent gerelateerd is aan “het patiënt-zijn”. Tegelijk beseffen we hoe de keuze voor deze aanspreekvorm de krachten en mogelijkheden die in iedere patiënt aanwezig zijn mogelijks op een tweede plan kan plaatsen.

of haar leven (CBO 2014). De focus op zelfmanagement heeft in het Verenigd Koninkrijk geleid tot de oprichting van zogenaamde *expert patient* programma's. Deze programma's beogen patiënten tot expert te maken in het dagelijks managen van de chronische conditie die ze met zich meedragen (Wilson et al. 2006). Op vandaag is de rol van deze *expert-patiënten* zodanig geëvolueerd dat ze ook medepatiënten trainen en actief ondersteunen in het omgaan met hun ziekte (Boulet 2016). Naast het bevorderen van het zelfmanagement is *patient engagement* een steeds belangrijker wordende hoeksteen van kwaliteitszorg binnen ziekenhuizen (Bombard et al. 2018). Patient engagement gaat om zorgverleners en patiënten die samen de verantwoordelijkheid nemen om de zorgverlening te verbeteren (Prey et al. 2013).

In het vervolg van de inleiding wordt het patiëntperspectief en het concept patiëntdeskundigheid verkend, gesitueerd en gepositioneerd binnen huidige theorieën en concepten. Vervolgens willen we kansen en uitdagingen in kaart brengen. Kanttekening hierbij is dat patiëntdeskundigheid als concept nog maar beperkt beschreven is (Burda et al. 2016; Castro 2018). Als het al beschreven wordt, dan wordt het steeds geplaatst tegenover vormen van professionele deskundigheid.

2. Inleidende verheldering van gekozen terminologie

Patiëntdeskundigheid en ervaringsdeskundigheid

Patiëntdeskundigheid verwijst naar de Nederlandstalige vertaling van het begrip patiënt *expertise*. Etymologisch kan in het begrip patient expertise naast het woord patiënt ook het woord expert herkend worden, afkomstig van het Latijnse woord *expertus*, wat in het Nederlands 'ervaren' betekent (Oxford online woordenboek). Vrij vertaald kan dus patiëntdeskundigheid omschreven worden als mensen die experientiële deskundigheid opgebouwd hebben als patiënt. Burda et al. (2016) omschrijven ervaringsdeskundigheid als het gebruik maken van de kennis, ervaringen en deskundigheid die men met zich meedraagt als patiënt in relatie tot anderen. Zo kan men als patiënt de eigen verworven ervaringsdeskundigheid inzetten om andere patiënten te ondersteunen in het dagelijks omgaan met de gevolgen van hun chronische ziekte.

Echter, ervaringskennis en ervaringsdeskundigheid als begrippen zijn meer gangbaar binnen de geestelijke gezondheidszorg en welzijnszorg (Castro 2018). Patiëntkennis en patiëntdeskundigheid zijn begrippen die vooral meer gehanteerd worden binnen de algemene gezondheidszorg.

Omwille van hun identieke betekenis, zullen in dit proefschrift de begrippen ervaringsdeskundigheid en patiëntdeskundigheid door elkaar gebruikt worden, met evenwel een voorkeur voor het begrip patiëntdeskundigheid. Dit komt omdat we juist de betekenis van het patiëntperspectief in de zorg willen benadrukken. De particuliere kennis die de patiënt vanuit zijn rol als patiënt opbouwt, ontwikkelt en inzetbaar maakt in de klinische zorgpraktijk is immers de centrale focus van dit proefschrift.

Patiënt versus zorgverlener/ professional

We opteren om in dit proefschrift het woord patiënt te gebruiken. Het woord patiënt stamt etymologisch af van het Latijnse woord *patientia*, wat lijden, geduld en volharding betekent (Oxford online woordenboek) en wat ons wel toepasselijk lijkt binnen een proefschrift dat handelt over de ervaringen die patiënten en ervaringswerkers inzetten in de zorg. En dus niet voorbij te gaan aan de kwetsbaarheid (fysisch, psychisch, sociaal, combinatie van) die ze met zich meedragen. We beseffen echter ook dat het gebruik van dit woord de mens met een psychiatrische of andere problematiek mogelijks kan reduceren tot een zieke. We opteren er toch voor om het woord patiënt te gebruiken, benadrukkend dat we daarmee de mens bedoelen die eveneens in het woord patiënt vervat zou moeten zijn. Ook de andere rollen die deze patiënt met zich meedraagt verdienen de nodige aandacht, maar dit geldt ook voor de zorgverlener/professional. Net zoals een patiënt zorgverlener kan zijn, kan een zorgverlener ook ervaringen met zich meedragen als patiënt of als naastbetrokkene. We verwijzen in dit kader naar de studie van Oates et al. (2018) waarbij getuigenissen van zorgverleners opgetekend werden die in hun persoonlijk leven ervaringen hadden met psychische kwetsbaarheid.

Expertise: een gelaagd en niet neutraal begrip

We hadden het reeds over de Latijnse betekenis van het woord expertus. Expert heeft echter ook nog een tweede betekenis. Als zelfstandig naamwoord in het Nederlands wordt expert in het ‘Oxford online woordenboek’ omschreven als: 1) iemand die een grote kennis of een specifieke vaardigheid met zich meedraagt in een welbepaald domein. Het antoniem van expert is volgens dezelfde bron *layman*, wat vrij vertaald *leek* betekent. Antoniemen van expert zijn: non-expert, non-professional, amateur, non-specialist, man van de straat. Expertise kan omschreven worden als het verwerven van een steeds hogere vorm van deskundigheid door het voortdurend integreren van kennis en ervaring (Benna & 0’Boyle 2013; Sanderson & Angouri 2013). Expertise kan vanuit deze definitie dus opgevat worden als een ontwikkelingsproces dat fasegewijs verloopt. Een bekend voorbeeld van dit fasegewijs verloop van expertise binnen de verpleegkunde is het Dreyfus-model zoals ontwikkeld door Patricia Benner (Benner 1982). Expertise ontwikkelt zich in interactie met een bepaalde praktijkcontext. De exclusiviteit van de opgebouwde expertise geeft de eigenaar status en identiteit en benadrukt het professionalisme van een bepaalde beroepsgroep (Sanderson & Angouri 2013). Expertise is geen neutraal begrip. Zo kan expertise geclaimd en gedefinieerd worden door professionele instituties en beroepsbeoefenaars (bv. artsen) (Oborn et al. 2019). Expertise wordt zo een machtsmiddel dat ingezet wordt om de dominantie binnen een bepaald domein te behouden. Dergelijke begripshantering verhindert of vertraagt fundamentele veranderingen in de (context van de) praktijkvoering en dwingt degenen zonder of met niet erkende expertise in een underdogpositie. Toch zien we dat ook patiëntengroepen sinds eind de twintigste eeuw deze expertstatus meer en meer opeisen. We refereerden reeds naar de expert-patiënten, die zichzelf en lotgenoten met een chronische ziekte ondersteunen in het adequaat omgaan met hun eigen conditie (Kennedy et al. 2007). Het zichzelf definiëren als expert wordt echter ook bekritiseerd. Zo kan het de kloof tussen patiënt en hulpverlener vergroten en dus niet bijdragen aan een toegankelijke en democratisch georganiseerde gezondheidszorg (Prior 2003). Repper & Carter (2011) benadrukken dan weer in hun systematische review over ervaringsdeskundigheid dat ervaringswerkers zich niet dienen te meten met professionele zorgverleners, maar juist ernaar dienen te streven om een deskundige te zijn in het *niet expert* zijn en hoe dit heel wat deskundigheid vraagt. Het zijn bevindingen die aansluiten bij het concept *patient experience* dat nadruk legt op de betekenis die zorgverleners dienen te geven aan de ervaringen die patiënten met zich meedragen (Warne & Mc Andrew 2007).

3. Genese van patiëntdeskundigheid

Genese is een uit het Frans vertaald woord dat afkomstig is van het Griekse woord *genesis*, wat letterlijk vertaald kan worden als ‘de oorsprong, ‘de wording’ (Van Dale 2008). In deze paragraaf willen we dus zicht krijgen op hoe patiëntdeskundigheid ontstaat en zich vervolgens verder ontwikkelt en wat hierover geweten is.

Patiënten bouwen al een bepaalde vorm van kennis op zonder dat ze daar besef van hebben. Uotinen (2010) omschrijft deze kennis als ruwe, ongefilterde kennis die door het lichaam en de zintuigen van de patiënt constant geproduceerd wordt en die in normale omstandigheden verborgen blijft voor de betrokkene. Maar die in een noodsituatie, wanneer het bewust denken uitgeschakeld is, een primaire bron van kennis wordt (Uotinen 2010).

De kennis die patiënten over hun ziekte/problematiek met zich meedragen gaat professionele kennis vooraf. Zo hebben patiënten bv. weet van aspecten van hun ziekte of problematiek nog voordat deze gedeeld werd met hun behandelaars. Polanyi (1958, 1966) omschrijft deze vorm van kennis als stille kennis. Patiënten zullen bv. niet zomaar praten over hun *non-compliant* gedrag. Ook pure belevingskennis is iets waar patiënten moeilijk met hulpverleners zullen over praten, zoals bv. hoe het voelt en wat het met je doet wanneer je in jezelf snijdt (Debyser et al. 2011). Patiënten delen ook bepaalde kennis over zichzelf met zorgverleners. Denk maar aan hun persoonlijke voorkeuren, wensen, verwachtingen, levensstijl-gerelateerde aspecten, prioriteiten, waarden, enz. Deze kennis en ervaringen die patiënten verwerven over hun ziekte wordt steeds meer gedeeld met lotgenoten op het internet, bv. via allerhande online fora (Foster 2016). Onderzoek naar de effectiviteit van deze fora staat nog in zijn kinderschoenen. Zo is er bv. nog onvoldoende bewijs of actieve betrokkenheid in *peer to peer support-fora* al dan niet een rol spelen in het terugdringen van psychiatrische symptomen bij jongeren. Toch betekent dit niet dat deze fora niet gewaardeerd werden door de participerende jongeren. De praktische bruikbaarheid van de informatie en steun die met mekaar gedeeld wordt, het gemak van connectie die men kan maken met mensen die zich in een gelijkaardige situatie bevinden en de garantie dat het forum een veilige plaats is om met mekaar in gesprek te gaan, waren hierin de belangrijkste meespelende elementen (Ridout & Campbell 2018). Online *peer*-contacten blijken ook vaak een stimulans en ondersteuning voor mensen met ernstige GGZ-problemen om hulp en ondersteuning te zoeken voor hun problemen. Voorwaarde is wel dat het online forum een veilige omgeving is zodat negatieve vormen van communicatie of informatie geen kans maken (Naslund et al. 2016).

Vanuit het traject dat patiënten doorlopen, doen patiënten heel wat ervaring en wijsheid op met betrekking tot de diagnosestelling van hun ziekte/problematiek, de behandeling ervan, het herstel, de aanpak. Ze worden ook blootgesteld aan diverse zorgverleners, zorgsystemen (bv. dagbehandeling, residentiële behandeling) en modellen van zorgorganisatie. Verder geven of krijgen ze steun doorheen hun traject van lotgenoten. Prior (2003) beschrijft in dit kader hoe patiëntdeskundigheid ontstaat als gevolg van een poging om de onontkoombare aspecten van de chronische conditie waar men aan blootgesteld wordt te integreren met de complexiteit van het dagelijks leven en de persoonlijke activiteiten die men onderneemt. Het is een deskundigheid die ook ingezet kan worden ten behoeve van anderen (Civan & Pratt 2007). Zo bouwen (ex-)GGZ-patiënten doorheen hun herstel een deskundigheid op in het leven met hun psychische aandoening[2]. Vanuit deze opgebouwde specifieke expertise worden ze ervaringsdeskundigen[3] genoemd (Van Erp et al. 2011). In toenemende mate gaan ED aan de slag als ervaringswerker. In deze functie stellen ED hun expertise ten dienste van de GGZ. Volgens Van Haaster et al. (2013, p. 14) moeten ervaringswerkers aan bepaalde eisen voldoen: 'Je hebt

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[2] Het is 'ervaringsdeskundigheid' die wordt opgebouwd door persoonlijke ervaringen ernstig te nemen, deze voor zichzelf te verwerken en daarop te reflecteren. Bovendien vereist deze vorm van deskundigheid openheid voor het herstelproces van lotgenoten. Dit krijgt vorm door te luisteren naar hun ervaringen, deze ernstig te nemen en ook daarop te reflecteren (Van Erp *et al.* 2011, Van Haaster *et al.* 2013).

[3] Bemerk dat dit vooral een begrip is dat gangbaar is binnen de GGZ.

jezelf als het ware ‘kundig’ gemaakt om je eigen ervaringen en die van anderen te kunnen toepassen in een bepaalde (beroeps)praktijk.’ Ervaringswerkers worden ingezet in verschillende domeinen binnen de GGZ. Ze nemen er taken op zoals het ondersteunen van het herstelproces van lotgenoten; participeren in een team met hulpverleners; geven van voorlichting en psycho-educatie; adviseren bij initiatieven voor herstel-ondersteunende zorg (Van Bakel et al. 2013, Van Haaster et al. 2013).

4. Bronnen van kennis die vorm geven aan patiënt- of professionele deskundigheid

De kennis die professionele zorgverleners inzetten, is zowel propositioneel als procedureel van aard, maar kan ook uit de ervaring komen (Caron-Flinterman et al. 2005). Volgens Hartzler & Pratt (2011) is het de kennis die professionelen verwerven als gevolg van hun werk in de klinische praktijk, training en opleiding. Professionele zorgverleners zetten in verhouding vooral meer propositionele kennis dan ervaringskennis in tijdens hun klinische praktijk (Caron-Flinterman et al. 2005). Polanyi (1966) spreekt ook wel van expliciete of tastbare kennis, waarmee aangegeven wordt dat het kennis is die verkregen wordt door logisch te redeneren en die geverifieerd kan worden door empirische evidentie. Patiënten zetten in vergelijking met professionele hulpverleners meer impliciete of niet tastbare kennis in. Het gaat bv. over die kennis die patiënten nodig hebben om ervoor te zorgen dat wat ze zelf bv. als hun voorkeursbehandeling zien, ook toegepast wordt (Foster, 2016). Of de impliciete kennis die ervaringswerkers met zich meedragen doordat ze weet hebben van wat het met je doet als je familie- of werkomgeving bv. afwijzend reageren op je psychiatrische problematiek (Oborn et al. 2019). Ervaringswerkers zetten dus meer ervaringskennis in die persoonlijk verworven werd (Caron-Flinterman et al. 2005). Collins & Evans (2007) beschrijven deze ervaringskennis als interactionele kennis, juist omdat het kennis is die zich ontwikkelt in een sociale context. Het is expertise waar ervaringswerkers mee aan de slag gaan om tot een verbindend contact te komen met psychiatrische patiënten op basis van het wederzijds delen van ervaringen met betrekking tot het leven met een psychiatrische kwetsbaarheid (Oborn et al. 2019). De kennis die patiënten met mekaar delen is meestal ook heel praktische kennis, die hier en nu gerelateerd en holistisch van inslag is (Borkman 1976). Kennis gegenereerd door patiënten betreft ook kennis die uit de eerste hand verkregen wordt. Daar waar zorgverleners op basis van diezelfde kennis hiermee pas uit tweede hand aan de slag gaan (Proudfoot et al. 2012; Hutchison et al. 2017). Kennis die professionelen inzetten, is vaak ook meer technische kennis (Tyreman 2005). Volgens Prior (2003) hebben patiënten in tegenstelling tot professionele hulpverleners niet de technische deskundigheid om de behandeling die ze krijgen te beoordelen. Sanderson & Angouri (2013) nuanceren deze stelling. Op basis van hun kwalitatief onderzoek waarin ze expert-patiënten met reumatoïde artritis bevroegen rond hun gezondheid, stelden ze vast dat deze patiënten heel wat up-to-date kennis hebben over hun ziekte. Het is kennis die deze patiënten in staat stelt om hun chronische conditie over de tijd zorgvuldig te monitoren. Vooral in geval van minder voorkomende ziektes kunnen patiënten zelfs over kennis beschikken die nog niet bekend is bij hulpverleners (p. 179, P.G. Cooper in het Editoral Nursing Forum (2008)).

Doordat professionele kennis geacht wordt gestoeld te zijn op meer objectieve en accurate kennis, wordt ze soms als superieur gezien ten opzichte van de (subjectieve) ervaringskennis die patiënten met zich meedragen (Prior 2003). Caron-Flinterman et al. (2005) benadrukken om in dit discours bewust te zijn van het paradigma dat men hanteert in het evalueren van kennisbronnen. Zo kan iemand vanuit een meer positivistisch geïnspireerd denkkader naar ervaringskennis kijken, waardoor deze persoon dus normatief zal denken over de validiteit van ervaringskennis. Maar evengoed kan iemand een relativistisch perspectief innemen naar kennisontwikkeling en dus aandacht hebben voor hoe bv. culturele waarden en/of persoonlijke interesses meespelen in kennisontwikkeling. Een meer pragmatisch standpunt is dus gerechtvaardigd, waarbij kennis onderscheiden wordt van wat geen kennis is. Door te focussen op de nuttigheid van deze ervaringskennis voor de context waarin de kennis ingezet wordt en door de complementariteit van deze kennisbron in relatie tot professionele kennis mee te nemen, kan deze pragmatiek in de praktijk gebracht worden (Caron-Flinterman et al. 2005).

Professionele expertise wordt soms ook in één adem genoemd met professionalisme. Hilton & Slotnick (2005) beschrijven hoe studenten geneeskunde professionalisme kunnen verwerven in domeinen zoals ethische praktijkvoering, zelfbewustzijn, verantwoordelijkheid opnemen voor de beslissingen die men neemt, respect voor patiënten, teamgerichtheid en het opnemen van sociale verantwoordelijkheid. Volgens deze auteurs is het summum van professionalisme wanneer men over praktische wijsheid (*phronesis*) beschikt. Deze praktische wijsheid ontstaat wanneer men onder invloed van positieve rolmodellen gestimuleerd wordt te reflecteren over de kennis en de ervaring die men opdoet als arts. Praktische wijsheid veronderstelt dat men in staat is om de zes domeinen waarbinnen men professionalisme kan verwerven, probeert te integreren in praktijksituaties. Concreet betekent dit bv. dat een arts in staat is om in een kritieke situatie een delicate beslissing te nemen en de onzekerheid die hiermee gepaard gaat, kan hanteren en hiervoor verantwoordelijkheid kan opnemen. Hilton & Slotnick (2005) spreken van proto-professionalisering om het rijpingsproces aan te duiden vanaf start van de opleiding totdat men een volwaardige professional geworden is. Proto-professionalisering is ook een term die gebruikt wordt om aan te duiden dat leken de begrippen en omgangsvormen die professionals gebruiken gaan overnemen en hun problemen vertalen in medische ziektes of psychische problemen (de Swaan 1982).

5. Ervaringskennis, patiëntkennis & ervaringsdeskundigheid

We gaven hoger reeds aan hoe ervaringskennis en ervaringsdeskundigheid begrippen zijn die vooral in de GGZ ingang gevonden hebben (Castro 2018). Patiënten ontwikkelen gewoonlijk eerst subjectieve kennis over hun ziekte/problematiek vooraleer ze met meer formele kennis in aanraking komen. Deze subjectieve kennis ontwikkelen ze vanuit het (zelf)bewust ervaren van hun ziekte/problematiek. Deze vorm van kennis wordt ervaringskennis genoemd (Borkman 1976). Het is kennis die niet los kan gezien worden van het leven dat de patiënten leiden en de sociale context waarin ze dit leven vorm geven (Oborn et al. 2019). De psychose die ze doormaken bv. is gerelateerd aan een specifieke tijd en plaats en de invloed van het ziektebeeld op hun sociale relaties en vice versa. In die zin is het kennis die context- en situatiespecifiek is (Caron-Flinterman et al. 2005).

Pols (2014) spreekt niet zozeer van ervaringskennis, maar wel van patiëntkennis. Ze benoemt deze kennis als een vorm van kennis die patiënten benutten om de meer medische en technische kennis te vertalen en praktisch bruikbaar te maken in het dagelijks leven. Ze wijst er bv. op hoe COPD-patiënten vaak heel creatieve oplossingen bedenken om dagelijkse routines te hanteren en te managen ondanks de beperkingen die ze ervaren als gevolg van hun COPD. Het is kennis die ze delen met lotgenoten. Het is kennis die Pols als *know-how* en *know-now* kennis (nu-kennis) benoemt en die patiënten nodig hebben voor hun zelfzorg in het leven met hun chronische ziekte (Pols 2014). Ervaringsdeskundigheid is een vorm van ervaringskennis die van een hogere orde is, in die zin dat de eigen ervaringskennis nu ingezet wordt om lotgenoten te ondersteunen die zich in eenzelfde situatie bevinden (Davidson et al. 2005; Repper & Carter 2011). Gillard et al. (2013) koppelt het begrip aan de herstelbenadering. Volgens deze auteurs hebben ervaringsdeskundigen[4] het vermogen ontwikkeld om op basis van hun eigen herstelervaring ruimte te maken voor het herstel van anderen. Specifiek aan ervaringswerkers is dat ze over gedeelde kennis beschikken vanuit bv. weten wat het is om psychofarmaca in te nemen of opgenomen te worden onder dwang. Ze hebben dus een soort van uniek socialisatieproces met patiënten gemeen vanuit het delen van gemeenschappelijke ervaringen die tijd en plaats specifiek zijn (Oborn et al. 2019). In Vlaanderen & Nederland wordt voor het onderscheid tussen ervaringskennis & ervaringsdeskundigheid vaak verwezen naar Hilko Timmer (Hilko Timmer in Van Erp et al. 2011). Ook Timmer verwijst naar het kunnen overstijgen van de eigen herstelervaring om van ervaringsdeskundigheid te spreken. Verder wordt ook nadruk gelegd op reflectie en vorming als

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[4] Gillard et al. (2013) geven in hun studie hun voorkeur aan het begrip *peer worker* (en dus niet *expert by experience*) omdat het begrip zowel de werkgerelateerde aspecten als de generieke betekenis van ervaringswerk benadrukt. We volgen deze redenering en zullen verder in dit proefschrift opteren om te spreken van "ervaringswerkers".

belangrijke opstap in het verwerven van ervaringsdeskundigheid. Castro (2018) benadrukt hoe ervaringsdeskundigen het vermogen ontwikkelden om hun kennis bruikbaar te maken voor anderen. Ze ontwikkelen deze deskundigheid vanuit het kunnen loslaten van het eigen perspectief, maar ook door toegang te hebben tot de ervaringskennis van anderen, bijvoorbeeld via een patiëntenvereniging. In dit kader wordt ook gesproken over collectieve ervaringsdeskundigheid die op micro-, meso-, macro en metaniveau ingezet kan worden. Ervaringsdeskundigheid differentieert zich daardoor van peer support. De inzet van ervaringsdeskundigheid is lijkt niet alleen belangrijk voor de uitbouw van patiëntenparticipatie en het toewerken naar een grotere patiëntgerichtheid, maar ook om empowerment op de genoemde niveaus te bevorderen (Castro 2018). Empowerment wordt binnen de herstelvisie als een sleutelelement gezien om het persoonlijk herstel van mensen met een psychische kwetsbaarheid te bevorderen (Winsper et al. 2019). Zorgverleners kunnen empowerment bevorderen wanneer ze mensen ondersteunen in het (her)opnemen van hun persoonlijke verantwoordelijkheid, aandacht geven aan het leven dat ze willen leven en focussen op de krachten en mogelijkheden van patiënten bij henzelf en in hun omgeving (Leamy et al. 2011).

6. Verpleegkundigen en ervaringsdeskundigheid

In België zijn in vergelijking met de ons omringende landen zoals Nederland en het Verenigd Koninkrijk een veel kleiner aantal ervaringswerkers in actief dienstverband tewerkgesteld in de GGZ. Hun aantal neemt wel jaar na jaar toe. Er mag verwacht worden dat ze in steeds meer posities terecht zullen komen waar ze direct of indirect zullen samenwerken met voornamelijk verpleegkundigen. Verpleegkundigen vormen immers de grootste groep van zorgverleners binnen de GGZ. Verpleegkundigen en ervaringswerkers delen gemeenschappelijke werkervaringen (Hurley et al. 2016). Ze zijn mekaars natuurlijke bondgenoten, omdat ze beiden vertrekken vanuit de hier-en-nu ervaringen van de patiënt (en context) en de gevolgen hiervan op hun dagelijks leven, gezondheid en welbevinden. Verder is het ook zo dat ze allebei dicht bij de patiënt staan (Hurley et al. 2016; Cleary et al. 2011). Onderzoek laat zien dat er evenwel barrières zijn die een partnership in de weg staan tussen verpleegkundigen en ervaringswerkers. McCann et al. (2006) toetsten de attitudes van GGZ-zorgverleners ten aanzien van de actieve participatie van ervaringswerkers binnen een residentiële psychiatrische setting. Uit de studie kwam naar voor dat de subgroep verpleegkundigen vooral een onzekere en ambivalente houding aannam ten aanzien van de actieve participatie van ervaringsdeskundigen op de afdeling. Deze houding kwam vooral naar voor wanneer de ervaringswerkers taken en rollen opnamen die overlapten met rollen en taken die de GGZ-verpleegkundigen beschouwden als behorend tot hun professiedomein. Verpleegkundigen bleken verder ook bevreesd te zijn dat toetreden van (goedkopere) ervaringswerkers tot het reguliere werkveld hun tewerkstelling in het gedrang zal brengen (Moran et al. 2013). Repper & Carter (2011) inventariseerden hoe ook andere opvattingen bij zorgverleners de integratie van ervaringswerk in de praktijk kunnen belemmeren, zoals bv. dat het binnenhalen van ervaringswerkers betekent dat kostbare tijd verloren zal gaan aan coachen van ervaringswerkers of dat ervaringswerkers kwetsbare mensen blijven waar niet kan op gerekend worden. Tegenover deze potentiële bedreigingen staan ook kansen die op zich een pleidooi zijn om te investeren in het onderhouden van collaboratieve relaties met ervaringswerkers. Ervaringswerkers hebben bv. een andere kijk op risicogedrag en wijzen bv. op hoe risico's nemen inherent is aan het leven en dus gevaloriseerd dient te worden, ook binnen de psychiatrische zorgverlening (Holley et al. 2015). Hun aandacht voor hun persoonlijk welbevinden en welzijn, hun gevoeligheid voor wat als stigmatiserend ervaren kan worden of het belang van ondersteuning in de post-ontslagfase, zijn maar enkele voorbeelden van hoe ervaringswerkers van complementaire waarde kunnen zijn in een samenwerkingsverband met bv. verpleegkundigen (Hurley et al. 2016; Moll et al. 2009).

7. Doel van dit proefschrift en algemeen overzicht

Doel van deze dissertatie is om een beter inzicht te verwerven in de specifieke betekenis en waarde van patiëntdeskundigheid in de zorg. Uitgangspunt hierbij is het transitieproces van patiënt tot ervaringswerker, met aandacht voor de opeenvolgende fases die een patiënt doorloopt in z'n ontwikkeling tot ervaringswerker. In dit kader is het dus interessant om de voorwaarden in kaart te brengen die noodzakelijk zijn om deze patiëntdeskundigheid tot ontwikkeling te laten komen. Maar ook hoe patiëntdeskundigheid ontkiemt, welke levenscyclus het kent, of er al dan niet gradaties zijn in patiëntdeskundigheid, wat patiëntdeskundigheid kenmerkt, de (potentiële) waarde en betekenis van patiëntdeskundigheid en de implicaties hiervan voor het samenwerken met ervaringswerkers, zijn voorwerp van studie.

Overkoepelende onderzoeksvragen zijn:

- Welke factoren hollen patiëntdeskundigheid uit?
- Welke factoren versterken of verrijken patiëntdeskundigheid?
- Welke dynamieken spelen een rol die patiëntdeskundigheid valoriseren en/of denatureren?

De dissertatie is opgebouwd in lijn met de ontwikkeling die een patiënt doorloopt tijdens zijn proces van patiënt tot ervaringswerker (zie tabel 1).

Table 1: Overview of studies and methods in each chapter of this dissertation

Chapter	Title	Research questions/ Objectives	Methodology
2.	Involvement of inpatient mental health clients in the practical training and assessment of mental health nursing students: Can it benefit clients and students	(1) What conditions influence gathering of meaningful client feedback to enhance the student's learning process and client's wellbeing? (2) Does the use of the developed practical model for client feedback lead to positive experiences, and if so, under what condition? (3) To what extent is a client's feedback on the student's work performance consistent with feedback from the mentor (nurse from the ward), the teacher and the student?	Qualitative study. Semi-structured interviews with patients, students, nurses & teachers (n = 15). Grounded theory study.
3.	The Evaluation of Nursing Students by Patients instrument (ENSPa): development and validation	To develop and validate an instrument that enables patients to evaluate nursing students during their internship.	Mixed method study. A three-phased validation process was conducted: (1) Development of instrument through literature and patient interviews; (2) Content and response process validation by use of cognitive interviews and pilot-testing;

			(3) Testing construct validation and reliability of the instrument by 244 hospitalized patients.
4.	Constructing a positive identity: A qualitative study of the driving forces of peer workers in mental health-care systems	What are the driving forces of individuals with lived experience of mental health problems to fulfil a position as a peer worker in mental health-care systems?’	Qualitative study. Semi-structured interviews with 14 peer workers. Grounded theory study.
5.	Peer workers’ perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review.	What are peer workers’ perceptions and experiences of barriers to the implementation of peer worker roles in mental health services? (exploring how peer workers’ perspectives are related to: (1) the nature of the innovation (in this study interpreted as characteristics of peer workers and peer worker roles), (2) the involved professional staff, (3) the involved service users, and the (4) social, (5) organizational, and (6) economic and political context).	Literature review. Electronic databases were searched between October 2014 and December 2015 including PubMed, CINAHL, Web of Science, The Cochrane Library, and PsycARTICLES.
6.	The transition from patient to mental health peer worker: A grounded theory approach	To investigate how peer workers experience their transition, and which processes facilitate it.	Qualitative study. Semi-structured interviews with 17 peer workers. Grounded theory study.
7.	Mental health nurses and mental health peer workers: Self-perceptions of role-related clinical competences	To understand how both groups perceive their own respective role-related competences.	Qualitative study with principles of the critical incident technique. 132 cases were described.

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Hoofdstuk 2

Involvement of inpatient mental health clients in the practical training and assessment of mental health nursing students: Can it benefit clients and students?

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Summary

Even though the central position of the client has been recognized in psychiatric nursing education, the client is seldom formally involved in the feedback provided to students during practical training. This research paper focuses on three questions: (1) What conditions support the gathering of meaningful client feedback to enhance the student's learning process and client's wellbeing? (2) Does the use of the practical model for client feedback lead to positive experiences, and if so, under what conditions? (3) To what extent is a client's feedback on the student's work performance, consistent with feedback from the mentor (nurse from the ward), the teacher and the student? Based on a literature review, participatory observation and contacts with experts, a practical model was developed to elicit client feedback. Using this model in two psychiatric inpatient services, clients were actively and formally involved in providing feedback to four, final year psychiatric nursing students. Clients, nurses, teachers and students were interviewed and data were analyzed using a qualitative explorative research approach. Analyses revealed that client feedback becomes meaningful in a safe environment created by the psychiatric nurse. Client feedback generates a learning effect for the student and supports the student's recognition of the value and vulnerability of the psychiatric client.

1. Introduction

1.1. Problem statement

Although client participation has become increasingly important in the nurse–client relationship, until now the active and formal input of clients in assessing the practical training of student nurses during their psychiatric assignment has not been directly sought. This lack of involvement of psychiatric clients is inconsistent with the idea that clients are the experts of their own condition (Repper & Breeze 2007), and that because they experience nursing care first hand, their views should not be neglected in the assessment process of nursing students. The growing body of knowledge on user and carer involvement in nursing education sets the tone for further development (Stringer et al. 2008).

In the study reported here, the feasibility of psychiatric client involvement in giving feedback to nursing students was explored. A practical model was developed, and the study focused on the following three main research questions: (1) What conditions influence gathering of meaningful client feedback to enhance the student's learning process and client's wellbeing? (2) Does the use of the practical model for client feedback lead to positive experiences, and if so, under what condition? and (3) To what extent is a client's feedback on the student's work performance consistent with feedback from the mentor (nurse from the ward), the teacher and the student?

1.2. Literature review and designing a framework

An explorative literature review was carried out using the databases MEDLINE, CINAHL and Psycarticles for the 1990–2009 period. Our search strategy focused on reviews and consisted of the following combination of keywords: ‘psychiatric nursing’, ‘education assessment’, ‘user involvement’ and ‘student’. The retrieved references were then selected by title and abstract with the following criteria for inclusion: 1) studies that dealt with user involvement in nursing education and in psychiatric nursing in particular, 2) studies that provided insight into the student–patient relationship during practical training, 3) studies that examined how nursing students are assessed during practical training. Twenty-two articles remained after selection.

Despite the increase of literature on user involvement in medical professions and social care (Stringer et al. 2008), literature examining the active contribution of clients in assessing nursing students, is limited (Suikkala & Leino-Kilpi 2005). There is little evidence on how client feedback should be obtained (Repper & Breeze 2007). The exploration of the literature, revealed, however, some critical issues on involving clients in student assessment. These issues can be divided into three categories: those relating to the client, to the mentor or to the student. Client-related issues included the representativeness of the client (Felton & Stickley 2004), the interferences of psychopathology or personality (Hansen et al. 2004), stress for the clients and the stereotype (of prejudice) that clients generate poor, valueless feedback (Forrest et al. 2000). Issues also included the fear that clients will use the student assessment time as a soapbox for putting their problems or concerns in the center instead of paying attention to the student's work performance during practical training (Mc Andrew & Samociuk 2003). Mentor related issues included the insufficient skills or insufficient time to assist clients in their role to assess students (Hickey & Kipping 1998; Repper & Breeze 2007; Lathlean et al. 2006). Student related issues included the countertransference during the nurse–patient relation- ship which can affect the assessment process. For instance, students may put pressure on clients to express positive feedback or they may internalize client feedback (Morgan & Sanggaran 1997). In addition to these three main categories of issues, other issues mentioned in literature on client feedback are: the exploitation of clients for educational purposes and confidentiality (Forrest et al. 2000).

Many of the obstacles mentioned above can be overcome. Hanley et al. (2004) discussed the issue of representativeness by stating that it is important to realize that only one perspective is offered and that a range of perspectives can be provided, for example by involving more clients in the student's assessment. Although client feedback may be stressful for some clients, it is found that it is also rewarding and helpful for clients (Ahuja & Williams 2005; Wood and Wilson-Barnett 1999). It was also noted that guaranteeing voluntary participation of clients in providing feedback can avoid stress (Hickey & Kipping 1998), and if clients feel stressed by the assessment procedure, stress could be reduced by debriefing sessions after the feedback (Twinn 1995). Finally, the literature on user and carer involvement in educational matters underlines the significance of preparing clients, giving full attention to their needs and concerns and actively involving them in the setting up of the entire process. It was noted that clients need to be taken seriously and educators need to believe in what clients can offer (Le Var 2002; Levin 2004; Wood and Wilson-Barnett 1999; Happell & Roper 2003).

Since literature on involving clients in the assessment process during nursing education is scarce, it is not surprising that there is little evidence that this is affecting the outcome of the learning process and the quality of care (Lathlean et al. 2006). Also, there is no clear view on the weight that should be given to assessment of clients within the overall assessment scheme (Norman et al. 2002). However, although service user feedback could assist both the decision about competence and students learning, the pass/fail decision should remain with the mentor (Peers 2007).

Because we could not find a usable framework for client feedback in assessing students in practical training on psychiatry wards, we developed a practical model for use in this study. It is based on literature findings, participatory observation and international contacts with authorities and organizations in nursing research and in mental health. The practical model was generated in the following way: (1) Profound preparation (in terms of purpose and information) of the client, the student, the staff and in particular the nurse who elicits the client's feedback (further referred to as nurse), the mentor and the teacher, (2) Voluntary participation of both the client and the student, (3) A supportive, coaching approach by the nurse, (4) Use of feedback questions which focus on values and attitudes and ask for concrete experiences, (5) Formal, planned, guided and repeated conversation — at least two well-structured meetings (student and client in the presence of the nurse), (6) Client and student debriefing by the nurse, (7) The nurse should not be the mentor of the student. Before the practical model was implemented, it was discussed with the nursing staff of the involved wards. All the participants were informed about the practical model by letter (students, clients and teachers), or by action chart (nurses and mentors). This was done to give all the participants a clear view on what was expected from them.

2. Methods

2.1 Research design

A qualitative explorative research design was chosen to elaborate and describe personal experiences and to establish meaning behind people's views and actions (Sandelowski 2000; Baarde et al. 1998). In this explorative study, client feedback was organized according to the practical model developed for this study, and reactions to it were studied using observation and semi-structured interviews with all the parties involved, eliciting their experiences with the process of client feedback.

2.2. Setting

Two specialized inpatient psychiatric wards in Flanders were selected for the study, a substance abuse unit for people with mainly drinking problems and a unit for eating disorders. The participating wards all had experience in offering practical training opportunities for nursing students and the clients had no major impairments of cognitive and social abilities. In both settings efforts were already made to establish a participative culture on the wards. Selection of these settings guaranteed a more positive attitude towards client participation and consequently created less resistance against client feedback (Repper & Breeze 2007).

2.3. Participants

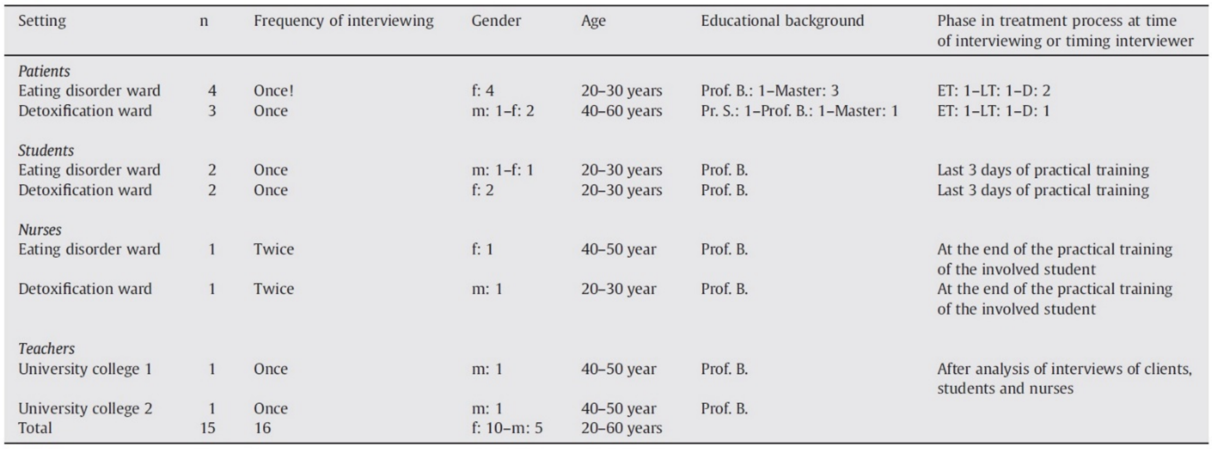
With the approval of the ethics committees, clients, students, nurses and teachers were recruited. All invited participants agreed to take part in the study and signed an informed consent document. Seven clients, four students, two nurses and two teachers were interviewed. More details on the characteristics of the participants are given in Table 1.

2.4. Data collection

In total, sixteen semi-structured interviews were held with the participants of the study as follows: Clients were interviewed after they had participated in the assessment of a student. The clients on the substance abuse unit, were interviewed in the presence of the researcher only. Due to the sensitivities of the clients on the eating disorder ward (e.g. their need to experience a confidential climate), they were interviewed in the presence of the nurse. For three clients, interviews were planned earlier, due to the scheduled discharging date of the client or due to the transfer of the client to another treatment group. The interviews with the clients, the students and the nurses generally took place on one of the last three days of the practical training of the student. The two nurses who elicited the client feedback on the two psychiatric wards, were interviewed after the practical training of each student. The teachers were interviewed when all the students involved had finished their practical training. In sum, both nurses were interviewed twice while the students, clients and teachers were interviewed once.

The interviews lasted an average of 37 min (range between 28 and 55 min) and were conducted using an interview guide which contained the following questions: What did it mean to you to be involved in client assessment? How important was it for you to be involved? What weight do you give your contribution to the assessment process? What were your thoughts and feelings about involving clients in the assessment of students in practical training before the assessment took place? How do you think or feel about the assessment and the practice model now? What factors had an influence on your contribution?

Table 1



Setting	n	Frequency of interviewing	Gender	Age	Educational background	Phase in treatment process at time of interviewing or timing interviewer
Patients						
Eating disorder ward	4	Once!	f: 4	20–30 years	Prof. B.: 1–Master: 3	ET: 1–LT: 1–D: 2
Detoxification ward	3	Once	m: 1–f: 2	40–60 years	Pr. S.: 1–Prof. B.: 1–Master: 1	ET: 1–LT: 1–D: 1
Students						
Eating disorder ward	2	Once	m: 1–f: 1	20–30 years	Prof. B.	Last 3 days of practical training
Detoxification ward	2	Once	f: 2	20–30 years	Prof. B.	Last 3 days of practical training
Nurses						
Eating disorder ward	1	Twice	f: 1	40–50 year	Prof. B.	At the end of the practical training of the involved student
Detoxification ward	1	Twice	m: 1	20–30 year	Prof. B.	At the end of the practical training of the involved student
Teachers						
University college 1	1	Once	m: 1	40–50 year	Prof. B.	After analysis of interviews of clients, students and nurses
University college 2	1	Once	m: 1	40–50 year	Prof. B.	
Total	15	16	f: 10–m: 5	20–60 years		

Legend:
f: female–m:m m: man.
Pr. S.: Primary school–Prof. B.: Professional bachelor.
ET: Early treatment–LT: Late treatment–D: Discharge period.
!: 1 interview with 2 clients (Eating disorder ward).

2.5. Data analysis

Data collection and data analysis took place in a cyclical process. All interviews were tape recorded and fully transcribed. Transcripts and field notes were carefully read and coded, using ‘open’ and ‘axial coding’ (Strauss & Corbin 1994). The themes generated were regularly revised and categorized as data collection progressed. They were constantly compared with each other and with the data. Analyses resulted in a conceptual framework and a quadrant model (see Figs. 1 and 2). Qualitative computer software NVivo-7 (QSR-International, Doncaster, Victoria, Australia) was used to facilitate this process. Analyses were validated during the whole process by means of researcher triangulation.

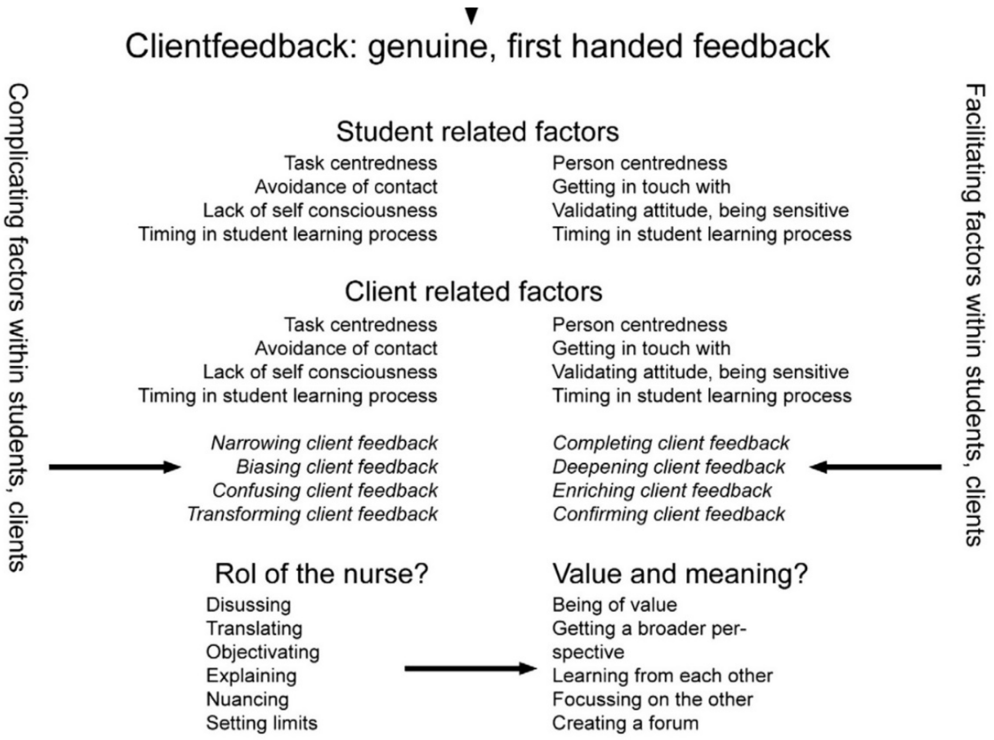


Fig. 1. Conceptual frame work.

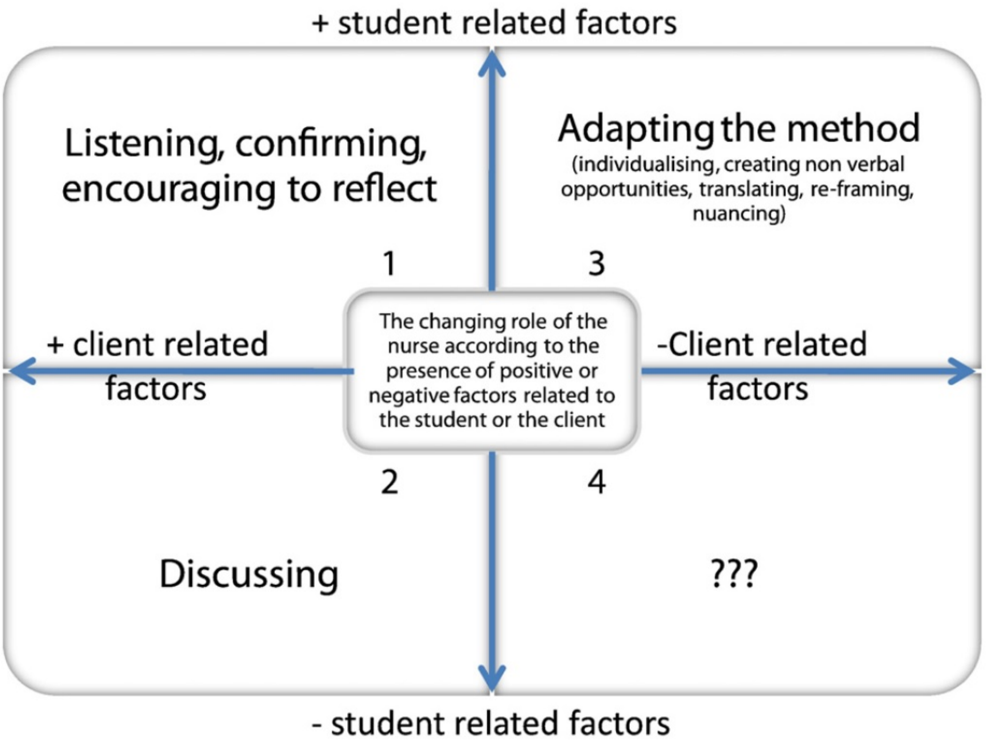


Fig. 2. Quadrant model.

3. Results

3.1. Initial perceptions of students, clients and nurses

The interviews revealed that client perceptions of being involved in feedback during practical training of students were positive. Clients considered being involved as being recognized and listened to and as being taken seriously and of equal value. In the beginning, nurses, students and teachers expressed a more ambiguous attitude toward client feedback in the assessment of the practical training. Although they supported the idea of gathering client feedback, initially they felt uncertain, had doubts and were skeptical about the added value of the project.

3.2. The practical model

All participants valued the practical model as a useful and a valuable tool to elicit client feedback. They stressed the fact that it gave them a clear and flexible framework. Clients, students and nurses felt they needed to be well prepared and needed clear guidance on what was expected of them. They welcomed that the model included several meetings during the practice period. It gave them the opportunity and the time to become familiar with the method and to get to know each other. The clients also stressed that their feedback should not serve as the primary means of evaluation. The critical role of the nurse during the assessment process came to the fore. In accordance with the model, client feedback was generated during well organized group meetings and the group atmosphere and the presence of the nurse facilitated the feedback from the client. Creating a trustful and relaxing environment for students and clients was found to be an important task for the nurse involved. These findings are consisted with previous research, where stakeholders view about service user involvement in the assessment of students were elicited (Peers 2007).

3.3. The meaning and value of client feedback

Client feedback was experienced as concrete and authentic feedback. The presence of the student during the process of client feedback increased the authenticity of the feedback.

We identified client- and student-related factors that were facilitating or complicating the assessment process (see conceptual framework, Fig. 1). The client-related factors pertain to characteristics of the client such as maturity and personality traits. They can also be related to the phase in the client's treatment process and to the sometimes rigid thinking of clients. It seemed some clients were preoccupied with demonstrating a positive attitude towards the student. Student-related factors that facilitated the process were: person-centeredness and a sensitive and validating attitude towards clients. When students were more task-centered, had a lack of self-consciousness, were reluctant to participate in practical learning or lacked openness towards clients, the assessment process was more difficult. Timing of client feedback during practical training came forward as an important issue. For instance, obtaining client feedback in the beginning of practical training was not valued as being useful.

All participants stressed the importance of a flexible role of the nurse for effective eliciting of feedback. The quadrant model developed in the analysis (see Fig. 2) presents the changing role of the nurse in case of facilitating or complicating factors related to the student or the client. If facilitating factors in both student and client were present, the role of the nurse was one of listening, confirming, validating and encouraging both student and client to reflect on what was being (or had been) discussed. If facilitating factors in the client and complicating factors in the student were present, some (mature) clients gave first hand complementary feedback to the student. However, most clients expressed their attitude towards the student in a more indirect and masked way. They conveyed their feelings by avoiding contact with the student, or giving disapproving feedback during the assessment. It seemed important that the nurse actively supported clients in discussing their experiences. Hence, the nurse needed to be a good listener and needed to maintain close contact with the client and the student. If facilitating factors were present in the student but not in the client, feedback was expressed indirectly. The role of the nurse was to adapt the method to the characteristics of the clients by individualizing the assessment procedure or by creating non-verbal opportunities to express feelings and attitudes towards the student.

Overall, the study results indicate that giving clients the possibility to express themselves about students was a valuable and meaningful experience to all participants. It encouraged students to reflect more profoundly and diminished their level of uncertainty. Students were stimulated to take the role of the client seriously and were encouraged to become more self-conscious. The students became more fully aware of different kinds of aspects about themselves, how the clients experienced them when in contact and about what they felt was important to them. One student mentioned, for example, how clients had noticed her tension and insecurity during the first feedback. The fact they had mentioned it and that she could talk about it helped her a lot in dealing with it.

Client feedback gave nurses a more profound, detailed and sometimes surprising and refreshing view on the relationship between clients and students. The qualities of the client took a more central place in comparison with other activities. The clients valued the fact that they had a say and a forum in which to express their views. It was of great significance to them to be listened to and to get the occasion to say what they wanted to say. They felt that they were taken seriously. Client feedback enabled students and nurses to become more aware and more sensitive to the needs of clients.

3.4. What did clients value in students

Clients appreciated students who were authentic, spontaneous, sensitive and regarded the clients as individuals. They valued students who were significantly present and actively involved during their practical training. For clients this means: students took initiatives and made spontaneous contacts with clients. Most clients also felt students were spending enough time with them, exploring, searching, giving attention to follow-ups as well as joining in, taking interest in ward activities. Clients also praised students who did more than what was strictly necessary and who were sensitive for the client as a person.

3.5. Client feedback as a vital component of the overall assessment

It was interesting to observe that clients differed from students, nurses and teachers in the value they placed on their contribution in the overall assessment. According to the nurses and teachers, client feedback is complementary to the feedback from the mentor. The majority of the clients, however, perceived their feedback to be of inferior importance in comparison with that provided by the mentor. From our data we considered that this may be explained by the low self-esteem that this type of clients usually has.

4. Discussion and conclusion

This study is only a first exploration of the appropriateness of one way of organizing and executing client feedback in psychiatric nursing education.

5. Methodological considerations

Although the study only explored the use of client feedback in psychiatric nursing education and only a limited number of people participated, the intensity of the data collection and the resulting thickness of the data allowed for the identification of factors influencing the process of client feedback. Although the sample was selected with diversity in mind, the findings cannot be generalized. Certainly not all types of psychiatric patients were involved, and we did not examine the influence of psychopathology on the process of client feedback.

Objectivity was an important concern in the study, as the researcher was involved both in the development of the practical model and in its evaluation. Supervision by an independent researcher was used to offer critical appraisal of the process and of the interpretation of the findings. Researcher and data triangulation were used to validate the research findings.

Although the researcher was present in the setting where the study took place, he did not have another role other than that of researcher. This made it possible for clients, students and nurses to interact reasonably freely with him. The study certainly benefited from a Hawthorne effect with the involved parties feeling good about being asked to participate in the study.

The interviews with clients with eating disorders were held in the presence of the nurse. This may have influenced the results. However, the interviews revealed that the presence of the nurse during the interview was important for creating an atmosphere of trust which helped clients to fully cooperate during the interview.

Literature on client involvement in research stresses the importance of actively involving clients during every stage of the research. In this study, clients were involved during the whole process, but due to time constraints, their involvement in the development of the research design was rather limited. According to the perspective of the participating nurses and teachers, the involved students performed well during their practical training. This raises questions about what happens when students under-achieve during their practical training. Therefore, future research to test and refine the developed models is important. Future research can also answer the question to what extent client feedback can be fruitfully elicited in other categories of clients.

5.1. The potential of client feedback

All participants in this study welcomed client feedback. Client feedback contributes to the student's learning process by generating a more holistic understanding of the client and adding an extra dimension to the existing feedback. According to Robb et al. (2002), students frequently experience the lack of continuity in mentorship, due to limited contact between the mentor and the student. In comparison with mentors or teachers, clients are always present during practical training. Clients can therefore play a key role in the continuity of the learning process.

Client feedback is first hand and concrete feedback. It has the potential to enhance the self-efficacy of the student. Client feedback encourages students to be more self-conscious and to reflect more profoundly and deeply. The students who participated expressed that it helped them to become more in tune with the client and it stimulated empathy with the client.

Client feedback is not only fruitful for the student's learning process, it also affects the clients involved in a positive and meaningful way, by raising their self-esteem. Client feedback furthermore benefits the involved nurses. It gives them a deepened, nuanced and sometimes surprising and refreshing view on clients and students. Client feedback has more value and meaning when a safe environment is created for the clients and when facilitating factors in the student and the client are present. When these conditions are fulfilled, client feedback enriches and reinforces the assessment, making it more complete. However, when complicating factors predominate in the student and in the client, it is expected that client feedback may narrow, bias, transform or confuse the assessment process. Even if complicating factors are involved, genuine client feedback can be generated thanks to the interventions of the nurse who plays a key role in eliciting feedback. If many complicating factors are present in the student and the client, for ethical reasons, client feedback should not be elicited.

5.2. Implications for practice

At present, involving clients in mental health nursing in a formal and collaborative way is not common practice. The developed practical model, the developed conceptual framework and the quadrant model can help nurses and staff to implement client feedback on their own ward. Client feedback can reinforce the holistic perspective on nursing and can contribute to enhancing communication with all parties involved in an open and authentic way. Psychiatric services and schools of nursing have to take a role in this process. Working towards a diversity-sensitive culture and developing new ways to actively involve clients in education, could positively contribute to this process. Adequate application of client feedback requires that the nurse actively demonstrates her/his (psychiatric) nursing competences. This generates a double learning effect for the student. The student learns from the client feedback and also learns from the nurse how to use and obtain feedback from the clients and how to deal with clients during the process of client feedback. For the psychiatric client, being involved means practicing skills necessary for recovery and reintegration in society.

As the study was explorative and only focused on the use of client feedback, further research on this topic is necessary to make sure that all issues have been addressed and to embed client feedback in existing theory.

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Hoofdstuk 3

The evaluation of nursing students by patients instrument: development and validation

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Summary

Background: Patient participation is increasingly used in different aspects of healthcare due to its positive outcomes. Still, instruments for involving patients in the evaluation of nursing students during their internship are scarce.

Objectives: To develop and validate an instrument that enables patients to evaluate nursing students during their internship.

Design and methods: A 3-phased validation process was conducted: (1) development of an instrument through literature and patient interviews; (2) content and response process validation by use of cognitive interviews and pilot-testing; (3) testing construct validity and reliability of the instrument which was completed by 244 hospitalized patients.

Settings and Participants: Patients from a variety of wards in a general hospital were recruited for the different phases. In phase 1, 17 interviews and 47 thought shower sessions with patients were performed. In phase 2, 9 cognitive interviews and pilot testing by 4 patients evaluating actual nursing students were used to refine the instrument. In phase 3, 380 patients were eligible to participate. Of these patients, 317 completed the instrument. A sample of 244 completed instruments was useful to perform the psychometric analyses. To assess the test-retest reliability, 50 patients completed the instrument twice with a 4 hour time interval.

Results: The 19-item Evaluation of Nursing Students by Patients instrument (ENSPa) is designed. The ENSPa-instrument comprises 7 items that assess whether the patient can place trust in the student, 5 items evaluating person-oriented skills, four items appraising caring and 3 items to grade the integrity and honesty of the nursing students. Each item is scored both for importance and rating. The instrument shows high reliability and consistency ratings.

Conclusions: The ENSPa-instrument is a valuable instrument for collecting data on the performance and skills of nursing students during their internship from the patient’s perspective. By receiving structured feedback from patients, important learning opportunities are created for nursing students.

1. Introduction

Since the beginning of the century, the patient’s role has changed dramatically (Baker 2001). Whereas patients used to have a passive role, power imbalances shifted and evolved towards care that aspires collaboration between patients and caregivers. Nowadays, it is increasingly common to consider patients as experts of their health and to stimulate them to participate in their care process. Such patient participation has many advantages, such as positive treatment outcomes and increased patient satisfaction (Castro et al. 2016).

In addition, patients also have become more involved in other dimensions of healthcare. Patients participate in developing interventions, advise policy-makers and set research agendas. The benefits of being involved in these practices contributes to enhanced quality of care (McDermott and Pedersen 2016). Patients are therefore becoming more involved in the education and training of healthcare workers (Repper & Breeze 2007). However, such inclusion remains a challenge to integrate in the nursing profession and in clinical education in particular (Suikkala et al. 2018). Most nursing curricula include extensive clinical internships, but do not regard engaging patients in the evaluation of nursing students as a common practice (Debyser et al. 2011). Currently, nursing students are predominantly evaluated by their clinical supervisor and mentors from school. Involving patients in the assessment of nursing students could be worthwhile, since patients have a clear, yet different perspective on quality of care (Sixma et al. 1998). Their unique perspective could contribute to an accurate assessment of the performance of students in practice (Gibbons et al. 2002; Scammell et al. 2015). Furthermore, there are indications that patients feel comfortable and want to have an active role in the evaluation of nursing students (Heggland & Hausken 2014; McMahon-Parkes et al. 2016). Students themselves appreciate and value receiving feedback from patients during their learning process (Jones et al., 2017). However, studies also report ambiguities in relation to the readiness of patients (and carers) in assessing nursing students (Haycock-Stuart et al, 2016). Nursing students can also be reluctant or ambivalent to ask for feedback, particularly in relation to patients who are seen as ‘other’ rather than ‘ordinary’ (Speers & Lathlean 2015). Consequently, a structured instrument that provides the patient’s feedback in an anonymous way, together with a guided and supportive approach might be helpful (Speers & Lathlean 2015; Suikkala et al. 2018).

Currently, there are 2 drawbacks to implementing structured patient feedback to nursing students. First, studies on engaging patients in students’ evaluation mostly adopted a qualitative approach through observations, semi-structured interviews and focus groups (Suikkala et al. 2018). Qualitative approaches have their limitations as they are time-consuming and difficult to undertake with a larger number of students, which is a distinctive characteristic of preregistration adult field nursing programmes (Holloway & Wheeler 2015; Scammell et al. 2015). Second, national and international research on patient involvement in the evaluation of the internship of nursing students is mainly limited to mental healthcare (Debyser et al. 2011; Scammell et al. 2015). The fact that mental healthcare represents a rather specific selection of the entire patient population, hampers its transferability. Extension to a broader patient population is advised (Debyser et al. 2011; Scammell et al. 2015). McMahon-Parkes et al. (2016) already piloted and implemented successfully the patient testimony tool derived from the work of Chapman et al. (2011) in an acute general healthcare facility. Although this instrument was co-designed with patients, staff, educators and practice providers, adopting the instrument to a general hospital setting remains challenging as the instrument has not been tested on its psychometric properties. The incorporation of reliable evaluation methodologies in the assessment process of nursing students is increasingly supported by a growing body of international guidelines (WHO 2009; NMC-standards, United Kingdom). Although patient participation is gaining increasing importance at all levels, there are no national guidelines promoting the involvement of patients in the assessment of healthcare students in hospital policy in the country where the study took place (Malfait et al. 2018).

To the best of our knowledge there is no empirically validated instrument available for involving patients in assessing students during their internships. A validated instrument might offer nursing practice and education the needed opportunity to structurally involve patients and value patient's opinion about nursing students during internships. Most nursing curricula include extensive clinical internships, but engaging patients in the evaluation of nursing students is still limited (Suikkala et al. 2018). This study aims to develop and validate such an instrument in order to introduce the merits of patient participation in the evaluation of nursing students in the adult field practice.

2. Methods

2.1. Objectives

This study aims to develop and validate an instrument that enables patients to evaluate nursing students during their internship. The ENSPa-instrument aims to enable patients to rate the nursing student's behaviour and to measure the degree of importance of the behaviour from the patient's perspective.

2.2. Design and ethical considerations

A 3-phased validation psychometric study was conducted. Authorization for the study was granted by the central ethics committee of the Ghent University Hospital and the general hospital Saint-John's of Bruges-Ostend (B670201422531). Each participant gave verbal and signed informed consent after receiving an information letter and verbal explanation.

Phase 1: Instrument development

Aim. The instrument aims to enable patients to rate the nursing student's behaviour and to measure the degree of importance from the patient's personal perspective.

Methods. 2 complementary approaches were used to develop the items of the instrument. First, a scoping review was conducted to identify competences that patients found important in nursing students, and/or to identify similar instruments. The review was performed within Pubmed, Cinahl & The Cochrane Library using the following search terms: 'patient', 'inpatient', 'student, nursing', 'nurse-patient relations', 'patient participation', 'consumer participation', 'nursing evaluation research', 'patient satisfaction' and 'patient preference'. Articles in Dutch, French and English from the past ten years were included. Eight studies were eligible. Second, patients were recruited from a variety of wards in one general hospital to participate in either individual interviews or shorter individual thought shower sessions, depending on the patient's health status. To be included, patients had to (i) have contact with nursing students, (ii) master the Dutch language and (iii) be at least 18 years old. To specifically focus on patients with general health conditions, patients with primarily psychiatric problems were excluded. Palliative patients were also not approached to avoid giving them an extra burden. The thought shower sessions and interviews took place in the patient's room in the absence of nursing staff or students. Both were digitally recorded and transcribed verbatim immediately afterwards. Before analysis, these transcripts were read repeatedly to get familiar with the data. An inductive, content analysis method was used to order the collected data into categories (Schamber, 2000). The interviews were coded, and concepts and meanings were identified and linked together. Next, the content of the thought shower sessions was coupled and compared to these concepts. The constant comparative method was used to optimize the trustworthiness of the data (Cho and Trent 2006). Coding and interpretation of the data were discussed and refined by 3 researchers (Anney 2014; Morse 2015; Patton 1999).

Results. Phase 1 resulted in an instrument with 10 categories, formulated into 23 items. To maximize comprehensibility, simple words and short sentences were used. All the items were formulated in the first-person perspective, in order to represent the patient's perspective. This first-person perspective was accentuated multiple times, in the introduction and the instrument itself. As the aim of the instrument was to assess - from a patient perspective - both student's behaviour and perceived importance of the behaviour, each item was assessed by 2 questions, to be measured on a six-point Likert scale. By using a 6-point Likert-scale, a neutral point was avoided which forces respondents to make a decision and avoid ambivalence (Klopfer & Madden 1980). For instance, patients were asked to rate the following item: ‘the student reassures me’, varying from ‘strongly disagree’ (1), ‘disagree’ (2), ‘slightly disagree’ (3), ‘slightly agree’ (4), ‘agree’ (5), to ‘strongly agree’ (6). Patients were also asked to rate the importance they attach to the mentioned item, varying from ‘not important at all’ (1), ‘not important’ (2), ‘slightly not important’ (3), ‘slightly important’ (4), ‘important’ (5), to ‘very important’ (6). So for example, firstly patients were asked to rate to what degree they agree or disagree with the item: ‘the student reassures me’. Secondly, patients were asked to rate the degree of importance they attach to the mentioned item from their personal perspective. Figure 1 provides an overview of this 3-phased process.

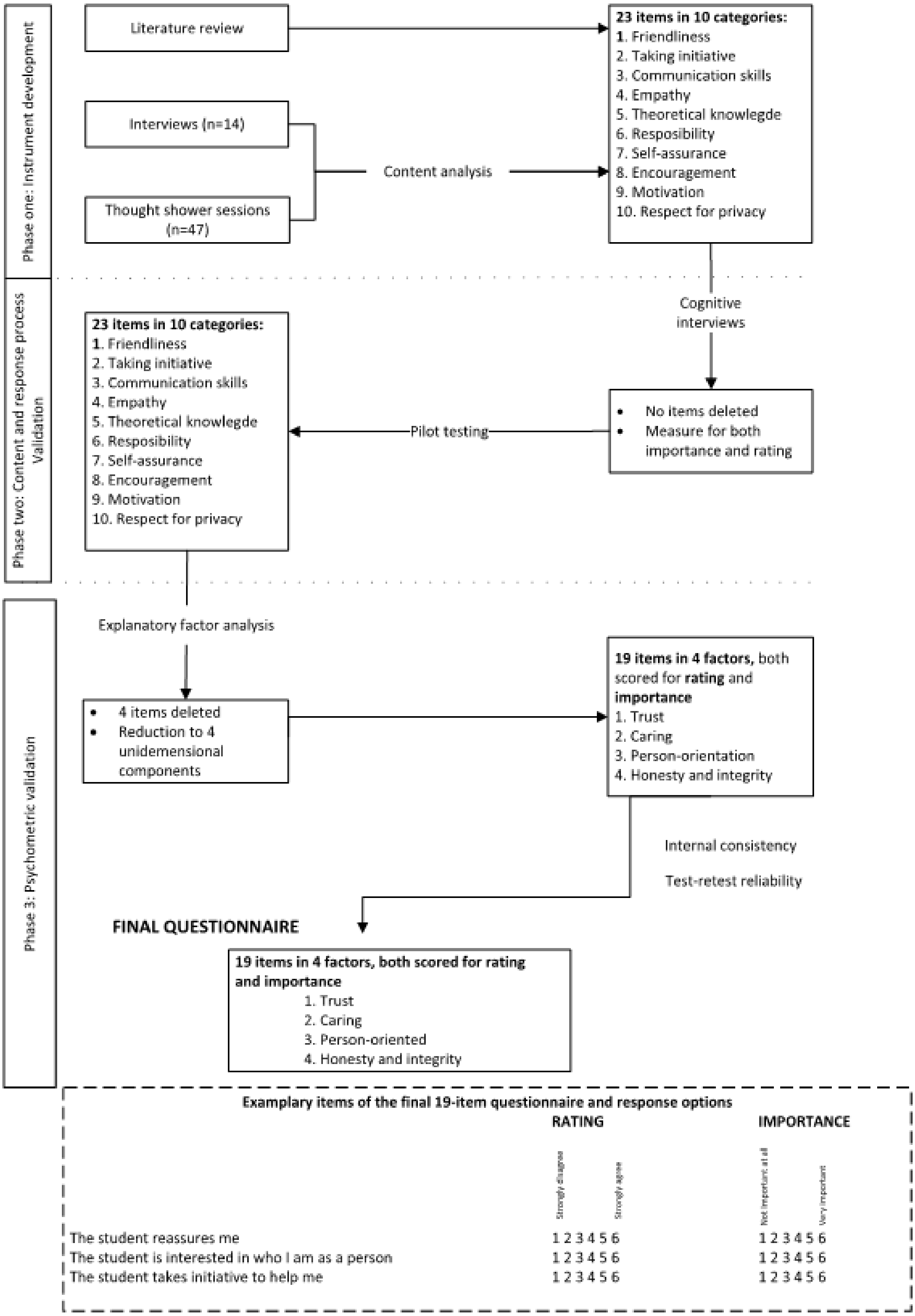

Figure 1: Overview of the 3-phased validation process

Instrument. A 23-item instrument was generated; each item was scored both for rating and for importance.

Phase 2: Content and response process validation

Aim. The aim is to validate the content of the instrument as developed in phase 1.

Methods. Cognitive interviewing and pilot-testing were used to provide evidence for validity on content and response processes. Cognitive interviewing is useful for instrument development when there is a probability of response errors due to interpretation, language and recall problems (Peterson, Peterson & Powell 2017). The aim of cognitive interviewing was to evaluate clarity and interpretation of the instrument, both its objective and its items, and to obtain a more in-depth understanding of how respondents perceive, interpret and respond to items. Next, pilot testing was used to determine the feasibility of the instrument (Van Teijlingen & Hundley 2002). The patients who participated in this phase were recruited from the same general hospital as in phase 1. To be included, patients had to (i) have sufficient contact with the student who is to be evaluated, (ii) master the Dutch language, (iii) be at least 18 years old, (iv) be able to read and understand the instrument, and (v) recognize the student from a photograph. Patients who were hospitalized because of palliative or psychiatric care needs were excluded for the same reasons mentioned in phase 1.

Results. Nine cognitive interviews were conducted using the first version of the instrument, and resulted in several changes: formulations were clarified, word choices were adapted and the introduction was elaborated. The pilot testing of the adapted instrument involved four patients. They filled in the instrument, evaluating a student, while the researcher questioned the patient's thoughts about the items.

Instrument. The patients' remarks were used to rephrase the items. No items or components were removed from the instrument after phase 2, and it remained with 23 items.

Phase 3: Psychometric validation

Aim. The aim is to measure the construct validity and the test-retest reliability of the final instrument.

Methods. To determine the construct validity in phase 3, exploratory factor analysis and reliability testing, with determining internal consistency and test-retest reproducibility, were performed. Patients from 25 wards (i.e. internal medicine, surgical and older age medicine) were recruited. To be included, the same inclusion and exclusion criteria were applied as in phase 2. In total, a sample of 230 patients was targeted in order to have 10 respondents per item (Polit & Beck 2008).

Using SPSS 25.0, an exploratory principal axis factor analysis with Varimax rotation was performed to cluster the items into subscales. Sample adequacy was tested with the Kaiser-Meyer-Olkin (KMO) measure over 0.50 and the Bartlett's test of sphericity. Eigenvalues >1 was applied to determine the number of extracted factors. To improve the model fit and reduce the number of items in the instrument, items were removed from the initial instrument following 3 criteria: (i) if their factor loading was below 0.40 (ii) or loaded on more than 1 factor, and (iii) factors had to comprise a minimum of three items (McNeish, 2017). Potential exclusion of an item was always discussed among several researchers to ensure content validity.

To check the internal consistency, inter-item correlations were calculated at subscale and scale level. A Cronbach's alpha higher than 0.80 was considered 'good' (Gliem & Gliem 2003).

To check the test-retest reliability (i.e. stability), a convenience sample of patients was used. Every participant was asked if (s)he was willing to complete the test a second time. As soon as 50 patients handed over a second instrument, recruitment was stopped. Patients were instructed to hand in the first instrument immediately after completion and complete the second file on the same day with a minimum of four hours between completing both instruments in order to counteract a possible recall bias, whilst still being able to judge the same student and situation. The reproducibility as test-retest reliability was assessed by calculating intraclass correlation coefficient (ICC) by using a 2-way random effects model with absolute agreement. Reliability coefficients of ≥0.70 were considered 'satisfactory' (Polit & Beck 2008). The mean score of the total scale and each subscale were calculated. No missing values were allowed for calculating the mean score of the subscales, whereas for the total scale a maximum of 3 missing answers was tolerated. All data were collected between September 2016 and February 2017.

Results. Of the 380 patients that were eligible to participate, 317 patients agreed to participate. After assessing the instruments for response patterns to exclude acquiescence response bias and deleting instruments that were missing more than 25% of the items, a sample of 244 instruments was useful for analysis. An overview of the patient characteristics can be found in Table 1.

Table 1: Overview of the patient's self-reported characteristics included in phase 3 (n = 244)

Characteristics	n	%	Characteristics	n	%
Gender			Dependence of care		
Female	133	54.5	High care need	41	16.8
Male	111	45.5	Moderate care need	88	36.1
Age (years)			Low care need	96	39.3
< 35	9	3.7	No care need	9	3.7
35 – 44	17	7	Missing	10	4.1
45 – 54	27	11.1	Length of stay (days)		
55 – 64	69	28.3	1 – 2	26	10.7
65 – 74	70	28.7	3 – 4	65	26.6
≥ 75	51	20.9	5 – 7	62	25.4
Missing	1	0.4	8 – 14	53	21.7
Educational degree			≥ 15	32	13.1
None	10	4.1	Missing	6	2.5
Primary education	39	16.0	Frequency of contact with student (/week)		
Secondary education	118	48.4	1	22	9.0
College / University	64	26.2	2 – 5	135	55.3
Other	11	4.5	6 – 10	61	25.0
Missing	2	0.8	> 10	18	7.4
Number of admissions			Missing	8	3.3
1	33	13.5	Mean length of contact with student (minutes)		
2 – 5	123	50.4	1 – 4	54	22.1
6 – 10	50	20.5	5 – 15	139	57.0
> 10	37	15.2	16 – 30	37	15.2
Missing	1	0.4	> 30	7	2.9
			Missing	7	2.9

The Varimax-rotated analysis resulted in 19 items, clustered in 4 unidimensional factors: (1) the factor ‘trust’, refers to whether nursing students can gain the trust of the patient by introducing themselves, explaining what they are going to do and showing that they have knowledge and competence to execute the planned procedure. The factor ‘trust’ consists of 7 items and explained 17.89% of the variance; (2) the factor ‘person-oriented’ refers to the degree to which the patient perceives that the nursing student regards him as a person rather than someone who is merely hospitalized. The factor ‘person-oriented’ consists of 5 items and explained 15.29% of the variance; (3) the factor ‘caring’ refers to how patients describe nursing students appear to them. The factor ‘caring’ consists of 4 items and explained 10,67% of the variance; 4) the factor ‘honesty and integrity’ refers to the perceived ethical behaviour of nursing students. The factor ‘honesty and integrity’ consists of 3 items and explained 8,07% of the variance. These 4 unidimensional factors explained 51,93% of the variance.

Concerning internal consistency, a Cronbach’s alpha of 0.826 was found for the subscale trust, 0.861 for the subscale ‘person-oriented’, and 0.801 for the subscale ‘caring’. These results demonstrate a strong internal consistency. For the subscale ‘honesty and integrity’, a Cronbach’s alpha value of 0.670 was found and was regarded as sufficient as no items could be deleted in order to preserve the criterion of a minimum 3 items per factor. The Cronbach’s alpha for the entire 19-item instrument was 0.995. All subscales demonstrated excellent test-retest reliability with ICC values of 0.996 for the subscale ‘trust’, 0.994 for the subscale ‘person-oriented’, 0.995 for the subscale ‘caring’ and 0.997 for the subscale ‘honesty and integrity’. The entire scale demonstrated an ICC value of 0.989 (95% CI = 0.980-0.994). An overview of the instrument and the psychometric characteristics can be found in Table 2.

Instrument. Finally, a 19-item questionnaire was obtained, clustered in 4 unidimensional factors. Each item was scored both for rating and importance. As patients differ from each other in so many ways (age, sex, religion, background, how they experience health or illness), the instrument allows patients to not only individually rate the nursing students’ behaviour but also enables patients to measure the degree of importance they attach to each item from their personal point of view. An overview of the instrument and the psychometric characteristics can be found in Table 2.

		Factor loading						
Description	**mean**	**F1**	**F2**	**F3**	**F4**	**Cronbach's alpha**	**Alpha if item deleted**	**Intraclass correlation coefficient**
Trust						0.826		0.996 (95% CI=0.992-0.997)
The student presents himself with name and function	3.97	0.428					0.850	
The student explains what he is doing or will do	5.22	0.532					0.795	
The student reassures me	5.24	0.631					0.796	
The student looks self-confident	5.23	0.605					0.804	
The student has knowledge about my disease	4.69	0.635					0.806	
The student shares tips and advice concerning my disease	4.16	0.770					0.776	
The student encourages me to do myself what is important to me	4.66	0.582					0.799	
Person-oriented						0.861		0.994 (95% CI=0.992-0.997)
The student takes time to listen to me	5.27		0.752				0.828	
The student can easily talk to me about things not related to my disease	4.78		0.589				0.840	
The students takes into account what I am used to do	4.84		0.613				0.831	
The student is interested in who I am as a person	4.70		0.632				0.822	

The student empathises with my situation	5.00	0.658				0.837	
Caring					0.801		0.995 (95% CI=0.991-0.997)
The student greets me	5.67		0.627			0.769	
The student has a friendly appearance	5.60		0.705			0.719	
The student takes initiative to help me	5.41		0.462			0.773	
The student radiates enthusiasm	5.49		0.580			0.740	
Honesty and integrity					0.670		0.997 (95% CI=0.995-0.998
The student asks help to the nurse when needed	5.50			0.654		0.528	
The student is honest	5.59			0.760		0.422	
The student does not talk about other patients, students or colleagues in my presence	5.82			0.414		0.702	

Table 2: the ENSPa-instrument and the psychometric properties

3. Discussion

In modern healthcare, patients are encouraged to take an active role in their healthcare process. Whilst patient participation is becoming common in many aspects of healthcare, the patient's perspective in evaluating nursing students in general hospital settings is still underrepresented. However, research on the involvement of patients in evaluating nurses and student nurses in mental healthcare showed promising results (Debyser et al. 2011). In order to facilitate patient participation in nursing student evaluation, the ENSPa-instrument was developed and validated.

3.1. Content

It is evident that the ENSPa-instrument should reflect those skills and behaviours that are highly valued by patients themselves. Therefore, patients' views on the quality of the internship were already sought during the development of the instrument. Additionally, the instrument gives patients the possibility to score both the behaviour of the student and the importance attached to the specific behaviour. However, patients are inclined to give high scores, possibly causing a ceiling effect which could reduce the discriminating power of the instrument (Kang & MacDonald 2010). Such ceiling effect could result from the patient's fear to give negative feedback. Patients may fear to hurt the student's feelings or to have a negative impact on their future study trajectory (Stickley et al. 2011). One could argue that this renders scoring of patients less informative. However, due to the homogeneity of the scoring, an 'outlier' score (1 or 2) is highly informative, and can be used as a critical indicator (Lee 2004). Discussing such indicators with students, and thus exploring the origin of a low score for highly valued behaviour offers a good opportunity for feedback and learning. Although this instrument is a valuable start for involving patients in the evaluation of nursing students, other dimensions, which are perhaps less likely to be mentioned by patients but equally important like spirituality (Ross 1995), caring behaviour (Khademian & Vizeshfar 2008) or patient safety (Longtin et al. 2010), are not included. Further in-depth, qualitative research is needed to identify these dimensions. As patient characteristics influence what patients regard as important, developing a generic and exhaustive instrument is perhaps impossible (Rahmqvist & Bara 2010). However, the double purpose of how the ENSPa-instrument is designed, allows students to become more familiar with what patients perceive as important in what students do. Although rating the importance of attributes seems a difficult task for patients at first, we noticed during the cognitive interviewing and pilot-testing that patients completed it very accurately.

Another explanation for these high scores (i.e. ceiling effect) and the fact that +/- 41% of the patients did not (completely) fill in the instrument, is that patients are perhaps afraid to give negative feedback in order to avoid substandard care or to be labeled as inflexible or troublesome (Joseph-Williams et al. 2014). As patients depend on nurses and nursing students during their hospitalization (Longtin et al. 2010), patients often opt for a passive and accepting role rather than a more active and critical role (Suikkala et al. 2018). Moreover, such behaviour could also lead to attrition bias. Certain types of patients, like those with low health literacy (Brabers et al. 2017) or patients from ethnic minorities (Schouten et al., 2007), often declare that they do not feel confident enough to participate, or evaluate a student (Haycock-Stuart et al., 2016). In order to involve these groups of patients, anonymity and recognition of the patient's unique knowledge is paramount (Eldh et al. 2006). Moreover, the involvement of patients in the assessment of nursing students needs to be embraced within a broader framework where patients are listened to and seen as full partners of their own care. The person-centered nursing framework can serve this goal as it focusses on meaningful engaged relationships and is embedded in a person-centered care-environment (McCormick et al. 2010). Therefore, patients, staff and educators need to work together to establish a culture of mutual respect and understanding to address common issues of concern for everyone involved in the assessment process of nursing students (Scammell et al. 2015).

3.2. Methodological considerations

There are 3 main methodological limitations to this study.

A first limitation is the fact that literature describing competences that patients deemed important, was mostly conducted in mental health settings and a majority of the publications concerned skills of nurses instead of nursing students (Debyser et al. 2011; McMahon-Parkes et al. 2015). As research on patient participation in evaluating nursing students in general hospital settings has only recently fallen under the interest of academics, literature was almost non-existent (Debyser et al. 2011) and the setting of the research was thus not considered a criterion for exclusion. It is likely that different patient participation cultures exist between settings (McDermott & Pedersen 2016). However, as the study extensively interviewed patients in a general hospital, the researchers are confident that the retrieved results are applicable to general hospital settings.

A second limitation concerns the factor 'honesty and integrity'. Although the psychometric properties and factor loadings of the Varimax rotation were good, the Cronbach's alfa of this component was lower than expected. Still, no items could be deleted as each component should at least contain 3 items (Mortelmans & Dehertogh 2008) and all 3 items were also considered relevant. Therefore, this component should be used cautiously.

A third limitation concerns the hospitalization period of patients, which might be too short to know the nursing student they evaluate (Suikkala & Leino-Kilpi 2005). In this study, no data was collected concerning this variable, and no definitive answer on the question can be given. Although the duration of admission and the relationship with the nursing students might influence a patient's ability to judge nursing students, the qualitative data collection methods in this study (i.e. interviews and thought shower sessions) revealed that patients feel that all patients, even those hospitalized for short periods of time should be provided the opportunity to use the instrument. Still, this aspect remains a question that should be further explored. A possible solution to this issue could be to have the instrument completed by at least 2 patients per student.

3.3. Future research and use in nursing practice/education

Due to the current methodological limitations, the uncertainty about the completeness of the instrument and the scoring behaviour of patients, all described above, this instrument should not be used exclusively as a method to calculate the final grade of students. The instrument should rather have a signaling function, and needs to be complemented by mentor, supervisor, and self-reflective feedback. Furthermore, the instrument should be administered in such a way that patient's anonymity is guaranteed at all times (Eldh et al. 2006). In order to further refine the instrument, explaining factors should be added, a strict protocol on administration should be included to support all involved actors, it should be tested to determine if ratings remain consistent over time and if it is useful outside general hospital settings. It is worthwhile to reflect on required prerequisites or adaptations to the instrument that would enable a greater diversity of people to be involved in the assessment process of the students (for instance patients with cognitive impairments, palliative patients, etc.). For instance, a relative could be invited to fill in the questionnaire, but only if the relative has the perspective of the patient in mind and not his/her own perspective as a family member. Future research is also required for modifying the instrument to permit patients with reduced skills or abilities to complete the questionnaire. As the scale is developed and validated in Dutch, linguistic and cultural validation is needed before the instrument can be used internationally as a standard element in nursing students' evaluations.

4. Conclusions

Involving patients in the evaluation of nursing students can be the next step in the evolution towards more person-centered healthcare and education. As this study developed an instrument which covers areas that patients find important and can assist them in the evaluation process, the study can reduce the lack of empirical research of patient involvement in this particular area of clinical nursing practice (Scammell et al. 2015).

The ENSPa-instrument was developed through a rigorous 3-phased validation process and shows good psychometric properties. It consists of 19 items, divided in 4 unidimensional factors: ‘trust’, ‘person-orientation’, ‘caring’, and ‘honesty and integrity’. All items are judged both for importance from the patient’s perspective and the degree to which the student demonstrates these expectations. Together, these 4 important topics for patients explain more than half of the variances in the judgment of patients about nursing students. This instrument is a first step in structurally involving the -up until now- largely neglected voice of patients in the assessment process of nursing students during their internships. Future research concerning this topic should aim to identify the other factors that influence the patient’s judgment of nursing students. This instrument provided a unique perspective on nursing students’ behaviour. Above all, the ENSPa-instrument (Evaluation of Nursing Students by patients) should be considered as a potentially promising tool to enhance a tripartite dialogue facilitated by the mentor. It allows patients to express to students what really matters to them regarding what they perceive is important in their nursing care.

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Hoofdstuk 4

Constructing a positive identity: A qualitative study of the driving forces of peer workers in mental health-care systems

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Summary

There is growing recognition in mental health for the perspective of individuals with lived experience of mental health problems and mental health service use. As peer workers, these individuals can use their specific experience to benefit and support peers and professional caregivers, and to participate at all levels of mental health-care systems. The aim of the present study was to develop a conceptual framework representing the driving forces of peer workers to fulfil their position in mental health-care systems. A qualitative interview approach was employed using principles of grounded theory. Over a period of 5 months in 2014–2015, semi-structured interviews were conducted with 14 peer workers in residential and community mental health-care systems. The emerged conceptual framework reveals that peer workers strive towards constructing a positive identity. This process is powered by driving forces reflecting a desire for normalization and an urge for self-preservation. Peer workers realize a meaningful employment by using their lived experience perspective as an asset, liberating themselves out of restrictive role patterns, and by breaking down stigma and taboo. As a precondition to engage in these normalization processes, peer workers perceive they need to secure their self-preservation by balancing the emergence of adverse emotional fluctuations. The conceptual framework can inform the development of work contexts in which peer workers have an authentic and meaningful contribution, while being offered sufficient support and learning opportunities to manage their well-being.

1. Introduction

1.1. Background

In many regions, and particularly in Anglophone countries, the recovery model increasingly influences the mission and policies of mental health-care systems (Ahmed et al. 2012; Slade et al. 2008). In contrast with the traditional 1-D biomedical focus on symptoms of illness and clinical outcomes, the recovery model centralizes the whole person by emphasizing the empowerment and social inclusion of service users and their self-determination in goal-setting and decision-making (Farkas et al. 2005; Slade et al. 2014). The enhancement of the recovery model has induced growing recognition for the involvement of service users based upon their lived experience with mental health problems and mental health service use (Millar et al. 2016; Tambuyzer et al. 2014). Understanding the perspective of service users and translating it into mental health policies and practice is perceived to be a valuable source of increasing mental health-care systems' responsiveness for the needs and goals of service users. For this purpose, one particular strategy is the integration of peer workers in the mental health workforce (Asad & Chreim 2016; Gillard et al. 2013).

Peer workers are individuals with lived experience of mental health problems and mental health service use who use their acquired knowledge and skills to support peers (Davidson et al. 2012). International evidence suggests that peer workers can engage with service users on a deep and authentic level (Mead et al. 2001), and that this authentic engagement is fundamental to the effectiveness of the services they provide (Chinman et al. 2014; Davidson et al. 2012; Lloyd- Evans et al. 2014; Pitt et al. 2013). Peer workers are mainly employed within community and residential mental health-care systems, and in organizations run by peer workers (Moran et al. 2013). Reflecting their potential tasks and responsibilities, peer workers spend most of their working hours in direct contact with peers, constituting relationship building, experiential sharing, and goal setting (Jacobson et al. 2012). Furthermore, peer workers can participate in multidisciplinary teams, provide training to peers and professional caregivers about recovery, and facilitate and lead peer support groups (Rebeiro Gruhl et al. 2016; Walker & Bryant 2013).

In the past, the number and diversity of peer worker roles have grown exponentially (Bennetts et al. 2013). While this evolution has created opportunities, some unfavourable trends have emerged. Evidence suggests a risk of diluting the authentic contribution peer workers can make based upon their lived experience perspective (Gillard et al. 2015; Rebeiro Gruhl et al. 2016; Vandewalle et al. 2016; Walker & Bryant 2013). This concern is especially relevant in traditional mental health-care systems, where peer workers can become socialized in professional dominant cultures. Particularly in this context, the distinctiveness and authenticity of the peer workers' contribution can be affected by professional definition and interpretations of peer worker roles, and an over-formalization of its preconditions.

Trends towards 'over-professionalization' and 'over-formalization' can be countered by supporting an authentic integration of peer workers in mental health-care systems (Rebeiro Gruhl et al. 2016). Several researchers point to the crucial position of mental health nurses to facilitate this authentic integration (Byrne et al. 2017; Hurley et al. 2016). Yet studies also indicate that mental health nurses might adopt a patronizing approach towards peer workers, which can negatively affect their participation (Cleary et al. 2011). One expression of this approach is that some mental health nurses recommend peer workers to restrict experiential sharing and close engagement with service users in order to maintain their emotional well-being. Although such professional restriction might be well intentioned, it might also undermine the effectiveness and core values of peer support (Gillard et al. 2015; Rebeiro Gruhl et al. 2016).

To support the development and implementation of authentic peer worker roles, the current study focussed on the driving forces of peer workers. One study with a similar focus was that of Moran et al. (2014). Moran et al.’s (2014) study, inspired by the self-determination theory, explored the motivations of paid peer workers to work in mental health-care systems (Moran et al. 2014). External motivations were related to moving away from negative work experiences, and generic occupational goals. Internal motivations were associated with the basic needs of autonomy (e.g. work accords with personal values), competence (e.g. using lived experience to help others), and relatedness (e.g. connecting with peers). Two characteristics of Moran et al.’s (2014) study warrant further study of this topic. First, the researchers were able to include only paid peer workers, for whom the mean length of employment was over 4 years. Second, the study was conducted in the northeast of the USA, a region where the implementation of the recovery model in mental health-care systems is advanced (Ahmed et al. 2012).

As the recovery orientation of mental health-care systems is crucial for the successful implementation of peer worker roles, special attention must be given to regions where the advancement of the recovery model and the integration of peer workers are in their infancy (Davidson et al. 2012). In Flanders, the Dutch-speaking part of Belgium, the growing emphasis on service user involvement in mental health-care systems triggers policy makers to take the first steps in creating positions for peer workers and elaborating preconditions (Tambuyzer et al. 2014). These pioneering positions are now gradually fulfilled by individuals with lived experience of mental health problems. Particularly in this premature phase, it is deemed necessary to gain knowledge of the peer workers’ driving forces in order to enable the development and implementation of authentic peer worker roles.

1.2. Aim

The present study was designed to generate a conceptual framework that answers the following question: ‘What are the driving forces of individuals with lived experience of mental health problems to fulfil a position as a peer worker in mental health-care systems?’.

2. Methods

2.1. Design

A qualitative research design was adopted, inspired by core principles of grounded theory (Glaser & Strauss 1967; Stern et al. 1984). Data collection and analysis interacted iteratively to explore and understand the concepts, the relationships between concepts, and the processes reflecting the driving forces of peer workers to fulfil their position in mental health-care systems. To inform data processing, the researchers transformed the following driving force definition: 'the impetus, power, or energy behind individuals to fulfil a position as a peer worker in mental health care systems' (Dictionary.com 2017).

2.2. Participants

Potential participants were approached by practitioners who collaborate with peer workers in residential and community mental health-care systems. These gate-keepers contacted the researcher (JV) who in turn contacted the interested participants either face to face or via email. Initially, four peer workers were recruited based on the following inclusion criteria: (i) lived experience of mental health problems; (ii) able to speak Dutch; (iii) minimum age of 18 years; and (iv) a peer worker in a mental health-care system.

After interviewing the first participants, the emerging concepts from the constant comparison of data guided the process of sampling, as recommended in grounded theory research (Cutcliffe 2000; McCrae & Purssell 2016). During this iterative process, diversity of the participants was taken into account in terms of sex, age, educational level, status of employment as a peer worker, work hours, length of employment, and work setting. Recruitment continued until saturation of the core categories was established (Glaser 2002; Glaser & Strauss 1967).

2.3. Data collection

Data were collected between October 2014 and February 2015. A junior male researcher (JV), coached by two experienced qualitative researchers (BD, SV), conducted the one-off semi-structured interviews with 14 Dutch-speaking peer workers. The interviewer did not have a close relationship with the participants. An interview guide was used comprising open questions based on a brief literature search and the opinion of practitioners who collaborate with peer workers. Interviews were initiated with open questions, such as 'What does it mean for you to be active as a peer worker?'. The interviews lasted on average 73 min (range: 39-116) and were conducted at the preferred location of the participants, which was either at their home or workplace. All interviews were audio-recorded and transcribed verbatim.

Reflecting the evolving nature of grounded theory studies, after interviewing the first four participants, the emerging concepts guided the process of data collection (Glaser 2002; Glaser & Strauss 1967). This step-wise approach resulted in data-informed sampling decisions in order to broaden, deepen, confirm, or disconfirm the insights that were emerging from the preliminary analysis. It was observed that the first participants reported generally positive experiences with fulfilling a position as a peer worker. One participant was then included who quit as a peer worker, and one participant who felt ambivalent about continuing as a peer worker. These participants had predominantly negative experiences with fulfilling a peer worker position. Based on the sampling recommendation of Morse (2015), the researchers considered that developing an understanding of a range of peer workers' experiences with a varying level of intensity would enable them to enhance the understanding of the processes under study.

In addition, one participant was included who aspired to be a peer worker. This decision was based on our peer-reviewed literature review on barriers to the implementation of peer worker roles in mental health-care systems (Vandewalle et al. 2016). The findings of this review suggest that peer workers can become socialized in professional dominant work cultures, and that this socialization process might affect the authentic contribution and perspective of peer workers. Based on this insight, it was assumed that the aspiring peer worker could provide an open-minded perspective of fulfilling a position as a peer worker that is not, or less, influenced by practice.

2.4. Ethical considerations

The ethics committees of the participating settings approved this study. One researcher (JV) fully informed the participants about the goal of the study, the voluntary character of their participation, and the confidential treatment and anonymity of the data. All participants provided verbal and written informed consent prior to inclusion.

2.5. Data analysis

For the data analysis, the constant comparative method, as proposed by grounded theory, was used (Glaser 2002; Glaser & Strauss 1967). Three researchers (JV, BD, SV) participated in the iterative process of data collection and data analysis. For each interview, JV made field notes and reported a synthesis in order to enhance the researchers' understanding of the research context and to identify preliminary categories. JV and BD read the transcripts repeatedly, while SV read some of the transcripts. All three researchers added memos to retain their reflections. Following these preparatory steps, a substantive coding process was initiated using NVivo 10 (QSR International, Burlington, MA, USA). By systematically comparing the coded fragments with new data within and between interviews, and the analysis of field notes and memos, codes were refined and conceptually formulated. The three researchers regularly crosschecked their codes and memo's to identify relations between concepts. The codes were then grouped and tested iteratively through rereading the original text fragments. To ensure the richness of the analysis, the three researchers discussed the concepts and meanings until all agreed on the structure of the conceptual framework. Finally, to support the explanatory power of the framework, an explorative literature review was conducted (Hickey 1997; Stern et al. 1984).

2.6. Rigor

The criteria of Lincoln & Guba (1985) were applied to establish the trustworthiness of the study process. Three main strategies were used to enhance the credibility of the study findings. First, the researchers followed the recommendations of Glaser & Strauss (1967) to evaluate whether the emerging categories were meaningfully relevant, were able to explain the subject under study, and were applicable to the data under study. Second, researcher triangulation was established by involving three researchers in the data analysis. Third, by analysing data from participants with varying characteristics and experiences, discussion was encouraged about possible explanations of the emerging categories.

In addition, dependability and confirmability of the study were enhanced through an audit trail consisting of a transparent reporting of the research steps and decision-making. Furthermore, with regards to reflexivity, the interviewer (JV) reflected systematically on his interview skills, his professional background as a mental health nurse, and his view on the implementation of peer worker roles. As part of peer debriefing (Creswell 2014), a transcript of these reflections was shared and discussed with two experienced researchers (BD, SV).

TABLE 1: *Demographic data of the participants*

	Length of employment as a peer worker (months)						
Characteristic	NA	≤12	13–24	25–36	37–48	>48	n = 14
Sex							
Female	1	3	3	1			8
Male	1	1	1		1	2	6
Age (years)							
30–40	1	2			1		4
41–50		1		1			2
51–60	1	1	4			1	7
>60						1	1
Education							
Secondary school	2		1	1		1	5
Undergraduate/ bachelor		2	2			1	5
Master		2	1		1		4
Employment status							
NA	2						2
Paid		2			1	1	4
Voluntary		2	4	1		1	8
Working hours							
NA	2						2
Variable interval schedule		1				1	2
10–19 hours week		3	1				4
≥20 hours week			3	1	1	1	6

NA, not active: participants who either have quit, or aspire for a position as a peer worker.

3. Results

3.1. Sample description

Fourteen peer workers were recruited, of which eight had a voluntary status, four had a paid status, and two were unemployed. The employed peer workers performed their role in psychiatric hospitals and community-based mental health-care systems. In these contexts, the peer workers attend and facilitate peer support groups, design and lead group activities, share their recovery stories, support peers in their recovery, perform administrative tasks, and participate in multi-disciplinary meetings at the team and policy level. Demographic data of the participants are summarized in Table 1.

3.2. Major findings

Peer workers perceived that fulfilling their position enables them to move away from a devalued identity and strive towards constructing a positive identity. While peer workers associated a devalued identity with experiencing stigma, being in the margins of society, and having a low self-worth, they associated a positive identity with being accepted as a full person, making socially-valued contributions, and having a positive self-worth. In order to develop this positive sense of identity, peer workers engage in dynamic processes of meeting and balancing a desire for normalization, and an urge for self-preservation. Participant quotes that illustrate the findings are included in Table 2. These quotes were translated from Dutch into English.

3.3. Desire for normalization

Peer workers strive for normalization by realizing a meaningful employment in which they perceive opportunities to use their lived experience perspective as an asset, liberate themselves out of restrictive role patterns, and break down stigma and taboo.

3.4. Using lived experience perspective as an asset

Peer workers feel a sense of meaningfulness when they can use their own illness and recovery experiences as an asset to help and support peers. They referred to their approach as ‘providing recovery-oriented care’, which is characterized by adopting an unconditional positive regard, being present, and evoking hope in a positive outcome. In addition, some peer workers stated that it is their mission to advocate and translate the perspective of service users (e.g. during team meetings) (Table 2, Q1–Q2).

Peer workers reported a desire to be listened to and with their experiences as a user of mental health-care services. While some peer workers described having experienced patronizing and coercive practices, others described having experienced meaningful opportunities to participate in their own care and treatment. These experiences activated the peer workers' drive to promote change in mental health-care systems, to inspire values, and to demonstrate that individuals with mental health problems do have a future (Table 2, Q3–Q4).

Peer workers reported a desire to be listened to and to experience their participation making a meaningful difference in the organization. Based on this desire, some peer workers complained about the slow processing of their proposed ideas. This led to demotivation of peer workers who initially were highly motivated. Others relativized this issue by emphasizing that organizations are not yet ready to operationalize all peer workers' suggestions. Particularly in such situations, peer workers appreciated it when they received transparent and honest feedback (Table 2, Q5).

TABLE 2: *Illustrative quotes*

Q1	In the end, I'm really trying to work toward recovery of service users. That is truly focussing on talents, abilities, and skills that people have. While traditional caregivers pay less attention to these aspects.
Q2	I always stand beside the service user and then see how we can combine the service user's goals and interests with the interests of the organization.
Q3	As a peer worker, I encourage that drive, that hopeful message to professional caregivers to work in a recovery-supportive way with service users. I think this is one of my core tasks.
Q4	It would be disturbing for me to see that some caregivers still react in the same way as during my admissions. Then I would like to enable change, and even discuss these malpractices with policy makers.
Q5	If you eventually experience that your efforts are used as a kind of varnish, or I don't know. . .then it will just have the opposite effect. Something you thought to be meaningful, turns out to be meaningless. Hence my doubt whether or not I need to continue my efforts (as a peer worker).
Q6	Being a peer worker gave me back a place and function in the society. I can say now I facilitate a self-care group for individuals with experience of mental health problems.
Q7	I was teacher in a girls' school until 1999. I loved being a teacher. . .and now as a peer worker, I can show my competencies again, my power, my talent to stand in front of a group and to be able to teach something to others. That is a confirmation for me that I am still worth something.
Q8	My job gives me stability, a great sense of responsibility, and a lot of recognition. Because if your illness lasts for so long, then you start to question your identity and your self-worth, but if you have a success story with this work, your self-worth and self-esteem come back to a normal level.
Q9	I do get appreciated and people actually listen to me, but I do not have the status of a professional caregiver. So I think I would be a fuller member if I obtain a paid position.
Q10	I'm a little afraid that we won't get tasks and opportunities anymore if we don't follow a training programme.
Q11	I would try to present myself as normal as possible. So people think, 'yes it (developing mental health problems) can happen to anyone, not just to fools'. . .I think this would have a great value for me. To reflect at the end of my life. . .I have done a great effort to break down this stigma.
Q12	There is openness, and yes, that is actually a revelation to me. I thought for so many years, whatever I say, people don't listen and don't take me seriously because I am a mental health service user, and that is changing now.
Q13	In competitive work, if you say after 1 week: 'I need to rest for 2 days', then they will say, 'Look, it is over!' or 'We hire someone else!' As (a) peer worker within a mental health-care system, there is much more understanding for such situations.
Q14	When sharing my story with peers, then I learn to remain alert and always think a step further: 'How is it for me?' My self-reflection, my critical view, an ongoing critical look at myself. I think this is important in my recovery.
Q15	I thought it would be good to share my experiences, but that was a total disappointment. . .I felt that during my involvement in a peer group, I was preoccupied with my former suicidal thoughts. . ..Now (after quitting as a peer worker) it is easier for me to manage my emotions.
Q16	A little silicone to fix it when it (psychologically) begins to sputter and stumble. I can compare that silicone with my regular Alcoholics Anonymous (AA) meetings.
Q17	Listening and stimulating didn't help apparently. To some, it was helpful, but not in the majority of service users. That's when I thought, I am going to come to a dead end, I will get exhausted. I have to get out of this before I get an aversion of my work.
Q18	Then I get that shared feeling of powerlessness, but all I can do is say: 'I cannot guarantee you, but it is likely that you will get better at a certain point'. But I have no recipe, because the suffering is different for everyone. You must develop a personal recovery recipe by means of help and support.
Q19	In the last 6 years, I have not got any opportunities for personal development, and then, when I started as (a) peer worker, I experienced a magical feeling that was like 'wow, the world opens up for me'. Having this feeling, it was very important to reflect, 'Okay, these are my tasks and responsibilities, but I have to make choices in order to prevent exceeding my boundaries'.
Q20	I knew this workload was too much for me. . .but nevertheless, I wanted to hold my tasks and responsibilities a little bit longer.
Q21	After seriously exceeding my boundaries. . .a couple of times, I thought. . .I really need to make choices in the offer of tasks and responsibilities.
Q22	I believe that peer workers must give an extra dimension to being present to service users, but at the same time, we need to guard our boundaries.

3.5. Liberating themselves out of restrictive role patterns

Peer workers related several restrictive patterns with having mental health problems and adopting a role as a service user. These patterns are associated with losing social roles, feeling a sense of loneliness, having a place in the margins of society, and suffering a lack of future prospects. In order to liberate themselves from these restrictive patterns, peer workers emphasized that starting employment has great meaning because it enabled them to feel a 'sense of belonging' and to make socially-valued contributions (Table 2, Q6).

Peer workers also described how they regained life goals and prospects due to a range of opportunities for personal growth. For example, through attending team meetings and supporting peers, peer workers perceived they could develop personal and interpersonal competencies. Upon receiving positive feedback from professionals and peers, peer workers reported feeling validation and a positive sense of self-worth (Table 2, Q7–Q8).

Peer workers emphasized the importance of being accepted by the professional caregivers they collaborate with. In striving towards a sense of recognition for their efforts, some peer workers felt a need to obtain official training certificates or a paid position. Others were concerned that meeting such professional standards would become a precondition to work as a peer worker. For example, they stated that receiving a salary could increase their sense of responsibility, and could restrict the provision of flexible working conditions. Following these considerations, a number of voluntary peer workers preferred to retain the flexible character of their positions (Table 2, Q9–Q10).

3.6. Breaking down stigma and taboo

Based on their desire for normalization, peer workers perceived that there is no place for mental health stigma and taboo. They spontaneously reported experiences of discrimination by former employers, and stigmatizing comments from family members and professional care- givers. These experiences activate the peer workers' drive to share recovery stories in order to normalize societal perceptions and to enhance the openness around experiencing mental health problems (Table 2, Q11).

Peer workers talked about daily-life situations (e.g. competitive employment) where they felt a need to conceal their background of mental health problems in order to avoid discrimination. Comparing these situations with the culture in their current work context, peer workers perceived less negative labelling and enhanced opportunities for self-disclosure. Particularly among peers, peer workers cherish the mutual acknowledgement and understanding in respect to each other's experiences (Table 2, Q12).

3.7. Urge for self-preservation

The urge for self-preservation reflects the daily considerations of peer workers to prevent the emergence of adverse emotional fluctuations. To adequately manage challenging situations in the course of their employment, peer workers engage in flexible and supportive working conditions, and develop and employ self-care skills and strategies.

3.8. Experiencing supportive working conditions

Peer workers experienced mental health benefits because of certain work characteristics. Generally, they reported that engaging in work as a structured daytime activity can reduce the emergence of adverse emotional fluctuations. More specifically, peer workers indicated being able to manage their well-being when experiencing flexible and supportive conditions, including working a feasible amount of hours, working at one's own pace, and having opportunities to rely on peers and professionals. Reflecting on their employment experiences, peer workers felt that the flexible working conditions in their current positions contrasted with more rigid arrangements in competitive positions (Table 2, Q13).

3.9. Developing and employing self-care skills and strategies

Peer workers entered a role that they perceived as more socially valued than a role as a service user. Longing to hold their position, peer workers perceived a need for self-care during challenging situations. At the same time, they indicated that engaging in challenging situations enabled them to learn to deal with personal and interpersonal boundaries (Table 2, Q14).

An important issue reported by the peer workers was the possibility of feeling emotional distress when engaging in experiential sharing with peers. For one participant, the repetitive experience of feeling overwhelming emotions was even a reason to quit as a peer worker. In order to secure their self-preservation, many peer workers preferred cautious involvement with peers, characterized by showing commitment while preventing themselves from feeling overwhelming emotions. For the same purpose, most peer workers continued to attend peer support groups and consultations with professional caregivers as a service user (Table 2, Q15–Q16).

Peer workers were encouraged when they perceived progress in the recovery of the peers they supported. Conversely, when peers did not recover as expected, peer workers felt a sense of powerlessness and disappointment. As such experiences can affect one's well-being, peer workers perceived that they had to learn to adopt a realistic perspective when supporting peers. They indicated that peers themselves need to discover what either helps or hinders their recovery (Table 2, Q17–Q18).

Peer workers also reported a risk of crossing personal boundaries in terms of work overload. They considered it important to let go of responsibilities at the right moment, to step on the brake on time, and to learn to say 'no'. Employing these self-care skills and strategies at the right time was a real challenge, especially because peer workers found it hard to balance their engagement in attractive normalizing activities while maintaining sufficient attention for their well-being (Table 2, Q19–Q20).

3.10. Searching for an acceptable balance between driving forces

When interpreting the emerged conceptual framework presented in Figure 1, an important insight is that peer workers' driving forces constitute an interplay of dynamic processes. While striving to construct a positive identity, peer workers continuously search for an acceptable balance between their desire for normalization and their urge for self-preservation. For example, while engaging in meaningful, helping relationships, some peer workers felt that experiential sharing with peers could trigger emotional distress. In essence, peer workers emphasized that balancing the emergence of emotional distress is a precondition to retain meaningful employment (Table 2, Q21–Q22).

FIG. 1: *Peer workers' driving forces and the interplay of dynamic processes.*

4. Discussion

The present study generated a conceptual framework of the driving forces of peer workers in mental health-care systems. Using constant comparison analysis, the understanding emerged that peer workers strive towards constructing a positive identity by searching for an acceptable balance between their desire for normalization and their urge for self-preservation. When this balance is not found, peer workers might give up their position as a peer worker or might experience a relapse of mental illness. This understanding was supported by including one participant who was no longer active as a peer worker and one participant who felt ambivalent about continuing as a peer worker. These findings provide new insight in how peer workers maintain their well-being while realizing meaningful employment.

In the scientific literature, the process of identity construction has received increasing attention. An important evidence base in this respect is the CHIME framework (Leamy et al. 2011). This framework reveals that developing a positive sense of identity is an important construct in the recovery of individuals with lived experience of mental health problems. In addition, the emerged core category 'desire for normalization' can be related to Wolfensberger's (1972, 2011) 'principle of normalization', which he later renamed 'social role valorisation'. Wolfensberger's theoretical framework revealed that population groups (e.g. individuals with mental health problems) can be stigmatized and socially excluded as a result of perceived psychical, emotional, or mental health deviancies. Countering these devaluing social processes, the goal of normalization is 'the establishment, enhancement, or defence of the social role(s) of a person or group, via the enhancement of people's social images and personal competencies' (Wolfensberger 2011, p. 435). Consulting this theory enabled the researchers to enhance and validate the understanding of the peer workers' driving forces. In general, peer workers perceived starting employment as an opportunity to make a valued social contribution. More specifically, they perceived that their role as a peer worker can be normalizing when it includes opportunities to use their lived experience perspective as an asset, to perform tasks that validated their personal competencies and lived experiences, and to promote the societal perception of mental health problems.

The core category 'urge for self-preservation' reflects the recurring challenges that peer workers experience to maintain their well-being. Challenges articulated by peer workers in the present study, including feeling overwhelming emotions and experiencing work overload, have been identified earlier (Gates & Akabas 2007; Moran et al. 2013). Our findings indicate that peer workers should not be automatically restricted from engaging in such challenging situations, but rather have the opportunity to explore these situations as part of a learning process. Having this opportunity can enable peer workers to increase their self-care behaviour and to enhance their knowledge about mental health and recovery (Bailie & Tickle 2015; Moran et al. 2012).

Future studies should apply longitudinal designs to enhance the understanding of how peer workers' driving forces evolve and interact over the course of their employment. In order to support sustainable positions for peer workers, further theoretical clarification is needed of the process of balancing one's mental well-being while realizing meaningful employment. At the same time, it is valuable to further examine how the driving forces of peer workers are related to their work context, and the interactions they have with peers and mental health nurses. Therefore, it is recommended that peer workers who perform different roles within different organizational and cultural contexts are recruited for future studies.

Limitations

Potential cross-cultural differences must be taken into account when interpreting and operationalizing the conceptual framework. For example, as the form and magnitude of mental health stigma can vary among populations, the association between stigma experiences and the desire for normalization is likely to be pronounced differently in different parts of the world (Angermeyer et al. 2016; Griffiths et al. 2006).

In addition, the conceptual framework might be subject to limitations of the data-collection method. Bargh & Chartrand (1999) indicated that humans have implicit driving forces that they are hardly aware of. The question arises whether these driving forces were fully captured by the one-off semi-structured interviews. A follow-up interview might have added value to address this potential limitation.

Furthermore, it is likely that the fullness of the concepts has not become entirely clear from the analysis. For example, while the desire for normalization was identified as a core category comprising several interrelating concepts, the researchers might have not been able to establish an in-depth exploration of all the dimensions of normalization.

5. Conclusion

The present qualitative study explored the driving forces of peer workers to fulfil their position in mental health-care systems. The understanding emerged that peer workers strive towards constructing a positive identity by searching for an acceptable balance between their desire for normalization and their urge for self-preservation. This knowledge can inform policies and working conditions that support the authentic and sustainable implementation of peer worker roles in mental health-care systems. Mental health nurses should have knowledge of peer workers' driving forces so that they can offer tailored support to peer workers, and validate and promote their competencies and lived experience perspective.

6. Relevance for practice

The emerged conceptual framework can inform the establishment of work contexts in which peer workers have opportunities to realize meaningful employment, to develop self-care skills and strategies, and to engage in supportive working conditions. Knowledge of peer workers' driving forces can be applied to inform role descriptions and training programmes to support peer workers in daily practice. In particular, the findings indicate that peer workers want to learn about self-care skills, and how they can constructively approach peers and professional caregivers. These expectations are closely related to their drive to help peers, their desire for meaningful participation, and their urge for self-preservation.

The core categories, 'desire for normalization' and 'urge for self-preservation', reflect that the preferred peer worker position is one that respects, and is based on, the authentic lived experiences of peer workers with mental health problems and mental health-care service use. As mentioned in the Introduction, researchers argue that the authentic nature of peer workers' contribution might become diluted because of overly-professional definitions and interpretations of peer worker positions (Gillard et al. 2015; Vandewalle et al. 2016, p. 247; Walker & Bryant 2013). With regards to this concern, the current findings show a resolute search of some peer workers to conform to professional standards in order to gain acceptance of professional caregivers. This might be an indication of peer workers becoming socialized in work cultures where stakeholders strongly uphold professional norms. Other studies have found that some peer workers are willing to follow generic professional training, even if this is at the expense of providing authentic peer support based on their lived experiences (Asad & Chreim 2016; Rebeiro Gruhl et al. 2016). These findings should stimulate study and debate about the extent to which acquisition of professional skills is effective for peer workers, and how, when, and where this skill acquisition can dilute the authentic nature of peer support.

The findings indicate that peer workers attach strong meaning to the interactions with the professional care-givers they collaborate with. In particular, because of the interpersonal nature of their work, several researchers refer to the crucial position of mental health nurses to promote and take leadership in the implementation of peer worker roles (Byrne et al. 2017; Cleary et al. 2011; Hurley et al. 2016; Vandewalle et al. 2016). When interacting with peer workers, mental health nurses can provide support, share knowledge and values about establishing interpersonal relationships with service users, and validate peer workers' competencies and authentic contribution (Byrne et al. 2017; Dziopa & Ahern 2008; Peplau 1997). Furthermore, reflecting on key findings of the current study, mental health nurses can support peer workers' sense of self-worth and belonging by offering positive feedback to peer workers and by validating and operationalizing their ideas and suggestions. In addition, mental health nurses should enable peer workers to develop their self-care behaviour, and to express and discuss their need for support. This calls for mental health nurses who engage in a coaching and collaborative way with peer workers.

Several peer workers' accounts point to the presence of professional stigma towards individuals with lived experience of mental health problems. This apparent sensitive issue among peer workers is elaborated further in our literature review (Vandewalle et al. 2016). The review indicates that peer workers themselves can experience 'ongoing' professional stigma, and that this stigma is a main barrier to their integration and participation. Cleary et al. (2011) indicated that a key strategy to promote the integration of peer workers is to challenge the attitudes of professional caregivers, and in particular, those of mental health nurses. For this purpose, educational programmes can incorporate knowledge of peer workers' driving forces to encourage mental health nurses to reflect on the potential stigmatizing attitudes of themselves and their colleagues. This in turn can enable nurses to engage in normalizing and supportive interactions with peer workers and mental health-care service users.

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Hoofdstuk 5

Peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review

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Summary

Objectives: To identify peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services.

Design: Review of qualitative and quantitative studies.

Data sources: A comprehensive electronic database search was conducted between October 2014 and December 2015 in PubMed, CINAHL, Web of Science, The Cochrane Library, and PsycARTICLES. Additional articles were identified through hand-search.

Review methods: All articles were assessed on quality. A thematic analysis informed by a multi-level approach was adopted to identify and discuss the main themes in the individual studies. Reporting was in line with the 'Enhancing transparency in reporting the synthesis of qualitative research' statement.

Results: Eighteen articles met the inclusion criteria. All studies adopted qualitative research methods, of which three studies used additional quantitative methods. Peer workers' perceptions and experiences cover a range of themes including the lack of credibility of peer worker roles, professionals' negative attitudes, tensions with service users, struggles with identity construction, cultural impediments, poor organizational arrangements, and inadequate overarching social and mental health policies.

Conclusions: This review can inform policy, practice and research from the unique perspective of peer workers. Mental health professionals and peer workers should enter into an alliance to address barriers in the integration of peer workers and to enhance quality of service delivery. Longitudinal research is needed to determine how to address barriers in the implementation of peer worker roles.

What is already known about the topic?

International mental health policies increasingly promote the involvement of service users. Within this evolution, the implementation of peer worker roles is a fast growing innovation in mental health services.

Based upon their lived experience with mental health problems, peer workers can have a unique contribution in mental health care, particularly by interacting with service users.

Multiple challenges, mainly in collaborating with professional caregivers, hinder successful implementation of peer worker roles.

What this paper adds:

Peer workers perceive and experience personal, inter- personal and contextual barriers to their integration in mental health services. An integrative multi-level approach is needed to address these barriers and to establish an authentic integration of peer workers.

Because of the explicit focus on peer workers' perceptions and experiences within a multi-level framework, this review can inform mental health policy and practice with respect to the unique perspective of peer workers.

1. Introduction

1.1. Background

While traditional mental health policies were predominantly determined by medical models, these policies are now increasingly influenced by value-based recovery models (Farkas et al. 2005; Slade et al. 2008). Compared to medical models, which focus on problems and the alleviation of symptoms of service users, recovery models emphasize social inclusion and self-determination, and the value of expertise gained by managing mental health problems (Davidson 2005). To establish and sustain recovery-orientation, the policies and mission of mental health organizations must be grounded in recovery values such as the use of lived experiences to realize mutual support and the involvement of service users at all levels of the organization (Farkas et al. 2005). One particular strategy is the development of roles for service users whereby their experience of recovery is given enhanced recognition. Recently, this strategy has resulted in the implementation of peer worker roles in mental health services (Gordon & Bradstreet 2015; Salzer et al. 2010; Slade et al. 2014).

Acknowledging multiple terms and definitions are associated with peer worker roles, the main feature of the role is the use of lived experiences to support individuals (peers) in similar situations (Davidson 2005; Repper & Carter 2011). For instance, peer workers can be employed in residential and community mental health services, and in organizations led by peer workers (Slade et al. 2014). According to the meta-synthesis of Walker & Bryant (2013), peer workers can be role models, establish rapport with service users, reduce stigma, and teach professionals about recovery. Previous reviews focused primarily on the effectiveness of services provided by peer workers. Low to moderate evidence was found indicating that peer workers can promote service user outcomes including hopefulness for recovery, empowerment, reduction in use of crisis units, and a reduction of substance use (Chinman et al. 2014; Davidson et al. 2012; Lloyd-Evans et al. 2014; Pitt et al. 2013; Walker & Bryant 2013). In addition, Repper & Carter (2011) found benefits for peer workers themselves including improvement of self-esteem and personal recovery.

Based on this growing body of knowledge, mental health services increasingly implement peer worker roles as an innovation. However, implementing evidence-based innovations can be challenging (Grol & Grimshaw 2003). As concluded by Davidson et al. (2012), implementing peer worker roles is complicated because it requires a radical change of culture and practice in mental health organizations. It is assumed that professionals operating from medical models, including mental health nurses, have considerable defensiveness toward the integration of peer workers. For instance, while some nurses adopt a patronizing approach regarding the mental health status of peer workers, others feel it is confronting when peer workers question their standards of practice (Bennetts et al. 2011; Roper & Happell 2007). In addition, stakeholders can have conflicting perspectives on barriers to the integration of peer workers. For instance, in multidisciplinary teams, some professionals perceive they are working as equals while some peer workers perceive they are in unequal positions (Gillard et al. 2013). Conflicts also arise concerning the use of lived experiences with mental health problems. Some professionals recommend that peer workers restrict disclosing their lived experiences in order to maintain their personal wellbeing. However, peer workers indicate that this restriction can cause an impersonal engagement with service users, which reduces the meaningful nature of peer support (Gillard et al. 2015; van Erp et al. 2010).

Gillard et al. (2013) assert that professionals’ recommendations are an indication of professional dominance over the position of peer workers. This power imbalance can result in an overly professional definition and interpretation of peer worker roles, which constrains the distinctive contribution peer workers can make based on their lived experiences (Walker & Bryant 2013). Following this evidence, it is deemed necessary to explicitly capture the peer workers' perceptions and experiences of barriers to the implementation of peer worker roles (Moran et al. 2013; Walker & Bryant 2013). The authors acknowledge this delineated focus is both strength and limitation of this review, which will be addressed in the discussion section.

1.2. Aim

This literature review is designed to answer the following question: What are peer workers' perceptions and experiences of barriers to the implementation of peer worker roles in mental health services?

The authors aim to explore how peer workers' perspectives are related to: (1) the nature of the innovation (in this study interpreted as characteristics of peer workers and peer worker roles), (2) the involved professional staff, (3) the involved service users, and the (4) social, (5) organizational, and (6) economic and political context.

2. Methods

2.1. Search methods

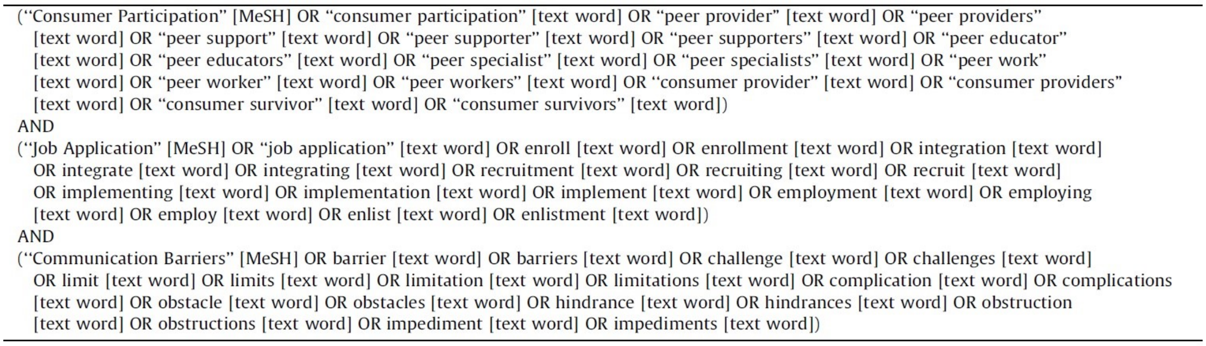
Electronic databases were searched between October 2014 and December 2015 including PubMed, CINAHL, Web of Science, The Cochrane Library, and PsycARTICLES. Search terms were identified through a literature review and expert consultation. The strategy used in PubMed formed the basis for similar strategies in other databases (Table 1). In addition, reference lists of reviews and included articles were hand-searched. One reviewer (JV) searched and identified the articles for inclusion. The following inclusion criteria were applied: (1) studies with quantitative or qualitative design, (2) articles written in English or Dutch, (3) peer workers older than 18 employed in mental health services, (4) focus on peer workers' perceptions and experiences of barriers to implementation of peer worker roles.

2.2. Quality appraisal

To assess the methodological quality of qualitative studies, the instrument 'Critical Appraisal Skills Programme' was used (Milton Keynes Primary Care Trust 2002). This tool was applied to enhance review transparency by systematically determining the rigor, credibility, and relevance of individual studies. Ten questions assisted the reviewer (JV) by addressing the aim, methodology, design, sampling, data collection, reflexivity, ethical issues, data analysis, findings, and the value of the research.

Three studies used separate quantitative parts in their methodology. While one study was outside the scope of this review, the two other studies had small sample sizes, adopted a cross-sectional survey design, and were explorative in nature. Considering these specific characteristics, the authors conducted no separate quantitative assessment because this would give a compromised and incorrect portrait of the study quality.

Table 1
Search filter entered in PubMed.



("Consumer Participation" [MeSH] OR "consumer participation" [text word] OR "peer provider" [text word] OR "peer providers" [text word] OR "peer support" [text word] OR "peer supporter" [text word] OR "peer supporters" [text word] OR "peer educator" [text word] OR "peer educators" [text word] OR "peer specialist" [text word] OR "peer specialists" [text word] OR "peer work" [text word] OR "peer worker" [text word] OR "peer workers" [text word] OR "consumer provider" [text word] OR "consumer providers" [text word] OR "consumer survivor" [text word] OR "consumer survivors" [text word])
AND
("Job Application" [MeSH] OR "job application" [text word] OR enroll [text word] OR enrollment [text word] OR integration [text word] OR integrate [text word] OR integrating [text word] OR recruitment [text word] OR recruiting [text word] OR recruit [text word] OR implementing [text word] OR implementation [text word] OR implement [text word] OR employment [text word] OR employing [text word] OR employ [text word] OR enlist [text word] OR enlistment [text word])
AND
("Communication Barriers" [MeSH] OR barrier [text word] OR barriers [text word] OR challenge [text word] OR challenges [text word] OR limit [text word] OR limits [text word] OR limitation [text word] OR limitations [text word] OR complication [text word] OR complications [text word] OR obstacle [text word] OR obstacles [text word] OR hindrance [text word] OR hindrances [text word] OR obstruction [text word] OR obstructions [text word] OR impediment [text word] OR impediments [text word])

2.3. Data extraction and synthesis

Thematic analysis was used to synthesize the results of individual studies in a transparent way, while staying close to the peer workers' perspectives (Thomas & Harden 2008). Analysis comprised several stages in line with the procedure outlined by Braun & Clarke (2006). Research data were extracted by one reviewer (JV) and inserted into pre-piloted forms comprising information about main purposes, year of publication, setting, study design, data collection, sample (peer workers), and peer workers' perceptions and experiences. An independent reviewer supervised this process by revising the pre-piloted forms. Articles were read multiple times to gain familiarity with the research topic. Text fragments under the headings 'results' and 'findings' were extracted into word processing software. In articles containing perspectives of multiple stakeholders, this extraction was restricted to fragments with an explicit reference to the perspective of peer workers. One reviewer (JV) initiated line-by-line coding to capture important nuances (Holloway & Wheeler 2010). Afterwards, codes within and between articles were compared, which brought codes on a more conceptual level. Subsequently, as part of the inductive process, codes were grouped into potential themes conceptually informed by a multi-level framework. Experienced barriers were identified and discussed on six levels including the nature of the innovation (in this study interpreted as characteristics of peer workers and peer worker roles), the involved professionals and service users, and the social, organizational, and economic and political context (Grol & Wending 2004). Themes were reviewed while simultaneously rereading original text fragments. To ensure themes adequately represent the original data, regular meetings with authors (JV, BD & TV) were organized to discuss potential bias in the analysis (Braun & Clarke 2006).

3. Results

3.1. Results of searching

The electronic literature search yielded 2802 articles of which 342 were duplicates. Based on title screening, 2182 articles did not meet the eligibility criteria. Reasons for exclusion were: not in mental health context (1493), not a focus on peer workers (571), and not a focus on barriers (118). Subsequently, the remaining 278 articles were expanded with four articles identified by hand-search. This selection was screened on abstract, resulting in the exclusion of 241 articles. Reasons for exclusion at this stage were: not in mental health context (65), not a focus on peer workers (115), not a focus on barriers (49), not written in English or Dutch (8), and reviews (4). Finally, the full texts of 37 articles were screened leading toward the exclusion of 19 articles which did not have a focus on peer workers' perceptions and experiences of barriers to implementation of peer worker roles. The final selection included 18 articles. The search process is outlined in Fig. 1.

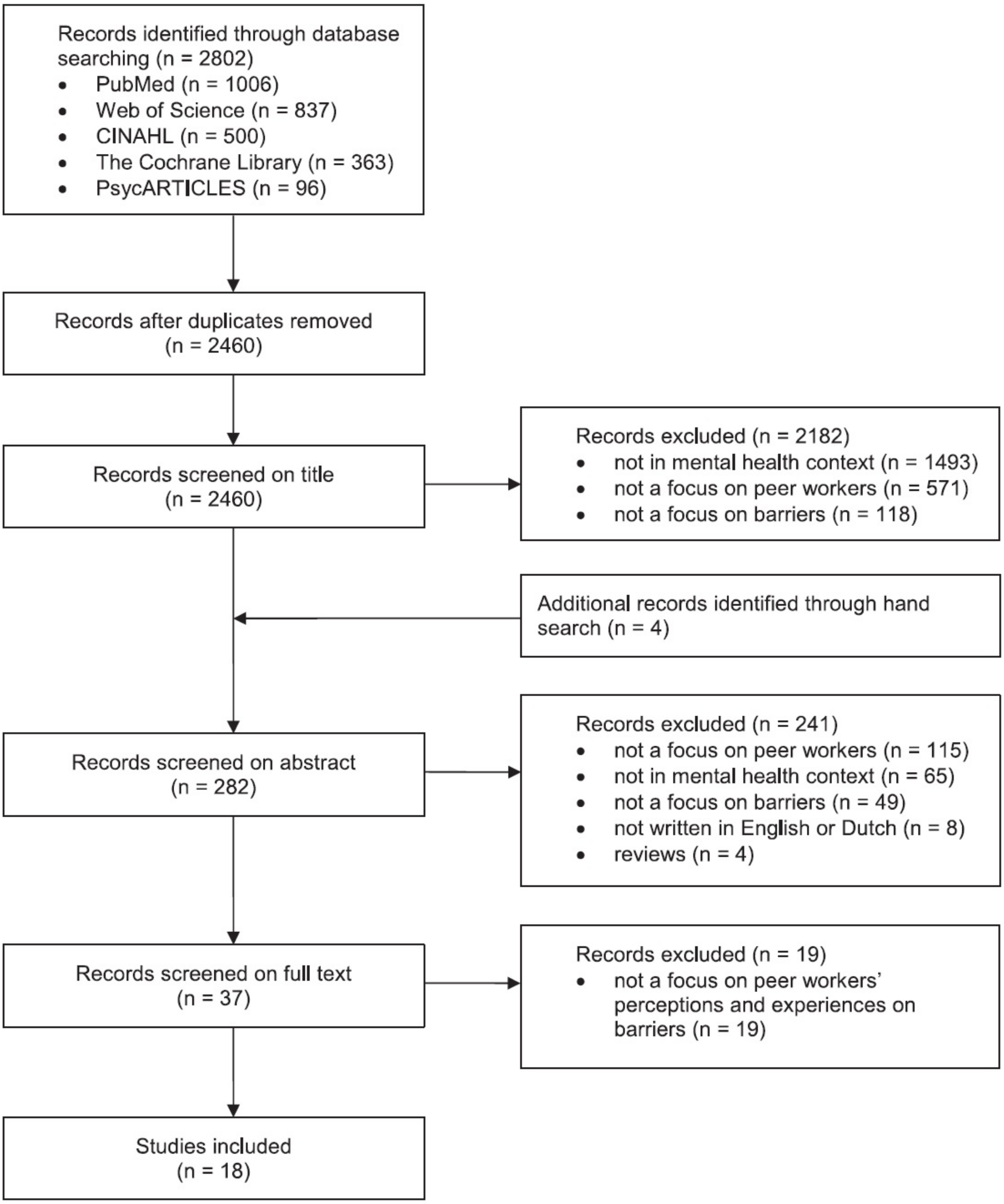


Fig. 1. Decision flowchart for identified studies.

3.2. Study characteristics

This review includes 18 articles published between 1998 and 2015. All studies used a qualitative research design, of which three applied additional quantitative methods. All articles were written in English. Studies were conducted in the United States of America (8), Canada (3), England (3), Australia

(2), New Zealand (1), and The Netherlands (1). Authors focused mainly on peer workers integrated in community-based and inpatient mental health services (e.g. hospitals). A minority of studies focused on peer-led organizations. Ten studies explored the views of multiple stakeholders including peer workers, peer worker supervisors, service users, professional caregivers, directors, and managers. Peer workers' sample sizes ranged from 3 to 86. The majority of peer workers worked part-time either in voluntary or paid positions. The age of participants ranged between 18 and 65 years. Data were mostly collected through individual and focus group interviews by the support of an interview guide. Of each study, the main purpose, methodology, peer workers' sample, and main peer workers' perceptions and experiences are summarized in Table 2.

Based on the Critical Appraisal Skills Program (Milton Keynes Primary Care Trust 2002) for quality appraisal of qualitative studies, an average of 25% of the items was evaluated negatively in the individual studies (range 0–50%). Only three articles adequately considered the relationship between researcher and participants. In eight articles there is a lack of in-depth outline of the analysis process, which raises questions about their rigorousness. In five articles, there is no adequate discussion of evidence for and against researcher's arguments. Finally, some studies had small sample sizes. The inclusion of these studies was considered in the light of the quality criterion 'thick description'. Because the small-sample studies described rich and detailed information about the study context, participants, and the studied phenomenon, it was decided to include these studies (Polit & Beck 2010). Overall, no quality threshold was adopted and no articles were excluded because of methodological quality. An overview of the quality assessment is given in Table 3.

Table 2
Characteristics of individual studies.

Study	Main purpose	Methodology		Sample	Main peer workers' perceptions and experiences
		Setting (country)	Design and data collection		
Ahmed et al. (2015)	Explore the experiences of peer workers with focus on the roles, benefits and potential challenges of fulfilling a peer worker position.	Peer-led services in traditional mental health systems (USA)	Qualitative and quantitative, survey (e.g. 'Peer Specialist Experiences Survey')	84	Peer workers perceive a poor financial compensation, a lack of variation in peer worker roles, job stress, emotional challenges when supporting peers, and difficulties in maintain personal wellbeing.
Asad and Chreim (2015)	The authors explore how peer worker' roles are integrated in multidisciplinary teams, and how peer workers relate to professionals and service users.	Community treatment teams and hospitals (Canada)	Qualitative, semi-structured, open-ended interviews	12	Peer workers experience role ambiguity and a lack of education. Peer workers feel stigma of professionals and pressure to justify their role. They apply strategies to counteract the perceived lack of acceptance in the team. Setting boundaries with service users is challenging.
Cabral et al. (2014)	Explore how peer worker roles are defined across stakeholders and how peer workers are integrated across services.	Community and residential mental health organizations (USA)	Qualitative, semi-structured interviews and focus groups	44	Peer workers report unshared expectations toward their role result in role ambiguity. Further, they report insufficient supervision during their performance as a peer worker.
Chinman et al. (2008)	The authors explore challenges in the implementation of peer worker roles.	Traditional and peer-led organizations, Department of Veterans Affairs (USA)	Qualitative, Grounded Theory, focus groups during a conference	59	Peer workers perceive ambiguous role definitions and report a lack of training and supervision. Professionals' attitudes impede participation in the team and initiate challenges with self-disclosure. Further, they report low financial compensation, being the only peer worker, boundary problems, and an inadequate plan for role development.
Francis et al. (2002)	Explore the changes a social services organization has made to adjust to the Americans with Disabilities Act, and the impact of these changes on peer workers.	Community mental health organizations largely staffed by peer workers (USA)	Qualitative, ethnography, exploratory case study, focus group, semi-structured interviews, field notes	13	Peer workers report negative professionals' attitudes and low expectations regarding their contribution. They report challenges of identity construction, team hierarchy, and 'formalized demands'.

Table 2 (*Continued*)

Study	Main purpose	Methodology		Sample	Main peer workers' perceptions and experiences
		Setting (country)	Design and data collection		
Gates and Akabas (2007)	Explore what policies, procedures and structures can be provided to support the contribution of peer workers in mental health systems.	Conventional mental health organizations (USA)	Qualitative, semi-structured telephone interviews and focus groups	15	Peer workers experience difficult integration in the team due to professionals' stigmatizing attitudes. They experience poorly defined roles, unshared role expectations, and role conflicts. Finally, they report barriers related to policies concerning confidentiality.
Gillard et al. (2013)	(1) Describe the emergence of peer worker roles from the perspectives of stakeholders. (2) Describe the organizational benefits and challenges of introducing peer worker roles.	Mental health NHS Trusts, community organizations (England)	Qualitative, informed by Grounded Theory, Secondary analysis	15	Peer workers experience inadequate training and supervision, challenging boundaries, emotional distress, and a conflicted sense of identity. Problems in the team are related to hierarchy, unshared expectations, role devaluation, and a lack of support.
Gillard et al. (2015)	Examine whether conditions supporting integration of peer worker roles apply across all mental health organizations, or whether there are implementation issues specific to particular organizational contexts.	Inpatient psychiatric wards and community mental health services (England)	Qualitative, Comparative Case Study, interviews with structured and in-depth questions	22	Peer workers perceive unclear role descriptions and expectations. They experience that their approach can contrast with organizational values. Further, peer workers perceive supervisors have insufficient knowledge and skills to support the peer worker role.
Hamilton et al. (2015)	Explore the perspective of peer workers, team members, and service users on the implementation of peer worker roles.	Community-based, intensive case management (USA)	Qualitative, interviews	5	Peer workers report a lack of knowledge about standard workplace behavior, a lack of training, and difficulties with performing administrative tasks.
Kemp and Henderson (2012)	Explore the challenges faced by peer workers and the solutions they considered would be most effective in overcoming these challenges.	Mental health organizations employing peer workers (Australia)	Qualitative, Nominal Group Technique (NGT), structured group meeting	7	Peer workers report role ambiguity, heavy workloads, ambivalence about self-disclosure, and inadequate supervision, training and certification. Further, they struggle with stigma and unequal positions in the team.

Table 2 (*Continued*)

Study	Main purpose	Methodology		Sample	Main peer workers' perceptions and experiences
		Setting (country)	Design and data collection		
Moll et al. (2009)	Explore perceptions of both new and established peer workers related to key elements in traditional mental health services.	Traditional mental health organizations (Canada)	Qualitative, collective case study, in depth interviews	6	Peer workers report unclear role definitions and problems with acceptance in the workplace. They experience difficulties in transitioning from 'being a service user' to 'being a service provider'.
Moran et al. (2013)	Develop a conceptual framework that illuminates challenges experienced by peer workers in diverse settings and roles.	Mental health organizations including traditional and peer-run organizations (USA)	Qualitative, interviews in two waves	31	Peer workers perceive role ambiguity, poor work conditions, stigmatization, and lack of recovery-orientated cultures. Further, they report relapse of symptoms, a lack of training, and having a 'peer worker identity'.
Mowbray et al. (1998)	Explore peer workers views on benefits resulting from their roles as well as their perspectives on role limitations.	Residential and community settings, case management (USA)	Qualitative, semi-structured interviews	11	Peer workers experience professionals' negative attitudes, inadequate training and supervision, devalued team positions, and low financial compensations. Further, peer workers report challenges of maintaining wellbeing, boundary issues, and frustration with uncooperative peers.
Rebeiro Gruhl et al. (2015)	Examine the role of peer workers, along with the challenges and benefits of their employment. Examine why peer work is not more integrated in conventional services.	Peer worker programs, 'Native Friendship Centers', mainstream mental health organizations (Canada)	Qualitative and quantitative, exploratory mixed-method, surveys and focus groups	86	Peer workers experience challenges to establish and maintain boundaries with service users. They emphasize the need for self-care and the risk for burnout. Peer workers feel pressure to gain acceptance in the organization.
Scott et al. (2011)	Explore the perspectives of peer workers and peer work managers on the ways that risks of violence, suicide and self-harm are managed within peer support settings.	Large mental health trusts and small trusts led by peer workers (New Zealand)	Qualitative, in-depth interviews and group interviews	24	Peer workers experience stigma, emotional distress, and problems with their dual role as both peer and service provider. Further, peer workers report team collaboration is impeded because of conflicting perspectives.

Table 2 (*Continued*)

Study	Main purpose	Methodology		Sample	Main peer workers' perceptions and experiences
		Setting (country)	Design and data collection		
Simpson et al. (2014)	Describe and evaluate the preparation, selection, and training of peer workers recruited to provide support to service users discharged from acute psychiatric units.	Conventional aftercare for service users discharged from acute psychiatric units (England)	Qualitative and quantitative, focus groups and survey	11	Peer workers feel insufficiently prepared to manage emotional challenges. In this regard, they perceive a lack of basic and ongoing training.
Yuen and Fossey (2003)	Explore peer workers' views on working in a program where individuals with lived experience of mental illness are assisted to access recreation.	Community recreation program (Australia)	Qualitative, informed by naturalistic inquiry, semi-structured-interviews	3	Peer workers perceive professionals' negative attitudes, problems with team cooperation, challenging work demands, and tasks without concrete outcomes. Further, they report allocation of minor duties, a conflicted sense of identity, and challenges to maintain wellbeing.
van Erp et al. (2010)	Explore whether the education program for peer workers succeeds in preparing students for their role as peer worker. Examine how participants function in mental health teams.	Traditional mental health organizations (The Netherlands)	Qualitative, semi-structured interviews	22	Peer workers experience tensions when interacting with service users, negative attitudes of professionals, and problems with team collaboration. Further, peer workers perceive low pay as discriminatory, complain about unclear role descriptions, and report ambivalence of self-disclosure.

Table 3
Overview of quality assessment using the Critical Appraisal Skills Program (Milton Keynes Primary Care Trust, 2002).

References	Items									
	Was there a clear statement of the aims of the research?[a]	Is a qualitative methodology appropriate?[b]	Was the research design appropriate to address the aims of the research?[c]	Was the recruitment strategy appropriate to the aims of the research?[d]	Where the data collected in a way that addressed the research issue?[e]	Has the relationship between researcher and participants been adequately considered?[f]	Have ethical issues been taken into consideration?[g]	Was the data analysis sufficiently rigorous?[h]	Is there a clear statement of findings?[i]	How valuable is the research?[j]
Ahmed et al. (2015)	Yes	Yes	No	Yes	No	No	Yes	No	Yes	Yes
Asad and Chreim (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Cabral et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Chinman et al. (2008)	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes
Francis et al. (2002)	Yes	Yes	Yes	No	Yes	No	No	No	No	Yes
Gates and Akabas (2007)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Gillard et al. (2013)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Gillard et al. (2015)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Hamilton et al. (2015)	Yes	Yes	No	Yes	Yes	No	No	Yes	No	Yes
Kemp and Henderson (2012)	No	Yes	No	Yes	Yes	No	Yes	No	No	Yes
Moll et al. (2009)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Moran et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mowbray et al. (1998)	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes
Rebeiro Gruhl et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Scott et al. (2011)	No	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes
Simpson et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Yuen and Fossey (2003)	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes
van Erp et al. (2010)	No	Yes	Yes	Yes	Yes	No	No	No	No	Yes

[a] Consider:
- What the goal of the research was.
- Why it is important.
- The research relevance.

[b] Consider:
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants.

[c] Consider:
- If the researchers have justified the research design (e.g. have they discussed how they decided which methods to use?).

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

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

[f] Consider whether it is clear:
- If the researchers critically examined their own role, potential bias and influence during
  - ○ Formulation of research questions.

○ Data collection, including sample recruitment and choice of location.

- How the researchers responded to events during the study and whether they considered the implications of any changes in the research design.

[g] Consider:

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

[h] Consider:

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

[i] Consider:

- If the findings are explicit.
- If there is adequate discussion of the evidence both for and against the researchers' arguments.
- If the researchers have discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.).
- If the findings are discussed in relation to the original research questions.

[j] Consider:

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

3.3. Experienced barriers

Experienced barriers of peer workers are assorted within a multi-level framework for implementing innovations in health-care. As outlined in Table 4, results are related to the nature of the innovation (in this study interpreted as characteristics of peer workers and peer worker roles), the involved professionals and service users, and the social, organizational, economic and political context (Grol & Wensing 2004). Although experienced barriers are structured, the results indicate implementation of peer worker roles in mental health services is a dynamic process whereby multiple levels are simultaneously integrated.

3.3.1. Nature of the innovation

Barriers experienced at this level are related to clarity and credibility of peer worker roles, and characteristics of peer workers fulfilling these roles.

Lack of role clarity: Peer workers across a variety of settings experience unclear and ambiguous description and operationalization of their tasks and duties (Asad & Chreim 2015; Cabral et al. 2014; Chinman et al. 2008; Kemp & Henderson 2012; Moran et al. 2013; Mowbray et al. 1998). This lack of role clarity can induce frustration and confusion in fulfilling their position, and hesitancy in demonstrating their true potential as a peer worker (Chinman et al. 2008; Gates & Akabas 2007; Moran et al. 2013). As a result of unclear role operationalization, peer workers feel they need more time to adapt to their role (Gillard et al. 2015; Hamilton et al. 2015; Moll et al. 2009; Mowbray et al. 1998; van Erp et al. 2010).

Pressure to gain acceptance: Peer workers often perceive that they are not accepted by stakeholders because their role lacks credibility (Asad & Chreim 2015; Chinman et al. 2008; Scott et al. 2011). They feel a continuous need to justify their position because of stakeholders' misunderstanding and negative attitudes toward the contribution of peer workers. While this pressure encourages some peer workers to prove themselves, others eventually get demotivated (Asad & Chreim 2015; Chinman et al. 2008; Francis et al. 2002; Gillard et al. 2015). Peer workers indicate acceptance of their role is undermined due to its lack of professional standards, and by the inadequate provision of training and financial compensation. For instance, although voluntarism is experienced as an opportunity for meaningful employment, some peer workers indicate this flexible statute reflects the limited valuation of their role (Gillard et al. 2015; Moran et al. 2013; Rebeiro Gruhl et al. 2015). To enhance their position in professional contexts, peer workers feel pushed to educate themselves, take on more responsibilities, or follow generic training, even if this is at the expense of providing authentic peer support (Asad & Chreim 2015; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015).

Table 4
Peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services.

Levels envisioned to examine barriers to the implementation of peer worker roles (Grol and Wensing, 2004)	Components of barriers experienced by peer workers based on review data	References (see numbers at the bottom of the figure)
Nature of the innovation (characteristics of peer worker roles and peer workers)	Unclear description and operationalization of the peer worker role	2, 3, 4, 6, 8, 9, 10, 11, 12, 13, 17
	Pressure to gain acceptance due to the lack of credibility of peer worker roles	2, 4, 5, 8, 12, 13, 14, 15
	Affected work performance of peer workers due to residual and recurring health issues	1, 2, 7, 11, 12, 13, 14, 15, 16, 17
Individual professional	Affected by professionals' misunderstanding and stigmatizing attitudes	1, 2, 4, 5, 6, 7, 8, 10, 11, 12, 15, 17
	Conflicts with professionals arising from professional routines	1, 2, 6, 7, 8, 11, 12, 13, 14, 17
Service user	Affected by service users lack of interest and uncooperativeness	2, 4, 6, 12, 13
	Challenging personal and interpersonal boundaries resulting from emotional attachment to peers	2, 7, 10, 12, 13, 14, 16, 17,18
	Adverse effects of self-disclosure on wellbeing and service users' expectations	2, 3, 4, 10, 11, 12
Social context	Struggles with integration and collaboration in multidisciplinary teams	2, 6, 7, 8, 11, 12, 13, 14, 15, 17, 18
	Conflicted sense of identity when constructing either 'professional identity' or 'peer worker-identity'	1, 2, 4, 6, 7, 10, 11, 12, 13, 15, 17, 18
	Lack of recovery-oriented culture in the work context	2, 4, 8, 12, 13, 14
Organizational context	Lack of (adequate) training	2, 4, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17
	Inadequate supervision	1, 2, 3, 4, 8, 10, 12, 13, 16
	Lack of resources and adverse effects of working conditions	1, 2, 4, 5, 6, 8, 11, 12, 13, 14, 16, 17
	Dissatisfaction with rigid organizational structures and task allocation	1, 2, 5, 8, 10, 11, 12, 13, 14, 15, 17
Economic and political context	Dissatisfaction with contracting and recruiting policies	1, 2, 4, 12, 13, 17, 18
	Lack of recognized certification for peer workers and inadequate funding	3, 4, 7, 9, 10, 11, 12, 13, 14
	Interference of work with social security benefits	1, 6, 13

References and respective numbers: (1) Ahmed et al. (2015); (2) Asad and Chreim (2015); (3) Cabral et al. (2014); (4) Chinman et al. (2008); (5) Francis et al. (2002); (6) Gates and Akabas (2007); (7) Gillard et al. (2013); (8) Gillard et al. (2015); (9) Hamilton et al. (2015); (10) Kemp and Henderson (2012); (11) Moll et al. (2009); (12) Moran et al. (2013); (13) Mowbray et al. (1998); (14) Rebeiro Gruhl et al. (2015); (15) Scott et al. (2011); (16) Simpson et al. (2014); (17) van Erp et al. (2010); (18) Yuen and Fossey (2003).

Residual and recurring health issues: While recognizing peer workers use experiences with mental illness as a strength, potential residual cognitive, social or emotional limitations might affect their work performance and ability to adapt to work routines (Moll et al. 2009; Mowbray et al. 1998). Moreover, some peer workers report being affected by work-related stressors, which further challenges their performance. As Moll et al. (2009) describe, upon interacting with peers, peer workers are determined to share stories on a personal level and to project themselves as more approachable than professionals. Peer workers acknowledge this close involvement with peers can trigger emotional distress, which can initiate relapse of psychiatric symptoms or burnout (Ahmed et al. 2015; Gillard et al. 2013; Moran et al. 2013; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015). Maintaining wellbeing can be challenging when problems of peers approach their own experiences. Tensions can arise across a variety of settings including peer workers who interact with peers in crisis situations, work autonomously in community services (e.g. Assertive Community Treatment), or work in settings that are clinically demanding. Consequently, peer workers emphasize the 'need to be ready' when entering their position and to positively cope with work-related stressors (Asad & Chreim 2015; Gillard et al. 2013; Moran et al. 2013; Scott et al. 2011; Simpson et al. 2014; van Erp et al. 2010).

3.3.2. Individual professional

Barriers experienced at this level are related to professionals' knowledge, attitudes, and routines.

Misunderstanding and negative attitudes: Particularly among professionals operating from medical models, peer workers report misunderstanding and insufficient knowledge regarding peer worker roles and the value of using lived experiences (Ahmed et al. 2015; Asad & Chreim 2015; Chinman et al. 2008; Gillard et al. 2015; Moran et al. 2013). Peer workers indicate misunderstandings can initiate prejudices such as the professionals' perception that peer workers are unable to cope when they experience work-related stressors (Gates & Akabas 2007; Kemp & Henderson 2012). Peer workers report being affected by professionals' attitudes and cognitions expressed as indirect and direct stigmatization. Indirect experienced stigma emerges when professionals use disrespectful language and treatment toward service users. Direct stigma experiences are associated with professionals' patronizing attitudes toward peer workers' diagnoses and history as service users. Stigmatization might be an ongoing concern for peer workers who become colleagues of former or current clinicians (Ahmed et al. 2015; Asad & Chreim 2015; Chinman et al. 2008; Gates & Akabas 2007; Gillard et al. 2013; Scott et al. 2011). Peer workers use terms such as 'patronizing', 'devaluing', and 'overprotective' to describe the way they sometimes feel approached by professionals. While some peer workers perceive this approach as an act of discrimination, others link stigmatization to insufficient knowledge of professionals about core principles of peer support (Asad & Chreim 2015; Chinman et al. 2008; Francis et al. 2002; Gates & Akabas 2007; Moran et al. 2013). Peer workers feel self-disclosing experiences with mental illness can decrease how professionals expect and value their contribution. As such, they struggle with questions concerning what, when, how and how much to disclose (Chinman et al. 2008; Gates & Akabas 2007; Kemp & Henderson 2012; Moll et al. 2009; Moran et al. 2013; van Erp et al. 2010).

Impeded by professional routines: Tensions can arise when professional staff and peer workers have different beliefs of what constitutes proper care for service users (Ahmed et al. 2015; Asad & Chreim 2015; Mowbray et al. 1998; van Erp et al. 2010). For instance, peer workers closely involved with peers experience that professionals do not support their informal approach, do not believe in its effectiveness, or label it as 'unprofessional' (Gates & Akabas 2007; Gillard et al. 2013; Moll et al. 2009; Mowbray et al. 1998). Peer workers explain that conflicts with professionals originate from the different nature of their respective work. While peer workers in traditional organizations report often being impeded by professional routines, this is less an issue in voluntary settings where peer workers make up the majority of the workforce (Asad & Chreim 2015; Gillard et al. 2015; Moran et al. 2013; Rebeiro Gruhl et al. 2015).

3.3.3. Service user

Barriers experienced at this level are related to cooperation of service users, maintaining personal and interpersonal boundaries, and self-disclosure.

Lack of interest and uncooperativeness: Peer workers report how some service users are not interested in services provided by peer workers or do not believe in its effectiveness. They indicate some service users label peer support as 'not helpful' because their mental health problems differ from those of the peer worker. Moreover, peer workers report that service users question the ability to care for employees who did not pass a formal training or who have mental health problems (Asad & Chreim 2015; Chinman et al. 2008; Gates & Akabas 2007; Moran et al. 2013). In addition, peer workers can be affected by service users' behaviour and severity of mental health problems. Helplessness can emerge when dealing with service users in crisis situations (e.g. self-injurious behaviour), when service users do not recover, or when service users are uncooperative, for instance during involuntary treatments (Asad & Chreim 2015; Moran et al. 2013; Mowbray et al. 1998).

Challenging personal and interpersonal boundaries: When peer workers are employed in small rural regions, in services for long-term care, or in organizations where peer workers once were service users, they are often familiar with the service users assigned to them. Especially in these particular situations, peer workers emphasize the importance of maintaining boundaries because of the risk of developing ‘friendships’ with service users, which might affect the relationship’s effectiveness and mutual benefits (Asad & Chreim 2015; Gillard et al. 2013; Kemp & Henderson 2012; Moran et al. 2013; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015; van Erp et al. 2010).

Peer workers report that emotional attachment to service users can result in going beyond personal boundaries in terms of emotional involvement and work overload. However, they feel ambiguous in discussing boundaries with service users because it can interfere with establishing a meaningful connection (Gillard et al. 2013; Moran et al. 2013; Mowbray et al. 1998; Simpson et al. 2014). While contextual specificity determines the likelihood of establishing friendships, it also determines how friendships are experienced. For example, peer workers running a recreation program cherished the friendships they established with service users (Yuen & Fossey 2003).

Adverse effects of self-disclosure: Although peer workers believe self-disclosure is a critical element of peer support, they also refer to its potential adverse effects (Cabral et al. 2014; Moran et al. 2013). Some peer workers experienced distress when they shared too much of their lived experiences. Some peer workers also encountered service users who felt overwhelmed when peer workers’ disclosure was not framed in a way that supported recovery (Asad & Chreim 2015; Kemp & Henderson 2012; Moran et al. 2013). In addition, peer workers are cautious with self-disclosing success stories of recovery. They refer to the risk of being portrayed as role models resulting in unrealistic expectations of service users toward their contribution (Asad & Chreim 2015; Chinman et al. 2008; Moll et al. 2009; Moran et al. 2013).

3.3.4. Social context

Barriers experienced at this level are related to team integration and collaboration, identity construction, and workplace cultures.

Struggles with team integration and collaboration: When integrated in multidisciplinary teams, some peer workers indicate feeling isolated or not being an equal team member. Peer workers explain their ‘sense of belonging’ is affected by their social position as neither service user nor professional and by the patronizing approach of team members regarding their health status (Ahmed et al. 2015; Chinman et al. 2008; Gillard et al. 2013; Kemp & Henderson 2012; Moll et al. 2009; Moran et al. 2013; Scott et al. 2011). Barriers to collaboration are often linked to unclear operationalization of the peer worker role, which is associated with role conflicts and distribution of unreasonable responsibilities (Gates &

Akabas 2007; Kemp & Henderson 2012; Mowbray et al. 1998; van Erp et al. 2010). Peer workers also report challenges with communication during team meetings. These challenges include power struggles with professionals, feeling uncomfortable with public speaking, and having little understanding of clinical terminology (Ahmed et al. 2015; Asad & Chreim 2015; Gillard et al. 2013; Moll et al. 2009; Yuen & Fossey 2003).

Conflicted sense of identity: Peer workers switch positions from being a service user toward being a service provider. This transformation reflects the unique social position of peer workers, which in turn determines how their identity is constructed (Moll et al. 2009; Scott et al. 2011; van Erp et al. 2010). Peer workers indicate establishing a 'conflicted sense of identity' in organizations where peer workers and professionals perform similar tasks and duties. When conforming to this generalist approach, then some peer workers feel pressure to act as a professional. They link this generalist approach to the value organizational leaders give to degrees and routine training rather than to the use of lived experiences. Peer workers often feel little autonomy from these stakeholders who have a major impact on how their role is integrated and established (Gates & Akabas 2007; Gillard et al. 2013; Moll et al. 2009; Moran et al. 2013; Rebeiro Gruhl et al. 2015; van Erp et al. 2010). While some peer workers feel uncomfortable with being identified as a professional, others express concerns about constructing a 'peer worker-identity'. They perceive their position as a peer worker defines 'who they are' and 'what competencies they have'. Keeping in mind effects of societal stigma, peer workers experience constructing a 'peer worker-identity' further limits opportunities for occupational directions beyond the mental health domain (Asad & Chreim 2015; Moll et al. 2009; Moran et al. 2013; Mowbray et al. 1998; Scott et al. 2011; Yuen & Fossey 2003).

Lack of recovery-oriented culture: Some peer workers in traditional organizations perceive their work context has a lack of 'recovery-orientation'. They refer to their work context as 'crisis-oriented' and 'without service user involvement' (Chinman et al. 2008; Moran et al. 2013; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015). Asad and Chreim (2015) found peer worker roles to be more integrated for teams in 'Assertive Community Treatment' in comparison with teams in traditional hospitals. The authors explained this finding by referring to the importance of recovery-oriented values underlying service models. Peer workers in peer-led services acknowledge this statement. They believe their integration is grounded in shared values of recovery and peer support (Gillard et al. 2015; Moran et al. 2013).

3.3.5. Organizational context

Barriers experienced at this level are related to training, supervision, working conditions, job structure, allocation of tasks, and organizational arrangements.

Inadequate provision of training: Regarding their individual and team performance, some peer workers report feelings of inadequacy, disappointment, and uncertainty (Mowbray et al. 1998; Scott et al. 2011). To support their performance, many peer workers express a need for specific, basic and ongoing training (Asad & Chreim 2015; Chinman et al. 2008; Gillard et al. 2015; Hamilton et al. 2015; Kemp & Henderson 2012; Moran et al. 2013; Simpson et al. 2014). However, across different settings, peer workers experience a mismatch between the training provided and the specificity of peer work. Training programs insufficiently address peer workers' perceived lack of skills in communicating with service users, in applying lived experiences, in dealing with overwhelming emotions, and in performing administrative tasks. Furthermore, peer workers express a need for training about self-disclosure, peer relationships, involvement with family members of peers, workplace policies, and functioning in team meetings (Asad & Chreim 2015; Gates & Akabas 2007; Gillard et al. 2013; Hamilton et al. 2015; Kemp & Henderson 2012; Moll et al. 2009; Moran et al. 2013; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015; Simpson et al. 2014). Finally, some peer workers report concerns about increased standardized training due to the risks of losing role flexibility and being trained too much as a professional (Kemp & Henderson 2012; Rebeiro Gruhl et al. 2015; van Erp et al. 2010).

Inadequate supervision: Peer workers perceive supervision as an essential component of their personal development. However, they experience guidance and supervision to be inadequate, particularly at the beginning of their employment (Cabral et al. 2014; Chinman et al. 2008; Kemp & Henderson 2012; Mowbray et al. 1998). Peer workers question the competences of supervisors, and complain about the time and frequency of contacts. They also describe the focus of supervision as inadequate or superficial, referring to supervisors emphasis on task performance rather than emotional concerns, boundary issues, and personal development (Ahmed et al. 2015; Asad & Chreim 2015; Gillard et al. 2015; Kemp & Henderson 2012; Mowbray et al. 1998). Reflecting on the potential detrimental effects of insufficient supervision, peer workers report their wellbeing may be affected when opportunities to discuss responsibilities and emotional concerns are scarce (Chinman et al. 2008; Moran et al. 2013; Mowbray et al. 1998; Simpson et al. 2014).

Lack of resources and adverse effects of working conditions: Peer workers complain about low financial compensation and perceive a lack of resources including workspace, computer, and access to service user records (Ahmed et al. 2015; Asad & Chreim 2015; Gates & Akabas 2007; Moran et al. 2013;

Mowbray et al. 1998; van Erp et al. 2010). Some peer workers perceive these poor working conditions reflect their inferior position in the organization (Asad & Chreim 2015; Moran et al. 2013).

To facilitate maintenance of wellbeing, many peer workers work limited hours, receive additional support or work within flexible terms. Although this flexibility is often appreciated, peer workers also feel working under supportive conditions can decrease the value attached to their position (Ahmed et al. 2015; Francis et al. 2002; Gillard et al. 2015; Moll et al. 2009; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015; Simpson et al. 2014). At the same time, peer workers indicate organizations do not provide a clear path for promotion and future work directions, which they perceive as a barrier to ongoing development of the peer worker role (Chinman et al. 2008; Gates & Akabas 2007; Moran et al. 2013).

Dissatisfaction with rigid organizational structures and task allocation: Peer workers experience hierarchical structures and formalized policies that can interfere with values of peer support (Francis et al. 2002; Gillard et al. 2015; Moll et al. 2009; Mowbray et al. 1998; Rebeiro Gruhl et al. 2015). For instance in Scott et al. (2011), peer workers were requested to use checklists to assess risk among service users. However, they found this formal approach neglects risk as a learning opportunity and impedes the meaningful nature of peer support. Contrarily to peer workers in traditional organizations, some peer workers in peer-run organizations report experiencing too little hierarchy, which induces confusion about decision- making and accountability (Gillard et al. 2015; Moran et al. 2013). Regarding allocation of tasks, peer workers report their tasks lack concrete outcomes and clearly defined goals. Moreover, they complain about their high workload, and performance of overly administrative, generic or minor tasks. Peer workers, even in peer-run organizations, experience this allocation of tasks competes with what they perceive as core to their role, namely providing authentic peer support (Ahmed et al. 2015; Asad & Chreim 2015; Francis et al. 2002; Gillard et al. 2015; Kemp & Henderson 2012; Moran et al. 2013; Rebeiro Gruhl et al. 2015; van Erp et al. 2010).

3.3.6. Economic and political context

Barriers experienced at this level are related to financial regulations and overarching policies including recruiting, contracting, funding, certification, and social regulations. Dissatisfaction with contracting and recruiting: Many peer workers across different settings complain about poor or non-existent financial compensation. Some of them perceive these financial regulations reflect the lack of credibility of peer worker roles (Asad & Chreim 2015; Chinman et al. 2008; van Erp et al. 2010; Yuen & Fossey 2003). Peer workers desire for better financial regulations might be partly related to dissatisfaction with their economic status. Survey findings of 84 peer workers show that half of them were dissatisfied with their financial status (Ahmed et al. 2015; Mowbray et al. 1998).

Criticism has also been voiced on recruitment policies. Peer workers feel dissatisfied about the low numbers of peer workers, high unemployment rates, and provision of temporary contracts, which they associate with income insecurity. They perceive this inadequacy of recruitment strategies impedes genuine participation of peer workers, especially in promoting change in mental health systems (Ahmed et al. 2015; Chinman et al. 2008; Moran et al. 2013; van Erp et al. 2010).

Lack of recognized certification and funding: Peer workers perceive the lack of a recognized certification impedes the acceptance of peer worker roles and its large-scale integration in mental health services (Chinman et al. 2008; Gillard et al. 2013; Kemp & Henderson 2012; Moran et al. 2013; Rebeiro Gruhl et al. 2015). Furthermore, this lack of certification is perceived to influence the amount and duration of funding. Several researchers studied the implementation of peer worker roles as part of a temporary project. The moment project funding ended, some peer workers were disappointed and frustrated because they became unemployed. Looking back at this experience, they perceive policies inadequately support sustainable implementation of peer worker roles (Cabral et al. 2014; Hamilton et al. 2015; Moll et al. 2009; Mowbray et al. 1998).

Interference of work with social security regulations: In the survey of Ahmed et al. (2015), more than half of peer workers reported their employment offers no employee benefits such as health insurance or paid holidays. Moreover, when they start their employment, some peer workers complain they are then excluded or restricted from social security disability benefits and access to employer health-care (Gates & Akabas 2007; Mowbray et al. 1998).

4. Discussion

This review adopted a multi-level framework to identify and discuss peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services. The structured results can support the development of tailored strategies to effective integration of peer workers (Grol & Grimshaw 2003). Practitioners must also think beyond this structure because the implementation of peer worker roles is a dynamic process whereby multiple levels are simultaneously integrated. For example, the 'pressure to gain acceptance' peer workers experienced was structured under the level 'nature of the innovation'. This level is of a higher order since acceptance and credibility of an innovation are essential preconditions to its successful implementation (Grol & Grimshaw 2003). Though, it should be realized that factors influencing experiences of acceptance are multifaceted including peer workers' health status, knowledge and attitudes of professionals, and financial compensation. In addition, acceptance of peer worker roles might also be affected by the limited and low-quality evidence-base regarding effectiveness of peer support services (Chinman et al. 2014; Lloyd-Evans et al. 2014).

To enhance the integration of peer workers, some administrators recommend formalizing peer worker roles in accordance with roles of professionals. For instance, as outlined in Gates & Akabas (2007): ‘peer workers should be compensated and evaluated on the same performance standards as professional staff’. This pressure to formalization is likely to be reinforced by peer workers themselves, who search for acceptance from stakeholders by attending standardized training and obtaining a recognized certification (Vandewalle et al. 2018). However, over the course of time, peer workers perceive the formalization of peer worker roles can initiate dilution of the meaningful nature of peer support (Gillard et al. 2015). This might indicate that peer workers are becoming ‘socialized’ in organizational cultures whereby stakeholders uphold specific standards of practice and professional norms. In contrast, where peer worker roles are implemented within a culture of shared values of recovery and peer support, peer workers were given the opportunity to develop a distinctive contribution based on lived experiences. These findings indicate establishing recovery-oriented cultures is essential in facilitating implementation and effectiveness of peer worker roles. This effectiveness is deemed to be undermined in organizations where peer workers are expected to carry out exclusively professional tasks or are recommended to avoid personal relationships with service users (Davidson et al. 2012; Gillard et al. 2015; Pitt et al. 2013).

Recognizing risks of ‘over-formalization’ and ‘over-professionalization’, organizational arrangements such as role descriptions and training should reflect peer workers’ experiences and the core principles of peer support (Gillard et al. 2013; Moran et al. 2013). When perspectives of peer workers are not taken into account, potential beneficial and adverse effects of organizational arrangements stay unrecognized. As an example, while administrators emphasize a need for a standardized description of peer worker roles, some peer workers perceive a loose role description as an opportunity to personally define and adapt the role in accordance with the peer worker’s strengths and service users’ needs (Asad & Chreim 2015; Cabral et al. 2014; Chinman et al. 2008; Moll et al. 2009). As this review identified perspectives of peer workers on multiple levels, it is emphasized that peer workers are central actors in the implementation process and their voice should be heard and respected on each of these levels. Adopting a multilevel framework highlighted the major influence of various stakeholders including service users, professional caregivers, supervisors, managers, and funders. In line with process theories, all key stakeholders should be involved in the implementation and development of peer worker roles (Grol et al. 2007). However, establishing shared expectations is challenging within hierarchical organizations characterized by professionals’ dominance over peer workers. To support implementation of peer worker roles, professionals should relinquish the power they hold and accept the legitimacy of the expertise gained from lived experience (Cleary et al. 2011, p. 442). Consequently, strategies should target professionals’ cognitions and attitudes. In this regard, focusing on mental health nurses is legitimate because nurses comprise the largest professional group of the mental health workforce, work in a variety of settings, often work closely with peer workers, and share values and understanding with peer workers about establishing relationships with service users. This implicates mental health nurses should take the leadership in creating recovery-orientated cultures and in facilitating the implementation of peer worker roles. Nurses and peer workers must enter into an alliance to address barriers in the integration of peer workers and to enhance quality of service delivery (Cleary et al. 2011; Happell et al. 2015; Hurley et al. 2016; Simpson et al. 2014). However, also reflecting their important position, patronizing and defensive attitudes of mental health nurses are perceived as a major barrier to integration of peer workers (Roper & Happell 2007). Educational programs for mental health nurses should address these defensive attitudes by involving peer workers and by incorporating peer workers’ experienced barriers (Cleary et al. 2011; Happell et al. 2015).

On a policy level, shared expectations should be established concerning how, why, and in which roles peer workers can be integrated (Davidson et al. 2012; Gillard et al. 2015). Since contextual factors explain variation in barriers, stakeholders across mental health services should share experiences with integrating peer workers in order to identify good practices and to develop effective strategies (Repper 2013). Reflecting the origin of individual studies, strategies for implementation of peer worker roles mainly appear to be established in developed Anglophone countries. This geographic spread can be explained by the advancement of the recovery model in these countries (Ahmed et al. 2012; Leamy et al. 2011). In regions were the implementation of peer worker roles is less established, policy makers should proactively address barriers and promote the authentic integration of peer workers in mental health services.

4.1. Methodological considerations

Limitations of this study need to be acknowledged. First, the authors chose to identify barriers exclusively from the perspective of peer workers. However, as this review found that various stakeholders importantly influence the implementation of peer worker roles, their perspectives should be captured to support the integrative nature of implementation.

Second, the review did not focus on facilitators to implementation of peer worker roles. While the in-depth focus on barriers is perceived as strength of this review, the authors believe focusing on facilitating factors would have provided a more complete and positive image of the implementation of peer worker roles. Third, although some individual articles had considerable quality limitations, all were included in the final selection. The lower methodological quality in these studies can affect the validity of the results. Fourth, the literature search was restricted to English and Dutch articles. The review mainly identified studies with origin in Anglophone countries. Although the advancement of the recovery model in these countries might explain this geographical spread, a risk for publication and language bias should be considered (Centre for Reviews and Dissemination 2009). Fifth, with regard to the thematic analysis, Sandelowski et al. (1997) emphasize the risk of losing the integrity of individual qualitative studies when synthesize findings. This means that original findings are out of the context in which they acquired their meaning. This limitation was partly addressed by adopting a multi-level framework, which enhanced the ability of this review to identify and discuss contextual variety on barriers.

4.2. Future research

All studies in this review applied qualitative research methods. Possible explanation is that qualitative research is most appropriate to identify peer workers' perceptions and experiences (Holloway & Wheeler 2010). Future studies should apply longitudinal quantitative designs to examine the effectiveness of interventions to address barriers to implementation. Further, researchers should be encouraged to focus on various stakeholders' perspectives of barriers and facilitators to implementation of peer workers roles in mental health services. As was done in this review, the authors suggest identifying these perspectives in a range of settings by the means of a conceptual framework. Reflecting the apparent vulnerability of peer worker positions, researchers should respect peer workers' perspectives and consider the potential impact of their research and recommendations on the meaningful nature of peer worker roles. For this purpose, the authors suggest to directly involve peer workers in the design and conduct of research.

5. Conclusions

This literature review provides a synthesis of perceptions and experiences of peer workers of barriers to implementation of peer worker roles in mental health services. A range of themes was identified and discussed including the lack of credibility of peer worker roles, negative attitudes of professionals, tensions with service users, struggles with identity construction, cultural impediments, poor organizational arrangements, and inadequate overarching social and mental health policies. Because of the specific aim to identify the perspectives of peer workers in a multilevel framework, this review can inform policy, practice, education and research from the unique peer workers' perceptions and experiences. Professionals should critically reflect on their attitudes and work in a collaborative and honest way with peer workers. This will not only facilitate the integration of peer workers, but will also promote their genuine and authentic participation. Longitudinal research is needed to determine how to address barriers in the implementation of peer worker roles.

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Hoofdstuk 6

The transition from patient to mental health peer worker: A grounded theory approach

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Summary

Peer workers are increasingly being engaged in contemporary mental health-care. To become a peer worker, patients must evolve from having a patient identity to a peer worker identity. This study aims to understand how mental health peer workers experience their transition and how it affects their view of themselves and their direct working context. A grounded theory approach was used. Seventeen mental health peer workers in Belgium were recruited through theoretical sampling. Semi-structured interviews were conducted and analyzed according to the constant comparative method. The results indicate that novice peer workers experience peer work as an opportunity to liberate themselves from the process of mental suffering and realise an acceptable form of personal self-maintenance. As peer workers become more experienced, they are confronted with external factors that influence their self-maintenance and personal development. Experiencing clarity in their duties and responsibilities, equality, and transparency in the workplace reinforce their experience of self-maintenance and positively influence their self-development. Experiencing a lack of clarity in their duties and responsibilities, inequality, and lack of openness discourage peer workers' self-development process. These experiences challenge their personal motivations to become peer workers, which are usually linked to building a meaningful life for themselves. The insights can encourage organizations to build up a supportive environment collaboratively with peer workers and ensure that peer workers can exert their authentically unique role in mental health-care.

1. Introduction

Worldwide, there is a growing interest to deploy people with lived experience (peer workers) in a diverse and increasing number of domains, such as education, politics, social sectors, health-care and welfare, and research (Wallcraft 2012). In this study, peer workers were defined as people who have experienced mental health problems and who want to use this experience to support others (Davidson et al. 2012). Particularly in mental health-care, an increasing number of peer workers are entering the workplace and are valued for the unique perspective they bring (Bryant et al. 2008). They can connect more easily with patients than other care providers due to their understanding of the process patients are going through. This also enables them to be a bridge between care providers and patients (Chinman et al. 2010). In addition, they often act as role models for patients and can encourage patients to seek help for their problems (Forchuk et al. 2007; Chinman et al. 2008).

As peer workers themselves prove that recovery is possible, they can increase care providers' faith in their patients' recovery possibilities (Tambuyzer et al. 2014). Moreover, peer workers' experiences working in health- care organizations can add value to their own recovery process, by offering them: (i) more self-confidence, (ii) more self-esteem, and (iii) a widening of their social network (Holley et al. 2015; Walker & Bryant 2013).

To become a peer worker, patients must evolve from being a user of care to a provider of care, using their experience as a patient to support the recovery process of other people with a mental health diagnosis (Cabral et al. 2014). This change process over time can be defined as a transition (Ludin et al. 2013), during which peer workers are challenged to redefine their personal roles and identity and adjust to their new social reality as a peer worker (Ellis 2010). This requires them to build a professional identity without denying their patient identity (Bryant et al. 2008; Moll et al. 2009). They must therefore shape their role as a peer worker from a dual identity, that is the identity of a patient and the identity of a professional member of the care team. Simpson et al. (2017) argue that peer workers perceive themselves and are viewed by others (patients, peers and staff) as service users, staff, and friends. Serving in different roles can have negative repercussions on their identity formation as a peer worker as it generates a lack of clarity of what can be expected of the peer worker in terms of patient support, care management, health promotion, education, or advocacy (Hurley et al. 2018). Yet, this contrasts with the motive of many people who become peer workers to get rid of their negative identity of having been a patient with a mental health diagnosis. According to them, peer work provides the opportunity to make a valued social contribution and build a positive identity (Vandewalle et al. 2018).

The transition that peer workers need to go through coincides with a paradigm shift in mental health-care, where more and more organizations are switching from a primarily medical-psychiatric problem-oriented approach to a recovery-oriented approach (Sklar et al. 2013). Recognizing the importance of peer support expertise is key within this approach (Sklar et al. 2013). To realize this transition, mental health-care organizations want to have peer workers as a new group of health-care workers. However, research shows that these organizations are not always prepared for embedding peer workers in their organizations (Cleary et al. 2011; Gillard et al. 2014; Vandewalle et al. 2016). Crane et al. (2016) highlight a lack of clarity about roles that peer workers take on within mental health-care organizations. Using their own lived experiences to inspire and guide patients is an example of what peer workers themselves perceive as their specific expertise and that complements the expertise of mental health nurses (Debyser et al. 2018). However, the lack of clarity regarding the roles peer workers are taking on may result in peer workers executing tasks that do not match their specific and complementary expertise. For instance, this can result in peer workers who focus on motivating patients to comply with prescribed treatment, rather than inspiring patients to make decisions for themselves Crane et al. 2016, p. 283). Peer workers might also have different views to other care providers about issues such as risk management and self-disclosure (Higgins et al. 2016; Kemp & Henderson 2012).

In summary, the transition of a patient to a peer worker reflects the mental health-care context that is also in transition. In relation to this process of double transition, it is therefore interesting to investigate how peer workers experience their transition, and which processes facilitate it. This insight will allow peer workers to be more adequately prepared for their transition and supported within the health-care organization during the development of their new role.

2. Methods

2.1. Design

Given the nature of the research questions and the objective to gain an integrative analysis of the natural transition process from patient to peer worker, a qualitative study was set up based on a constructivist grounded theory approach and inspired by symbolic interactionism (Charmaz 2006). Grounded theory as a research approach allows us to look specifically at dynamics and processes that focus on perception and creation of meaning (Holloway & Wheeler 2015). The grounded theory approach is suitable for the exploration of a complex social reality (Glaser & Strauss 1967). Symbolic interactionism was used as the theoretical framework to understand the social reality in which participants gave meaning to their transition from patient to peer worker (Blumer 1969).

2.2. Sampling

Participants were selected in Flanders (Belgium). Eighty-seven coordinators of mental health-care organizations and networks were informed about this study and invited to provide information flyers to peer workers within their organization/network. The inclusion criteria were as follows: (i) Dutch-speaking; (ii) at least 18 years; (iii) completion of a treatment course in a residential mental health-care; and (iv) a minimum experience of five direct interactions with patients as a peer worker (for example, sharing their recovery story with patients, setting up joint activities like walking or biking, leading group activities such as recovery group meetings). Interested peer workers could then pass on their contact details to the researchers, who in turn documented work-related characteristics of the participants (e.g. concrete experience as a peer worker, nature of the peer work). The third and fourth criteria were added to exclusively select peer workers who had a minimum experience as a peer worker and at the same time had a deep insight into what it means to be a mental health patient. Until now, mental health-care in Belgium strongly relied on institutional mental health-care to treat people with mental health problems. The switch to community mental health-care started in 2010 and is still ongoing (Tambuyzer et al. 2014). Within the sample, a balance was sought between homogeneity and heterogeneity. Situational diversity was created based on (i) gender; (ii) age; (iii) education level; (iv) nature of the mental health diagnosis; and (v) paid or unpaid nature of the work, duration, and average hours working as a peer worker. Based on the insights gained from the data, theoretical sampling was gradually applied in a grounded theory (Holloway & Wheeler 2015). This issue is further discussed in the data processing section.

2.3. Data collection

Data were collected between October 2014 and May 2015. Seventeen semi-structured interviews were conducted by an experienced qualitative researcher. Location and time of interview were arranged according to the preference of the peer worker. The interview followed an interview guide that started with the same open question: Can you tell us about your experience of becoming a peer worker? The outline of questions is provided in Table 1. The researcher especially encouraged in-depth exploration of what was raised by the peer worker during the interview. The questions in the topic guide were only introduced once participants had no further information to contribute.

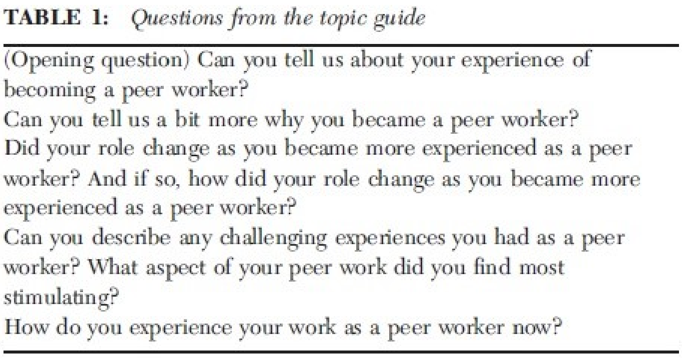

TABLE 1: *Questions from the topic guide*

(Opening question) Can you tell us about your experience of becoming a peer worker?
Can you tell us a bit more why you became a peer worker?
Did your role change as you became more experienced as a peer worker? And if so, how did your role change as you became more experienced as a peer worker?
Can you describe any challenging experiences you had as a peer worker? What aspect of your peer work did you find most stimulating?
How do you experience your work as a peer worker now?

2.4. Ethical aspects

The study was approved by the local and central ethics committees of the participating organizations (B670201421755). All peer workers who participated in the study gave their informed consent prior to the study. Anonymity and confidentiality were assured throughout the research process.

2.5. Data processing

Data collection and analysis alternated with an iterative process (i) to discover relationships between concepts and (ii) to map the facilitating or inhibiting dynamics in the transition process from patient to peer worker (Holloway & Wheeler 2015). Reflecting the evolving nature of grounded theory studies, the emerging concepts guided the process of data collection (Glaser 2001; Glaser & Strauss 1967). Data-informed sampling decisions were taken to broaden, deepen, confirm, or disconfirm the insights that gradually emerged. As it was observed that the first participants generally reported negative experiences regarding their work context, in the consecutive interviews and concurrent data analysis, special attention was paid to positive experiences regarding the work context of the peer worker participants. Since an objective of this study was to examine the transition of patient to peer worker as a natural occurring process, initial data analysis was done for the majority of the peer worker participants who did not complete any form of formal training. Later, when the core categories were identified and described, it was decided to explore if the retrieved insights were also applicable to a broader group of peer workers by including two participants who had very recently received formal training to become a peer worker. The interviews were transcribed verbatim by the researcher who conducted the interviews and were analyzed with the NVivo 10 software program (QSR International Pty Ltd., Doncaster, Australia). All the transcribed interviews were read a number of times by several researchers first to get a general overview of the content and important themes and later to understand meaningful details. Use was made of the constant comparative method (Holloway & Wheeler 2015). The process of data analysis was characterized by an inductive approach. In constructing our understanding of the data, the analysis was situated more on a conceptual and theoretical level as a basis of building a model clarifying the transition process of mental health peer workers. The method of data coding and categorizing was regularly checked and verified by a third and fourth researcher. The process of interviewing and analyzing stopped after achieving saturation of the developed concepts and of the theoretical relationships between these concepts. Based on the insights that emerged from the interviews, a model was developed, discussed, and refined. At the end of the analysis process, the final text was submitted to a qualitative researcher who is actively working as a peer worker in a mental health-care facility. The insights of this researcher were helpful to ensure that the paper was written in a comprehensible and accessible language that conveys respect for the perceptions and experiences of patients with mental health problems.

2.6. Quality assurance

After each interview, the researcher conducting the interviews reflected in writing about the interview style, inter-subjectivity, and the influence of the researcher’s own experiences and opinions. These insights were discussed with a supervisor researcher skilled in qualitative research. Peer debriefing was also used. Throughout the research process, data analyses were validated by using repeated rounds of researcher triangulation. The research group was diverse in areas such as field of professional background, age, work experience, and level of familiarity with the concept of peer support expertise. A second researcher followed the process closely, read all the transcriptions, checked the coding and meanings, regularly commented on the themes that emerged from the analyses, personally analyzed them, and searched for meaningful themes.

3. Results

3.1. Characteristics of the participants

All potential participants recruited from four Belgian provinces were eligible for the study and took part in it. Initially, fifteen semi-structured interviews were conducted with peer workers who received no formal training to become a peer worker. Later, to explore whether the emerging theory was applicable to a broader group of peer workers, it was decided to include two participants who very recently received formal training. Most of the participants received no formal peer worker training. Diversity of the sample was guaranteed by including peer workers of different gender, age, level of education, duration and level of activity as a peer worker, and the paid or unpaid nature of the peer work (see Table 2). Participants had very diverse roles as peer workers, such as telling their recovery stories, performing policy-supporting work, offering individual recovery support to patients, participating in network consultative bodies, setting specific consultation structures, and guiding recovery working groups. The nature of the underlying mental health diagnosis also varied among the participants, including mood disorders, trauma-related problems, personality disorders, substance-related problems, anxiety disorders, or combinations of previous diagnoses. The interviews lasted on average 73 min (range 39–116 min).

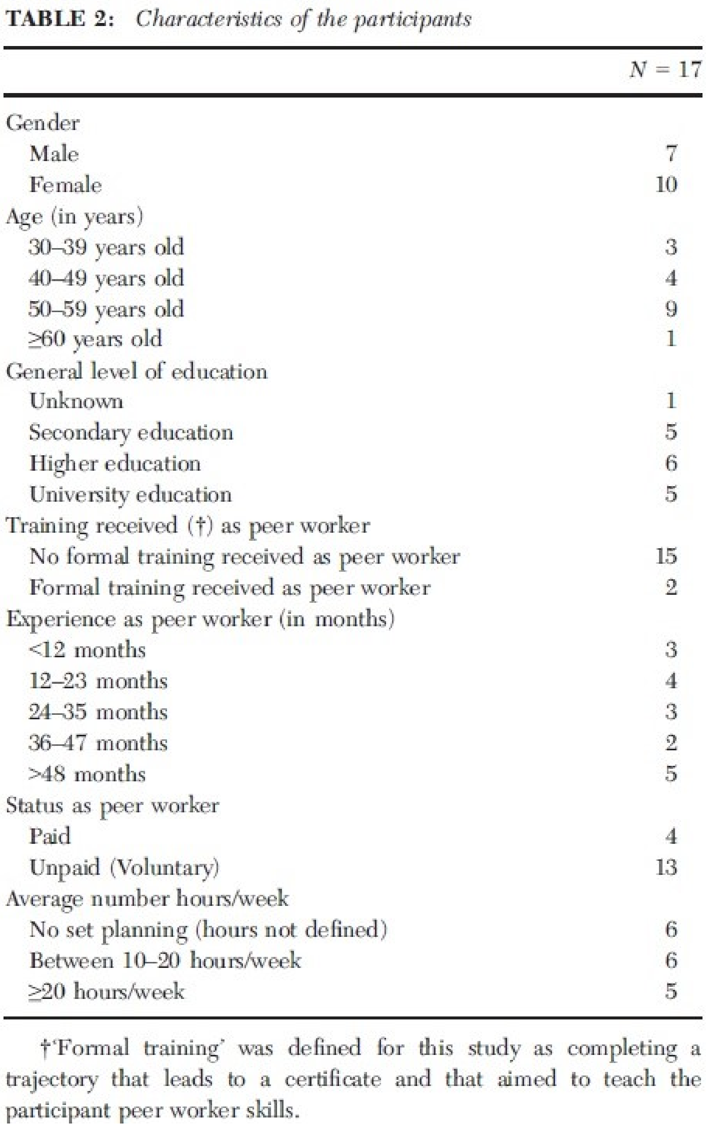

TABLE 2: *Characteristics of the participants*

	$N = 17$
Gender	
Male	7
Female	10
Age (in years)	
30–39 years old	3
40–49 years old	4
50–59 years old	9
≥60 years old	1
General level of education	
Unknown	1
Secondary education	5
Higher education	6
University education	5
Training received (†) as peer worker	
No formal training received as peer worker	15
Formal training received as peer worker	2
Experience as peer worker (in months)	
<12 months	3
12–23 months	4
24–35 months	3
36–47 months	2
>48 months	5
Status as peer worker	
Paid	4
Unpaid (Voluntary)	13
Average number hours/week	
No set planning (hours not defined)	6
Between 10–20 hours/week	6
≥20 hours/week	5

†'Formal training' was defined for this study as completing a trajectory that leads to a certificate and that aimed to teach the participant peer worker skills.

3.2. The transition process from patient to peer worker

The experience of becoming a peer worker is characterized as a process of weighing opportunities and risks. The opportunities offered by peer work are initially at the forefront of the participants' story. How- ever, the participants are also aware of the risks and uncertainties. As the incorporation of peer work becomes more concrete and the experience as a peer worker grows, these risks and uncertainties are brought out more clearly in the interviews. Below, we describe the themes that are central to this transition process.

3.3. Taking up peer worker roles as an opportunity to ensure personal recovery

3.3.1. The process of mental suffering as a catalyst

Many participants describe strong, emotionally colored experiences related to the period in which their mental health problems had a prominent place in their lives. Examples include isolation, incomprehension, stigma, inferiority, and alienation from their personal 'self'. They point to their mental health problems, the assistance received, and the interaction with care providers as important factors that affected these experiences. Participants indicate that they often did not feel heard or understood during difficult periods, and sometimes felt stigmatized and labelled. Participants often experienced a lack of trust or did not feel they were being taken seriously. They indicate that there was little understanding of their potential and positive qualities. As a result, their self-esteem, self-respect, and the belief in their own abilities were severely affected, which in turn stimulated their perception of being alone. The data show that these experiences not only left a deep impression on the participants, but also acted as a catalyst for them to do something with their own lived experiences.

> *(Participant 14) And I was also admitted once, without reason really. I wasn't under the influence of medication or alcohol, I wasn't aggressive. I was just attending a consultation with my psychiatrist, with my husband. They constantly suggested to me: "should you not stay here for a while? It would be better if you stayed here until you are better". And I said: "I'm not staying here, I want to go home." And from that it was decided to take me in like a criminal, to tie me up, yes, to give me an injection, probably to settle me down, but it meant I was locked in while fully conscious and was locked in a cell and that was a very traumatic experience for me at the time. And that made me very angry towards the health-care sector, that they treated me in this way and humiliated me. And during my admissions, when I was confronted with it again and saw how other people were restrained, l always have been very sensitive to that. It is for that reason that I stand up for the rights of the underdog, for the rights of the patient. That is also why I work within the safety management working group of the hospital.*

Positive experiences with care providers also acted as a stimulus for many participants to start working as a peer worker. Some participants reflect on this in the interviews in detail and with gratitude.

> *(Participant 6 spontaneously talking about his admission to a treatment centre for substance dependency) [...] I am delighted to be able to help someone. I myself have received a lot of support in the past. Why would I not give that back or share it? That is the strength!*

3.3.2. Liberating from trapped dynamics and discovering personal strengths

Becoming a peer worker offers participants the opportunity to break the negative spiral of mental health problems and suffering. It enables them to use their experience of suffering as a patient with mental health problems in a positive way. Moreover, some participants describe in the interviews how these experiences make them feel more connected.

> *(Participant 16 reflecting on the decision he had taken at the time to become a peer worker) If I hadn't been a borderline person, I would not be able to talk about it. If I wasn't an impulsive person, I would not be able to warn against that. If I hadn't been a manipulator, I could not warn against that either. The lectures I now give in schools and hospitals keep me straight. I am working on that for a full day. These lectures have made me into the knight on the white horse. I am no longer the manipulator, the aggressive person. I am no longer seen as a number, but as a person.*

We can see from the interviews how this process is strongly linked with recovery and building more resilience against mental health problems. The participants indicate how positive experiences related to their recovery were significant in rebuilding their resilience. Examples include experiencing fair treatment in their relations with care providers, experiencing support and understanding, and being offered opportunities to discover new skills or qualities in themselves, such as in art, poetry, and humor. These experiences are meaningful because they helped the person to have a different perspective of themselves. Other examples of shared recovery-enhancing experiences include establishing structure and rhythm in daily life and being alert for personal warning signs towards a mental health breakdown or a mental health crisis. These experiences are also significant because they reinforce the belief that their mental health problems can be brought under control and that recovery is possible.

Participants describe in detail what they personally learned from these experiences and how they were valuable for their recovery. They also stipulate how these experiences were significant for their peer work.

> *(Participant 9) I have learned to be kinder to myself. This is precisely why I can recognise when the patient is kind to himself and is not too strict in assessing himself.*

> *(Participant 13) It is also the case that in having contact with patients, you help them in their process for a while, but your own process also continues. Often, seeing how*

> *other patients deal with it means that you learn things for yourself as well. So that is a dynamic that goes in both directions.*

3.3.3. Using one's own experiences as a patient to offer hope in facing challenges

Based on their positive and negative experiences as a patient, the participants have an image of what is needed to improve the quality and results of mental health-care, and ways they can contribute to it. These experiences also help guide them in developing a positive peer worker role.

The participants describe a peer worker primarily as someone who is taboo-breaking. To be taboo-breaking, personal shame, isolation, (self) stigma, and taboo need to make room for openness and speaking without being embarrassed about experiences related to their mental health problems.

> *(Participant 3) I have already gone through a very long treatment process. So, I already have a certain stability and built up a very strong will (participant laughs) and I became a peer worker because I wanted to contribute very strongly in this way to break the taboo. And my opinion or vision is: breaking the taboo starts with our- selves. If we cannot speak openly about our mental health problems to the people that surround us, it is not possible to break the taboo in the outside world.*

Furthermore, the participants describe a peer worker as someone who primarily initiates hope. According to them, only the peer worker can reinforce the patient's confidence that his/her current situation is not the end, but instead offers opportunities. The participants explain that a peer worker stands next to the patient, is easily approachable and attaches great importance to building a relationship of trust, and who above all supports recovery. A peer worker supports the patient to get control of their mental health problems by helping them recognize signals that things are not going well so they can do something about it. Participants also see the peer worker as the patient's spokesperson when they cannot (or can no longer) rep- resent themselves because of their mental health problems. The peer worker's experience as a patient justifies this role. It is a role in which peer workers want to be recognized. For the participants, the peer worker should be the ally of the patient, and someone who is as impartial and independent as possible. Only in this way can the peer worker make a complementary voice heard in the teams in which they offer their services.

> *(Participant 4) On the one hand, I have the desire: I want to get paid to work. On the other hand, I am not going to say that I am afraid of it, but I must also remain very alert that my impartiality does not diminish, in the sense that I have to ensure that I remain an ally of the patient.*

To be a source of hope, participants point to the importance of developing an adequately balanced life themselves. For example, participants note that sharing their recovery story can inspire others, but it can also be confrontational if they do not have their personal life on track. They indicate how important it is for them to distance themselves from negative perceptions they have of their mental health diagnosis. Participants also note that it is important they adequately control their personal mental health problems. According to them, however, this is only partly possible, because their mental health problems are unpredictable and might still cause them to drop out as a peer worker. But in looking at things positively, they indicate that successfully overcoming relapse makes them stronger as a peer worker.

> *(Participant 9) It is important as a peer worker to have a certain stability. And it is the case that when you become unstable again, if I can express it that way, it is important for both the people you are working with and for yourself to take a step backwards. And that this is allowed and that you can do that, without it affecting your peer work. It becomes a new experience that you can use in your ongoing peer work.*

3.3.4. The meaning of confidential counsellors

Assuming peer work is viewed by the participants as an opportunity to find a positive balance for themselves, and it was striking how people who played a key role in their recovery process took a meaningful role in it. These people were defined for this study as ‘confidential counsellors’. Participants generally indicate health-care practitioners (nurses, psychiatrists) served in this role, but some participants also mention peers, family members, or friends were their confidential counsellors. These confidential counsellors not only supported the participants to have faith in themselves to become a peer worker, but also provided information about peer work roles and recovery available in books, leaflets, or educational initiatives so that a motivated and informed decision could be made.

> *(Participant 10) I was desperately searching for a new job as part of my rehabilitation process. One day, my psychiatrist asked me: “why not become a mental health peer worker?” I had never heard anything about peer work before, but it made me interested and very curious. So, I started to search the internet. And the more I read about peer work, the more I believed it fits with who I am.*

Sometimes, however, a patient’s decision to become a peer worker was criticized and discouraged rather than encouraged.

> *(Participant 1 talking about reactions in her environment/family at the moment he/she indicated that he/ she was going to start doing peer work) You should rest instead. Let go of that idea to become a peer worker. Just go and work and act normally, and don't make a fuss. I often hear these classic sentences. And that is why I should not bravely say that I am now working as a peer worker, because that is not appreciated at all. They think: "She would be better off doing something smarter," whatever that might be.*

3.4. Continued growth as a peer worker and implications for personal development

As a peer worker becomes more involved in the workplace and assumes more duties, the perception of their role as a peer worker is increasingly colored by factors that can strengthen or threaten their personal development. These are factors that can vary according to time and situation.

3.4.1.Tailor-made peer work that enhances personal development

We already indicated that participants' own problems and the associated recovery process form the basis from which the peer work gains meaning. Peer workers who have been active for some time in the field also refer to this. Participant peer workers view peer work as an opportunity to keep reviewing their own (recovery) experiences. It ensures that their story gains meaning, and that they are encouraged to (further) continue their personal recovery process.

The extent to which the peer work is adapted to personal characteristics and qualities influences how the peer work is experienced. Participants give examples of how work as a peer worker inspires them to expand their field of interest, listen more actively to people, develop a greater sense of empathy, show more assertiveness in communication with others, focus more on others (instead of on themselves), and work more closely with others.

> *(Participant 7) (reflecting about her role as a peer worker originating from her lived experience as a residential mental health patient and where she was not allowed to leave the hospital to assist her daughter who experienced problems at school) l asked the nurse to leave the hospital, but she was very rude and very strict towards me and she said: "you do not have the permission to leave the hospital." l was shocked by her reply, as it was not the easiest way for me to stand up for the needs of my daughter. It was (again!) all about giving trust and confidence. And at that moment, l also had to deal with the nurse's authoritarian style of behaving towards me, something l have experienced so many times in my childhood. And this story is always pursuing me. But*

> *if this incident should happen again with me or with another patient (speaks louder and with stronger voice), l would show the nurse what l feel in relation to this event and stand up for my feelings. l would tell the nurse that the way she speaks to me intimidated me, and how this way of behaving triggered bad memories. Now l also under- stands that at that moment, "l was too frightened to respond to her!" But now it helps me to give meaning to my role as a peer worker. That's why l motivate them to validate their feelings and stand up for themselves.*

3.4.2. Balanced deployment of positive attributes

The participants stipulate the importance of a balanced use of their positive attributes. Showing too much drive as a peer worker, for example, potentially affects their well-being as a person and as a peer worker. The participants are particularly alert to signs of being stressed. They mention that they have learned to use strategies in such situations, such as guarding against negative thinking about themselves, using humor or avoiding the stressful event for a while. These strategies were inspired by what has worked for them in the context of their recovery and they want to pass them on to patients.

> *(Participant 8 talking about the situation in which she had a hard time maintaining herself as a peer worker) You can deal with it in two ways. Either you notice that about yourself and you indicate: "Okay, I will take a step backwards." Or, if you have good contacts with the people around you, they speak to you about it: "Okay, what is happening, what do you need now? Do you need a break? Do you need other help?".*

3.4.3. The encounter experienced within the organization/team

The meaning that peer workers associate with their work is affected by factors relating to the organization and their work context. The interviews show that participants did not always experience a supportive and positive work context where the peer workers were trusted and treated as an equal, and where there was clear and open communication. Examples of this are as follows: having to cope alone as a peer worker, experiencing discomfort in relation to care providers, being excluded by care providers' use of professional jargon during patient consultations, being refused access to patient files, not being included in the team, being approached as a 'patient' rather than as a peer worker, experiencing lack of clarity about what the team/organization expects from the peer worker, and feeling approached with exaggerated (patronizing) care.

> *(Participant 5) Having access to the patient files would be helpful for me to better understand my role as a peer worker in relation to the needs and problems the patient*

> *is struggling with. But since I am not allowed to consult the patient files, from the beginning there is inequality, as one group of health-care workers has access to information while another group of people does not. And the people who have the information can blame you for not knowing what is important in relation to the patient's case.*

These are experiences that strongly affect and dis- courage participants and complicate their integration as a peer worker. These experiences not only create uncertainty, frustration, and doubt about the credibility of the organization and the people they work with, they also cause the peer workers to have doubts about themselves. They reinforce the sense of insecurity that some peer workers inherently feel or had to deal with as a patient or contribute to feelings of skepticism and isolation. Some peer workers, however, draw strength and energy from these experiences and advocate for peer work that takes the challenges they face into account.

> *(Participant 2 reflecting on his/her experiences of participating in a management steering group as a peer worker) At the end of that meeting, I really wanted to quit peer work! That experience was just so discouraging for me! Yes, that giant feeling of not being acknowledged. But now, I realize that this also has something to do with the fact that all these people were very little involved with patients. And especially their language, they didn't bother at all to adapt their language to me. They spoke in a very academically pompous language where I sometimes wondered if one of them still understood the other. But when I asked occasionally: can you explain that in easier words? I don't think I am a stupid person. But then I really got a glimpse of (shows a face with raised eyebrow). And then they say it again and again, but in the end, you haven't got it. When I came out of that meeting, I still had to take the train, I wrote a whole text in one go, to get rid of my frustration. But in retrospect I thought something like I should not be discouraged because of these bad experiences. As there are many places where my contribution can make a difference, it is there where I can be heard and where I want to do my share.*

The interviews show how peer workers are often reluctant to discuss negative experiences with their supervisors (supervisors were defined in this study as the first line contact persons of the peer workers within the organization where they work). Being confronted with cumbersome organizational structures makes addressing issues more difficult. The interviews also show that being dependent on the organizations/health-care providers' interpretation of the peer work makes it hard for them to raise issues of concern. Throughout some interviews, it is noticeable that peer workers can rarely undertake certain interventions with patients by themselves and are supposed to work under the guidance of other members of their team. It seems that ‘staying on good terms with a team’ is a prerequisite for their work as a peer worker, but this is not necessarily viewed negatively.

> *(Participant 14 reflecting on an initiative to launch a peer-based buddy project for discharged mental health patients) [...] We [referring to the group of peer workers] have written a complete text about this buddy project. [...] But we must accept that just because we have an initiative or an idea as a peer worker, doesn’t mean it can be implemented immediately. Because this must first be discussed in different working groups of the hospital and get the approval of different organizational committees. Hence sometimes there is a bit of impatience among some people in the group. Yes, we have got meetings with the peer workers for more than a year now and we haven’t been able to do almost anything yet, except being present as a peer worker at the family meeting (while meanwhile sighing deeply).*

Yet, there are also participants who share positive experiences in the interviews. They describe situations where they feel heard and recognized as a peer worker, where they are listened to and receive opportunities to develop themselves personally and expand their networks. For some participants, being able to do peer work at the unit where they were a patient was motivating and built their confidence. These examples of positive experiences signal to the peer workers that the organization supports them, and this further stimulates their personal recovery process.

> *(Participant 11) For me it is the case that the contacts between the care providers and me are very positive. From the moment something goes wrong, a few people immediately jump in to look at the problem, to think about possible solutions. This also gives me support, which is also very important for my recovery process. Because before, I had never experienced such collegiality in my life. That stability in my work makes me more stable in my private life.*

4. Discussion

This study mapped out the core processes that were experienced as helping or hindering the transition from patient to peer worker.

The participants experienced this transition as an active and challenging process that supported their personal recovery. This transition took place through the interplay of factors related to their personal recovery process and work context, during which the encounters they experienced in the organization (team) and their confidential counsellors played a meaningful role.

In this study, the participants explain that peer work offers opportunities to initiate a positive recovery. Becoming a peer worker allows them to give scope to their own mental health problems and to work with positive personal qualities that they have (re)discovered or developed during their recovery process. Peer work allows them to transcend their own mental health and further safeguard their personal recovery process. It gives them a chance to build a life in which personal well-being, connection, and integration are central. The participants describe how they had to overcome important obstacles, such as the release of (self) stigma, negative perceptions related to their mental health diagnosis, and how they achieved adequate stability for themselves in relation to their own mental health. This process of personal development is perceived by the participants as a core process to become a peer worker. Working towards patients' educational growth and supporting patients' personal development are unique features of peer workers working in traditional mental health services (Crane et al. 2016). Moreover, recovery is described as a searching process that reflects a struggle to achieve stability and find a certain calm and balance (Wilken 2010). Vandewalle et al. (2018) also point out how peer workers want to give a positive meaning to their personal recovery process. To utilize their experiences in health-care, peer workers strive for an optimal alignment of their skills, expertise, and experience within the scope of their role and overall work context. Experiencing a climate of equal, clear, and honest communication supports them in reaching this purpose. However, the interviews show how a work climate characterized by inequality, lack of clarity about roles or expectations, and lack of openness can strongly affect them, because it can challenge their motivations and expectations for starting peer work. This is even more so if the peer worker experienced an unequal and unsupportive relationship with care providers when they were a patient.

Recent studies emphasize the difficult integration of peer workers in the work context (Moran et al. 2013; Vandewalle et al. 2016). The participants of this study also share experiences that reconfirm this. They provide examples of how they were caught between the patient's identity and the identity of being part of a mental health-care organization or team (Moll et al. 2009; Simpson et al. 2017). In the present study, however, we also identified positive factors, such as a high level of awareness that was present among the participants in relation to their mental health problems, strengths, and challenges. Their considerable attention to self-care and self-maintenance is also a positive factor in their peer work. Additionally, our findings show how carefully the participants weighed the opportunities and risks of the personal and contextual peer work-related challenges they face (for example, the impact of being paid or not being paid to function in an independent role as a peer worker). This study further highlights how the participants feel their confidential counsellors played a significant role in their transition process. Confidential counsellors play a key role in helping participants decide whether to enter the field of peer work. They also play a crucial role in the further development of peer workers by increasing or decreasing the scope within which the peer work takes shape. In addition, the participants' experience of care not only facilitates or hinders their personal recovery process, and it can also set the pace for how the peer worker develops in his/her role and work. Meleis et al. (2000) stated how feeling connected, interacting, developing confidence, and coping are important indicators that characterize a healthy transition process. These findings accord with the pre- sent study as similar factors were identified.

4.1. Methodological considerations

The study was carried out in a geographic region where recovery-oriented care and the integration of peer workers are still under development (Tambuyzer et al. 2014). Some peer workers held a solo position within their organization. Participants belong to a relatively select group of pioneers of peer workers, who are only able to exert their peer work roles because of the willingness of the organizations/health-care providers involved.

To understand the transition process as a natural phenomenon, we wanted to study the transition process among participants who had not attended training as a peer worker. Therefore, the study included more peer worker participants who were not following training compared to peer workers who were. However, encoding and analyzing the interviews of participants in the later phase of the study who did follow training indicated that the retrieved insights were also applicable to this group of peer workers. Peer workers under the age of 30 were not represented in this study. The question therefore arises whether the transition process is different for younger peer workers.

Several actions were undertaken to guarantee rigor in the research process. Throughout the study, researcher triangulation was used to underpin the validity of the interpretations and to build an emic perspective of peer workers. Theoretical saturation was also achieved.

4.2. Recommendations for further research

In this study, the focus was on the peer workers' perspectives. It also might be relevant to explore how care providers and support figures perceive the transition process of peer workers, as well as what it means for care providers to work with peer workers, and what impact peer work might have on individualized person-centered nursing care.

In this study, the personal growth process of the peer workers was the key focus. Growth, however, is not synonymous with expertise. The study therefore provides no insights about the expertise of the peer worker participants. It is recommended to study how the expertise of peer workers is influenced throughout their transition from patient to peer worker and what makes them discontinue their peer work.

5. Conclusion

The study uncovered core processes that peer workers need to develop and sustain to support their positive transition from patient to peer worker. These are conditions that are inherent in every recovery process, such as the need for humanity, compassion, recognition, support, transparency, openness, clarity, and hope. Peer workers see their mission to create sanctuaries for patients, so that their experiences can be recognized and normalized.

Despite the challenges they encounter in their transition to peer worker, they mainly experience their transition as an opportunity to complete their recovery process. Based on the results, an emic perspective could be developed of what peer workers themselves considered necessary to evolve their peer worker capacity.

6. Relevance for practice

Organizations that implement peer work are advised to set up a support framework in collaboration with the peer workers themselves. Transparency, clarity, openness, equality, and active involvement of peer workers must be core values in how support is offered. These values function as process and outcome indicators of the recommended support framework. Peer workers expect care providers to be accessible, straightforward, and to support them as much as possible to participate in a meaningful way. Therefore, to establish equality in their relationship with peer workers, care providers should be careful not to push their agenda forward in a way that overrides the views and agenda of peer workers, and instead should mutually strive for balanced cooperation. These insights are in line with how Wilken (2010) describes the role of the care provider within recovery care. Care providers can reinforce the strengths of peer workers when they take an appreciative and coaching role (Debyser et al. 2018;

Hurley et al. 2018). The positive factors that were identified by participants of this study can inspire care providers to positively shape peer worker roles. This will also help build sustainable, collaborative relationships between care providers and peer workers and support the continual process of peer worker recovery.

This implies that care providers should be aware of the deeper meaning their role can have for peer workers, especially when they have been involved in a peer worker's recovery process. They need to understand how becoming a peer worker encompasses aspects of personal discovery. Working alongside peer workers allows care providers not only to be a privileged witness of this ongoing learning journey in adopting new roles as a peer worker, but also enables them to work together with peer workers in the process of developing a sense of identity and mastery as a peer worker. Meleis et al. (2000) identified both objectives as key healthy outcomes of a transition process. From this perspective, working together with peer workers towards these aims is not only highly valuable, it is an essential prerequisite to create a sustainable partnership between care providers and peer workers (Hook 2006). Based on the insights of this study, this partnership can be achieved if care providers connect to peer workers through a shared human understanding of the transition journey they are going through. This viewpoint echoes with the views of peer worker recipients, since according to them, it is not so much experiencing the instant connection by sharing common lived experiences with peer workers that gives peer support its ultimate meaning, but the true capacity of peer workers to build and maintain an authentic relationship with their recipients (Miyamoto & Sono 2012).

Educational initiatives that support patients to become peer workers should also focus on clarifying and explaining the importance of the personal recovery process rather than initiating them in the culture, language, and working methods that are common in mental health-care facilities. Furthermore, there is a risk of dilution of authenticity of what peer workers can contribute to the mental health-care when their support initiatives mainly include procedural approaches and generic training, as these initiatives put pressure on peer workers to assume the values and attitudes of the mental health-care providers (Schmidt et al. 2008). In contrast, taking account of the complex interplay of contextual and 'peer worker'-related factors that influence the transition process can safeguard what really matters to peer workers.

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Hoofdstuk 7

Mental health nurses and mental health peer workers: Self-perceptions of role-related clinical competences

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Summary

In a mental health-care that embraces a recovery-oriented practice, the employment of mental health peer workers is encouraged. Although peer workers are increasingly working together with nurses, there is a lack of research that explores how nurses and peer workers perceive their role-related competences in clinical practice. The aim of this study was to clarify and understand these self-perceptions in order to identify the specificity and potential complementarity of both roles. This insight is needed to underpin a successful partnership between both vocations. A qualitative descriptive research design based on principles of critical incident methodology was used. Twelve nurses and eight peer workers from different mental health-care organizations participated. A total of 132 reported cases were analyzed. Rigor was achieved through thick description, audit trail, investigator triangulation and peer review. Nurses relate their role-related competences predominantly with being compliant with instructions, being a team player and ensuring security and control. Peer workers relate their role-related competences with being able to maintain themselves as a peer worker, building up a relationship that is supportive for both the patient and themselves, and to utilize their lived experience. Both nurses and peer workers assign a major role to the team in determining their satisfaction with their competences. Consequently, what is perceived as important for the team appears to overshadow their self-assessment of competences. The findings highlighted the importance of paying more attention to identity construction, empowerment and role competence development of nurses and peer workers in their respective education and ongoing training.

1. Introduction

An unambiguous and sound definition of a ‘peer worker’ is lacking in the literature (Gillard et al. 2014; Moran et al. 2013). In general, the term ‘peer worker’ refers to a person with lived experiences of mental health problems who supports the recovery of peers. Several other names are used interchangeably, including consumer provider, expert by experience, peer specialist, and consumer consultant (Gillard et al. 2014). Acknowledging the use of different terms, in the present study we opted to use the term ‘peer worker’, because it emphasizes both the work-related aspects and the generic meaning of peer support (Gillard et al. 2014), and defines peer workers as people with a mental vulnerability who support the recovery of peers in a formally-mandated role (Gordon & Bradstreet 2015). In the past decade, the added value of peer support for mental health care has received increasing attention. Mental health peer workers can function as role models who are a source of hope for patients (Gordon & Bradstreet 2015). Owing to their respective experience with recovery, they can build bonds of trust and understanding in their relationship with patients (Cabral et al. 2014; Fox 2002; McCann et al. 2006). Peer workers help to ensure that a patient's perspective is taken into account in the decision-making process (Cabral et al. 2014; Repper & Watson 2012). They can also promote social participation and rehabilitation of people with mental problems (Walker & Bryant 2013). In addition, peer workers can contribute to an organizational culture that supports recovery, and to the mental fitness and personal well-being of employees (Repper & Watson 2012).

Despite the positive findings of what peer workers can contribute to mental health care, a recent review of Vandewalle et al. (2016) study indicated that peer workers can experience and perceive personal, interpersonal, and contextual barriers to their integration in mental health care. Research also documents the slow creation of peer worker roles, even in countries where recovery principles are widely adopted (Gordon & Bradstreet 2015). McCann et al. (2006) explored the attitudes of mental health-care providers towards the active participation of peer workers within a residential mental health-care setting. They concluded that, compared to other caregivers, nurses were more resistant to the active participation of peer workers in the department. This was especially the case when peer workers assumed and performed tasks and roles that overlapped with those the nurses felt belong to their professional domain (McCann et al. 2006). Yet while studies highlight defensive attitudes of nurses towards the integration of peer workers, several authors indicate that mental health nurses can play a key role in facilitating the integration of peer workers in mental health-care organizations (Byrne et al. 2017; Cleary et al. 2011; Compton et al. 2014; Hurley et al. 2016; Vandewalle et al. 2016). These authors argue that mental health nurses comprise the largest group of health-care providers, and share values and understanding with peer workers about establishing relationships with patients. In this regard, nurses fulfil a privileged position that can establish an alliance with peer workers, and can work with them to create a recovery-oriented culture (Byrne et al. 2017). As a prerequisite for the integration of peer workers, nurses should relinquish power and critically reflect on their opinions and views in order to create a more person-focused service (Byrne et al. 2017). However, in times of reduced resources, handing over power to peer workers can be perceived as an erosion of mental health nursing roles (Jones et al. 2016).

The aim of the present study was to clarify and understand how mental health nurses and peer workers perceive their roles and competences in clinical practice in order to identify the specificity and potential complementarity of the two roles. In contrast with research starting from a predefined description of core competences, the competence of a nurse or a peer worker was not defined in advance (Ewalds-Kvist et al. 2012). Given the potential risk for nurses and peer workers to have conflicting perceptions of what belongs to their core role and competences, it is interesting to understand how both groups perceive their own respective role-related competences. In this way, the present study might be able to identify the specificity and potential complementarity of the two roles. Moreover, this new knowledge can provide an impetus for identifying opportunities for role differentiation between the two groups. A better understanding of how both vocations perceive their role-related competences can also aid the identification of potential barriers and facilitators affecting how nurses and peer workers work together to foster better mental health care.

2. Methods

2.1. Design

A qualitative, descriptive design with principles of the critical incident technique was applied. Critical Incident technique is an inductive study method initially developed by Flanagan (1954), and due to its practical focus, was later modified to serve in nursing research (Bradbury-Jones & Tranter 2008). In a critical incident technique study, actual practice-related situations are the subject of the study. It is designed to have participants describe situations in a structured and specific manner by which the implicit underlying thinking processes and related interpretations can be revealed (Schluter et al. 2007). The technique enables researchers to collect rich contextual data and uncover tacit knowledge relatively quickly by prompting and supporting participants to be as specific and concise as possible in a timely, structured manner (Bradbury-Jones & Tranter 2008).

2.2. Participants

Management executives and mental health-care network coordinators in three Dutch-speaking, geographically-dispersed regional districts of Belgium were informed about the study by one researcher (R1). They in turn informed eligible nurses and peer workers verbally and in writing about the study. The inclusion criteria for nurses were: (i) employment in a clinical mental health-care context; and (ii) active in a professional interest group within or outside the organization that supports the exchange of professional knowledge (through training, work-related support, sharing professional knowledge etc.). The inclusion for peer workers were: (i) to have at least 10% of full-time equivalent contact with patients weekly; and (ii) to be involved in some form of peer worker competence development (training, support from peer workers with similar experiences etc.). The criteria listed in (ii) were added to select persons with a suggested familiarity with what constitutes and was related to their respective job- related competences.

2.3. Ethical considerations

Approval was obtained from the local and central committees of medical ethics (no. B670201523199). All nurses and peer workers who participated in the study gave informed consent prior to participation in the study. Anonymity and confidentiality were assured.

2.4. Data collection

The data were collected separately from nurses and peer workers in the form of personal case reports that reflected their daily role as nurse or as peer worker. At the beginning of the study, one researcher (R1) explained to each nurse and peer worker the format of a worksheet they could use to describe twice a week as clearly as possible a case in which they thought they acted less or more competently as nurse or peer worker. A worksheet, including a template with guiding questions supplied in digital form and on paper, was offered to the participants (Appendix I). The guiding questions helped participants to describe the cases as clearly as possible in terms of situational particularities, contextual factors, actions taken, and outcomes. Furthermore, the participants were asked to explain as clearly as possible why they thought they acted more or less competently. When participants completed the worksheet, data were forwarded in mail or electronically to the researchers.

Sociodemographic variables were recorded, including age, sex, percentage of full-time equivalent, work experience, and education level. Reflecting the classification in the model of Benner (1982), the nurses had to indicate whether they perceived themselves as novice, beginner, competent, proficient, or expert. At the same time, the peer workers were asked to indicate in which illness phase they felt being overwhelmed by the illness, struggling with the illness, living with the illness, or living beyond the illness (Spaniol & Wewiorski 2012).

2.5. Data analysis

Data analysis was done separately for both groups of participants.

To allow a holistic and broad understanding of the data per group of participants, data were first organized in two separate Excel datasets: one for the nurses and another for the peer workers. Second, to achieve a more interpretive analysis per participant and across participants, all data (including the description and explanation of the cases) were organized per participant. The cases were then analyzed separately by two researchers (R1, R2) with the aim of understanding the core meaning of each case. Codes were assigned to relevant fragments of each case (Holloway & Wheeler 2010). In order to achieve the widest possible interpretation, the case description and the reasoning and reflection of the way they acted in relation to their competence as nurse or as peer worker were taken into account. Coding was initially open and inductive, and became more axial and selective as the analysis progressed (Holloway & Wheeler 2010). After coding all cases, similar codes and sub-codes were clustered. More axial codes were grouped into a cluster of codes with a rather positive and a rather negative appreciation of the participant's self-assessed, role-related professional competence. The systematic way of clustering enabled the emergence of the core themes under study.

Third, the identified themes in the two datasets were reported in writing by the first author (R1). This report was extensively and repeatedly reviewed by three experienced qualitative researchers (R1, R2, R3) until substantive and textual agreement on themes and content was reached. To identify themes that can underpin a potential complementarity of the two roles, the retrieved core themes were finally compared across the two datasets (nurses and peer workers) and discussed by the main researchers (R1, R2).

2.6. Rigor

To safeguard the validity of the research process, thick description, audit trail, investigator triangulation, and peer review were used (Holloway & Wheeler 2010). Thick description was used to analyze both the shape, structure, and the way in which the participants delivered the data. The template with guiding questions was intended to encourage the participants to reflect and to report as accurately as possible the cases they independently chose. The audit trail was achieved by describing the structure and rationale of meanings assigned to the data, which strengthened dependability (Lincoln & Guba 1985). A thorough form of researcher triangulation was undertaken by regularly comparing, discussing, and testing the data analysis. Researcher triangulation was achieved by involving three nurses with a mental health nursing background, one nurse with a general nursing background, and one mental health peer worker. All of them were both familiar with qualitative research and could rely on their working experience as nurse or as peer worker.

After data redundancy was achieved, peer review was done by an independent postgraduate study group. This group was composed of researchers and educators in mental health nursing and mental health nurses working in mental health care. A random number of anonymous cases from the two datasets was examined and discussed by this study group in two discussion rounds of 2 hours each. Their reflections confirmed the research results. In addition, sampling was carefully considered. Therefore, different organizations were asked to participate in the study. This was done to minimize the influence of team members on the appraisal of their role-related competences.

3. Results

3.1. General participant characteristics

Twelve nurses and eight peer workers participated in the present study. Diversity was guaranteed by recruiting nurses and peer workers of different sexes, age, education level, percentage of full-time employment, working experience, and working context. The participants' characteristics are summarized in Table 1. The 12 nurses worked in four different organizations with distinct patient groups. All nurses except one were employed in inpatient mental health-care facilities. Two nurses perceived themselves as 'beginner', seven as 'competent', and three as 'proficient'. The peer workers offered services in eight different mental health-care facilities in a wide geographical area. These services were offered by most of them on a part-time basis across a wide range of facilities, varying from services in community-based mental health-care facilities to semi-residential mental health-care facilities or psychiatric hospitals. Most of the peer workers were employed by the health-care sector by contractual agreements between the mental health-care facility and the peer worker. They all worked alongside non-peer staff and service users to whom they offered a service as peer worker. Six of the eight peer workers indicated that they were 'living beyond the illness'. Two peer workers indicated that they considered themselves in the phase of 'living with the illness'.

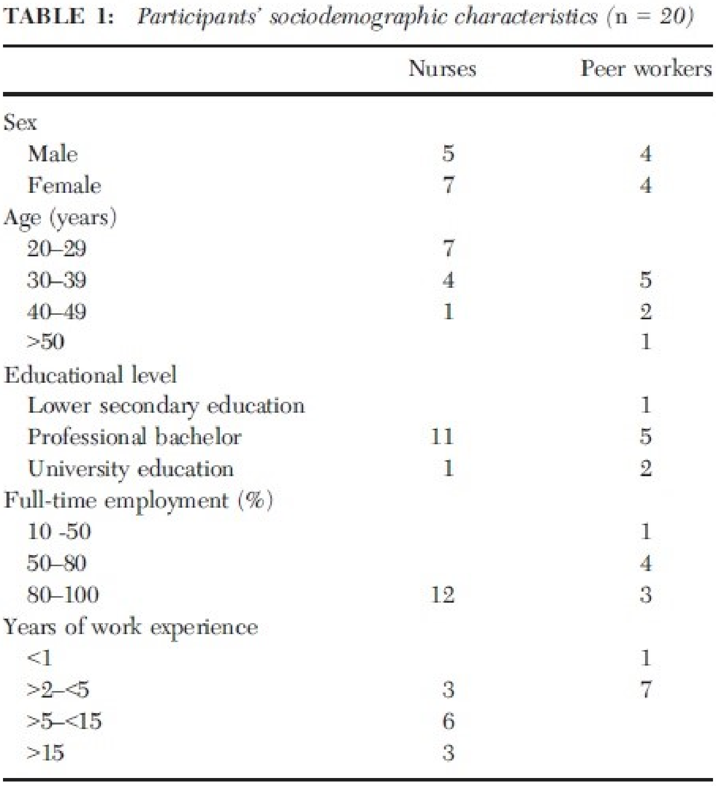

TABLE 1: *Participants' sociodemographic characteristics* (n = 20)

	Nurses	Peer workers
Sex		
Male	5	4
Female	7	4
Age (years)		
20–29	7	
30–39	4	5
40–49	1	2
>50		1
Educational level		
Lower secondary education		1
Professional bachelor	11	5
University education	1	2
Full-time employment (%)		
10 -50		1
50–80		4
80–100	12	3
Years of work experience		
<1		1
>2–<5	3	7
>5–<15	6	
>15	3	

3.2. Nurses’ and peer workers’ self-perceptions of their role-related competences

The features and factors affecting the nurses’ and peer workers’ perceived competences are described. The results are illustrated with some cases reported by nurses (Table 2) and peer workers (Table 3). The case reports in the Tables were selected to be representative and to clarify the results described.

TABLE 2: *Case reports by mental health nurses*

Case	Case reports by mental health nurses (participant no.)	Explanation of perceived competence and satisfaction
1	(a) I have a late shift (together with another colleague) and invite the guys to exercise together. I also invite X, but she refuses to come along. I know that this is a first sign, since normally J goes with us to exercise.…After exercising, I notice that X has been in her room. My colleague asks if I want to try to establish contact. (b) and (c) X is clearly in phase 3 (crisis development model), and at that stage of the crisis, she has completely withdrawn into herself. She doesn't let us in. She doesn't answer my questions. She is sitting shrunk away in a corner of the bathroom with a grimace on her face. I try to establish contact…I tell her in a quiet, concerned way that it is important to try to focus on something else. I suggest that we go to the comfort room to watch a DVD together. She replies that we must leave her alone. I say that we will go now together to the comfort room. I take her arm and take her along. She resists. Kindly but firmly I push her slightly forward, my arm around hers, my other hand pushes her shoulder further. My colleague does the same. After arriving in the comfort room, she takes a seat on the couch. I ask her what she wants to watch. She does not respond. I say that we are going to watch Mr Bean. It is easy to follow. I take a seat next to her on the couch. She is not watching the DVD. I ask her repeatedly to make an effort to watch. I tell her that this is the way to look outside of herself. I tell her that in this way, she will make it more bearable for herself. After a few minutes, I notice that she is watching. I don't react, I just let it be. After 20 min, I see a smile on her face. After a while, she is laughing aloud. I am laughing with her. Perhaps, it is because we succeeded together to overcome the crisis? (d) When the DVD is finished, we make arrangements for the rest of the evening. (3)	**Competence explanation:** Teamwork is required to overcome crises. Together with the patient we are a team. The crisis card (made with the participation of the patient) clearly indicated what had to be done in this case. **Satisfaction explanation:** Results lead to a feeling of satisfaction. We came from a situation where there was no willingness to cooperate and have evolved to a situation in which agreements could be made.
2	(a) A youth had his dial-a-bus service at 11:19 on Sunday to depart to his institution. He refused to leave. He preferred to stay in the department. Only the youth and I were involved. Young people are supposed to comply with the weekend regulation, which allows them to make 2-day trips home or to the institution every other weekend. (b) At that moment my job was to follow the regulation and let the youth leave on the weekend and to carry out the instructions of the department. The problems of the youth should nonetheless be taken into account. An hour before he was supposed to leave, I woke him up and asked him to get ready. He said that he was not willing to go to the institution. (c) I: 'Why don't you want to leave?' Youth: 'Because I don't want to, I am not going to the stupid institution'. I: 'Oops, that's unfortunate, now we have a problem'. Youth: (getting more tense): 'I don't want to'. I: 'You are supposed to leave on the weekends, when you choose to be admitted to this department, you agree with the work regulations'. Youth: unresponsive. I: "'I'll give you some time to think'. I returned to the room after 10 min. I gave a calmer expression, but I could still feel the tension. I: 'Have you thought about it?' Youth: 'Yes, I'll stay here in the department. I don't feel good in the institution. I don't trust anybody there. I do here. I sit there the whole day alone'. I: 'You have been there already more than a year. How do you cope then?' Youth: 'I bottle up my anger and sometimes it explodes'. I: 'Mm…boy, it must be very difficult for you'. Youth: 'Ha'. I: 'You are supposed to stay in your room all day long, and you do know that here you will be alone too'. Youth: 'Better here than in my institution'. I: 'It's a pity'. We will look into the matter further with the team.	**Competence explanation:** I think I remained calm, but personally, I found it annoying that he did not comply with the instructions and kept refusing. I liked that I was able to establish communication with him and gave him space to take his own decision. I kept in mind that he gets very angry with the word 'must'. **Satisfaction explanation:** I am satisfied that I managed to communicate with him and was able to reach an agreement for today. Personally, I found it very annoying that I could not make him leave. I also asked myself if I could have approached it differently.

TABLE 2: *Continued*

Case	Case reports by mental health nurses (participant no.)	Explanation of perceived competence and satisfaction
	(d) The youth stayed in his room and did not get out of bed all afternoon. I informed the institution. (2)	
3	(a) A new patient, who has just been admitted, is rather animated in the group. On the way to the restaurant to have dinner, she crossed physical boundaries with a fellow patient. She literally allowed the other patient to look at and smell her breasts in order to guess what kind of perfume she was wearing. The fellow patient responded by feeling her breasts, given the enthusiastic attitude of the new patient. (b) In such a situation, I am expected to restrict physical contact. I am also expected to remind them of the hospital regulation to respect each other's personal space and privacy, especially so the rules are clear to the new patient. (c) I clearly asked them to keep their distance and not rub elbows with each other. (d) Initially, they were somewhat shocked that I had seen them and they addressed the issue. Then the incident was laughed off with the excuse that it was innocent, without bad intentions. (7)	**Competence explanation:** I spoke to them clearly regarding their unacceptable behaviour which is against department rules. **Satisfaction explanation:** Satisfied that I spoke to them both in a group.
4	(a) C has been with us for a long time already. She used to have alcohol problems, but has been sober for years, and in recent years, her weight has increased enormously, and her motor skills have deteriorated to such an extent that she moves with a rollator walker. Large plastic bags hang from the rollator walker. They have been hanging there forever, and they are always full and smelly. C collects basically everything that goes through her hands, i.e. (dirty) hotel porcelain of the hospital, used tea bags, full, empty, and half-empty jam jars, cutlery, scraped pots of pudding, fruit etc. That Saturday morning, C is sitting beside me having breakfast, and during a pleasant conversation I see her stashing her cup with a used tea bag. In the bag that she opens, I see a second dirty cup. (b) and (c) I want to tell her 'this is unacceptable', but at the same moment I decide not to, which is totally against my standpoint that it is so important to respect the rules. I know that C collects things and we try to restrict this every week and I know that the tea bag, brown and dried up, will still be hanging there during the next inspection on Wednesday, but I kept silent because we will have a serious confrontation on Wednesday again, which is so heavy for her. (d) I turn a blind eye to her so that she won't feel attacked again, but actually it did not feel so good to me, because it was against my 'attitude' and I am usually very consistent. Towards her: my response was okay and even well done from my perspective. (9)	**Competence explanation:** Because I acted according to the patient (disobedient as care provider!) and did not want to enter in a confrontation with her again. **Satisfaction explanation:** Because of the mixed feelings I had in retrospect. To speak to her and to point out the house rules is one of my duties of my job, but if I reflect ethically, I can still justify my actions in this case.
5	A certain patient has an addiction problem. A drug test came back positive. The patient denied using drugs. Some team members wanted to immediately implement the instructions regarding drug use (no way out). I tried to advocate for the patient and succeeded in sending the sample to the lab. Eventually, the test turned out to be negative. So our first test was a false positive. (1)	**Competence explanation:** Despite the history of drug abuse, I tried to remain unbiased while listening to the patient and advocated for her (she knew nothing about this discussion). The fact that someone believed her was, in my opinion, educational for her. **Satisfaction explanation:** The fact that the team listened and the fact that the patient had not been using drugs made me satisfied. I saw the good in the patient and was rewarded for this. I was satisfied that the patient knew nothing about the discussion within the team.

TABLE 2: *Continued*

Case	Case reports by mental health nurses (participant no.)	Explanation of perceived competence and satisfaction
6	(a) The patient has to move from a single to a double room, following a turn-taking system, based on the admission date for everyone who does not pay a fee. She disagrees, fears very much that her privacy will not be respected, but also doesn't know how she can handle the situation and make agreements regarding her privacy. (b) To convey the message to the patient that she will have to move soon in a way that is comfortable for her and not so desperate. (c) I try to say that she is not alone in confronting this, that we can look at it together and discuss how we can make concrete agreements, and that it would be good if she agreed and gained a different experience. If it really doesn't succeed, it is always negotiable, after she has at least tried it. (d) The patient continues to threaten to leave as a solution for moving rooms and protests. (7)	**Competence explanation:** Considering her traumatic past history, I wonder whether I should have taken some extra care to offer a clearer framework, such as a concrete proposal to try for 2 weeks and see then if it works. I would be able to bring up her hospitalization with the team considering the threshold is very high. On the other hand, expecting that it won't work might be too easy for her. If we give up because of the threat, we will give her too much power in this situation. **Satisfaction explanation:** I hope that the patient can hold on due to the bond and trust that we are trying to build with each other. It would be a shame if she chooses to leave. Nevertheless, you will then also know that you cannot handle it (as nurse). It is just difficult to feel this way and to give it a try to carry on with it rather than clearing it up from the beginning.

TABLE 3: *Case reports by peer workers*

Case	Case reports by peer workers (participant no.)	Explanation of perceived competence and satisfaction
1	A woman of about 45 years old doesn't see her children anymore, suffers from depression, is in a difficult separation. I had already been in touch with her together with a care provider; now I was alone and talked with her for 2 hours about what it meant to be psychologically vulnerable and what it was like to be poor. This was a very good conversation, we were both very satisfied with it. There was a lot of signs of recognition. (4)	**Competence explanation:** It was very helpful for the woman's recovery that she could tell her story to someone who knew what it was like. **Satisfaction explanation:** I recognized what she was experiencing and we took steps together and we were very open to each other.
2	One of our patients follows day therapy in the psychiatric centre. That day she did not have any transport home. I came to work by car, and I offered to bring her home. We did not have any problems, but afterwards the team coordinator told me it is not what is expected. If I use my own car to do something, I'm not insured. (1)	**Competence explanation:** The transportation went smoothly, but I neglected to find information in advance regarding insurance issues. Good will is nice, but sometimes you need to have a feasibility check for a well-intentioned impulse. That is the lesson I learned. **Satisfaction explanation:** Initially I was very pleased with the fact that I could help this woman. Later that sentiment was overshadowed by the realization that I had risked too much.
3	A while ago, we needed new lids for our cooking pots. I had already reported this several times, but decided after a while to take things in my own hands and look for a good lid. When I reported this to the manager, she repeated three times how glad she was that I got involved. (5)	**Competence explanation:** This proves to me that everyone is equal and has an equal voice. **Satisfaction explanation:** I am satisfied with how I handled this situation because it reminds me that I can think and reason independently.
4	(a) My manager called for my assistance when one of our patients was in a very bad shape. I biked with her to her apartment to help her to work on a positive diary. I talked with her for an hour. (b) We made an appointment on Monday to work on the positive diary and I offered to bike to her home with her. (c) I listened a lot and shared my experiences with black thoughts and going into crisis. (d) Afterwards I biked back to work and briefed the supervisor. (7)	**Competence explanation:** I give this a high rating because I know what I am talking about when it comes to going into crisis, suicidal thoughts that pop up and emotions that overwhelm you. **Satisfaction explanation:** I am satisfied because I feel like I have done what I could. I also appreciate that my manager trusts me and gives me opportunities to be involved in the 'tandem guidance' for patients. She believes in me and that feels good
5	(a) A patient with a severe alcohol problem who does not dare to come outside. The last time I visited her she was very drunk. Yesterday, I visited her again. I wasn't exactly looking forward to it. Luckily, she had only drunk two glasses, because her alcohol was finished. She was very sceptical towards me, perhaps partly because she knew I had received the same training she had. She told me about her family and that she had many issues with boredom and loneliness and that was the reason why she was drinking. I let her first speak out and then I summarized the points she raised. Then I suggested we drink a cup of coffee together on the terrace. She agreed. At the end I gave her a kiss. (b) My job was mainly to look for the bright side of the story, to give her hope and definitely not to judge. (c) I cannot say much about the consequences of my intervention, because I haven't seen her since then. (d) The fact that she agreed to go outside was a big step for her. (4)	**Competence explanation:** I let her talk, we even laughed. I feel that she felt accepted and this helped her to succeed in taking a step outside. **Satisfaction explanation:** At first, I did not exactly look forward to it. Yet I had a good chat.

TABLE 3: *Continued*

Case	Case reports by peer workers (participant no.)	Explanation of perceived competence and satisfaction
6	(a) Peer review group on 20/4, a working meeting of peer workers. It is a monthly meeting during which we exchange experiences, but also discuss the future agenda, look into potential training for advanced learning. Fifteen peer workers are involved, some are more experienced than others. We are an open group, anybody interested is welcome. (b) I am a link within the whole group; when my ideas or opinion are valuable, I can share them with the group. (c) In connection with a peer support educational programme which is planned to be set up in Antwerp, I've said that I find it important that it does not become very time consuming. This is because a full-time programme with or without an internship would be too intensive not only for me. I've also said that in terms of an internship, I think it's important that if someone does not wish to be directly active in the field, someone can opt for more policy-related work. (d) My comments were noted and were shared at the next meeting about this educational programme. (3)	**Competence explanation:** I felt I made a useful contribution **Satisfaction explanation:** Same reasoning as above.
7	(a) Someone from the working group said during the work group meeting that she would perform euthanasia (Although euthanasia is allowed in case of terminal illness when there is unbearable suffering without the ability of getting relief, this practice remains controversial especially in cases of mental suffering/disease). (b) I was leading the meeting, making sure that everything was running smoothly and that the points on the agenda were tackled one by one. (c) I reacted very emotionally and did not say anything else. (d) I did not finish the meeting, a colleague finished the rest of the meeting for me. (8)	**Competence explanation:** Because I was not able to continue the meeting, but I also know that this can and may happen, which is why there are always two peer workers present at the meetings. **Satisfaction explanation:** I knew the message would be announced and I thought I could handle it, but I got completely overwhelmed by emotions and was not able to be there for other members.

3.3. Nurses' self-perceptions

3.3.1. General features of the cases recorded by the nurses

Eighty-four cases were recorded by the nurses. Of these cases, 46 conveyed an image of the nurse as a satisfied and competent professional, 33 portrayed a nurse who is not satisfied with their professional competence, and five reported a mixed image.

Of the 84 cases, 79 were about situations in which the nurse had to deal with a patient or group of patients. The nurses described a wide range of role-related tasks and competences, such as supporting a patient after a confrontational therapy, dealing with patient non-adherence, taking care of patients who self-injure, responding to absconding patients, and managing transgressive behavior or patients with physical complaints. In cases that did not involve a nurse–patient interaction, two focused on a family member, two were about a team meeting, and one was about an administrative task. In general, the nurses wrote detailed and comprehensive descriptions of their cases in accordance with the questions given in the registration guide. Some cases were partly written using the 'we' form, in which the 'we' referred to 'we as a group of nurses' (Table 2, case 6).

3.3.2. Factors affecting nurses' perceived competence and satisfaction to comply with instructions

The nurses felt it was important to act in accordance with institutional instructions and regulations, and to make sure other health-care providers acted accordingly. These instructions and regulations included implementation of care plans, medication records, crisis cards, relapse prevention plans, suicide assessment checklists, tasks of the day or evening shift, and the weekend program checklist. The nurses evaluated themselves critically against these standards. When patients did not follow the instructions, the nurses tried to reach an agreement or made clear to the patients what behavior was expected (Table 2, case 3). When the nurses were able to carry out the instructions correctly, they felt satisfied (Table 2, case 2).

3.3.3. Being a team player

The way the cases were described showed that the nurses attached great value to teamwork. For example, there were several cases that reflected a need for short interactions with colleagues before or after a patient intervention (Table 2, case 1). In some cases, the nurses served as a team messenger or based their actions on perceived team expectations (Table 2, case 2). There were also cases in which the nurses described a dilemma: whether to follow a team decision or stand up for (and ultimately choose) the patient's perspective (Table 2, case 4). Regarding their role-related competence, the nurses considered it important to discuss their actions with their team and to reach an agreement. In addition, more hidden information reflected the importance nurses gave to the team. This could be derived from expressions in which the case was partly described and/ or evaluated in the 'we' form (Table 2, cases 6 and 1).

3.3.4. Ensuring safety, tranquility, and control

Many of the cases included elements of threats, such as confrontations with disruptive patient behavior or violation of house rules. Nurses felt more competent if they were able to ensure or restore safety and tranquility and follow-up regulations (Table 2, case 3). In some cases, the merit of the team in dealing successfully with the crisis was explicitly reported (Table 2, case 1). Some of the cases portrayed a blended image of how the nurse dealt with a crisis: acting as a carefully sensitive and watchful listener, while also acting intrusively to bring the patient to the comfort room (Table 2, case 1).

There were a few cases in which nurses indicated that they were unsure whether the personal viewpoint of the patient or the perspective of the team was more important (Table 2, case 4). In these cases, the nurses tried to reconcile the different perspectives. When the team supported the nurses' viewpoint, the nurses felt satisfied (Table 2, case 5).

3.3.5. Self-reflection and role-related competence as a nurse

In some cases, nurses praised their actions, although they did not evaluate their behavior in a critical way. In case 1, the nurse occupied a dominant position over the patient, but this active intervention was not questioned (Table 2). The participant in case 3 was satisfied with the way she acted, although there was only a normative intervention, and the case was not explored in depth (Table 2). In contrast, there were also a few cases in which nurses were not satisfied with the way they acted, and criticized their actions and suggested more appropriate interventions (Table 2, case 4).

Disparity was also reflected in how nurses perceived their role-related competence, given that the nurses generally did not reflect on their role-related competence in cases they thought they handled the situation successfully (Table 2, case 2).

3.4. Self-perceptions of the peer workers

3.4.1. General features of the registered cases

In total, there were 48 cases described by the peer workers. All but one focused on the peer workers' interactions with, for example, patients, a group of patients, and/or care providers. There was diversity in tasks, assignments, and contexts described in the cases, such as household tasks, participation in meetings, counselling interviews, and leisure activities with patients. In some situations, the peer worker was directly present alongside the patient; in other situations, they worked together with a care provider or another peer worker. Sometimes they were instructed what to do. Other times they took initiative themselves to organize activities.

3.4.2. Factors affecting the peer workers' perceived competence and satisfaction maintaining themselves as peer workers

Peer workers described their duties on two levels. First, in relation to the patient, the peer workers described situations they experienced as challenging, such as being confronted with a conflict or verbal aggression in a group of patients, having their role criticized by fellow peers, finding the right balance between distance and proximity in a patient interaction, being directly confronted with alcohol use during a patient home visit, or being informed of the desire to perform euthanasia. When peer workers indicated they were able to successfully handle these situations, they felt very satisfied, and sometimes this was explicitly stated in the report (Table 3, case 4). Second, in relation to the people they collaborate with, the cases demonstrated that the peer workers paid a lot of attention to how care providers perceived the peer workers' behavior (Table 3, case 2). The recognition and appreciation peer workers received from care providers had a great impact on their perception of competence and satisfaction (Table 3, case 3). The peer workers also found it important to be heard and to experience equality; for example, when they contributed to discussions (Table 3, case 6).

3.4.3. Building a relationship that is supportive for both

According to the peer workers, doing activities with patients helped to build a relationship that was supportive for both of them, especially when their interaction was spontaneous. At the same time, experiencing reciprocity in the relationship, or the lack thereof, affected how satisfied the peer worker felt. This was regardless of whether the relationship involved patients, other peer workers or care providers. When the peer workers received immediate positive feedback and shared common experiences, they felt satisfied in their engagement with a patient (Table 3, case 5).

3.4.4. Referring to their lived experience

There were several cases in which peer workers thought they acted very competent. These included cases where they were able to work with methods that fit their expertise, such as writing their recovery story, using and sharing personal knowledge and experiences, and serving as a bridge between a patient and a care provider (Table 3, case 1).

3.4.5. Self-reflection and role-related competence as a peer worker

Generally, the peer workers based their role-related competence primarily on the appreciation they received, and to a much lesser extent, on how they provided input to patient care or support. Case 2 described a situation in which a peer worker brought a patient home using his own car (Table 3). The peer worker was criticized by their superior because she was not insured in case of an accident. The peer worker did not feel she was acting competently, because she failed to find sufficient information about insurance. Her perception did not take into account the positive aspects of her support to the patient. Overall, the peer workers based the assessment of their role-related competence on the degree to which the care providers sup- ported their actions (Table 3, case 3). Peer workers self-assessed their actions more critically when they felt they acted less competently (Table 3, case 7).

4. Discussion

The findings from the analysis of data gathered from the nurses and peer workers revealed an apparent parallel pattern. Both nurses and peer workers assign a major role to the team in determining their role-related competence. We will elaborate this main finding, first in relation to the nurses, and then in relation to the peer workers.

The present study revealed that the nurses evaluate their role-related competence in terms of how it related to team-oriented work. They invest a lot in discussing and checking their actions with their team members. The choices and decisions they make are driven primarily by group norms and team agreements. When they felt they worked well together with their team and followed the rules, they were more satisfied. Nurses in our study generally did not fall back on nursing-related principles and values to evaluate their role-related competence, but on whether they were able to meet external standards, such as institutional instructions or team-based regulations. Sometimes the nurses were so com- mitted to following team rules that they let it over-shadow reasonable patient needs. The results demonstrated that, in a limited number of situations, nurses faced a dilemma regarding whether they should violate the (team-based) agreed rules or support the justifiable interests of the patient. Based on our research, we are not able to determine what exactly prompts nurses to make such decisions. However, the research results of the nurses are in line with other studies. Hospitalized mental health patients perceive that nurses are often too involved in rule enforcement, medication administration, and ensuring security in wards, while they want nurses to focus on genuine therapeutic engagement (Santangelo et al. 2017; Stewart et al. 2014). A possible explanation might be that nurses have difficulties in finding the right balance between providing 'protection' and offering 'growth opportunities' during interactions with patients with a mental health vulnerability (Alexander 2006; Stewart et al. 2014).

In contrast with nurses, the peer workers relate their self-perceived competences to core values of peer support, such as relying on their lived experience and enjoying reciprocity in their relationships. They appreciate daily activities, which they can do with patients and which they both enjoy. These activities are often the starting point for establishing rapport with patients. Furthermore, the present study revealed how important it is for the peer worker to be validated, and how this directly affects their feelings of competence and satisfaction. For peer workers, it is important to meet what they perceive to be team expectations. These findings are consistent with the work of Simpson et al. (2017), who described how peer workers are laying 'betwixt and between' the multiple roles they play as peer workers in being service users, friends, and staff.

Peer workers also perceive themselves competent if they can uphold their role and make use of their lived experience. Based on the data collected, we were not able to deduce the reasons behind these perceptions. However, the process of using the lived experience perspective as an asset has been described as a main driver to fulfil a peer worker position (Vandewalle et al. 2018).

Both nurses and peer workers appear to assess their own competences in relation to what is perceived as important by the team. They also reflect less critically in cases where their actions were perceived as consistent with the team. When nurses and peer workers are not satisfied with their actions, they are more inclined to reflect more critically on their actions.

As role-related competence evolves over time, future research is needed to gain more insight into the factors that ameliorate or complicate the role-development process of nurses and peer workers. By setting up data collection at different points during the developmental process of nurses and peer workers, a deeper understanding can be achieved of how both groups view their role-related competences. For nurses, future studies can explore factors that encourage them to deviate from protocols in certain situations, which then enables the provision of person-centered care. For peer workers, particular interest should be given to the impact of conformity on perceived role-related competences.

Methodological limitations

The nurses selected for the present study were all active in a professional interest group. The addition of this selection criterion might have made our sample slightly different from nurses more generally in terms of reflective skills. The nurses, almost all employed in inpatient settings, yielded approximately twice as many cases (n = 84) compared to the participating peer workers (n = 48). In Belgium, only a small number of peer workers with limited work experience currently work in a variety of mental health-care organizations. Therefore, it was more difficult to recruit peer workers than nurses for the present study. It is possible that the time-consuming written data collection also deterred potential participants. Because the cases of nurses and peer workers were assessed separately, the imbalance in the number of recorded cases did not affect the data analysis. The frameworks used to self-rate the competence levels could be questioned, as different frameworks were used for nurses and for peer workers. However, nurses' roles differ from peer workers' roles, mainly because peer workers' roles are underpinned by lived experiences of mental health problems. The retrieved themes were compared and peer reviewed by nurse researchers only. Reflecting on the apparent vulnerability of peer workers' positions, the involvement of a researcher with lived mental health experiences in the design and conduct of the research could have further deepened the analysis of the retrieved themes in the present study. Despite these limitations, several actions were undertaken to guarantee rigor in the research process. The measures that were taken into account were discussed extensively in the Methods section.

5. Conclusion

The present study increases our understanding of how nurses and peer workers perceive their respective role-related competences. Nurses associate their self-perceived competence and satisfaction predominantly with team-oriented work, compliance with relevant work instructions, and their ability to ensure security and control. Peer workers attribute their self-perceived competence and satisfaction with being able to maintain themselves as peer worker, build up supportive relationships, and utilize their lived experience. The retrieved results can be interpreted as encouraging nurses and peer workers to become more self-aware and self-confident in judging their role-related competences. For this purpose, nurses need to rely more on their nursing based principles and values.

Peer workers need to validate their unique capacity to build authentic relationships, and should be encouraged to stick to their core values as peer workers, even in a context of a dominant professional perspective.

6. Relevance for practice

The findings highlight the importance of paying more attention to the identity construction, empowerment, and competence development of nurses and peer workers in their respective practice and basic and ongoing education. The findings revealed how nurses and peer workers are dependent on teams to feel competent and satisfied. Consequently, opportunities to trust and offer their unique and specific expertise are often considered unimportant or ignored. Although it can be justified to be subservient to the team, this should not rule out speaking and acting from their own perspective as nurse or as peer worker. For nurses, the results can be interpreted as a call to adopt a more tailored approach towards their clinical practice in line with contemporary mental health nursing standards of care. If nurses want to deliver more patient-tailored care, it is desirable to identify the conditions and factors that support nurses in making their own assessment of situations, rather than passively following rules. Literature also emphasizes that nurses should proactively utilize their expertise to harmonize their closeness and personal commitment to patients with more task-oriented, organizational, and coordination aspects of care (Delaney & Johnson 2014). Excellent mental health nursing is related to giving attention to the basics of the relationship, being attentive to what really matters for the patients, being compassionate and engaged, and sharing power with patients, even when harmful situations might be involved (Gunasekara et al. 2014; Holley et al. 2015; Santangelo et al. 2017). When nurses succeed in articulating the unique, complex, challenging, and often intangible work they perform in a person-centered manner, it will not only increase their visibility within a team but can also enhance their sense of professional identity, empowerment, and even personal identity (Hurley et al. 2009; Santangelo et al. 2017). Strong nurse leadership will be needed to enable nurses to develop their professional profile as a mental health nurse based on a person-centered, wellness-oriented, and collaborative care delivery model (Santangelo et al. 2017).

For peer workers as an emerging group of care providers in mental health care, the present study encourages the implementation of peer support services in clinical practice. Vigilance should be exercised regarding the peer workers' potential dependence on (mainly supervisory) care providers, which might risk diluting the specific added value of peer support. Attention should be given to the ongoing support of peer workers to feel confident with the unique perspective they can offer and the unique competences they can contribute. In this perspective, supervision and support from people with lived experience should be promoted (Vandewalle et al. 2016). Cleary et al. (2011) point to the ideal position of nurses in supporting the implementation of peer support systems in the field. As a group of health-care providers that spend a great amount of time with patients, nurses have the potential to validate and to recognize the unique peer support perspective during their daily interaction with peer workers. In this way, cooperation with peer workers can be enhanced, and a base can be created for jointly discussing and shaping role-related competences (Byrne et al. 2017; Hurley et al. 2016). However, attention is further needed in relation to nurses' perceived barriers and concerns regarding working collaboratively with peer workers. As both vocations are involved in similar situations, tasks, and activities, peer workers can be perceived by nurses as a threat in relation to their job security, for example. Particularly if nurses' distinct roles are not acknowledged and recognized, tensions might arise and might even jeopardize encouraging efforts working towards a collaborative practice in which they are supported to explore and learn from each other.

To foster the competence development of nurses and peer workers, the case reports in the present study offer a wealth of relevant practical cases, particularly suitable for this purpose. Previous research in the field of the transition process of nurse practitioners already demonstrated how reflective case vignettes are helpful to deliver compassionate and person-centered care (Ter Maten-Speksnijder et al. 2012). The cases collected in the present study could be helpful during discussions among and between nurses and peer workers to deter- mine and define their specific role-related competences and strengthen reflective practice. The case reports might also be useful for educational purposes. By exploring the cases in-depth with nurses and/or peer workers, a broad repertoire of strategies for person-centered care can be built up. Components of identity construction as nurse or as peer worker in relation to the sometimes intangible reality of the clinical practice can be developed.

These results are relevant for the development and implementation of recovery-oriented practice, especially in a country where this is still developing. The peer workers selected for the present study were all recently employed and were adopting a new role. In Belgium, the country of the study, various formal structures (financing and job descriptions) for peer workers are gradually being created in the mental health care (Tambuyzer et al. 2014). The findings can be interpreted in the perspective of collaborative engagements between nurses and peer workers (Wiggins 2008). As nurses strive to be good team players and are able to put this aspiration into practice, nurses can support peer workers in their integration process in teams. They also can help them to maintain themselves as peer workers and realize their full potential. As peer workers strive to build up supportive relationships, it can inspire nurses to acknowledge the value of 'being with and together' with patients. By doing so, nurses put in practice what is echoed by nursing theories (Santangelo et al. 2017).

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Hoofdstuk 8

Algemene discussie

1. Inleiding

Doel van dit proefschrift is om inzicht te verwerven in de specifieke betekenis en de waarde van de deskundigheid die patiënten verwerven op basis van hun 'lived experiences'. Rekening houdend met de inzichten die uit de besproken studies naar voor komen, is het een kwestie die niet eenvoudig kan beantwoord worden. We botsen immers op de vraag wie er bepaalt wat als deskundigheid gezien wordt en wanneer deze deskundigheid benut wordt, of wanneer ze ongemoeid gelaten wordt. In een hedendaagse sterk geprofessionaliseerde zorg is het risico groot dat deskundigheid pas als deskundigheid gezien wordt wanneer het aansluit of versterkend werkt voor wat professionele zorgverleners belangrijk en waardevol vinden. Het is dus nodig om waakzaam te zijn dat wie de macht heeft in de zorg en in de relatie, niet bepaalt wat kennis en kundigheid is (Foucault 1982). Wie de macht heeft in de zorg en in de relatie, bepaalt daarenboven ook wat aandacht krijgt en wat niet. Patiënten bouwen doorheen hun zorgtraject ervaringsexpertise op: ze verwachten dat deze kennis serieus genomen wordt en dat zorgverleners die ook erkennen binnen de directe zorgrelatie. Ze kunnen hierin echter teleurgesteld worden wanneer ze bv. tijdens een heropname geconfronteerd worden met betuttelende of vermijdende zorg.

Niet alleen binnen de relatie patiënt-zorgverlener, maar ook op een meer systemisch niveau speelt deze macht. Zo kan kennis en expertise zelfs gebruikt worden om te beletten dat anderen (lees: ervaringswerkers) aan invloed winnen binnen de organisatie (Scholz et al. 2019). Uit studies blijkt dat ervaringswerkers die werkzaam zijn in (GGZ-)organisaties aanzienlijk minder invloed en zeggenschap hebben in vergelijking met andere medewerkers en daardoor ook minder mogelijkheid hebben om hun perspectief naar voor te brengen (Bellingham et al. 2018; Bennets et al. 2011).

Dit kan dus tot de volgende paradoxale situatie leiden, namelijk dat ervaringswerkers aangeworven worden omwille van het alternatieve perspectief dat ze kunnen binnenbrengen in de zorg, maar in de praktijk blijkt dat dit perspectief niet opgepikt of zelfs tegengewerkt wordt (Silver & Nemec 2016). Dit is vooral zo binnen zorgsystemen waarin het biomedisch model nog sterk van invloed is op de organisatiecultuur (Bennetts et al. 2011).

Patiëntdeskundigheid kan dus niet los gezien worden van de relatie met de professionele zorgverleners en de systemen waarbinnen deze zorgverleners functioneren.

Maar patiëntdeskundigheid kan ook niet los gezien worden van de ruimere context waarbinnen patiënten functioneren, zoals bv. de context van een afdeling, een organisatie en het geheel van interacties die zich hierbinnen afspelen. Vanuit de besproken studies zien we hoe vertrouwenspersonen van grote betekenis zijn om patiëntdeskundigheid tot ontwikkeling te laten komen (hoofdstuk 2, hoofdstuk 7). De relaties en bij uitbreiding de context waarin patiënten/ ervaringswerkers met hun ervaringen naar voor komen is steeds een beïnvloedende en soms zelfs een bepalende factor voor de betekenis die aan patiëntdeskundigheid wordt toegekend. Beïnvloedend omdat ze van belang zijn voor de mate waarin patiënten/ervaringswerkers zich uitgenodigd of belemmerd voelen om hun ervaringen te delen. Bepalend in de zin dat de finale waarde die toegekend wordt aan de ingebrachte ervaringen, afhankelijk is van de appreciatie die er wel of niet aan gegeven wordt. In hoofdstuk 7 komt bv. naar voor hoe de context een bepalende rol speelde in het inschatten van de 'rol-bekwaamheid' van de verpleegkundigen en de ervaringswerkers. Het zijn inzichten die in lijn liggen met hoe macht niet een statisch maar een dynamisch gegeven is, dat zich zowel positief als negatief kan ontwikkelen binnen een geheel van relaties (Turner 2005). Zorgverleners dienen dus zelfbewust en transparant in relatie te staan met patiënten, zodat er geen subtiele en eerder onzichtbare machtsverhoudingen blijven doorwerken in hun communicatie met patiënten/ervaringswerkers (Cutcliffe &Happell 2009).

2. De waarde en betekenis van patiëntdeskundigheid

2.1. De legitimiteit van de patiëntervaring an sich

Een kerninzicht dat uit de studies naar voor kwam is dat de authentieke ervaringen die de patiënten en de ervaringswerkers met zich meedragen op zichzelf betekenis hebben en een potentiële waarde genereren voor anderen. Dat het vanuit de ervaring komt, is voldoende om er legitimiteit aan toe te kennen. Ook al staat de ervaring van een patiënt volledig los van andere patiëntervaringen, of staat ze haaks op deze ervaringen (bv. gevoeligheid voor recidief psychose hanteren door louter aan levensstijl-management te doen en geen antipsychotica in te nemen), dan nog is deze ervaring relevant.

Patiëntervaringen zijn wel aan dynamieken onderhevig, in die zin dat ze afhankelijk van het tijdstip en de context (interacties) waarbinnen de ervaring ingezet wordt, een positieve of een negatieve betekenis kunnen hebben voor de ander. Ervaringen zijn van betekenis wanneer ze op de relatie met de ander een positieve (stimulerende) invloed hebben. Ervaringen zijn van negatieve betekenis wanneer ze op de relatie met de ander een negatieve invloed hebben.

De betekenis van de ervaring is in de tijd bepaald. Hiermee wordt bedoeld dat een ervaring die op dit ogenblik van betekenis is voor de ander, later in de tijd terug aan kracht kan verliezen. Zo kan bv. de ervaring van 'buiten de maatschappij te vallen als psychiatrisch patiënt' bij een eerste ontmoeting met een ervaringswerker die dezelfde ervaringen van desintegratie met zich meedraagt, voor een 'instant' connectie zorgen (Wallcraft 2012). Maar deze connectie kan op een later tijdstip terug onder druk komen te staan en aan werkzaamheid verliezen wanneer de actie die genomen werd om deze desintegratie op te heffen (bv. stimulans om aansluiting te zoeken bij een lotgenotengroep), niet aansluit bij het waardensysteem van de betrokkene.

De kracht/betekenis van de patiëntervaring hangt evenwel niet samen met het specifieke tijdstip binnen het herstelproces waarop deze ervaring ingezet wordt. Met andere woorden, ook wanneer de patiënt nog volop in de patiëntenrol zit, zet hij ervaringen in die waarde en betekenis hebben voor anderen, medepatiënten en toekomstige zorgverleners (hoofdstuk 2 en 3). Voorwaarde is wel dat er een zorgcontext aanwezig is die ontvankelijk is voor deze ervaringen en ze bestaansrecht geeft. Met ontvankelijkheid wordt bedoeld dat er een basis van intersubjectieve herkenbaarheid aanwezig is en dat een gerichte dialoog mogelijk is. De zorgverlener speelt op dat moment een mediërende rol. Door na te gaan hoe en waar deze authentieke ervaringen een meerwaarde kunnen geven in de zorgpraktijk en hoe en waar ze eventueel een gevaar zouden kunnen betekenen, kan de zorgverlener faciliterend dan wel begrenzend of structurerend tussenkomen. Om dit te kunnen doen, dienen zorgverleners erover te waken dat ze niet van hun eigen referentiekader vertrekken, maar steeds rekening houden met de mate waarin de ervaring die ingezet wordt, matcht met de specifieke context waarin dit gebeurt. Patiënten die nog (verslavende) middelen gebruiken bv. en die ambiëren om lotgenoten te ondersteunen als ervaringswerker in hun herstel, zouden kunnen ontraden worden om dit te doen op basis van het argument dat ze nog steeds middelen gebruiken. Echter, in een (behandel)context waar het realiseren van schadebeperking een belangrijke doelstelling is, kan het juist een troef zijn dat een ervaringswerker deel uitmaakt van het team die de filosofie van schadebeperking zelf concreet toepast in zijn leven. Ze laten zo zien naar de patiënten toe dat schadebeperking geïntegreerd kan worden in het persoonlijk leven (Tockey et al. 2018).

De betekenis van de patiëntervaring hangt evenmin samen met de mate van het aanwezige kennisniveau (bv. beschikken over een afdoende wetenschappelijke basiskennis) en/of de (communicatieve) vaardigheden van wie zijn ervaring inbrengt. De betekenis van de ervaring is echter wel afhankelijk van zowel de persoon die de ervaring inbrengt als de mate waarin deze ervaring herkenbaar is en aansluit bij noden/behoeften/kenmerken van degenen voor wie ze van tel kan zijn. We baseren ons hiervoor op de sociale leertheorie van Bandura (1977), die het leren binnen een relatie kenmerkt, én op de kijk van Foucault (1992) over macht binnen de relatie. Vanuit de sociale leertheorie van Bandura (1977) weten we dat mensen niet zomaar iets aannemen van anderen. Om zich te kunnen identificeren met de ervaring/het verhaal/de inbreng van de ander, is het belangrijk dat de ander voldoende kenmerken in zich draagt waarmee men zich kan identificeren. Toegepast op de context van de gezondheidszorg, met mensen die een heel diverse achtergrond en socioculturele status hebben, betekent dit dus dat het streven naar een brede mix van mensen die van mekaar verschillen op vlak van kennisniveau, (zorg)ervaring, vaardigheden, enz., belangrijk zal zijn om een meerwaarde te creëren.

Verder bepaalt ook diegene die de macht heeft in de relatie, welke patiëntervaringen ingezet worden in de zorg. Wanneer de professionele zorgverlener niet met de ervaringen van patiënten aan de slag gaat, dan heeft de patiënt (en bij uitbreiding de ervaringswerker) geen (volwaardige) mogelijkheid om zijn ervaringen in te brengen (Cutcliffe & Happell 2009). Het gevolg hiervan is dat de macht bij de zorgverlener blijft. Het kan ook dat een zorgverlener enkel die ervaringen meeneemt die aansluiten bij zijn visie of kijk. Grant (2015) spreekt in dit kader over een vorm van *confirmation-bias*, omdat de zorgverlener eenzijdig beslist welke info uit het verhaal van de patiënt valide is en welke info niet. We komen hierop terug onder het punt 'voorwaarden om patiëntdeskundigheid tot ontwikkeling te brengen'.

2.2. Patiëntdeskundigheid: inherent verbonden met het persoonlijk ontwikkelingsproces als patiënt

In de inleiding van dit proefschrift gaven we reeds aan hoe patiëntdeskundigheid ontwikkelingsmatig verloopt en in interactie met een bepaalde praktijkcontext. De uitgevoerde studies beklemtonen het intrinsieke belang van dit ontwikkelingsproces en van de rol van de zorgverleners in het ondersteunen van dit proces, onafhankelijk van tijdstip of fase in het transitieproces van patiënt tot ervaringswerker.

Betrokken worden in het leerproces van studenten tijdens een stage geeft patiënten een forum om hun ervaringen naar de student terug te koppelen. Voor patiënten met een psychiatrische kwetsbaarheid betekent het een gehoord en beluisterd worden. Voor studenten is het een kans om wat voor de patiënt van tel is, blijvend in het vizier te houden (hoofdstuk 2). De verpleegkundige speelt in dit hele proces van ontlokken van feedback bij patiënten een sleutelrol, niet alleen om goeie contextvoorwaarden te creëren, maar ook om op basis van een goed kennen, van patiënt én student, de methodiek op maat van beide betrokkenen aan te passen. Zo behoeven sommige patiënten de nodige tijd en het vertrouwen om met hun ervaringen met betrekking tot de student voor de dag te komen. Vaststellen dat hiervoor ruimte genomen wordt en die ruimte krijgen, werkt versterkend en verbindend naar de relatie toe met de verpleegkundige en heeft een identiteitsversterkend effect op de patiënten zelf (hoofdstuk 2).

In hoofdstuk 5 en 6 stonden we stil bij hoe in het transitieproces van de patiënt tot ervaringswerker, ook het individueel ontwikkelingsproces centraal staat voor wie hij wil zijn en wat hij wil betekenen als persoon. De aspiratie om ervaringswerker te worden sluit aan bij het intrinsiek verlangen tot normalisatie en het zoeken naar een zo afgestemd mogelijke manier om een positieve identiteit op te bouwen. De evolutie tot ervaringswerker wordt gepercipieerd als een kans om een betekenisvol en zinvol leven uit te bouwen voor zichzelf (hoofdstuk 4). Ook het doorgroeien in de rol als ervaringswerker wordt gezien als een verder aan de slag gaan met dit proces van persoonlijke ontwikkeling (hoofdstuk 6).

Deze inzichten sluiten tot op zekere hoogte aan bij de uitgangspunten voor ervaringswerk, zoals beschreven door Mead et al. (2001), waarin ervaringswerk omschreven wordt als “een inclusief model dat mensen toelaat om te ontdekken en te ervaren wie ze zijn, in welke richting ze willen doorgroeien en vanuit de ondersteuning die ze tijdens dit proces ervaren een start kunnen maken met het helpen veranderen van grotere structuren.” (Mead et al. 2001, p. 136)

2.3. Verwerven van deskundigheid als patiënt: een evolutief dynamisch proces

De deskundigheid waarop ervaringswerkers bouwen om hun ervaringswerk vorm te geven, krijgt op een andere manier vorm dan hoe deskundigheid klassiek ontwikkeld wordt, nl. zich via training of scholing bepaalde competenties eigen maken. Toch mag deze tegenstelling niet zo scherp gezien worden. Binnen zorgberoepen is de impact van opleiding relatief, zeker voor het verwerven en beheersen van minder vatbare professionele competenties zoals empathie, zorg, connectie, steun. De deskundigheid krijgt vorm tegen de achtergrond van het persoonlijk levensverhaal, de persoonlijke leefwereld van de ervaringswerker en het leven als patiënt in het bijzonder. Levenskennis die in ieder persoon aanwezig is en dus ook bij zorgverleners, maar waar in opleiding van zorgverleners weinig tot geen aandacht voor is. Het is voor GGZ-ervaringswerkers een proces van loskomen uit beperkende rolpatronen en toewerken naar een positieve identiteit, van (weer) vertrouwen opbouwen in mensen (en zichzelf), van het (opnieuw) uitbouwen van zingeving in het leven en in relaties. Het is een proces van zich staande houden in soms moeilijke omstandigheden, van evenwicht vinden in het verlangen om te normaliseren en de drang om te stabiliseren (hoofdstuk 4). Het is een proces dat ook beïnvloed wordt door betekenisvolle anderen, door zorgverleners en door hoe men de zorgverlening (of de afwezigheid ervan) ervaren heeft. Het is een proces waarbij de eigen doorleefde ervaringen met zorg (behandeling/begeleiding) het beeld bepalen van wie men wil zijn als ervaringswerker (hoofdstuk 6).

Het patroon van hoe deze deskundigheid vorm krijgt, kan sterk verschillen van ervaringswerker tot ervaringswerker. In tegenstelling tot hoe professionele deskundigheid zich meestal ontwikkelt, verloopt patiëntdeskundigheid meestal niet rechtlijnig, maar kent het vaak een heel grillig patroon. Dit komt omdat de deskundigheid die ervaringswerkers zich eigen maken niet los kan gezien worden van het persoonlijk herstelproces dat ze doormaken. Zo beschreven we in hoofdstuk 4 hoe GGZ-ervaringswerkers soms te maken krijgen met terugval, waardoor de patiëntenrol weer heel centraal kan komen te staan en ze tijdelijk hun activiteiten als ervaringswerker dienen te staken. Toch hoeft dit niet te betekenen dat ze als gevolg van deze terugval dienen in te boeten op vlak van patiëntdeskundigheid. Het positief doorkomen van deze fase van terugval kan hen juist versterken in hun rol als ervaringswerker. Het persoonlijke doorgemaakte proces biedt (nieuwe) kansen om van betekenis te zijn voor patiënten die verstrikt geraakt zijn in dit proces van terugval (bv. als gevolg van schaamte, frustratie). Vanuit hun persoonlijke doorleefde ervaring geven ervaringswerkers zo het recht door aan medepatiënten om het te proberen, maar ook om te mogen falen (Barrenger et al. 2019).

Patiëntdeskundigheid staat niet zozeer in relatie met de gekregen opleiding of het aantal dienstjaren dat men op de teller heeft als ervaringswerker. Ook niet met de variatie en intensiteit van rollen die men opneemt als ervaringswerker. Patiëntdeskundigheid is bovenal een vorm van deskundigheid die ervaringswerkers zich eigen maken op basis van een persoonlijk doorleefd proces in interactie met anderen én deze deskundigheid geeft waarde voor de ander wanneer deze ervaring direct aansluit bij wat de ander op dat moment nodig heeft.

Uit de studies kwam naar voor hoe het inzetten van deze ervaringen niet een gratuit proces is. Ervaringswerkers botsen vaak op weerstand wanneer ze met hun ervaringskennis aan de slag willen gaan. De polemiek die rond ervaringswerk heerst bij vele professionele zorgverleners, hangt deels samen met de positie die ervaringswerkers bekleden binnen de zorg- en hulpverlening, hoe gekeken wordt naar wat patiënten/ervaringswerkers aan extra deskundigheid kunnen binnenbrengen en wat voor ervaringswerkers zelf drijfveren zijn om een rol op te nemen als ervaringsdeskundige. Ervaringswerkers zijn nog bezig met hun plaats te veroveren in de reguliere gezondheidszorg. Ze dienen vorm te geven aan een nieuwe rol in een GGZ die zelf volop in verandering is. Hun integratie is nog volop aan de gang in Vlaanderen en ze botsen hier op vele barrières op micro-, meso- en macroniveau (hoofdstuk 5). De (tussen)positie die ervaringswerkers innemen, is geen makkelijke positie. Ervaringswerkers zijn immers noch patiënt, noch hulpverlener (Simpson et al. 2017). Toch zijn het hun persoonlijke patiëntervaringen die hen in de eerste plaats drijven om rollen op te nemen als ervaringswerker. Hun exclusieve troef is immers dat ze vanuit hun ervaring met wat het is om (nog) geen hulp te willen bv., een direct verbindend contact kunnen leggen met patiënten (hoofdstuk 4 en hoofdstuk 7). En vanuit dit contact kunnen ze een brugfunctie opnemen ten aanzien van het aanreiken van passende hulpverlening. De diverse ervaringen die ze met zich meedragen zijn dus zowel bron als medium waarmee ze hun ervaringswerk vorm geven.

2.4. Meerwaarde van ervaringen die ingezet werden

In dit proefschrift kwam aan bod hoe de uitgevoerde studies (binnen de voorwaarden zoals besproken in de respectievelijke studies) nieuwe inzichten opleverden over de waarde van het inzetten van ervaringen die patiënten/ervaringswerkers met zich meedragen. In hoofdstuk 2 werd belicht hoe vanzelf waarde gegenereerd wordt wanneer patiënten feedback delen over studenten . Patiënten kregen een forum aangeboden waarin ze hun ervaringen met betrekking tot studenten konden delen. Wat patiënten terugkoppelden over de student, versterkte zijn self-*efficacy* van de student. De verpleegkundige die de feedback ontlokte bij de patiënten, werd uitgedaagd om haar interpersoonlijke competenties optimaal in te zetten zodat ze de gegenereerde feedback van waarde kon laten zijn voor zowel de student als de patiënt. In hoofdstuk 3 werd belicht wat de complementaire meerwaarde zou kunnen zijn wanneer op een structurele manier feedback van patiënten binnen een algemeen ziekenhuis meegenomen wordt in het stage-evaluatieproces van studenten verpleegkunde. In hoofdstuk 4, 5, 6 en 7 werd de meerwaarde van het inzetten van ervaringswerkers in de geestelijke gezondheidszorg verduidelijkt. Ervaringswerkers kunnen helpen om te normaliseren en bespreekbaar te maken van wat patiënten liever verhullen (hoofdstuk 4). Ervaringswerkers kunnen teams helpen om te verbeteren wat ze doen en om te stoppen met uitvoeren wat patiënten (en naastbetrokkenen) niet vooruithelpt. Ze fungeren in die zin als een soort spiegel voor wat teams doen en voor wat ze (nog) niet doen. Ervaringswerkers dagen verpleegkundigen uit om hun wezenlijke rollen niet uit het oog te verliezen (hoofdstuk 7). Vanuit hun specifieke rol kunnen ze ook als spiegel voor de organisatie fungeren en helpen om duidelijk te maken waar het patiëntperspectief meer meegenomen dient te worden en wat hierin nog als belemmerend ervaren wordt (hoofdstuk 5). Uit hoofdstuk 6 blijkt verder dat ervaringswerkers gevoelig zijn voor het klimaat binnen een organisatie (gelijkwaardigheid, vertrouwen, enz.). Ervaringswerkers kunnen in die zin ook spiegelend zijn naar de organisatie toe wat betreft de mate waarin er een klimaat aanwezig is dat groeikansen geeft aan mensen in de brede betekenis van het woord. Zo zullen ervaringswerkers (maar ook patiënten) bv. vlugger signalen geven dan medewerkers wanneer het werkklimaat als ongunstig ervaren wordt. Deze spiegel kan ook de maatschappij voorgehouden worden, waardoor terechte aandacht kan ontstaan voor maatschappelijke determinanten die een psychiatrische problematiek veroorzaken, in stand houden of versterken.

2.5. Factoren en processen die de inzet van patiëntdeskundigheid kunnen versterken of kunnen uithollen

In de studies werden factoren in kaart gebracht op micro-, meso- en macroniveau, die de inbreng en integratie van ervaringswerkers in de GGZ bemoeilijken of vergemakkelijken. Opmerkelijk was hoe uit deze studies naar voor kwam dat de voorwaarden die noodzakelijk zijn om bij patiënten feedback te ontlokken, bij een groep van gehospitaliseerde GGZ-patiënten volledig in lijn liggen met de voorwaarden die de ervaringswerkers belangrijk vinden om hun rol als ervaringswerker volwaardig te kunnen opnemen. Het gaat om punten zoals het ervaren van een veilig en duidelijk kader, het opzetten van een dialoog waarin er aandacht en ruimte gemaakt wordt voor de ervaringen van de ander, en waar er een klimaat van openheid, gelijkwaardigheid en procesgerichte aandacht uitgebouwd wordt. In beide studies werd ook de rol belicht van vertrouwenspersonen naar de betrokken patiënten (studie beschreven in hoofdstuk 2) of ervaringswerkers toe (studie beschreven in hoofdstuk 6). Hoewel hun rol in beide studies vnl. faciliterend en ondersteunend van aard was, werd deze wel als heel betekenisvol gepercipieerd door respectievelijk de betrokken studenten (hoofdstuk 2) en de in transitie zijnde ervaringswerkers (hoofdstuk 6). Het zijn inzichten die aansluiten bij andere onderzoeksresultaten. Suikkala et al. (2018) geven aan hoe het betrekken van patiënten in de opleiding van studenten verpleegkunde impliceert dat het leren van de mentor als rolmodel verlegd wordt naar wat er in de relatie gebeurt tussen de patiënt en de student (Suikkala et al. 2018). Kenmerkend voor de beschreven studies in hoofdstuk 2 en hoofdstuk 6 is ook dat de zorgverlener niet langer aan het stuur zit, maar de controle overdraagt aan respectievelijk patiënten of ervaringswerkers. Ook dit is een essentiële voorwaarde die in vorige punten reeds belicht werd. Wanneer patiëntervaringen niet tot expressie (kunnen) gebracht worden, niet 'gelezen' of opgepikt worden, dan blijven ze ondergesneeuwd. Het tot expressie brengen van patiëntervaringen is een proces dat reeds begint vanaf de prille start van iedere zorgrelatie. Zorgverleners hebben de sleutel in handen voor de mate waarin ze ruimte geven aan het beluisteren en meenemen van de deskundigheid die potentieel in iedere patiënt & context aanwezig is (Peplau 1997; Warne & Mc Andrew 2007; Cutcliffe & Happell 2009). Ook in dit proefschrift werd dit gegeven in zo goed als alle studies belicht.

Verder dienen organisaties/zorgverleners vooral de voorwaarden en omstandigheden te creëren die patiënten en ervaringswerkers nodig hebben om met hun deskundigheid naar voor te komen. Organisaties kunnen hierin het voortouw nemen door een herstelgerichte zorgcultuur te implementeren en door maatregelen te nemen die de participatiecultuur kunnen bevorderen (Vandewalle & Malfait et al. 2017). Op die manier kan een duurzame, reflectieve dialoog tot stand gebracht worden, zodat gericht geluisterd wordt naar de ervaringen die patiënten met zich meedragen. En zodat ruimte en tijd gecreëerd worden opdat (patiënten) ervaringswerkers betekenisvol hun authentieke ervaringen kunnen inbrengen of inzetten, met wederzijdse aandacht voor wat hiervoor nodig is. Een dergelijke cultuur laat ook toe dat factoren die betekenisvolle participatie ondergraven, voorkomen worden of vroegtijdig gedetecteerd en aangepakt .

Op macroniveau leren de resultaten uit dit proefschrift hoe, ondanks het credo van herstelgerichte visie, het in de klinische praktijk moeilijk blijft voor ervaringswerkers om volwaardig hun plaats in te nemen binnen zorgorganisaties en gezondheidszorgbeleid. In hoofdstuk 5 werden barrières die GGZ ervaringswerkers ervaren op organisatie- en organisatie-overstijgend niveau, zoals bijvoorbeeld het ervaren van gebrekkige werkcondities, af te rekenen hebben met rigide werkafspraken, verloning die niet in verhouding staat tot de geleverde inspanningen, onzekere rechtszekerheid, enz. In hoofdstuk 6 en 7 werd de afhankelijkheid van de ervaringswerker belicht t.o.v. de organisaties waarin ze actief zijn en hoe deze afhankelijkheid het voor hen ook moeilijk maakt om negatieve ervaringen tijdens de uitvoering van hun ervaringswerk aan te kaarten. In hoofdstuk 2 en 3 werd dan weer belicht hoe de stem van de patiënt nog onvoldoende meegenomen wordt in de opleiding van toekomstige zorgverleners. Op basis van deze beschouwingen kan men de terechte vraag stellen wat de invloed is van traditionele (organisatiespecifieke/ organisatieoverstijgende) structuren op hoe ervaringswerkers hun ervaringswerk vorm geven. En in welke mate deze structuren belemmerend dan wel ondersteunend zijn in wat ervaringswerkers kunnen betekenen voor de mensen aan wie ze zorg geven. En indien het antwoord op deze vraag bevestigend is, of er geen institutionele hervormingen nodig zijn opdat ervaringsdeskundigen als belangengroep meer kunnen wegen op het gevoerde beleid binnen de gezondheidszorg?

3. Betekenis van de inzichten uit dit proefschrift voor de zorgpraktijk

Effectieve GGZ-verpleegkunde kan maar tot stand komen wanneer verpleegkundigen zich openstellen voor de ervaringen die patiënten met zich meedragen (Mc Andrew et al. 2014). In dit proefschrift toonden we aan dat door patiënten reeds in de opleiding van toekomstige verpleegkundigen actief te betrekken en een volwaardige stem te geven, hieraan bijgedragen kan worden. Hoewel de patiënt centraal staat in het zorgproces, wordt er in de verpleegkundige praktijk nog weinig beroep gedaan op zijn expertise. Het is wenselijk om hiaten op dit vlak in kaart te brengen en te onderzoeken hoe en op welke manier en voor welke thema's het zinvol en gewenst is dat patiënten (en naastbetrokkenen) actief betrokken kunnen worden in de verpleegkundige praktijk. Het concreet samen met de patiënt onderzoeken en aan de slag gaan met de ervaringen die hij meedraagt, is in dit kader dus belangrijk. Dit is een eerste belangrijke implicatie voor de verpleegkundige praktijkvoering.

Hoewel in dit proefschrift uitgebreid de barrières omschreven zijn waardoor patiënten/ ervaringswerkers aan de kant blijven staan en niet betrokken worden (hoofdstuk 5), hebben we in dit proefschrift ook gedurfde initiatieven opgezet, zoals bv. het betrekken van patiënten in stage-feedback van studenten verpleegkunde (hoofdstuk 2 en 3). Verpleegkundigen zijn bijzonder goed geplaatst om samen met ervaringswerkers co-creatietrajecten op te zetten binnen hun professioneel domein. De mogelijkheden zijn onuitputtelijk, op voorwaarde dat de betrokken ervaringswerkers over relevante ervaringen beschikken en bereid zijn om ze gericht af te stemmen op wie ze van toepassing kunnen zijn. Voorbeelden kunnen zijn: trajecten opzetten rond thema's als leefmilieu-issues, taboe en stigma, ontslagvoorbereiding, opname, educatienoden, medicatie, coping.

GGZ-verpleegkundigen en ervaringswerkers hebben mekaar dus veel te bieden. Dit werd expliciet besproken in zo goed als alle hoofdstukken van dit proefschrift. Heel wat auteurs wijzen op het natuurlijk bondgenootschap tussen verpleegkundigen en ervaringswerkers (Byrne et al. 2016; Hurley et al. 2016). Verpleegkundigen die veel ervaring hebben met het voortdurend aangaan en afsluiten van relaties met patiënten, kunnen ervaringswerkers ondersteunen op vlak van hanteren van grenzen in hun contact met patiënten (Simpson et al. 2014). Maar ook het omgekeerde is waar. Ervaringswerkers kunnen verpleegkundigen ondersteunen om ook in precaire situaties te blijven kiezen voor humane zorginterventies (Holley et al. 2015).

Om dit doel te kunnen bewerkstelligen, dienen organisaties die patiëntervaringen/ervaringswerk willen honoreren, ervaringswerkers in de eerste plaats ruimte en kansen te geven opdat ze hun (complementaire) inbreng kunnen doen. Hiertoe is een volgehouden dialoog nodig met patiënten/ ervaringswerkers, zodat ze in partnership een samen-verhaal kunnen schrijven. Dit verhaal zal telkens met de nodige zorgvuldigheid dienen geschreven te worden, gezien ervaringen van patiënten/ ervaringswerkers op zichzelf staan en uniek zijn. De rol die ervaringswerkers opnemen is een waardevolle, maar absoluut geen evidente rol. Doordat ze noch teamlid noch patiënt zijn, riskeren ze tussen wal en schip te vallen (Simpson et al. 2017). Waakzaamheid en aandacht is geboden opdat hun specifieke rol en eigenheid niet eroderen. Daarom dienen organisaties die aan de slag willen met ervaringswerkers een duidelijk kader en een gedragen visie op te bouwen op herstel, de implementatie van ervaringswerkers en interventies voor reductie van stigmatisering. Deze visie is niet te vatten in een checklist of protocol dat eenvoudig afgevinkt kan worden, maar vooral een proces waar iedereen (inclusief de ervaringswerker zelf) vanaf het prille begin medeauteur van is en dat waarden-gedreven is (Buchanan-Barker & Barker 2008). De perceptie van de ervaringswerker dient de continue toetssteen te vormen in dit leerproces. Een proces waarvan authentieke communicatie en een duurzaam engagement de bouwstenen zijn. Patiënten willen zorgverleners die authentiek met hen omgaan, bij wie echte betrokkenheid en engagement centraal staan. Zorgverleners dienen zich bewust te zijn van hoe ze in relatie staan en dus bewaken niet onbewust patronen in stand te houden die patiënten in een afhankelijke rol houden ten opzichte van de zorgverlener. Op die manier kan een machtsongelijkheid ontstaan die betekenisvolle participatie in de weg staat (Scholz et al. 2018). Er dient dus waakzaamheid te zijn dat er geen patroon ontstaat van zorgverleners die aangeven wat patiënten moeten doen bv., en patiënten die uitvoeren wat zorgverleners van hen verlangen (zie hoofdstuk 7 waarin dit patroon beschreven werd). Een zekere terughoudendheid en bedachtzaamheid is dus nodig, opdat tijd en ruimte genomen kan worden zodat de relatie tussen zorgverleners en ervaringswerkers zich kan vormen.

In dit integratieproces is er ook aandacht nodig voor die zorgverleners die in hun samenwerking met patiënten/ervaringswerkers zich meer defensief opstellen: hun bekommernissen moeten afdoende meegenomen kunnen worden (zoals bv. de vrees dat ervaringswerkers op termijn hun jobzekerheid in het gedrang zouden kunnen brengen). Maar er is ook aandacht nodig voor zorgverleners die ervaringswerk genegen zijn, zeker wanneer de structuren in de organisatie (nog) niet ontwikkeld zijn om dit de plaats te geven binnen de organisatie die het toekomt. Deze groep verpleegkundigen kunnen vanuit hun gedrevenheid in die mate aan de kar duwen dat er voorbij gegaan wordt aan het tempo en de richting die de ander(en) willen (kunnen) gaan.

Organisaties dienen dus vooral in te zetten op het ondersteunen van volwaardig partnership tussen zorgverleners en ervaringswerkers. Zoals hoger reeds aangegeven kan op die manier voorkomen worden dat klassieke rolpatronen die kenmerkend zijn voor de relatie verpleegkundige-patiënt, zich herhalen in de relatie verpleegkundige-ervaringswerker. Dat dit een reëel risico is, blijkt uit de studie van Jorgensen et al. (2018) waarbij er aandacht was voor de implementatie van patiënten-participatie in de concrete werkpraktijk van verpleegkundigen. Uit deze studie komt naar voor hoe verpleegkundigen weliswaar participatieve zorg veel waarde toedichten, maar in de concrete dagelijkse praktijk vaak terugvallen in een klassieke, paternalistische manier van werken (Jorgensen et al. 2018). Ook in het samenwerken met ervaringswerkers bestaat dus het risico dat er een schijnsamenwerking tot stand komt.

Verwacht mag worden dat met een groeiende implementatie van ervaringsdeskundigen in het werkveld, er een toenemende druk zal ontstaan om ervaringswerk vast te leggen en te omschrijven in specifieke taken of rollen, of met andere woorden de rol van de ervaringswerker te formaliseren en te professionaliseren. Het is een ontwikkeling die kritisch dient opgevolgd te worden om meerdere redenen. Het vastleggen van wat taken en rollen zijn van ervaringswerkers kan bv. eenzijdig door beleidsmakers (of andere actoren) bepaald worden, met het risico dat ervaringswerkers een referentiekader opgelegd krijgen dat niet aansluit bij de ervaringen die ze inzetbaar willen maken en in een taal bv. die voor hen vreemd en onnatuurlijk aanvoelt. Een ander risico is dat zorgverleners, maar ook ervaringswerkers zelf bepaalde ervaringskennis een hogere waarde zullen toekennen dan andere ervaringskennis. Er kan dus een categorisering optreden van enerzijds meerderwaardige vormen van ervaringswerk en anderzijds minderwaardige vormen van patiëntdeskundigheid. De authentieke ervaringen van patiënten worden niet langer gehonoreerd als betekenisvolle ervaringen op zich in relatie tot de context waarbinnen ze ingezet worden, maar wel of deze ervaringen passen en aansluiten bij het denk- en waardenkader van zorgverleners/organisaties. Of ervaringen van patiënten worden maar echt gehonoreerd wanneer ze het geschopt hebben tot gecertificeerde ervaringswerkers.

Uit de beschreven studies kunnen tenslotte enkele aanbevelingen weerhouden worden die gidsend zijn bij de implementatie en integratie van ervaringswerk binnen organisaties. Zo dienen organisaties kansen en mogelijkheden aan te bieden om diverse rollen als ervaringswerker uit te bouwen. Verder dienen ze aandacht te hebben voor de uitdagingen die ervaringswerkers ervaren in het uitbouwen van hun rol als ervaringswerker. Dit kunnen ze doen door te zorgen voor een gelijkwaardige context die zorgverleners en ervaringswerkers met mekaar verbindt en waarin een duurzame dialoog tot stand gebracht wordt. Een context waar gezamenlijk een duidelijk en transparant kader bepaald wordt waarbinnen ervaringswerk uitgebouwd kan worden. Een context die ervaringswerkers ondersteunt, hun vertrouwen en ruimte geeft. Een context ook die rekening houdt met de soms tegengestelde dynamieken zoals deze in de beschreven studies blootgelegd werden. Dit impliceert bv. dat ervaringswerkers ondersteund worden om hun eigen zelfbehoud niet uit het oog te verliezen én tegelijkertijd de nodige steun krijgen om hun grenzen te verleggen en/of om zich te ontwikkelen. Of voor wat anderen nodig hebben en belangrijk vinden. Dat er gerichtheid is op het contact houden en het afgestemd blijven met zichzelf als ervaringswerker, én gerichtheid op het contact en het uitbouwen van een afgestemde relatie met de ander.

4. Betekenis van de inzichten uit dit proefschrift voor het onderwijs

De onderzoeksresultaten hebben implicaties voor de opleiding voor ervaringswerkers en voor de inzet van ervaringsdeskundigheid in onderwijs/educatie voor zorgverleners en patiënten. We gaan hierna dieper in op deze implicaties en bespreken dit per doelgroep.

4.1. Implicaties van de onderzoeksresultaten voor de opleiding van ervaringswerkers

Een eerste, wat provocatieve, stelling die we willen naar voor brengen, is of opleiding -specifiek naar mensen die een rol opnemen als ervaringswerker- niet eerder tegenaangewezen kan zijn, zeker wanneer bepaalde principes niet in acht genomen worden bij de opzet van deze opleiding.

In dit proefschrift werden factoren in kaart gebracht die het risico inhouden dat ervaringswerkers hun ervaringsdeskundige kijk inruilen voor een professionele kijk. Zo gaven we in hoofdstuk 7 aan hoe ervaringswerkers (maar ook verpleegkundigen) zich afhankelijk opstellen ten aanzien van het team om zich professioneel bekwaam en tevreden te voelen. We wezen erop hoe dit gevolgen heeft voor de rolinvulling van ervaringswerkers en het kunnen wegen op de interdisciplinaire besluitvorming. De solopositie die vele ervaringswerkers bekleden in het team, bemoeilijkt dit nog. Bellingham et al. (2018) geven aan dat het formaliseren van de rol van ervaringswerker (bv. via opleiding en training, en het verwerven van een diploma), het risico inhoudt dat de ervaringswerker dreigt weg te gaan van zijn kerncompetenties, nl. het uitbouwen van een natuurlijke, spontane en wederkerige relatie met de mensen aan wie hij ondersteuning kan geven. Ervaringswerkers kunnen zich als gevolg van vorming een discours eigen maken die niet het hunne is, zeker wanneer deze opleiding het resultaat is van wat zorgverleners vinden dat ze moeten kennen en kunnen.

Toch betekent deze stellingname niet dat opleiding niet waardevol kan zijn. Cronise et al. (2016) stelden vast dat vorming die aansluit bij wat ervaringswerkers opnemen van rollen en taken, een belangrijke voorspeller was van werktevredenheid. Ook de besproken studies in dit proefschrift breken een lans om aandacht te geven aan het versterken van de intrinsieke mogelijkheden van mensen die ervaringswerker willen worden, en bij uitbreiding van iedereen die in de zorg werkt en van de patiënten die in behandeling zijn. Opleiden dient dus een ontwikkelingsgerichte focus te hebben, zodat de kennis over zichzelf in relatie tot de andere bevordert wordt, en dat het proces van persoonlijke groei gestimuleerd wordt.

In het kader van de opleiding en training van mensen die ervaringswerk ambiëren, betekent dit dat het persoonlijk ontwikkelingsproces van de ervaringswerkers zelf versterkt wordt in de opleiding. *Empowerment*, het aan de slag gaan met eigen krachten en talenten, het versterken van de zelfreflectie, het oefenen en versterken van het ‘therapeutisch leren gebruiken van de eigen persoon’ in situaties die ervaringswerkers meemaken, zijn hier voorbeelden van (Zie ook MacLellan et al. 2015). De focus dient minder te liggen op kennisoverdracht, maar meer op het expliciteren van de persoonlijke ervaringen die men met zich meedraagt en aan het doorleven is, en dit in relatie met anderen. Met de bedoeling dat men op een meer meta-niveau inzicht krijgt in de vele variaties van betekenissen die mensen geven aan deze ervaringen, bv. wat het met een persoon doet om een (psychiatrische) diagnose te krijgen, wat het betekent als de vervolgbehandeling niet goed geregeld is, wat een empathische benadering teweeg brengt als je in een miserabele toestand in een psychiatrische kliniek opgenomen wordt, wat het met je doet als het (patiënten)recht op privacy niet gerespecteerd wordt en hoe je erin slaagde om dit recht alsnog af te dwingen, hoe je zelfstigma overwonnen hebt. Binnen opleidingen voor ervaringswerk dient er dus voldoende tijd en aandacht te gaan naar het afdoende articuleren van de *lived experiences* die de ervaringswerker met zich meedraagt, maar ook naar wat gedaan moet worden opdat deze doorleefde ervaringen betekenisvol ingezet kunnen worden in een bepaalde praktijkcontext. Het zijn inzichten die aansluiten bij het werk van Mc Carthy et al. (2018). In hun studie benadrukken ze hoe ook voor ervaringswerkers geldt dat gestructureerde interventies (zoals bv. WRAP (*Wellness Recovery Action Plan*)-vormingen aanbieden aan patiënten) veel beter geaccepteerd worden wanneer voorafgaandelijk een samenwerkingsrelatie tussen ervaringswerker en patiënt tot stand was gekomen. Volgens deze auteurs is het wenselijk dat er binnen het opleidingsaanbod voor ervaringswerkers een goed evenwicht nagestreefd wordt tussen enerzijds het aanbieden van (op ervaringsdeskundigheid geïnspireerde) methodieken en anderzijds op het uitbouwen van natuurlijke, authentieke relaties met patiënten als ervaringswerker. Voor dezelfde reden dienen opleidingen voor ervaringswerkers er bijzonder waakzaam voor te zijn dat niet de gangbare taal, gewoontes, regelgeving, de organisatorische aspecten van de gezondheidszorg en hoe vorm gegeven wordt aan beleid en management, centraal staan binnen deze opleiding.

4.2. Implicaties van de onderzoeksresultaten voor de opleiding van zorgverleners

Deze ontwikkelingsgerichte focus is niet alleen relevant voor ervaringswerkers, maar dient ook in belangrijke mate geïntegreerd te worden in de opleiding van zorgverleners. Door hier voldoende aandacht aan te besteden in hun basisopleiding, kunnen er zorgverleners gevormd worden die oog hebben voor het proces dat de ander doormaakt als gevolg van confrontatie met ziekte of lijden. Zorgverleners die zich competent voelen wanneer ze gangmaker en supporter kunnen zijn van dit proces, eerder dan dat ze zelf met oplossingen of voorstellen voor de dag komen. Zorgverleners die op een empowerende manier in relatie kunnen staan met anderen, die het actief samenwerken met patiënten en naastbetrokkenen als inherent zien aan iedere actie die ze ondernemen, die kansen creëren opdat patiënten, maar ook ervaringswerkers, betekenisvol kunnen participeren en die het als hun rol en opdracht zien om hierin te faciliteren. Zorgverleners die oog hebben voor structuren die patiënten ondersteunen in wat zij belangrijk vinden, en waarin reflectie en dialoog centraal staan. Zorgverleners die het vanzelfsprekend vinden om in co-creatie met patiënten zaken te ontwikkelen, maar ook hiervan durven af te wijken, en die dus niet co-creatie omwille van de co-creatie toepassen.

Ervaringswerkers dragen vanuit hun doorleefde ervaringen als patiënt een uniek perspectief met zich mee. Dat stelt hen in staat om in relatie tot patiënten aandacht te geven aan die zaken waar zorgverleners minder op gericht zijn. De legitimiteit van de authentieke ervaringen die patiënten en bij uitbreiding ervaringswerkers met zich meedragen, dient daarom meer gehonoreerd te worden binnen vormingen van (toekomstige) zorgverleners. Dit kan door hun stem nog nadrukkelijker naar voor te brengen binnen de zorgopleidingen. Hiervoor is structurele inbedding nodig van het patiënten-perspectief binnen de opleiding en vorming van mensen die kiezen voor een zorgberoep. Dit kan bv. door binnen de opleiding meer aandacht te geven aan de multideskundigheid (Boevink) die mensen met zich meedragen, in de zin dat de meesten ook ervaringen hebben met wat het betekent om patiënt te zijn, om naastbetrokkene te zijn, om zorgverlener te zijn, enz. Opleidingen kunnen deze multideskundigheid van de studenten valoriseren door het patiëntenperspectief dat zij zelf met zich meedragen binnen de opleiding het volle bestaansrecht te geven. Binnen een zorgopleiding is het bijzonder relevant dat studenten leren (van bv. ervaringswerkers) hoe ze dit perspectief op een afgestemde manier kunnen inzetten in de zorgverlening. Dat studenten leren wanneer het onthullen van deze ervaringen, patiënten sterker kan maken en wanneer het de zorg en de zorgrelatie kan bemoeilijken of onder druk zetten. Hiervoor aandacht hebben binnen de opleiding laat toe dat zorgverleners deze multideskundigheid meer zullen valoriseren in hun klinische praktijk. Dit kan ertoe leiden dat zorgverleners de *peer-to-peer* contacten binnen hun werkcontext meer honoreren en bevorderen. Het natuurlijk en spontaan delen van ervaringen van patiënten onderling, de instrumentele of andere steun die patiënten aan andere patiënten geven, wordt zo meer erkend en ondersteund. Verpleegkundigen kunnen in dit proces een belangrijke rol spelen, gezien ze van alle zorgverleners het dichtst bij de patiënt staan en het meeste contact hebben met patiënten (of althans de mogelijkheid daartoe hebben). Uit onderzoek in een psychiatrische residentiële setting blijkt evenwel dat er niet zoveel begrip is voor peer-to-peer contacten en dat zorgverleners meer de risico's ervan benadrukken dan dat ze oog hebben voor de potentiële en intrinsieke waarde (Galloway & Pistrang 2019). Opleidingen voor zorgverleners dienen dus afdoende in te zetten op het versterken van relationele competenties van de zorgverleners die zich uitermate bewust zijn van de rol en de ruimte die ze innemen binnen de relatie met de ander. Studenten dienen te leren dat het heel professioneel kan zijn wanneer de zorgverlener zich in de rol van niet-wetende plaatst, en dat deze positie heel wat kansen genereert voor de ander, juist omdat deze dan ruimte krijgt en uitgenodigd wordt om met zijn expertise voor de dag te komen. Dat het heel professioneel is wanneer ze hun kennis en macht delen of zelfs overdragen aan patiënten, zodat deze beschikken over de nodige kennis en competenties om de voor hen juiste beslissingen te nemen aangaande hun leven, welzijn en welbevinden. Ook als het zorg dragen voor zichzelf of anderen nog belastend of zelfs een ontwrichtend karakter heeft voor de (student)verpleegkundige en dus nog niet inzetbaar gemaakt kan worden, is het waardevol om er binnen de opleiding de nodige aandacht aan te geven. Niet alleen vanuit puur humane redenen, maar ook omdat de verpleegkundige ermee gebaat is wanneer het curriculum gericht is op welbevinden, persoonlijke ontwikkeling en herstel (Doyle et al. 2018). Op die manier zijn verpleegkundigen (en GGZ-verpleegkundigen in het bijzonder) voldoende voorzien van een breed palet aan competenties waarbij er niet alleen aandacht is voor de problemen waar mensen mee zitten, maar waar ook actief ingespeeld kan worden op de mogelijkheden van de mensen (en context) aan wie zorg/begeleiding gegeven wordt. Om deze paradigmashift binnen het verpleegkundig onderwijs kracht bij te zetten, is input van ervaringswerkers bijzonder interessant, vooral omdat voor veel ervaringswerkers dagelijkse volgehouden aandacht voor zelfzorg en welbevinden een (levens)noodzakelijk gegeven is. Ervaringswerkers die dergelijke rol opnemen kunnen beschouwd worden als *wellness-coaches* Bochicchio et al. 2018). Door studenten binnen hun opleiding reeds kennis te laten maken met ervaringswerkers, verkleint de stap om later in hun beroepsloopbaan als verpleegkundige een duurzaam partnerschap uit te bouwen en bv. samen fysieke problemen en een gezonde leefstijl aan te pakken bij mensen met ernstige psychiatrische problemen (Swarbrick et al. 2011; Bochicchio et al. 2019).

5. Methodologische overwegingen

De methodologische beperkingen voor iedere afzonderlijke studie werden reeds beschreven in het corpusgedeelte van dit proefschrift. Hieronder geven we enkele algemene overwegingen met relevantie voor dit proefschrift.

In de meeste studies stond het perspectief van de patiënten/ervaringswerkers centraal. Deze werkwijze werd toegepast om een *emic* perspectief te kunnen construeren met betrekking tot de centrale onderzoeksvraag. Zo kon een coherent inzicht opgebouwd worden van hoe patiënten in diverse fases van hun transitie tot ervaringswerker hun specifieke rol en bijdrage beleven en ervaren. In hoofdstuk 7 werd vertrokken vanuit de vraag hoe GGZ verpleegkundigen en GGZ ervaringswerkers hun rolbekwaamheid percipieerden. Mogelijks had de vraag aan de participanten van hoe ze van betekenis waren geweest als verpleegkundige of als ervaringswerker een ander (lees genuanceerder) beeld opgeleverd. Echter, het beeld zoals beschreven in de hoofdstuk sluit heel erg aan bij observaties in de praktijk (Gunasekara et al. 2014).

Door het perspectief van de patiënten/ervaringswerkers centraal te plaatsen in dit proefschrift, zijn mogelijks andere perspectieven onderbelicht gebleven. Denk bijvoorbeeld aan de invloed van maatschappij- en cultuurspecifieke waarden op de beleving van het ervaringswerk. In hoofdstuk 4 werd belicht hoe ervaringswerk als een opstap naar betekenisvol werk gezien werd en dus als een uitweg om zich te ontdoen van beperkende rolpatronen die meegedragen worden als psychiatrische patiënt. In hoofdstuk 6 werd belicht hoe ervaringswerk soms ook nog beschouwd wordt als een minderwaardige vorm van werk. In het licht van een maatschappij waarin ‘betekenisvol werk hebben’ een belangrijke waarde is, stelt zich de vraag of gangbare maatschappelijke normen en waarden niet mee van invloed waren op hoe ervaringswerk wordt ingevuld/ gedefinieerd en in de geestelijke gezondheidszorg wordt uitgebouwd.

De inzichten uit deze studies zouden nog verrijkt kunnen worden door ook de perspectieven mee te nemen van de mensen voor wie ze zich inzetten als patiënt/ ervaringswerker en van de mensen die de ervaringswerkers zelf ondersteunen.

Alle studies werden opgezet in een cultuur waar ervaringswerkers nog niet mainstream geaccepteerd zijn. De inzichten die uit de studies naar voor komen zijn dus vooral relevant voor organisaties die aan het begin staan of nog volop bezig zijn met de integratie van ervaringswerkers in hun organisaties.

Vijf van de zes studies hadden als exclusief toepassingsgebied de geestelijke gezondheidszorg. Eén studie werd uitgevoerd binnen de context van de algemene gezondheidszorg. Het kan interessant zijn om de rol en betekenis van ervaringswerk binnen algemene ziekenhuizen specifieker te onderzoeken. Zo kan in vervolgonderzoek nagegaan worden of patiëntdeskundigen binnen de algemene gezondheidszorg dezelfde drijfveren hebben om aan de slag te gaan als ervaringswerkers binnen de geestelijke gezondheidszorg.

Het actief betrekken van patiënten/ervaringswerkers in het opzet, het design, de uitvoering en de evaluatie van onderzoeksprojecten wordt steeds meer gepromoot. Door patiënten van meet-af aan te betrekken, is de kans groter dat het onderzoek aansluit op hun behoeften, wat dus een patiëntgerichte zorg en beleid ten goede komt (Gill et al. 2016). Er zijn echter ook kanttekeningen aan het betrekken van patiënten in het onderzoek. Zo is er het risico dat onderzoeksprocedures minder strikt verlopen indien patiënten betrokken worden (Stewart et al. 2011). Of kan zich, vanuit het credo om patiënten steeds te betrekken in onderzoek, een formalisering installeren, waardoor de specifieke meerwaarde voor de patiënt zelf, de eventuele kost of belasting minder in rekening wordt gebracht (Garlfield et al. 2015). In dit proefschrift waren in alle studies de ervaringen van patiënten bij uitstek voorwerp van studie. Zo vormden in hoofdstuk 3 bv. de ervaringen van patiënten met studenten verpleegkunde niet alleen het vertrekpunt van waaruit de vragenlijst 'Evaluatie van Studenten Verpleegkunde door Patiënten' vorm kreeg, de patiënten werden ook actief betrokken in de tussentijdse toetsing (cognitieve interviews) en de finale evaluatie van de vragenlijst ('test-retest' betrouwbaarheid). Het niet vertrouwd zijn met het betrekken van patiënten in onderzoek en het niet kunnen beschikken over patiënt-ervaringswerkers die over specifieke onderzoekscompetenties beschikken, speelde mee waarom patiënten in sommige studies niet of slechts beperkt betrokken werden in de conceptualisatie en uitvoering van de diverse studies.

6. Aanbevelingen voor verder onderzoek

Verwacht mag worden dat vanuit de overheid en vanuit de sector de verwachting om ervaringswerkers te werk te stellen, zal toenemen. Zo is er een aanbeveling binnen het globaal plan ervaringsdeskundigheid om ervaringswerkers deel te laten uitmaken van het normpersoneel binnen de psychiatrische ziekenhuizen (Globaal Plan Ervaringsdeskundigheid, Steunpunt Geestelijke Gezondheidszorg, 2018). De vraag is of deze toenemende gerichtheid op het inzetten van ervaringswerkers hand in hand zal gaan met aandacht voor het voorbereiden van de diverse contexten waarin ervaringswerkers hun rollen opnemen. Deze gerichtheid op de context waarbinnen het ervaringswerk vorm krijgt, is noodzakelijk opdat niet voorbij gegaan wordt aan de specifieke noden en behoeften van de ervaringswerkers. In dit proefschrift gaven we aan hoe het ervaren van een participatieve en herstelgerichte context aansluit bij wat ervaringswerkers nodig hebben om hun rollen optimaal te kunnen vervullen. Vertrekken vanuit een brede definitie van 'herstelgerichtheid' én 'context' is hierbij aangewezen. Het gaat daarbij om herstelgerichte contexten die niet alleen aandacht geven aan klinische of persoonlijke aspecten van herstel, maar ook functionele en sociale aspecten afdoende meenemen (Lloyd et al., 2008). In toekomstig onderzoek is het daarom interessant om de invloed na te gaan van de invulling die institutionele structuren of organisaties geven aan het herstelconcept en op de aard van activiteiten die ervaringswerkers binnen deze organisaties kunnen ontplooien. Met andere woorden, gaat een brede hantering en integratie van het herstelconcept binnen de organisatie ook hand in hand met een bredere en dynamischere invulling van ervaringswerk?

Op basis van de beschreven studies weten we hoe niet-herstel-ondersteunende zorgcontexten de ervaringswerkers belasten en belemmeren in het opnemen en uitbouwen van hun rollen. Dit komt omdat hun persoonlijke aspiraties en drijfveren om in deze contexten een rol op te nemen als ervaringswerker (bv. bron van steun en hoop zijn voor patiënten) in conflict komen met de organisatiecultuur die ze ervaren en de druk om er loyaal aan te zijn. Het gevolg hiervan is dat de ervaringswerkers na verloop van tijd inboeten op vlak van hun specifieke meerwaarde. Het is dus wenselijk dat nagegaan wordt hoe beleving van werkcontext invloed heeft op de zelfontplooiingskansen van ervaringswerkers. In het verlengde hiervan zou nagegaan kunnen worden welke factoren verklarend zijn voor uitval bij ervaringswerkers. Op basis van de huidige stand van onderzoek is hier nog niet zoveel over geweten.

Naarmate ervaringswerk meer en meer geaccepteerd wordt en meer en meer ervaringswerkers actieve rollen opnemen binnen de GGZ, is het aangewezen om de zorg die patiënten krijgen van ervaringswerkers als focus van onderzoek te nemen. Interessante vragen hierbij zijn: hoe beleven mensen deze steun van ervaringswerkers? En waarin verschilt deze steun van de zorg die ze krijgen van professionele zorgverleners? Hoe trouw blijven ervaringswerkers bv. aan de uitgangspunten en basisprincipes die ervaringswerk kenmerken? Antwoorden op deze vragen kunnen bijdragen om de specifieke rol die ervaringswerkers opnemen binnen teams nog beter te omschrijven.

Patiëntdeskundigheid werd in het kader van dit proefschrift voornamelijk onderzocht binnen de context van de reguliere formele geestelijke gezondheidszorg. Het is relevant om patiëntdeskundigheid ook te onderzoeken in minder formele (geprofessionaliseerde) contexten, zoals bv. in contexten die (nog) buiten het directe gezichtsveld van professionals vallen. Een interessante onderzoeksfocus is bovendien hoe zorgverleners die ervaringen met zich meedragen als patiënt en/of als naastbetrokkene en hoe ze deze hanteren in hun klinische praktijk. Welke mechanismen bepalen bv. dat zorgverleners hun ervaringen wél inzetten of dit juist niet doen? En wat betekent dit voor de patiënten als zorgverleners deze ervaringen met hen delen? Er zijn hier al studies rond gebeurd, maar de invloed van contextuele factoren op de *disclosure* van de eigen ervaringen dient nog beter in kaart gebracht te worden (Oates et al. 2017). Waar in sterk geprofessionaliseerde contexten bv. self-*disclosure* van de zorgverlener naar de patiënt toe als *not done* werd beschouwd, riskeren we nu dat onder invloed van maatschappelijke evoluties zorgverleners hun eigen ervaringen vooropstellen binnen hun zorgrelatie met de patiënt, zonder dat nagegaan wordt of dit wel een meerwaarde biedt of aangewezen is.

Ook het bestuderen van vormen van patiëntdeskundigheid in een vroegere fase van het transitieproces van patiënt tot ervaringswerker, kan de bekomen inzichten nog verdiepen. Zo kan het interessant zijn om meer inzicht te krijgen in hoe medepatiënten interageren op wat voor hen 'moeilijk gedrag is van medepatiënten'. Welke rol nemen ze dan op? In welke mate betrekken ze de zorgverleners hierin? In welke mate sluit wat ze doen aan bij hoe zorgverleners met zo'n situaties omgaan? Waarin verschillen hun tussenkomsten? En hoe duurzaam is de ondersteuning die medepatiënten geven? Antwoorden op deze vragen kunnen meer inzicht geven in de betekenis van informele ondersteuningsvormen en hun belang in de preventie van crisisgedrag.

Dit proefschrift leverde ook interessante inzichten op die nuttig zijn voor de invulling en uitbouw van het onderwijs van zorgverleners. Het is wenselijk deze inzichten verder te onderbouwen. Opzet van vergelijkend effectonderzoek is daarom aan te bevelen binnen deze opleidingen voor zorgverleners zodat bv. bepaald kan worden in welke mate inbreng van ervaringsdeskundigheid van invloed is op meer aandacht voor zelfzorggedrag bij patiënten en bij de zorgverleners zelf.

In vele hoofdstukken van het proefschrift stonden we stil bij het integratieproces van ervaringswerkers in de klinische zorgpraktijk (hoofdstuk 4, 5, 6 en 7). De resultaten geven aan dat ervaringswerkers niet altijd te maken hebben met een werkcontext die hun terechte noden en behoeften (h)erkent, laat staan er ook rekening mee houdt in hun verdere integratieproces. Op basis van de inzichten uit de beschreven studies werden heel wat concepten in kaart gebracht die de basis zouden kunnen vormen van een instrument dat ondersteunend kan zijn bij de implementatie van ervaringswerkers in de klinische praktijk. Geciteerde punten zoals 'verlangen naar normalisatie', 'drang tot zelfbehoud', 'uitbouw van een positieve identiteit', 'zich staande houden als ervaringswerker', 'een relatie kunnen opbouwen die voor beiden goed aanvoelt', 'ervaringswerk gestoeld op de eigen lived experiences' kunnen concepten zijn waarrond dit instrument opgebouwd wordt. We geven een eerste mogelijke insteek voor dergelijk instrument. Op basis van de onderzoeksresultaten lijkt het afvinken van een rigide checklist met to do's, niet aan de orde. Het gaat eerder om een instrument dat het brede kader van ervaringswerk onder de aandacht brengt, vertrekkend vanuit de relatie waarbinnen de ervaringen van de ervaringswerker ingezet worden en de context waarbinnen dit gebeurt. Het instrument heeft in de eerste plaats een signalerende functie voor de mate waarin het ervaringswerk afgestemd is op de noden en behoeften van de ervaringswerker. Het instrument draagt dus bij tot het in kaart brengen van knelpunten en succesfactoren in de integratie van de ervaringswerker. Verder beoogt het instrument te verhelderen en bespreekbaar te maken wat de ervaringswerker nodig heeft om zich te ontwikkelen als ervaringswerker binnen de eigenheid van de specifieke werkcontext. Het instrument bevordert de dialoog tussen de ervaringswerker en de organisatie waarbinnen hij functioneert. Op die manier kan nagegaan worden wat nodig is om de ervaringswerker en het ervaringswerk op zich optimaal in te passen binnen de gegeven context.

Om recht te doen aan het perspectief van de ervaringswerker zelf, opteerden we ervoor om het instrument uit te werken als een zelfrapportage-instrument. De items zijn open geformuleerd en laten toe om ervaringen, ideeën, percepties, situaties, en dergelijke te beschrijven om op die manier tot een genuanceerd beeld te komen van mogelijkheden en beperkingen. In lijn met de huidige tijdsgeest van *quick scans of quality* zou geopteerd kunnen worden om te werken met kleurcodes. Er kan gekozen worden om de items te markeren met groen, oranje of rood naargelang men vindt dat men akkoord gaat met de stelling of men helemaal niet akkoord is met de stelling. Hopelijk leiden deze codes niet tot een kort assessment, maar blijven ze appelleren aan een dialoog waarbij niet enkel aandacht is voor het (samen) zoeken naar verbeteracties voor de oranje en rode items, maar waar er ook op de groene items ingegaan wordt. Op basis van de onderzoeksresultaten kan immers geconcludeerd worden dat de kans groot is dat de items snel groen zullen ingekleurd worden door de ervaringswerker en daardoor geen voorwerp meer zullen zijn van gesprek.

Ervaren van een context…	
	waar kansen en mogelijkheden zich situeren om mijn rol als ervaringswerker volwaardig te kunnen uitbouwen
	waar je terecht kan bij iemand
	waarbinnen wat voor jou telt ter harte genomen wordt
	die je de nodige duidelijkheid geeft (bijv. door kort op de bal te spelen)
	die je ondersteunt in wat voor jou van tel is
	waarin je moeilijkheden/ hindernissen bespreekbaar kan maken
	die je ondersteunt om je valkuilen te ontdekken als ervaringswerker
	die je ondersteunt om sterktes, mogelijkheden en krachten te ontdekken
	die je ondersteunt in je persoonlijke ontwikkeling
	die je de ruimte geeft om wat je in je mogelijkheden hebt te realiseren
	die je stimuleert om te (blijven) doen wat voor jou nodig en van belang is
	die je stimuleert om te doen wat voor de ander van tel en van belang is
	die je als uitdagend beleeft als ervaringswerker
Ervaren voor jezelf …	
	dat je een spontane relatie kan uitbouwen die voor jou goed aanvoelt
	dat je een spontane relatie kan uitbouwen die voorde ander goed aanvoelt
	dat je jezelf staande kan houden als mens (als persoon)
	dat je jezelf staande kan houden binnen de context waarbinnen je je ervaringswerk vorm geeft
	dat je tevreden bent met wie je bent als mens (als persoon)
	dat je in voeling kan blijven met wat voor jou van tel is
	dat je in voeling kan blijven met wat voor de ander van tel is
	dat ervaringswerk je ondersteunt in de weg die jij wilt gaan
	van een gelijkwaardigheid in het contact met patiënten
	van een gelijkwaardigheid in het contact met andere zorgverleners
	dat je ervaringswerk kan uitbouwen volgens jouw mogelijkheden en kwaliteiten

Instrument: In kaart brengen van noden en behoeften vanuit het perspectief van ervaringswerker

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Summary

Health care is changing rapidly. In mental healthcare in particular, we see a transformation from a paternalistic interpretation and management of care with a strong biomedical approach to a more inclusive and strength based care focusing on empowerment. New care visions (e.g. the recovery approach, the chronic care model, patient-centered care), but also professional and social developments have contributed to this transformation. This change led to a shift in the way the role of a 'patient' is interpreted. Until recently 'being a patient' was a role that expected the person to adhere to guidelines (e.g. treatment). Nowadays, however, patients are expected to take a more active role in their healthcare. For example, patients are now expected to be responsible for early recognition, monitoring and follow-up of their illnesses and problems. Organizations and caregivers regard patients more and more as potential partners who they can learn and benefit from. Patients' direct experiences are considered relevant for organizations to improve the overall quality of care and support to patients.

In the introduction of this dissertation (chapter 1), we indicated how patients always carry with them a certain form of expertise, regardless of whether their patient role is still dominant or whether they have already taken up peer work roles. For example, we stipulated how patient expertise relates to implicit knowledge, knowledge that is not (yet) shared with professionals, knowledge that is connected with the patient's life, practical knowledge, first-hand knowledge, knowledge resulting from experience of illness, problems, care, and also from experience with care provision and care systems. In developing the design of this dissertation, it was therefore interesting to investigate patient expertise in line with the transition process from patient to (mental health) peer worker.

In chapter 2, we explored what patients can contribute to the assessment process of final-year student nurses during their internships in inpatient mental health care facilities. To support this investigation, a qualitative study was set up inspired by grounded theory. At that time there was rather limited knowledge about the contribution patient involvement can have in the nursing curriculum. More specifically, there were no examples in the literature of how patients could be involved in a formal and systematic way in the learning process of student nurses during their internships. This was quite surprising as internships of nursing students take place around the patient par excellence. The study confirmed how feedback from patients generated value for all who were involved. Patients who were involved in the feedback process felt listened to, heard and recognized also with respect to the vulnerability they carry with them. The nurses involved in the feedback process were inspired to see what patients transferred to students, which gave the nurses a new or broader perspective of certain patients. For the students, patient feedback related to who they are as a person. Students not only learned more about themselves from the patient feedback, but also from the way the nurse dealt with the patient feedback. Hence, a double learning effect was generated.

In chapter 3 we conducted a psychometric validation study of a questionnaire that was developed with the aim of formally and actively involving hospital patients in the internship evaluation process of student nurses The questionnaire was developed from input of a literature study, supplemented by interviews and brainstorming sessions with patients hospitalized in general hospital settings. The questionnaire was tested for comprehensibility and clarity through cognitive interviews and finally the construct validity and test-retest reliability of the instrument was measured. A 19 item questionnaire was designed, allowing patients not only to individually rate the student nurses' behaviour but also to measure the degree of importance they attach to each item of the questionnaire from their personal viewpoint. The questionnaire includes 4 factors which cover areas that patients find important and can assist them in the evaluation process of student nurses. The factor 'trust', referring to whether student nurses can gain the trust of the patient by introducing themselves, the factor 'person-oriented' referring to the perceived interest and concern of student nurses in who they are as a person; the factor 'caring' referring to how patients describe student nurses appear to them; the factor 'honesty and integrity' referring to the perceived ethical behaviour of student nurses. The questionnaire scored well globally in terms of internal consistency and 'test-retest' reliability. The developed questionnaire is an important first step to structurally involve patients on a larger scale in the internship process of students. The instrument should be considered as a promising tool which facilitates and enhances a tripartite dialogue between student, mentor and patient. Since the instrument allows patients to express to students what really matters to them regarding what they perceive is important in their nursing care, it can contribute to a more person-centered care within the context of a general hospital.

In summary, the studies discussed in chapters 2 and 3 dealt with the (complementary) role and significance of what patients can mean in the development process of nurses in training. Indirectly, both studies dealt with prerequisites that need to be fulfilled to bring the patient perspective to the fore. We emphasized in both studies the important role of the nurse as mentor, for example to enhance a trusting atmosphere. Also the importance of a clear, structured but flexible framework to elicit authentic feedback from the patients was stressed.

In chapters 4, 5, 6 and 7, the 'emic' perspectives of peer workers were investigated. We explored what the driving forces were for individuals with lived experience of mental health problems to fulfill a position as a peer worker in mental health-care (chapter 4), what peer workers’ perceive and experience as barriers in the implementation of peer worker roles (chapter 5), how peer workers themselves experience their transition from patient to peer worker (chapter 6) and what they perceive as their role-related competences within the practices where they take up peer worker roles (chapter 7). In all these studies, we paid attention to potentially influencing contextual factors facilitating or hindering the process of becoming a peer worker. We also concentrated on the role of the nurses in order to identify the specificity and potential complementarity of both distinctive roles.

Chapter 4 explored the driving forces for peer workers to take up a position as a peer worker. The results demonstrate that the peer workers strive toward constructing a positive identity and want to move away from a devalued identity, characterized by being in the margins of society, experiencing stigma, concealing mental health problems, having low self-worth and being overwhelmed by problems. In their endeavor to build up a meaningful and positive life, two main processes were identified. On the one hand, there is a desire for normalization and on the other hand, there is an urge for self-preservation. Peer workers are continuously searching for an acceptable balance between both forces. The desire for normalization can be realized by working towards meaningful employment, getting rid of restrictive role patterns and breaking down stigma and taboo. The urge for self-preservation can be safeguarded through experiencing supportive working conditions and developing self-care skills or strategies. To handle the above mentioned main driving forces, peer workers choose a cautious engagement as a peer worker. By giving attention to their driving forces, peer workers can take up peer work positions in a meaningful way which allows them to bring to the fore their unique perspective as a peer worker. Nurses and other caregivers can take into account these underlying driving forces by actively involving peer workers in the development of a flexible and recovery-oriented working environment.

In chapter 5, we extensively discussed the barriers experienced by peer workers in their integration as peer workers in mental health care. As peer work is a new and emerging role in healthcare, the ‘implementation of change model’ (Grol & Wensing 2004) was used to write out these experienced barriers by peer workers at multiple levels. For example, barriers from the included studies were identified and discussed at the level of the implementation itself (peer workers who take up roles as peer workers), the caregivers and patients involved and finally the broader social, organizational, economic and political context within which the change was implemented. The literature study unraveled how barriers cannot be identified at one single level and how there is an interplay of experienced personal, interpersonal and contextual barriers hindering the integration of peer workers within mental health services. We also addressed how these barriers can be tackled and we pointed to the pivotal role nurses and organizations can play in the integration of peer workers within mental healthcare facilities. However vigilance is warranted in order to ensure that goodhearted positive interventions to improve the integration of peer workers do not have contrary effects. More specifically we discussed the risk of diluting the peer worker role in striving to formalize peer worker roles. We also discussed the importance of working towards a mainstream participatory culture within organizations.

In chapter 6, we discussed how peer workers themselves experience their transition from patient to peer worker. For this purpose, individual qualitative interviews were conducted with peer workers who were active as peer workers throughout Flanders in various roles and organizations. A central insight emerging from this study was that peer workers see their transition as a continuation of their recovery process. Becoming a peer worker was perceived as a chance to transcend their own mental health and to further safeguard their personal recovery process. The study also uncovered core processes that peer workers need to develop and sustain in their transition process. For instance, we pointed to the role of confidential counsellors who play a key role for peer workers in entering the field of peer work as well as in the further development of peer workers by increasing or decreasing the scope within which the peer work takes shape. The study also revealed the conditions that peer workers perceive are important for developing themselves as peer workers, and how these conditions are linked to every recovery process, such as experiencing humanity, compassion, recognition, support, transparency, openness, clarity and hope. The study also indicated how peer workers want to create sanctuaries for patients, in which space and time can be given to recognize and normalize their experiences as (psychiatric) patients, and how only a peer worker can assume this as his or her exclusive domain.

The barrier study (chapter 5) and the transition study (chapter 6) were a source of inspiration to set up a study with the purpose of gaining insight into how professional active mental health care peer workers perceived their roles and competences (chapter 7). A better understanding of how both vocations perceive their role-related competences can aid the identification of potential barriers and facilitators affecting how nurses and peer workers work together to foster better mental health care. This insight is needed to underpin a successful partnership between both vocations. This study allowed us to map out the complementarity of the two functions with respect to each other. A qualitative study based on the principles of the critical incident methodology was set up (chapter 7). Participants were offered a worksheet and were asked to describe twice a week as accurately as possible a case in which they thought they acted less or more competently. A total of 132 reported cases were analyzed. Robust analysis of the data showed that both nurses and peer workers assign an important role to the team in determining their role competence. The choices and decisions nurses make are driven primarily by group norms and team agreements. In a limited number cases however, nurses faced a dilemma regarding whether they should violate the (team-based) agreed rules or support the justifiable interests of the patient. Peer workers also want to meet team expectations. Although peer workers relate their role-competence to the basic values of peer work (such as mutual support, building a relationship that feels good to both), in some situations they neglect these basic values in order to meet team expectations. The study also teaches something about what both vocational groups can offer to each other. More specifically, they can use their personal aspirations to strengthen the other person's role. For example, peer workers can be a source of inspiration for nurses to pay more attention to the intrinsic value of offering closeness and to be there for the patient. Nurses, who want to be good team players, can support peer workers in their integration within the team and within the organization.

The insights that emerged from this dissertation are in the first place a plea to fully respect the authentic experiences patients carry with them and to give their experiences a right to exist. Even those who are still patients and are dependent on care from others should be seen and addressed as someone from whom a lot can be learned. This is independent of the stage they are at in their development as patients. Patients should not be first a 'trained' or experienced peer worker or a patient expert before their input and contribution is worth listening to and taken into account. The process of mutually listening to each other and adapting to the other is in itself a very meaningful process, which should not be overlooked in any caring relationship.

Peer work generates its value if it is tailored to the individual peer worker and is aligned to the person or service who can benefit from what peer workers contribute. However, careful attention is needed when formalizing peer worker roles. A too strong emphasis on formalization of peer worker roles risks that peer workers can get stuck in their roles as a peer worker, especially when a sustained and mutual dialogue between peer worker and caregivers is lacking.

The overall insights of this dissertation should be read as an encouragement to think in a nuanced way about patient expertise. Patient expertise cannot be viewed as a separate phenomenon and should be regarded within a broader framework or context. This broader framework is the way professional caregivers relate to patients and the systems in which these caregivers operate. Ultimately caregivers (organizations) regulate the degree and the amount of space in which patients/peer workers can deploy their lived experiences. Consequently, what really matters for patients can only truly come to the fore if caregivers (organizations) are aware of this power-imbalance in their relationships with patients/ peer workers. Therefore, caregivers (organizations) have a key role in creating an reflective atmosphere characterized by openness, trust, equality, transparency and clarity, so that people are listened to with respect to who they are as a person and where the experiences of everyone are validated. Such a climate is vital to enable patient expertise to grow and flourish as it helps to support the development process of everyone who is involved. In other words, the process of working together step by step with patients (peer workers) towards this goal is itself already a very fruitful and inspiring process for every person involved. Moreover, it will ensure that caregivers/organizations stay in tune with their core tasks as a caregiver/organization.

Samenvatting

De gezondheidszorg is volop in transitie. We zien een shift van eerder een paternalistische invulling en aansturing van de zorg met een sterk medische benadering naar een meer samenlevingsgerichte zorg met focus op empowerment. Nieuwe zorgvisies (herstelvisie, chronisch zorgmodel, *patient-centered care*), maar ook beroepsinhoudelijke en maatschappelijke ontwikkelingen hebben hiertoe bijgedragen. Ze hebben geleid tot een verschuiving in hoe gekeken wordt naar de rol van 'patiënt'. Waar tot voor kort 'patiënt-zijn' een rol was waar de drager van die rol verwacht werd om zich te onderwerpen aan de begeleiding of behandeling die hem werd aangeboden, zien we nu hoe de rol van patiënt een veel actievere lading krijgt. Zo worden patiënten bv. nauw betrokken in het mee monitoren en opvolgen van hun ziekte/problematiek. Of ze worden gezien als mensen die vanuit hun ervaring met zorg van betekenis kunnen zijn wanneer organisaties bv. kwaliteitsverbeterende initiatieven ondernemen. Of hun opgebouwde ervaringskennis wordt ingezet om bv. lotgenoten/medepatiënten te ondersteunen. In de inleiding van dit proefschrift gaven we aan hoe patiënten steeds een bepaalde vorm van deskundigheid met zich meedragen, onafhankelijk of ze nog volop in de rol van patiënt zitten of ze reeds doorgroeiden in deze rol en een bepaalde vorm van ervaringswerk op zich namen. Zo stonden we in de inleiding van dit proefschrift (hoofdstuk 1) stil bij hoe patiëntdeskundigheid onder andere te maken heeft met impliciete kennis, kennis die (nog) niet gedeeld wordt met professionelen en niet los kan gezien worden van het leven van de patiënt, praktische kennis, kennis uit eerste hand, voortvloeiend uit het ervaren van ziekte, problematiek en zorg, maar ook uit ervaring met zorgverlening en zorgsystemen. In het kader van de vormgeving van dit proefschrift was het dus interessant om patiëntdeskundigheid verder te onderzoeken in lijn met het ontwikkelingsproces (rijpingsproces) dat patiënten doormaken en in relatie tot die groep van zorgverleners waar ze het meest gemeenschappelijke raakvlakken mee delen, nl. verpleegkundigen.

In hoofdstuk 2 gingen we na wat meerwaarde was van patiëntfeedback voor laatstejaarsstudenten die stage lopen binnen de intramurale geestelijke gezondheidszorg. Hiervoor werd een kwalitatieve studie opgezet geïnspireerd vanuit de *grounded theory*. Deze studie was baanbrekend, omdat er op dat moment geen voorbeelden beschikbaar waren in de literatuur van hoe patiënten op een formele en systematische manier betrokken konden worden in het leerproces van studenten verpleegkunde. Er was algemeen ook weinig kennis over wat de waarde was van het betrekken van patiënten op het leerproces van de student. Dit was toch wel een verrassende vaststelling gezien de stage een gebeuren is dat zich bij uitstek om en rond de patiënt afspeelt. De studie bevestigde hoe de feedback van de patiënten voor alle betrokkenen waarde genereerde. Voor de patiënten was het betrokken worden in het feedbackproces een vorm van erkend, gehoord en beluisterd worden, ook in de kwetsbaarheid die ze met zich meedragen. Voor de betrokken verpleegkundigen was het verrijkend om te zien wat patiënten aanbrachten, waardoor ze een frisse en nieuwe kijk kregen op bepaalde patiënten. Voor de studenten zorgde de feedback van de patiënten ervoor dat de persoon van de student meer op de voorgrond kwam. Studenten leerden niet alleen door de feedback van de patiënten zelf, maar ook door de manier waarop de verpleegkundigen omgingen met de feedback die de patiënten gaven aan de studenten. Op die manier werd een dubbel leereffect gecreëerd.

In hoofdstuk 3 bespraken we een psychometrische validatiestudie van een vragenlijst die ontwikkeld werd met als doel ziekenhuispatiënten formeel en actief te betrekken in het stage-evaluatieproces van studenten verpleegkunde. De vragenlijst kreeg vorm op basis van input vanuit een literatuurstudie, aangevuld door interviews en brainstormsessies met patiënten die opgenomen waren op algemene ziekenhuisafdelingen. De vragenlijst werd vervolgens via cognitieve interviews getest op begrijpelijkheid en helderheid en tenslotte werd de constructvaliditeit van het instrument nagegaan, alsook de ‘test-retest’ betrouwbaarheid. Finaal werd vragenlijst met 19 items ontworpen, waar ieder item beantwoord diende te worden aan de hand van een Likertschaal met twee deelvragen: de evaluatie van de student, en het (persoonlijk) belang dat de patiënt aan ieder item hecht. De vragenlijst telde 4 factoren, nl. de mate van vertrouwen die de patiënt stelt in de student, de mate waarin de patiënt vindt dat de student gericht is op zichzelf als persoon, de mate waarin de patiënt vindt dat de student hartelijk en zorgend is, en de mate waarin de patiënt vindt dat de student eerlijk en integer is. De vragenlijst scoorde globaal goed op vlak van interne consistentie en ‘test-retest’ betrouwbaarheid. De ontwikkelde vragenlijst is een belangrijke eerste stap om patiënten op grotere schaal structureel te betrekken in het stageproces van studenten. Het instrument helpt ook om wat patiënten centraal stellen in hun individuele zorg meer naar voor te brengen en bespreekbaar te maken in het driegesprek tussen student, stagementor en patiënt. In die zin kan het instrument dus ook bijdragen tot een meer persoonsgerichte zorg binnen de context van een algemeen ziekenhuis.

Samengevat handelden de studies besproken in hoofdstuk 2 en hoofdstuk 3 dus over de (complementaire) rol en betekenis van patiënten in het ontwikkelingsproces van verpleegkundigen in opleiding. Indirect ging het in beide studies over voorwaarden die vervuld moeten worden, zoals bv. de waarde om vanuit het eigen perspectief als patiënt iets te kunnen zeggen over wat studenten doen of nalaten te doen. En hoe de verpleegkundige die feedback ontlokt over de manier waarop de vragenlijst is opgemaakt, hiertoe kan bijdragen.

In de hoofdstukken 4, 5, 6 en 7 probeerden we een *emic* perspectief op te bouwen van hoe patiënten zich ontwikkelen tot ervaringswerkers, wat hun drijfveren hierbij zijn (hoofdstuk 4), wat ze als barrières ervaren (hoofdstuk 5), hoe ze hun transitie van patiënt tot ervaringswerker beleven (hoofdstuk 6) en wat ze zelf zien als hun rol-gerelateerde competenties binnen de praktijken waar ze als ervaringswerker aan de slag zijn (hoofdstuk 7). We hadden in deze studies telkens ook aandacht voor de invloed van de context op het ontwikkelingsproces van de ervaringswerker.

Hoofdstuk 4 exploreerde de drijfveren van ervaringsdeskundigen om een functie als ervaringswerker op zich te nemen. De resultaten tonen aan dat ervaringsdeskundigen worden aangestuurd door een verlangen naar normalisatie en een drang naar stabilisatie. Ze normaliseren hun lage zelfwaarde door een zinvolle tewerkstelling te realiseren, zich te ontdoen van beperkende rolpatronen en het stigma en taboe te doorbreken. De waakzaamheid voor zelfbehoud staat centraal in hun stabilisatieproces. Hierdoor opteren ervaringswerkers voor een behoedzaam engagement. Vanuit een acceptabel evenwicht tussen hun hoofddrijfveren bouwen ze aan een positieve identiteit. Hun actieve participatie is aanbevolen in de uitbouw van een flexibel en herstel-georiënteerd werkklimaat. Door de aandacht voor hun drijfveren kunnen ervaringswerkers zinvol participeren en kan hun unieke perspectief tot ontplooiing komen. Dat het ontplooien en zich realiseren als ervaringswerker een proces is met veel hindernissen en belemmeringen, kwam uitvoerig aan bod in de literatuurstudie die handelde over de barrières waarop ervaringswerkers botsen in hun integratie als ervaringswerker in de geestelijke gezondheidszorg (hoofdstuk 5). Gezien ervaringswerk een nieuw gegeven is binnen de gezondheidszorg, inspireerden we ons op het werk van Grol & Wensing (2004) om deze barrières op verschillende niveaus uit te schrijven. Zo werden barrières vanuit de geïncludeerde studies geïdentificeerd en bediscussieerd op het niveau van de doorgevoerde verandering zelf (ervaringswerker die rollen opneemt), van de betrokken stafleden en patiënten en tenslotte van de ruimere sociale, organisatorische, economische en politieke context waarbinnen de verandering doorgevoerd werd. Uit deze literatuurstudie werd duidelijk hoe barrières niet af te lijnen zijn tot één niveau, maar ook doorwerken op andere niveaus. Maar ook hoe waakzaamheid geboden is opdat goedbedoelde positieve ingrepen van buitenaf, om de integratie van ervaringswerkers te verbeteren, tegenovergestelde effecten met zich kunnen meebrengen. In de literatuurstudie stonden we onder andere stil bij het gevaar van het formaliseren en professionaliseren van de rol van de ervaringswerker, vooral omdat daardoor de unieke, authentieke bijdrage die ervaringswerkers binnenbrengen op termijn verloren kan gaan. Maar ook de rol die verpleegkundigen kunnen spelen bij de integratie van ervaringswerkers kwam in de discussie aan bod, evenals het belang om toe te werken naar een participatieve cultuur binnen organisaties die ervaringswerk willen uitbouwen.

In hoofdstuk 6 belichtten we hoe ervaringswerkers zelf hun transitie van patiënt tot ervaringswerker beleven en ervaren. Hiervoor werden individuele kwalitatieve interviews afgenomen met ervaringswerkers die in verschillende rollen en organisaties actief zijn over heel Vlaanderen. Een centraal inzicht dat uit deze studie naar voor kwam was dat ervaringswerkers hun transitie zien als een verderzetting van hun herstelproces. De studie benadrukte ook de rol van de context in dit hele transitieproces, hoe steunfiguren bv. belangrijk waren bij het instappen als ervaringswerker, maar hoe deze ook een rol hebben in het doorgroeien als ervaringswerker, en hoe belangrijk een klankbord is om de soms tegengestelde dynamieken (zoals bv. de behoefte om zich staande te houden en de behoefte om zich te ontwikkelen als mens en als persoon) binnen de ervaringswerker zelf te beluisteren en bestaansrecht te geven. Inzichten die aangeven hoe belangrijk het is dat organisaties die samenwerken met ervaringswerkers investeren in een competentiegericht ondersteuningskader dat samen met ervaringswerkers zelf vorm en gestalte gegeven wordt. Interessant aan deze studie was nog dat processen die eerder in dit proefschrift reeds naar voor kwamen, nu beter in hun samenhang konden gezien worden. Zo legde de studie bv. de voorwaarden bloot die ervaringswerkers nodig hebben om zich als ervaringswerker te kunnen ontwikkelen. En hoe deze voorwaarden verbonden zijn met ieder herstelproces, zoals het ervaren van menselijkheid, mededogen, erkenning, ondersteuning, transparantie, openheid, duidelijkheid en hoop. Of hoe ervaringswerkers vrijplaatsen willen creëren voor patiënten, waarin ruimte en tijd genomen kan worden om hun ervaringen als (psychiatrische) patiënt te erkennen en te normaliseren. En hoe niemand anders dan een ervaringswerker dit tot zijn exclusief terrein kan rekenen.

De barrièrestudie (hoofdstuk 5) en de transitiestudie (hoofdstuk 6) waren meteen dé inspiratiebron om een studie op te zetten met als doel inzicht te krijgen in hoe beroepsactieve GGZ-ervaringswerkers hun eigen rolbekwaamheid en roltevredenheid percipiëren (hoofdstuk 7). Vanuit het perspectief van de wenselijke uitbouw van een partnerschap tussen GGZ-verpleegkundigen en GGZ-ervaringswerkers enerzijds, en mogelijke conflicterende percepties op wat beide groepen als hun rol of (professionele) opdracht zien anderzijds, leek het interessant om ook bij beroepsactieve GGZ-verpleegkundigen na te gaan hoe ze hun eigen rolbekwaamheid percipiëren en hoe tevreden ze daarover zijn. Met dit onderzoek kon mogelijk ook de complementariteit van beide functies ten opzichte van elkaar in kaart gebracht worden. Hiertoe werd een kwalitatieve studie opgezet, gebaseerd op principes van de kritische incidentmethodiek. 132 neergeschreven situaties uit de praktijkcontext van de participerende GGZ-verpleegkundigen en GGZ-ervaringswerkers, werden verzameld. In relatie tot deze (beroeps-specifieke) praktijksituaties motiveerden zowel de verpleegkundigen als de ervaringswerkers hun rolbekwaamheid als verpleegkundige of als ervaringswerker. Robuuste analyse van de data toonde aan dat zowel de verpleegkundigen als de ervaringswerkers een belangrijke rol toekennen aan het team in het bepalen van hun rolbekwaamheid. Verpleegkundigen stellen zich soms zo teamgericht op, dat ze de regels van het team laten primeren op de terechte nood van de patiënt. Maar ook ervaringswerkers willen tegemoet komen aan teamverwachtingen. Alhoewel zij hun rolbekwaamheid relateren aan de basiswaarden van ervaringsdeskundigheid (zoals wederzijds steun betekenen, relatie uitbouwen die voor beiden goed aanvoelt), verloochenen ze in sommige situaties deze basiswaarden om tegemoet te komen aan teamverwachtingen. Toch leert deze studie ook iets over wat beide beroepsgroepen mekaar kunnen bieden. Ze kunnen immers hun persoonlijke aspiraties inzetten om de ander te versterken in zijn rol. Zo zouden ervaringswerkers voor verpleegkundigen een bron van inspiratie kunnen zijn om meer aandacht te geven aan de intrinsieke waarde van het bieden van nabijheid en er echt te zijn voor de patiënt. Verpleegkundigen die goeie teamspelers willen zijn, kunnen vanuit deze drijfveer voor ervaringswerkers een bron van steun zijn in hun integratie binnen het team en binnen de organisatie.

De inzichten die uit dit proefschrift naar voor kwamen zijn in de eerste plaats een pleidooi om de authentieke ervaringen die patiënten met zich meedragen ten volle te respecteren en bestaansrecht te geven. Ook wie nog volop patiënt is en afhankelijk is van zorg van anderen, dient gezien en aangesproken te worden als iemand waar veel kan van geleerd worden. En dit onafhankelijk van de fase waar ze zich bevinden in hun ontwikkeling als patiënt. Patiënten moeten het niet eerst geschopt hebben tot een ‘opgeleide’ (en ervaren) ervaringsdeskundige opdat hun inbreng en bijdrage de moeite waard is om te beluisteren en er rekening mee te houden. Het proces van wederzijds beluisteren van mekaar en zich instellen op de ander is trouwens op zichzelf reeds een zeer betekenisvol proces, dat niet overgeslagen mag worden in welke zorgrelatie dan ook.

Ervaringswerk genereert echte waarde wanneer het afgestemd is op de persoon van de ervaringswerker en aansluit bij wat de ander nodig heeft. Dit inzicht vanuit dit proefschrift is dan ook een pleidooi om bijzonder behoedzaam te zijn om ervaringswerk te formaliseren. Vanuit de gedane studies weten we immers dat voor de ervaringswerker zelf het persoonlijk herstelproces dé drijfveer is om ervaringswerk op te nemen en te blijven opnemen. Een te sterke formalisering van het ervaringswerk riskeert dan ook dat ervaringswerkers in bepaalde rollen vast kunnen raken, zeker wanneer een volgehouden en wederzijdse dialoog tussen ervaringswerker en zorgverlener ontbreekt.

Ervaringswerkers kunnen organisaties en zorgverleners helpen om te blijven focussen op hun kernopdrachten. Opdat dit mogelijk wordt, dienen organisaties en zorgverleners wel voor een goed klimaat te zorgen, waardoor ervaringswerk zich kan ontwikkelen en tot bloei kan komen. De sleutel hiertoe ligt in de eerste plaats bij de zorgverlener en de organisatie zelf. De gedane studies in dit proefschrift leverden op dit vlak heel wat interessante informatie en inzichten aan. Opmerkelijk was dat deze informatie nooit zwart of wit was, maar steeds in perspectief diende gezien te worden van andere elementen. Dit inzicht is ondersteunend om ook genuanceerd te denken over patiëntdeskundigheid. Zo kan patiëntdeskundigheid bv. niet als een losstaand fenomeen bekeken worden, het is afhankelijk van de mate waarin anderen (bv. zorgverleners, verpleegkundigen) er oog voor hebben en er gericht op inspelen.

Curriculum Vitae

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EDUCATION

1982 - 1985	Graduate education in hospital nursing - University college HIV, Roeselare	
1986	Graduate education in mental health nursing - University college HIPB, Ghent	
1988	Certificate of educational competence - University college HIPB, Ghent	
1996	Professional qualification in intensive and emergency nursing care - KATHO HIVB - prolongation of qualification June 2007	
2005 - 2007	Master of science in Nursing and Midwifery - Ghent university	
	Thesis:	The involvement of inpatient mental health patients in the practical training and assessment of nursing students: does it benefit practice?
2015 - current	PhD student - university Centre for Nursing & Midwifery - Department of Public Health Ghent University	

WORK EXPERIENCE

1986 - 1989	Employed as Nurse during military services at the Belgian army in Germany (Spich, Soest (military hospital))
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1989 - 1992	Nurse, Psychiatric hospital, Pittem
1992 - 2008	Part-time lecturer and researcher VIVES University College - Roeselare
	Part-time Nurse Sint-Andriesziekenhuis Tielt - Intensive Care Unit
2008 - current	Lecturer Nursing and Researcher - University college VIVES, Department of Health, Roeselare
2008 - current	Research staff member - Psychiatric clinic Pittem (0,1 FTE)
	2019 – 2020 - Mental health Nurse - Learning innovation Centre - Psychiatric clinic Pittem in collaboration with University college VIVES, department of health (0,2 FTE)
2008 - current	Emergency ambulance services 112, Red Cross Tielt (volunteer work)

ADDITIONAL TRAINING

2017	Workshop Qualitative Evidence synthesis, European Congress of Qualitative Research

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Debyser, B. (2013). De kracht centraal zetten: jongeren helpen jongeren. Gepresenteerd op de studiedag van kinder- en jeugdpsychiatrie, Antwerpen.

REVIEWER

Verpleegkunde, Nederlands-Vlaams wetenschappelijk tijdschrift voor verpleegkundigen.

AWARDS en NOMINATIONS

Debyser, B. & Degrande, A. (2013) Van “PrIT” tot “PEER”: samen groeien door betekenisvol omgaan met de eigen ervaringskennis. Reintegration award, VVGG, 2013.

Debyser, B., Deproost, E., Verkest A. & Verhaeghe S. (2012). Inzet van ervarings- en hersteldeskundigheid in geestelijke gezondheidszorg en hoger onderwijs: een verhaal van dialoog en authentiek ontmoeten. Genomineerd voor de prijs ‘humane psychiatrische zorg’, 2012.

Persoonlijke bijdrage doctoraatsstudent

STUDIE 1.

Involvement of inpatient mental health clients in the practical training and assessment of mental health nursing students: Can it benefit clients and students?

Beknopte beschrijving studie:

Kwalitatieve exploratieve studie gebaseerd op principes van grounded theory met als doel na te gaan wat het betekent voor patiënten, studenten, verpleegkundigen en docenten wanneer GGZ patiënten formeel en actief betrokken worden in het evaluatieproces van laatstejaars studenten GGZ verpleegkunde.

Bijdrage doctoraatsstudent:

Bart Debyser was betrokken in de ontwikkeling van het praktijkmodel om de stagefeedback te ontlokken bij de patiënten. Verder was hij betrokken in het opzet van de studie, het ontwikkelingsproces (aanvraag commissie medische ethiek, rekrutering, data-collectie) en de data-analyse. Bart Debyser schreef het artikel uit, van eerste draft, tot eindresultaat, diende het artikel in bij het tijdschrift en volgde nadien nauwgezet als eerste auteur alle stappen verder op tot publicatie van het artikel (Nederlandstalig & Engelstalig).

STUDIE 2.

The evaluation of nursing students by patients instrument: development and validation

Beknopte beschrijving studie:

Psychometrische validatiestudie van de vragenlijst 'evaluatie van studenten verpleegkunde door patiënten van algemene ziekenhuisafdelingen'. Deze validatiestudie gebeurde aan de hand van een proces dat in drie tijden werd uitgevoerd: 1) ontwikkeling van de vragenlijst aan de hand van een explorative literatuurstudie en kwalitatieve interviews met patiënten; inhoud en respons-proces validatie; 3) constructvaliditeit en test-retest betrouwbaarheid nagaan van het instrument

Bijdrage doctoraatsstudent

Bart Debyser initieerde mee de studies die aan basis liggen van artikel. Hij was betrokken in het opzet van de studie, het ontwikkelingsproces van de studie (aanvraag commissie medische ethiek, verschillende rekruteringsrondes, datacollectie) en de data-analyse. Bart Debyser schreef mee het artikel uit en diende het artikel in bij het tijdschrift. Hij volgde het reviewproces op en zal ook de eventuele verdere stappen in het revisie-proces opvolgen.

STUDIE 3.

Constructing a positive identity: A qualitative study of the driving forces of peer workers in mental health-care systems.

Beknopte beschrijving studie:

Kwalitatieve explorative studie gebaseerd op principes van grounded theory met als doel na te gaan wat voor GGZ ervaringswerkers drijfveren zijn om aan de slag te gaan als ervaringswerker.

Bijdrage doctoraatsstudent:

Bart Debyser was als copromotor direct betrokken in de masterproef van Joeri Vandewalle met als thema “Drijfveren van ervaringsdeskundigen in de geestelijke gezondheidszorg: opbouwen van een positieve identiteit” (2014 - 2015). Bart Debyser volgde mee alle stappen op van idee tot uitvoering, data-collectie, data-analyse en finale uitschrijving van de masterproef. Op basis van deze masterproef werd een manuscript ontwikkeld. Bart Debyser nam een cruciale rol op in het ontwikkelen, uitschrijven en kritisch reviseren van het manuscript.

STUDIE 4.

Peer workers' perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review.

Beknopte beschrijving studie:

Systematische review waarbij barrières in kaart gebracht werden die ervaringswerkers ervaren in hun integratie als ervaringswerker binnen de geestelijke gezondheidszorg.

Bijdrage doctoraatsstudent:

Bart Debyser was betrokken bij deze review van opzet tot publicatie. Het uitwerken van de zoekfilter, de (quality-)assessment van de artikels, de data-analyse, het uitschrijven van het manuscript en het kritisch reviseren van het manuscript.

STUDIE 5.

The transition from patient to mental health peer worker: A grounded theory approach.

Beknopte beschrijving studie:

Doel van deze studie was het transitieproces van GGZ patiënt tot GGZ-ervaringswerker in kaart te brengen vanuit het perspectief van de GGZ ervaringswerkers zelf. Hiervoor werd een kwalitatieve exploratieve studie opgezet gebaseerd op de grounded theory benadering.

Bijdrage doctoraatsstudent

Bart Debyser was direct betrokken in het opzet van de studie, de aanvraag commissie medische ethiek, de datacollectie, data-analyse en schreef het artikel uit. Hij diende het artikel in bij het tijdschrift en volgde nadien alle stappen verder nauwgezet op tot finale publicatie van het artikel.

STUDIE 6.

Mental health nurses and mental health peer workers: Self-perceptions of role-related clinical competences.

Beknopte beschrijving studie:

Doel van deze studie was om inzicht te krijgen in hoe GGZ verpleegkundigen en GGZ ervaringswerkers hun rol-gerelateerde competenties als GGZ verpleegkundige of als GGZ ervaringswerker percipiëren. Hiervoor werd een kwalitatief beschrijvend design opgezet gebaseerd op de principes van de kritische incidentmethodologie.

Bijdrage doctoraatsstudent

Bart Debyser was betrokken in het opzet van de studie, het ontwikkelingsproces (aanvraag commissie medische ethiek, rekrutering, data-collectie) en de data-analyse. Bart Debyser schreef het artikel, diende het in bij het tijdschrift en volgde nadien nauwgezet alle stappen verder op tot finale publicatie van het artikel.

Dankwoord

Het voelt wat vreemd aan om een punt te zetten achter dit doctoraatstraject. Een traject waar ik eigenlijk vooral ingerold bent, net zoals een mantelzorger in de zorg rolt. Ik had nooit gedacht dat ik na mijn masteropleiding nog een doctoraatsproject zou starten, laat staan voleindigen.

Het voelt wat bevreemdend aan om dit traject succesvol te eindigen net op een moment dat de COVID-19-crisis wereldwijd zo hard toeslaat. Ik wil daarom ook eventjes stilstaan bij deze pandemie in dit dankwoord, in de eerste plaats om het relatieve karakter van de realisatie van dit proefschrift te onderstrepen ten opzichte van de beproevingen die zoveel mensen nu (en morgen) moeten doorstaan. Het doet me nadenken bij wat we als mensheid nu nodig hebben om door deze crisis heen te groeien en finaal sterker te staan om toekomstige uitdagingen die op ons pad komen aan te pakken, zoals de klimaatverandering. Samenwerken over alle muren heen, los van de maatschappelijke klasse, leeftijdsgroep, professie of cultuur waartoe je behoort, mensen empoweren zodat het beste in hen naar boven komt en het gericht inzetten van zowel op wetenschap gestoelde inzichten en kaders als de ervaringen die mensen met zich meedragen, lijken me in dit verhaal bijzonder belangrijk. Het waren ook allemaal elementen die van betekenis waren om dit proefschrift tot een goed einde te brengen.

Mijn gedachten zijn vandaag dan ook in de eerste plaats bij iedereen die getroffen wordt door deze verschrikkelijke crisis. Tegelijk maakt het me ook wel wat trots, maar ook bezorgd, dat onze sector, de zorgsector, nu de rots in de branding is en al wekenlang op de toppen van hun tenen staan om deze crisis het hoofd te bieden. Naast zorgverleners en verwante professionelen zijn er zoveel andere mensen die hun steentje bijdragen, vanuit wie ze zijn als mens of vanuit hun specifieke expertise. Ik denk dan bijvoorbeeld aan de mensen die mondmaskers maken, die beademingsmachines in mekaar knutselen, de spontane peer support die ontstaat in dorpen en steden en hoe mensen met kleine acties duurzame relaties smeden met mensen die voorheen nog vreemden waren. Ik denk ook aan de ouders die zorgen dat het leven van hun kinderen zo normaal mogelijk kan blijven verlopen, door samen met hen bijvoorbeeld op berenjacht te gaan in de straten van hun wijk of stad. Ik denk ook aan ons allemaal en hoe we in korte tijd leerden onszelf heel wat discipline op te leggen door in ons ‘kot’ te blijven en aan *social distancing* te doen. Last but not least denk ik vooral aan wie in de afgelopen periode ziek werd of ondersteuning behoefde, en hoe het wellicht niet vanzelfsprekend was om het vertrouwen te geven aan zorgverleners en aan een zorgsysteem dat sterk onder druk staat en toch te blijven erop vertrouwen dat het terug goed zou komen.

Het brengt me bij enkele parallel verlopende kernelementen die ook de rode draad waren bij het tot stand brengen van dit proefschrift, zoals het omringd zijn door zoveel gewone maar bijzondere mensen die me een inkijk gaven in hun beproefde leven, het aan de dag leggen van een sterke zelfdiscipline, vertrouwen te hebben in een goeie afloop, het stap voor stap en systematisch tewerk gaan, het mogen en durven creatief en inventief denken, de steun, het vertrouwen en het geloof in mij als persoon van zo vele mensen.

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Een bijzondere dank gaat verder uit naar de promotoren Prof. dr. Sofie Verhaeghe en Prof. Dr. Ann Van Hecke die mij vanaf de start bijzonder goed gecoacht hebben. Ik kon bij jullie steeds terecht en jullie leefden me voor om steeds verder te denken en bepaalde onderzoeksresultaten eens vanuit een ander perspectief te bekijken. Jullie weten hoe de klok tikt in de zorg en waar de uitdagingen zich situeren. Ondanks jullie bijzonder grote expertise heb ik jullie mogen ervaren als twee heel gewone mensen die geworteld zitten in het alledaagse leven en bijzonder vertrouwd zijn met de zorg van vandaag. Zonder jullie stond ik hier niet.

Sofie: als eerste contactpersoon voor mij was het een groot voorrecht om jou als promotor te hebben. Ik heb bijzonder veel geleerd van jou! Je hebt met veel zorg en toewijding m'n doctoraatstraject opgevolgd. Ik mocht je kennen als een hartelijke en warme persoon die beslagen is in je vakgebied en over een ijzersterke methodologische kennis beschikt. Je was de persoon die me bij uitstek het vertrouwen gaf en me stimuleerde om open te breken en mijn grenzen steeds weer ietsje verder te leggen. Je voelde steeds heel goed aan wanneer je zelf wat meer op de achtergrond kon verdwijnen, je was er echter ook steeds wanneer het in functie van de voortgang of het lijn houden in het doctoraatstraject nodig was om mee het roer in handen te nemen. Hoe je hierin samenwerkte met Ann, was bijzonder. Jullie waren meer dan goed op mekaar afgestemd!

Ann: ik mocht je tijdens het hele traject ervaren als een onderzoeker die van alle markten thuis is. De zorgvuldigheid en je zin om steeds heel systematisch en methodisch te werk te gaan hielpen mij om de kern te zien en me niet te verliezen in een veelheid van gegevens. Ik bewonder de accuraatheid en scherpte waarmee je steeds voor de dag kwam en hoe je in teksten waarvan ik dacht dat die tekstueel af was nog terechte pijnpunten blootlegde.

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Geachte Prof. Dr. Dimitri Beeckman; beste Dimitri. Ook u wil ik bedanken. Samen met Ann en Sofie zorgt u ervoor dat het Universitair Centrum Verpleegkunde en Vroedkunde een kwaliteitskeurmerk draagt in binnen- en buitenland. Bedankt om deel uit te maken van de begeleidingscommissies en de steun en bijdrage in het reviseren van de artikels.

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Ook de leden van de jury wil ik uitdrukkelijk bedanken: Prof. Dr. Kurt Audenaert , Prof. dr. Piet Bracke, Prof. dr. Peter Goossens, Professor dr. Em. Mieke Grypdonck, dr. Nienke Kool, Professor Dr. Koen Van Herck: Bedankt voor uw betrokkenheid, uw waardevolle opmerkingen en goede suggesties die het proefschrift echt verbeterden.

Ik wil ook heel graag mijn collega's van het UCVV en onze vakgroep van nu en vroeger bedanken. Speciale dank aan Joeri Vandewalle, dr. Veerle Duprez, dr. Tina Vandecasteele en dr. Simon Malfait voor hun specifieke bijdrage aan dit proefschrift.

Joeri: Je was samen met Tina mijn *soulmate* tijdens mijn doctoraatstraject. Dank om het eerste auteurschap te delen voor de drijfverenstudie en de barrièrestudie, twee belangrijke studies die deel uitmaken van dit proefschrift. Het was voor mij erg aangenaam om met jou samen te kunnen werken. Het was fijn om samen met jou enkele studies te kunnen voorstellen op het internationale congres *refocus on recovery* in Nottingham (2017). Groot was wel mijn verbazing toen je voorstelde om een ochtendprogramma van het congres te skippen en in de plaats hiervan een bezoekje te brengen aan het legendarische voetbalstadion van Nottingham Forrest (☺).

Tina: als senior-doctoraatstudent was je me telkens een stapje voor doordat de finalisering van jouw doctoraatstraject voorafging aan het mijne. Je stond me steeds met raad en daad bij waar je kon. Je droge humor, je uitgebreide kennis, je positieve kracht en vriendelijk enthousiasme stimuleerden me om door te gaan. Samen met Melissa Riviere was je een bron van steun om stressmomentjes tijdens het onderzoeksproces te helpen dragen. En ik vergeet nooit, wanneer we samen participeerden aan het internationale congres '*Violence in the Health Secto*r' in Dublin dat je 'mij' (!) zowaar om kledingadvies op de dag dat je je presentatie moest geven!

Veerle: dank dat ik op je grote wijsheid en je sterke onderzoekskwaliteiten beroep mocht doen! Jouw insteken zorgden ervoor dat we uitgekiemde oplossingen vonden voor de vaak complexe en technische vraagstukken die gepaard gingen met het reviseren van de manuscripten.

Simon: ook jou wil ik uitdrukkelijk bedanken voor je loyale steun en bijdrage aan de ENSPa-studie.

I would like to thank especially my sister in law, Kim Smith as she was involved in the editing work of the English manuscripts. Kim, it was great to work with you. Your editing work was outstanding. I still remember the evening at the end of August when I received a message that it was no longer possible to upload our revised manuscript to the journal. I was in total despair and I called you to discuss the issue. Your tranquility and sensitive listening helped me to calm down. Together we reread the message and compared it with previous e-mails from the journal. We noticed that the mentioned final submission date was not in line with what was previously communicated. By sending a friendly mail to the editor of the journal they acknowledged their mistake and I could submit our manuscript. What a relief then! Thank you for your great work and your great support during my PhD-trajectory. You will always stay in my heart.

Ik wil ook graag de directie en collega's van de VIVES Hogeschool, Campus Roeselare, bedanken. Het is fijn om deel te kunnen uitmaken van een warme hogeschool, waarin er oprechte interesse en een laagdrempelige betrokkenheid is van docenten naar mekaar toe en naar de studenten toe, waar er ruimte is om je te realiseren in datgene waar je goed in bent en waar de persoon van de student sterk centraal staat. Bijzondere dank aan Eveline Crevits en Inge Maes. Jullie dragen net als ik ervaringswerk heel diep in jullie hart. Ik heb me altijd bijzonder sterk gesteund gevoeld door jullie beiden. Speciale dank aan Melissa Riviere, Hade Blockeel en Tina Vandecasteele, mijn bureaugenoten. De collegialiteit en vriendschap die ik van jullie elke dag terugkrijg is hartverwarmend. Ook dank aan de collega's van het vakteam GGZ: Hilde Decrop, Ilse Patoor, Ellen Vanhaverbeke en Hade Blockeel om de steun die ik ook van jullie mocht ontvangen tijdens dit traject. Dank ook aan oud-collega Henk Verschoren om telkens zo goed te luisteren als ik met bepaalde ideeën bij jou over de vloer kwam. Jij was m'n eerste aftoetspersoon. Dankzij jou wist ik of een idee de moeite waard was om verder uit te werken, of indien het beter in de prullenbak thuishoorde.

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