Unveiling inequity: diversity and power in collaborative care networks

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Chapter 2

Exploring the collaboration between formal and informal care from the professional perspective - a thematic synthesis

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Abstract

In Dutch policy and at the societal level, informal caregivers are ideally seen as essential team members when creating, together with professionals, coordinated support plans for the persons for whom they care. However, collaboration between professionals and informal caregivers[1] is not always effective. This can be explained by the observation that caregivers and professionals have diverse backgrounds and frames of reference regarding providing care. This thematic synthesis sought to examine and understand how professionals experience collaboration with informal caregivers to strengthen the care triad. PubMed, Medline, PsycINFO, Embase, Cochrane/Central and CINAHL were searched systematically until May 2015, using specific key words and inclusion criteria. Twenty-two articles were used for thematic synthesis. Seven themes revealed different reflections by professionals illustrating the complex, multifaceted and dynamic interface of professionals and informal care. Working in collaboration with informal caregivers requires professionals to adopt a different way of functioning. Specific attention should be paid to the informal caregiver, where the focus now is mainly on the client for whom they care. This is difficult to attain due to different restrictions experienced by professionals on policy and individual levels. Specific guidelines and training for the professionals are necessary in light of the current policy changes in the Netherlands, where an increased emphasis is placed on informal care structures.

Introduction

Care for people with chronic conditions is often provided by informal caregivers combined with support from professionals arranged in so-called ‘care triads’ (Kemp et al. 2013), a care network consisting of a client, informal caregiver, and healthcare (allied health and nursing) and social professional(s). Professionals together with informal caregivers create support plans for the person for whom they care (Talley & Crews 2006). However, the collaboration between informal care and professionals is not always effective (Lefebvre et al. 2007).

In the Netherlands, there is an increased emphasis on informal care structures. Based on developments from policy and social perspectives (Boer de & de Klerk 2013), the number of informal caregivers will rise in the next decade (Verbeek-Oudijk et al. 2014). Given the shift from the traditional welfare state to the participation society, where citizens are expected to be primarily responsible for their own health and welfare, de-institutionalisation of healthcare is taking place. Care will be provided in the community with support of informal caregivers and professionals, and only complex care will be given within an institution (Kaljouw & van Vliet 2015). Given this shift, it is important to find out how the collaboration between professionals and informal care is taking place.

Twigg (1989) describes three models that outline frames of reference for the relationship between professionals and informal care: informal care as resource; informal care as co-worker; and informal care as co- client. On the Dutch policy level, informal caregivers are ideally seen as essential team members (Verbeek-Oudijk et al. 2014). Consequently, when referring to informal caregivers as co-workers, we use Twigg´s outline. In this frame of reference, the professional works in parallel with the informal sector, having an enabling and supportive role (Twiggs, 1989). However, this might create underlying difficulties when put into practice because informal caregivers and professionals have different perspectives in providing care to the care recipient (Jacobs et al. 2014).

Research on the informal caregivers’ perspective shows that most problems arise in communication and results from different expectations between professionals and informal caregivers (Jacobs *et al*. 2014). Dutch research has shown informal caregivers have mixed feelings about their collaboration with professionals. They do not feel involved or recognised as a partner in the care provided by professionals (Wittenberg et al. 2012; de Boer & de Klerk 2013). Almost half of the informal caregivers claim they rarely or never get the opportunity to participate in decisions or share their concerns (de Klerk et al. 2015).

In contrast, little research has examined professionals’ perspectives regarding working and collaborating with informal caregivers (de Boer & de Klerk 2013; Jacobs et al. 2014). To improve the collaboration between informal caregivers and professionals, we must examine what we

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[1] In chapter 2 and 3 informal carers are referenced as caregivers. In the later stages of this PhD thesis, chapter 4-6 and the general introduction and discussion, the term caregiver has been changed to carer. This choice was made in order to emphasize the reciprocal relationship between carers and care recipients.

can learn about the professional perspective on collaboration with informal caregivers. A quick scan of the Dutch literature revealed that this topic is marginally researched in the Netherlands; therefore, a broader review is performed based on international literature.

This thematic synthesis aimed to explore the collaboration between professionals and informal caregivers to gain a better understanding of experiences of professionals on the collaboration with informal caregivers and to further understand their perspective and to strengthen care triad in the future within the community setting.

Methodology

As we were interested in what is known in international literature about the experience of professionals regarding the collaboration with informal caregivers, we chose a review method in qualitative studies (Thomas & Harden 2008). Campbell et al. (2003) suggest that syntheses of qualitative research give a stronger voice to experiences than single studies do. Consequently, we performed a thematic synthesis pertinent to the topic at hand. The thematic synthesis was based on the methodology proposed by Thomas and Harden (2008) and followed four phases: 1) search and study selection, 2) critical appraisal of the selected studies 3) data extraction, and 4) thematic synthesis. Each phase will be explained in the following paragraphs.

Search Strategy and Study Selection

In phase 1, we searched six electronic databases: PubMed, Medline, PsycINFO, Embase, Cochrane/Central, and CINAHL. We systematically searched for papers published between 2000 and May 2015, based on a search strategy with the following key terms: formal care AND support AND informal caregiv* AND diversity AND perspective. The basic search strategy was expanded using synonyms, which were found in the thesaurus (see the final search strategy in Appendix 1).

The inclusion criteria were: 1) published between 2000 and May 2015; 2) written in English or Dutch; 3) describing the experiences of allied health, nursing, or social work; 4) focusing on the professional perspective of collaboration with the informal caregiver; and 5) published in a peer-reviewed journal. Although the logical choice in this review is to focus only on community settings, we also included other settings due to the lack of articles specifically focussing on community settings.

All studies were independently selected, based on titles and abstracts in the first round and full text reading in the second round. This was done by the first and second author (AHH and MvH). Disagreements about selected articles were subject to discussion to reach consensus.

Quality Appraisal

In phase 2, we used the Critical Appraisal Skills Programme (CASP) to appraise the methodological quality of the studies. All items on this 10-item CASP Qualitative checklist for the appraisal of qualitative studies were scored with ‘yes’ or ‘no’ depending on whether the topic, e.g. research design, recruitment, ethical considerations, were described sufficiently. An additional score of ‘unclear’ was added to differentiate between sufficiently and insufficiently. This resulted in three options: 1, 1/2, and 0. The higher the total score, the better the methodological quality, with a maximum score of 10. All remaining studies were independently appraised with the CASP by the first and second author (AHH and MvH) and all items that were scored differently were subject to discussion to reach consensus.

Data Extraction and Thematic Synthesis

Phase 3 consisted of data extraction and thematic syntheses, carried out by the first author (AHH). This process was peer reviewed by the second author (MvH). Furthermore, the findings were discussed with all authors. The goal of this process was the synthesis of the extracted findings regarding the experiences of professionals as described in each study. For this phase we followed the procedure, as described below, as proposed by Sandelowski and Barrosso (2003) and Thomas and Harden (2008).

First, the results sections from all included articles were, verbatim, extracted and placed in AtlasTI. The data were read as a whole and meaningful segments were labelled. Second, the data were coded using a system of line-by-line coding followed by a process of axial coding. Using line-by-line coding made *translation* of concepts from one study to another possible, which is one of the key tasks when preforming a synthesis. Third, descriptive themes were developed by looking at the differences and similarities between the codes and grouping them together. Fourth, overarching thematic themes were developed. Developing thematic themes meant that the authors went beyond the themes of the primary studies (Thomas & Harden 2008). This was done by using a cyclical process of further interpretation and discussion between the authors about the final themes to describe and explain all initial descriptive themes (Thomas & Harden 2008, p7). When the final thematic elements were developed, citations from initial studies were checked to confirm and support the different themes.

Results

Searches in all six databases resulted in 1151 possible articles. These were screened based on title and abstract. Subsequently, the full text of 68 articles was examined. Twenty-eight articles were selected for methodological appraisal, and, finally, 22 articles were used for thematic synthesis (see flow chart in Figure 1).

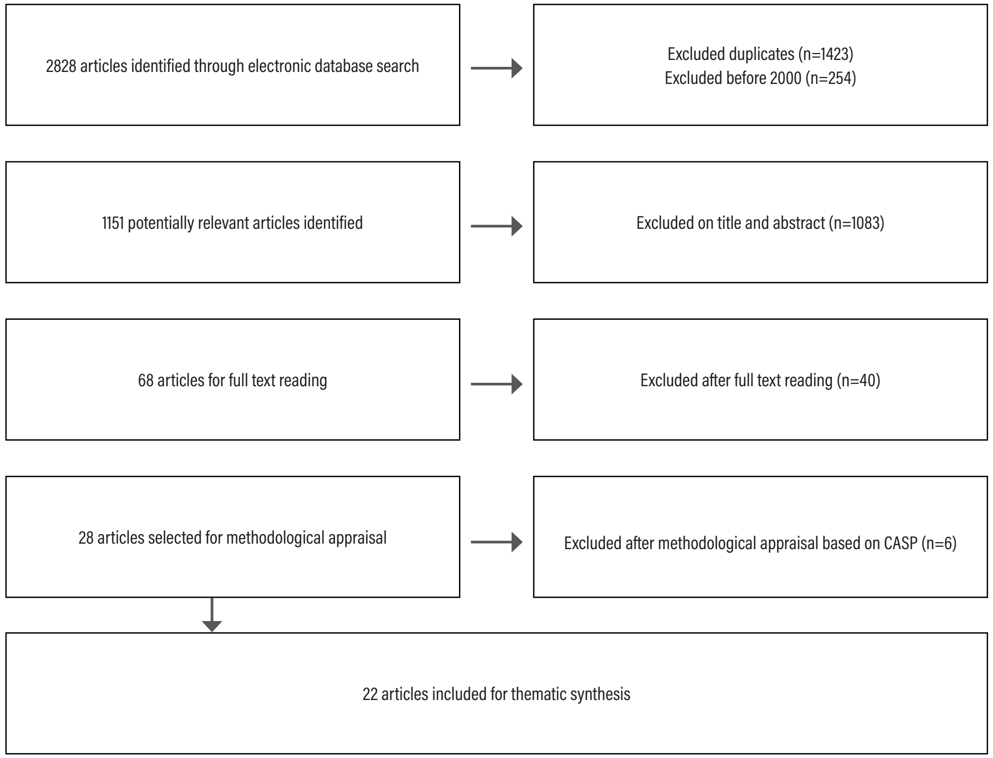

Figure 1. Flowchart of included and excluded studies

Characteristics of Included Studies

Most studies were conducted in Canada (10/22), followed by Europe (5/22). In Europe, studies were conducted in France, Belgium, Germany, Norway, and the United Kingdom. The other studies were conducted in the United States (2/22), Australia (2/22), New Zealand (1/22), Israel (1/22), and South Africa (1/22).

Table 1 provides an overview of the characteristics by study. Nurses (n=206) were most represented in the studies, followed by case managers (n=16); occupational therapists (n=6); physiotherapists (n=4); managers (n=4); social workers (n=3); and support staff (n=3). However, this overview does not give a complete picture because not all articles were completely clear on the number participants per profession. Most informal caregivers cared for a frail elder (12/22), with four studies on dementia care. There were two studies on HIV care, and two on mental health. Four studies had a diverse population in their sample.

Methods and Quality of Included Studies

Table 1 shows the study characteristics of all included studies. All studies aimed at exploring the collaboration between professionals and informal care. Most studies used interviews (19/22) varying from semi-structured to in-depth interviews. Nine studies used a combination of interviews with either a focus group, observation, survey, or logbook. Only two studies used focus groups, and one study used thematic analyses of meetings and referral letters as well as a survey. The CASP score varied from 5-8 with a mean of 5.9. Studies with a lower score mostly lacked explanations of ethical procedures and a description of the relationship between researcher and participant.

Table 1. Study characteristics

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Agee & Blanton (2000)	United States	To explore the professional context within which families make decisions about elder caregiving. To increase the understanding of the interface between informal structures of families/friends and formal structures of the service provider network.	Exploratory qualitative	Interviews	Health providers from adult day care, aging service, assisted living, chaplain/ hospice, geriatric assessment, home health service, large- and small-scale nursing home administration, geriatric medicine (n=9)	Frail elderly	6
Aujoulat et al. (2002)	France and Belgium	To describe the communication process between healthcare professionals and family caregivers in the field of AIDS, to analyse the difficulties they face, and to get a better understanding of the experience and expectations on both sides.	Mixed methods, emphasis on qualitative methods	Survey and interviews	Healthcare professionals n=70 (nurses n=25, doctors n=19), others n=26 (pharmacists, psychologists, social workers)	AIDS	5
Boros (2010)	South Africa	Addressing identified gaps by providing information about interaction between formal and informal care.	Qualitative	Semi-structured interviews	Home based caregivers n=22, nurses n=6, other n=4	Diverse	6.5
Buscher et al. (2011)	Germany	To investigate the relationship between nurses and family caregivers and its impact of the actual care provided	Grounded theory	Interviews	Family caregivers n=57, nurses n=31	Diverse	8
Carpentier et al. (2008)	Canada	To explore the interface between healthcare practitioners and caregivers of people with Alzheimer's disease living in the community	Exploratory interpretative	Semi structured interviews	n= 20 (nurses n=4, coordinators n=4, animator n=1, support staff n=9, substitute caregivers n=2, medical staff n=2)	Dementia	8
Cohen-Mansfield et al. (2013)	Israel	To compare formal and informal caregivers' perceptions of delusions and hallucinations in community residing older PWD's	Mixed methods	Assessments and interviews	n=151 PWD's, n=90 formal caregivers, n=151 informal caregivers	Dementia	6.5

Table 1. continued

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Dal Bello-Haas et al. (2014)	Canada	To describe formal and informal caregivers' perceptions of the challenges and needs associated with providing services, care and support for individuals with dementia living in rural and remote regions in Saskatchewan, Canada.	Mixed methods Exploratory	Thematic analysis of consultation meetings, telephone and email questionnaire, referral letters	communities n=13, physicians n=55, referral letters n=250, caregivers n=151	Dementia	6.5
Fjelltun et al. (2008	Norway	To describe carers' and nurses' appraisal of workload in care of frail elderly awaiting nursing home placement	Comparative cross sectional	Workload scale Interviews	Carers n=11, nurses n=11	Frail elderly	7
Goodwin & Happell (2006)	Australia	To examine the issue of consumer, carer participation in mental health care from the perspectives of consumers, carers and psychiatric/ mental health nurses.	Qualitative	Focus groups	Carers n=19, nurses n=30	Mental Health	7
Guberman et al. (2006)	Canada	To identify home care practitioners' understanding of caregiver responsibilities, difficulties and need for support.	Multiple case study	Logbook and interviews	n=55 (nurses, social workers, physical therapist, occupational therapist, home care worker, managers)	Diverse	6.5
Jansen et al. (2009)	Canada	To explore formal care providers' perceptions of their experiences with Canadian home- and community-based dementia care.	Descriptive interpretative	Focus groups	Nurses, social workers, therapists	Dementia	6.5
Levesque et al. (2010)	Canada	To explore the experience of caregivers and practitioners who took part in a field test of the Family Caregivers Support Agreement (FCSA) tool.	Qualitative	Focus groups and interviews	Social workers n=4, nurses n=2, caregivers n=17	Elderly	7.5
McPherson et al. (2014)	New Zealand	Exploring carers and professional perspectives on how informal caregivers and formal services interface with one another and identifying how formal services could better interface with informal carers.	Qualitative descriptive	Focus groups and interviews	Informal carers n=39, formal care n=31	Diverse	8
McWilliam, et al. (2001)	Canada	To illuminate the components and activities of shared experience of in-home care prior to a planned shift to an approach of flexible, client-driven in-home service delivery.	Hermeneutic phenomenology	Interviews	Clients n=6, informal caregivers n=6, service providers n=9	Elderly	7
Mitchell (2009)	Australia	To bridge the gap between action focussed and structure focussed accounts of roles in mental health care	Discourse analysis	Group interview	n=41 (primary health and social care agencies, stake holders from communities)	Mental health	7

Table 1. continued

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Mosack & Wendorf (2011)	United States of America	To describe HIV health care providers' perspectives on the involvement of informal supporters in their HIV health care and health care decision-making.	Qualitative	Semi-structured interviews	Physicians n=7, nurse practitioners n=3, registered nurse n=1	HIV	7
Peckman et al. (2014)	Canada	To examine how professional case managers from across the care continuum perceive and attempt to balance informal and formal care in their day-to-day work.	Mixed methods	BoC model and follow up interviews	36 homogeneous BoC groups and case managers n=10	Older persons	5
Pickard & Glendinning (2002)	United Kingdom	To explore the factors which distinguish family caregiving from professional caregiving, comparing and contrasting carer's roles and approaches with that of nurses. To establish how lay and professional carers can work together effectively, ensuring that family carers will be supported in the most appropriate way.	Qualitative Ethnographic approach	In-depth interviews and observation	Carers n=24, district nurses n=12, community psychiatric nurses n=12	Frail elderly	5
Toscan et al. (2012)	Canada	To investigate care coordination for older hip fracture patients from multiple perspectives, including patients, informal caregivers, and health care providers to determine the core factors related to poorly integrated care.	Focussed ethnography	Semi-structured interviews and observations	Informal caregivers n= 6, general practitioner n=1, physiotherapists n=4, occupational therapists n=4, nurses n=3, case managers n=6	Hip fractures	6.5
Walker & Dewar (2001)	United Kingdom	To produce a set of indicators for good practice that would facilitate the involvement of carers in decision-making.	Case study design	Interviews, focus groups, field notes and documentation	Carers n=20, nurses n=17, occupational therapists n=2, doctors n=5, social workers n=2, community nurses n=3	Dementia	6.5
Ward-Griffin (2001)	Canada	To describe and explore the relationship between nurses and female family members caring for elderly in the home.	Critical ethnography	In-depth interviews	Nurses n=23, family caregivers n=23	Frail elderly	6
Ward-Griffin & McKeever (2000)	Canada	To examine the relationship between community nurses and family members providing home care to older persons in urban Canada.	Critical ethnography	In-depth interviews	Nurses n=23, family caregivers n=23	Frail elderly	5.5

Synthesis of Results

Thematic synthesis of 22 articles resulted in 150 segments or codes meaningful to the aim of this research. These 150 segments were grouped into descriptive themes, and in the final phase interpreted into seven thematic themes: 1) the struggle experienced by professionals between being an expert versus partner towards the informal caregiver, 2) communication within the care triad, 3) the experienced hierarchy in the care triad, 4) professionals regarded informal caregivers as essential, 5) professionals reported a mismatch between the provided services and the needs of informal caregivers, 6) professionals felt restricted by the collaboration, and 7) some professionals reflected on diversity in collaboration with informal caregivers. Table 2 gives an overview of the primary studies from which meaningful segments were used for thematic themes.

Table 2. Overview thematic themes

	Agee & Blanton (2000)	Aujoulatt et al. (2002)	Boros (2010)	Buscher et al. (2011)	Carpentier et al. (2008)	Cohen-Mansfield, Golanderr & Heinik (2013)	Dal Bello-Haas et al. (2014)	Fjelltjun et al. (2008)	Guberman et al. (2006)	Goodwin & Happell (2006)	Jansen et al. (2009)	Levesque et al. (2010)	McPherson et al. (2014)	McWilliam et al. (2001)	Mitchell (2009)	Mosack & Wendorf (2011)	Peckman, et al. (2014)	Pickard & Glendinning (2002)	Toscan et al. (2012)	Walker & Dewar (2001)	Ward-Griffin (2001)	Ward-Griffin & McKeever (2000)
Professionals are expert versus partner		x			x			x	x	x	x	x	x	x		x	x			x	x	x
Communication in the care triad	x	x	x	x	x					x		x	x	x	x		x	x	x			
Hierarchy in care triad		x	x		x			x		x	x	x		x		x	x	x		x	x	x
Caregivers are essential			x	x				x		x	x	x	x			x	x	x		x	x	
Mismatch between services and needs						x	x				x		x	x				x			x	x
Professionals feel restricted in collaboration with the caregiver		x	x	x	x	x	x			x	x	x								x	x	x
Diversity in the care triad					x						x						x				x	

Professionals are experts versus partners

The professionals' perspective regarding their role in the collaboration comprised a continuum between the feeling of being the expert and trying to work in partnership with the caregiver. Dal Bello- Haas et al. (2014) found professionals saw a partnership approach as desirable for the informal caregiver. Other research shows professionals understood the importance of a partnership approach to empower caregivers 'and give them a greater sense of self-worth' (Levesque et al. 2010: 882). However, it seems that often professionals did not use a partnership approach in their practice but mostly acted as an expert. They 'use their own knowledge, status and authority to accomplish the tasks and goals of the system and their prescribed professional mandates, with little attention to the knowledge, status and authority of clients as potential partners in care' (McWilliam et al. 2001: 60).

Pickard and Glendinning (2002) and Levesque et al. (2010) showed that when professionals claimed to work in partnership this was not always a true partnership. 'Professionals and family carers work in such a way that each are able to do their allotted tasks in a process that may be described as complementarity' (Pickard & Glendinning 2002: 147). Several strategies were identified by professionals to form a partnership approach, namely sensitive listening, asking enabling questions, and not imposing own views (Walker & Dewar 2001, Levesque et al. 2010). McPherson et al. (2014) and Carpentier et al. (2008) added that taking time to build trust was essential.

These strategies sometimes contradicted the roles and approaches professionals assume in a collaboration. Agee and Blanton (2000) emphasised the professionals' role of educator, 'where teaching and sharing information are used more often than listening' (p. 322). The professionals in the research of Carpentier et al. (2008) used both roles as listener and educator. The approach which focuses on empowerment of the informal caregiver was only used sometimes (p. 725). Ward-Griffin and McKeever (2000) and Ward-Griffin (2001) described four roles for professionals of which the manager-worker and co-worker were most often adopted. Within the role of co-worker, the nurse is a teacher and there was only a notion of teamwork with a controlling role for the nurse. The manager-worker is more or less a coach, whereby the nurses gradually transfer their actual caregiving time and monitor the coping and competence of the informal caregiver. However, the nurses were not always working in partnership given the sparse meetings with the informal caregiver.

Communication in the care triad

The communication between professionals and informal caregivers was only described in terms of difficulties and no best-practices were mentioned in the included articles. Upon first contact, the collaboration was often described as difficult; professionals reported uncertainties about responsibility in collaborating and communicating with the informal caregiver. Toscan et al. (2012), Boros (2010), Buscher et al. (2011) and Goodwin & Happell (2006) described a lack of communication in general between professionals and informal caregivers, which was insufficient and irregular (Boros 2010). Buscher et al. (2011) described the communication as unstructured and informal. In Goodwin and Happell (2006), a professional described being caught between the sandwich of the client and the caregiver. Aujoulat et al. (2002) added that it was sometimes unclear what could be shared with the caregiver and what was 'creating a huge barrier for effective communication' (Goodwin & Happell 2006: 138).

Hierarchy in care triad

In the care triad, there were different forms of hierarchy between the professional, informal caregiver, and the client. Agee and Blanton (2000: 331) argue professionals will be more or less inclined to collaborate with the informal caregiver given their perspective. Some professionals described themselves as being secondary in home care and the informal caregiver as primary (Ward-Griffin 2001). Others placed the informal caregiver at the bottom of the hierarchy, then the nurse, then the therapist, and the case manager at the top (McWilliam et al. 2001).

Sometimes there was a conflict in the professionals' reflection on the position of the caregiver with respect to the client, as mentioned by, for example, Goodwin and Happell (2006). On the one hand, the opinion of professionals was that informal caregivers have as much right to be included in the care process as the client. On the other hand, they argued that the involvement and collaboration with the informal caregiver was 'not always feasible and in the best interest' of the client (Goodwin & Happell 2006: 139).

The focus was often more on the client than on the informal caregiver (Carpentier et al. 2008). Although listening to both client and informal caregiver is often seen as essential, this was not always done in practice (Aujoulat et al. 2002, Pickard & Glendinning 2002). Carpentier et al. (2008) reported that the worries and concerns about the informal caregiver were not always reported by professionals because they did not immediately affect the relationship with the client (p. 725).

Caregivers are essential

The professional perspective on the informal caregiver was also dichotomous. Boros (2010) mentioned informal caregivers made the job easier for the professional. Jansen et al. (2009) went further by arguing that professional care is impossible to maintain without informal caregivers. In this light, professionals sometimes identified specific tasks for the informal caregiver. They were mostly seen as being able to do 'dirty hands-on work that is easily learned' (Ward-Griffin 2001: 70), keeping clients socially connected, helping with activities of daily living (ADLs'), and providing peace of mind for the client (Peckham et al. 2014). Additionally, some professionals' mention that informal caregivers were said to play a vital role in keeping older persons in the community (Peckham et al. 2014). Walker & Dewar (2001) argued that the quality of care given to the client increased when the informal caregiver was involved.

There were also concerns expressed. Mosack and Wendorf (2011) described that informal caregivers can be helpful and unhelpful in the care provided by professionals to clients. For example, the emotions expressed by the informal caregiver can influence the freedom of choice for the client (Buscher et al. 2011). Informal caregivers may also have unrealistic expectations of the service system, which leads to unhelpful behaviour (Goodwin & Happell 2006).

That caregivers were seen as essential can also create difficulties: professionals took caregivers for granted (Walker & Dewar 2001), or they confirmed that informal caregivers took on too much responsibility (Fjelltjun et al. 2008). Although most professionals understood the informal caregiver as playing a large role, they realised this can be difficult for the informal caregivers. Professionals noted that informal caregivers need extra support services (Dal Bello-Haas et al. 2014), with a special emphasis on respite services. Jansen et al. (2009) suggested professionals should provide information about terminology unknown to the informal caregiver. When services are provided, a caregiver should be able to choose the professional for the service, although this is not always available (Ward-Griffin 2001).

Mismatch between services and needs

Professionals reported a mismatch often exists between services for informal caregivers and their needs (Jansen et al. 2009, McPherson et al. 2014). Several studies show that a mismatch might be the result of competency. For example, providing emotional or psychological support for the caregiver was seen as essential, but for professionals this was more difficult to do (Ward-Griffin 2001, Aujoulat et al. 2002, Carpentier et al. 2008). It was sometimes easier to instrumentalise the caregiver's needs, rather than providing emotional support (Levesque et al. 2010). By doing so, the caregiver turned into a quasi-professional, 'whose main role is to compensate for their frail relative's losses and to provide nursing care, obliterating the difference between intimate and professional relationships' (Guberman et al. 2006: 47). At times this created a feeling of insecurity among professionals. Fjelltjun et al. (2008) gave an example: 'regional nurses often feel helpless when they do not have the resources to relieve the situation' (p. 62).

Moreover, there were difficulties in coordinating support services (Dal Bello-Haas et al. 2014) or in unclear expectations within the collaboration. Professionals were not always proactive in offering informal caregivers rest or respite care (Ward-Griffin & McKeever 2000, Pickard & Glendinning 2002) while informal caregivers may be used to having services suggested instead of asking for them (Levesque et al. 2010). A mismatch may also be found in the difference of opinion about the provided care between professionals and informal care (Aujoulat et al. 2002, Boros 2010). Informal caregivers are often negative, while professionals are often positive about the interactions (Boros 2010). Both parties could have a different opinion and perspective on what a relationship should entail (Carpentier et al. 2008, Buscher et al. 2011).

Professionals feel restricted in collaborating with the caregiver

From the macro level, professionals described that collaborating with informal caregivers was done within a system of parameters and criteria. This often limited the possibilities for collaboration (Jansen et al. 2009). A major restriction was the societal and legislative system in which professionals work. Organisational structures and stakeholders influence the collaboration (Walker & Dewar 2001, Carpentier et al. 2008, Buscher et al. 2011). The professional has a legal obligation towards the client but not to the caregiver (Goodwin & Happell 2006).

The partnership approach is often mentioned as a way to support informal caregivers but, as already mentioned, this is a difficult thing to do. Reasons for this are found in the partnership approach because it often takes more time than is available (Leveque et al. 2010). This is based on the situation in which cost cutting solutions are implemented by the government, making the interface between professionals and informal care a constant topic of negotiation (Ward-Griffin 2001). This has a direct influence on the roles professionals want and can take.

Restriction was often further worsened by lack of agreement between professionals (Dal Bello-Haas et al. 2014) regarding how to collaborate with informal caregivers. A professional might be 'fearful of being reprimanded (by colleagues) and therefore restrict themselves to only give basic advice (Carpentier et al. 2008: 729). This may be linked to feelings of not being competent in providing support to an informal caregiver. Dal Bello-Haas et al. (2014) described that one-fourth of their sample was uncomfortable or not confident in providing support. Jansen et al. (2009) reported that more than half of their sample did not feel completely confident (p. 9). Buscher *et al*. (2011) brings to light that trust building is often seen as important when supporting caregivers, but trust building is not included in the educational preparation of nurses. Respondents in the study by Dal Bello-Haas et al. (2014) expressed a desire for more information and training on family support strategies.

Diversity in the care triad

Some professionals saw diversity as an aspect that influences collaboration and which has to be taken into account. Carpentier et al. (2008) argued that diversity can be stimulating or stressful. When the diversity in a relationship is experienced as stressful, it complicates the collaboration with the informal caregiver and becomes problematic. Pickard and Glendinning (2002) observed that cultural differences have an impact on the balance of roles within the collaboration.

Other dimensions of diversity mentioned included urban versus rural areas, gender, economic stages, and age. In an urban community, one can sometimes only rely on kin-caregivers and not on neighbours (Jansen et al. 2009). Gender matters because professionals expressed that male caregivers required more support from a professional (Pickard & Glendinning 2002). Pickard and Glendinning (2002) described the impact of economic status on the support caregivers may receive. Professionals expressed that families who have a higher economic status could not get the same support as a lower income family. Ward-Griffin (2001) argued that younger women should be encouraged to lead their lives while older women should be encouraged to be an informal caregiver.

Discussion

Based on a thematic synthesis of 22 studies, seven themes emerge in which different experiences and reflections of professionals reveal the complex, multifaceted, and dynamic interface of professional and informal care. The 22 studies were originally conducted in the United States, Canada, South Africa, Israel, Australia, New Zealand, and different countries in Europe. Table 2 shows the seven themes organised per country, with countries in Europe grouped together. It is likely that policy environments influence the professional perspective on the collaboration with informal caregivers. However, it is not possible to make the link between policy environments of the different countries and the identified themes based on the rather small number of included studies and that, as shown in Table 2, the themes are rather evenly divided among the countries.

Twigg (1989) describes three frames of reference regarding the relationship with informal caregivers. The policy structures in the Netherlands, as described in the introduction, ideally see informal caregivers as co-workers. In this frame of reference there is an aim at cooperation and an enabling role for professionals. As comes forward in the first theme, professionals themselves argued for a partnership approach or family-centred approach when working with a care triad. This partnership goes even further and includes shared decision-making about the care provided for the care recipient. However, such a thorough partnership has not yet been achieved in practice due to the complex context in which supporting informal caregivers takes place. Although the main legal obligation of the professional is towards the care recipient, the professionals acknowledged that the informal caregivers should be supported and involved in the care triad. This was, in some countries difficult due to many restrictions on the individual and policy levels.

Professionals expressed that they were not confident or qualified to support informal caregivers and work in a satisfactory partnership with them. The level of including the informal caregiver was restricted mostly to informing and involving the informal caregiver in what the professional was doing from their professional viewpoint. The final stage at the other end of the continuum of complete participation and working in a partnership with shared decision-making had not yet been reached.

Strengths and Limitations

All 22 studies focused on the professionals' experience regarding working with informal caregivers. Studies were gathered from six different electronic databases and represented 10 different countries and at least eight different professions. All studies were published after 2000. This increases the transferability and trustworthiness of the findings (Sandelowski & Barosso 2003). The search strategy, using six databases and a combination of MeSH and free-text terms, produced a heterogeneous set of studies. There are several potential limitations to this review. Articles were included only if they were published in English or Dutch. Therefore, some assessments may have been excluded. The first selection was made on abstracts; thus, it is theoretically possible that studies about the professional perspective could have been missed. However, we checked the reference lists from the included articles, so this is unlikely.

A well-established method for reviewing, data extraction, summary and thematic synthesis was used in this study. All phases of this study were peer reviewed. Creating a thematic synthesis goes beyond the preliminary results and results in a higher level of evidence regarding the interface between informal caregivers and professionals (Sandelowski & Barosso 2003).

The findings might be less applicable to social work professionals and professionals at the management level as they are underrepresented in the included studies. This may also be the case for professionals working with caregivers with a different cultural background; the included studies mostly did not take this aspect into account. Because the included articles all originate from Western countries, there might be a bias towards perspectives on care, in that this will mainly be a Western perspective on care. Also, all caregivers were providing care for children; all care recipients in the included studies were adults. This might have affected the experienced outcome of working together with informal caregivers.

Caution should be taken when considering the transferability of our findings as the care system in each country will influence the triad. However, the act of synthesis could be viewed as similar to the role of a research used when reading a piece of qualitative research and deciding how useful it is to their own situation. In the case of thematic synthesis, professionals' experiences captured in themes translate from one situation to another.

Implications for practice, research, and education

Implications for practice become evident in all themes. A partnership approach should be pursued rather than simply working alongside an informal caregiver. Furthermore, there should be a dialogue in the interface between professionals and informal caregivers to eliminate the discrepancies in experiences between professionals and informal caregivers. Support for informal caregivers should be included more in the curricula of allied health, nursing, and social work education. This aligns with the emphasis policies are placing on informal care structures (Kaljouw & van Vliet 2015). While there is no correspondence between policy and practice, this can be addressed through education.

On the policy level, emphasis was placed on informal care structures, which requires the support of professionals to prevent caregiver burden and create a satisfactory working environment (Kemp et al. 2013). Currently, informal caregivers play a large role that can have both positive and negative impacts on the caregiver (Verbeek-Oudijk et al. 2014). It can provide a sense of meaning and satisfaction (Tonkens et al. 2008) and can also lead to stress and caregiver burden. Providing informal care can influence aspects of emotional, relational and material wellbeing, showing that the caregiver role is adversely associated with health (Berglund et al. 2015). However, the influence on the wellbeing of the caregiver is associated with other factors, for example the timing and intensity of the provided care (Vlachantoni 2016). Vlachantoni (2013) also show that 'the impact of informal care provision on the health status of informal carers should be considered alongside other aspects of, and transitions between, an individual's social and economic roles, and alongside the carer's demographic and health characteristics before, during and after the caring activity' (p. 117).

This is put into perspective by the observation that there is often no time provided by organisations to support informal caregivers. Support for informal caregivers is in most cases only provided when there is time left over after caring for the care recipient. As a consequence, it is done informally and without structure.

Further research is necessary to deepen our understanding of collaboration within the care triad. Creating specific guidelines for professionals so they can navigate through the complex context of the care triad, with an emphasis on the partnership approach and family-centred care are needed. In particular, the diversity of informal caregivers and professionals should be taken into account, as little knowledge about the diversity component emerged in the current research included in this systematic review. Further research should be focussed on the entire care triad, therefore research should also include the care recipient. From the 22 studies included in the review, only one included care recipients in their sample. Due to the discrepancies in experiences between professionals and informal caregivers, participatory action research would be suitable; then the care triad can work together towards a satisfactory solution.

Conclusion

Working in collaboration with informal caregivers requires a different way of functioning for professionals. Professionals should not only be focussed on enabling participation of the client but also on supporting the informal caregiver by working in collaboration with him or her. The urgency to meet the support needs of informal caregivers is high. It is necessary to cultivate an awareness of how professionals can support these needs in collaboration with the caregivers and the care recipient.

From the professional's perspective, the collaboration was influenced by different factors on different levels. The context of collaboration was adversely affected by decisions of a political and organisational nature. The perspectives of the professional and informal caregiver on collaboration differ and professionals who are not confident limit themselves to only giving basic advice. This makes the collaboration a complex endeavour in need of specific guidelines and training for the professionals. Therefore, supporting informal caregivers should be included in the curricula of allied health, nursing, and social work education with an emphasis on diversity. This is necessary in light of the current policy changes in the Netherlands where an increased emphasis is placed on informal care structures.

Appendix 1

(((formal care*[tiab] AND informal care*[tiab]) OR (formal[tiab] AND informal care*[tiab]) OR (health service provider*[tiab] AND informal[tiab] AND care*[tiab]) OR (health provider*[tiab] AND informal[tiab] AND care*[tiab]) OR (health practitioner*[tiab] AND informal care*[tiab]) OR (health care practitioner*[tiab] AND informal care*[tiab]) OR (healthcare practitioner*[tiab] AND informal care*[tiab]) OR (home care service*[tiab] AND informal[tiab] AND care[tiab]) OR (practitioner*[ti] AND (family care*[ti] OR informal care*[ti])) OR formal care*[ti] OR formal support*[ti] OR formal service[ti] OR informal care*[ti] OR informal support*[ti] OR informal family care*[ti] OR ("Caregivers"[Majr] AND (informal[ti])) AND (formal OR professional* OR practitioner* OR nurse* OR occupational thera* OR physical thera* OR speech thera* OR dietitian* OR social work* OR allied health professio* OR physician assistant*) AND ("Social Support"[Mesh] OR "Communication"[Mesh] OR "Cooperative Behavior"[Mesh] OR "Delivery of Health Care"[Mesh:NoExp] OR cooperat*[tiab] OR assist*[tiab] OR communicat*[tiab] OR collaborat*[tiab] OR empower*[tiab] OR facilitat*[tiab] OR support*[tiab] OR provid*[tiab] OR affect*[tiab] OR perception*[tiab] OR coach*[tiab] OR enable[tiab] OR advocate[tiab] OR consult*[tiab] OR coordinat*[tiab] OR educat*[tiab] OR engage[tiab] OR relation*[tiab] OR reflect*[tiab]) AND ("Socioeconomic Factors"[MeSH Terms] OR "Sociological Factors"[Mesh] OR "Personality"[Mesh] OR "Demography"[Mesh] OR "Age Factors"[MeSH Terms] OR "Sex Factors"[MeSH Terms] OR "Social Class"[Mesh] OR "Culture"[Mesh] OR "Race Relations"[Mesh] OR "Interpersonal Relations"[Mesh] OR "Religion"[Mesh] OR demograph*[tiab] OR age[tw] OR gender[tw] OR ethnic*[tw] OR race*[tw] OR religion*[tw] OR social class*[tw] OR intersectionalit*[tw] OR identity marker*[tw] OR characteristic*[tw] OR factor*[tw] OR need*[tw] OR psychosocial[tw] OR difficult*[tiab] OR differ*[tiab]) AND ("Attitude"[Mesh:NoExp] OR "Attitude of Health Personnel"[Mesh] OR "Perception"[Mesh] OR feel*[tiab] OR experience*[tiab] OR perception*[tiab] OR perspective*[tiab] OR attitude*[tiab] OR view*[tiab] OR relation*[tiab] OR connect*[tiab] OR role*[tiab] OR focus*[tiab])))

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How am I a part of it? The struggles of participatory research

After a long day of teaching, I walked to the subway. My thoughts were already turning to my next appointment. I had planned a preparatory meeting, an informal gathering with a group of women who cared for family members with acquired brain injury. The meeting had been organized by a community social worker who had connected me to the organization to offer a potential starting point for carers' input into my PhD research.

On the way, I scrolled through my notes. I wanted to arrive prepared, focused and grounded. But as I left the station and tried to navigate towards the location, I felt uncertain. Was I going the right way? I hesitated for a moment in front of the building before pushing open the door. Inside, a room was filled with laughter and chatter. About twenty women stood or sat in small groups, some stirring pots in the kitchen, others handed out food. The air was filled with the smell of cardamom, fried onions and something sweet I couldn't place. For a moment, no one looked at me. I asked a woman nearby if I was in the right place. She smiled and replied that she didn't speak Dutch. Before I could feel entirely out of place, a vibrant woman walked up. "There you are!" she said loudly, clapping her hands to draw attention. The room fell silent. She introduced me to the group. Apparently, I was in the right place, but my carefully prepared notes now felt useless.

As the conversations began, curiosity emerged between us in unexpected ways. The women leaned forward with questions, not about acquired brain injury, but about me: Questions that felt intimate, even confrontational. "How much money do you make?" "Are you married? No? Why not?" "Do you have children?" "No?" "You have grey hair, it is time" I laughed but then hesitated. What am I sharing? Their questions were not harsh. They were woven with humour and genuine interest. There was no small talk, only the deep stuff, immediately. I felt the tension between wanting to be honest and the fear that honesty might set me apart. Would they feel alienated? Would they judge me, or worse, feel judged? The woman sitting next to me sensed my discomfort; she put her hand on my arm and smiled teasingly at me, which was comforting without words. As the evening unfolded, the directness of their questions was disarming, even refreshing. Curiosity softened the edges of discomfort. Despite the language barrier, we found ways to connect.

There was something deeply human about the way the conversations bounced back and forth, unstructured, sometimes off-topic, but honest. I left the meeting with more questions than answers. But I also left with a new sense of direction. I thought about trust not as something I could design or script, but as something that grows in warmth, in shared food, in stories exchanged.

In another conversation, weeks later, while visiting a Ghanaian church, I was speaking with a group of carers when someone said, mid-sentence: "We feel disadvantaged in Dutch healthcare because of our heritage." Suddenly, I was no longer in church. I was back in Ghana, walking through predominantly black communities as a white researcher. I remembered the sense of being different but never disadvantaged. My European privilege cushioned every encounter. I remembered the silent unease I felt when I visited Fort Elmina and tried to make sense, within its stone walls, of a history of colonial violence and the Atlantic slave trade. How do I respond to these comments now, not just as a researcher, but as a human being? Is it my place to answer or only to listen?

I began to see that the conversations that seemed off-topic, about history, identity, exclusion, were not detours at all. They were context. They shaped how carers entered care networks, how they were seen, heard or ignored within the healthcare system. Feelings of being an outsider or being treated differently, however subtle, colour the whole care experience.