
Qualitative Research

Ethical challenges in primary care: a focus group study with general practitioners, nurses and informal caregivers

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Abstract

Background. General practitioners (GPs), nurses and informal caregivers are often jointly involved in healthcare situations in which ethical issues play an important role.

Objectives. To describe ethical problems from the perspective of these three groups and to investigate whether there is a common experience of ethical issues in primary care.

Methods. We conducted six focus groups with general practitioners, nurses and informal caregivers in Germany. We asked the participants to describe at least one experience of ethical problem in detail and documented the findings by an illustration software that visualized and structured the discussion. We used thematic analysis to identify ethical problems and to develop categories of ethical issues.

Results. Problems reported barely overlapped. GPs had to do mainly with uncertainty about the scope and limits of their responsibility for patients. Nurses were concerned about bureaucratic and other barriers to professional care and about dual loyalty if they had to consider the conflicting interests of patients and family members. They often felt powerless and unable to act according to their professional standards. Informal caregivers reported problems that resulted from role strain and being both a family member and a caregiver. GPs, nurses and informal caregivers sometimes perceived the other parties as a source of ethical problems.

Conclusions. All parties may benefit from ethics support services, a rarity in German primary care so far. Furthermore, nurses' self-confidence towards GPs, demanding patients and family members has to be strengthened. Informal caregivers, the most vulnerable group, need more attendance and tailored support.

Key words: Attitudes of health personnel, caregivers, focus groups, medical ethics, primary care, quality of care.

Introduction

General practitioners (GPs), nurses and informal caregivers are often jointly involved in challenging healthcare situations in which ethical issues play an important role. The need to choose diagnostic

and therapeutic procedures in the light of uncertain prognosis and in consideration of the principles of patient autonomy, non-maleficence, beneficence and justice (1) may aggravate these situations and lead to decisional conflicts (2,3).

The majority of the research on ethical issues focuses on inpatient settings (4–12), whereas only few studies investigated ethical issues in primary care (13–17). Studies in this area focus on family physicians and/or nurses (13–19) and many studies are based on surveys (14–20) with the aim of finding the most frequent or difficult-to-solve ethical problems. End-of-life issues, patient autonomy, justice, disagreement among caregivers and physical abuse are some of the frequent issues found in these surveys. These issues and categories stem directly from the ethics literature or studies about clinical dilemmas but do not necessarily represent the perspective of the actors involved.

To our knowledge, no study has explored the perspectives of these main parties in the primary care setting. The aim of this study was to identify ethical issues from the perspective of family physicians, primary care nurses and informal caregivers and to investigate whether there is a common experience of ethical issues in primary care. This may enable clinicians and other stakeholders to provide appropriate support based on detailed information about ethical conflicts and how they are perceived by the parties involved.

Methods

This is a qualitative study using focus groups to explore family physicians', nurses' and informal caregivers' experiences with ethical problems in their everyday practice (21,22). The Methods section follows the Standards for Reporting Qualitative Research (23).

Context

In Germany, basic medical care is provided by GPs, by primary care nurses in the home care setting and often by informal caregivers locally and organizationally separated from hospital care (24). GPs, nurses and family members as informal caregivers (25) act mostly independently, unless all stakeholders are involved in the care of the same patient accidentally or in chronic care models (26). For most patients, healthcare costs are covered by statutory health insurances (27), whereas home nursing care is covered by statutory long-term care insurance funds and is provided by not-for-profit or for-profit primary care services. These services depend on being engaged by family members and are often recommended by GPs.

Recruitment and participants

The study started in June 2013 and took place in Göttingen, a mid-sized town in the German federal state of Lower Saxony, and its rural catchment area. We sent out invitation letters to 75 randomly selected GPs and 23 primary care nurses and recruited informal caregivers via newspaper advertisements and flyers at primary care practices. Only GPs and nurses who were involved in primary patient care were included in the study. Inclusion criteria for informal caregivers were experiences of ethical problems while caring for a family member. We decided to conduct six focus groups (two for each group) to account for the variability of the three groups of participants. The last focus group session took place in October 2013.

Data collection

All focus groups were supervised and moderated by two facilitators (IG, AH, SH, NF), one male and one female. They all were experienced in qualitative research and either in medical ethics or general practice. They had no relationship with any of the participants in the focus groups.

Focus group discussions were stimulated by an open question: Please think about situations you experienced as full of conflict and where you did not agree with the opinion of [optionally: the GP, the family members, the nurse]. Each participant was invited to report one situation in detail and there was space for discussions.

Mind-mapping was used to structure the material during the group sessions and in the final analysis (28). It also helped to reduce the material in a “meaningful way” (29). For the documentation of these findings, we used Mindjet™, an illustration software that designs mind maps in order to visualize the discussion (see an example in Supplementary Figure S1).

The findings were projected simultaneously onto a screen so that all focus group members could see the documentation of their reported issues and could assess the correctness of the findings. This enabled participants to review the themes for validity and to enhance the trustworthiness of the qualitative results (30).

The group sessions were audio recorded and selected parts of the audio-recordings were transcribed. We sent the maps out to all participants to confirm the results and to receive feedback and whether any aspects were missing.

Data analysis

WH, SH and IG performed a thematic analysis (31) with the aim of identifying, analysing and reporting ethical problems in their specific contexts, taking into account the view of each actor, in our case, GPs, nurses or informal caregivers (31). One of the two moderators documented the reported experiences in Mindjet™ while the other moderated the discussion.

We condensed the content of each Mindjet™ documentation, identified and labelled all reported and discussed problems independently. On the basis of these labels, we developed categories of ethical issues by inductive thematic analysis to represent the participants' perspectives. Coding was performed in an iterative process and independently by two of the authors (IG, WH).

Disagreements during the analysis were discussed within the group to achieve consensus. We used audio recordings to complete missing information and to illustrate ethical problems by suitable quotes. The German quotes were translated into English by a professional translator.

Results

Setting and participants

All focus groups were performed at the Department of Family Medicine. We conducted one focus group with five GPs and one focus group with six family physicians, two focus groups with seven primary care nurses each and two focus groups with six informal caregivers each, in most cases spouses or children of patients (Table 1). The focus groups lasted approximately two and a half hours (range: 126 to 151 minutes).

The experience of family physicians

The analysis of the focus groups with GPs revealed four categories of ethical issues, dealing with treatment responsibility, expectations, family involvement and contact with other stakeholders (Table 2, exemplary quotes in Supplementary Table S1).

Scopes and limits of responsibility

A significant source of problems for family physicians was uncertainty about their responsibility. They reported several problems in

which they had difficulties in deciding whether, how and to what degree they should engage in a patient's healthcare.

An important problem in this category was uncertainty about the patient's treatment needs. For example, a patient with advanced COPD refused any further diagnostics but demanded, on the other hand, to be examined and asked whether it is really all that dire. The problem was triggered by changes of the patients' health condition or their unclear or changing expectations about what doctors should do.

GPs felt it difficult to address their medical responsibility when it contradicted patient autonomy. For example, a physician witnessed the increasing frailty of a patient, but the patient refused to move into a nursing home.

Overtreatment was a further problem in this category, especially in the treatment of terminally ill patients or if a patient's health condition changed and the GP was not sure what to do as the patient's advocate.

Incidental findings were another source of ethical problems that left the physician alone with the decision what to do. In one case, an incidental finding initiated by a specialist unsettled the patient so

much that the GP had the problem of deciding whether to conduct more diagnostics or not.

Conflicting expectations

GPs sometimes felt torn between guidelines and patient-oriented decisions. Although they generally favoured decisions that met patient needs, they feared claims for damages by family members.

Undesired involvement in family affairs

GPs also experienced problems when they felt involved in family affairs and were unsure whether and to what degree they should protect patients' needs against family members' interests.

Lack of agreement with other stakeholders

GPs reported conflicts with colleagues when there was a lack of agreement about the treatment goal for a patient. One participant reported a situation in which the decision to feed a terminally ill patient via gastric tube was made in a hospital, disregarding the patient's living will. She was neither asked nor informed before the tube was placed; thus, all parties involved had to address the consequences.

The experience of primary care nurses

We found four categories, focusing on professional standards, problems of dual loyalty, the nurse's responsibility and powerlessness (Table 2, exemplary quotes in Supplementary Table S2).

Barriers to professional care

Difficulties in fulfilling the professional standards of care were one of the most common problems for nurses. Some perceived discrepancies between professional standards and bureaucratic requirements seemed to them to be a barrier to delivering high-quality patient care.

Table 1. Participants

| Focus groups | Participants N | Women N | Duration hours:minutes |
|------------------------|-------------------|------------|---------------------------|
| Family physicians I | 5 | 3 | 2:24 |
| Family physicians II | 6 | 4 | 2:31 |
| Primary care nurses I | 7 | 5 | 2:06 |
| Primary care nurses II | 7 | 5 | 2:31 |
| Informal caregivers I | 6 | 6 | 2:21 |
| Informal caregivers II | 6 | 5 | 2:22 |

Table 2. Results from the focus groups with GPs, primary care nurses and informal caregivers

| Problems identified | Categories of ethical issues | |
|--|--|--|
| Patient's treatment needs not clear | <i>GPs' perspective</i> Scope and limits of responsibility | |
| Medical responsibility contradicts patient autonomy | | |
| Overtreatment | | |
| Dealing with incidental findings | | |
| Fearing consequences when favouring individual treatment decisions against guideline recommendations | Conflicting expectations | |
| Protecting the patient against the family | Undesired involvement in family Lacking agreement with other stakeholders | |
| Protecting the patient against other healthcare providers | | |
| Bureaucratic requirements | <i>Nurses' perspective</i> Barriers against professional care | |
| Lack of trust of patient or family member | | |
| Family members' financial interests | Dual loyalty | |
| Demanding and/or uncooperative family members | | |
| Patients or family members have different interests | | |
| Balancing patient's integrity and patient's protection | | |
| Care obligations | | |
| Limits of care | | |
| Fearing negative consequences of actions | | |
| Feeling of dependence/inferiority; being at the short end of the stick | | |
| Self-protection versus responsibility | | <i>Informal caregivers' perspective</i> Role conflict |
| Balancing two family roles | | |
| Role as a family member versus responsibility for others | Role strain | |
| High demands from patients and GPs | | |
| Lacking communication with healthcare providers | | |

Lacking trust was another issue. Financial interests were another barrier to nurses' professional standards. Family members were also sometimes perceived as a barrier to high-quality care.

Dual loyalty

Dual loyalty arose when actions for a patient's care conflicted with felt obligations towards the patient's family members, the legal requirements or even the trust of a patient. A common problem was weighing the competing requirements and interests of patients and family members. Nurses sometimes felt pressured if family members tried to achieve their interests via money.

Another issue was balancing loyalty towards the patient's integrity versus legal obligations if, for example, the harmful behaviour of a family member towards a patient was observed.

Scopes and limits of responsibility

Similar to GPs, nurses reported some problems resulting from uncertainties about their responsibility towards patients. In one case, for example, a nurse did not know whether or not a person should be tube-fed, although he had refused any food and drinks. In another case, a nurse was aware that an informal caregiver needed help, but she had the feeling that this question was beyond her official—and financed—duties.

Perceived powerlessness

Nurses felt repeatedly powerless towards some patients, family members and, above all, GPs. Fearing negative consequences, they did not initiate changes but perceived some of these situations as problems if, for example, a doctor refused to prescribe a drug that the nurse considered essential. The nurse disagreed with the physician but did not discuss this matter because she feared this might affect their future collaboration. This problem was fiercely discussed within the focus group. Nurses sometimes felt dependent on a family member, a daughter or a son of the patient, who was also involved in patient care.

The experience of informal caregivers

We found two categories of ethical issues for informal caregivers, which had to do with their different roles (Table 2, exemplary quotes in Supplementary Table S3).

Role conflict

Dealing with two roles simultaneously—as a family member and an informal caregiver—caused problems for many participants. They had difficulties in balancing their responsibility towards the sick relative and the rest of the family.

One issue was a conflict between the responsibility as a member of the caregiving team and self-protection as a family member. This problem was reported by a woman who felt responsible for her husband's healthcare but did not want to decide on every medical detail.

When caring for a sick relative, balancing two family roles was difficult for some participants. A woman, for instance, felt torn between the obligations of a mother and the duties of an informal caregiver for her husband, who had fallen very ill at a young age.

Role conflicts also resulted from the dilemma whether to act in the interests of a family member (e.g. in the role as a spouse) or with responsibility for others (e.g. a community whose members could be endangered), for example, in the case of driving a car.

Role strain

Many informal caregivers reported high demands on care and often experienced their obligations as overburdening. These problems were amplified, on the one hand, by an inability to distance themselves from the patient the way other health caregivers could and, on the other hand, lacking appreciation from patients, physicians or nurses.

Several participants complained about demanding GPs. An informal caregiver felt forced by her doctor to take over the responsibility of caring for her husband who had a stroke. The doctor was the couple's GP but directed his attention primarily on the husband and obviously disregarded the wife's problems and needs. Lack of communication with healthcare providers could also invoke problems.

In some instances, participants frankly reported feeling overwhelmed by caring for their loved ones, typically women. The underlying problem was the perceived obligation to help and the feeling of total exhaustion, especially as concrete assistance, such as institutionalized day care, was rejected by the patient.

Discussion

Our study investigated ethical issues from the perspectives of different stakeholders in primary care. While in the same setting, stakeholders reported almost completely different problems. Furthermore, the reported problems did not always touch on ethical principles in the strict sense as described by Beauchamp and Childress (1) but were obviously perceived by the participants as ethical issues that matter.

Many ethical problems of GPs could be categorized as uncertainty about the scope and limits of their responsibility for patients. Primary care nurses often talked about problems that had to do with dual loyalty and bureaucratic and other barriers to professional care. Informal caregivers reported problems that resulted from persistent role conflicts between being both a family member and a caregiver, or they reported role strain, which was especially dramatic for women. Problems reported by nurses and GPs referred to the same category only in the case of 'scope and limits of responsibility'. Even here, both parties differed in their descriptions, with doctors thinking about the options in an open way and nurses making clear that their contract as a nurse limits their choices. GPs, nurses and informal caregivers often perceived the other party as a source of or contributor to ethical problems.

Comparison with literature

GPs in our study were uncertain about the scope and limits of their professional responsibility for patient care—be they end-of-life issues, disagreements among caregivers or other issues. These issues exactly mirror the 'inherent uncertainties, wide-ranging responsibilities, and broad scope of family medicine that generate ethical complexity' (32).

'Overtreatment', a frequently described problem, for example, for physician trainees in hospital settings (4) and for most medical specialties (33), was also a problem for GPs in our focus groups, falling into the category of scope and limits of responsibility. 'Lacking agreement with other stakeholders' was another source of conflicts corresponding to the 'conflicts between parties', as detected by DuVal (5) in a telephone survey with internists.

A further category was 'undesired involvement in family issues', a typical issue in family practice caused by the fact that families may participate both as patients themselves and as concerned relatives

with whom the doctor deals on a regular basis (13). ‘Conflicting expectations’ occurred when physicians considered individual patient needs at the expense of guideline recommendations. This experience is a common problem, especially in frail multimorbid patients (34).

Although La Puma and Schiedermayer (3) identified ‘dual loyalty’ as a relevant issue in outpatient settings 30 years ago, we could not confirm their assumption for GPs. However, ‘dual loyalty’ was a major source of ethical conflicts for nurses in our focus groups. They often had to balance the different interests of patients and their family members or professional duties to a patient and obligations to the interests of a third party. Such conflicts were also reported from community mental health nurses who were grateful to informal caregivers but felt pressured when, for example, caregivers believed that a patient should be hospitalized. This experience interfered with the nurses’ emphasis on the patients’ self-management of their life and disease (35). Consequently, for nurses in our study, patients’ or informal caregivers’ demands or financial interests were perceived as barriers to professional patient care.

Some hotly debated ethical problems in the two focus groups of nurses could be traced back to ‘perceived powerlessness’. Although nurses’ difficult hierarchical position in hospitals has been described as a reason for powerlessness (9), the same perception is obviously present in the primary care setting. This experience may rather result in ‘moral distress’, that is, the experience to be prevented from doing what is seen to be the right thing, and has been described elsewhere (10,11,36). Nurses perceived GPs as well as patients and informal caregivers as intruders in the field of their professional competence and independence. Two qualitative studies from Canada identified as a key difference between both groups that physicians were held responsible for making decisions and nurses have to live with these decisions (9) and that informal caregivers may be another source of moral distress for nurses and other healthcare professionals working in home visiting organizations (16). However, two caveats are necessary. First, it is the lack of collaboration with GPs that gives misplaced power and responsibility to relatives, as we know from a Norwegian study in nursing homes (37). Second, the balance of power between families and nurses will—even if they experience it differently—always be at the nurse’s advantage, as Delmar (38) put it.

Ethical issues for informal caregivers were, first of all, a matter of role strain, caused by the needs of the sick family member and often amplified by physicians’ and nurses’ demands. Previous studies have already found that family caregivers are not well prepared for their role and feel uncertain, powerless, anxious, insufficient (39) or miss support, for example, in managing medication (40). This experience is similar to nurses’ and other healthcare professionals’ reports about problems resulting from challenging clinical situations and service delivery issues (10,11). Our results show that role strain may have the same effect. Role conflicts for family caregivers resulted from their uncertainty of how to balance different roles, such as being a loving spouse and a responsible community member. When these roles became antagonistic, family caregivers sometimes perceived health professionals as people who did not recognize this conflict or opted to solve it in favour of the caregiving role.

Strengths and weaknesses of the study

To our knowledge, this is the first study that compared the perspectives of three involved parties in experiencing ethical conflicts in the primary care setting. We ascertained the experiences and attitudes in an open and independent way, making use of focus groups to stimulate the discussion of ethical conflicts. We composed the groups of

single, rather than multiple, professions, to make discussion easier. We used focus groups and the illustration software Mindjet™ to illustrate the reported conflicts simultaneously. The combination of focus group discussions and data collection with a mind-mapping tool represents a novel approach that allows to specify the reported issue during the focus group sessions and to reassure its accuracy by the participants during their discussion.

We could not predict with certainty whether thematic saturation—as one criterion for the sample size in qualitative research—has been achieved as the sample size was pre-determined.

Focus groups are susceptible to bias because group and individual opinions can be swayed by dominant participants or by the moderator (21,22) so that we cannot exclude that some ethical issues may not be brought to light. Some participants may have felt controlled and reported their experience according to the expectations of others. However, we had the impression that the participants felt encouraged to share and discuss their experience within the group of their peers. Another limitation may be that we only analysed experiences with, and attitudes towards, ethical issues but did not study real situations and the assessment and handling of the reported problems.

Conclusions and implications for practice

Although acting in the same setting, GPs, nurses and informal caregivers reported different ethical problems, according to their ability to separate professional roles and personal involvement as well as their real and perceived power. GPs in our study handled the problems on a strictly professional level without any signs of threat to their personal and professional identity. For nurses, it was difficult to separate their professional role from patients’ privacy while sharing their living space. Informal caregivers often did not feel able to separate their different roles by protecting themselves against excessive demands, or by distancing themselves from the conflict.

Therefore, the type of help needed to cope with ethical problems has to be tailored for the three groups. Basically, all involved parties may benefit from ethics support services, a rarity in German primary care so far (41–43). Furthermore, nurses’ self-confidence towards GPs and demanding patients’ family members has to be strengthened. More attendance and support facilities are needed for informal caregivers, who appeared to be the most vulnerable group. GPs, should address both nurses’ and caregivers’ concerns in planned appointments to avoid that problems turn into stressful ethical challenges.

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