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To my grandfather Olavi, my father Veli-Matti,
my spouse Timo and my son Olavi

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ABSTRACT

Stroke is a common health problem which may cause long-term and ethically challenging changes in the lives of individuals with stroke (IwS). The study focused on the realization of central values in nursing practice as perceived by IwS and the potential changes in the perceived realization of values in post-stroke time, labeled as the ethical pathway. The main aim was to compose a theoretical construct of the ethical pathway. The ultimate goal was, by making the ethical pathway visible, to support the development and realization of ethically high-level nursing care.

The study was conducted in four steps. In the first step, based on a grounded theory study (n = 16 IwS) and scoping literature review (n = 15), the concept 'ethical pathway' and the life situational factors related to it were defined. In the second step, they were operationalized, leading to the Ethical Pathway of Individuals with Stroke (EPIS) instrument evaluating the realization of values and life situational factors in post-stroke time as perceived by IwS. In the third step, the concept of the ethical pathway and its association with the life situational factors were empirically tested in a cross-sectional study (n = 61 IwS) and a follow-up study (n = 36 IwS). In the fourth step, the obtained results were synthesized to form the theoretical construct of the ethical pathway.

The concept of the ethical pathway was defined as potential changes in the realization of values, including dignity, privacy, and autonomy, as perceived by individuals in temporal passage. The life situational factors related to the ethical pathway were defined as symptoms diminishing functioning, social environment, and self-empowerment. The theoretical construction of the ethical pathway consists of the concept of the ethical pathway and the life situational factors, and the association between these. As changes in the individual's health status may change the perceived realization values, health status is also represented in the theoretical construction of the ethical pathway. The ethical pathway is dynamic, and the association between the ethical pathway and the life situational factors fluctuates in temporal passage. In this study, the ethical pathway was made visible, and by understanding the ethical pathway, nurses may support the perceived realization of individuals' values during the care pathways.

KEYWORDS: autonomy, dignity, ethical pathway, individuals with stroke, instrument, nursing care, privacy

TURUN YLIOPISTO
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Hoitotiede
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TIIVISTELMÄ

Aivoverenkiertohäiriö (AVH) on yleinen terveysongelma, joka voi aiheuttaa pitkäaikaisia ja eettisesti haastavia muutoksia yksilön elämään. Tutkimuksessa tarkasteltiin AVH:n sairastuneiden näkemyksiä kolmen hoitotyön keskeisen arvon toteutumisesta ja siinä mahdollisesti tapahtuvia muutoksia sairastumisen jälkeisessä ajassa, nimettynä eettiseksi poluksi. Tutkimuksen päätarkoituksena oli muodostaa eettisen polun teoreettinen rakenne. Tavoitteena oli havainnollistamalla eettinen polku, tukea eettisesti korkealaatuisen hoitotyön kehittämistä ja toteuttamista.

Tutkimus toteutettiin neljässä vaiheessa. Ensimmäisessä vaiheessa määriteltiin eettisen polun käsite ja siihen yhteydessä olevat elämäntilannesidonnaiset tekijät pohjautuen grounded theory -tutkimukseen (n = 16 AVH:n sairastunutta) ja kartoittavaan kirjallisuuskatsaukseen (n = 15). Toisessa vaiheessa kehitettiin Aivoverenkiertohäiriöön sairastuneen eettinen polku -instrumentti, joka arvioi AVH:n sairastuneiden näkemyksiä arvojen ja elämänsidonnaisten tekijöiden toteutumisesta. Kolmannessa vaiheessa eettisen polun käsite ja sen yhteys elämäntilannesidonnaisiin tekijöihin testattiin empiirisesti poikkileikkaustutkimuksessa (n = 61 AVH:n sairastunutta) ja seurantatutkimuksessa (n = 36 AVH:n sairastunutta). Neljännessä vaiheessa tuloksista tehtiin synteesi muodostaen eettisen polun teoreettinen rakenne.

Eettisen polun käsite kuvaa yksilön näkemystä arvojen toteutumisesta ja siinä ajassa ilmenevää mahdollista muutosta. Arvoihin lukeutuvat arvokkuus, yksityisyys ja autonomia. Elämäntilannesidonnaisiin tekijöihin lukeutuvat toimintaa haittaavat oireet, sosiaalinen ympäristö ja oman elämän hallinta. Eettisen polun teoreettinen rakenne sisältää eettisen polun käsitteen sekä elämäntilannesidonnaiset tekijät ja niiden välisen yhteyden. Muutokset yksilön terveydentilassa voivat muuttaa yksilön näkemystä arvojen toteutumisesta ja tästä syystä myös terveydentila sisältyy eettisen polun teoreettiseen rakenteeseen. Eettinen polku on dynaaminen, ja myös eettisen polun ja elämänsidonnaisten tekijöiden välinen yhteys vaihtelee ajassa. Tutkimuksessa havainnollistettiin eettinen polku. Ymmärtämällä eettinen polku osaksi hoitopolkua, hoitajat voivat edistää terveyspalveluita käyttävien yksilöiden arvojen toteutumista.

AVAINSANAT: aivoverenkiertohäiriöön sairastunut, arvokkuus, autonomia, eettinen polku, hoitotyö, mittari, yksityisyys

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Abbreviations

CI	Confidence interval
EPIS	the Ethical Pathway of Individuals with Stroke (instrument)
HCP	Health care professional
IC	Informal caregiver
IPA	Impact on Participation and Autonomy (instrument by Cardol M & de Jong BA)
IwS	Individuals with stroke
MS	Multiple sclerosis
RQ	Research question
SD	Standard deviation
SDF	Symptoms diminishing functioning
SE	Social environment
SeEm	Self-empowerment
SO	Significant other
SPSS	The Statistical Package for the Social Sciences
TIA	Transient ischemic attack

List of Original Publications

This dissertation is based on the following original publications, which are referred to in the text by their Roman numerals:

I Rannikko S, Stolt M, Suhonen R & Leino-Kilpi H. Dignity realization of patients with stroke in hospital care: A grounded theory. *Nursing Ethics*, 2019; 26(2): 378–389.

II Rannikko S, Stolt M, Suhonen R & Leino-Kilpi H. Ethical issues in the care of patients with stroke: A scoping review. *Journal of Clinical Nursing*, 2019; 28(1–2): 20–31.

III Rannikko S, Leino-Kilpi H, Pasanen M & Suhonen R. The ethical pathway – Does the perceived realisation of the individuals' values change during the post-stroke time? *Clinical Ethics*. (Published online 31.1.2023)

IV Rannikko S, Suhonen R, Pasanen M & Leino-Kilpi H. The ethical pathway of individuals with stroke – A follow-up study. (Manuscript)

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1 Introduction

This is a clinical nursing ethics study focusing on individuals with a long-term health problem. Worldwide, long-term health problems affect a vast number of people. For instance, in OECD countries, more than every third person aged 16 or over has some long-term health problem (OECD 2022). The importance of the prevention of long-term health problems and the need of support for individuals living with such conditions have been recognized on both individual and societal level (WHO 2013, The European Parliament and the Council 2021).

Health problems occur as part of an individual's life span. Thompson et al. (2006) have described this as an individual's 'health career', where health problems involve greater dependence on other people and loss of autonomy. This is a dynamic process where responsibility is shifted from the individual to a caregiver, and vice versa, in line with the individual's health situation. However, long-term health problems do not necessarily mean life-long dependency on other people (Thompson et al. 2006), but they have been stated to constitute a challenge to individuals' quality of life (Ellepola et al. 2022, Peixoto et al. 2022) and the perceived realization of central values in nursing such as dignity (e.g., Grassi et al. 2022, Liu et al. 2022), privacy (e.g., Akyüz et al. 2022), and autonomy (e.g., Jones et al. 2022).

The universal human rights highlight the importance of dignity, privacy, and autonomy as equal rights of all human beings (United Nations 1948). Therefore, the perceived realization of the values of individuals with a long-term health problem deserve special attention, not only in the acute phase but also in the longer term in the health career. One of the most common long-term health problems is stroke (Feigin et al. 2017, WHO 2022).

The life-threatening health problem of stroke (Current Care Guidelines 2020) often has a sudden onset (Gonzalez-Castellon & Kitago 2015, Kjærhauge Christiansen et al. 2021). In the acute phase, stroke always requires professional health care (Current Care Guidelines 2020), and despite important and life-supporting technical solutions, the need for humane contact in care is evident (Loft et al. 2019). The uncertain situation, especially in the acute phase (Ni et al. 2018), but also the potential long-term impacts of stroke (Simeone et al. 2015, Kuenemund et al. 2016), may be frightening and stressful both for individuals with stroke (IwS)

(Ni et al. 2018) and their significant others (SOs) (de Boer et al. 2015). This highlights the importance for health care professionals (HCPs) to encounter IwS (Kitson et al. 2013) and SOs (Rejnö et al. 2013) in a humane and sensitive way. The importance of SOs' role in the care of IwS is well recognized (Chen et al. 2021), but in this study the focus is on IwS' perceptions. The expression 'individuals with stroke' has been used to describe all the individuals who have at some point of their life had a stroke. IwS may be considered as being in a vulnerable position (ten Have 2016) because of the stroke (Crowfoot et al. 2018, Loft et al. 2019, Kjærhauge Christiansen et al. 2021). Despite the vulnerable position, IwS have the right to be studied and to be heard.

Stroke causes diverse and sometimes permanent symptoms (Simeone et al. 2015, Kuenemund et al. 2016) impacting individuals' physical, psychical, or cognitive functioning (Current Care Guidelines 2020, Ullberg et al. 2021), causing potential dependency on other people (Crowfoot et al. 2018, Loft et al. 2019, Kjærhauge Christiansen et al. 2021). The symptoms may have a negative impact on IwS' self-esteem (Leahy et al. 2016, Crowfoot et al. 2018), self-identity (Timothy et al. 2016, Lou et al. 2017, Crowfoot et al. 2018, Large et al. 2020, van Dongen et al. 2021), social life (Kjærhauge Christiansen et al. 2021, van Dongen et al. 2021), control over own life (Luker et al. 2015), and empowerment (Leahy et al. 2016). The impacts of stroke may be present for the individual even in the case of mild stroke (Crowfoot et al. 2018, Hodson et al. 2019, Hodson et al. 2020).

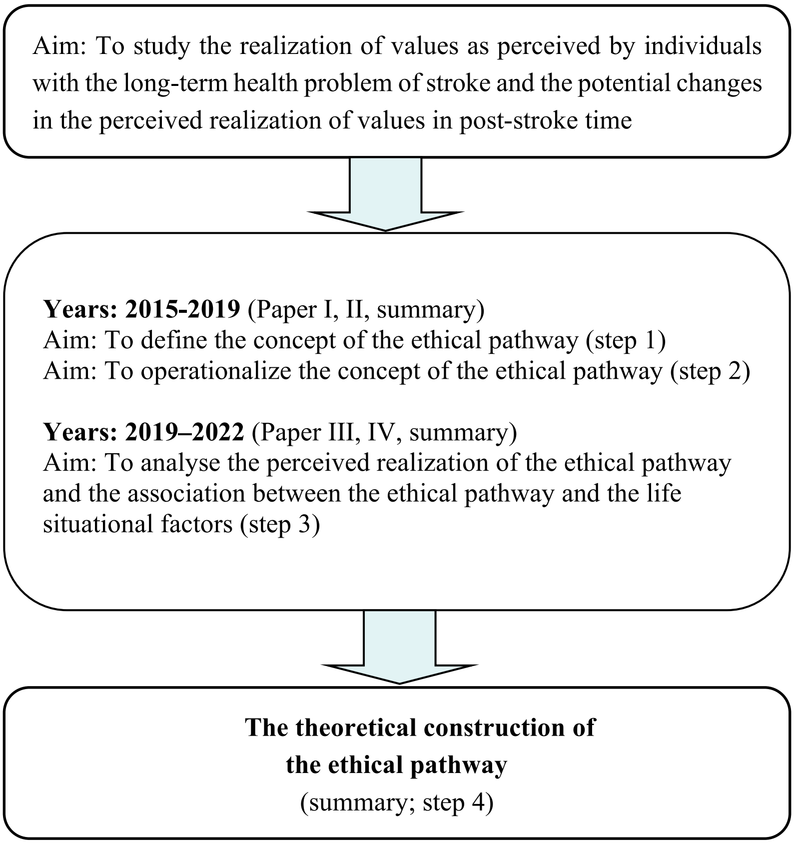
The care of IwS requires major activities of HCPs. The care pathways of IwS, partly structured and partly individual (Cowey et al. 2015, de Belvis et al. 2019), may be long and comprise several care facilities (Current Care Guidelines 2020). During the care pathway, IwS may have multiple needs. Even in the case of mild stroke, the individual's needs may be challenging to recognize (Crowfoot et al. 2018), and they are not always met (Ullberg et al. 2016, Heiberg et al. 2021). IwS occasionally perceive that care focuses on the physical aspects (Chen et al. 2021), whereas IwS desire comprehensive care including the presence of HCPs (Suddick et al. 2021) and HCPs also taking into account their emotional needs (Chen et al. 2021). In addition, IwS have reported challenges in the perceived realization of values during the care pathway (e.g., Proot et al. 2007, Kitson et al. 2013).

This study focused on the realization of values as perceived by individuals with a long-term health problem, i.e., stroke, and the potential changes in the perceived realization of values in post-stroke time (Figure 1). The values were studied, including three central values in nursing practice, instead of studying the content of individuals' value basis. The focus of interest was also on the potential association between the perceived realization of the values and some life situational factors. The changes in the perceived realization of values were studied using the novel concept of ethical pathway, and to illustrate this, the main aim of the study was to compose a theoretical construct of the ethical pathway.

To reach the main aim, the study was conducted in four steps. In the first step, the definition of the concept of ethical pathway was formulated based on grounded theory of dignity realization of IwS in hospital care (Paper I) and a scoping review of ethical issues perceived by IwS, SOs and HCPs in stroke care (Paper II). Also, the life situational factors related to the ethical pathway were defined. In the second step, the concept of the ethical pathway and the life situational factors were operationalized, leading to the Ethical Pathway of Individuals with Stroke (EPIS) instrument, which evaluates the realization of values and life situational factors in post-stroke time as perceived by IwS. In the third step, the concept of the ethical pathway and its association with the life situational factors were empirically tested. This was conducted by analyzing the perceived realization of the ethical pathway and its association with the life situational factors in a cross-sectional study (Paper III) and in a follow-up study (Paper IV). Finally, in the fourth step, the obtained results were synthesized to form the theoretical construct of the ethical pathway. The theoretical construction of the ethical pathway consists of the concept of the ethical pathway and the life situational factors, and the association between these. As changes in the individual's health status may change the perceived realization of values, health status is also represented in the theoretical construction of the ethical pathway. The theoretical construction of the ethical pathway was developed in the stroke context. However, the theoretical construct of the ethical pathway is not tied to a single health problem.

In this study, analysis of the values of IwS started from central values in nursing, including dignity, privacy and autonomy; during the study, this was expanded to the ethical pathway. First, dignity was selected for study as a central value (United Nations 1948), noted for being challenging for IwS (Kitson et al. 2013), and considered dynamic by patient populations with serious illness (van Gennip et al. 2015) (Paper I). The data deepened the researcher's understanding that the perceived realization of values is reconsidered after the incidence of stroke, but additionally, it gave rise to the question whether the perceived realization of other central nursing values are also challenging for IwS. Second, the ethical issues in the care of IwS were charted from literature (Paper II). In this study, ethical issues describe the whole scope of ethics, such as ethical principles, questions, problems, dilemmas and the perceived realization of these. As a result, the concept under investigation was labeled as the ethical pathway. The concept of the ethical pathway consists of two elements: potential change in temporal passage and the dimensions of the ethical pathway including dignity, privacy, and autonomy. The life situational factors include symptoms diminishing functioning, social environment, and self-empowerment.

In clinical ethics, the focus is on ethical issues arising in clinical practice, and by identifying, analyzing, and resolving these issues, aiming to improve the quality of patient care (Singer et al. 2001). Nursing is guided by professional ethics highlighting respect of the individual's human rights (International Council of Nurses 2021, The Finnish Nurses Association 2021). The universal human rights include, for instance, right to be treated with dignity, right to privacy, and right to decide on personal matters (United Nations 1948). In health care, these are understood as patient's legal rights (Ministry of Social Affairs and Health 1992) and core ethical principles (Thompson et al. 2006, ETENE 2011, Beauchamp & Childress 2013, ETENE 2018) and values (ETENE 2011). Both clinical ethics (Singer et al. 2001) and nursing ethics (Thompson et al. 2006) have an important role in practice and in education of HCPs, and in both, there is a need for the investigation of the topic from patients' perspectives (Singer et al. 2001).



Aim: To study the realization of values as perceived by individuals with the long-term health problem of stroke and the potential changes in the perceived realization of values in post-stroke time

Years: 2015-2019 (Paper I, II, summary)
Aim: To define the concept of the ethical pathway (step 1)
Aim: To operationalize the concept of the ethical pathway (step 2)

Years: 2019–2022 (Paper III, IV, summary)
Aim: To analyse the perceived realization of the ethical pathway and the association between the ethical pathway and the life situational factors (step 3)

The theoretical construction of the ethical pathway
(summary; step 4)

Figure 1. Study process.

2 Background

In this chapter, the focus is on stroke and ethics. First, stroke is described as a health problem from medical and nursing viewpoints (2.1). Second, the focus is on individuals and how they perceive stroke (2.2). At the end of the chapter, nursing ethics are described, including the values of dignity, privacy, and autonomy (2.3).

2.1 Stroke as a health problem

Stroke is a joint term for health issues of the cerebral blood vessels and circulation (Current Care Guidelines 2020). Stroke is commonly divided into ischemic and hemorrhagic stroke. Ischemic stroke is caused by thrombosis, embolism, or hypoperfusion leading to interruption or reduction of blood flow. (Gonzalez-Castellon & Kitago 2015.) In hemorrhagic stroke, further divided into intracerebral and subarachnoid hemorrhage, a blood vessel leaks or breaks (Centers for Disease Control and Prevention 2022a). The most common causes of bleeding are a rupture of an aneurysm or an arteriovenous malformation (American Stroke Association 2022b). Transient ischemic attack (TIA) is also often included as a type of stroke. Unlike ischemic and hemorrhagic stroke types, TIA includes only short-term symptoms, usually lasting less than one hour. After TIA, an individual has a high risk for a further ischemic stroke. (Current Care Guidelines 2020.)

Worldwide, 15 million individuals have stroke annually (WHO 2022). Stroke is the second-leading cause of death (Feigin et al. 2017) as stroke is fatal for a third of IwS (WHO 2022). Stroke is also one of the leading causes of disabilities (Feigin et al. 2017) as another third of IwS are permanently disabled (WHO 2022). In Finland, 25,000 individuals have stroke annually. The number includes 18,000 ischemic strokes, 1,800 hemorrhagic strokes, and 5,000 TIAs. It is estimated that 80% of the strokes occurring in Finland could be prevented. (Finnish Brain Association n.d.)

The symptom onset of stroke is often sudden (Gonzalez-Castellon & Kitago 2015, Kjærhauge Christiansen et al. 2021), and common acute stage symptoms include numbness or weakness on one side of body, problems in speaking or understanding, problems in vision, challenges in walking, loss of balance or coordination, or dizziness (Gonzalez-Castellon & Kitago 2015, Current Care Guidelines 2020), drooling from the corner of the mouth (Current Care Guidelines

2020), and headache (Gonzalez-Castellon & Kitago 2015). The long-term symptoms are individual, based on the location and extent of the lesion, including symptoms such as paralysis on one side of the body, problems in speech or vision, quick and inquisitive or slow and cautious behavioral style, and memory loss (American Stroke Association 2022a). In addition, approximately every third IwS is diagnosed with depression (Towfighi et al. 2017).

The outcomes of stroke are highly dependent on the early recognition of the symptoms (Gonzalez-Castellon & Kitago 2015). Neuroimaging, such as computed tomography, is essential for both excluding other acute neurological deficits but also to distinguish between ischemic and hemorrhagic stroke (Boulter et al. 2015), as the interventions for them are different (Gonzalez-Castellon & Kitago 2015). Proper acute stage care (Gonzalez-Castellon & Kitago 2015) provided in a specialized stroke unit and proper evaluation of the rehabilitation needs are associated with better outcomes (Current Care Guidelines 2020). For HCPs, care of IwS is both ethically (Rejnö & Berg 2015) and clinically demanding and requires multiple competencies (Jarva et al. 2021), such as neurological assessment competency (Bae & Roh 2022), competence in care process, interaction skills, and skills in acknowledging the family (Jarva et al. 2021).

The care and treatment of IwS follow clinical pathways. These are generally structured, but also individualized, based on stroke severity and recovery (Cowey et al. 2015, de Belvis et al. 2019). For many IwS, the progress is rather fast at the beginning of the recovery period (Loft et al. 2019). However, the length of rehabilitation may vary from weeks even up to years (Centers for Disease Control and Prevention 2022b), and thus, the clinical pathways of IwS, including both acute care and rehabilitation, may be long (Current Care Guidelines 2020). Rehabilitation has a vital role in IwS' long-term recovery outcomes (Forgea et al. 2021). However, IwS' perceived needs and the provision of rehabilitation services do not always meet (Ullberg et al. 2016, Heiberg et al. 2021) and for some IwS, based on, for instance, their home region, public rehabilitation services are not available at the same level (Koskinen 2016), causing inequality among IwS. Furthermore, long waiting times to receive rehabilitation services may hinder IwS from achieving the rehabilitation goals (Chen et al. 2021).

2.2 Stroke as perceived by individuals with stroke

Often, the sudden onset of stroke (Kuenemund et al. 2016, Nasr et al. 2016) does not provide an opportunity for individuals to prepare themselves for changes in life (Simeone et al. 2015, Kuenemund et al. 2016) and health (Brunborg 2009, Clery et al. 2020) which are often significant, but also potentially permanent (Simeone et al. 2015, Kuenemund et al. 2016). In this chapter, stroke is described from individuals' viewpoint and how they perceive stroke.

The impact of stroke is individual and although in many references described with a negative connotation (Crowfoot et al. 2018), IwS do not always perceive themselves as disempowered (Chen et al. 2021). Still, the impacts of stroke on an individual's life are evident, even in the case of a mild stroke. The impacts, as perceived by IwS, are not separate from their life spans, and therefore they are related to, for instance, the individual's previous health status and experiences of health care services. (Crowfoot et al. 2018.) Here, the impacts as perceived by IwS are divided into three areas including (1) symptoms and daily living, (2) self and social environment, and (3) sense of control.

In relation to **symptoms and daily living**, IwS perceive the stroke incidence and the residual symptoms as causing loss of independence (Lou et al. 2017) and freedom (Takashima et al. 2016), and changes in everyday life (Kjærhauge Christiansen et al. 2021). Many IwS have depressive thoughts related to the experiences and sense of anxiety associated with the loss of normalcy (Crowfoot et al. 2018). IwS have various experiences of own body (Leahy et al. 2016, Nasr et al. 2016, Timothy et al. 2016), which are not always related to stroke severity or characteristics of the impairments (Timothy et al. 2016). The experiences include conflict between pre-stroke and post-stroke body (Timothy et al. 2016), and own body as changed (Nasr et al. 2016) or strange (Timothy et al. 2016, Crowfoot et al. 2018). Sometimes IwS speak about the impaired parts as separate from their bodies (Timothy et al. 2016, Crowfoot et al. 2018). However, due to regained control and sense of freedom, IwS may regain a cohesive sense of own body (Timothy et al. 2016).

IwS frequently face challenges with independence (Crowfoot et al. 2018), daily activities (Forgea et al. 2021, Guidetti et al. 2022), and performing activities perceived as important, such as driving, and community mobility (Jaber et al. 2018). The ability to continue pre-stroke activities is important for IwS (Wray et al. 2019, van Dongen et al. 2021) and rehabilitation plays a crucial role in regaining abilities to perform these. However, IwS' engagement in rehabilitation is not self-evident and some facilitators and barriers to engagement have been recognized. The facilitators include self-efficacy, therapeutic relationship with HCPs, and factors enhancing motivation, such as knowledge. The barriers are related to the physical, psychological, and emotional impacts of stroke, such as visual deficits, lack of concentration, and a feeling of humiliation. (Forgea et al. 2021.) In addition, anosognosia may cause inability for IwS to understand their rehabilitation needs and thus be a barrier to engagement in rehabilitation (Byrd et al. 2020).

IwS also have positive post-stroke feelings and experiences related to stroke and its symptoms, such as gratitude for being alive, and for having minor (Kjærhauge Christiansen et al. 2021) and diminishing impairments (Simeone et al. 2015, Loft et al. 2019) and seeing the self as capable (Crowfoot et al. 2018). IwS have described hope as essential for the sense of stability and possibility (Bright et al. 2020). All in all, hope for the future and recovery have a major role for individuals after the incidence of stroke (Lou et al. 2017, Crowfoot et al. 2018, Wray et al. 2019, Bright et al. 2020).

Related to **self and social environment**, the post-stroke time is individual, and IwS tend to reflect the situation both related to self and to the social environment. Concerning diminished functional abilities caused by residual symptoms of stroke, IwS have described that they have a negative impact on self-esteem (Leahy et al. 2016, Crowfoot et al. 2018) and self-identity (Timothy et al. 2016, Lou et al. 2017, Crowfoot et al. 2018, Large et al. 2020, van Dongen et al. 2021), and cause IwS a sense of hopelessness (da Silva et al. 2016) and a feeling of being unintelligent (Crowfoot et al. 2018). Furthermore, the increased dependency on others may cause feelings of guilt, self-worthlessness (Large et al. 2020), being a burden to other people (Simeone et al. 2015, Takashima et al. 2016, Chen et al. 2021), and fear and concern (da Silva et al. 2016). IwS have frequently described changes in relationships (Thomas et al. 2018, McGrath et al. 2019), roles (Takashima et al. 2016, Thomas et al. 2018, Large et al. 2020, van Dongen et al. 2021) and responsibilities (Takashima et al. 2016, Large et al. 2020). IwS have reported reduction of their networks initiated by the other participants (Leahy et al. 2016) and people not taking them seriously (Crowfoot et al. 2018).

IwS perceive peer-support to be important (Kjærhauge Christiansen et al. 2021) and they wish to share thoughts with individuals with similar experiences (Leahy et al. 2016); however, confronting social situations may be demanding for IwS. IwS may withdraw from public life because of bodily uncertainty (van Dongen et al. 2021) and from social situations because of eating difficulties (Klinke et al. 2014), to avoid questions (Kjærhauge Christiansen et al. 2021), and to alleviate distress (Large et al. 2020). However, not all the withdrawing is caused by IwS' insecurity or unwillingness, but by restrictions set by the environment. IwS have reported frequent physical and structural environmental barriers related to, for instance, climate (Tang et al. 2019), lightning (Crowfoot et al. 2018, Tang et al. 2019), unadjustable furniture, and stairs (Tang et al. 2019).

Nevertheless, not all impacts of stroke to the self or the social environment are perceived as negative by IwS. IwS have described the incidence of stroke having a strengthening impact on the bonds among family members (da Silva et al. 2016). IwS have also described developing strategies to build new confidence (Lou et al. 2017) and coping (Stott et al. 2021) and resilience to rebuild own life (van Dongen et al. 2021), and further positive emotions such as joy and confidence (Crowfoot et al. 2018).

Related to **sense of control**, this sense is important to IwS (Timothy et al. 2016) but IwS may perceive lack of control leading to frustration and distress, and disempowerment because of, for instance, HCPs' attitudes (Luker et al. 2015), treatment by close ones (Leahy et al. 2016), and poor communication (Luker et al. 2015). The lack of control may also focus on one's own body because of lost bodily control (Timothy et al. 2016, Lou et al. 2017, Stott et al. 2021, van Dongen et al. 2021) or trust in own body (Crowfoot et al. 2018, van Dongen et al. 2021). The situation with stroke may cause significant concern for the future (Lou et al. 2017, Loft et al. 2019) related, for instance, to being able to live at home or being able to return to work (Loft et al. 2019). IwS have also described empowerment in relation to HCPs meeting them with dignity and respect, and a family-centered approach at discharge (Crowfoot et al. 2018).

The impact of stroke for individuals is described in various ways, and many of these descriptions are related to patient empowerment, for instance, in relation to management of own illness and own lives (Pekonen et al. 2020). Many of the impacts are also ethically loaded, such as dependency on other people (Crowfoot et al. 2018) and challenges to express oneself (Wray et al. 2019). Some of the elements are present for all individuals with stroke, at least in the acute phase, while some are present on the basis of individual symptoms. Along the individual symptom pathway, these may be transient, long-lasting, or even permanent (Current Care Guidelines 2020).

2.3 Values in nursing practice

Ethics, the core of nursing (Thompson et al. 2006, Beauchamp & Childress 2013, Leino-Kilpi & Välimäki 2014, Haahr et al. 2020), concerns the fundamental questions of human life, such as the central values in the determination of our lives and health (Thompson et al. 2006). Nurses make multiple decisions during their working shifts and these decisions need to be ethically justifiable (Thompson et al. 2006). To maximize the realization of ethical decision-making and care, nurses' associations have formulated nursing codes of ethics. These codes highlight respect of the individual's human rights. (International Council of Nurses 2021, Finnish Nurses Association 2021.) The universal human rights include, for instance, right to be treated with dignity, right to privacy, and right to decide on personal matters (United Nations 1948). In health care, these are understood as patient's legal rights (Ministry of Social Affairs and Health 1992) and core ethical principles (Thompson et al. 2006, ETENE 2011, Beauchamp & Childress 2013) and values (ETENE 2011). In nursing, the rights and values may be considered from different viewpoints; for instance, from nurse's or organization's perspective. In this study, these are considered from the viewpoint of individuals with a long-term health problem. Individuals with health problems do not always have the possibility to protect their rights and values (Thompson et al. 2006).

In neuroscience nursing, the patients' health problem of stroke is part of HCPs' everyday work. From the viewpoint of individuals, health problems are unique parts of their life span, sometimes even dividing their life into 'before' and 'after' the incident. To acknowledge individuals comprehensively, HCPs need to see patients with their personal history. (Thompson et al. 2006.) Life history does not only influence how individuals perceive their health problems but also how they perceive the realization of values (Moser et al. 2010, Tranvåg et al. 2016). Furthermore, when living with a long-term health problem, the perceived realization of values may be dynamic. van Gennip et al. (2015) studied dignity of seriously ill patients and found three varying courses of experienced dignity including fluctuating, declining and steady dignity. Patients' and nurses' understanding of the perceived realization values is not always aligned, as Torabizadeh et al. (2021) stated in terms of patients' dignity. Therefore, it is important to study the perceived realization of values from individuals' viewpoint.

In this study, the values are considered as three central values in nursing practice, i.e., dignity, privacy and autonomy. Theoretically, dignity, privacy, and autonomy are seen as being related to each other (e.g., Franco et al. 2021, Torabizadeh et al. 2021) but also observed as separate (e.g., Leino-Kilpi et al. 2001, Scott et al. 2003b, Jacobson 2009). In this study, these are considered as equal values in nursing practice. They all are challenging and multifaceted concepts with various definitions (Scott et al. 2003a, Jacobson 2009, Beauchamp & Childress 2013).

Dignity

Nurses have a responsibility to respect patients' dignity (International Council of Nurses 2021), but they describe respecting patients' dignity as difficult, for instance, with patients with cognitive impairments (Birrell 2006). Patient's dignity is being respected, for instance, by seeing the patient as a fellow human being, by being there for the patient, and the patient being heard. Patient's dignity is violated, for instance, when the patient is abandoned or neglected or the nurse puts her/himself in a position of power. (Lindwall & Lohne 2021.)

Dignity is presented in four ways by Nordenfelt (2004): 'dignity as a merit' based on an individual's position or social rank, 'dignity as a moral stature' based on the thoughts and deeds of an individual, 'dignity of identity' based on personal sense of dignity taking into account, for instance, life history and health status, and 'dignity of menschenwürde' based on being a human being.

Instead, Edlund et al. (2013) documented a dualistic presentation of dignity including absolute and relative dignity. Absolute dignity is inherent to all humans and unchanged, while relative dignity is an individual's experience related to someone or something, and changeable. In this study, the definition of dignity leans on Jacobson's (2009) presentation of dignity, including human dignity and social dignity. Human dignity is similar to all humans based on being humans. Social dignity manifests in social contexts and interactions, and it is further divided into two types: dignity-of-self and dignity-in-relation. Dignity-of-self is based on self-respect and self-worth, and dignity-in-relation is based on individual and collective behavior.

Privacy

In 1980, Rawnsley discussed privacy as a legal right, a social privilege, and a psychological function. It is argued that privacy as a legal right brings little to the definition of privacy, whereas disruption of privacy sets the boundaries of privacy. Privacy as a social privilege sees privacy as being related to status and status separation, where individuals with higher socioeconomical status have better access to privacy, for instance, in terms of private hospital rooms. Privacy as a psychological function highlights privacy in the social context, from both individual and group perspectives. Here, privacy is seen as both positive and negative for the individual, for instance as a way of self-actualization and alleviation of social stress, but also as loneliness and ostracism. From a group perspective, privacy may be dysfunctional and imply structural inadequacy. Burgoon (1982) described privacy from different perspectives; here, the focus is on three of them (Leino-Kilpi et al. 2001). The first perspective sees privacy as the unit experiencing privacy, including both the individual and the group, for instance privacy in relation to person-to-person or group-to-person. The second perspective describes privacy from desired privacy to achieved end state. Optimum state of privacy is the state where the desired and achieved privacy are equal. The third perspective sees privacy as reactive-proactive. Reactive privacy is a response to undesired stimuli, while proactive privacy is about control and freedom of choice. (Burgoon 1982, Leino-Kilpi et al. 2001.)

In this study, the definition of privacy leans on Burgoon's (1982) presentation of privacy through four dimensions. The physical dimension includes physical accessibility in terms of personal space, an invisible place surrounding an individual's body, and territoriality, giving an individual an opportunity to be alone. The psychological dimension includes an individual's ability to control cognitive inputs, such as the ability to think and formulate attitudes, and outputs, such as with whom and under what circumstances an individual shares thoughts. The social dimension includes an individual's ability to control contacts with other individuals in terms of participants in and frequency, length, and content of interaction. The informational dimension describes the right that an individual has considering how, when, and to what extent he or she releases personal information to another individual or organization. (Burgoon 1982, Leino-Kilpi et al. 2001.)

Autonomy

At its minimum level, autonomy is defined as self-rule which is free from other individuals' interference and other limitations preventing meaningful choice, such as individual's limited competence (Beauchamp & Childress 2013). Lindberg et al. (2014) identified five attributes for the concept 'patient autonomy in caring context' including to be seen as a person, the capacity to act, the obligation to take responsibility for one's actions, process, and (re-)constructing. In being seen as a person, autonomy should be viewed in the light of each individual and also keeping in mind the variations in the individual's different caring situations. Capacity to act describes the individual as a responsible agent who takes an active role in the decision-making considering their care. Skill for decision-making is not seen as all or nothing; it can be partial or decision-specific. The obligation to take responsibility for one's actions involves the individual dealing with the consequences of the decisions made. An individual may also relinquish the decision-making to the HCPs, which is a decision in itself. The process describes the contextual and dynamic nature of individual's autonomy, changing in line with the individual's mental and physical capacity. (Re-)Constructing describes the changing nature of autonomy. In the recovery process, the individual's autonomy is constructed, but not necessarily reconstructed, meaning that the construction process may not lead to the manifestation of autonomy similar to that previously experienced by the individual.

Providing information for a patient and a patient participating in the decision-making regarding care are recognized as crucial elements in the support of patient autonomy (Leino-Kilpi et al. 2000). In this study, the definition of autonomy leans on Scott's et al. (2003b) presentation of autonomy, including the components of information received by the individual and decision-making by the individual.

3 Review of the literature

In this chapter, previous literature concerning the dimensions of the concept of the ethical pathway and the use of the concept of the ethical pathway are described. Two separate literature reviews were conducted. The first review aimed to describe the dimensions (dignity, privacy, and autonomy) from IwS' viewpoint. The second review aimed to identify and analyze the use of the concept of the ethical pathway in the scientific literature.

3.1 Literature search

In both the first and the second reviews, literature searches were conducted in five electronical databases: PubMed/Medline, CINAHL, Philosopher's Index, PsycINFO, and Cochrane Library. In the first review, search terms related to stroke, ethics and the recognized dimensions of the concept of the ethical pathway (dignity, privacy, autonomy) were used. In the second review, the search term 'ethical pathway' was used. To find relevant references, different combinations of the search terms were used in the databases (Table 1). The searches were limited to English language and availability of the abstract in those databases where these limitations were available. Time limitation was not seen as relevant for the aims of the reviews. The references were first screened by title and abstract, and then assessed by full text for the eligibility for the topics (Table 2). As a result, 54 references were included in the first review and 2 references in the second review. The data was analyzed inductively (Hsieh & Shannon 2005, Elo & Kyngäs 2008) focusing on the manifest content (Graneheim & Lundman 2004). Furthermore, the definition of the concept of the ethical pathway was charted manually from dictionaries.

Table 1. Databases and search phrases used in the literature searches.

Database	**Search phrase**
PubMed/Medline **Limitations:** **English language** **Abstract available**	Review one: (stroke*[tiab] OR cerebrovascular disorder*[tiab] OR cerebrovascular accident*[tiab] OR "Stroke"[Mesh] OR "Cerebrovascular Disorders "[Mesh] OR "Intracranial Arteriosclerosis "[Mesh] OR "Intracranial Embolism and Thrombosis "[Mesh]) AND (digni*[tiab] OR privacy[tiab] OR autonomy[tiab] OR value bas*[tiab] OR "Ethics"[Mesh]) Review two: "ethical pathway*"[tiab]
CINAHL **Limitations:** **English language** **Abstract available**	Review one: (TI stroke* OR AB stroke* OR MH "Stroke+" OR TI "cerebrovascular disorder*" OR AB "cerebrovascular disorder*" OR TI "cerebrovascular accident*" OR AB "cerebrovascular accident*") AND (AB (ethic* OR digni* OR privacy OR autonomy OR "value bas*") OR TI (ethic* OR digni* OR privacy OR autonomy OR "value bas*") OR MH "Ethics+") Review two: TI "ethical pathway*" OR AB "ethical pathway*
Philosopher's Index **Limitations:** **English language** **Abstract available**	Review one: (TI stroke* OR AB stroke* OR TI "cerebrovascular disorder*" OR AB "cerebrovascular disorders*" OR TI "cerebrovascular accident*" OR AB "cerebrovascular accident*") AND (AB (ethic* OR digni* OR privacy OR autonomy OR "value bas*") OR TI (ethic* OR digni* OR privacy OR autonomy OR "value bas*")) Part two: TI "ethical pathway*" OR AB "ethical pathway*
PsycINFO **Limitations:** **English language**	Review one: (TI (stroke OR "cerebrovascular disorder* OR "cerebrovascular accident*") OR AB (stroke OR "cerebrovascular disorder* OR "cerebrovascular accident*") OR (exp Cerebrovascular Accidents/)) AND (TI (ethic* OR digni* OR privacy OR autonomy OR "value bas*") OR AB (ethic* OR digni* OR privacy OR autonomy OR "value bas*") OR (exp Ethics/)) Review two: TI "ethical pathway*" OR AB "ethical pathway*
Cochrane Library **Limitations:** **-**	Part one: (MeSH descriptor [Stroke] OR MeSH descriptor [Ethics]) AND (stroke* OR digni* OR privacy OR autonomy OR "value bas*" in Title, Abstract, Keyword) Review two: "ethical pathway*" in Title, Abstract, Keyword
Dictionaries	Manual search for the concept of the ethical pathway

Table 2. The reference selection for the literature reviews.

	REVIEW I	**REVIEW II**
Screened by title and abstract	1799	42
Assessed by full-text	132	19
Included references	54	2

3.2 Realization of values as perceived by individuals with stroke

The aim of the first literature review was to describe the dimensions of the ethical pathway (dignity, privacy, and autonomy) from IwS' viewpoint (Appendix 1). The informants were not restricted to IwS in order to form an extensive understanding of the topic. Thus, the informants also included informal caregivers (ICs) and HCPs. The dimensions of the ethical pathway were recognized in all three dimensions, i.e., dignity, privacy and autonomy.

Realization of dignity

The literature described the perceived realization of IwS' dignity in relation to the themes '**care and care environment**', '**social environment**', and '**relation to self**' (Table 3). None of the selected articles had IwS' dignity as the main topic; it emerged as part of the study results.

'Care and care environment'. IwS' dignity was maintained by fulfilling IwS' basic needs in a respectful manner, and by providing information based on individual needs (Mangset et al. 2008). IwS valued HCPs taking account of other patients' presence, in particular in mixed-sex rooms, and protecting IwS by closing bed-side curtains in care situations (Rhodes et al. 2003). For IwS, the progress in rehabilitation was important (Worrall et al. 2011), and HCPs described facilitating IwS' dignity by implementing rehabilitation tailored to IwS' individual needs and desires (Sundin et al. 2001). On the other hand, IwS described health care environment as a place where their dignity was in danger of being lost. Being in a position dependent on other people sometimes declined IwS' dignity. In a hospital, IwS reported, for instance, devices used in elimination as unfamiliar and as a threat for their dignity. (Kitson et al. 2013.) ICs described IwS' dignity as being declined by home care HCPs in situations where professionals kept IwS waiting for the care, took personal phone calls during visits, or performed care, for instance, in a routine manner or by sparing washing flannels (Pound & Greenwood 2016).

'Social environment'. IwS' dignity was maintained or facilitated by respect (Peoples et al. 2011, Tomkins et al. 2013), by being acknowledged as individuals (Sundin et al. 2001, Mangset et al. 2008, Peoples et al. 2011), and by taking into account personal values (Peoples et al. 2011). Both IwS and HCPs perceived trust in care relationship (Sundin et al. 2001, Mangset et al. 2008) and support for IwS as significant (Sundin et al. 2001, Peoples et al. 2011). For dignity of individuals with aphasia, it was important to be perceived as competent persons despite the communication disorder (Worrall et al. 2011, Tomkins et al. 2013). IwS with eating difficulties maintained their dignity in social eating situations by putting extra effort into socially acceptable eating behavior by, for instance, avoiding aids or certain

foods (Klinke et al. 2014). However, both communication disorders and eating difficulties sometimes constituted threats to IwS' dignity. Communication disorders could result in IwS feeling disempowered (Worrall et al. 2011), while eating situations where IwS could not reach their own standards were sometimes perceived as humiliating, and thus considered as declining their dignity. Consequently, difficulties in eating even led IwS to avoid social situations involving food or drink. (Klinke et al. 2014.) In social environment, negative encounters with HCPs (Peoples et al. 2011), including disrespectful behavior (Mangset et al. 2008), also led to a sense of subordination and disempowerment (Peoples et al. 2011) and sense of being degraded as a human being (Mangset et al. 2008).

'Relation to self'. IwS' dignity was related to a sense of the self being lost. In addition, dependency on other people led to changes in self-image as well as loss of self-esteem and self-confidence. (Kitson et al. 2013.)

The literature described the realization of IwS' dignity in various contexts and the factors facilitating and declining IwS' dignity realization. However, none of the selected articles focused on IwS' dignity and the results are therefore rather superficial. Furthermore, the literature does not describe the potential changes in the realization of IwS' dignity in the post-stroke time period.

Table 3. Characteristics of the literature of IwS' perceived dignity realization.

Characteristics		**Authors**
Context	Hospital	Rhodes et al. 2003
	Rehabilitation	Sundin et al. 2001, Mangset et al. 2008, Peoples et al. 2011, Worrall et al. 2011
	Varying health care facilities	Kitson et al. 2013, Tomkins et al. 2013
	Home	Klinke et al. 2014, Pound & Greenwood 2016
Informants	IwS	Rhodes et al. 2003, Mangset et al. 2008, Worrall et al. 2011, Kitson et al. 2013, Tomkins et al. 2013, Klinke et al. 2014
	ICs	Pound & Greenwood 2016
	HCPs	Sundin et al. 2001
Data collection	Interviews	Sundin et al. 2001, Rhodes et al. 2003, Mangset et al. 2008, Worrall et al. 2011, Kitson et al. 2013, Tomkins et al. 2013, Klinke et al. 2014, Pound & Greenwood 2016
	Literature review	Peoples et al. 2011

Realization of privacy

The literature described the perceived realization of IwS' privacy in relation to the themes '**physical privacy**', '**psychological privacy**', and '**social privacy**' (Table 4). None of the articles had IwS' privacy as the main topic; it was included as part of the study results.

'Physical privacy'. IwS described the health care environment in terms of maintaining their privacy (Kitson et al. 2013, Anåker et al. 2019). For them, the ward represented a safe place where they could move around, but to maintain physical privacy there was a requirement for a personal space (Kitson et al. 2013). Especially, a single room maintained IwS privacy as it enabled being alone, controlling the environment, and blocking out unpleasant noise, for instance (Anåker et al. 2019). However, physical privacy was sometimes also seen as a threat in terms of a sense of loneliness (Anåker et al. 2019) and isolation (Kitson et al. 2013).

'Psychological privacy'. IwS described the possibility of maintaining their personal integrity as vital (Kitson et al. 2013). After being transferred to rehabilitation from acute ward, IwS had to adjust to new HCPs, new co-IwS, and new care routines, which resulted in a psychological need for privacy (Lui & Mackenzie 1999). However, an unfamiliar environment with inflexible routines gave IwS a sense of lacking privacy (Peoples et al. 2011).

'Social privacy'. IwS described the importance of being sheltered from the eyes of others. In the case of facilities not meeting IwS' desires, IwS perceived it as important that they were protected, for instance, by closing the bed-side curtains in care situations (Rhodes et al. 2003). However, IwS reported lack of privacy in sensitive situations, such as toileting (Engler et al. 2014).

The literature described the realization of IwS' privacy in various contexts and in terms of factors maintaining and declining IwS' privacy realization. It is notable that privacy is not only perceived as positive but also as causing, for instance, a sense of isolation. None of the selected articles focused on IwS' privacy and the descriptions of privacy are shallow. Furthermore, the literature lacks the dimension of informational privacy and does not describe the potential changes in the realization of IwS' privacy in the post-stroke time period.

Table 4. Characteristics of the literature of IwS' perceived privacy realization.

Characteristics		**Authors**
Context	Hospital	Rhodes et al. 2003, Anåker et al. 2019
	Rehabilitation	Lui & MacKenzie 1999, Peoples et al. 2011, Engler et al. 2014
	Varying health care facilities	Kitson et al. 2013
Informants	IwS	Lui & MacKenzie 1999, Rhodes et al. 2003, Kitson et al. 2013, Engler et al. 2014, Anåker et al. 2019
Data collection	Interviews	Lui & MacKenzie 1999, Rhodes et al. 2003, Kitson et al. 2013, Engler et al. 2014, Anåker et al. 2019
	Literature review	Peoples et al. 2011

Realization of autonomy

The literature described the perceived realization of IwS' autonomy in relation to '**the experience of autonomy or declined autonomy, and the factors related**', '**individual's incapability to express own will**', and '**self-perceived impact of stroke to participation and autonomy**' (Table 5).

Table 5. Characteristics of the literature of IwS' perceived autonomy realization.

Characteristics		Authors
Context: 'the experience of autonomy or lost autonomy and the factors related'; 'self-perceived impact of stroke to participation and autonomy'	Hospital	D'Souza et al. 2021
	Rehabilitation	Proot et al. 2000a, 2000b, 2000c, 2002, Castellucci 2004, Proot et al. 2007, Mangset et al. 2008, Peoples et al. 2011, Luker et al. 2015, Lou et al. 2017
	Elderly care	Takashima et al. 2016
	Community	Logan et al. 2004, Mayer & Reid 2004, Olofsson et al. 2005, Fallahpour et al. 2011, Plow et al. 2017, Chen et al. 2018, Smith et al. 2018, Govender et al. 2019, Li et al. 2021
	Varying contexts	Löfmark & Hammarström 2005, Kitson et al. 2013, Tholin & Forsberg 2014, Li et al. 2020
	Survivors, context not specified	Cardol et al. 2002, Chen et al. 2017, Persson et al. 2018, Suttiwong et al. 2018, Törnbom et al. 2018, Palstam et al. 2019, Skoglund et al. 2019, Westerlind et al. 2020, de Vries et al. 2021
Context: 'individual's incapability to express own will'	Acute stroke	Spokoyny et al. 2015, McGehrin et al. 2018
	Stroke in general	Kelly et al. 2014
	Reduced consciousness	de Kort et al. 2017, Frey et al. 2020
	Aphasia	de Kort et al. 2017, Frey et al. 2020, Louw & Keeble 2020
	Cognitive disorder	de Kort et al. 2017, Louw & Keeble 2020
	Dying IwS	Alonso et al. 2017, Rejnö & Berg 2019
Informants	IwS	Proot et al. 2000a, 2000b, 2000c, Cardol et al. 2002, Castellucci 2004, Logan et al. 2004, Mayer & Reid 2004, Löfmark & Hammarström 2005, Olofsson et al. 2005, Proot et al. 2007, Mangset et al. 2008, Fallahpour et al. 2011, Kitson et al. 2013, Tholin & Forsberg 2014, Takashima et al. 2016, Chen et al. 2017, Plow et al. 2017, Chen et al. 2018, Persson et al. 2018, Suttiwong et al. 2018, Törnbom et al. 2018, Govender et al. 2019, Palstam et al. 2019, Skoglund et al. 2019, Li et al. 2020, Westerlind et al. 2020, de Vries et al. 2021, Li et al. 2021
	HCPs	Proot et al. 2002, de Kort et al. 2017, Rejnö & Berg 2019, Frey et al. 2020
	Family members	Frey et al. 2020
	IwS and HCPs	D'Souza et al. 2021
	IwS and ICs	Smith et al. 2018

Characteristics		Authors
Data collection	Interviews	Proot et al. 2000a, 2000b, 2000c, 2002, Logan et al. 2004, Löfmark & Hammarström 2005, Olofsson et al. 2005, Mangset et al. 2008, Kitson et al. 2013, Tholin & Forsberg 2014, Takashima et al. 2016, Smith et al. 2018, Govender et al. 2019, Rejnö & Berg 2019, D'Souza et al. 2021
	Instruments	Cardol et al. 2002, Mayer & Reid 2004, Fallahpour et al. 2011, Chen et al. 2017, Chen et al. 2018, Persson et al. 2018, Suttiwong et al. 2018, Törnbom et al. 2018, Palstam et al. 2019, Skoglund et al. 2019, Li et al. 2020, Westerlind et al. 2020, de Vries et al. 2021, Li et al. 2021
	Mixed methods	Castellucci 2004, Plow et al. 2017
	Observations with interviews and informal conversations	Frey et al. 2020
	Medical records	Alonso et al. 2017
	Medical records with semi-structured questionnaire	de Kort et al. 2017
	Literature reviews	Peoples et al. 2011, Kelly et al. 2014, Luker et al. 2015, Lou et al. 2017
	Concept analysis	Proot et al. 1998
	Articles with experts of the topic as authors	Sandman et al. 2008, Spokoyny et al. 2015, McGehrin et al. 2018, Cherney et al. 2020, Louw & Keeble 2020

‘The experience of autonomy or declined autonomy, and the factors related’. IwS autonomy and support for autonomy were perceived as important in health care, as IwS were the ones who lived with the consequences of the decisions (Sandman et al. 2008). IwS were eager for autonomy and to live their lives as before, prior to the stroke (Löfmark & Hammarström 2005). However, for autonomous decisions, IwS needed to have competency, which was sometimes restricted due to cognitive deficits (Sandman et al. 2008). For HCPs, evaluating competency was occasionally considered demanding, for instance, with IwS who had right hemisphere damage and had verbal skills that masked the incompetency (Cherney et al. 2020). Additionally, both IwS and HCPs recognized the power imbalance in the hospital environment which may decline IwS’ autonomy (D'Souza et al. 2021). Collaborative power-sharing required not only active participation but also sufficient and individual information (Peoples et al. 2011). The literature described IwS’ autonomy as declined (Mangset et al. 2008, Kitson et al. 2013, Tholin & Forsber 2014, Luker et al. 2015, Takashima et al. 2016, Lou et al. 2017, Plow et al. 2017, Smith et al. 2018, Govender et al. 2019) but also as maintained (Kitson et al. 2013, Plow et al. 2017), and autonomy changing in the post-stroke time period (Proot et al. 1998, Proot et al. 2000a, Proot et al. 2000b, Proot et al. 2000c, Proot et al. 2002, Proot et al. 2007).

Autonomy of IwS in health care facilities, including hospitals, rehabilitation, and nursing homes, was declined by factors related to IwS or to HCPs and the care environment (Table 6). Declined autonomy involved, for instance, restricting participation in activities and was related to social isolation (D'Souza et al. 2021),

Table 6. Factors declining IwS’ autonomy in health care facilities.

Factors		Authors
Related to HCPs and care environment	Disempowering staff attitudes, poor communication	Luker et al. 2015
	Unfamiliar environment	Proot et al. 2000b, 2002
	The restrictions and routines of the care facility	Proot et al. 2000a, 2000b, 2000c, 2002, Mangset et al. 2008, Kitson et al. 2013, Luker et al. 2015, D'Souza et al. 2021
	Lack of possibilities for familiar activities	Proot et al. 2000a, 2000c
	Lack of aids	Proot et al. 2000c
Related to IwS	Dependency on other people	Takashima et al. 2016
	Symptoms diminishing functioning	Proot et al. 2000a, 2000b, 2000c, Takashima et al. 2016, Lou et al. 2017
	Insecurity	Proot et al. 2000a, 2000c, Olofsson et al. 2005

sorrow, shame, and vexation (Takashima et al. 2016). In health care facilities, several factors facilitating IwS' autonomy were additionally identified (Table 7). Paternalism of HCPs was perceived both as facilitating (Proot et al. 2000a, Proot et al. 2000b, Proot et al. 2002) and declining autonomy (Proot et al. 2000a, Proot et al. 2000c, Proot et al. 2002, Lou et al. 2017). IwS with facilitated autonomy experienced less depression (Castellucci 2004).

Table 7. Factors facilitating IwS' autonomy in health care facilities.

Factors	Authors
Improving abilities and self-confidence	Proot et al. 2000a, 2000c
Iws taking responsibility	Proot et al. 2000a, 2000b, 2000c
Engaging in activities	Lou et al. 2017
Social support from HCPs	Proot et al. 2000a, 2000b, Luker et al. 2015
Social support and family, peer support	Proot et al. 2000a, 2000b, 2000c, 2002
Teamwork with HCPs	Proot et al. 2000b
Shared decision-making	Proot et al. 2000a, 2000c
Good information	Proot et al. 2000a, 2000b, 2000c, Luker et al. 2015
Communication	Luker et al. 2015

Autonomy of community-dwelling IwS was declined by dependency on other people (Smith et al. 2018, Govender et al. 2019) and symptoms that diminished functioning (Goverder et al. 2019), such as physical impairments (Plow et al. 2017, Smith et al. 2018), fatigue, and pain (Plow et al. 2017). Sometimes, these restricted participation in community and led to a sense of isolation (Govender et al. 2019). Declined autonomy was described as being associated with IwS' psychological burden (Smith et al. 2018). Improved autonomy, on the other hand, brought joy to IwS, for example, in cases where they were able to continue with their pre-stroke activities or return to their social roles (Govender et al. 2019). Community-dwelling IwS' autonomy was described to be facilitated by factors such as familiar environment, improvement in rehabilitation, social support, and information (Olofsson et al. 2005). Transportation, either independent or assisted, was vital for community-dwelling IwS' autonomy, but could also decline autonomy, for instance, when IwS lacked the self-confidence to use transportation or knowledge of transportation possibilities (Logan et al. 2004).

'Individual's incapability to express own will'. In cases where individuals were incapable of expressing their own will after stroke their autonomy could still be maintained if their will was known either by a close one (Louw & Keeble 2002, Kelly et al. 2014, de Kort et al. 2017, Rejnö & Berg 2019, Frey et al. 2020) or

available in written form (Louw & Keeble 2002, Kelly et al. 2014, Spokoyny et al. 2015, Alonso et al. 2017, de Kort et al. 2017, McGehrin et al. 2018, Frey et al. 2020). A precondition for a close one acting as a source of an individual's will were them knowing each other well and further, that the will in question had been expressed by the individual to the close one (Rejnö & Berg 2019). According to the study by de Kort's et al. (2017), expressing the will to a close one was more common than a written will. In addition, Alonso et al. (2017) found that the number of written wills recorded in patient records was low. A common feature of pre-stroke wills was that they tended to be worded in rather general terms (Kelly et al. 2014, Alonso et al. 2017) and were thus challenging to apply to a specific situation (Kelly et al. 2014).

'Self-perceived impact of stroke to participation and autonomy'. In all of the studies, the data were collected with the Impact on Participation and Autonomy (IPA) instrument. As IPA is a self-reported instrument, IwS were informants in all of the studies. IPA includes five domains: autonomy indoors, family role, autonomy outdoors, social relations, and work and educational opportunities (Cardol et al. 2002). In this review, the domains of autonomy indoors, family role, and autonomy outdoors were selected for study, as they present individual's possibilities to make autonomous decisions. The literature described IwS' autonomy in varying time lines after the acute phase of stroke.

IwS perceived least declines in autonomy indoors (Fallahpour et al. 2011, Chen et al. 2017, Chen et al. 2018, Persson et al. 2018, Törnbom et al. 2018, Palstam et al. 2019, de Vries et al. 2021), and many IwS reported that indoor autonomy had been maintained (Fallahpour et al. 2011, Chen et al. 2017, Chen et al. 2018, Persson et al. 2018, Suttiwong et al. 2018). However, IwS with impaired upper-extremity function at post-stroke day three also reported the declines in autonomy indoors getting worse in the post-stroke time period (Skoglund et al. 2019). The most declined domain was reported to be either family role (Cardol et al. 2002, Mayer & Reid 2004, Persson et al. 2018, Suttiwong et al. 2018, Li et al. 2021) or autonomy outdoors (Fallahpour et al. 2011, Chen et al. 2017, Chen et al. 2018, Li et al. 2020). Several factors, presented in Table 8, were identified to be associated with the autonomy declines.

The literature described the realization of autonomy in various contexts, several factors facilitating and declining IwS' autonomy realization, and over different post-stroke time periods. Although the literature is more extensive than that on dignity and privacy, a comprehensive understanding of the course of autonomy realization in the post-stroke time is difficult to gain from articles with various designs and different definitions of autonomy.

Table 8. Factors associated with autonomy declines regarding the three IPA-domains.

Domain	Less declines	Authors	Frequent declines	Authors
The three IPA-domains (autonomy indoors, autonomy outdoors, family role)	Better physical functioning*	Fallahpour et al. 2011, Chen et al. 2018	Older age, severe stroke	Palstam et al. 2019
	Activities on daily living	Chen et al. 2017, Chen et al. 2018	Depression	Fallahpour et al. 2011, Palstam et al. 2019
	Being in working life	Westerlind et al. 2020	Anxiety	Fallahpour et al. 2011
	Social support	Suttiwong et al. 2018	Fatigue	de Vries et al. 2021
Autonomy indoors -domain	Physical functioning, self-efficacy	Li et al. 2021	Depression	Suttiwong et al. 2018
	Functional ability	Suttiwong et al. 2018		
Autonomy outdoors -domain	Functional ability, balance performance	Suttiwong et al. 2018	Secondary health problems	Suttiwong et al. 2018
	Social support, knowledge of stroke, resignation	Li et al. 2021	Sequelae of stroke, depression	Chen et al. 2018
	Monthly income	Chen et al. 2018	Anxiety	Chen et al. 2017
Family role -domain	Physical functioning, self-efficacy	Li et al. 2021	Time between attack and admission to hospital, sequelae of stroke	Chen et al. 2018
	Knowledge about stroke	Chen et al. 2018	Depression	Suttiwong et al. 2018
	Female sex	Fallahpour et al. 2011	Anxiety	Chen et al. 2017
			Female sex	Palstam et al. 2019

*Note: less global disability at discharge was associated with more declines one year post-stroke (Törnbom et al. 2018)

3.3 Ethical pathway

The aim of the second literature review was to identify and analyze the use of the concept of the ethical pathway in the scientific literature (Appendix 2). The concept of the ethical pathway was recognized in only two references. The types of references were an editorial (Savulescu & Singer 2019) and a research article (Sendjaya et al. 2020). The concept of the ethical pathway was used in relation to gene editing and leadership in the fields of bioethics and business. Furthermore, the definition for the concept of the ethical pathway was searched from dictionaries.

The reference related to gene editing focused on research ethics. The concept of the ethical pathway was used only in the title but was not defined or used later in the reference. An individual was noted mainly in the risk assessment of benefit versus risk for an individual in a trial. Although the ethical pathway was not defined or used, the authors presented a transitional pathway which describes an ethically justifiable pathway to human germ line gene editing. (Savulescu & Singer 2019.)

In the reference related to leadership, the concept of the ethical pathway was used to describe the underlying influence process. The process was included in the purpose of the study, which was to explain how servant leadership affects organizational citizenship behavior, with psychological ethical climate as a key mediator. (Sendjaya et al. 2020.)

Dictionaries did not provide a concise definition for the concept of ethical pathway (Kielikone Oy 2022, Merriam-Webster 2022). When observing the terms separately, 'ethical' is related to moral principles, used as an adjective defining what is morally good or correct (Kielikone Oy 2022) and right or wrong behavior, expressing accepted standards of conduct, and used in judgements expressing what is morally approved or disapproved (Merriam-Webster 2022). 'Pathway' is a noun describing a path or a course (Merriam-Webster 2022); more precisely, a course of an action or a way to achieve a result, and a track that either constitutes or serves as a path (Kielikone Oy 2022).

The concept of the ethical pathway was identified from scientific literature but without a consistent definition. Moreover, in neither of the scientific references was ethical pathway used to describe potential changes perceived by individuals. The dictionaries did not recognize the concept.

3.4 Summary of the literature review

The literature described the dimensions of the ethical pathway, including dignity, privacy, and autonomy, from IwS' viewpoint, but regarding the dimensions of dignity and privacy, these were not the main topic in any of the articles. Furthermore, the knowledge was at various levels regarding the dimensions of the ethical pathway as there was a large amount of knowledge related to autonomy and only a limited amount related to dignity and privacy. Two information gaps were recognized. First, in addition to the limited amount of knowledge related to dignity and privacy, the literature lacked knowledge of the overall picture, including all three dimensions. Second, the literature focused on certain parts of the post-stroke time, lacking a longitudinal perspective. This knowledge would be especially important in the care of patients with long care pathways to support the development and realization of ethically high-level nursing care.

The literature did not provide a consistent definition for the concept of ethical pathway. In particular, the reference related to gene editing lacked a proper definition. Neither of the scientific references identified the ethical pathway as potential changes perceived by individuals although they indicated that temporal changes related to ethical questions may be present.

4 Aims

This study of clinical nursing ethics focused on the realization of values as perceived by individuals with the long-term health problem of stroke and the potential changes in the perceived realization of values in post-stroke time, labeled as **the ethical pathway**. In the focus of interest was also the association between the ethical pathway and the life situational factors. The main aim of the study was to compose a theoretical construct of the ethical pathway, including defining the concept of the ethical pathway and analyzing its realization. The care pathways of individuals with long-term health problems may be long and consist of different health care units or organizations. By making the ethical pathway visible, the ultimate goal of this study was to support the development and realization of ethically high-level nursing care.

The main research question (RQ) of the study was:
What constitutes the theoretical construction of the ethical pathway?

Regarding *the concept of the ethical pathway*, the targeted RQs of the study were:

1: What is the definition of the concept of the ethical pathway? (Papers I, II, summary)

2: How can the concept of the ethical pathway be operationalized? (summary)

Regarding *the perceived realization of the ethical pathway*, the targeted RQs of the study were:

3: How is the ethical pathway realized as perceived by individuals with the long-term health problem of stroke? (Papers III, IV, summary)

4: What is the association between the IwS' perceived realization of the ethical pathway and the life situational factors, if any? (Papers III, IV, summary)

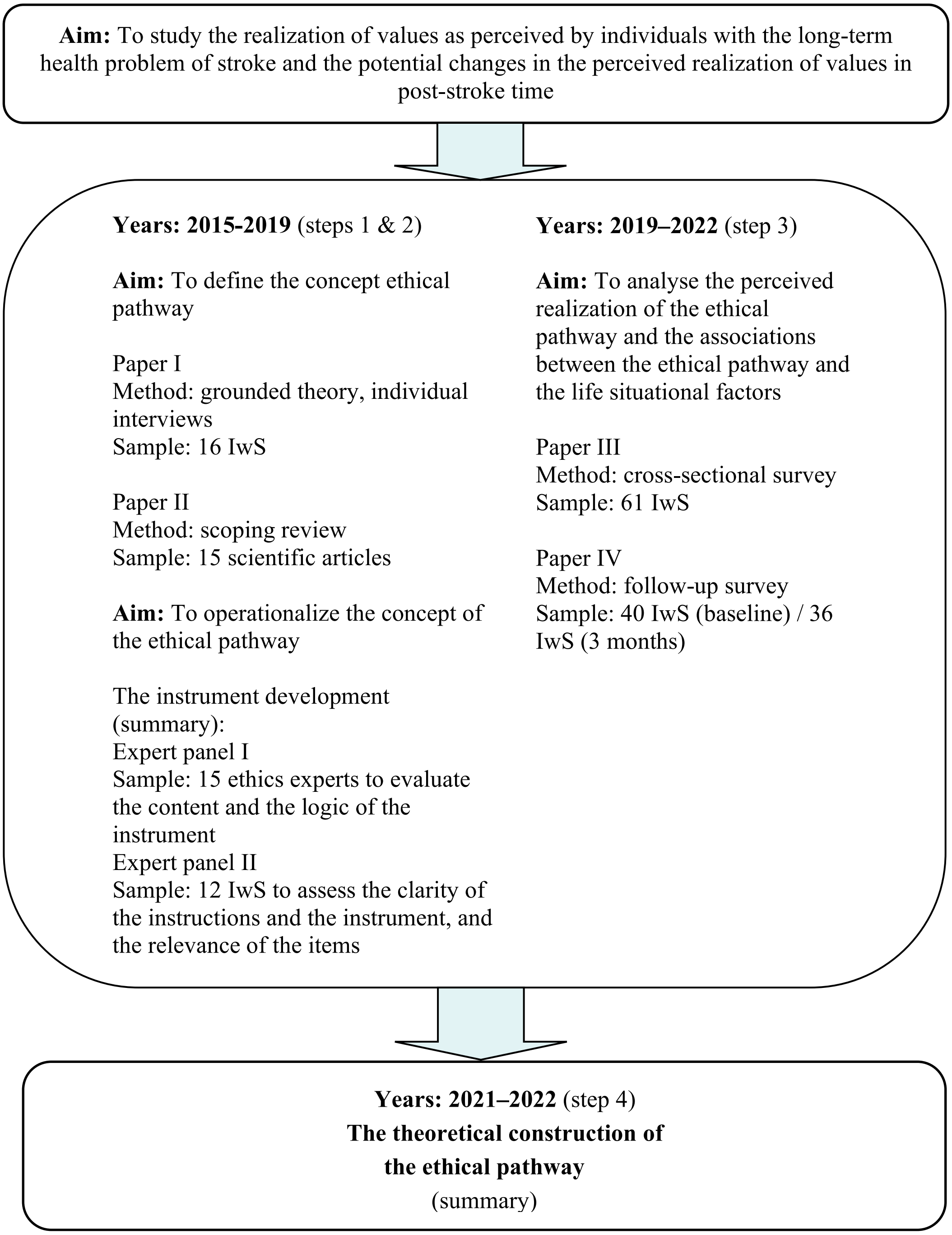
5 Materials and Methods

To reach the main aim, i.e., to compose a theoretical construct of the ethical pathway, a study with four steps was conducted (Figure 2). In step one, the concept of the ethical pathway and the life situational factors were defined based on grounded theory (Paper I) and a scoping review study (Paper II). In step two, the concept of the ethical pathway and the life situational factors were operationalized. In step three, the concept of the ethical pathway and its association with the life situational factors were tested empirically based on a cross-sectional study (Paper III) and follow-up study (Paper IV). In step four, the obtained results were synthesized to form the theoretical construct of the ethical pathway.

The study used an inductive-deductive approach (McKenna 1997, Lauri & Kyngäs 2005) including varying designs and methods which are presented in this chapter (Table 9). In the study, elements of an integrative strategy to concept development (Meleis 2017) and theory development were applied (Chinn & Kramer 1995, McKenna 1997, Lauri & Kyngäs 2005, McEwen 2007, Meleis 2017).

In keeping with the intention of observing the phenomenon as perceived by the individuals with personal experiences of stroke, IwS were the primary informants. However, previous literature on the topic was scarce, and therefore an exception was made in the case of the scoping review (Paper II). To capture a comprehensive understanding of the topic, the informants and viewpoints were expanded to HCPs and SOs. This exception is justified with the argument that the two groups have significant roles in the care of IwS (Kitson et al. 2013, Chen et al. 2021).

At the end of this chapter, ethical considerations of the study are presented.



Aim: To study the realization of values as perceived by individuals with the long-term health problem of stroke and the potential changes in the perceived realization of values in post-stroke time

Years: 2015-2019 (steps 1 & 2)

Aim: To define the concept ethical pathway

Paper I
Method: grounded theory, individual interviews
Sample: 16 IwS

Paper II
Method: scoping review
Sample: 15 scientific articles

Aim: To operationalize the concept of the ethical pathway

The instrument development (summary):
Expert panel I
Sample: 15 ethics experts to evaluate the content and the logic of the instrument
Expert panel II
Sample: 12 IwS to assess the clarity of the instructions and the instrument, and the relevance of the items

Years: 2019–2022 (step 3)

Aim: To analyse the perceived realization of the ethical pathway and the associations between the ethical pathway and the life situational factors

Paper III
Method: cross-sectional survey
Sample: 61 IwS

Paper IV
Method: follow-up survey
Sample: 40 IwS (baseline) / 36 IwS (3 months)

Years: 2021–2022 (step 4)
The theoretical construction of the ethical pathway
(summary)

Figure 2. Materials and methods of the study.

Table 9. Summary of the designs, sampling, samples, settings, data collection and data analysis (Papers I-IV).

Years	Design; paper	Sampling	Sample; setting; (data no)	Data collection	Data analysis
2015–2018	Grounded theory; Paper I	Purposive	Individuals with stroke (n=16); neurological ward; (Data 1)	Semi-structured face-to-face interviews	Constant comparison of grounded theory
	Scoping review; Paper II	Selective, based on criteria	Research literature (n=15), databases CINAHL, Cochrane Library, Philosopher's Index, PsycINFO and PubMed/Medline; professional stroke care in diverse settings; (Data 2)	Systematic literature search	Charting descriptive numerical data, content analysis
2018–2022	Cross-sectional study with descriptive and correlational survey design; Paper III	Random	Individuals with stroke (n=61); non-limited; (Data 3)	Questionnaire: sociodemographics, EPIS instrument	Statistical analysis
	Follow-up study with descriptive and correlational survey design; Paper IV	Consecutive	Individuals with stroke (n=36); from neurological ward to home; (Data 4)	Questionnaire: sociodemographics (1st measurement), clinical pathway (2nd measurement), EPIS instrument	Statistical analysis

5.1 Design, setting and sample

The study was conducted in four steps which varied in terms of design and methods. Each step guided the next one with the objective of reaching the main aim, i.e., to compose a theoretical construct of the ethical pathway (Figure 2).

The first step aimed to define the concept of the ethical pathway and the life situational factors related to the ethical pathway. This was based on two studies with inductive approaches, one with **grounded theory** design (Paper I) and the other with **scoping review** design (Paper II). The second step aimed to operationalize the concept of the ethical pathway and the life situational factors, resulting in the EPIS instrument (see chapter 5.2). The third step aimed to test empirically the concept of the ethical pathway and its association with the life situational factors by analyzing the perceived realization of the ethical pathway and its association with the life situational factors. A **cross-sectional study** and **follow-up study** with deductive approaches were conducted, both with descriptive and correlational survey designs (Paper III & IV). Finally, in the fourth step, the obtained results were synthesized to form the theoretical construct of the ethical pathway (see chapter 6.4).

Grounded theory (Paper I) was chosen to explore the perceived realization of individual's values after the incidence of stroke. Grounded theory is a suitable method to a study a topic with a limited amount of previous study findings (Glaser & Strauss 1967) and to gain a deep understanding of lived experiences (Olshansky 2014) located in the social context (Glaser & Strauss 1967), such as nursing (Mediani 2017). Grounded theory (Glaser & Strauss 1967) also paved the way for the identification and definition of the concept (Meleis 2017).

Purposive sampling was used to reach the lived experiences of IwS (Campbell et al. 2020) in hospital setting. The participants were recruited by a contact nurse while the IwS were still in a neurological ward located in a Finnish university hospital. The recruitment targeted IwS who were well enough to participate, 18 years old or older, and Finnish speaking (see Paper I for more detailed inclusion and exclusion criteria). In grounded theory, the sample size is not determined *a priori* but aims at saturation (Vasileiou et al. 2018). Saturation was determined to have been reached after recruitment of sixteen participants (Data 1; Table 10).

Scoping review (Paper II) was chosen to expand understanding of the perceived realization of IwS' values. Scoping review is a suitable method to examine the extent, range, and nature of the literature on a selected topic and to summarize the findings (Arksey & O'Malley 2005), and therefore considered to be a relevant review type to expand the preliminary definition of the concept (Meleis 2017). The review type allows the inclusion of various methodological approaches (Arksey & O'Malley 2005), and the selection was therefore confirmed after the preliminary literature searches where the existing literature of the topic was observed to be scarce and methodologically scattered.

The literature search was conducted following a systematic search process (Arksey & O'Malley 2005). The search process targeted literature with focus on ethics in professional stroke care in diverse settings with empirical research data (see Paper II for more detailed inclusion and exclusion criteria). The viewpoint was expanded from patients to SOs and HCPs because based on the preliminary searches, data were known to be scarce. Limiting the year of publishing was not considered necessary. The literature search resulted in fifteen empirical research articles (Data 2; Table 10).

For the **cross-sectional study** (Paper III), non-limited post-stroke time and non-limited context were chosen to capture the realization of values of IwS with a broad view, i.e., with different post-stroke time periods and care pathways. Random sampling (Emerson 2015) was used in the recruitment of IwS via the Finnish Brain Association (Finnish Brain Association 2021). The association, with altogether 2,406 members, is intended for individuals with stroke or developmental language disorders or those who are otherwise interested in the theme. An invitation to participate was published in the association’s electronical newsletter sent via email to the members and on the association’s social media page. The recruitment targeted IwS who were adults and Finnish speaking with a previous diagnosis of stroke (see Paper III for more detailed inclusion criteria). Compliance with criteria was based on participants’ self-evaluation. The association was evaluated suitable for the recruitment because it was evaluated as having a fairly large number of IwS members. For an instrument that had not been used before, recruitment targeting one hundred participants was based on evaluation by a biostatistician. The recruitment resulted in sixty-one participants (Data 3; Table 10).

The **follow-up study** (Paper IV) had two measurement points: after the onset of stroke and three months post-stroke. Consecutive sampling (Polit & Beck 2017) was used in the recruitment of IwS from all five Finnish university hospitals, from their nine neurological inpatient wards. The recruitment was conducted by contact nurses working in the hospitals. The recruitment targeted individuals with first-time diagnosed stroke, and who were well enough to participate, 18 years or older, and Finnish speaking (see Paper IV for more detailed inclusion and exclusion criteria). For an instrument that had not been used before, recruitment targeted at 120 participants was based on evaluation by a biostatistician. In the sample size evaluation, participant loss in the follow-up study was taken into account. Forty-five IwS were recruited; of them, forty returned the completed instrument with a signed informed consent form at baseline, and thirty-six returned the completed instrument three months post-stroke (Data 4; Table 10).

Table 10. Samples and sample characteristics.

Paper (data collection year)	Sample (data no.)	Sample characteristics
Paper I: **Grounded theory** (2015)	16 IwS (Data 1)	• Mean age: 66 years; 8 female (50 %), 8 male (50 %) • Mean duration of the hospitalization at the time of the interview: 6 days
Paper II: **Scoping review** (2017)	15 research articles (Data 2)	• Published between years 2000–2017 • Informants: HCPs (8 studies), IwS (6 studies), mixed including IwS, HCPs, and significant others (1 study) • Topic: autonomy (7 studies), truth-telling (1 study), and ethics from a wider aspect (7 studies)
Paper III: **Cross-sectional study** (2020)	61 IwS (Data 3)	• Age, median: 60 years; 39 female (64 %), 21 male (34 %), other/I don't want to tell 1 (2 %) • Type of stroke (multiple choices allowed): cerebral infarction 39 (64 %), intracerebral hemorrhage 11 (18 %), subarachnoid hemorrhage 16 (26 %), I can't tell 1 (2 %) • Post-stroke time: 0-30 years
Paper IV: **Follow-up study** (2019-2020)	36 IwS (Data 4)	• Age, median: 67 years; 15 female (42 %), 21 male (58 %) • Type of newly diagnosed stroke (multiple choices allowed): cerebral infarction 32 (94 %), intracerebral hemorrhage 2 (6 %)

5.2 Data collection

In **grounded theory** (Paper I), data may be collected with various methods (Singh & Estefan 2018). In this study, the participants were IwS in hospital care and therefore, individual face-to-face interviews were used to explore the experiences of IwS. The method provides a possibility for interview sessions with good rapport (Novick 2008) and with visual encounter (Irvine et al. 2013) in terms of observations of facial expressions and body language of the IwS (Novick 2008). For instance, facial expressions were helpful for evaluating whether a participant understood the questions on dignity, which is occasionally considered a complex topic (Jacobson 2009). Furthermore, for the quality of the data (Irvine et al. 2013) and ethical stance, face-to-face encounters enabled observing that the interview session was not too stressing for the individuals with recent stroke. Data were collected with semi-structured interviews (Olshansky 2014), which are considered suitable for complex and sensitive topics as they enable asking clarifying and additional questions (Barriball & While 1994). An interview guide (Olshansky 2014) was developed for the study based on literature of patients' dignity in hospital care. The beginning of the interview guide included questions on background variables, which enabled describing the participants. The subsequent questions focused on stroke symptoms, the care received and the hospital environment, and how they are related to the realization of participants' dignity. At the end of the interview, the participants were asked to define dignity in hospital care. The interview guide was piloted with two IwS and as no changes were made, these two interviews were included in the data. In 2015, the interviews were conducted in a peaceful room in the hospital ward and they varied from 8 to 47 min in length. With the permission of the participants, the interviews were tape-recorded (Holloway & Wheeler 2010) and transcribed verbatim afterwards (Whiting 2008). Field notes (Olshansky 2014) were made during and after the interviews.

In the **scoping review** (Paper II), conducted in 2017, systematic literature searches were conducted in five electronical databases: CINAHL, Cochrane Library, Philosopher's Index, PsycINFO and PubMed/Medline. The search terms focusing on stroke and ethics were included. Both free search terms with truncates when appropriate and subject headings suitable for each database were used. Two researchers selected the eligible articles for the review. To be included, an article had to focus on ethics in professional stroke care with empirical research data (see Paper II for more detailed inclusion and exclusion criteria). To gain an extensive understanding of the topic, neither viewpoint nor publishing year was limited. In the selection process, 1,948 hits were first screened by title and abstract, and 30 hits were assessed by full text for eligibility, resulting in 14 selected articles. After a manual search of the reference lists of the selected articles, the total number of the included articles rose to fifteen.

In the **cross-sectional study** (Paper III) conducted in 2020, data were collected with questionnaires administered in electronic format including questions on background variables (Table 11) and the EPIS instrument (Table 12). The link to fill in the questionnaire was included in the invitation to participate published in the Finnish Brain Association's electronic newsletter and social media page.

In the **follow-up study** (Paper IV) conducted in 2019–2020, data were collected with a paper and pencil format questionnaire. At the baseline, the contact nurses gave the participants envelopes with a questionnaire including questions on background variables (Table 11), clinical pathway calendar, and the EPIS instrument (Table 12) as well as a pre-paid return envelope. In the questionnaires, there were codes for each university hospital to gather the number of participants in each university hospital region. At three months, envelopes with a questionnaire including the EPIS instrument and a pre-paid return envelope were mailed to the participants. One remainder was sent (Streiner et al. 2015). In addition, the participants were requested to return the clinical pathway calendar that was given out with the first questionnaire with instructions to record all care periods and meetings with HCPs related to stroke.

Table 11. Background variables in the cross-sectional and follow-up studies.

Paper	Background variables
Paper III: **Cross-sectional study**	• Age • Gender • Highest education • Working situation • Living situation Stroke status • Type of stroke • Hemisphere of stroke • Number and time of stroke(s) • University hospital where the latest stroke was treated Health status • Other diseases Received rehabilitation Significant life changes after stroke
Paper IV: **Follow-up study**	• Name, address • Age • Gender • Highest education • Working situation • Living situation Stroke status • Type of stroke • Hemisphere of stroke • Admission to hospital Health status • Other diseases Clinical pathway (including clinical pathway calendar) Visits to other organizations (e.g. social care) New health issues Significant life changes

The development of the Ethical Pathway of Individuals with Stroke (EPIS) instrument

The Ethical Pathway of Individuals with Stroke (EPIS) instrument was developed to evaluate the realization of values and life situational factors in post-stroke time as perceived by IwS. The development process was conducted in four steps (Figure 3) applying DeVellis' (2017) scale development guidelines. **In the first step**, the structure of the instrument was formed. The structure (Table 12) was based on the dimensions of the ethical pathway and the life situational factors (chapter 6.1). Both of them made up a part of the instrument, i.e., part one of the instrument consists of the dimensions of the ethical pathway and part two of the life situational factors. The dimensions of the ethical pathway include dignity, privacy, and autonomy, while the factors related to it include the life situational factors of symptoms diminishing functioning, social environment, and self-empowerment. Each of the dimensions of the ethical pathway and the life situational factor form a scale in the instrument.

Furthermore, the scales of privacy, autonomy, and social environment include subscales (Table 12). In the name of the instrument, ‘pathway’ illustrates the potential change in the IwS’ perceptions over time and refers to the passage of time of the ethical pathway (chapter 6.1). However, the instrument itself does not detect changes; they are illustrated in the use of the instrument, for instance, with multiple data collection points or by acquiring information with background questions.

In the second step, the items of the two parts were generated. Literature was used in the operationalization and in the item construction of the scales of dignity (Jacobson 2009), privacy (Burgoon 1982, Leino-Kilpi et al. 2001), autonomy (Scott et al. 2003b) and symptoms which diminish functioning (Terveyskylä.fi 2017, Current Care Guidelines 2020, Finnish Brain Association 2022). Grounded theory (Paper I) and scoping review (Paper II) were used in the operationalization and in the item construction of the scales of social environment and self-empowerment. The item construction resulted in 30 items for each of the two parts of the instrument. Although including both positively and negatively worded items may cause challenges, such as confusion for participants (DeVellis 2017), this was made consciously to capture the exact content of each item.

In the third step, the instrument was evaluated by fifteen experts, especially for content and logic. The experts were all both nursing ethics researchers and HCPs. Those willing to participate in the evaluation received a paper format version of the instrument with a pre-paid return envelope. The experts marked their notes in the instrument and mailed it to the researcher.

In the fourth step, the instrument was assessed for clarity of instructions and the instrument and the relevance of the items by twelve IwS. Additionally, the time it took to fill the instrument was measured. At the time of the assessment, the IwS had their care period either in a neurological inpatient ward (n = 6) or in a neurological rehabilitation ward (n = 6). The contact nurses in the wards recruited IwS willing to participate in the assessment. The researcher went to meet the IwS, who first filled in the instrument individually, and were then interviewed by the researcher. Based on the content and logic evaluation and the clarity assessment, the structure and content of the instrument was not revised; however, some technical revisions were made to the instrument.

The EPIS consists of two parts, each of which has three scales (Table 12). The items are responded using a VAS scale from 0 (= does not describe my perception at all) to 100 (= describes my perception exactly) (Vasileiou et al. 2018). The VAS scale was selected because of its sensitive nature to detect potential changes when used in a follow-up study (DeVellis 2017). In the scales of the dimensions of the ethical pathway, a participant may additionally answer open questions on which factors have either promoted or hindered their perceived dignity/privacy/autonomy.

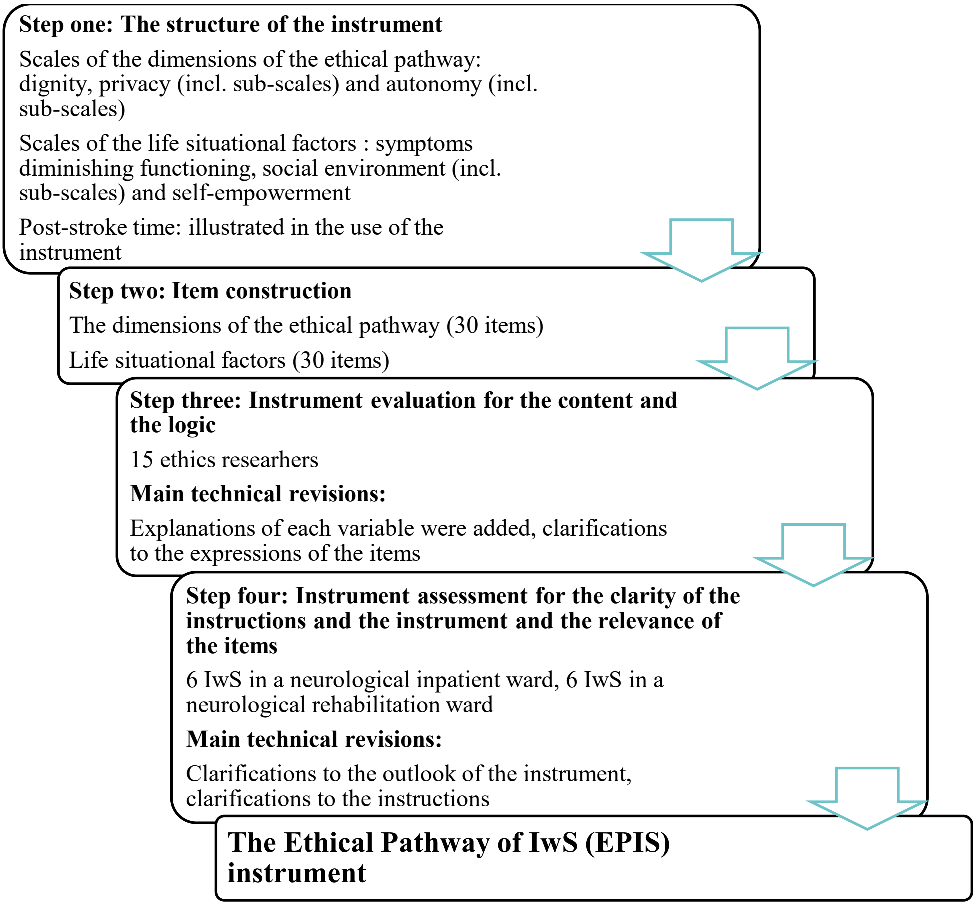


Figure 3. Development process of the EPIS instrument (years 2018–2019).

Table 12. The structure and content of the EPIS instrument.

	Scales and SUB-scales	Basis of scales and items
PART 1: The dimensions of ethical pathway	Scale: Dignity (10 items)	Core category: Dignity in a new situation (Paper I); Definition of dignity based on Jacobson 2009
	Scale: Privacy (altogether 10 items), incl. sub-scales • physical privacy (2 items) • social privacy (3 items) • psychological privacy (2 items) • informational privacy (3 items)	Environmental ethical issues: Privacy (Paper II); Definition of privacy based on Burgoon 1982, Leino-Kilpi et al. 2001
	Scale: Autonomy (altogether 10 items), incl. sub-scales • information received by the participant (4 items) • decision-making by the participant (6 items)	Care process specific ethical issues: Support for autonomy in the recovery process (Paper II); Definition of autonomy based on Scott et al. 2003b
PART 2: The life situational factors	Scale: Symptoms diminishing functioning (17 items)	Specific types of realization: Independence-related dignity (Paper I); Understanding of symptoms diminishing functioning base on Terveyskylä.fi 2017; Current Care Guidelines 2020; Finnish Brain Association 2022
	Scale: Social environment (altogether 8 items), incl. sub-scales • close ones (4 items) • HCPs (4 items)	Specific types of realization: Social-related dignity (Paper I); Understanding of social environment based on Paper I and II
	Scale: Self-empowerment (5 items)	Specific types of realization: Control-related dignity (Paper I); Understanding of self-empowerment based on Paper I and II

5.3 Data analysis

The data of the **grounded theory** study (Data 1, Paper I) was analyzed using the constant comparison of grounded theory (Glaser & Strauss 1967, Olshansky 2014, Singh & Estefan 2018, Tie et al. 2019), where the researcher is viewed as a neutral inquirer (Singh & Estefan 2018). The comparison was conducted throughout the analytic work, including comparison within and between transcripts, codes, subcategories, categories, and a developing theoretical construct. The analysis was conducted in three phases, although along the nature of grounded theory, the phases were partly conducted simultaneously and when relevant, checks and revisions were made to the previous phases (Glaser & Strauss 1967, Olshansky 2014). To enhance the constant comparison, questions were set to the data in each phase of the analysis (Figure 4). In the first phase, to stay close to the participants' original expressions, the original expressions in the transcripts were coded using *in vivo* codes (King 2012). In the twofold second phase, (a) subcategories were composed by comparing the similarities and differences of the codes, and furthermore, to reach a more abstract level (Glaser & Strauss 1967), (b) categories were composed by comparing the nature and properties of the subcategories. In the third phase, the core category, the generic elements of the new situation, and the dignity realization types were identified by comparing the connections, similarities, and differences of the categories.

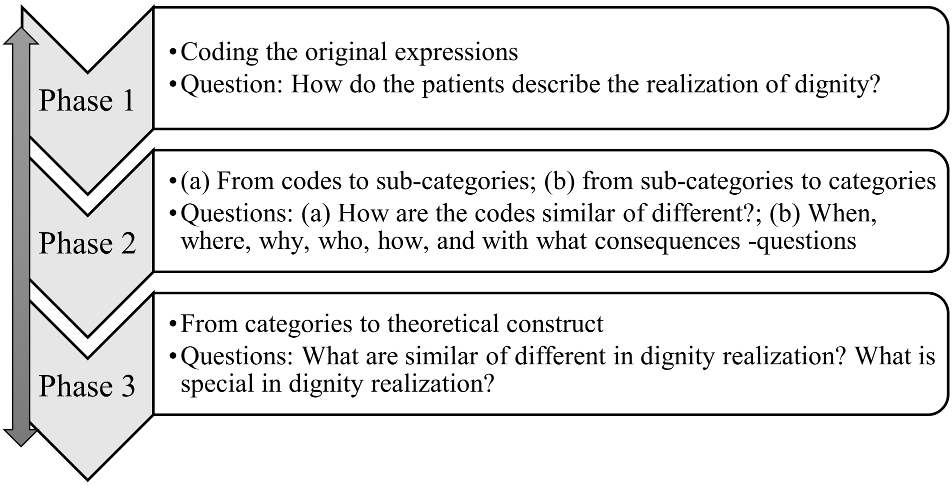


Figure 4. Analysis process of the grounded theory.

The data of the **scoping review** (Data 2, Paper II) was analyzed in two phases. In the first phase, the descriptive numerical data of the studies was charted focusing on (1) authors, publication year, location of the study; (2) main concept; (3) health care context; (4) informants; (5) data collection method; and (6) data analysis. (Arksey & O'Malley 2005, Levac et al. 2010.) In the second phase, content analysis with inductive approach (Graneheim & Lundman 2004) was conducted in five phases focusing on the results of the studies. The content analysis proceeded as follows: (1) original expressions focusing on ethical issues were selected and considered as units; (2) units were coded by giving them a representative name; (3) codes were grouped into subthemes on the basis of shared concepts and representativeness of the ethical issues; (4) subthemes were grouped into main themes on the basis of the abstract level comparison of their similarities and differences; and finally, (5) narrative representations of the main themes were written.

The data of the **cross-sectional study** (Data 3, Paper III) and **follow-up study** (Data 4, Paper IV) were analyzed using the Statistical Package for the Social Sciences (SPSS) version 26.0.0.0 and R version 4.0.0. with different statistical methods (Table 13). In the cross-sectional study, the missing responses were imputed using the K-nearest neighbor algorithm. In the follow-up study, data imputation was not conducted because of the small sample size. For both data sets, descriptive statistics were used to describe the sample and the study variables. The total sum scores were calculated for each scale of the EPIS instrument, and for the sub-scales of the scale privacy, autonomy, and social environment. For Data 3, based on the linearity of the connections, Pearson’s correlation coefficients (Akoglu 2018) were used to evaluate associations between the dimensions of the ethical pathway and the life situational factors, and Spearman's rank correlation coefficient was used to evaluate associations between the dimensions of the ethical pathway and the time from stroke. For Data 4, based on the small sample size without imputation, Spearman's rank correlation coefficients (Akoglu 2018) were used to evaluate associations between the dimensions of the ethical pathway and the life situational factors.

To evaluate the ethical pathway, the statistical methods used varied between the cross-sectional study (Data 3) and the follow-up study (Data 4). In the cross-sectional study, the associations between the dimensions of the ethical pathway and the time from stroke were analyzed with Spearman's rank correlation coefficient (Akoglu 2018). Furthermore, to evaluate associations among the dimensions and life situational factors and the interaction with post-stroke time, three separate explorative regression models were fitted. In each model, one of the value dimensions was the dependent variable, while the two other dimensions and the life situational factors were independent variables in the post-stroke time period. In the models, IwS were divided into IwS with shorter post-stroke time (the first stroke ≤ 3 years ago) and IwS with longer post-stroke time (the first stroke > 3 years ago).

In the follow-up study, to describe the change in the dimensions of the ethical pathway and the life situational factors, range and median with 95% confidence intervals were calculated (Grove et al. 2013, DeVellis 2017).

The internal consistency of the EPIS instrument was calculated with Cronbach's alpha and corrected item-total correlation.

Table 13. Statistical analysis in the cross-sectional and follow-up studies.

Target of the analysis	Statistical method
To describe the sample and the study variables	Descriptive statistics: frequencies, mean, range, standard deviation (Paper III & IV), median (Paper IV)
To evaluate associations between the dimensions of the ethical pathway and the life situational factors	Pearson’s correlation coefficient (Paper III), Spearman's rank correlation coefficient (Paper IV)
To evaluate associations between the dimensions of the ethical pathway and the time from stroke	Spearman's rank correlation coefficient (Paper III)
To evaluate associations among the dimensions of the ethical pathway and life situational factors and the interaction with post-stroke time	Explorative regression models (stepwise model selection with bidirectional elimination) (Paper III)
To describe the change in the dimensions of the ethical pathway and the life situational factors	Median [95% CI], range (Paper IV)
To evaluate the internal consistency of the EPIS instrument	Cronbach's alpha, corrected item-total correlation (Paper III)

5.4 Ethical considerations

The study was conducted following the guidelines on the responsible conduct of research of the Finnish National Board of Research Integrity (2012) and the ethical principles for the protection of human subjects of research presented in the Belmont Report (1979). These ethical principles include respect for persons, beneficence, and justice.

Responsible conduct of research

Honesty, accuracy, and high ethical standards were followed throughout the study, including study plan, data collection, data analysis, reporting data, and data storage. The results are published in open fashion but also with protection of the participants’ identity. In data handling and storage, special attention has been given to directly identifying information, and the data have been handled pseudonymized whenever possible. Because of the sensitivity of the data, it will not be available in public or shared with other researchers. Ethical approval and permission to conduct the studies were applied for according to national standards (Table 14). The work and achievements of other researchers and experts are respected by citing their publications appropriately. Funding and conflict of interests are reported in a responsible fashion. (Finnish National Board on Research Integrity 2012.)

Table 14. Ethical approval and permission to conduct the studies in Papers I-IV.

Paper: study (year)	Ethical approvals	Permissions to conduct the studies
Paper I: Grounded theory	Ethics Committee of the University of Turku (Statement 17/2015)	From the university hospital (25.5.2015)
Paper II: Scoping review	Not applicable	Not applicable
Paper III: Cross-sectional study	Ethics Committee of the University of Turku (Statement 53/2017)	From the association
Paper IV: Follow-up study	Ethics Committee of the University of Turku (Statement 53/2017); Ethics Committee of HUS (HUS/2513/2019)	From the five university hospitals (11.11.2019; 1.10.2019; 15.11.2019; 9.10.2019; 17.6.2019)

Respect for persons

The principle of respect for persons includes the conviction of treating individuals as autonomous agents, and vice versa, protecting individuals with diminished autonomy (The Belmont Report 1979). Autonomous decision-making, referred to in this study as an autonomous decision to participate in the study, requires adequate competence (Beauchamp & Childress 2013). The competence may be diminished temporarily or permanently, for instance, due to a health problem (The Belmont Report 1979), such as stroke (Slyter 1998). Since it may be challenging to recognize a mild cognitive deficit or aphasia, contact nurses who were familiar with the IwS conducted the recruitment in the neurological wards (Paper I & IV). Additionally, the recruitment process respected the privacy of the IwS who were not willing to participate.

Respect for persons includes individuals receiving adequate information about the research and the participation being voluntary (The Belmont Report 1979, Finnish National Board on Research Integrity 2019). In the recruitment process, information of the study was provided orally (Paper I & IV) and in written form (Paper I, III & IV). The information contained details about the study, participation, data handling, reporting results, and data storage. The IwS interested in taking part in the study had the possibility to read the privacy statement (Paper III & IV) before consenting to participate. For possible further questions, the researchers' contact information was provided. Furthermore, voluntariness of participation as well the right to discontinue or withdraw participation was presented in the information (Finnish National Board on Research Integrity 2019). As in some circumstances individuals engage in research in which they would not otherwise take part (The Belmont Report 1979), the information included a mention that unwillingness to participate does not impact current or possible future care. The participants gave their informed consent to participate in the study in written form (Paper I & IV) or electronically (Paper III).

Beneficence

The principle of beneficence is twofold, including (1) avoiding harm and (2) maximizing benefits and minimizing harms (The Belmont Report 1979), also known as the two separate principles of beneficence and non-maleficence (Beauchamp & Childress 2013). In the study, the possible harm was considered in relation to the sensitive topic and recruiting individuals with a recent stroke. The sensitive topic was acknowledged as being a possible cause for mental distress in a situation where individuals go through their own experiences of stroke. The risk of mental distress was evaluated to be minor as individuals not willing to go through their own experiences were considered not willing to participate in the study. The participants were also informed of the possibility to discontinuing their participation in the study (Finnish National Board on Research Integrity 2019). Individuals with a recent stroke may be in a vulnerable health state. In the recruitment, the contact nurses evaluated the health state of the IwS, i.e., whether their health condition enabled their participation in the study. The researcher, familiar with neurological symptoms, observed the participants during the interviews (Paper I) to see whether they showed signs suggesting that the interview should be discontinued, such as fatigue. With the paper form questionnaires, the participants had the possibility to fill in the questionnaires in parts (Paper IV).

In the study, individual participants did not benefit from the participation. Instead, the study may benefit future IwS as the results may be used in developing ethically high-level care, care pathways, and services of IwS.

Justice

The principle of justice set the questions of who receives the benefits of the study, and who are the ones bearing its burdens. These questions may be observed from multiple formulations, such as ‘to each individual an equal share’, or ‘to each individual according to one’s needs’. (The Belmont Report 1979.)

In the study, justice was considered (a) as an equal opportunity to participate among IwS, and (b) as an opportunity to participate as an individual with a serious health problem. In the recruitment, contact nurses in neurological wards screened the suitable IwS using inclusion and exclusion criteria. The criteria included aspects only relevant to the study and research ethics, avoiding all types of discrimination. In addition, in Finland, acute stroke care is organized in public hospitals and therefore, the patients represent the whole variety of individuals, from different cultural and social backgrounds, for instance.

It may be argued that IwS are a vulnerable group based on their health problem (Crowfoot et al. 2018, Loft et al. 2019, Kjærhauge Christiansen et al. 2021), and therefore, one might question whether some other group should have been used as informants in this study. Alternative informants in this study would have been HCPs and SOs as they are important in the care of IwS (Kitson et al. 2013, Chen et al. 2021). However, the researcher wanted to protect the IwS' right to participate in the study focusing on stroke and furthermore, to give IwS a possibility to make their voice heard.

6 Results

In this chapter, the results of the study will be presented in accordance with the RQs (chapter 4). First, the definition of the concept of the ethical pathway will be presented (RQ 1; chapter 6.1). In addition, the definition for the life situational factors related to ethical pathway will be described. The definitions are based on the grounded theory of IwS' dignity realization (Paper I) and the scoping review of ethical issues in the care of IwS (Paper II). Second, the EPIS instrument will be described (RQ 2; chapter 6.2). In the instrument development, the definitions set the base for the development. The preliminary testing of the instrument was conducted in the cross-sectional study (Paper III). Third, the perceived realization of the ethical pathway of IwS will be analyzed (RQ 3), including the association between the ethical pathway and the life situational factors (RQ 4; chapter 6.3). The analysis of the perceived realization of the ethical pathway and the association is based on the cross-sectional study (Paper III) and follow-up study (Paper IV). Finally, as an answer to the main RQ, the theoretical construction of the ethical pathway will be presented (chapter 6.4). More detailed results are presented in Papers I–IV.

6.1 Describing and defining the concept of the ethical pathway

Dignity realization as perceived by individuals with stroke

For the grounded theory of dignity realization of IwS in hospital care, sixteen hospitalized IwS were interviewed (Table 10). As a result, the 'Theory of Dignity Realization of Patients with Stroke in Hospital Care' was composed (Paper I; Figure 5). The core category of the theory, dignity in a new situation, includes generic elements of the new situation and dignity realization types. Stroke represents a new situation in an individual's life in which dignity may be realized in a new way.

Generic elements in the new situation were identified as health history, life history, individuality, and stroke. Both in health and life history, the previous experiences were connected to the views of the present moment, also connected to the descriptions of dignity. The IwS had individual understandings of dignity and various experiences of stroke. However, for all of them, stroke was clearly present in their descriptions. The generic elements were present for all of the IwS, but dignity was realized in different ways for them.

In the new situation, five dignity realization types were identified: (1) person-related dignity type, (2) control-related dignity type, (3) independence-related dignity type, (4) social-related dignity type, and (5) care-related dignity type. In the first type, the individual has a strong vision of self. Dignity is realized in relation to self, instead of stroke, as the individual perceives him/herself as equally valuable as before the stroke. In the second type, control and being aware of the situation are important, not only related to stroke but also related to the individual self. The awareness is also linked with a sense of safety. In the third type, physical and cognitive abilities to function are vital. The feelings of being a burden and being at the mercy of others are the result of lost independence. In the fourth type, interaction in social encounters is vital. The individual is eager to be encountered as a human being, and responding to the needs of the individual is important in the behavior of the HCPs. In the fifth type, appropriate care is important for the individual. They consider HCPs' role as being there for the patient and responding to the individual's needs quickly and in a professional manner.

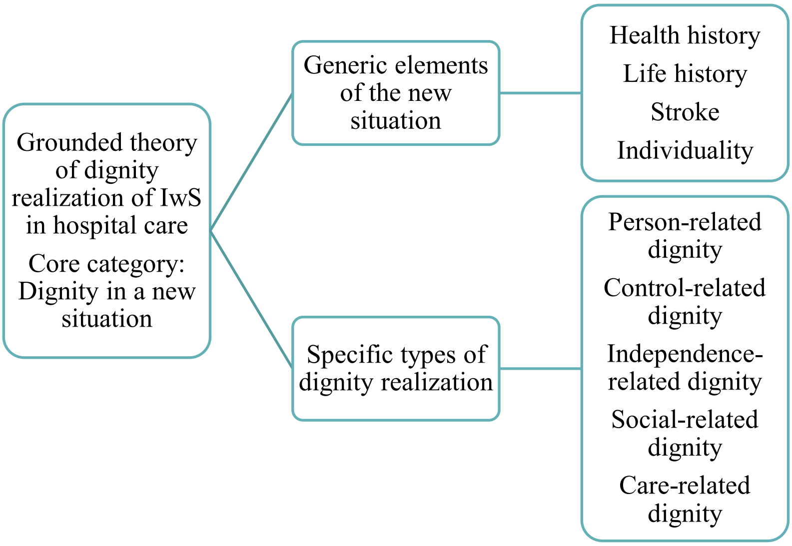


Figure 5. Dignity realization of patients with stroke in hospital care (Modified from Figure 2 in Paper I).

Perceived ethical issues in stroke care

The perceived ethical issues in stroke care (Paper II) were based on a scoping review including 15 research articles with empirical data (Table 10). The studies were published after the year 2000. Most of the studies were conducted in Europe (n = 13) and used a qualitative approach (n = 12). The informants included HCPs (n = 8), IwS (n = 6), and mixed participants including IwS, HCPs, and SOs (n = 1). Almost half of the studies had autonomy as the main topic (n = 7) or examined ethics from a wider perspective (n = 7); the remaining one study had truth-telling as topic.

The data analysis resulted in three themes: (1) decision-making as an ethically challenging act, (2) care process-specific ethical issues, and (3) environmental ethical issues. Furthermore, each of the themes had three subthemes (Figure 6).

The theme 'decision-making as an ethically challenging act' included subthemes of (a) decisions on life-sustaining treatments, (b) communication as a key issue in decision-making, and (c) proving good care on the basis of the decisions taken or not taken. The decisions on life-sustaining treatments focused on ethically demanding situations from the viewpoint of HCPs. This tended to occur in situations where there was no consensus of the IwS' prognosis at the acute stage of stroke. HCPs were worried of prolonging the patient's death and of causing unnecessary suffering. In ethically demanding situations, HCPs considered communication as a key issue in the decision-making both among HCPs and between HCPs and SOs. Although communication between professionals was seen to reduce ethical problems, it was sometimes considered problematic and as delaying decision-making. In cases where the patient was not able to communicate, SOs were considered valued informants, but it was also occasionally questioned whether they told HCPs their own will instead of the patient's will. Because of the decisions taken or not taken, HCPs sometimes felt it impossible to provide good care. HCPs wanted to act in line with the ethical principles of beneficence and nonmaleficence, but instead, they felt that the treatment was harming the patient. In the case of conflicting views, HCPs considered advocacy for the patient to be important.

The theme 'care process-specific ethical issues' included subthemes of (a) ethical dilemmas around a dying patient, (b) support for autonomy in the recovery process, and (c) multidimensional paternalism in rehabilitation. In the case of a dying patient, the SO tended to have the leading role instead of the patient. HCPs wanted to protect the SO, and occasionally this meant giving patients treatment based on the SO's will instead of the patient's medical condition. To protect the SO, HCPs also sometimes considered that telling the truth was difficult. They valued telling the truth to the SO but at the same time, feared that the truth would hurt the SO. From dying IwS to recovering ones, support for the autonomy of the IwS was considered important. IwS perceived their autonomy as diminished compared to the pre-stroke situation, but as improved during the rehabilitation. An active role of IwS, improving abilities, and received therapy were considered to have a positive impact on autonomy. Both HCPs and SOs had important roles in supporting IwS' autonomy. At the beginning of the rehabilitation, IwS considered paternalism relevant as they were still dependent on others. However, it was considered important that HCPs recognized IwS' improving abilities, which gradually reduced paternalism. This was not always the case, for example, when HCPs acted in an over-protective manner.

The theme 'environmental ethical issues' included subthemes of (a) privacy, (b) prioritization, and (c) available and lacking resources. IwS' privacy was related to the physical environment and social environment in terms of the other IwS. In the environment, the lack of single rooms was a threat to the IwS' privacy. HCPs considered prioritization ethically demanding in various situations. This was described in situations such as moving a patient to a less intensive unit when the move was not based on the patient's medical condition. Prioritization was related to the availability and lack of resources. HCPs were forced to prioritize work tasks based on available resources, heavy workload, and lack of time.

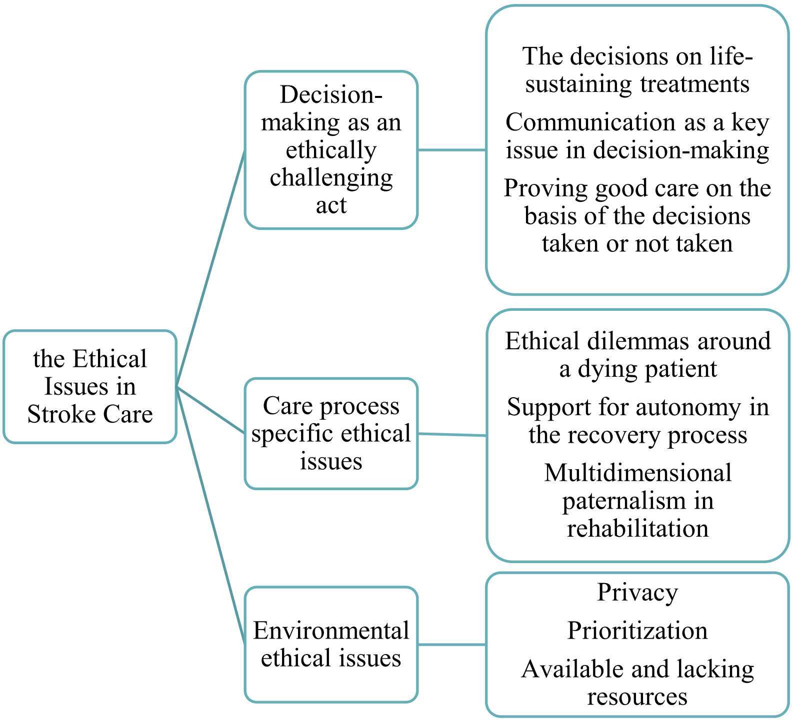


Figure 6. The ethical issues in stroke care (Modified from Figure 3 in Paper II).

Development of the concept of the ethical pathway and the life situational factors related to the ethical pathway

The grounded theory and the scoping review set the base for the concept development. The preliminary basis of the concept of the ethical pathway was in the generic elements of the grounded theory and the scoping review's subtheme of 'support for autonomy in the recovery process'. The generic elements of 'health history' and 'life history' and the subtheme formed the understanding that individuals' perceived realization of values is continuous during the life span and potentially changing in temporal passage. Furthermore, the generic elements of individuality and stroke stated that the perceived realization of values is individual, and significant life events, such as stroke, are present in the perceived realization for individuals.

The concept of the ethical pathway was identified as being composed of two elements, potential change in temporal passage and dimensions of the ethical pathway (Table 15). The first element, potential change in temporal passage, was derived from the grounded theory's generic elements of 'health history' and 'life history', and the scoping review's subtheme of 'support for autonomy in the recovery process'. These formed the understanding that perceived realization of values was recognized to potentially change in the temporal passage after the onset of the life-threatening and long-term health problem of stroke. The second element, dimensions of the ethical pathway, were derived from the grounded theory's core category of 'dignity in a new situation' and the scoping review's subthemes of 'support for autonomy in the recovery process' and 'privacy'. These three central values in nursing practice – dignity, privacy, and autonomy – were recognized as important for IwS, but at the same time, the realization of these was perceived as challenging by IwS.

The concept was labeled as the ethical pathway. The ethical pathway was defined as potential changes in the realization of values, including dignity, privacy, and autonomy, as perceived by individuals in temporal passage. Although the concept of the ethical pathway was developed in the stroke context, the definition of the concept of the ethical pathway is not tied to the existence of a health problem.

Table 15. The elements of the concept of the ethical pathway and their core idea.

The concept	The elements of the concept	The elements core idea from
Ethical pathway	Potential change in temporal passage	Generic elements of the new situation - Health history - Life history
		Care process specific issues - Support for autonomy in the recovery process
	The dimensions of the ethical pathway	Dignity: Core category - Dignity in a new situation
		Privacy: Environmental ethical issues - Privacy
		Autonomy: Care process specific issues - Support for autonomy in the recovery process

Some life situational factors related to the ethical pathway were identified (Table 16). The factors were derived from the grounded theory's dignity realization types of 'control-related dignity type', 'independence-related dignity type', and 'social-related dignity type'. Furthermore, these were confirmed by the scoping review's subthemes of 'support for autonomy in the recovery process', 'multidimensional paternalism in rehabilitation', and 'privacy'. The life situational factors related to ethical pathway were labeled as symptoms diminishing functioning, social environment, and self-empowerment. Life situational factors represent the life situation in which the individuals perceive the values to be realized.

Table 16. The life situational factors and their core idea.

The group of factors	The factors core idea from
Life situational factors related to the ethical pathway	Symptoms diminishing functioning: Specific types of dignity realization - Independence-related
	Social environment: Specific types of dignity realization - Social-related
	Self-empowerment: Specific types of dignity realization - Control-related

6.2 The Ethical Pathway of Individuals with Stroke (EPIS) instrument

The Ethical Pathway of Individuals with Stroke (EPIS) is an instrument for evaluating the realization of values and life situational factors in the post-stroke time as perceived by IwS. The instrument was developed for this study and the development is described in detail in chapter 5.2.

The EPIS instrument includes two parts, each with three scales. The first part, the dimensions of the ethical pathway, includes the scales of dignity (10 items), privacy (10 items), and autonomy (10 items). Furthermore, privacy includes four sub-scales and autonomy two subscales. The second part, the life situational factors, includes the scales of symptoms diminishing functioning (17 items), social environment (8 items), and self-empowerment (5 items). Furthermore, social environment includes two sub-scales. The sub-scales are presented in Figure 7.

The EPIS instrument is meant for self-evaluation and can be used in both paper-pencil and electronical format. The instrument uses a Visual Analog Scale from 0 (= does not describe my perception at all) to 100 (= describes my perception exactly). The items are both positively and negatively worded, and in the analysis, the scores of the negatively worded items were reverse-scored to form the sum variables. Higher scores of the sum variables mean stronger perceived realization of values, less symptoms diminishing functioning, a more satisfying social environment, and stronger self-empowerment. The EPIS instrument is easy to administer and takes approximately 35 minutes to complete.

Preliminary testing of the EPIS instrument

The preliminary testing of the EPIS instrument suggests that the instrument is suitable for evaluating the perceived realization of values and the life situational factors in the post-stroke time period. The internal consistency evaluation, conducted with the data in the cross-sectional study (Table 10), shows internal consistency being at acceptable level. The item-total correlations were 0.296–0.868, which is in line with the suggested > 0.3 (DeVon et al. 2007), except for one item. The Cronbach alpha values were 0.848–0.929, which is in line with the suggested > 0.7 (Nunnally & Bernstein 1994) (Table 17).

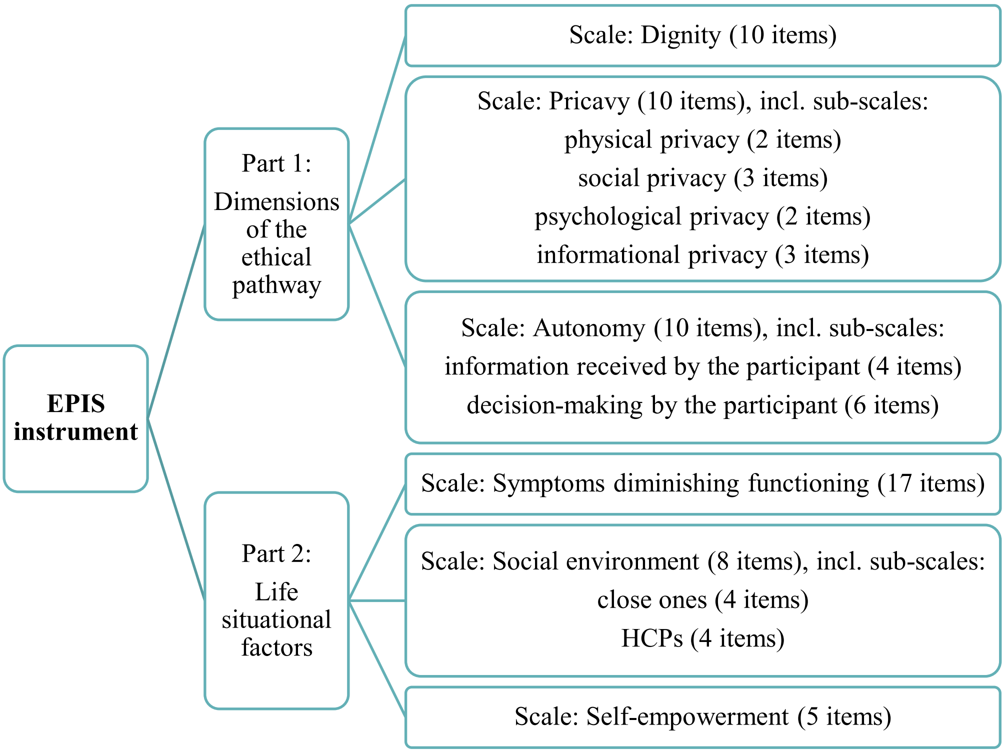


Figure 7. The structure of the EPIS instrument.

Table 17. Preliminary internal consistency evaluation of the EPIS instrument (n = 61 IwS) (Modified from Table 5 in Paper III).

Scale	Corrected item-total correlations	Cronbach's alpha values
Dignity (10 items)	0.437–0.796	0.915
Privacy (10 items)	0.317–0.748	0.848
Autonomy (10 items)	0.423–0.791	0.891
Symptoms diminishing functioning (17 items)	0.296–0.718	0.886
Social environment (8 items)	0.679–0.829	0.929
Self-empowerment (5 items)	0.572–0.868	0.914

6.3 The perceived realization of the ethical pathway

The perceived realization of the ethical pathway is presented by the courses of the ethical pathway of IwS. The courses of the ethical pathway are conducted for both non-limited post-stroke time and for the first three post-stroke months. To describe the course of the ethical pathway of individuals with non-limited post-stroke time (Paper III), data were collected from 61 IwS in a cross-sectional study (Table 10). To describe the course of the ethical pathway of IwS in the first three post-stroke months (Paper IV), data was collected from 36 IwS in a follow-up study (Table 10). In addition, the association between the ethical pathway and the life situational factors is presented in both non-limited post-stroke time and the first three post-stroke months.

The course of the ethical pathway of individuals with stroke

There were individual variations in the perceived realization of the dimensions of the ethical pathway in both IwS with non-limited post-stroke time (n = 61) and IwS in the first three post-stroke months (n = 36) (Table 10).

IwS with non-limited post-stroke time. In the ethical pathway, based on the associations between the dimensions and the time from stroke, the dimensions of dignity and privacy had a declining course in the post-stroke time while autonomy emerged with a stable course. In the dimension of privacy, physical, social, psychological, and informational privacy all had a declining course. In the dimension of autonomy, information received by the participant emerged with a stable course, and decision-making by the participant with a declining course (Table 18).

Table 18. The descriptive statistics and course of the ethical pathway in non-limited post-stroke time.

The dimensions of the ethical pathway (course)	Range; participants' mean score (SD)	Correlation with the post-stroke time
Dignity (🡣)	20.5–99.4; 72.26 (20.45)	-0.34**
Privacy (🡣)	39.1–99.6; 78.72 (16.47)	-0.35**
Physical (🡣)	20.0-98.0; 75.51 (19.43)	-0.12
Social (🡣)	14.0-100; 81.24 (18.96)	-0.39**
Psychological (🡣)	37.5-100; 84.09 (17.08)	-0.30*
Informational (🡣)	21.67-100; 74.75 (22.51)	-0.26*
Autonomy (🡢)	22.8–100; 77.80 (18.57)	-0.03
Information (🡢)	5.25-100; 73.05 (26.23)	0.04
Decision-making (🡣)	32.0-100; 80.96 (17.27)	-0.14

Symbols: 🡢 stable course; 🡣 declining course
*P≤0.05. **P<0.01. ***P<0.001

IwS in the first three post-stroke months. In the ethical pathway, based on the change between two measurement points, the dimension of dignity had a declining course, privacy had rather steady course, while autonomy had an increasing course.

In the dimension of privacy, physical and social privacy had slightly increasing courses, psychological privacy had a steady course, while informational privacy had a declining course. In the dimension of autonomy, both information received by the participant and decision-making by the participant had increasing courses (Table 19).

Table 19. The descriptive statistics and course of the ethical pathway in the first three post-stroke months.

The dimensions of the ethical pathway (course)	**Change in the follow-up: Range**	**Change in the follow-up: median (n); [95% CI]**
Dignity (↓)	-36.90–39.00	-7.10 (n=31); [-9.30, -4.00]
Privacy (→)	-7.80–32.10	0.50 (n=31); [-3.40, 5.80]
Physical (↑)	-28.50–83.00	3.25 (n=34); [0.00, 8.50]
Social (↑)	-3.33–62.00	4.33 (n=33); [0.00, 22.33]
Psychological (→)	-20.00–47.50	0.00 (n=36); [-1.00, 0.25]
Informational (↓)	-48.33–33.33	-10.67 (n=36); [-11.33, -9.50]
Autonomy (↑)	-29.00–71.20	10.20 (n=30); [2.20, 20.00]
Information (↑)	-52.50–84.50	7.62 (n=32); [1.25, 12.75]
Decision-making (↑)	-22.17–99.67	9.25 (n=32); [1.67, 28.33]

Symbols: ↑ increasing course; → stable course; ↓ declining course

The associations between the ethical pathway of individuals with stroke and the life situational factors

There were variations in the associations between dimensions of the ethical pathway and life situational factors in both IwS with non-limited post-stroke time (n = 61) and IwS in the first three post-stroke months (n = 36) (Table 10).

IwS with non-limited post-stroke time. The dimensions of the ethical pathway and the life situational factors had varying associations (Table 20). Symptoms diminishing functioning correlated moderately with overall privacy and weakly with dignity, physical privacy, social privacy, psychological privacy, informational privacy, overall autonomy and decision-making by the participant. Social environment correlated strongly with dignity and psychological privacy, moderately with overall privacy, social privacy and informational privacy, and weakly with physical privacy, overall autonomy, information received by the participant and decision-making by the participant. Self-empowerment correlated moderately with overall autonomy and decision-making by the participant, and weakly with dignity, overall privacy, social privacy, psychological privacy, informational privacy and information received by the participant.

Table 20. The associations between the dimensions of the ethical pathway and the life situational factors in non-limited post-stroke time.

The dimensions of the ethical pathway	Positive correlations with SDF	Positive correlations with SE	Positive correlations with SeEm
Dignity	0.47***	0.71***	0.43***
Privacy	0.55***	0.69***	0.43***
Physical	0.38**	0.43***	0.21
Social	0.47***	0.60***	0.36**
Psychological	0.46***	0.73***	0.37**
Informational	0.49***	0.56***	0.44***
Autonomy	0.44***	0.44***	0.56***
Information	0.28*	0.30*	0.39**
Decision-making	0.49***	0.49***	0.59***

Abbreviations: SDF=symptoms diminishing functioning; SE=social environment; SeEm=self-empowerment
Correlations: low (0.3–0.5), medium (0.5–0.7), high (0.7–0.9), or very high (>0.9) (Mukaka 2012)
*P≤0.05. **P<0.01. ***P<0.001

Two groups, including IwS with shorter post-stroke time (the first stroke ≤ 3 years ago, n = 31) and IwS with longer post-stroke time (the first stroke > 3 years ago, n = 30), were compared in regression analysis (Table 4 in Paper III). Three separate explorative regression models were fitted, with one dimension of the ethical pathway as the dependent variable, respectively, and the two other dimensions of the ethical pathway and the three life situational factors as independent variables in the post-stroke time. Here, the results regarding associations between the dimensions of the ethical pathway and the life situational factors are presented (see Paper III for a more detailed presentation).

In regression analysis with **dignity** as dependent variable (Table 4 in Paper III), symptoms diminishing functioning had a significant interaction with the length of the post-stroke time but no significant association with dignity. For the IwS with longer post-stroke time, when symptoms diminishing functioning increased, dignity declined (β = -0.103). For the IwS with shorter post-stroke time, when symptoms diminishing functioning increased, dignity increased (β = 0.123). Social environment had significant associations with dignity and significant interactions with the length of the post-stroke time. When social environment increased, dignity increased for both IwS with shorter (β = 0.955) and longer (β = 0.282) post-stroke time.

In regression analysis with **privacy** as dependent variable (Table 4 in Paper III), social environment had significant associations with privacy and significant interactions with post-stroke time. When social environment increased, privacy increased for both IwS with shorter (β = 0.779) and longer (β = 0.048) post-stroke time. Furthermore, symptoms diminishing functioning had a positive association with privacy, but the association was the same (β = 0.124) for IwS with shorter and longer post-stroke time.

In regression analysis with **autonomy** as dependent variable (Table 4 in Paper III), there were no significant interactions with post-stroke time. Self-empowerment (β = 0.477) had a positive association with autonomy, but the associations were the same for IwS with shorter and longer post-stroke time.

IwS in the first three post-stroke months. The dimensions and the life situational factors had only few statistically significant associations with each other, all of them with the life situational factor of social environment (Table 21).

Table 21. The associations between the dimensions of the ethical pathway and the life situational factors in the first three post-stroke months.

The course of value dimensions	**Correlations with life situational factors (statistically significant, $p<0.05$)**
Dignity	-
Privacy	-
Physical	-
Social	-
Psychological	Positive correlation with social environment incl. SOs
Informational	-
Autonomy	Negative correlation with social environment incl. HCPs
Information	Negative correlation with overall social environment
Decision-making	-

Abbreviations: HCPs=health care professionals; SOs=significant others

6.4 The theoretical construction of the ethical pathway

The ethical pathway describes potential changes in the realization of values, including dignity, privacy, and autonomy, as perceived by individuals. Changes in the individual’s health status, such as health problems, may change the perceived realization of the values. The health status and the life situational factors describe the current life situation in which the individuals perceive the values to be realized.

In the theoretical construction of the ethical pathway, individuals are considered from a comprehensive viewpoint (Figure 8). For this, two clarifications were set. First, health and health problems are considered as a natural part of individuals’ life span. Second, health, health problems and the realization of the dimensions of the ethical pathway are considered from individuals’ viewpoint and as they perceive them.

The theoretical construction of the ethical pathway consists of the concept of the ethical pathway and life situational factors, and the association between these. As changes in the individual's health status may change the perceived realization of values, the health status is also represented in the theoretical construction of the ethical pathway.

The ethical pathway includes three dimensions: dignity, privacy, and autonomy. Dignity describes how valuable individuals perceive themselves and how they perceive other people respecting them as human beings. Privacy describes how individuals perceive privacy in the physical environment and in social situations, and how individuals perceive control over personal matters and their confidentiality. Autonomy describes individuals' perceptions of whether they receive enough information considering their health problem and whether they are able to decide on their personal matters.

The life situation includes three factors: symptoms diminishing functioning, social environment, and self-empowerment. Symptoms diminishing functioning describes symptoms which disturb individuals' everyday lives. Social environment describes the people the individuals are in contact with in their everyday lives as well as interaction with them. Self-empowerment describes how individuals perceive control, ranging from control over current life situation to control over future plans.

The ethical pathway and the life situational factors are related. The ethical pathway is dynamic, and the association between the ethical pathway and the life situational factors also fluctuates in temporal passage.

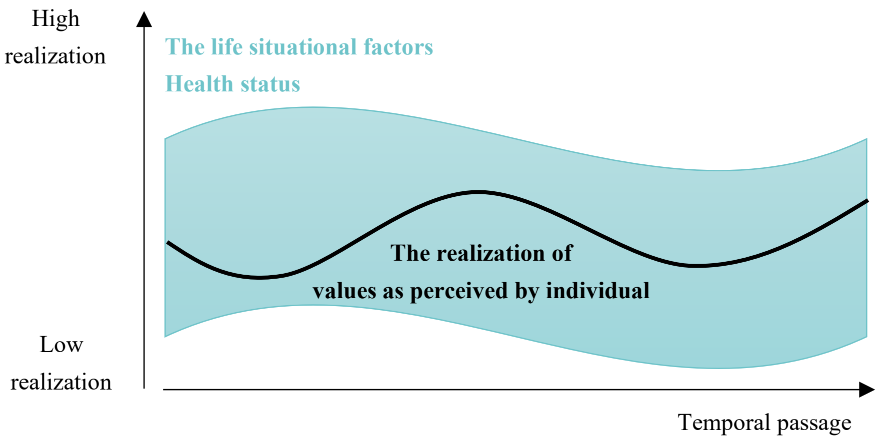


Figure 8. The theoretical construct of the ethical pathway.

7 Discussion

The main aim of the study was to compose a theoretical construct of the ethical pathway. The theoretical construction is a synthesis and the main result of the study. For nursing, it provides an understanding that the realization of the values as perceived by individuals is dynamic. It also presents factors which are related to the realization of the perceived ethical pathway.

The concept development of the ethical pathway formed the structural framework for the topic under interest and is therefore considered as a prerequisite for further study of the topic. Operationalization of the concept made it possible to observe the perceived realization of the ethical pathway. The study focused on the viewpoint of individuals and therefore, to test the concept empirically and to compose the theoretical construction of the ethical pathway, it was essential to conduct empirical observation. In this chapter, the results are discussed step by step (Figure 1) in accordance with the study process (7.1).

Because of the novelty of the ethical pathway, the study includes limitations. These are discussed within the validity and reliability of the study (7.2). The limitations guided the suggestions given for further research (7.3). Despite the limitations, the study produced new knowledge in the form of a concept, an instrument, an empirical description of the topic, and a new theoretical construct. All of these provide practical implications (7.4).

7.1 Discussion of the results

The concept of the ethical pathway

Concepts that are developed and defined guide what individuals see, enabling an enhanced understanding of situations (Meleis 2017). A concept defining the topic of the study was not clearly detected from scientific literature; this revealed the need for concept development. As a result, the new concept of the ethical pathway was developed and defined. The developed concept enables nurses to have an enhanced understanding of the perceived realization of patients’ values.

At the beginning of the concept development process (Meleis 2017), it was not clear whether the topic is composed of one or more concepts. The development process revealed one concept, the ethical pathway, and three factors which are related to the ethical pathway. The concept of the ethical pathway includes two elements: potential change in temporal passage and the dimensions of the ethical pathway.

The results of the grounded theory study (Paper I) gave an understanding for the researcher that the significant life event of stroke is present in the perceived realization of dignity, and the realization may be dynamic in its nature. Furthermore, the dynamic nature of the perceived realization of values was identified in the scoping review (Paper II) as autonomy was sensed to change during the recovery process. The dynamic nature seemed to follow temporal passage. In this study, temporal passage is understood along the linear time concept (see Lewis 2000). Therefore, it is not directly relevant for cultures with different time concepts.

The dimensions of the ethical pathway were derived from research by the researcher instead of selection of the dimensions by the study participants, i.e., individuals with a long-term health problem. Therefore, the dimensions do not represent participants' perceptions of the importance of the dimensions but on which level the participants perceive the realization of the dimensions. This selection was made consciously to standardize the dimensions of the ethical pathway so as to be similar for each participant at each measurement point, enabling the construction of a general ethical pathway instead of an individual ethical pathway.

The derived dimensions cover dignity, privacy, and autonomy. These warrant two observations. First, they were theoretically derived from the scarce literature available (see Papers I and II) and therefore, it is possible that there are additional values which should be included in the dimensions of the ethical pathway. Secondly, the population in this study was IwS, and it is possible that these dimensions are not comprehensive in every life situation. However, the derived dimensions are central values in nursing (see e.g., Thompson et al. 2006) and in human life (United Nations 1948), which supports their relevance as not being specific to a certain health problem.

The factors related to the ethical pathway represent the life situation in which the individuals perceive the values to be realized. These factors, central to living with a long-term health problem, include symptoms diminishing functioning, social environment, and self-empowerment. The factors warrant the same two observations as the dimensions of the ethical pathway. First, the factors were theoretically derived from the scarce literature available (see Papers I and II) and therefore, it is possible that other central factors exist as well. Secondly, the population in this study was IwS. Therefore, it is possible that the factors are not comprehensive or relevant in every life situation or for individuals with some other health problem.

The literature which formed the basis for the concept development was scarce. However, the concept development was conducted carefully; furthermore, the analysis of the perceived realization of the ethical pathway confirmed the existence of the ethical pathway. The nature of concepts is understood to be dynamic and responsive to new knowledge and data (Meleis 2017). Therefore, the developed concept describes the concept at the time of its development process. After the development conducted in this study, the concept should not be considered as ready or permanent.

The developed concept of the ethical pathway does not describe its empirical state. Therefore, to fully reach the aim of study, there was a need to operationalize the concept of the ethical pathway and further, to test it empirically.

The Ethical Pathway of Individuals with Stroke (EPIS) instrument

In the area of ethics, it is important to consider what should be measured and how it should be measured (see Islam & Greenwood 2022). In this study, the Ethical Pathway of Individuals with Stroke (EPIS) instrument was developed (chapters 5.2 & 6.2). The instrument evaluates the realization of values and life situational factors in post-stroke time as perceived by IwS. The rationale was, with help of a self-evaluation instrument, to give a vulnerable patient population the opportunity to be heard. Normally, individuals decide for themselves and protect themselves (ten Have 2016). Vulnerable individuals may be considered as in a need of special protection (ten Have 2016) due to a factor creating vulnerability, such as a health problem or disability (Mergen & Akpınar 2021). By measuring the perceived realization of the ethical pathway, the special circumstances and needs of IwS on this selected topic may be detected.

Concepts in the area of ethics, such as dignity (Jacobson 2009), privacy (Scott et al. 2003a) and autonomy (Beauchamp & Childress 2013), are multifaceted, with various definitions. Two observations regarding their measurement are presented. First, operationalizing multifaceted concepts with various definitions is challenging. As it is possible that participants understand the concepts in various ways, one could even question whether measuring the perceived realization of these is relevant at all. In health care, the target is the good of individuals, and ethical questions are grounded in the nature of health care (Thompson et al. 2006). This argues for the need for instruments measuring ethics in a way that is easy to administer with large populations. In this study, to enable the participants to understand what is meant by the dimensions of the ethical pathway, their definitions used in this study were included in the instrument.

Second, when developing an instrument in the area of ethics, the instrument developer sets an assumption of what is good or desirable (Islam & Greenwood

2022). However, good and desirable are not the same for every individual. In ethics, these may include, for instance, strong cultural elements (Laufer & Wolfe 1977, Bentwich et al. 2018). Thus, the instrument does not present only the topic, but the developer as well (see Islam & Greenwood 2022). Although the content of the items has a basis (DeVellis 2017) in literature, they also reflect the instrument developer's understanding and cultural background. The instrument developer has the power, as well as responsibility, to decide what is included in the instrument and, conversely, what is excluded. In this study, the selection of the items was conducted carefully. To strengthen the content of the instrument and the relevance of the items, the developed instrument was evaluated by experts in nursing ethics and health care and assessed by IwS (chapter 5.2).

The developed EPIS instrument was used successfully in both electronical (REDcap n.d.) and paper format. This expands the possibilities of using the instrument with diverse individuals in diverse environments. The use of paper version is justified in studies where the population is located in care facilities and may confront difficulties in access to electronical devices. In addition, especially older individuals may not be familiar with using them (Wilson et al. 2021). The paper version also enables completing the instrument in parts, which may be important when the individual does not have enough strength to complete it all at once. The electronical version may be a better option, for instance, when studying work-age population or younger persons who prefer to use electronical devices. The electronical version also spares researchers' resources when the answers do not need to be transferred into electronical form.

In this study, the EPIS instrument was both assessed and used by IwS. Based on this, the EPIS instrument was evaluated to be easy to administer by individuals with rather minor stroke or with longer post-stroke time.

The instrument was named the Ethical Pathway of Individuals with Stroke (EPIS), and it includes two parts: the dimensions of the ethical pathway and the life situational factors. Although 'pathway' relates to potential change in temporal passage, the instrument itself does not include this information. It needs to be collected with additional questions in the case of a cross-sectional study, or with multiple data collection time points in the case of a follow-up study. Still, as the focus of the study was on potential changes in the perceived realization of values in temporal passage, a conscious decision was made to include 'pathway' in the name of the instrument. However, it is worth considering that the instrument may be used in measuring content without the potential aspect of change.

The perceived realization of the ethical pathway

The ethical pathway had various courses as shown by the dimensions of the ethical pathway (Paper III & IV). There were associations between the dimensions of the ethical pathway and the life situational factors, but not in a consistent way.

The results of this study indicated the dynamic nature of the realization of the values as perceived by IwS, and not all IwS perceived that their values had been realized to a large extent. Proot et al. (2007) have described the dynamic nature of IwS' autonomy in the rehabilitation context. At admission, IwS' autonomy was stated to be declined, but it showed an increasing course during rehabilitation and at the time of discharge. In this study, IwS' perceived that realization of autonomy was increased during the first three post-stroke months, which is in line with the finding of Proot et al. (2007). Furthermore, IwS with a non-limited post-stroke time period perceived that realization of autonomy emerged with a stable course. Together, these follow the parabolic curve of a person's lifetime health career described by Thompson et al. (2006). In the curve, the degree of autonomy is declined at the time of individual's dependency on care providers and increased at times of declined dependency.

The study provides new knowledge regarding the courses of the perceived realization of dignity and privacy. In the ethical pathway, the perceived realization of dignity had a declining course, including IwS with non-limited post-stroke time and IwS in the first three post-stroke months. The understanding of stroke and the possible long-term symptoms usually evolves in the weeks or even months post-stroke (Kirkevold 2002). Straight after the incidence of stroke, individuals often feel grateful for being alive (Kuenemund et al. 2016) and stroke may seem transient for them (Kirkevold 2002). The hospital is a safe place for rehabilitation with HCPs around, whereas at home, individuals are often without professional help in their natural living environment. The impacts of stroke may even be present for individuals with mild stroke (Crowfoot et al. 2018, Hodson et al. 2019, Hodson et al. 2020), and the impacts and their meaning for everyday life may only be realized after discharge (Kirkevold 2002). A careful discharge plan is important in IwS' successful transition from hospital to home (Chen et al. 2021), and for some individuals, early discharge (Visvanathan 2019) may mean going home before feeling ready (Crowfoot et al. 2018). According to the study results, it is obvious that IwS' perceived realization of dignity requires more support. In health care, this should be viewed not only at the present moment but also in the longer term.

In the ethical pathway, the perceived realization of informational privacy had a declining course in the first three post-stroke months, while privacy all in all had a declining course in non-limited post-stroke time. In health care, in order to be able to provide care, HCPs are forced to get involved in individual's personal matters, sometimes in all four dimensions of privacy, including the physical, psychological, social, and informational dimension (Burgoon 1982, Leino-Kilpi et al. 2001). However, this violates individuals' perceived privacy realization only in the extent their achieved privacy falls short of their desired privacy (Altman 1975 along Burgoon 1982). For that, individuals may have different interpretations depending on the kind and extent of access to self, and further, who has access and by which means (Beauchamp & Childress 2013). The results of the study suggest that IwS at the acute stage do not consider HCPs getting involved in their personal matters as violating their privacy. However, it seems that as time goes by, IwS become more aware of their personal matters, especially, regarding their informational privacy. In temporal passage, IwS meet more HCPs but also other professionals, such as social workers, and by meeting several professionals, it is possible that IwS become more sensitive of their personal matters. HCPs have both an ethical (The Finnish Nurses Association 2021) and legal obligation to protect patients' privacy (Finlex 1994). This requires more sensitivity from HCPs but also from other professionals who are in contact with IwS outside health care facilities.

There were variations in the associations between the dimensions of the ethical pathway and the life situational factors. In non-limited post-stroke time, social environment seemed important for IwS' dignity and privacy, and self-empowerment for autonomy. In the first-three post-stroke months, the associations were not evident.

In previous studies, social environment has been identified as important for IwS' dignity. Social environment can both maintain (Sundin et al. 2001, Mangset et al. 2008, Peoples et al. 2011, Tomkins et al. 2013) and decline IwS' perceived realization of dignity (Mangset et al. 2008, Peoples et al. 2011, Kitson et al. 2013). IwS may be considered as being in a vulnerable position (Crowfoot et al. 2018, Loft et al. 2019, Kjærhauge Christiansen et al. 2021). Many IwS have concerns about their future, such as whether they can manage at home or be able to return to work (Loft et al. 2019). Some IwS have negative a sense of self, such as a feeling of being a failure or being useless (Large et al. 2020). With all these concerns and thoughts, HCPs have a major role to alleviate IwS' distress. When HCPs do not succeed in that role, IwS feel that their needs are unmet (Loft et al. 2019).

Based on previous literature, very little is known about the realization of privacy as perceived by IwS. Individuals with another neurological long-term health problem, multiple sclerosis (MS), have stated the importance of trustful relationships with nurses. This meant, for instance, that individuals felt free to talk more openly about their personal matters. However, the individuals with MS and the nurses did not always agree on the presence of SOs in care consultations. Nurses preferred to include them whereas individuals with MS did not always want their presence. (Witzig-Brändli et al. 2022.) To maximize IwS' perceived realization of values, it is vital to be aware of individual's viewpoint instead of conducting care as usual or based on nurse's own opinion.

Previous literature of the perceived realization of IwS' autonomy described self-confidence (Proot et al. 2000a, Proot et al. 2000c) and self-efficacy (Li et al. 2021) as facilitating IwS' autonomy while insecurity declined it (Proot et al. 2000a, Proot et al. 2000c, Olofsson et al. 2005). The finding of this study strengthens the understanding that a sense of confidence and a sense of control are important for IwS' autonomy. It seems that these may be hindered by other persons, as Luker et al. (2015) found that disempowering staff attitudes decline IwS' autonomy. Previous literature has also described information (Proot et al. 2000a, Proot et al. 2000b, Proot et al. 2000c, Olofsson et al. 2005, Luker et al. 2015) and knowledge of stroke (Li et al. 2021) as facilitating IwS' autonomy. In this study, the understanding varied, as information received by the individual was considered to be part of the definition of autonomy (Scott et al. 2003b).

Theoretical construction of the ethical pathway

The results of the concept development of the ethical pathway and the empirical testing of the concept and its association with the life situational factors were synthesized in the theoretical construction of the ethical pathway.

The theoretical construction of the ethical pathway was conducted in the stroke context. The ethical pathway is not tied to the existence of a health problem as it describes potential changes in the realization of an individual's values during the life span. However, a health problem may change the perceived realization of values, and therefore, individual's ethical pathway requires special attention in the presence of a health problem.

The ethical pathway has the viewpoint of an individual. However, as the ethical pathway is about *perceived realization* of values, the social aspect is evident, both in the dimensions of the ethical pathway but also in the life situational factors related to the ethical pathway. In the theoretical construct of the ethical pathway, the factors describe the current life situation in which individuals perceive the values as realized. Health care is social by its nature, and in the event of a health problem, HCPs are in a significant role in individuals' perceived realization of values. In the life situational factors, the social environment was detected as one of the factors. It is evident that individuals perceive things differently, and therefore there are differences between individuals in the amount of weight they put on the social environment in their perceived realization of values.

In health care, there are descriptions of care pathways. Although these descriptions are beneficial for both patients and HCPs, they are mechanical descriptions of the care. In patient care, there is always an individual following the pathway who has the right to be cared for based on both their personal values and the values of health care practice. Thus, there is always an ethical pathway included in the care. The theoretical description makes the ethical pathway visible, and thus supports the development and realization of ethically high-level care.

7.2 Validity and reliability of the study

The study included various methods and designs (Table 9). In this chapter, the validity and reliability of these are discussed in line with the selected methods. Furthermore, their strengths and limitations are presented in Table 22. The EPIS instrument is evaluated within the validity and reliability evaluation of the cross-sectional study and the follow-up study. At the end of the chapter, the validity of the theoretical construction is presented.

Validity related to grounded theory

First, a grounded theory study was conducted (Paper I). The validity of the grounded theory was evaluated in terms of credibility, transferability and dependability (Lincoln & Guba 1985, Graneheim & Lundman 2004, Holloway & Wheeler 2010).

Credibility refers to the focus of the study, including how the context, participants, and data deal with the aim of the study (Graneheim & Lundman 2004, Polit & Beck 2017). The context of the study was hospital care, more precisely in the case of IwS, neurological ward. The data was collected with interviews and the interviews were conducted in that particular context, in a neurological inpatient ward.

In the study, the focus was on IwS' viewpoint, and even if IwS in hospital care may be considered as vulnerable based on their health status (ten Have 2016), it was seen as meaningful to collect the data from the IwS themselves. However, it is worth noting that the interviewed participants represent IwS in good condition. Still, the participants varied in terms of their demographic characteristics and health condition, which increased their representativeness.

For the data collection, face-to-face interviews were selected as they enabled observing the participants during the interview, for instance, in the case of emotional expressions or signs of insecurity towards a question posed. To avoid unclear questions, the interview guide was piloted with two participants. As no changes were made to the interview guide, these interviews were included in the data. When talking about their experiences, the participants often referred to the time before the incidence of stroke. Participants were allowed to answer questions freely, and as the interviews proceeded, these reflections on their own history were understood as meaningful for the topic under interest. During the interviews, a SO chosen by the participant was allowed to be present. Although it was known that this could possibly affect participants' answers, the decision was made based on an ethical stance.

Credibility also includes the viewpoint of truth (Lincoln & Guba 1985, Holloway & Wheeler 2010, Polit & Beck 2017). Here, truth is understood as truth told by the participants (Holloway & Wheeler 2010) and as the researcher's truth for the data (Glaser 1992, Holloway & Wheeler 2010, Polit & Beck 2017). The participants were requested to answer the questions based on their experiences. In interviews, social desirability bias is possible (Bergen & Labonté 2020); this was minimized by conducting the interviews in a private room and by reminding the participants that the researcher is not part of the ward staff and of the confidentiality of the interviews. The descriptions of the participants' experiences were considered as truth about the world as they see it (Holloway & Wheeler 2010). This was maximized by minimizing the time from stroke to the interview by conducting the interviews while the participants were still in hospital care. In the data analysis, the researcher kept an open mind towards the data and avoided preunderstandings of the topic (see Glaser 1992). However, the researcher has a history of working in a neurosurgical ward, which may have subconsciously impacted her understanding and interpretation of the topic and the data.

Transferability refers to how clearly the context, participants, and collection and analysis of data are described (Lincoln & Guba 1985, Graneheim & Lundman 2004). This enables transferring the results to similar situations or participants (Lincoln & Guba 1985, Polit & Beck 2017). In this study, the context and the participants are described as clearly as possible while at the same time protecting the identity of the participants. The ward of the study is described in chapter 5.1 and in Paper I, without revealing the hospital in question. However, as culture varies between different locations (Sadegi et al. 2022) affecting the transferability of the results (Graneheim & Lundman 2004), the location of the study, western Finland, was stated. The description of the inclusion and exclusion criteria (chapter 5.1 & Paper I) set the frames for the participants; furthermore, the demographic characteristics of the participants are described in detail but so that it is not possible to recognize individual participants. However, the participants comprised 16 IwS and transferring the results should therefore be conducted with caution.

Dependability refers to the consistence and accuracy of the results (Holloway & Wheeler 2010). Inconsistency in the data collection may be due to long data collection time or asking different questions from study participants (Graneheim & Lundman 2004). In this study, data collection was conducted during a relatively short time period. Furthermore, the semi-structured interviews were conducted by one researcher following an interview guide. This ensured that the same questions were asked of all participants, but it also enabled detailed questions, which was considered important for the grounded theory approach. Grounded theory is a complex methodology (Tie et al. 2019), especially for a novice researcher, and the researcher carefully became familiar with the literature beforehand. The analysis was conducted carefully, with an open mind. Although the analysis is described as a process (Paper I), the different phases were conducted partly simultaneously, and the researcher made checks to the previous phases whenever needed (Glaser & Strauss 1967). The interpretation of the data was conducted by one researcher, which may be a limitation of the study. However, throughout the process, the analysis was discussed with the research team.

The study grounded on the lived experiences of IwS and was conducted diligently according to method, which strengthens the validity of the study. However, the interviewed IwS were in rather good condition, which limits the transferability of the results to patients with more severe stroke.

Validity related to the scoping review

Second, scoping review was selected as the type of review (Paper II), and the review process was conducted systematically following the steps of this review type (Arksey & O'Malley 2005, Levac et al. 2010). The literature search was conducted in five electronical databases including CINAHL, Cochrane Library, Philosopher's Index, PsycINFO and PubMed/Medline. The databases were selected to find as many eligible studies as possible relevant for a review in nursing science (Subirana et al. 2005) and in ethics. The free search terms used were similar in every database, and appropriate cuts and subject headings were used, modified for the requirements of each database. The technical appropriateness of the search phrases was checked by an information specialist. General words concerning ethics were included in the search phrases (see Paper II). Therefore, some relevant literature may have been excluded from the results. However, this was a conscious decision as selecting specific words, such as ethical principles, would have resulted in the question of which specific words should be included or excluded. The study selection process was conducted independently by two researchers, strengthening the validity of the review.

The interpretation of the data was based on one researcher’s understanding, which may be a limitation of this review. However, the content analysis (Graneheim & Lundman 2004) was conducted carefully, and the analysis process and the study results were discussed thoroughly in the research team. Quality assessment for the selected articles was not conducted, which may be considered as a limitation for a literature review but is in line with the selected review type (Arksey & O'Malley 2005, Grant & Booth 2009, Levac et al. 2010). In addition, publication language was limited in English.

In this summary, the scoping review was partly updated with the focus deepened on the dimensions of the ethical pathway. Furthermore, the viewpoint of ethical issues was limited to IwS. Here, the selection process was conducted by one researcher.

Validity and reliability related to the cross-sectional and follow-up studies

Third, a cross-sectional study (Paper III) and fourth, a follow-up study (Paper IV) were conducted. In both of them, the data were collected with the EPIS instrument from IwS. Therefore, the validity and reliability are discussed together, first related to the EPIS instrument and second, related to the strengths and limitations of the studies. Validity refers to whether an instrument measures what it is intended to measure, while reliability refers to repeatability of an instrument (Jacobson 1997, DeVellis 2017).

The EPIS instrument was developed for the study (chapter 5.2) as no relevant instruments to measure the topic under interest were found. To enhance the content validity of the instrument, the items were carefully generated based on results (Jacobson 1997) of the grounded theory study and the scoping review, and literature (Burgoon 1982, Leino-Kilpi et al. 2001, Scott et al. 2003b, Jacobson 2009). This requires a mention that the literature in the scoping review was scarce. Although the literature search was conducted carefully and in multiple databases, it is possible that not all relevant literature was caught. This may have caused bias in the results of the scoping review and may have further biased the instrument development.

First, the instrument was evaluated by fifteen individuals, both experts in nursing ethics and professionals in health care. To evaluate content validity (Jacobson 1997, DeVellis 2017) and feasibility (Jacobson 1997) of the instrument, they were asked to evaluate the content and logic of the instrument. Based on their statements, clarifications were made to the items and to the instructions of the instrument. Second, the instrument was assessed by twelve IwS. To gather IwS with various post-stroke times, they were recruited from both a neurological inpatient ward and a neurological rehabilitation ward. Content validity (Jacobson 1997, DeVellis 2017) and feasibility (Jacobson 1997) of the instrument were under assessment as the IwS were asked to assess the relevance of the items and the clarity of the instructions and the instrument. Based on their assessment, one item and the instructions and the layout of the instrument were clarified.

The internal consistency of the EPIS instrument was evaluated in the cross-sectional study (Paper III). The item-total correlations were 0.296–0.868 for all but one item, which is in line with the suggested > 0.3 (DeVon et al. 2007). The Cronbach alpha values were 0.848–0.929, which is in line with the suggested > 0.7 (Nunnally & Bernstein 1994). This preliminary testing of the instrument suggests that the instrument is suitable for evaluating the perceived realization of values and the life situational factors in post-stroke time. However, it is clear that more testing and evaluation is needed.

In both the cross-sectional study and the follow-up study, in spite of the efforts made, the sample sizes were rather small, which limits the generalizability of the results. In the cross-sectional study, a leaflet with a link to participate in the study was included in the association's electronic newsletter sent by email to the members and employees of the association. It was also published on the association's social media site. In the follow-up study, regular contact was kept with the contact persons and they were reminded of the recruitment. It seems that although their number is not small, IwS are hard to reach as research participants. Therefore, to achieve larger sample sizes, recruitment of patients for research requires more effective ways or more extensive resources, such as salaried study nurses.

In the follow-up study, there is a risk for bias of the study participants as individuals willing to commit to a study for the long term may differ from the target group (Grove et al. 2013). Furthermore, in both the cross-sectional study and the follow-up study, the participating IwS were in good condition, either because of having had rather mild stroke (Paper III & IV) or because of the possible progress achieved in the rehabilitation during the post-stroke time (Paper III). Thus, it warrants mention that they do not represent IwS with all stroke severities and limits the generalizability of the results.

Validity of the theoretical construction of the ethical pathway

The theoretical construction of the ethical pathway was conducted as a process. In the process, each step (see chapter 5) guided the next one. To strengthen the theoretical construction of the ethical pathway, minor revisions or checks were made to previous steps when needed. The theoretical construction of the ethical pathway consists of the concept of the ethical pathway and the life situational factors, and the association between these. As changes in the individual's health status may change the perceived realization of values, the health status is also represented in the theoretical construction of the ethical pathway. By making the ethical pathway visible, the ultimate goal of this study was to support the development and realization of ethically high-level nursing care. Therefore, the theoretical construction is evaluated from the perspective of the nursing metaparadigm including the individual, health, environment, and nursing.

The theoretical construction of the ethical pathway was conducted from **individuals'** viewpoint. This guided the data collection in different steps of the study, and all the empirical data were collected from IwS themselves. The dimensions of the ethical pathway were pre-defined for IwS, but the realization of the dimensions was considered as perceived by IwS. Individuals' viewpoint was related to the understanding of **health**. Although the recruitment focused on individuals with a clinical diagnosis of stroke, in the study this health problem was considered from individuals' viewpoint and as they perceived it. In the life situational factor of symptoms diminishing functioning, the focus was not on whether such symptoms exist, but to what extent the individual perceives them as diminishing functioning. Furthermore, health and health problems were considered as a natural part of individuals' life span and therefore, the study was not limited to a certain context of care, such as hospital, but instead, had a more extensive view of individuals' life spans. Life situational factors represent the life situation, including the social **environment**, in which individuals perceive the values as being realized. Environment is also included in the dimensions of the ethical pathway. This is most evident in the case of privacy, including the views of both social and physical environment. **Nursing** acts are not directly included in the theoretical construction of the ethical pathway. However, the ethical pathway includes three central values in nursing named as the dimensions of the ethical pathway. The theoretical construct of the ethical pathway may be used to maximize the perceived realization of individuals' values in nursing practice.

The theoretical construction of the ethical pathway was conducted related to the health problem of stroke. Thus, it is not directly transferable to individuals with other health problems.

Table 22. Strengths and limitations of the studies in Papers I-IV.

Paper	Strengths	Limitations
Paper I: Grounded theory	Clear, pre-tested interview guide based on the literature of patients' dignity in hospital care The IwS' experiences were fresh during the interviews which were conducted while the IwS were still in hospital care Quality of the data was strengthened by one researcher conducting all the interviews Rich data represented IwS with various backgrounds Quality of the analysis was strengthened with in-depth discussions with the research team	Challenging methodology for a novice researcher Interpretation of the data was conducted by one researcher
Paper II: Scoping review	Systematically conducted process Comprehensive set of databases for a nursing ethics literature review The selection process was conducted by two researchers Quality of the analysis was strengthened with in-depth discussions with the research team	The search words were limited to general words concerning ethics Language restriction was used Interpretation of the data was conducted by one researcher
Paper III: Cross-sectional study	The structure and the content of the instrument were based on literature Data represented IwS with various backgrounds Analysis was conducted with a statistician	Data were collected with a new instrument Limited sample size
Paper IV: Follow-up study	The structure and the content of the instrument were based on literature Data represented IwS with various backgrounds Analysis was conducted with a statistician	Data were collected with a new instrument Small sample size

7.3 Suggestions for further research

According to the results, the following suggestions for further research are recommended.

The concept of the ethical pathway and the life situational factors

1. The study was conducted in the context of a long-term health problem, but the ethical pathway is not tied to a single health problem. Therefore, the relevance of the concept of the ethical pathway needs to be tested in the contexts of other health problems but also in contexts without a health problem, e.g., in health promotion.
2. The dimensions of the ethical pathway were derived from the scarce literature available. In the future, it is important to study whether the dimensions provide a comprehensive coverage or whether other dimensions should be included. This could be conducted by a study evaluating the importance of the existing and the potential dimensions of the ethical pathway.
3. In terms of the life situational factors, especially symptoms that diminish functioning, it is important to study whether these are relevant and comprehensive in other contexts.

The EPIS instrument

1. The structure of the instrument is based on the concept of the ethical pathway and the life situational factors. In the event of changes to the conceptual base, revision for the instrument is required.
2. The sample sizes in the cross-sectional and follow-up studies were limited for a many-sided, robust evaluation of the psychometrics of the EPIS instrument. Obviously, the instrument requires full psychometric evaluation regarding construct validity and analysis at item level.
3. To enable the international use of the instrument, it needs to be translated to other languages and validated for other cultures.

The empirical ethical pathway evaluation

1. The study provided a new understanding of the realization of the central values in nursing as perceived by individuals with a long-term health problem, i.e., stroke, and possible changes in the realization of values in temporal passage. To broaden the understanding, empirical analysis of the ethical pathway needs to be conducted in various contexts.

2. The participants in this study were individuals with stroke, and despite this life-threatening health problem, they were in rather good condition. In the future, it is important to conduct empirical analysis of the ethical pathway of individuals in more severe condition. This could be conducted, for instance, with the assistance of significant others.
3. Health care users' realization of the ethical pathway could be evaluated as perceived by both health care users and health care professionals, and further, to compare the results. This could provide new understanding for patient-centered care.

The theoretical construction of the ethical pathway

1. The theoretical construction of the ethical pathway requires empirical testing. This enables the possible modification of the theoretical construct, such as including details and expansion of the construct.
2. The study was conducted in the context of a long-term health problem. Therefore, empirical testing needs to be conducted in various contexts.

7.4 Practical implications

Based on the results of the study, practical implications are presented for nursing practice, nursing administration, nursing education and nursing science, and society.

Implications for nursing practice

1. Ethical questions follow a pathway. By understanding the ethical pathway nurses can support the perceived realization of individuals' values during the care pathways.
2. Nurses can support the perceived realization of individuals' values by reflecting on the life situational factors and the health status from individuals' viewpoint. This provides understanding for nurses of the current life situation in which the individuals perceive the values to be realized.

Implications for nursing administration

1. Nurse administrators need tools for quality assurance. The EPIS instrument would be useful in evaluating ethical quality.

2. The needs of specific patient groups regarding ethical questions need to be included in nurses’ further education. It is important that health care organizations enable further ethics education for all nurses.
3. In developing care pathways, it would be important for health care organizations to listen to health care users in ethical questions, i.e., their ethical pathway. This would maximize patient-centered care.

Implications for nursing education and nursing science

1. Ethics education needs to be conducted both on theoretical and practical level and it is important that the needs of specific patient groups are included in ethics education with the perspective of the realization of patients’ values.
2. For nursing students, it is important to understand that besides care pathways, there are ethical pathways as well. This would increase their understanding of holistic care.
3. Applying the new theoretical construct of the ethical pathway and the EPIS instrument to nursing science could strengthen nursing ethics research.

Implications for society

1. There are a large number of individuals living with a long-term health problem. In society, there is a need to discuss their needs and to maximize respectful behavior towards them.
2. Every individual has the right to be treated with human dignity and to perceive the full realization of values, also when living with a long-term health problem. It is important that this guides the decision-making process at all levels of society and in policymaking.

8 Conclusions

This study focused on the realization of values as perceived by IwS and the potential changes in the perceived realization of values in post-stroke time, labeled as the ethical pathway. The ethical pathway was made visible, stating its existence as part of the care pathway. However, the ethical pathway is not tied to the care pathway; it comes before and goes beyond it. Individuals' perceived realization of values is continuous during the life span and potentially changing in temporal passage. The perceived realization of values is individual, and significant life events, such as stroke, are present in the perceived realization of values.

Nurses have a moral duty to respect and support individuals' values. The findings indicate that there are challenges in the realization of dignity and privacy as perceived by IwS, and these challenges continue beyond the stroke care. This requires understanding of the ethical pathway on the part of HCPs and special attention that extends beyond the care they provide in the organization or in a certain unit.

Health care organizations recognize the importance of patient-centered care. However, to provide authentic patient-centered care, there is a need to listen to the service users on the quality of care and the special needs of the service users. This should also include the ethical aspects of the quality and needs. This study gave a voice to a group of individuals who may be considered vulnerable while living with the long-term health problem of stroke and who have special needs for their perceived realization of values.

In summary, this study described new knowledge regarding the realization of values as perceived by IwS. The ethical pathway was made visible, enabling support for the development and realization of ethically high-level nursing care of IwS. In the future, it is important to study the realization of values as perceived by individuals with other long-term health problems.

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Appendices

Appendix 1. Articles included in literature review on the dimensions (dignity, privacy, and autonomy) of the ethical pathway from IwS' viewpoint.

Author, year, country, dimension(s)	**Aim (direct quote)**	**Method, sample, analysis**	**Main findings related to the dimensions**
Alonso et al. 2017, Germany, Autonomy	To analyze ADs in dying stroke patients (AD = Advance directive)	Observation from medical records 143 died IwS Analysis according to criteria and content (type of advance directive; applicability to the circumstances at presentation; specifications referring to medical and therapeutic actions)	Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals' will was known in written form, but the number of written wills, marked in patient records, was low. Common in pre-stroke expressed wills were, that they tend to be expressed in rather general level.
Anåker et al. 2019, Sweden, Privacy	To explore patients' experiences of the physical environment at a newly built stroke unit	Semi-structured individual interviews 16 IwS Content analysis	IwS described health care environment maintaining their privacy in terms of a single room, although it could lead to the sense of loneliness.
Cardol et al. 2002, The Netherlands, Autonomy	To describe the impact of a chronic disabling condition on participation and to identify variables that may explain perceived restrictions in participation	The IPA questionnaire, Sickness Impact Profile, the scales 'mental health' and 'pain' of the Rand-36 126 individuals of which 27 IwS Statistical analysis	IPA instrument address "the personal impact of illness on participation and autonomy and related experience of problems". IPA instrument includes five domains: autonomy indoors, family role, autonomy outdoors, social relations, and work and educational opportunities (the first three are included to the results of this study). The most declined domain was family role (IPA).
Castellucci et al. 2004, USA, Autonomy	To examine the relation between a person's perceived ability to make self-determined choices and the level of depression he or she experiences poststroke	Hertz's Perceived Enactment of Autonomy Scale (PEA), and depression scores as measured by Beck's Depression Inventory (BDI); a guided interview 20 elderly IwS	IwS with facilitated autonomy experienced less depression.

		Statistical analysis; analysis for patterns and themes	
Chen et al. 2017, China, Autonomy	To describe how first-stroke survivors perceive their participation and the problems with such participation in life and to determine the factors associated with perceived participation at three months after hospital discharge	The Chinese version of the IPA questionnaire, Barthel Index, Chinese Stroke Scale, Hospital Anxiety and Depression Scale, Social Support Rating Scale 257 IwS Statistical analysis	IwS perceived maintained indoor autonomy. The most declined domain was autonomy outdoors (IPA). In the domain of autonomy indoors (IPA), activities on daily living was related to less declines in autonomy. In the domain of autonomy outdoors (IPA), activities on daily living was related to less declines in autonomy, while anxiety was related to frequent declines. In the domain of family role (IPA), activities on daily living was related to less declines in autonomy, while anxiety was related to frequent declines.
Chen et al. 2018, China, Autonomy	To describe perceived participation of first-stroke survivors in mainland China, and to determine variables that may correlate with perceived participation 6 months after discharge	The Chinese version of the IPA questionnaire, Barthel Index, Chinese Stroke Scale, Hospital Anxiety and Depression Scale and Social Support Rating Scale 236 IwS Statistical analysis	IwS perceived maintained indoor autonomy. IwS perceived most declines in the domain of autonomy outdoors (IPA). In the domain of autonomy indoors (IPA), better physical functioning and activities on daily living were related to less declines in autonomy. In the domain of autonomy outdoors (IPA), better physical functioning, activities on daily living and monthly income were related to less declines in autonomy, while sequelae of stroke and depression were related to frequent declines. In the domain of family role (IPA), better physical functioning, activities on daily living and knowledge about stroke were related to less declines in autonomy, while time between attack and admission to hospital and sequelae of stroke were related to frequent declines.
Cherney et al. 2020, USA, Autonomy	We focus on the ethical principle of respect for autonomy, which raises issues relevant to patients	Discussion paper	Informed decisions require cognitive competency. For HCPs, evaluating competency was occasionally considered requiring, for instance,

	with RHD who have impaired executive control functions (RHD = right hemisphere damage)		with IwS who had right hemisphere damage, and had verbal skills which masked the incompetency.
De Kort et al. 2017, The Netherlands, Autonomy	We assessed current practices in the decision whether or not to install treatment restrictions in incapacitated patients with severe stroke	Medical records with semi-structured questionnaire 60 IwS Analysed by hand, coding verbatim was not used	Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals' will was known either by close one or in written form. Expressed will to the close one was more common than a written will.
De Vries et al. 2021, The Netherlands, Autonomy	To examine the association of fatigue with long-term participation in aneurysmal subarachnoid haemorrhage survivors	The IPA questionnaire, the Sickness Impact Profile-68, the Community Integration Questionnaire, the Fatigue Severity Scale, the Center for Epidemiologic Studies-Depression scale 59 IwS Statistical analysis	Participation outcomes were worse in the fatigued group than in the non-fatigued group.
D'Souza et al. 2021, Australia, Autonomy	To explore barriers and facilitators to patient communication in an acute and rehabilitation ward setting from the perspectives of hospital staff, volunteers and patients following stroke	Focus groups; interviews 51 acute and rehabilitation doctors, nurses, allied health staff and volunteers; 7 IwS including three with aphasia Qualitative analysis (not specified)	In hospital, there is a power imbalance between patients and HCPs. Patients also perceive that in hospital, they have to do what is expected. These limit patients' environment related freedom.
Engler et al. 2014, Brazil, Privacy	To assess the prevalence of diminished frequency of bowel movements, lumpy or hard stools, intestinal constipation, straining, incomplete evacuation,	Semi-structured interviews 98 IwS Statistical analysis	IwS reported lack of privacy in sensitive situations, such as toileting.

	incontinence (bowel dysfunctions) in patients with brain injury resulting from cerebrovascular accident, either self-reported or reported by their caregivers; to describe the type and frequency of such dysfunctions; and the prevalence of laxative use both before and after stroke		
Fallahpour et al. 2011, Iran, Autonomy	To describe perceived participation and autonomy among a sample of persons with stroke in Iran and to identify different aspects of functioning and contextual factors predicting participation after stroke	the Persian version of the Impact on Participation and Autonomy questionnaire, The Mini-Mental State Examination scale, The Hospital Anxiety and Depression Scale, The Fugl-Meyer Motor Assessment, The Short version of Stroke Impact Scale, Barthel's ADL Index 102 IwS Statistical analysis	IwS perceived maintained indoor autonomy. The most declined domain was reported autonomy outdoors (IPA). In the domains of autonomy indoors, autonomy outdoors and family role (IPA), better physical functioning was related to less declines in autonomy, while depression and anxiety were related to frequent restrictions. In the domain of family role (IPA), female sex was related to less declines in autonomy.
Frey et al. 2020, The Netherlands, Autonomy	To ethnographically study how these complex decisions are taken in clinical practice [the decision whether or not the patient should receive tube feeding]	Observation and interviews 16 IwS Informed by practice theory -approach	Informed decisions require cognitive competency. Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals' will was known either by close one or in written form.
Govender et al. 2019, South Africa, Autonomy	To explore cerebrovascular accident (CVA) survivors' experiences of community integration	Semi-structured interviews 8 IwS Thematic analysis	Autonomy of IwS was declined by dependency on other people and symptoms diminishing functioning. Declined autonomy sometimes restricted participation in community and lead to

			sense of isolation. Improved autonomy brought joy to IwS.
Kelly et al. 2014, USA, Autonomy	We highlight several timely ethical issues in stroke, including predictive models for stroke outcome; the role of surrogate decisionmakers; variations in practice patterns for stroke patients; and the challenges of using mortality as a quality marker in stroke	Literature review (data search not described)	Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals’ will was known either by close one or in written form. Common in pre-stroke expressed wills were, that they tend to be expressed in rather general lewel, and thus challenging to apply to a specific situation.
Kitson et al. 2013, The United Kingdom, Dignity Privacy Autonomy	To test these assumptions we decided to use the Fundamentals of Care Template and take a sample of interviews from people who had had a stroke and explore what they said about their experiences of fundamentals of care, if anything (“-- we do not have a clear theoretical or conceptual understanding of how we deliver fundamentals of care within the healthcare setting. Also, we have not explored the experience of fundamentals of care from the patient’s perspective in any systematic way.”)	A secondary analysis of narrative interviews 15 IwS Thematic analysis	Health care environment was described a place where IwS’ dignity was in danger to be lost, for instance, for being dependent for other people. Health care environment was described a place where IwS’ privacy was maintained, but privacy was sometimes additionally seen as a threat to the sense of loneliness. IwS’ autonomy was described maintained, but restrictions and routines of the care facility were seen declining autonomy.
Klinke et al. 2014, Iceland, Dignity	To explore and describe the experience of eating and eating-related difficulties in	In-depth interviews 7 IwS	IwS with eating difficulties maintained their dignity in social eating situations by putting extra effort for socially acceptable eating behaviour by, for instance, avoiding aids or certain foods.

	stroke survivors living at home	Colaizzi's approach	Difficulties in eating could also lead IwS avoiding social situations including food or drink.
Li et al. 2020, China, Autonomy	To investigate the current status of participation and explore the characteristics of individuals with different levels of participation among stroke survivors in mainland China	The Chinese version of the Impact on Participation and Autonomy Questionnaire, Modified Rankin Scale, the Perceived Social Support Scale, the Medical Coping Modes Questionnaire, the Herth Hope Scale 517 IwS Statistical analysis	The most declined domain was autonomy outdoors (IPA).
Li et al. 2021, China, Autonomy	To explore the level and associated factors of perceived participation and autonomy among stroke survivors in Shanghai, China	The Chinese version of the Impact on Participation and Autonomy Questionnaire, modified Rankin Scale, Self-efficacy for Managing Chronic Disease six-item Scale, Medical Coping Modes Questionnaire, Multidimensional Scale of Perceived Social Support 431 IwS Statistical analysis	The most declined domain was family role (IPA). Social support, knowledge of stroke and resignation were related to less declines in autonomy outdoors -domain (IPA). Physical functioning and self-efficacy were related to less declines in the domains of autonomy indoors and family role (IPA).
Logan et al. 2004, The United Kingdom, Autonomy	This study explored attitudes and barriers to the use of transport with the aim of informing rehabilitation	Semi-structured interviews 24 IwS Constant-comparative methodology	Transportation was vital for community-dwelling IwS' autonomy, either by self or assisted, but could also decline autonomy, for instance, when IwS lacked self-confidence using transportation or knowledge of transportation possibilities.
Lou et al. 2017, Denmark, Autonomy	To provide a systematic overview of current qualitative systematic reviews and metasyntheses of patients' and informal carers' experiences with	Literature review (a review of reviews) 7 qualitative reviews Thematic coding and analysis	IwS autonomy was described declined. Social support was important to autonomy, although paternalism were perceived as declining autonomy.

	rehabilitation and life after stroke following discharge		
Louw & Keeble 2002, The United Kingdom, Autonomy	To demonstrate common ground between Medical Ethics and Jurisprudence	Short paper	In the case individual was incapable to express own will after stroke, individual’s autonomy could still by maintained, if the individual’s will was known either by close one or in written form.
Lui & MacKenzie 1999, China, Privacy	To identify the rehabilitation needs of Chinese elderly patients following a stroke	Semi-structured interviews 15 IwS Systematic approach	IwS had a psychological need for privacy after being transferred to rehabilitation from acute ward. In the new ward they met new HCPs and fellow patients, and needed to adjust to new care routines.
Luker et al. 2015, Australia/Sweden, Autonomy	To report and synthesize the perspectives, experiences, and preferences of stroke survivors undertaking inpatient physical rehabilitation through a systematic review of qualitative studies	Systematic review of qualitative studies 32 documents representing 31 separate studies Thematic synthesis	Disempowering staff attitudes, poor communication, and the restrictions and routines of the care facility were declining IwS’ autonomy, while social support from HCPs, communication and good information could facilitate autonomy.
Löfmark et al. 2005, Sweden, Autonomy	To analyze from a gender perspective how elderly women and men responded to treatment and care after stroke in the acute care setting	Semi-structured interviews in the stroke ward and 4 to 6 weeks after 12 IwS Grounded theory	IwS eagered for autonomy and to live their lives as prestroke.
Mangset et al. 2008, Norway, Dignity Autonomy	To identify factors contributing to elderly stroke patients’ satisfaction with rehabilitation following stroke	Semi-structured interviews in a stroke rehabilitation unit and once after hospital discharge 12 IwS Analysis in accordance with an approach described by Malterud	IwS’ dignity was maintained by fulfilling IwS’ basic needs in a respectful manner, and by provinding information based on individual needs, by being acknowledged as individuals. HCPs disrespectful behaviour lead to sense of degraded as a human. IwS’ autonomy was described declined by restrictions and routines of the care facility.

Mayer et al. 2004, Canada, Autonomy	To assess the levels of autonomy and participation in community-dwelling older adults who have suffered a stroke (pilot study)	Baseline: The Impact on Participation and Autonomy Questionnaire, The Functional Autonomy Measurement System, The Centre for Epidemiological Studies Depression Scale; 3 months later: The Impact on Participation and Autonomy Questionnaire 18 IwS Statistical analysis	The most declined domain was reported family role (IPA).
McGehrin et al. 2018, USA, Autonomy	This article discusses some of the challenges of preserving patient autonomy in patients presenting with acute stroke and the advent of a stroke advance directive (Coordinating Options for Acute Stroke Therapy [COAST]) aimed to overcome these obstacles	Discussion paper	Individual's will expressed in written from enabled maintaining autonomy of the individual who was incapable to express own will.
Olofsson et al. 2005, Sweden, Autonomy	To find out about the experiences of stroke patients concerning their falling ill, their stay in hospital, discharge and homecoming	In-depth interviews 9 IwS Analysis according to procedures described by Miles and Huberman	Community-dwelling IwS' autonomy was described facilitated by factors, such as familiar environment, improvement in rehabilitation, social support, and information. While still in hospital care, insecurity was perceived declining IwS' autonomy.
Palstam et al. 2019, Sweden, Autonomy	To evaluate the participation and autonomy of persons with stroke, five years after a stroke, and to explore potential associations between factors and	Baseline: the Impact of Participation and Autonomy-questionnaire; 5-year follow-up: the Impact of Participation and Autonomy-questionnaire, the Stroke Impact Scale 281 IwS	IwS perceived least declines in autonomy indoors -domain (IPA). Older age, severe stroke and depression were related to more frequent declines in the domains of autonomy indoors, autonomy outdoors and family role (IPA). Female sex was related to more frequent declines in family role -domain (IPA).

	perceived restrictions in participation and autonomy	Statistical analysis	
Peoples et al. 2011, Denmark/The Netherlands, Dignity Privacy Autonomy	To obtain the best available knowledge on stroke survivors' experiences of rehabilitation	Systematic review of qualitative studies 12 studies Meta-summary	IwS dignity was facilitated with respect by being acknowledged as individuals and personal values to be taken into account, while negative encounters with HCPs were described as a threat to dignity. IwS' privacy was described lacked. Collaborative power-sharing required active participation and sufficient and individual information.
Persson et al. 2018, Sweden, Autonomy	To investigate the life situation 5 years after a SAH including physical/emotional status, participation and HRQoL (SAH = subarachnoid haemorrhage; HRQoL = health-related quality of life)	The Impact of Participation and Autonomy Questionnaire, EuroQol 5-Dimensions, Stroke Impact Scale, Occupational Gaps Questionnaire 26 IwS Statistical analysis	IwS perceived maintained indoor autonomy. The most declined domain was reported family role (IPA).
Plow et al. 2017, USA, Autonomy	To examine the relationships between stroke impairments and physical activity, sleep, and nutrition	Mixed method: face-to-face focus groups, followed by a one-to-one phone interview (all semi-structured); questionnaires incl. the Godin Leisure-Time Exercise Questionnaire, the Neuro-QOL eight-item short form (version 1), a five-item nutritional survey, the Stroke Impact Scale IwS Thematic analysis; statistical analysis	IwS' autonomy was described both declined and maintained. Fatigue, mobility impairments, and pain were often described declining autonomy.
Pound & Greenwood 2017,	This paper explores the post-stroke experiences of older carers from BME and White	Semi-structured interviews	IwS' dignity was declined by home care HCPs in a situation where professionals kept IwS waiting for

The United Kingdom, Dignity	British populations receiving home care (BME = black and minority ethnic)	50 carers (carer = caring for someone after a stroke access and engage with social care services) Thematic analysis within a phenomenological framework	the care, took personal phone calls during visits, or performed care in inappropriate manner.
Proot et al. 1998, The Netherlands, Autonomy	This article presents a concept analysis of autonomy in relation to the rehabilitation of stroke patients	Concept analysis 31 articles	Biomedical ethics provides three concept of autonomy related to the rehabilitation of IwS: self-governance, self-realization and actual autonomy. IwS' autonomy described as changing in post-stroke time.
Proot et al. 2000a, The Netherlands, Autonomy	To determine which facilitating or constraining factors regarding patient autonomy during rehabilitation are identified by stroke patients in rehabilitation wards in nursing homes	Interviews with an open-ended interview guide 17 IwS Grounded theory	IwS' autonomy was described changing in post-stroke time, as IwS' autonomy was described increased compared to the time of admission. However, there were described factors both facilitating and declining IwS' autonomy related to IwS and environment. IwS-related factors were conditions of patient and strategies of IwS. Environmental factors included nursing home, strategies of health professionals and strategies of family.
Proot et al. 2000b, The Netherlands, Autonomy	To pinpoint which dimensions of autonomy are identified by stroke patients rehabilitating in nursing homes and to determine which factors, in the stroke patients' perception, facilitate or constrain patient autonomy on admission	Interviews with an open-ended interview guide 21 IwS Grounded theory	IwS' autonomy was described changing in post-stroke time, while IwS' autonomy was described declined compared to pre-stroke time. However, there were described factors both facilitating and declining IwS' autonomy related to IwS and environment. IwS-related factors were conditions of patient and strategies of IwS. Environmental factors included nursing home, strategies of health professionals and strategies of family.
Proot et al. 2000c, The Netherlands, Autonomy	To determine which facilitating or constraining factors regarding patient autonomy at discharge are	Interviews with an open-ended interview guide	IwS' autonomy was described changing in post-stroke time, as IwS' autonomy was increased related to the time during rehabilitation. However, there were described factors both facilitating and

	identified by stroke patients in nursing homes	20 IwS Grounded theory	declining IwS' autonomy related to IwS and environment. IwS-related factors were conditions of patient and strategies of IwS. Environmental factors included nursing home, strategies of health professionals and strategies of family.
Proot et al. 2002, The Netherlands, Autonomy	To pinpoint which dimensions of autonomy are identified by care providers, and to determine which factors, in their opinion, influence patient autonomy during the rehabilitative process	Interviews with an open-ended interview schedule 27 care providers, incl. 6 (registered) nurses, 7 nursing aides, 3 doctors, 3 physiotherapists, 3 occupational therapists, 3 speech therapists, 2 social workers Grounded theory	HCPs described IwS' autonomy as changing in post-stroke time. There were described factors both facilitating and declining IwS' autonomy related to IwS and environment. IwS-related factors were conditions of patient and strategies of IwS. Environmental factors included nursing home, strategies of health professionals and strategies of family.
Proot et al. 2007, The Netherlands, Autonomy	To explore stroke patients' experiences of health professionals' approach towards autonomy in a longitudinal way	Interviews with an open-ended interview guide Admission 21 IwS, during rehabilitation 17 IwS, discharge 20 IwS Grounded theory	IwS' autonomy was described changing in post-stroke time (more detailed: Proot et al. 2000a, 2000b, 2000c).
Rejnö & Berg 2019, Sweden, Autonomy	To illuminate the communication and its meaning in unexpected sudden death with stroke as example, as experienced by stroke team members and next of kin	Secondary analysis of studies A-D A: individual interviews; 10 registered nurses B: focus group interviews; 19 stroke team members, incl. 4 physicians, 9 registered nurses, 6 enrolled nurses C: individual interviews, 15 stroke team members, incl. 4 physicians, 7 registered nurses, 4 enrolled nurses	Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals' will was known by close one. Precondition for close ones as a source of individuals' will were them knowing each other well and further, the will in question, was expressed by the individual to the close one.

		D: individual interviews; 12 next of kin of 8 patients who died due to acute stroke during hospital stay Qualitative content analysis	
Rhodes et al. 2003, The United Kingdom, Dignity Privacy	(i) To explore, from the perspectives of consumers themselves, admission processes (for hospital and for the acute stroke unit) following stroke (ii) To understand, by way of exploring real life episodes of consumers, the experience and perceptions of being admitted to, and nursed within, a MSE (MSE = mixed sex environment)	Semi-structured qualitative interviews 30 IwS Content analysis	IwS' dignity and privacy were facilitated in a mixed sex environment by closing bed-side curtains in care situations.
Sandman et al. 2008, Sweden, Autonomy	To analyse and discuss the ethically problematic conflict raised by patients with stroke who refuse nutritional treatment	Discussion paper Literature, clinical cases, research experience Normative analysis	IwS autonomy and support for autonomy were perceived important in health care, as IwS were the ones who live with the consequenses of the decisions. For autonomous decisions, IwS needed to have competency, which was sometimes restricted for cognitive deficits.
Skoglund et al. 2019, Sweden, Autonomy	To investigate different aspects of self-perceived impact of stroke 1 and 5 years after stroke onset, with a focus on self-perceived participation	1-year post-stroke and 5 years post-stroke: the Impact on Participation and Autonomy Questionnaire, the Stroke Impact Scale, the European Quality of Life 5 dimensions 45 IwS Statistical analysis	IwS with impaired upper-extremity function at post-stroke day three, reported autonomy indoor - related declines getting worse in post-stroke time (IPA).

Smith et al. 2018, The United Kingdom, Autonomy	To investigate the experiences and ongoing needs of community-dwelling stroke survivors with a dysfunctional upper limb and their caregivers	Semi-structured interviews 6 participants, incl. 3 IwS, 3 caregivers Analysis using an interpretative phenomenological approach	IwS' autonomy was described declined by dependency on other people and physical impairments. Declined autonomy was described being associated with IwS' psychological burden.
Spokoyny et al. 2015, USA, Autonomy	This article presents a means to improve the consent process itself, as well as the level of understanding that patients and surrogates might have regarding possible treatment options	Discussion paper	Autonomy of the individuals, incapable to express own will, was able to be maintained if the individuals' will was known by written will.
Sundin et al. 2001, Sweden, Dignity	To illuminate the meaning of the care providers' lived experiences of the care relationship with patients with stroke and aphasia	Narrative interviews 5 care providers, incl. 2 registered nurses, 3 enrolled nurses Analysis using a phenomenological-hermeneutic approach	HCPs respected IwS' human dignity. The HCPs described facilitating IwS' dignity by acknowledging them as individuals and by implementing rehabilitation tailored to IwS' individual needs and desires.
Suttiwong at al. 2018, Thailand, Autonomy	To describe perceived participation among persons with first stroke and to identify the predictors based on the International Classification of Functioning, Disability and Health (ICF) concept of participation after stroke	the Impact on Participation and Autonomy Questionnaire, Personal Resource Questionnaire, Hospital Anxiety and Depression Scale, personal history 121 IwS Statistical analysis	IwS reported maintained indoor autonomy (IPA). The most declined domain was family role (IPA). In the domain of autonomy indoors (IPA), social support and functional ability were related to less declines in autonomy, while depression was related to frequent declines. In the domain of autonomy outdoors (IPA), social support, functional ability and balance performance were related to less declines in autonomy, while secondary health problems were related to frequent declines. In the domain of family role (IPA), social support was related to less declines in autonomy, while depression was related to frequent declines.

Takashima et al. 2017, Japan, Autonomy	To examine how post-stroke users of a long-term elderly care facility had experienced changes in movement resulting from hemiplegia	Interviews (2-3 per participant) 18 IwS Thematic analysis	IwS' autonomy was described declined by symptoms diminishing functioning and dependency on other people. Declined autonomy was related to sorrow, shame, and vexation.
Tholin & Forsberg 2014, Sweden, Autonomy	To investigate how people with stroke experienced their care, rehabilitation, support, and participation from hospital to community care	Qualitative interviews 11 IwS Qualitative content analysis	IwS' autonomy was described declined.
Tomkins et al. 2013, Australia, Dignity	To explore the factors influencing the satisfaction and dissatisfaction of people with aphasia with regards to their health care	Semi-structured in-depth interviews 50 IwS Qualitative content analysis	For dignity of the individuals with aphasia, it was important to be perceived as competent persons despite of their communication disorder.
Törnbom et al. 2018, Sweden, Autonomy	To describe self-assessed participation and autonomy and to explore factors associated with the same at 1 year post stroke	the Impact on Participation and Autonomy Questionnaire 79 IwS Statistical analysis	IwS perceived least declines in autonomy indoors. Less global disability at discharge was associated more declines of autonomy at one year post-stroke.
Westerlind et al. 2020, Sweden, Autonomy	To investigate whether returning to work would predict self-perceived participation and autonomy in everyday life after a stroke, from a long-term perspective	Baseline: the Charlson comorbidity index, the National Institutes of Health Stroke Scale, the Glasgow Coma Scale, the modified Rankin Scale; 5-year follow-up: the Impact on Participation and Autonomy Questionnaire 109 IwS Statistical analysis	Being in working life was related to less declines in the domains of autonomy indoors, autonomy outdoors and family role (IPA).

Worrall et al. 2011, Australia, Dignity	To describe the goals of people with aphasia and to code the goals according to the ICF (ICF = the International Classification of Functioning, Disability and Health)	Semi-structured in-depth interviews 50 IwS Qualitative content analysis	A communication disorders could result IwS feel disempowerment, and for dignity of the individuals with aphasia, it was important to be perceived as competent persons despite of their communication disorder.

Appendix 2. Articles included in literature review on the use of the concept of the ethical pathway in the scientific literature.

Author, year, country	**Aim (direct quote)**	**Method, sample, analysis**	**The use of the concept of the ethical pathway**
Savulescu & Singer 2019, The United Kingdom	-	Editorial	The concept of the ethical pathway was used only in the title but not defined or used later in the reference.
Sendjaya et al. 2020, Indonesia	To examine psychological ethical climate as a key mediator between servant leadership and citizenship behavior	Servant Leadership Behavior Scale short-form, Ethical Climate Questionnaire, OCB measure 123 leader–follower dyads Statistical analysis	The ethical pathway was used to describe the underlying influence process. The process was included in the purpose of the study which was to explain how servant leadership affects to organisational citisenship behavior with psychological ethical climate as a key mediator.

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