

ETHICAL ISSUES IN THE CARE OF PATIENTS WITH STROKE: A SCOPING REVIEW

ABSTRACT

Aims and objectives: The aim was to identify and analyze the ethical issues in the care of patients with stroke (PwS). The goal was to understand the nature of the existing knowledge on the topic and to identify whether there are ethical issues specific to the care of PwS.

Background: Stroke is a disease with possible multiple effects on the patient's overall condition and experienced ethical issues in the care. Additionally, stroke impacts the life of the significant other. For health professionals, the care of PwS is challenging at different stages of the care process. The care of stroke includes several ethically sensitive situations from the perspectives of all participants.

Design: Scoping review.

Methods: The review was conducted following the five-stage methodological framework of Arksey & O'Malley (2005). The literature search was conducted in several electronic databases and complemented with a manual search, resulting in 15 reviewed articles. The analysis was conducted by charting descriptive numerical data and by content analysis of the narrative representations.

Results: The studies focused on hospital or rehabilitation contexts and a high number of studies had a qualitative approach. Three main themes were identifiable: 'decision-making as an ethically challenging act', 'care process-specific ethical issues' and 'environmental ethical issues'.

Conclusions: Ethical issues occur at different stages of the care process of PwS and from the viewpoints of all those involved. However, not all the recognized ethical issues were stroke-specific. As the number of the reviewed articles was limited, more research is needed for a comprehensive understanding of the topic.

Relevance to clinical practice: Individual health professionals may use the results in observing their own action from an ethical perspective and to deepen the ethical understanding of the care of PwS. In health care organizations, the results may be used in developing the ethical quality of care.

Keywords: Ethics, Stroke, Neurology, Care, Literature review

Summary box:

What does this paper contribute to the wider global clinical community?

- It is known that ethically demanding situations exist at different stages of the care process of PwS.
- The ethical issues in the care of PwS include both stroke-specific ethical issues and ethical issues common in the health care environment.
- The existing research on the ethical issues in the care of PwS is limited mainly to the situation of dying patients and the rehabilitation context.

INTRODUCTION

The presence of ethical issues is evident in all caring situations (Beauchamp & Childress, 2013). In the care of vulnerable patients, power imbalances highlight the importance of ethics (Dinç & Gastmans, 2012). One of the vulnerable patient groups is PwS due to their potential dependency on other people, e.g. in terms of mobility and daily tasks (Kitson et al., 2013); as a result, they are not free to make independent decisions and plans concerning their daily activities (Hodson et al., 2016). Regarding autonomy, the dependency on other people may be related to the PwS' experience of diminished realization of dignity (Kitson et al., 2013). As a whole, PwS describe stroke as an all-embracing experience (Dowswell et al., 2000) affecting their lives comprehensively (Hodson et al., 2016; Maratos et al., 2016; Dowswell et al., 2000). From the onset of stroke, patients may experience physical, functional and cognitive changes (Vanhook, 2009), changes in their social roles (Hodson et al., 2016; Burton, 2000) and even in their personalities (Dowswell et al., 2000). Experiences of various losses, such as loss of control and independence, are familiar to many PwS (Hodson et al., 2016). All in all, the new way of living with the impacts of stroke requires a degree of adaptation on the part of the patients (Maratos et al., 2016; Kirkevold, 2002; Burton, 2000).

Stroke is not only a disease having comprehensive impacts on patients' lives, but it is also a common disease affecting a large number of people. Worldwide, stroke is the second leading cause of death (WHO, 2017) causing over six million deaths annually (Feigin et al., 2017). Additionally, there are large numbers of stroke survivors with different kinds of disabilities. In the year 2013, the number of survivors was almost 26 million; furthermore, the number of disability-adjusted life-years was 113 million (Feigin et al., 2017). Still, PwS are not the only ones impacted by the disease. The impacts of stroke also affect the lives of others, both in the case of stroke survivors (e.g. Cecil et al., 2013) and in the case of dying PwS (e.g. Rejnö et al., 2012).

The onset of stroke is often sudden and the new role of the significant other of a PwS is set without any warning (Camak, 2015). The new role as a significant other of a PwS includes multidimensional duties (Camak, 2015; Vanhook, 2009; O'Connell et al., 2001) and constantly acting as an advocate of the PwS (Bäckström & Sundin, 2009). In addition, as a result of the time spent on the care, the significant other may feel isolated and forced to balance between the care of the close one and other responsibilities (Camak, 2015), which forces the significant other to prioritize between different duties. The time and strengths required by taking care of the PwS may make the significant other feel both mentally and physically exhausted (Camak, 2015; O'Connell et al., 2001) and they often miss support (Camak, 2015). The caregiver may have significant educational expectations, but the communication with health professionals is often complicated (Camak, 2015).

From the perspective of health professionals, the care requirements and the nature of ethical issues change at different stages of the care. In the acute stage, the outcome may be uncertain and the situations ethically problematic (Rejnö et al., 2012), for example, from the viewpoint of truth-telling and nonmaleficence (Rejnö et al., 2017). During rehabilitation, health professionals must balance between meeting the patient's needs and not doing too much for the patient, and they must also respect and support the patient's autonomy (Proot et al., 2002). As the effects of stroke may be very comprehensive (Vanhook, 2009), health professionals face various challenges in communicating with patients as well as different kinds of situations in terms of the patient's cognition and mood (Kumlien & Axelsson, 2000). If the stroke is considered severe and perhaps even fatal, the health professionals face multiple challenges, including ethical issues, in handling the situation (Rejnö et al., 2012).

The literature reveals ethical issues and ethically problematic situations in the care of PwS. However, the research on the topic is scarce and fragmented. As ethics is fundamental in nursing (Beauchamp & Childress, 2013), there is a need to scope the literature of ethical issues in the care of PwS to aggregate the existing knowledge. As a literature review of the topic has not been conducted before, this scoping review was conducted to identify and analyze the ethical issues in the care of PwS. The goal was to understand the nature of the existing knowledge of the topic and to identify whether there are specific ethical issues in the care of PwS. In this review, the concept of ethical issues was selected to describe the whole variety of ethics which patients, significant others or health professionals encounter in the care of PwS, such as ethical principles, questions, problems, dilemmas and the realization of these in the care. Care was considered as care provided by health professionals from the onset of stroke to all the subsequent stages in the care process both in health care facilities and at home.

METHODS

The literature review aimed to examine the extent, range and nature of the literature on the ethical issues in the care of PwS and to summarize the findings and identify the research gaps. Scoping review was therefore selected as method for the review. (Arksey & O'Malley, 2005.) Throughout the study, the five-stage methodological framework by Arksey & O'Malley (2005) was applied: identifying the research question, identifying relevant studies, study selection, charting the data, and collating, summarizing and reporting the results.

Identifying the research question

To get an overall picture, the scope of the review was set wide. Therefore, it was not considered meaningful to restrict the topic 'ethical issues' to ethical principles or ethical problems, and the viewpoints or informants were not limited, either. The quality of the research articles was not restricted; furthermore, the quality of the selected studies was not analyzed, which is in line with the scoping review method (Arksey & O'Malley, 2005).

The research question was divided into two questions as follows: 'What research has been conducted on the topic of ethical issues in the care of PwS?' and 'What is known about ethical issues in the care of PwS?'.

Identifying relevant studies

The literature search was conducted using five electronic databases: CINAHL, Cochrane Library, Philosopher's Index, PsycINFO and PubMed/Medline in April 2017. The words stroke, cerebrovascular disorders, cerebrovascular accident, ethics, morals and bioethics were used as free search terms with appropriate cuts and as subject headings suitable for each database. The search was limited to English language and title/abstract level. Time limitation was not used in the search. The search yielded a total of 1,948 hits. After the study selection, a manual search was conducted in the reference lists of the articles selected on the basis of the title and the abstract.

Study selection

The study selection process (Figure 1) was conducted in two phases independently by two researchers (XX, XX). First, the articles were selected on the basis of the title and the abstract and second, on the basis of the full text. The inclusion and exclusion criteria were used throughout the study selection. The inclusion criteria were (1) adult PwS as the patient group, (2) ethical issue or ethical principle as the main topic, (3) health care as the research context, and (4) a research article with empirical data. The studies were excluded if the focus was (1) stroke as a complication, (2) stroke caused by trauma, (3) PwS as organ donors and (4) research ethics. To reflect the views and ideas of the identification process, the researchers met at the beginning, in the middle and at the end of the study selection process. The final number of selected studies was 15 full texts.

Charting the data and collating the results

The data analysis was conducted in two phases. In the first phase, data from the selected articles were charted (Arksey & O'Malley, 2005) as follows: (1) authors; year of publication; geographical location of the study, (2) main concept, (3) health care context, (4) informants, (5) data collection method, (6) data analysis (Table 1). The first phase of the analysis answers the first research question and the results are presented as a descriptive numerical summary (Levac et al., 2010).

In the second phase, a content analysis was applied. The analysis focused on the manifest content of the aim, the main topic and the context of the studies and the results. The data were observed inductively. First, all original expressions of ethical issues in the texts were selected and considered as units. Second, these units were coded and given a representative name. Third, of the named codes, nine subthemes were formed on the basis of shared concepts and representativeness considering ethical issues. In the fourth phase, the similarities and differences of the subthemes were compared on an abstract level, resulting in the identification of three main themes. An example of the analysis from an original expression to the main theme is presented in Figure 2. Fifth, as a final step, the narrative representations of each theme were written to give an answer to the second research question. (Graneheim & Lundman, 2004.)

RESULTS

Description of the studies

The selected studies (n=15) were published between 2000 and 2017. More than half of the studies were conducted by two research groups; in the rest of the studies, the research group varied. Thirteen

of the studies were conducted in Europe and the remaining two in Canada and USA, respectively. The topic of seven studies was the ethical principle of autonomy; one of them concentrated on truth-telling, while the rest had ethics from a wider aspect as their topic. The studies focused quite evenly on hospital or rehabilitation contexts whereas the context of home care was lacking. The most common group of informants was health professionals composed of one or more occupational groups. Health professionals were informants in eight studies and patients in six. Only one study had significant others as informants; the whole group of informants consisted of patients and health professionals in addition to significant others. Except for two of the studies, the number of the informants was rather small, less than fifty. Two of the studies used a longitudinal and thirteen a cross-sectional design. One of the two studies with a longitudinal design included three of the selected cross-sectional studies. In six studies, the data were collected using individual interviews and another data collection method, while in nine studies data were collected using a single data collection method. Data were analyzed by statistical methods in three studies while a qualitative approach was used in twelve studies. The interpretation of the qualitative approach varied. However, it was notable that Grounded Theory was used in five studies.

The ethical issues in the care of PwS

As is evident with the topic of ethical issues, the value basis was strongly present. The nature of the ethical issues varied and did not concentrate only on ethical problems. In the study selection and in the analysis, the ethical issues were not predefined but considered as the authors of the studies themselves had set them. Some of the ethical issues were clear, representing ethical principles of autonomy (Mar et al., 2015; Proot et al., 2007; Castellucci 2004; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) and privacy (Eriksson et al., 2014; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) or paternalistic care practice (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a). However, the others needed discerning. In the results of the selected articles, the value basis guided the decision-making (Rejnö et al., 2015, 2013, 2012; Eriksson et al., 2014) and care (Rejnö et al., 2015, 2012) including the aspects of prioritization (Yger et al., 2016; Theofanidis, 2015; Rejnö et al., 2015, 2012) and limited resources (Rejnö et al., 2015, 2013, 2012; Rochette et al., 2014; Proot, Crebolder et al., 2000a). Acting on own values pointed to nonmaleficence (Eriksson et al., 2014) and furthermore, beneficence and nonmaleficence were considered important in the care (Rejnö et al., 2015, 2012; Eriksson et al., 2014). Although there were several ethical issues identified from the results of the selected articles, the ethical nature of all of the issues was not clear and thus they may

have been clinical issues instead. In this review, however, the original results of the selected articles are presented.

The narrative representation was difficult to formulate because of the heterogeneous nature of the studies. However, the following three main themes of ethical issues in the care of PwS were identifiable: ‘decision-making as an ethically challenging act’, ‘care process-specific ethical issues’ and ‘environmental ethical issues’ (Figure 3). In the next chapters, these themes will be described in detail.

Theme 1: Decision-making as an ethically challenging act. In decision-making, the ethical issues were related to ‘the decisions on life-sustaining treatments’, ‘communication as a key issue in decision-making’ and ‘proving good care on the basis of the decisions taken or not taken’. The decisions on life-sustaining treatments were considered ethically demanding in the care of PwS (Rejnö et al., 2015, 2013, 2012; Eriksson et al., 2014) and communication was deemed important in reducing ethical problems (Rejnö et al., 2012). However, communication itself had some ethically problematic aspects (Eriksson et al., 2014). The health professionals wanted to act along the ethical principles of beneficence and nonmaleficence but sometimes considered the provision of good care impossible (Eriksson et al., 2014; Rejnö et al., 2013, 2012).

In the decision-making on life-sustaining treatments, the situations were ethically difficult when there was no consensus on the survival of the patient (Eriksson et al., 2014). Some of the health professionals tried to buy time by postponing the decision (Rejnö et al., 2015, 2012; Eriksson et al., 2014). In these cases, questions arose as to whether this prolonged the patient’s death (Rejnö et al., 2012) and caused unnecessary suffering for the patient. Avoiding unnecessary suffering and advocating the patient’s best interests were considered important aspects in decision-making. (Eriksson et al., 2014.)

In the ethically challenging decision-making on life sustaining treatments, health professionals wanted their decisions to be in accordance with the views of significant others (Rejnö et al., 2015, 2013, 2012). Occasionally, the decision concerning the care alignment was changed once the significant others got used to the situation with a dying close one (Rejnö et al., 2015). All in all, the health professionals considered it a relief to be able to revise their decisions if the situation changed (Rejnö et al., 2015, 2012; Eriksson et al., 2014). However, it was sometimes questioned whether the changes were made on too light a basis (Eriksson et al., 2014) or just to please the significant others (Rejnö et al., 2012).

In ethically demanding decision-making, communication was seen as key among the health professionals (Rejnö et al., 2015, 2013, 2012) and between health professionals and significant others (Rejnö et al., 2015). Successful communication between different parties was considered ideal in decision-making (Rejnö et al., 2015, 2013, 2012) and was seen to reduce ethical problems in the care of PwS (Rejnö et al., 2012). However, successful communication between different health professionals was not self-evident. At times, the health professionals selected those among the professionals to whom they delivered information about the patient, but sometimes the existing topics were not discussed at all. Problems in communication seemed to delay decision-making; in addition, they made it difficult to adhere to the decisions already made. (Eriksson et al., 2014.) Among health professionals, when communication led to disagreement, conflicts involving not accepting different views were likely to occur (Rejnö et al., 2013, 2012). To ease communication and decision-making in the units, there were rehabilitation rounds and palliative checklists that could be used, although the health professionals' attitudes towards them varied (Eriksson et al., 2014).

In decision-making, health professionals considered it ethically challenging if the health status of the PwS did not enable communication with the patient, which would allow them to become aware of the patient's will. In these cases, the significant others were considered as valuable informants. (Rejnö et al., 2012.) However, from the viewpoint of decision-making, it was questioned whether the significant others were telling the truth (Eriksson et al., 2014) or, for example, voicing their own will as the patient's will (Rejnö et al., 2012).

Providing good care was sometimes considered impossible because of the decisions taken or not taken (Eriksson et al., 2014; Rejnö et al., 2013, 2012). This was reported by nursing staff when the doctors stated it as their duty to save lives (Eriksson et al., 2014). In these cases, the health professionals considered it impossible to act based on the ethical principles of beneficence and nonmaleficence, as the treatment was seen as doing harm to the patient (Eriksson et al., 2014; Rejnö et al., 2012). There were also views of overtreatment and patient's reduced right to die (Eriksson et al., 2014).

Advocacy for the patients was considered as an important part of good care among the health professionals (Rejnö et al., 2015, 2012). This was seen both among health professionals (Rejnö et al., 2012) and significant others in situations involving conflicting views (Rejnö et al., 2015). The differences in views among health professionals were sometimes due to cultural aspects. Although the physician was responsible for the treatment, the nurses sometimes made their own decisions when they were not pleased with the decision made by the physician. (Eriksson et al., 2014.) Although there were multiple ethically challenging situations with the significant others, the health professionals also valued their presence. The significant others were an important source of information about the PwS,

and this was invaluable for providing individual care when the patient was unable to communicate. (Rejnö et al., 2012.)

Theme 2: Care process-specific ethical issues. In care process-specific ethical issues, the ethical issues were related to ‘ethical dilemmas around a dying patient’, ‘support for autonomy in the recovery process’ and ‘multidimensional paternalism in rehabilitation’. In the care of dying PwS, not all ethical issues were related to the patients but instead to the significant others (Rejnö et al., 2017, 2015, 2013, 2012; Eriksson et al., 2014). In the care of recovering PwS, the ethical issues tended to concentrate to ethical principle of autonomy (Proot et al., 2007; Castellucci 2004; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) and paternalistic care practice (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a).

Around a dying patient, the ethical issues seemed to be related to the significant other. All in all, the role of the significant other was highlighted in these cases (Rejnö et al., 2017, 2015, 2013, 2012; Eriksson et al., 2014) whereas the role of the PwS was seen as minor (Rejnö et al., 2017, 2012). In these cases, the health professionals wanted to support the significant other (Rejnö et al., 2015, 2012). In the care, this occasionally meant giving treatment to the PwS not because the patient’s state required it, but because the significant other was not ready to give up on the treatment (Rejnö et al., 2015). However, in some cases treatment that had been stopped was restarted because of the improved state of the PwS. For the significant others, this was not always without problems as they were forced to reconsider their own roles, from the significant other of a dying PwS to the significant other of a recovering PwS. (Eriksson et al., 2014.)

Creation of confidence was considered important in relation to the significant other (Rejnö et al., 2017, 2012). This was ethically problematic especially in cases of whether to tell the truth to the significant other or not. On the one hand, truth was valued above all, but on the other, the health professionals wanted to shield the significant other from the truth by resorting to an alternative solution, such as telling part of the truth. (Rejnö et al., 2017.)

The health professionals also faced other kinds of ethical problems with the significant others (Rejnö et al., 2015, 2013, 2012; Eriksson et al., 2014). Some of these arose from the situation (Rejnö et al., 2012), some from the significant others (Rejnö et al., 2015, 2013, 2012), and some from the health professionals themselves (Rejnö et al., 2015, 2013). Providing information in an unstable situation was considered ethically challenging, as were situations where the health professionals could not be sure whether the significant other was able to take in the information given (Rejnö et al., 2012).

Additionally, there were situations where there were conflicts among the significant others (Rejnö et al., 2013) and the health professionals did not know who of them to inform (Eriksson et al., 2014). However, sometimes the challenges were related to the health professionals themselves (Rejnö et al., 2015, 2013), such as knowledge base or feeling affected (Rejnö et al., 2013).

Support for autonomy was important in the case of a recovering PwS (Proot et al., 2007; Castellucci 2004; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). Autonomy was considered to comprise three dimensions: self-determination, independence and self-care (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). All in all, autonomy was considered as challenged (Proot et al., 2002) and changed after the onset of stroke (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). Autonomy of the PwS was diminished after the onset of stroke (Proot et al., 2007; Proot et al., 2002; Proot, Crebolder et al., 2000a), but it also improved during the rehabilitation (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) and the year following the stroke (Mar et al., 2015).

The patient's condition was an important autonomy-related factor (Mar et al., 2015; Castellucci 2004; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a). However, this did not only concern the situation after the stroke (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) but also the factors existing before the stroke (Proot et al., 2002; Proot, Crebolder et al., 2000a), such as the patient's pre-stroke activity level (Proot et al., 2002). However, stroke would sometimes change a person so that they could not be compared to the pre-stroke person (Proot et al., 2002).

The active role of the PwS was important in improving autonomy (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). During rehabilitation, the PwS started to adapt to their situation (Proot et al., 2002; Proot, Crebolder et al., 2000a, 2000b) and their abilities began to improve (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al. 2000b). In addition, a nursing home (Proot et al., 2007; Proot et al., 2002) and therapy could have an effect on the improvement (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al. 2000a, 2000b). However, health professionals were not the only important persons for improvement of autonomy; support could also be provided by significant others as well as other patients (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b;). Moreover, co-operation (Proot et al., 2002; Proot, Abu-Saad et al., 2000) and teamwork with different participants was crucial (Proot et al., 2007; Proot et al., 2002; Proot, Crebolder et al., 2000a) in addition to giving information (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et

al., 2000a, 2000b) and the patient receiving evaluation (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b). In contrast, disabilities (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b) and multi-morbidity were seen as constraining the autonomy of PwS (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b). Although the nursing home as an environment was considered to support autonomy (Proot et al., 2007; Proot et al., 2002), there were also aspects reducing PwS' autonomy (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b), such as the care routines (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b).

Paternalism was considered as vital but multidimensional in the rehabilitation phase (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a). However, this was the case only at the beginning of the rehabilitation (Proot et al., 2007; Proot et al., 2002) when the PwS were dependent on other people (Proot et al., 2002) and had a passive role (Proot et al., 2007; Proot, Crebolder et al., 2000a, 2000b). As time went by, the need for paternalism decreased (Proot et al., 2007; Proot et al., 2002) as the patients were able to take on more responsibility (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b) and their needs changed (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b). It was important for the health professionals to recognize this (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000) and to change their own behavior accordingly, diminish paternalism (Proot et al., 2007; Proot et al., 2002) and share decision-making further (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b;). Although the actions of the health professionals were important, sometimes they were not very smooth (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b;). This was the case, for example, when the health professionals acted in an institutionalized (Proot et al., 2002; Proot, Abu-Saad et al., 2000) or overprotective manner (Proot et al., 2002; Proot, Crebolder et al., 2000b) or were paternalistic in a negative way (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). The paternalistic actions were not always done by health professionals but by significant others as well (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b;). However, in some cases the PwS wanted the significant other to make decisions for them, and in these cases it was not considered paternalistic (Castellucci 2004; Proot et al., 2002).

Theme 3: Environmental ethical issues. In the environment, the ethical issues were related to 'privacy', 'prioritization' and 'available and lacking resources'. The health professionals sometimes

considered the realization of patients' privacy difficult because of environmental restrictions (Eriksson et al., 2014; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b). The environment also caused other kinds of ethical issues in terms of prioritization (Yger et al., 2016; Theofanidis, 2015; Rejnö et al., 2015; 2012) and resources Rejnö et al., 2015, 2013, 2012; Rochette et al., 2014; Proot, Crebolder et al., 2000a)

Privacy of the PwS was challenged because of environmental ethical issues. In the rehabilitation context, the nursing home as a physical environment was a threat to privacy (Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b), the presence of other patients being an additional threat (Proot et al., 2002). In the case of the dying PwS, the physical environment, and more precisely, the lack of single rooms, posed a threat to the PwS' privacy (Eriksson et al., 2014).

Prioritization was considered ethically demanding by the health professionals (Yger et al., 2016; Theofanidis, 2015; Rejnö et al., 2015; 2012). Prioritization was considered both in the intense phase of the care of stroke (Yger et al., 2016; Theofanidis, 2015) as well as in some single tasks in the care provided by health professionals (Rejnö et al., 2015; 2012). When PwS arrived in the emergency room, the health professionals considered it ethically demanding if they were forced to move the patient to a less intensive unit, e.g. based on the patient's age as opposed to the severity of stroke. Health professionals wanted to see changes in this and admitted sometimes acting against the policy. (Theofanidis, 2015.)

Available and lacking resources appeared ethically demanding in the care of PwS (Rejnö et al., 2015, 2013, 2012; Rochette et al., 2014; Proot, Crebolder et al., 2000a). The resources were related to prioritization as different kinds of working tasks had to be prioritized according to the resources available (Rejnö et al., 2015; 2012). In addition, lack of time (Rejnö et al., 2015, 2013, 2012) and high work-load (Rejnö et al., 2015, 2013) were related to the prioritization when, for example, communication with significant others was not prioritized (Rejnö et al., 2012). All in all, significant others were not considered and the family-centered approach was not applied as much as the significant others would have wanted (Rochette et al., 2014). Additionally, as resources had to be shared with other patients (Rochette et al., 2014; Proot, Crebolder et al., 2000a), PwS considered this to have an effect on their autonomy in the rehabilitation context (Proot, Crebolder et al., 2000a).

However, part of the lack of resources was related to a lack of knowledge resources for the health professionals considering the care of PwS (Rejnö et al., 2015, 2013). Additionally, the health professionals had difficulties with the knowledge concerning appropriate social behavior (Rejnö et

al., 2015). For health professionals, additional challenges were caused by the high staff turnover (Eriksson et al., 2014; Rejnö et al., 2012).

DISCUSSION

The results

The aim of the scoping review was to identify and analyze the ethical issues in the care of PwS. Based on the review, the existing literature is heterogeneous and focuses mainly on two stages in the care process of PwS: the dying patient and the rehabilitation context. Additionally, the informants in the studies varied, health professionals being the most common ones. In these studies, the time point was usually the acute stage of stroke where there are demanding decisions concerning the care to be made (Eriksson et al., 2014) and in some cases, the decision is about whether to continue the care or not and with what intensity (Rejnö et al., 2015, 2013, 2012; Eriksson et al., 2014). The perspective of PwS was the second most common in the selected studies concentrating on the PwS' autonomy after the acute stage (Mar et al., 2015; Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b; Castellucci, 2004). Among the studies, it was remarkable that although significant others have an important role in the care of PwS (Cecil et al., 2013) there were hardly any studies from the viewpoint of significant others.

The analysis was challenging because of the heterogeneous nature of the literature, and it was also challenging to deal with the results as the ethical nature of the issues was not always clear. In this review, however, it was a conscious decision not to divide the issues into ethical and clinical ones but to understand them as the authors of the selected articles had represented them. Despite the challenges, the aim of the scoping review was reached, resulting in three themes of ethical issues in the care of PwS: 'decision-making as an ethically challenging act', 'care process-specific ethical issues' and 'environmental ethical issues'. The nature of the themes varies. The first main theme is about actions in the care of PwS, the second main theme is about the different stages in the care process of PwS, while the third main theme is about the health care environment. Selecting these themes of different nature was a conscious decision. The analysis could also have been conducted otherwise, for example, on the basis of the health care context or the stage of the care process. However, this was not seen as a meaningful starting point for analysis as the aim was to focus on ethical issues; as a result, the analysis focused on ethical issues as opposed to the care context, for example.

Each of the three main themes included three subthemes. In the first main theme, ‘decision-making as an ethically challenging act’, the subthemes were observing the decision-making from different angles: concentrating on life-sustaining treatments, the role of communication and the consequences of the decisions taken or not taken. The second subtheme, ‘care process-specific ethical issues’, included the subthemes dying patient, recovery time and rehabilitation context. The third main theme, ‘environmental ethical issues’, represented three different aspects linked to the ethical issues in the health care environment. However, as the existing literature was found to be limited and heterogeneous, it is possible that the results of this review, including the main themes and subthemes, may not represent the ethical issues in the care of PwS comprehensively, and the results may thus be skewed.

In the three main themes, the intensity of the presence of stroke varied. In the first main theme, ‘decision-making as an ethically challenging act’, the presence of stroke focused on the sudden onset of symptoms (Rejnö et al., 2015), the uncertain survival of the patient (Eriksson et al., 2014), the rapidly changing health situation of the patient (Rejnö et al., 2015, 2012; Eriksson et al., 2014) and patients’ inability to communicate because of their health status (Rejnö et al., 2012). However, it may be questioned whether these are specific only to the care of PwS or whether they can also be expanded to the care of other sudden life-threatening diseases or injuries, such as ischemic heart attack or severe traumatic brain injury. In the second main theme, ‘care process-specific ethical issues’, the presence of stroke was the most evident. In the subthemes, the patient’s condition (Mar et al., 2015; Castellucci 2004; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a) and unstable situation caused by stroke (Rejnö et al., 2012) were remarkable, in addition to possible personality changes (Proot et al., 2002). Additionally, stroke was present in the meaning of rehabilitation (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al. 2000a, 2000b) and recovery (Proot et al., 2007; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000b). However, the third main theme, ‘environmental ethical issues’, seemed to comprise more general issues specific to the health care environment, such as limited resources (Rejnö et al., 2015, 2013, 2012; Rochette et al., 2014; Proot, Crebolder et al., 2000a) and health care policy (Theofanidis, 2015). On the basis of the existing literature, it seems that the number of stroke-specific ethical issues is rather small. However, this statement cannot be confirmed by the limited and heterogeneous literature; there is an evident need for future research on this topic.

Future research

The scoping review revealed several needs for future research. The literature of ethical issues in the care of PwS is currently focused on certain ethical aspects at limited stages of the care process. With research focusing on other stages of the care process, the results could be generalized to the whole care process of PwS. Additionally, as autonomy was experienced as changing by PwS (Proot et al., 2007; Proot et al., 2002; Proot, Abu-Saad et al., 2000; Proot, Crebolder et al., 2000a, 2000b), longitudinal studies of ethical issues would help to clarify whether also other ethical issues in the care of PwS are changing and what kinds of changes may follow the onset of stroke. In only one study, one group of informants consisted of significant others (Rochette et al., 2014). As stroke also changes the lives of significant others (Cecil et al., 2013), more research of ethical issues from their viewpoint is needed. Additionally, as the importance of the research of the lived experiences of the patients is recognized (Gastmans, 2013), more research of ethical issues from the patients' viewpoint is needed, with the patients themselves as informants. This enables health care professionals to respond adequately to patients' expectations and health care organizations to tailor services from the viewpoint of service users.

Strengths and limitations

A scoping review was selected as the research method as literature on the topic was known to be scarce and this type of review allows inclusion of different kinds of study designs (Arksey & O'Malley, 2005). The literature search was conducted systematically in several electronic databases. The search words were selected by two researchers (XX, XX) and the correctness of the search phrase was confirmed by an information specialist. The search phrase included general words concerning ethics. Ethical issues were not divided into smaller units, such as ethical principles. Selecting more specific words would have resulted in the question of which more specific words should be included or excluded. The authors are aware that this decision may have had an effect on the results of the literature search.

As required by the inclusion criteria, the selected studies were about ethical issues. The authors did not have a further definition or requirements for ethical issues. Instead, in this scoping review, the ethical issues were considered as the authors of the studies had set them. In the selected articles, there was variation as to how profoundly the concepts were explained.

All in all, stroke research on ethical issues was found to be very limited and heterogeneous. Because of the latter, the themes were challenging but could finally be formulated. The selected studies were mainly conducted using qualitative methods, which may restrict the generalizability of the results.

However, this methodological approach may have provided deeper knowledge of the topic. Further, as for the existing literature, the variety of the topics remained limited, leaving several ethical aspects outside the scope of the review.

CONCLUSION

The scoping review identified three main themes in the ethical issues in the care of PwS. The issues were focused on decision-making, on certain stages of the care process, and on environmental issues. Ethical issues were recognized from the perspectives of all parties involved: patients, significant others and health professionals. However, not all the recognized ethical issues were stroke-specific; some were common to other sudden life-threatening situations or general to the health care context. In addition, the ethical nature of the issues was not always clear. However, the literature of the ethical issues in the care of PwS was found to be very limited, and future research is thus needed to achieve a comprehensive understanding of the topic.

RELEVANCE TO CLINICAL PRACTICE

The results of the scoping review may be used by individual health professionals but also on unit or health care organization level. For individual health professionals, the results provide a starting point to examine and question their own action from an ethical perspective both in acute care and in the rehabilitation context. In addition, the results may deepen individual health professionals' understanding of the situation as a whole and from the perspectives of others, i.e. patients and other health professionals. On unit or organization levels, the results may be used for developing ethically high-level practices and ward climate, for example, by promoting open communication.

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FIGURE LEGENDS

Figure 1. Flowchart of the study selection.

Figure 2. An example of the analysis from original code to a main theme.

Figure 3. The Ethical Issues in the Care of Patients with Stroke.