



FEATURE ARTICLE

Comparative review of family–professional communication: What mental health care can learn from oncology and nursing home care

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ABSTRACT: *Because family members take on caring tasks and also suffer as a consequence of the illness of the patient, communication between health-care professionals and family members of the patient is important. This review compares communication practices between these two parties in three different parts of health care: oncology, nursing home care, and mental health care. It shows that there are important differences between sectors. Mental health stands out because contacts between family members and professionals are considered problematic due to the autonomy and confidentiality of the patient. The article explores several explanations for this, and, by comparing the three health sectors, distils lessons to improve the relationship between family members and health-care professionals.*

KEY WORDS: *communication, cross sector learning, family members.*

INTRODUCTION

Long-term illness not only affects patients, but also has a large impact on their family members. Many family members take on carer roles and have to cope emotionally with the patient's condition and their caring obligations (Bittman *et al.* 2004; Burden *et al.* 2000). Moreover, policy-makers increasingly expect family members of patients to take care of their relatives who are ill or have disabilities (Bittman *et al.* 2004; Burden *et al.* 2000). Because of the increased emphasis on the carer role of family members, it is important that health-care professionals, both doctors and nurses, not only recognize their position and their needs but also support them in their care-giving activities. When family members assume some

of the care activities that were previously provided by professionals, coordination and communication between professionals and relatives takes on new significance.

The position of family members generally seems to be acknowledged by health-care professionals. However, mental health care seems different in this regard. A recent study (Van de Bovenkamp & Trappenburg 2010) showed that family members of psychiatric patients report numerous difficulties; they find it difficult to share information with mental health-care professionals and feel that the professionals do not consult and support them enough. Family members report that mental health-care workers refer to the privacy and autonomy of the patient, which prohibits them from contacting family members. Many studies similarly emphasize the importance of family members in the care process and their need for support (Cheng & Chan 2005; Gasque-Carter & Curlee 1999; Gutierrez-Maldonado *et al.* 2005; Harden 2005; Legatt 2007; Rose 1997), while reporting simultaneously that, in practice, mental health-care professionals continue to pay little attention to family members (Clarke 2006;

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Gasque-Carter & Curlee 1999; Harden 2005; Legatt 2007; Ostman *et al.* 2000; Rose 1997). Although attention is often paid to family members in professional guidelines and in mental health-care policy (Lloyd & King 2003; Van de Bovenkamp & Trappenburg 2008), interestingly, such policy does not seem to be followed in mental health-care practice. This indicates the need for further study on how communication between professionals and family members of patients within the mental health sector can be improved.

In this paper, we discuss the results of a literature review on communication between health professionals and family members of patients under long-term care. We feel that a comparison of sectors might shed light on the situation regarding family members in mental health care. Therefore, in this article, we compare mental health to the sectors oncology and nursing home care. We chose these sectors because family members can play an important role in the care for cancer patients and nursing home patients as well. Hence, communication between professionals and family members is important in these sectors. Comparing these sectors might help us gain insight into the particularities of mental health care and provide us with ideas for improvement. The aim of this study was threefold: (i) to see whether mental health care is, indeed, different compared to other sectors with regard to the position of family members; (ii) to identify possible explanations for these differences; and (iii) to identify lessons to improve the situation in mental health care.

In the remainder of this article, we will refer to people needing mental health care as ‘patients’. We are aware that this is not standard practice. Sometimes (and some places/countries vary in this respect) mental health patients are referred to as ‘clients’ or ‘consumers’, which is presumed to have and may, indeed, have an empowering effect. However, using the term ‘consumer’ might make society less inclined to show solidarity with mental health patients; it seems fair for tax payers to contribute to the medical needs of patients; it is much less obvious that one should pay for the mere preferences of mental health consumers. Be that as it may, we do not want to engage in political debate on this issue. We intend to compare patients’ family members in three different sectors, and, for simplicity and readability, we will stick to this terminology.

METHODS

To learn more about the situation in mental health care, we decided to compare this sector with oncology and nursing homes. By this comparison, we can learn

about the different ways that health-care professionals perceive family members and how this influences communication between the two. We chose these sectors because they have important similarities. In all three cases, the condition of the patient can have a large impact on family members and family members can take on important caring activities. Therefore, in all three sectors, communication between professionals and family members is important. By choosing these three specialties we have examples of the situation in both the cure and the care sector to compare to mental health. Hence, we can gain insight into a range of possible communication practices between professionals and family members, which could be used to draw lessons for cross-sector learning.

To explore the contacts between health-care professionals and family members in different health-care sectors, we performed a literature review. This method was chosen because literature reviews can give an overview of a subject with the possibility of identifying common themes across the different studies (Green & Thorogood 2009). In this case, it gave us the opportunity to obtain an overview of family–professional contacts in different sectors. We performed searches in the Pubmed/Medline database, the Cochrane Library and the Web of Science for the period January 1998–February 2011. Key words used were: ‘family member professional communication mental health’ (272 hits), ‘family member professional communication nursing homes’ (82 hits), and ‘family member professional communication oncology’ (115 hits). These key words were chosen because contacts between the two parties in the different sectors are captured this way. Furthermore, communication captures different types of contacts between family members and professionals: for instance, sharing information and consultation. Other search combinations were also tried, such as ‘family members oncology’, but this search strategy was too broad. Focusing on carers instead of family members resulted in too little information, as did search strategies focusing on ‘contacts’ rather than ‘communication’. The same held for a focus on ‘information’, which resulted in too little insight into the broader range of contacts.

We excluded articles that did not focus on family–professional contacts or focused on other sectors of care. In addition, we excluded articles that focused on the care of young children because, in this case, the parents are the formal representatives of their children, which makes them the primary focus of communication of health-care professionals. We did include articles that concerned the care for minors who had their parents as their legal representatives but who were old enough to form their own opinion about their care. Furthermore, we excluded

articles on end-of-life decisions, as these represent a very specific situation and cannot easily be compared to other family-professional contacts. We also excluded articles that were not written in English or could not be obtained through our national library system (for the period we studied, the national library system offered near complete access to the articles that came up in the search). We did not exclude articles on the basis of the validity of the studies because we were also interested in how communication between family members and health-care professionals was described and reflected on in a general sense. Therefore, we also did not exclude articles that did not have communication between professionals and family members as their core focus, because the way family members are talked about and how their role is framed in the care process also gave us valuable information. On the basis of an analysis of title and abstract and, in case of doubt, the analysis of the whole article, we included 85 articles in total: 28 studies on oncology, 25 studies on nursing homes and 32 studies on mental health care.

We performed a thematic content analysis on the included articles (Green & Thorogood 2009). On the basis of the research aims and first analysis of the data, we established an analytical schema. We analysed the articles on the following themes: (i) the nature of the study (empirical or not); (ii) the focus of the article (whether family member communication is the primary focus of the article); (iii) the role of family members in the care process (are they seen, for example, as fellow carers, fellow patients, or patient representatives?); (iv) contacts between family members and health-care professionals (are these contacts described as, for example, important/problematic or as part of the job of health-care professionals?); (v) difficulties encountered in the communication between the two (what are these difficulties and what is their nature?); and (vi) recommendations for the future (how can/should these contacts be improved?).

RESULTS

To structure the results, we first discuss each sector separately and then make a comparison between sectors. More information about the individual studies can be found in the tables.

Oncology: the patient and the family as a focus of care

Of the 28 included articles, only seven specifically focused on professional-family member contacts (DuBenske *et al.* 2010; Ostlund 2010; Ozdogan *et al.* 2004; Spetz *et al.* 2005; Tamayo *et al.* 2010; Turner *et al.* 2007; 2008). In the

remaining articles ($n = 21$), family members were one of several subjects discussed or mentioned in passing.

It is generally recognized in the literature that cancer seriously affects not only patients but also their relatives. As a result, contacts between family members and health-care professionals in oncology are considered part of the job of professionals. In the reviewed studies, patients and family members are often mentioned together (Arnaboldi *et al.* 2010; Charalambous *et al.* 2009; Coon *et al.* 2007; Fallowfield *et al.* 2004; Jakel 2002; Kataoka *et al.* 2005; Penner 2009; Radziewicz *et al.* 2001; Salminen *et al.* 2004; Weingart *et al.* 2009). It is acknowledged that both patients and their family members need to be informed and supported (Arnaboldi *et al.* 2010; Baider 2008; Charalambous *et al.* 2009; Coon *et al.* 2007; DuBenske *et al.* 2010; Fujimori *et al.* 2007; Ostlund 2010; Penner 2009; Repetto *et al.* 2009; Salminen *et al.* 2004; Spetz *et al.* 2005; Tamayo *et al.* 2010; Turner *et al.* 2007). In addition, it is mentioned that family members of oncology patients take on many caring activities (Charalambous *et al.* 2009; Coon *et al.* 2007; DuBenske *et al.* 2010; Ostlund 2010; Penner 2009; Spetz *et al.* 2005; Tamayo *et al.* 2010). Therefore, it is recognized that family members are important in the care process. Moreover, patients value the support of their family members and want them to be present at consultations (Fujimori *et al.* 2007; Kataoka *et al.* 2005; Repetto *et al.* 2009; Sapir *et al.* 2000; Young *et al.* 2003).

Although it is generally recognized that communication should be directed towards both patients and family members, some problems are identified. Daily practice is not always perfect. Professionals sometimes have a hard time working with family members (Baider 2008) and young children of patients with severe illness (Turner *et al.* 2007). In two studies, family members and patients report that they do not receive all the information and support that they feel they need (Coon *et al.* 2007; Salminen *et al.* 2004). Interestingly, our analysis shows that, in some cases, the focus on the family seems to be too strong. For example, in the case of young patients, the strong role of parents can marginalize patients themselves (Quinn *et al.* 2009; Young *et al.* 2003). In traditional family-oriented countries, such as Italy and Asian countries, the strong focus on the family also raises questions for some authors. In these countries, health-care professionals sometimes inform family members of the diagnosis and leave it up to the family to inform the patient or not. This can result in the patient not being informed because his or her family members think this is best (Fujimori *et al.* 2007; Kissane 2004; Repetto *et al.* 2009; Surbone *et al.* 2004; Ozdogan *et al.* 2004). This problem is

also identified in a study focusing on interpreters in Australia, who report being asked by family members not to translate all the information to the patient (Butow *et al.* 2010).

Although two authors claim that oncology should become more family focused (DuBenske *et al.* 2010; Ostlund 2010), our analysis shows that, in most countries, communication and support activities of professionals are directed at both patients and family members, although some practical problems do occur. In some countries, the balance between concentrating on the family and the patient is disturbed by focusing on the family too much. An overview of the articles on oncology is presented in Table 1.

Nursing homes: Building partnerships between professionals and family members

In the nursing home sector, family members are an object of research in their own right. Family members were the specific focus of a large part of the articles on nursing homes (19 of the 25 included articles) (Bluestein *et al.* 2007; Boise *et al.* 2004; Gladstone *et al.* 2000; Hertzberg *et al.* 2000; 2003; Isola *et al.* 2003; Kellet 2007; Marziali *et al.* 2006; Mellor *et al.* 2008; Robison *et al.* 2007; Rosen *et al.* 2003; Rosher *et al.* 2005; Lindgren *et al.* 2001; 2002; Looman *et al.* 2002; Pillemer *et al.* 1998; Ward-Griffin *et al.* 2003; Weman *et al.* 2006; Westin *et al.* 2009). The other studies mentioned contacts with family members in passing (Chang *et al.* 2009; Cohen-Mansfield *et al.* 2003; Gould *et al.* 2009; Hasson *et al.* 2011; Lopez 2009; Winn *et al.* 2004).

The relationship between family members and professional health-care workers is different in nursing homes than in oncology. Residents are often in such a dire state that they cannot represent their interests themselves. In these cases, family members make decisions for them. Contacts between professionals and family members occur regularly. It is acknowledged in the literature that family members may represent the interests of the patient, that they may have important information about the patient that professionals can use to provide good care, that they play an important support role for patients, and that they are affected by the condition of their family member themselves (Chang *et al.* 2009; Cohen-Mansfield *et al.* 2003; Gladstone *et al.* 2000; Gould *et al.* 2009; Hasson *et al.* 2011; Hertzberg *et al.* 2000; 2001; 2003; Isola *et al.* 2003; Kellet 2007; Lopez 2009; Marziali *et al.* 2006; Mellor *et al.* 2008; Robison *et al.* 2007; Rosen *et al.* 2003; Weman *et al.* 2006; Westin *et al.* 2009; Winn *et al.* 2004). Hence, communication with and support of family members is considered essen-

tial (Hertzberg *et al.* 2001; 2003; Isola *et al.* 2003; Kellet 2007; Lopez 2009; Marziali *et al.* 2006; Mellor *et al.* 2008; Robison *et al.* 2007; Westin *et al.* 2009; Winn *et al.* 2004;). Professionals report that family members are important and that contacts with family members are part of their job, although they do not always have the highest priority (Hertzberg *et al.* 2003; Weman *et al.* 2006). In this sector, authors write about building partnerships between professionals and family members to provide good care to the patient (Bluestein *et al.* 2007; Gladstone *et al.* 2000; Isola *et al.* 2003; Kellet 2007; Robison *et al.* 2007; Rosher *et al.* 2005; Weman *et al.* 2006).

The contacts between family members and professionals in nursing homes might cause problems, however, and many studies conclude that this relationship should be improved (Chang *et al.* 2009; Hasson *et al.* 2011; Hertzberg *et al.* 2000; Isola *et al.* 2003; Kellet 2007; Marziali *et al.* 2006; Mellor *et al.* 2008; Pillemer *et al.* 1998; Robison *et al.* 2007; Rosher *et al.* 2005; Weman *et al.* 2006; Westin *et al.* 2009; Winn *et al.* 2004; 2001). One study concludes that the focus on the family is too strong and the opinion of residents themselves is not always sought (Lopez 2009). However, more often, family members report that they want more and better contacts with professionals (Hertzberg *et al.* 2000; 2001; Isola *et al.* 2003; Kellet 2007; Marziali *et al.* 2006; Mellor *et al.* 2008; Robison *et al.* 2007; Westin *et al.* 2009). They also report on not being listened to or not being taken seriously (Marziali *et al.* 2006). Professionals sometimes find it difficult to attend to family members (Bluestein *et al.* 2007; Chang *et al.* 2009; Hertzberg *et al.* 2000; Lopez 2009; Robison *et al.* 2007; 2003; Weman *et al.* 2006), and studies show that they lack the necessary skills for this task (Bluestein *et al.* 2007; Chang *et al.* 2009; Hertzberg *et al.* 2000). In addition, it is claimed that the number of professional–family contacts is insufficient due to time constraints and the structure or philosophy of the care institution (Hertzberg *et al.* 2003; Rosher *et al.* 2005; Weman *et al.* 2006). Several studies suggest ways to improve the situation: for example, by training professionals and family members, by organizing family meetings, or by providing checklists (Bluestein *et al.* 2007; Chang *et al.* 2009; Hertzberg *et al.* 2000; Looman *et al.* 2002; Robison *et al.* 2007; Rosen *et al.* 2003; Rosher *et al.* 2005; Pillemer *et al.* 1998).

The literature on nursing homes focuses on building partnerships between family members and professionals. Although in practice this is not always carried out satisfactorily, generally, dealing with family members is considered part of the job of professionals. An overview of the articles on nursing homes can be found in Table 2.

TABLE 1: *Oncology*

Article	Type of study	Focus article	Findings regarding family members
Ostlund (2010)	Guest editorial	Plea for a paradigm shift towards family nursing in oncology care.	Cancer affects both patients and their families. Families are also a resource and need support. The activities of nurses should be directed at both. This happens too little in practice and more attention regarding and research into this topic is warranted.
DuBenske <i>et al.</i> (2010)	Empirical, secondary analysis RCT with caregivers (112) USA	Examination of the relationship between informal caregivers' information competence, their involvement within clinic visits, and their satisfaction.	Cancer affects both patients and their families. Effective communication with both is critical for their ability to cope. The ability of caregivers to make use of information increases the likelihood of their participation in clinic visits. At the same time, this participation may be a critical factor in caregivers getting their information needs met and being satisfied. Clinical systems need to recognize the caregiver's role and partner with both patient and family to deliver patient and family centred care.
Arnholdt <i>et al.</i> (2010)	Empirical, analysis of contacts between psychologists and patients and relatives (430) Italy	Evaluation of a psychosocial cancer phone centre for patients and their relatives.	Patients and relatives are mentioned together. Both need psychosocial support to deal with the situation. Both patients and relatives use the call centre; the majority ask for psychological support.
Tamayo <i>et al.</i> (2010)	Empirical, survey among family caregivers (194) USA	Description of quality of life and well-being of family caregivers of patients with leukaemia, and identification of strategies to improve QOL and well-being.	Family members who care for patients at home take on many caring tasks, experience burden, and report education and skill deficits. Health-care professionals should provide them with support. Recognition of educational, psychosocial and communication needs are very important.
Butow <i>et al.</i> (2010)	Empirical, focus groups with interpreters (30) Australia	Understanding interpreters' perceptions of their role, their challenges, and training and support needs. Family members are not the specific focus of the article but are one of the items discussed.	Family members can be a challenge for interpreters working in oncology wards. Family members are reported to ask them not to disclose a cancer diagnosis to the patient and family members interpret themselves giving the patient inaccurate information. Doctors should be responsible for managing these problems.
Charalambous <i>et al.</i> (2009)	Empirical, interviews with patients (25), nurses (20), and patient advocates (6) Cyprus	Description of experiences of patients of nursing care. Family members are not the specific focus of the article but one of the items discussed.	Patients and family members are often mentioned together; cancer affects them both and communication should be directed at both. In addition family members offer support and care to the patient. In that role, they can work together with nurses.
Penner (2009)	Review	Identification of psychosocial challenges of patients with head and neck cancer and their families.	Patients and family members are often mentioned together. They both need support. In addition to dealing with their own emotions family, members take on care activities, which also cause distress. Family members need psychological support from health-care providers. More research is needed into how to do this best.
Quinn and Vadaparampil (2009)	Empirical, interviews with paediatric oncologists (24) USA	Exploration of communication issues on fertility preservation regarding adolescent patients. Family members are an important focus of the article.	The topic of fertility preservation is a sensitive one for both parents and patients. Physicians should consider having these conversations separately with parents and patients. Professionals need training to do this well.
Weingart <i>et al.</i> (2009)	Descriptive USA	Examination of patient-oriented teamwork training for oncology patients and their families. The article does not have family members as its special focus; they are mentioned in passing.	Patients and family members are mentioned together. The training programme gives them more control.

Repetto <i>et al.</i> (2009)	Empirical, structured interviews with oncology patients over 65 (622). Italy	Research into the communication preferences of elder patients. The role of family members was one of the items in the study.	The majority of patients consider their family as their main source of support and want them to be informed and participate in consults. They also need to be supported by health-care professionals. Sometimes family members are informed but the patients themselves are not; this is considered an undesirable situation.
Turner <i>et al.</i> (2008)	Descriptive Australia	Description of the development of a manual to guide supportive care. It described the effects on children of patients and how to deal with them.	A cancer diagnosis affects the whole family, including the children of the patient. It is considered part of the job of nurses to support patients and their children, although they do find this difficult and do not know how to do this; therefore, they need to be trained.
Piredda <i>et al.</i> (2008)	Empirical, survey amongs oncology patients (111). Italy	Research on patient communication preferences. Family members are one of the items in the study.	Most patients want to be informed together with their family. They do not want their family to be informed before them, which is in contrast with the idea frequently held by Italian physicians and families.
Baidar (2008)	Short communication article.	Examination of how communication, in its multi-faceted forms, can be the conduit by which the patient, family, and health-care team negotiate their way through the illness trajectory.	Having a sick relative is not easy for family members. Professionals sometimes have a hard time dealing with family members because family members can be difficult.
Coon <i>et al.</i> (2007)	Empirical, diary of a wife of a cancer patient. New Zealand	Examination of what is important in health care from the perspective of patient and carer.	Patient and family members are mentioned together. Family members are severely affected by a cancer diagnosis. Family members are often primary carers. Communication and support of patients and family members is very important but does not always happen satisfactorily in practice.
Turner <i>et al.</i> (2007)	Empirical, four focus groups with nurses (24) and interviews with nurses (5). Australia	Study on the perceptions of nurses about the support of children with a parent with cancer.	Having a parent with cancer has a large impact on children; parents find it difficult to deal with this and need support from nurses. Nurses perceive this as their job but do find it difficult; they identify a lack of knowledge and skills. They also identify a culture in which the needs of family members are peripheral to clinical care.
Fujimori <i>et al.</i> (2007)	Empirical, survey among cancer patients (529). Japan	Study on patient preferences about the disclosure of bad news. One of the items focuses on the role of the family.	Patients want their family members to be informed and professionals to show concern about the feelings of their family. In Japan, the patient's family is often informed before the patient.
Spetz <i>et al.</i> (2005)	Empirical, field notes nurses and interviews with patients and family members. Sweden	Investigation of how the family responds to the implementation of a specialist nurse as a resource for the patient and the family.	Most of the family members in the study have much contact and are happy with the specialist nurse; he or she provides them with practical and emotional support and information. The patient and his or her family are mentioned together in this article as well as separately because they can have different needs. However, this is not considered a problem.
Kataoka <i>et al.</i> (2005)	Descriptive Japan	Description of the concept of multidisciplinary medical treatment used in a cancer centre in Japan, which will allow for medical care as desired by patients and family. Not a special focus on family members.	Important to provide the best care to patient and family members. The patient and his or her family are mentioned together.

TABLE 1: Continued

Article	Type of study	Focus article	Findings regarding family members
Surbone <i>et al.</i> (2004)	Literature review Italy	A review of the published data on informed consent and truth telling in Italy.	Family members still act as a filter of information in Italy, which could mean that the patient is not informed about his or her diagnosis.
Salmimen <i>et al.</i> (2004)	Empirical, survey among patients (96) and spouses (72). Finland	Examination of the needs and sources of disease information of breast cancer patients and their spouses. Family members are not the specific focus of the article but it is recognized that they need information as well.	Patients and family members are mentioned together. Family members are also affected by the diagnosis. Patients perceive a lot of support from their family. A number of them regularly accompany the patient to appointments. Some spouses reported that their information needs were ignored.
Kissane (2004)	Editorial	Examination on how to deal with differences of opinion between patients, family, and health-care professionals.	The position of family members is different depending on cultural context. Autonomy is not privileged above other principles, but is limited by a tension between the unencumbered self and an individual in a contextualized world.
Ozdogan <i>et al.</i> (2004)	Empirical, survey among family members (150). Turkey	Evaluation of relatives' attitudes towards informing cancer patients about their diagnosis.	Patients are not always informed about their diagnosis because the family thinks this is best (66%); they feel that the news would extremely upset the patient or they think the patient does not want this. On the basis of the literature, it is concluded that this situation is undesirable.
Fallowfield <i>et al.</i> (2004)	Literature review	Review of research on giving bad news. Family members are not a specific focus of the article but are mentioned in passing.	Patients and family members are mentioned together. It is important to improve communication about bad news.
Young <i>et al.</i> (2003)	Empirical, semi-structured interviews with parents (19) and patients (13). UK	Examination of young people's and parents' accounts of communication about cancer in childhood.	Parents take on an executive like role; they often decide what information their children receive. The patients welcomed their parents' involvement; however, some express unease with the constraining aspects of their parents' role. This did not mean that the young people regarded their parents' involvement in communication as inappropriate in principle.
Jakel (2002)	Descriptive	Overview of cancer related fatigue. Family members are not a special focus in the article.	Patients and family members are mentioned together. The importance of informing and communicating with them is emphasized.
Radziewicz <i>et al.</i> (2001)	Descriptive	Focus on how to deliver bad news. Family members are not a special focus in the article.	Patients and family members are mentioned together. Nurses should support and inform patients and their family.
Sapir <i>et al.</i> (2000)	Empirical, interviews with patients (103). Israel	Evaluation of patients' knowledge of their diagnosis and stage, their expectations of medical and nursing staff, and issues related to communication. Family members are not a special focus in the article.	Most patients report that they discuss news with and consult about treatment options with family members. A small percentage (6%) wants information conveyed to family members but not to themselves.
Carlsson <i>et al.</i> (1998)	Empirical, interviews with patients (24). Sweden	Focus on the information patients receive. Family members are not a special focus in the article.	There are several advantages of having a relative present when receiving information. However, not all of the patients had a family member present. When it is in accordance with the patient's and the family's wishes, efforts should be made to provide information at times when both can participate. The patient and the family should be considered as the unit of care.

RCT, randomized controlled trial.

TABLE 2: *Nursing homes*

Article	Type of study	Focus article	Findings regarding family members
Hasson and Arnetz (2011)	Empirical, cross-sectional survey among care recipients (541) and relatives (780) Sweden	Comparison of how care recipients and relatives perceive the quality of care in home-care and nursing homes	Relatives rate the quality of care in home-care significantly lower regarding different aspects of care. It is hypothesized that interactions between staff and relatives is harder in home-based care. Further research into potential hindrances to interact with family members is necessary, especially in home-based care. This is important because they often have an active role in care provision.
Gonid and Reed (2009)	Descriptive USA	Description of dementia care training and its development of direct care workers and nurses. Family members are not the specific focus of the article but are mentioned in passing.	The importance of family involvement in all aspects of care and decision-making is emphasized throughout the curriculum.
Westin <i>et al.</i> (2009)	Empirical, interviews with relatives (13) Sweden	Exploration of the meaning relatives give to encounters with nurses in nursing homes.	Relatives play an important role in the caring process. The meaning of relatives' experiences can be understood as being invited. Relatives too need to be invited and cared for. Most respondents had positive experiences with this, although there were also instances where they felt ignored. It is important to optimize encounters with relatives to provide a positive outcome for residents.
Lopez (2009)	Empirical interviews (10) with nurses and observations (74 hours) USA	Exploration and description of decision-making processes used by nurses to respond to acute illness of residents. Contacts with family members play an important role in this.	Nurses feel 'in the middle'; they want to create a treatment plan that is acceptable to family members, doctors, and residents. Sometimes the focus on family members is too strong, because regardless of residents' decision-making capabilities, nurses consult with family members first; the opinion of residents themselves is not always sought.
Chang <i>et al.</i> (2009)	Empirical, focus groups (5) and in-depth interviews (20) with health-care professionals. Australia	Examination of the challenges for key professional providers of care for people with advanced dementia living in residential aged care facilities. Family members are one of the points that are discussed but not the specific focus of the article.	Family members function as proxy decision-makers. Health-care professionals sometimes find it difficult to deal with family members; they feel they lack knowledge and skills.
Mellor <i>et al.</i> (2008)	Empirical, interviews with family members (15). Australia	Examination of the perspective of family members of depressed elderly care recipients on the skills of professional carers in detecting and monitoring depression.	Family members act as interest representatives of patients. Signs of depression are often overlooked by professionals. Communicating about depression is difficult, whereas this is not the case in communication about the physical condition of the patient.
Robison <i>et al.</i> (2007)	Empirical, RCT. US	Evaluation of a training project to improve the relationship between family members and professionals.	The importance of a partnership is emphasized to achieve optimal quality care. The intervention increased and improved involvement. Residents' behavioural symptoms also improved as a result.
Kellett (2007)	Empirical, interviews with family caregivers (14) and participant observations. Australia	Exploration of the ways family members reconstruct meaning through seizing possibilities for positive care giving in nursing homes.	Family members have to deal with stress and fear. Therefore, communication with professionals is important and they need to be supported. This does not always happen satisfactory in practice. A genuine partnership needs to be established.
Bluestein and Latham Bach (2007)	Descriptive	Study on how certain theoretical models can inform communication with family members.	Professionals have two patients: the patient himself and his family; the latter also needs support and information. In practice, this communication can be a challenge because of difficult family members. In addition, professionals feel they lack the necessary skills and have concerns about time demands. A model is developed on how to improve this.
Marziali <i>et al.</i> (2006)	Empirical, interviews with family members (9) who had persistent concerns about the care of their relative. Focus groups (2) with nurse managers. Canada	Examination of institutional and family caregiver characteristics that contribute to the failure to resolve families' persistent complaints.	Family members experience stress; some of them need support. The family members in this study report problems in communication: mostly they felt that what they had to say was misunderstood, ignored, or challenged. Factors associated with persistent discord are: perceptions of staff as incompetent, interfamilial conflicts, and unresolved psychosocial issues. Contributing institutional factors are: staff vulnerability in the face of challenges to their professional competence and stress due to disproportionate amounts of time spent educating and supporting health-care aids to cope with distraught families.
Weman and Fagerberg (2006)	Empirical, survey among nurses (210). Sweden	Understanding of those factors that influence how nurses are able to work together with family members of older people living in nursing home facilities.	Working together is in the interest of all the parties involved. Nurses feel that communicating with family members is important in their work. They also recognize that it is important to support family members; however, they do not always have time for this.
Rosher and Robinson (2005)	Empirical, pre-post study, survey among family members (37) prior to and after 2 years of the implementation of an intervention. USA	Examination of the effect of an intervention (the Eden Alternative, which concerns a holistic model of care) on family satisfaction.	The Eden Alternative provided many opportunities for family involvement. The improved satisfaction scores reflected greater communication and interaction among families, staff, and residents.

TABLE 2: Continued

Article	Type of study	Focus article	Findings regarding family members
Boise and White (2004)	Opinion article USA	Exploration of the role that family members play in providing person-centred care and ways to successfully achieve family participation in this model of long-term care.	Family members are important in person-centred care. They can play both a negative and a positive role. Nurses need to be able to deal with them.
Winn <i>et al.</i> (2004)	Clinical practice article USA	Provision of practical information for health-care professionals on improving communication, including with family members.	Family members and patients are mentioned together. Health-care professionals need to guide them through difficult decisions. They need to be informed and able to attend plan conferences. Family members also need to be supported.
Ward-Griffin <i>et al.</i> (2003)	Empirical, interviews with family-nurse dyads (17). Canada	Insight into the relationship between family members and nurses on a long-term care ward and on how to improve this relationship.	There are different types of relationships between nurses and family members. It is important that the approach is family-centred; family members should be given the opportunity to participate or not.
Isola <i>et al.</i> (2003)	Empirical, survey among family members (624). Finland	Report on the quality of care as evaluated by family members.	Family members are very satisfied with care in general. Family members can play an important role in the care process. Most of them felt they had been adequately informed, given opportunities for participation and support. A minority felt they received too little information, participation possibilities, and support.
Rosen <i>et al.</i> (2003)	Empirical, focus groups and survey among family members (18). USA	A web-based system of interactive video training was tested to enhance family participation in nursing home care.	Family members are in a difficult position. Their participation in care can be important. Family members have too little knowledge to participate well; the computer-based videos can help them gain such knowledge.
Hertzberg <i>et al.</i> (2003)	Empirical, interviews with nurses (19). Sweden	Exploration and description of nurses' views and experiences of relatives of residents who live in nursing homes.	Relatives were seen as a resource and nice, although demanding. The nurses saw relatives as part of their work, a part that could be time consuming and had low priority. The relationship could be improved.
Cohen-Mansfield and Lapsion (2003)	Empirical, physicians (6) and nurse practitioners (3) completed questionnaires that described medical decision making processes for 70 residents. US	Description of the medical decision-making process. Family members are mentioned as playing a role in this; this is not the special focus of the article.	Family members are seen as representatives of the residents and they are often mentioned together.
Loonan <i>et al.</i> (2002)	Empirical, interviews with nurse assistants (114). USA	Focus on nurse assistant reports of both positive and negative behaviours exhibited by family members of cognitively-impaired residents.	Nurse assistants want to be treated nicely and with respect by family members. They derive satisfaction and good feelings from seeing that family members remain involved. Lack of involvement is a source of great distress to nurse assistants.
Lindgren and Murphy (2002)	Empirical, survey among family members and nurses (36). Sweden	Focus on the degree of agreement between nursing home staff and families in assessing the needs of cognitively-impaired nursing home residents.	Family members agree with staff on most of the needs of the resident, but disagree in their assessment of some aspects of physical functioning and privacy and boredom. Family members perceive them as bigger problems than nurses do.
Hertzberg <i>et al.</i> (2001)	Empirical, interviews with family members (28). Sweden	Exploration and description of the experiences of relatives in the next generation to that of older persons living in nursing homes regarding their interactions and relationships with staff.	Family members are positive about the care in general but identify some problems in communication. They need to take initiative for communication themselves. They want more information to be delivered spontaneously.
Hertzberg and Ekman (2000)	Empirical, focus groups with relatives and staff. Sweden	Description of relatives' and staffs' experiences of each other in their relationships.	Some family members do not get the right and complete information; they find it difficult to obtain the proper information. Staff were sometimes unsure about what information to share with relatives (e.g. information that relatives may find shocking); they also were unsure about how to support relatives, a lack of knowledge, and skills was identified.
Gladstone and Wesler (2000)	Empirical, interviews with family members (27) and observations of care. Canada	Exploration of how families perceive their relationships with staff.	Family members appreciate it when care and attention is given to residents and themselves, when they are informed, and when they are given opportunities to engage in joint problem solving. They actively try to <i>get along</i> with the staff. They want the relationship to be like teamwork.
Pillemer <i>et al.</i> (1998)	Empirical, survey and interviews with family members and staff USA	Study of an intervention (partners in care-giving programme) to prevent communication problems.	Family members and staff should be partners; the initiative can help in improving this relationship.

RCT, randomized controlled trial.

Mental health care: focus on the autonomous patient

In mental health-care, family members seem to be an object of research in their own right. Family members were the specific focus of most of the included articles on mental health care (24 of 32 articles included) (Berman *et al.* 2008; Clarke 2006; Cleary *et al.* 2006; Endrawes *et al.* 2007; Gavois *et al.* 2006; Goodwin *et al.* 2007; Harden 2005; Jakobsen *et al.* 2006; Jeon 2004; Kaas *et al.* 2003; Marshall *et al.* 2000; 2003; Meer *et al.* 2002; O'Connell 2006; Resnick *et al.* 2005; Riebschleger 2002; Rose *et al.* 2004; Rowe 2010; Schmetzer *et al.* 2008; Sjöblom *et al.* 2005; Stengler-Wenzke *et al.* 2004; Van de Bovenkamp *et al.* 2010; Wuerker 2000; Wynaden *et al.* 2005). The eight remaining articles did not specifically focus on family members, although relatives were mentioned in passing (Cross *et al.* 2010; Curtin *et al.* 2010; Kingston *et al.* 2011; Langlands *et al.* 2008; Maheux *et al.* 2006; Rapport *et al.* 2010; Srebnik 1999; Truman 2005).

The studies on mental health care show a growing awareness of the fact that family members of mental health patients play an important role in the care of their sick relative. It is acknowledged that family members take on practical care activities, that they represent the patient's interest when the patient cannot do this himself or herself, that they have important information about the patient, and they can provide support to the patient (Berman *et al.* 2008; Cross *et al.* 2010; Gavois *et al.* 2006; Goodwin *et al.* 2007; Jakobsen *et al.* 2006; Jeon 2004; Kaas *et al.* 2003; Kingston *et al.* 2011; Marshall *et al.* 2003; Rapport *et al.* 2010; Riebschleger 2002; Rowe 2010; Sjöblom *et al.* 2005; Van de Bovenkamp *et al.* 2010; Wynaden *et al.* 2005). The effects of a person with mental illness on the lives of his or her family members can be substantial (Gavois *et al.* 2006; Harden 2005; Jakobsen *et al.* 2006; Jeon 2004; Riebschleger 2002; Rowe 2010; Sjöblom *et al.* 2005; Stengler-Wenzke *et al.* 2004; Van de Bovenkamp *et al.* 2010; Wynaden *et al.* 2005). Thus, communication between family members and professionals is deemed important, as is professionals lending support to family members to deal with the situation (Berman *et al.* 2008; Cleary *et al.* 2006; Goodwin *et al.* 2007; Kaas *et al.* 2003; Kingston *et al.* 2011; Maheux *et al.* 2006; Marshall *et al.* 2003; Riebschleger 2002; Rowe 2010; Sjöblom *et al.* 2005; Stengler-Wenzke *et al.* 2004; Van de Bovenkamp *et al.* 2010; Wynaden *et al.* 2005). However, contacts between mental health-care professionals and family members seem to be problematic, and not just for practical reasons similar to the ones in other sectors, such as lack of skills and resources (Goodwin *et al.* 2007;

Kaas *et al.* 2003; Rose *et al.* 2004; Sjöblom *et al.* 2005), but for more principled reasons as well.

It is reported that some mental health-care workers still adhere to the idea that family members, especially mothers, are to blame for the condition of the patient (Harden 2005; Kaas *et al.* 2003; Riebschleger 2002; Schmetzer *et al.* 2008; Wuerker 2000), which was a common notion from the 1950s till the 1980s (Riebschleger 2002). Although at present much more is known about the causes of mental illness, this belief still affects contacts between the two parties. More importantly, contacts between family members and professionals are considered problematic by mental health-care workers because of issues of confidentiality and privacy (Berman *et al.* 2008; Cleary *et al.* 2006; Goodwin *et al.* 2007; Harden 2005; Jakobsen *et al.* 2006; Maheux *et al.* 2006; Marshall *et al.* 2000; 2003; Meer *et al.* 2002; Rose *et al.* 2004; Rowe 2010; Schmetzer *et al.* 2008; Sjöblom *et al.* 2005; Stengler-Wenzke *et al.* 2004; Wynaden *et al.* 2005; Van de Bovenkamp *et al.* 2010). It is felt that mental health workers cannot consult with or inform family members because this could damage professional–patient confidentiality. By consequence, family members complain that they lack information about diagnoses, about care plans, and even general information about mental health care. Family members also feel that they are not consulted enough, even when the patient is discharged and his or her family is supposed to step in and take on caring activities. Finally, family members lack support from health professionals (Clarke 2006; Endrawes *et al.* 2007; Marshall *et al.* 2000; Rapport *et al.* 2010; Rowe 2010; Resnick *et al.* 2005; Rose *et al.* 2004; Sjöblom *et al.* 2005; Stengler-Wenzke *et al.* 2004; Van de Bovenkamp *et al.* 2010; Wynaden *et al.* 2005). Although many professionals in mental health care consider the contacts with family to be problematic, not all of them do. Variation in contacts with family members is reported; some professionals do inform, consult with, and support family members (Goodwin *et al.* 2007; Jakobsen *et al.* 2006; Marshall *et al.* 2000; 2003; Schmetzer *et al.* 2008; Van de Bovenkamp *et al.* 2010). Studies reporting on problems between family members and mental health-care professionals all argue that contacts between family members and professional staff need to be improved. Professionals could benefit from better training and education (Berman *et al.* 2008; Cleary *et al.* 2006; Kaas *et al.* 2003; Marshall *et al.* 2000; Riebschleger 2002; Schmetzer *et al.* 2008; Van de Bovenkamp *et al.* 2010; Wynaden *et al.* 2005). Legislation might strengthen the position of family members (Rowe 2010). Finally, patients might attribute a larger role to family members in advance directives (Srebnik 1999).

We may conclude that in the literature on mental health care it is recognized that family members can play an important role in the care for their relative and that they too are affected by the condition of the patient. However, in practice, this often does not lead to communication between professionals and family members, mostly because of confidentiality issues. An overview of the articles on mental health care can be found in Table 3.

Comparison of the different sectors

A first conclusion that can be drawn is that the sectors differ in terms of whether family–professional communication is considered to be an important subject for research. In oncology, the role of family members is not a specific subject of research; it is often one of the items discussed in studies with a broader scope. In nursing homes and mental health care, the relationship between professionals and family members is much more a subject of study in its own right. This might be an indication that in the latter two sectors, contacts between family members and professionals are a more frequent phenomenon, or these contacts raise more discussion or problems than in oncology. The latter seems to be the case when we look at the analysis of the studies in the different sectors.

A second interesting finding is that the position of family members is framed differently across the sectors. In oncology, patients and family members are often mentioned together and professionals communicate with both, and that seems to be the normal way of doing things. In nursing homes, family members are not so much framed as fellow patients but as fellow carers. Family members and professional health-care workers need to build partnerships to provide better care to the patient. In mental health care, family members are framed much more as outsiders. Although it is recognized that they too provide care to the patients and suffer as a consequence of illnesses, the autonomous patient is placed centre stage by health-care workers. This causes problems in the communication between family members and health-care professionals. In this sector, communication with family members is not seen as part of the health professional's role.

Third, and relating to this framing of the position of family members, the number and the nature of problems in regards to the communication between health-care professionals and family members differ. In oncology and nursing homes, problems are mostly of a practical nature. Between the two, more problems are reported in nursing homes. These problems include lack of skills and time of health-care professionals to communicate well with family members. In addition to these practical problems, an important finding from the study into oncology and

nursing homes is that they report on the danger that the focus on family members can also become too strong. In such a case, communication occurs mostly between the professionals and the family, and too little attention is paid to patients themselves. When we compare the findings of oncology and nursing homes with mental health care, we see that most problems occur in the mental health-care sector. What is interesting in this sector is that these problems go beyond ordinary communication problems and do not seem to be caused by time constraints alone. In mental health care, health-care workers consider contacts with family members to be problematic in principle because of autonomy and confidentiality issues. This difference from other health-care sectors has been reported in the reviewed studies (Clarke 2006; Kaas *et al.* 2003).

DISCUSSION: LOOKING FOR EXPLANATIONS

We should note some limitations to this study. First, we performed a literature review on three subsectors in health care, which limits the generalizability of the findings. A study of further health-care sectors might have provided us with a broader overview of family member–professional contacts. Although we tried out different key words to determine the best search strategy, it is possible that yet another strategy would have given us additional insights. However, we feel that because the results are based on the analysis of a substantive number of articles that provided us with a consistent picture of the situation in these different sectors, the study provides a good overview of family member–professional contacts for patients suffering from severe conditions in different sectors of care. By focusing on the level of sectors, we might have missed relevant differences within sectors. Of course, the group of patients within a certain sector is a heterogeneous group in itself. For instance, they comprise patients of different ages, with different conditions and different levels of helplessness. The same goes for professionals, a category that comprises both physicians and nurses, who can differ in the way that they relate to family members. However, our analysis shows that important general conclusions about these sectors can be drawn from our data that apply to both nurses and physicians.

From the comparison between sectors above we can conclude that mental health care stands out because of the uneasy relationship between professional workers and family members. Although in guidelines and mental health-care policy documents the importance of family involvement is increasingly recognized, in practice, many problems are identified in this relationship (Lloyd & King

TABLE 3: Mental health care

Article	Type of study	Focus article	Findings regarding family members
Kingston <i>et al.</i> (2011)	Empirical, review of the literature and Delphi consensus study Different countries	Development of mental health first aid guidelines for community members, such as family members, on how to assist someone developing a drug problem.	Community members, such as family members, are important for support and understanding for people with a drug problem; they can facilitate professional help, but need guidance on how to do this. The guideline can provide them with the information needed.
Curtin and Hangrove (2010)	Empirical, case study USA	Practicing psychology in small rural communities. Not a specific focus on family members, but there is attention on the system of clients.	The family can contribute to psychological problems; therefore, it is important to pay attention to them in therapy.
Cross and Bloomer (2010)	Empirical, focus groups (<i>n</i> = 7) Australia	Exploration of how mental health clinicians modify their communication to reconcile cultural differences and promote self-disclosure. Family members are not the specific focus.	Role of family varies in different cultures and attention and respect for this is important.
Rowe (2010)	Opinion article UK	An ethical case is made for sharing information with family caregivers.	Community care has increased the emphasis on the role of family caregivers in supporting mental health patients. Legislation does not acknowledge their position and legally sharing information with family members by nurses is difficult. The article argues for a reappraisal of the right to confidentiality. Guidance is needed on when to breach confidentiality that recognizes the dependency and relationship between caregivers and users.
Van de Bovenkamp & Trappenburg (2010)	Empirical, interviews with family members (<i>n</i> = 18), professionals (<i>n</i> = 7) and patients (<i>n</i> = 2). Observations of care practice and meetings The Netherlands	Learn about the support available to family members of mental health patients by focusing on the relationship between family members and mental health care workers.	The relationship between health-care professional and family members is problematic. A lack of information exchange, consultation, and support is reported. Autonomy and privacy of the patient is identified as an important cause of this problem. The situation is undesirable when family members are expected to fulfill their carer role. Professionals need to be trained to reframe their perception of the role of family members.
Rapport <i>et al.</i> (2010)	Empirical, survey free text analyses (<i>n</i> = 406) UK	Clarification of the perception of uncertainty about mental health conditions from provider, patients, and carers perspectives. Not a specific focus on family members but they are part of a larger study.	Parents play an important role in the care of the patient, but their needs often go unnoticed. Carers and parents see themselves as go-betweens; they carry messages between patients and professionals. The strong focus on medication by professionals is negatively perceived by parents; this puts them into the position of a bystander, while they have to deal with side effects. A lack of integrity of service delivery and choice is identified among carers and patients.
Schmetzer <i>et al.</i> (2008)	Descriptive USA	Presentation of a possible mechanism for increasing communication about psychiatric matters between physicians and families of persons with mental illness through a presentation in the education of physicians.	Some physicians still have concerns about communicating with family members due to issues of patient trust, confidentiality, or left over outmoded beliefs that families either cause mental illness or exacerbate its symptoms. Attention for family members in education can improve this.
Berman <i>et al.</i> (2008)	Descriptive USA	The importance of teaching residents to think family as part of core competencies.	Involving family members results in improved patient outcomes. There is, however, too little attention paid to family members. Autonomy is incorrectly seen as precluding family involvement.
Langlands <i>et al.</i> (2008)	Empirical, survey among mental health consumers, carers, and clinicians (157). International panel	Development of a guideline on how a member of the public could help someone who may be experiencing psychosis. Family members are mentioned in the article but are not the special focus.	Family and friends can be important facilitators of pathways to professional care. They lack necessary skills and need training to intervene effectively.
Endraves <i>et al.</i> (2007)	Empirical, interviews with family members (7). Australia	Exploration of the experience of Egyptian families caring for a relative with mental illness in Australia.	Having a relative with a mental illness has a large impact. People report a lack of information, involvement, and support of health-care professionals.

TABLE 3: Continued

Article	Type of study	Focus article	Findings regarding family members
Goodwin and Happell (2007)	Empirical, focus groups with carers. Australia	Description of carer experiences and understandings of participation in mental health care.	Carers' experiences vary; they are both positive and negative. Family members are not always listened to, and receive little information and support. There are differences between nurses in how they work with family members.
Maheux <i>et al.</i> (2006)	Empirical, survey among physicians (255). Canada	Documentation of with whom family physicians communicate when evaluating adolescents with mental health problems, to whom they refer, and their knowledge about accessibility of mental health services. Focus not specifically on family members.	Although most family physicians had communicated with parents at least once during the past year, few did so routinely. Confidentiality is raised as a possible explanation. Contacts are important because families can provide more information.
Clarke (2006)	Empirical, report of experiences of mother. UK	Description of contacts with staff.	Experienced many problems, little information exchange, and little regard for her situation. Felt that staff cannot deal with pro-active family members. Has not experienced similar problems outside mental health care.
Jakobsen and Severinsson (2006)	Empirical, interviews with parents (12) and literature review. Norway	Exploration of how parents of adult psychiatric patients experience collaboration with health professionals in community health care.	Health professionals do not want family members to be involved and do not inform, consult with, or support family members. Professionals' attitude to confidentiality frustrates parents most; however, not all professionals deal with it so rigorously.
Cleary <i>et al.</i> (2006)	Descriptive Australia	Description of the challenges of facilitating carer participation.	Interaction with carers in a respectful and collaborative manner and providing information and support is an essential part of modern mental health service delivery. There is a lot of staff confusion in the area of confidentiality and privacy. Confidentiality can be an excuse for not working with carers more actively. There are also time constraints.
O'Connell (2006)	Descriptive USA	Description of the needs of family members and the role nurses can play to help them.	Dealing with family members is part of the nurse's job. Family members also suffer and need support. Providers are sometimes reluctant due to confidentiality and some continue to view family members as causative factors.
Gavois <i>et al.</i> (2006)	Empirical, interviews with family members (12). Sweden	Development of a model of support based on the needs of families.	Family members play an important role, the effects on them are large, and they need support. Family members who are supported and who were included in the care process perceived less stress.
Truman (2005)	Literature review	Exploration of the effects of a more active role of patients and family members on the autonomy of the professional. Contacts with family members are not the central focus.	Family members and patients are mentioned together. Being a carer can have a toll on the individual; it is important that they are involved. Carers and professionals can think differently about the care that is provided.
Wynaden and Orb (2005)	Empirical, interviews with primary carers (27). Australia	Exploration of how patient confidentiality issues impact on carers.	Carers are expected to undertake the caring role with little support. Lack of collaboration with professionals increases level of distress. Confidentiality was one reason why professionals were unwilling to collaborate.
Resnick <i>et al.</i> (2005)	Empirical, survey among clients (902). USA	Exploration of correlates of informal and formal contact between clinicians and families of individuals with schizophrenia.	There is little contact between families and clinicians.
Harden (2005)	Empirical, interviews with parents (25). UK	Description of experiences of parents of young people with mental health problems.	Parents find it difficult to deal with the situation. They feel they are blamed by professionals. When their child turns 16, parents are formally excluded because of the privacy of the patient.
Sjöblom <i>et al.</i> (2005)	Empirical, focus groups (4) with nurses. Sweden	Examination of nurses' views of the family in psychiatric care.	Nurses acknowledge that family members are in a difficult position, that they need support, and that it is important to exchange information. However, they rarely involve families. Time constraints and the autonomy of the patient are considered to stand in their way.

Jeon (2004)	Empirical, interviews with nurses (6), family caregivers of older people with depression (7), and observations. Australia	Examination of the processes through which community mental health nurses work with families of older people with depression.	The importance of support for and involvement of family members is often not recognized. It is important to shape mutuality to make family members an integral part of care.
Stengler-Wenzke <i>et al.</i> (2004)	Empirical, interviews with family members Germany	Description of how relatives of people with obsessive-compulsive disorder experience stigmatization and discrimination in their everyday lives.	Family members are greatly affected because of burden of care and stigmatization. They receive little support and information from professionals. Confidentiality is used as a reason not to inform them. This leads to insecurity about how to deal with the illness.
Rose <i>et al.</i> (2004)	Empirical, focus groups (11) with families, patients, and health professionals. USA	Identification of barriers to family care in psychiatric settings, description of family and provider perspectives about what constitutes effective family care.	Current health policies do not show endorsement of a family care approach. Professionals report a lack of training and resources. Family members want improved communication and feel that this does not have to be time consuming. Confidentiality issues were also an alienating factor.
Marshall & Solomon (2003)	Empirical, survey among providers (59), family members (68), and interviews with providers (8). USA	Examination of how providers and family members interpret and implement confidentiality policies about the release of information to families.	Providers interpreted confidentiality policies very conservatively. There is a lot of confusion about what type of information is confidential. A minority feels that legislation does not stand in the way of informing families. The situation poses a barrier to collaboration between providers, consumers, and family members.
Kaas <i>et al.</i> (2003)	Empirical, survey among professionals (31). USA	Identification of experienced barriers to collaboration with families by mental health professionals.	Reported barriers are: lack of time, feelings of conflict about treating the patient versus the family, beliefs that involvement may be harmful, lack of visible results of the benefits, loss of hope with the family, stigma, feelings of guilt, client not wanting the family to be involved, and difficulty of family members in communicating with the client.
Meer and Van de Creek (2002)	Opinion article USA	Description of the conflict that many clinicians are likely to face with regard to confidentiality when working with clients from South Asia.	Confidentiality is the most important norm in relationship (aside from do not harm) between clients and psychologist. However, the subject of confidentiality is dealt with differently in different cultures; professionals need to recognize this.
Riebschleger (2002)	Empirical, survey among professionals (73). USA	Exploration of the initial assumptions of community mental health professionals to a practice simulation vignette concerning the role of the family.	Many professionals acknowledge that a mental illness has negative consequences for family members and that family members are positive treatment resources. A minority feels that family members can play a negative role.
Marshall and Solomon (2000)	Empirical, survey amongst family and consumer members of the National Alliance for the Mentally Ill. USA	Examination of the process of releasing information to families and the types of information they receive.	The majority of family members received general and some specific information. Few received information about the treatment plan. A large minority (41%) did not receive general information. Most of them were told this information was confidential. Few consumers were asked permission to release information to their families. Most consumers felt it was important that their family was involved.
Wuerker (2000)	Literature review	Review of research revealing a unique vulnerability to stress in persons with schizophrenia and suggesting that communication difficulties with family members may be due to a shared genetic heritage.	Previously, it was felt that family members were the cause of mental illness. After that, expressed emotion research implicitly accused family members. This article explores biological causes. Nurses need to be aware of biological knowledge so they can communicate better with family members.
Srebnik and La Fond (1999)	Descriptive USA	Description of types of mental health advance directives. No special focus on family members.	Advance directives can improve communication with family members because they can ensure agreement about their role.

2003; Van de Bovenkamp & Trappenburg 2008). Apparently, it is difficult to adhere to guidelines and policies: more difficult in mental health care than in oncology and in nursing home care. To offer possibilities for improvement, we feel that it is important to look at the underlying reasons for these difficulties. In this section, we will explore these possible reasons. We base these explanations on the findings of this review. However, to develop these explanations further, additional literature was sought. This was done to gain further insight into the particularities of mental health care.

Our review shows that patient autonomy and confidentiality can stand in the way of professionals communicating with family members of mental health patients. It is important to note, however, that patient autonomy and confidentiality are generally cherished values in health care, not just in mental health care. The importance of patient confidentiality in health care dates back to the beginning of medicine. In medical ethics as well as legislation, it is established that information about the patient should not be shared with a third party without the patient's permission. The autonomy principle puts the decision to share information in the hands of patients themselves (Hatlev 2007; Sokalska 2004).

On the basis of this study, we conclude that legal rules and policies regarding confidentiality are not applied in the same manner across different sectors. In our review, we did not find instances where confidentiality and autonomy figured in the relationship between professionals and family members in oncology or nursing homes. Sharing information with family members seems to happen on the basis of implied consent, a mechanism that can also be witnessed in the communication between health-care professionals (Hatlev 2007; Sokalska 2004). Our review shows that this mechanism can be applied to family members as well. The emphasis on building partnerships that we have seen in nursing homes is in line with this way of thinking. In mental health care generally, the mechanism of implied consent applied to family members seems to be mostly absent.

The principle of autonomy and patient confidentiality does not exclusively hold in mental health care, but seems to be taken much more seriously. We hypothesize that this might have to do with one of the more peculiar characteristics of this sector: the fact that professionals meet with the judicial system on a regular basis. Professionals in mental health care deal with additional legal rules concerning compulsory admission of patients (Legemaate 1995). Sociologist John Griffiths uses the concept of semi-autonomous social fields to explain the importance of the use of rules within a social context

(Griffiths 1996; 2003). People in a certain social context do, to a great extent, decide which rules are important in that environment. How legal rules work out in practice depends largely on these decisions. Therefore, rules are socially constructed to suit a social context. According to Griffiths, the medical sector enjoys a high level of autonomy regarding the application of legal rules. The social context is one of self-regulation. Medical professionals can decide whether or not to uphold legal norms, and in mental health-care, professionals seem to display a high regard for the law in their day-to-day work. They interpret the law conservatively, as the study of Marshall and Solomon included in our review shows (Marshall & Solomon 2003). Griffiths argues that the fact that people are aware of instances in which a rule was enforced can have important effects on their behaviour. This type of experience might pave the way for other formal judicial rules and regulations that could influence the behaviour of mental health-care professionals in other decisions (Griffiths 1996; 2003). For example, this could be reason for them to adhere to the rules on patient autonomy and confidentiality more strictly and, as a result, cause them not to inform the patients' family.

Deference to the judicial system is not the only explanation for the preponderance of patient autonomy in mental health care. The anti-psychiatry movement active in the 1960s and 1970s (Crossley 1998; Thomes 2006) also put an emphasis on this notion. The movement strove for more socially oriented, democratic, and alternative care, and raised the issue of the unequal relationship between professionals and patients. Patients should be empowered and recognized as full-fledged partners in care. Since this period, the care of people with mental illness has changed substantially and the position of patients has been strengthened. The concept of patient autonomy is an important tool for patient empowerment. However, the enduring emphasis on patient autonomy seems to have led to a neglect of family members. The focus on patient autonomy results in a focus on the patient as an individual, which sets him or her apart from his or her family. In other health-care sectors, the struggle against medical paternalism has never been as fierce as in mental health care; hence, the struggle for patient autonomy has never led to a split between the patient and his or her family (Trappenburg 2008).

Our review shows a third factor in the history of mental health care that could explain the difficult relationship between professionals and family members: the fact that, in the past, family were often blamed for a patient's mental illness (Harden 2005; Kaas *et al.* 2003; Riebschleger 2002; Schmetzer *et al.* 2008; Wuerker 2000). Although

this theory has been rejected, family members are sometimes still blamed for the condition of their relative (Harden 2005; Kaas *et al.* 2003; O'Connell 2006; Riebschleger 2002; Schmetzer *et al.* 2008). Obviously, if professionals feel that family members are part of the reason why their client has an illness in the first place, communication with and support for family members is given low priority or might even be considered a bad thing. There can, of course, be legitimate reasons for a difficult relationship between professionals and family members (Van de Bovenkamp & Trappenburg 2010). For instance, patients might explicitly ask professionals not to inform their family. This might be because of feelings of stigmatization, which are still an important problem in mental health care (MacInnes & Lewis 2008). Moreover, family members can indeed contribute or partially be a cause of the condition of mental health patients, because stress and early trauma are identified as risk factors (Van Os *et al.* 2005). However, this does not explain the structural difficulties found in this review, because, in most cases, family members are not the cause of mental illness. Moreover, the review also shows that 'difficult' family members are not found in mental health care alone.

Lessons learned

The previous section shows that the particular situation in mental health care can be explained by various factors. Although this information can explain why communication between family members and professionals is considered to be problematic, this situation is undesirable. The comparison between the sectors offers important lessons for improvement. We feel that although there are important differences between the sectors, comparing the situation to other sectors can help us view the subject from a different perspective.

Because of the important role of family members in caring for the patient and the emotional impact on family members, it is important to pay attention to family members in all sectors in health care. The review shows that in all three sectors, improvements can be made. However, most improvement can be made in mental health care.

The situation in mental health care may first be improved by applying the working method of professionals in other sectors of care. Informing, consulting, and supporting family members when necessary should become routine practice for mental health-care workers (as is already acknowledged in many guidelines and policy documents on mental health care). The fact that family members take on many caring responsibilities justifies their involvement in professional care. When family

members are seen as fellow carers, implied or presumed consent could also be applied to them (Hatlev 2007).

From the comparison of sectors, professionals in mental health care can learn that the autonomy of the patient and the legislation surrounding this subject do not have to frustrate contacts with family members. Of course, exceptions can be made when necessary: for instance, in cases where family members contribute adversely to a patient's condition or when a patient explicitly asks the professional not to inform their families. These exceptions do not have to determine regular practice.

Furthermore, it is important to note that certain mental health-care patients will never be able to enter into more equal relationships with their health professional. Consequently, just like residents in nursing homes, these patients need someone to represent their interests when they are unable to do so themselves. A family member, who is close to the patient, could perform this role. In addition, some support could be provided, as it is in other sectors although not always satisfactory, to family members to help them deal with particular situations.

To conclude, our comparison shows that, in certain cases, the focus on the family can become too strong. We saw this in both oncology and nursing home care. In these cases, communication focuses so much on the family that patients themselves are not informed or consulted properly. Therefore, although important lessons can be gleaned for mental health care from oncology and nursing home sectors, the oncology and nursing home sectors might learn from the mental health care sector that they cannot simply bypass the patient and solely deal with his or her family. We argue on the basis of this review that a balance should be struck between communication with patients and family members. This can have positive effects on the care of the patient, because formal and informal care will be more aligned, and on family members themselves, who will be better able to cope with their situation.

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