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ORIGINAL ARTICLE

The ethical pathway of individuals with stroke—A follow-up study

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Abstract

Aim: To analyse the ethical pathway as perceived by individuals with stroke (IwS) in the first three post-stroke months. In the novel concept of ethical pathway, dignity, privacy, and autonomy are considered as dimensions of the ethical pathway while the pathway illustrates their potential change in the post-stroke time. Furthermore, the focus of interest was on whether the perceived realisation of values is associated with the life situational factors of symptoms diminishing functioning, social environment, and self-empowerment.

Methodological Design and Justification: A follow-up study with a descriptive correlational design was used to capture the changes in the perceived realisation of values.

Ethical Issues and Approval: The study followed the ethical principles of research involving human participants. The study was approved by the ethics committee of the university and one of the university hospitals following national standards. Permission to conduct the study was obtained from the university hospitals.

Research Methods and Instrument: Data were collected from IwS after the onset of stroke and 3 months post-stroke with the Ethical Pathway of Individuals with Stroke instrument and background questions and were analysed statistically.

Results: Thirty-six participants completed the questionnaire at both measurement points. Wide variety in the ethical pathway was detected. IwS' perceived dignity decreased and autonomy increased. Privacy did not change significantly. Of the life situational factors, IwS perceived less symptoms diminishing functioning and stronger self-empowerment while social environment was perceived as rather stable. Only one association was detected between the dimensions of the ethical pathway and life situational factors: autonomy had a low negative correlation with social environment of health care professionals.

Conclusions and Study Limitations: The results provide preliminary evidence of the dynamic nature of the ethical pathway. The ethical pathway was incompletely realised for most participants and requires special attention and

improvement in health care. The sample size is small and the results are therefore not generalisable.

KEYWORDS

autonomy, dignity, ethical pathway, ethics, follow-up study, privacy, recovery, stroke, values

INTRODUCTION

Stroke is a life-threatening disease, often with a sudden onset [1]. The complex care of individuals with stroke (IwS) follows care pathways which are generally structured but also individual, based on the severity of stroke and the recovery trajectory [2, 3]. During the acute stage followed by recovery, IwS face diverse changes in health [4] and life [5] compared with their pre-stroke life, and the perceived realisation of values may also change (e.g. 6–8). The literature presents some evidence of the dynamic nature of the perceived realisation in post-stroke time [9]; however, the research evidence is scarce [6]. In this study, the potential changes in the perceived realisation of the values from IwS' viewpoint were analysed using the novel concept 'ethical pathway'. In the concept, the values of dignity, privacy, and autonomy are dimensions of the ethical pathway, the perceived realisation of which IwS have described as challenging (e.g. 6, 10). The pathway illustrates their potential change in post-stroke time. The stroke context is concerned as life situational factors potentially associated with the perceived realisation of values [6, 11]. The factors include symptoms diminishing functioning, social environment, and self-empowerment.

BACKGROUND

Worldwide, 15 million individuals experience stroke annually [12]. It is the second leading cause of death and one of the leading causes of disability [13]. A third of IwS are permanently disabled [12] and the majority of community-dwelling IwS diagnosed with mild-to-moderate stroke have some stroke-related health problems at 3 months post-stroke. The possible long-term impacts of stroke include a decline in the individual's cognition, physical functioning, communication skills, and mood [14]. Stroke may also impact other areas, such as IwS' self-concept, health perception, role identity, and social relationships [15]. The various impacts have been shown to be associated with the perceived realisation of IwS' dignity, privacy, and autonomy (e.g. 6–8, 10). These three are central values and patients' rights in nursing [16, 17] and in human life [18]. In this study, these values are considered as dimensions of the ethical pathway.

IwS have described the perceived realisation of *dignity* as challenging [10], mainly identified in relation to dependency and loss of control in the hospital setting. The physical and cognitive impairments often decrease post-stroke functioning [10, 11, 19], and thus, IwS may be dependent on other people in activities of daily living, such as dressing [10, 19], mobility, eating, and personal hygiene [10]. This dependency and sensitive care situations may cause IwS to feel shame [11] and humiliation and may thus be devastating to their dignity [10, 11]. Therefore, IwS long for special attention from health professionals in sensitive care situations to preserve their dignity [20]. A sense of control is central to IwS' dignity [11]. Post-stroke bodily uncertainty may cause a sense of lost control [11, 21] and be a threat to IwS' dignity [11]. Some of the impacts of stroke, such as an uncooperative body [22] or eating difficulties [23], may be even too overwhelming for IwS, leading them to withdraw from public life [22] or social situations [23].

IwS have described the perceived realisation of *privacy* as both preserved [20] and lacking [24], mainly identified from the perspective of physical privacy in a hospital setting. A single room in a hospital ward may be considered as preserving privacy [25], but with health professionals' awareness of the risks for individuals' privacy, IwS' privacy may also be preserved in hospital rooms with multiple patients including mixed sex bays [20]. Still, IwS may value single rooms highly as they enable the absence of other patients and prevent exposure to disturbing sounds. A single room also provides a space of one's own which IwS have described as homelike. However, a single room may also mean loneliness and lack of people to talk to [25].

IwS have described the perceived realisation of *autonomy* as both preserved and challenged, mainly identified from the perspectives of functioning, social environment, and lost control in rehabilitation and community settings. In rehabilitation, IwS autonomy has been identified to be improved by several factors, such as improved abilities and increased self-confidence, support and information provided by health professionals [26, 27], and emotional support from close ones [27]. Factors decreasing IwS autonomy seem to be related to the need of assistance in self-care [26], lack of control over treatment [24], insecurity (e.g. fear of falling), lack of information [26, 27], unreasonable

paternalism [27], and care routines of the care facility [24, 27]. Community-dwelling IwS seem to have rather high perceived autonomy related to participation in indoor activities, but low perceived autonomy in outdoor activities [28, 29]. Furthermore, their autonomy seems to be decreased, or even lacking, related to the need of help from others and limited participation in community [30]. In relation to social relationships [28, 30] and family roles [28, 29] IwS have reported both high and low perceived autonomy.

Perceived realisation of the dimensions of the ethical pathway shows changes in the post-stroke period including both improvement and decline according to the previous literature. However, the literature does not provide a comprehensive understanding of the changes during post-stroke time. In this study, these were analysed using the concept 'ethical pathway'. This study is a part of a larger study in which the concept was developed and tested [31, 32]. The concept is composed of two elements, potential change in temporal passage and the dimensions of the ethical pathway. The dimensions were predetermined based on previous literature [6, 11], instead of studying the content of individuals' value basis, and they represent three central values in nursing. Dignity was defined in terms of the understanding of human dignity and social dignity [33]. Privacy was defined as physical privacy, social privacy, psychological privacy, and informational privacy [34, 35]. Autonomy was defined as information received and decision-making by an individual [36]. Autonomy is often related to an individual's competence to make autonomous choice (e.g. 17). In this study, the focus is on the realisation of autonomy as perceived by individuals themselves, not whether they are capable for autonomous choices and therefore competence is not included in the definition. The literature presents life situational factors which associate with perceived realisation of the dimensions of the ethical pathway, including symptoms diminishing functioning, social environment, and self-empowerment. These are not included to the concept 'ethical pathway', but as they represent the stroke context, their association with the ethical pathway is under the interest in this study.

Stroke may cause ethically challenging changes in the lives of IwS during the recovery period (e.g. 6, 8). In this study, the focus is on the first three post-stroke months and the potential changes in the dimensions of the ethical pathway are presented as courses that increase, decrease, or remain stable. Via the courses and the possible associations with the life situational factors, the aim was to analyse the ethical pathway of IwS. The purpose of the new knowledge produced in the study is to support the development of ethically high-level care and care pathways of IwS.

The research questions were:

1. What are the courses of the ethical pathway of IwS as indicated based on the perceived realisation of the dimensions of the ethical pathway?
2. What are the associations between the perceived realisation of the dimensions of the ethical pathway and the life situational factors?

MATERIALS AND METHODS

Study design and data collection

The follow-up study employed a descriptive correlational study design. The data were collected from IwS at two measurement points: after the onset of stroke (baseline) and 3 months post-stroke (follow-up). The inclusion criteria for the participants were (a) diagnosed first-time stroke, (b) orientated, (c) able to give informed consent, (d) adults aged 18 years and above, and (e) Finnish-speaking. Exclusion criteria were patients with (a) stroke caused by trauma, (b) having anosognosia, and (c) having aphasia.

The participants were recruited from all five university hospitals, from altogether nine neurological wards, in Finland between November 2019 and June 2020. A contact person in each ward evaluated IwS eligibility for participation based on inclusion and exclusion criteria. The contact persons informed suitable IwS orally and in written form of the possibility to participate in the study. To those interested in participation, the contact person gave an envelope including a cover letter, a questionnaire, a written informed consent form and a prepaid return envelope. The participants were free to fill the questionnaire either during their hospital care period or after the discharge.

The follow-up questionnaires, with a prepaid return envelope, were mailed to the participants to the address provided by the participants in the baseline survey. The mailing took place at the time of 3 months after the stroke incidence. They were asked to return the completed questionnaires within 2 weeks. One remainder was sent.

Questionnaire

Data were collected with the Ethical Pathway of Individuals with Stroke (EPIS) instrument developed for the study [32]. The EPIS instrument evaluates the realisation of values and life situational factors in post-stroke time as perceived by IwS. The instrument has two parts including altogether 60 items. The first part, the dimensions of the ethical pathway, consists of three scales evaluating dignity (10 items, 5 negatively worded), privacy (with subscales of physical

privacy, social privacy, psychological privacy, and informational privacy; altogether 10 items, 4 negatively worded), and autonomy (with subscales of information received and decision-making by the participant; altogether 10 items, none negatively worded). The second part, the life situational factors, consists of three scales evaluating symptoms diminishing functioning (17 negatively worded items), social environment (with subscales of significant others and health professionals; altogether 8 items, none negatively worded), and self-empowerment (5 items, none negatively worded).

The instrument is self-reported in paper and pencil format. The items are evaluated on a VAS scale from 0 (=does not describe my perception at all) to 100 (=describes my perception exactly). Being aware of the challenges of using both positively and negatively worded items [37], this was done consciously to capture exactly what each item aimed at (e.g. 'I have been underrated as a human') and used only when evaluated that reverse item would have not succeed in that. Because of this, in the scale of symptoms diminishing functioning, all of the items were negatively worded as they described symptoms instead of none-existence of them. To calculate the sum variables, the scores of the negatively worded items were turned, resulting in a higher score of each item indicating a more preferable result.

In the development of the EPIS instrument, previous literature was used in identifying [6, 11] and operationalising [33, 35, 36] the dimensions of the ethical pathway and the life situational factors. Fifteen ethics researchers assessed the content and logic of the instrument, leading to specifications made to the instructions and items. Twelve IwS, including both those cared for in acute care and in a rehabilitation facility, evaluated the clarity of the instructions and the instrument, and the relevance of the items leading to clarification of one item, the instructions, and the layout of the questionnaire.

The EPIS instrument was used at both measurement points. Additionally, the baseline questionnaire included several background variables related to participants' sociodemographic factors, stroke and health status, and admission to care. In the follow-up questionnaire, the care pathway, appearance of new health problems and remarkable changes in life were inquired about. To capture the care pathway, the participants completed a calendar, marking each care period or visit to a health professional related to stroke during the follow-up period, and returned it to the researchers with the questionnaire.

Statistical analysis

The Statistical Package for the Social Sciences (SPSS) version 26.0.0.0 and R version 4.0.0 were used for the data analysis. The analysis was conducted on sum variable level and on item level. The sample ($n=36$) and the sum variables, consisting of the items in scales and sub-scales, respectively, were described using frequencies, mean, median, range, and standard deviation. To describe the change in the sum variables, median [95% CI] and range were calculated for the change in the scores of the sum variables. Because of the small sample, statistical significance was calculated with Wilcoxon signed rank test only for the main variables of the dimensions of the ethical pathway and for the same reason, data were not imputed in terms of missing responses. Spearman's rank correlation coefficient was used to evaluate the association between the changes (baseline—3 months poststroke) of the dimensions of the ethical pathway and the life situational factors. Correlations were considered as low (0.3–0.5), medium (0.5–0.7), high (0.7–0.9), or very high (>0.9) [38]. Frequencies were calculated in terms of for how many participants the dimensions of the ethical pathway increased, decreased, or remained stable. In the item-level examinations, frequencies were calculated in terms of for how many participants each item increased, decreased, or remained stable.

Ethical considerations

According to national and hospital standards, the Ethics Committee of the University (Statement 53/2017) and one of the university hospitals (hospital/2513/2019) approved the study. Permission to conduct the research was obtained from the five university hospitals according to each hospitals' protocol. Ethical principles of research were followed throughout the study [39, 40]. Participants gave written informed consent, and in the baseline questionnaire, their name and contact details for the follow-up questionnaires. All the data have been handled carefully throughout the research process with only the research team having the access to the data.

RESULTS

Participants

Forty-five IwS were recruited to the study and 40 of them returned the completed questionnaires with the signed informed consent form at the first measurement point. Thirty-six participants completed questionnaires at both measurement points and their answers were included to the analysis. The participant groups at both baseline and follow-up measurement points were rather similar. The most common type of stroke reported was cerebral infarction (94%), but the hemisphere of stroke varied (Table 1) Twenty-three participants had some additional

TABLE 1 Characteristics of the participants and participants lost to follow-up.

Demographic characteristics	Participants at baseline ($n=40$) n (%)	Participants at both times ($n=36$) n (%)	Participants lost to follow-up ($n=4$) n
Age			
Median, years	66.5	66.5	
Range, years	23–84	23–81	
Gender	$n=40$	$n=36$	
Female	16 (40)	15 (42)	1
Male	24 (60)	21 (58)	3
Other/I do not want to tell	0 (0)	0 (0)	0
Education	$n=39$	$n=36$	
Primary education	6 (15)	6 (17)	0
Upper secondary level	15 (39)	15 (42)	0
Bachelor's degree	4 (10)	3 (8)	1
Master's degree/PhD	10 (26)	8 (22)	2
Other	4 (10)	4 (11)	0
Work (before stroke)	$n=40$	$n=36$	
In working life	14 (35)	12 (33)	2
Unemployed	0 (0)	0 (0)	0
Retired	22 (55)	20 (56)	2
Student	1 (3)	1 (3)	0
Other	3 (8)	3 (8)	0
Living (multiple choices allowed)	$n=40$	$n=36$	
Alone	7 (18)	7 (19)	0
Together with spouse/partner	32 (80)	28 (78)	4
Together with child/children	0 (0)	0 (0)	0
Together with someone else	1 (3)	1 (3)	0
Stroke status and care			
Type of stroke (multiple choices allowed)	$n=37$	$n=34$	
Cerebral infarction	35 (95)	32 (94)	3
Intracerebral haemorrhage	2 (5)	2 (6)	0
Subarachnoid haemorrhage	0 (0)	0 (0)	0
I cannot tell	0 (0)	0 (0)	0
Hemisphere of stroke	$n=33$	$n=29$	
Right-side cerebral hemisphere	16 (49)	14 (48)	2
Left-side cerebral hemisphere	14 (42)	12 (41)	2
Both cerebral hemisphere	3 (9)	3 (10)	0
Treatment periods/visits within 3 months post-stroke	—	n	
Hospital inpatient ward	—	23	
Hospital outpatient clinic	—	9	
Rehabilitation inpatient ward	—	4	
Rehabilitation day ward	—	1	
Health centre inpatient ward	—	1	
Physician's practice	—	16	

(Continues)

TABLE 1 (Continued)

Demographic characteristics	Participants at baseline ($n=40$) n (%)	Participants at both times ($n=36$) n (%)	Participants lost to follow-up ($n=4$) n
Nurse's practice	—	4	
Physiotherapist's practice	—	6	
Occupational therapist's practice	—	3	
Speech therapist's practice	—	1	
Other	—	16	

disease, such as arterial hypertension, diabetes, or cancer. Completion of the questionnaire with another person was allowed, and at the first measurement point, six participants, and at the second measurement point, four participants reported filling it with a selected close one.

Participants were recruited from all five Finnish university hospitals, although the number of recruited persons per hospital is not completely in line with the size of the hospital district. The admission to hospital was without a referral to emergency department for most of the participants (76%), and a majority of the participants (91%) reported the admission as smooth. Only three participants reported negative experiences at admission, all related to the waiting time caused, for example, by health professionals not recognising the symptoms to be caused by stroke.

At the time of the follow-up measurement, all the participants were at home, and none received professional home care. Twenty-seven participants returned the calendar indicating the care periods or visits to the health professional related to stroke. Of these, relatively few had received rehabilitation (including physiotherapy, occupational therapy and speech therapy) (Table 1). Sixteen participants reported having some other care; for example, they had visited a neuropsychologist. Twenty-six reported having positive experiences of the care received in the follow-up period. Seven participants reported negative experiences, such as unmet needs in care. Six participants had visited some other organisation because of the stroke incidence (e.g. social care, Social Insurance Institution); of these, four reported negative experiences, for example, when the perceptions of the participant and a bureaucrat did not coincide. After the onset of stroke, eight participants had had new health problems, related to, for example, medication, and 14 had experienced significant life changes, such as driving ban as a consequence of stroke or restrictions caused by the COVID-19 pandemic.

The courses of the ethical pathway of IwS

Wide variation was detected in the perceived realisation of the dimensions of the ethical pathway and in the life situation factors (Table 2).

Dignity was perceived to be decreased by IwS during the post-stroke time (median −7.10 [95% CI, −9.30, −4.00]) (Table 2). At the baseline, dignity was perceived as the highest of the dimensions (median 97.40) but in the follow-up, as the lowest (median 89.80), and the majority of the IwS perceived dignity to be decreased ($n=27$). The perceived *privacy* (median 0.50 [95% CI, −3.40, 5.80]) did not change significantly ($p=0.183$). Informational privacy was decreased (median − 10.67 [95% CI, −11.33, −9.50]) (Table 2). In the follow-up, privacy was perceived as the highest of the dimensions (median 92.00). Most participants perceived physical ($n=22$) and social ($n=23$) privacy to be increased whereas informational privacy was perceived as decreased ($n=33$). *Autonomy* was perceived as increased by IwS during the post-stroke time (median 10.20 [95% CI, 2.20, 20.00]) (Table 2). At the baseline, autonomy was perceived as the lowest of the dimensions (median 79.85). At both measurement points, IwS perceived information received lower than decision-making by the participant. Most participants' autonomy increased ($n=26$).

Related to dignity and privacy, there were items where the perceptions of the participants decreased in the majority (Table 3), indicating less preferable results. Related to dignity, these items involved people being mean to the participants, people perceiving the participants as disgusting, the participants perceiving themselves as diminished human beings, and the participants perceiving themselves as being labelled on the basis of the disease. Related to privacy, these items concerned people enquiring the participants about things which they did not consider essential in regard to the situation, and the participants being scared of people revealing their private affairs to others. Related to autonomy, there were items where the perceptions decreased in only 10 participants (Table 3). These items concerned the participants having enough knowledge of the care of stroke, and the participants making decisions themselves on matters regarding their care.

Of the life situational factors (Table 2), IwS perceived symptoms diminishing functioning to be increased (median 5.68), indicating less symptoms diminishing functioning. Still, it was perceived as the lowest of the life

TABLE 2 Descriptive values of the ethical pathway dimensions and life situation factors in the follow-up period.

	Baseline		3 months		Change in the follow-up
Variables	**Mean (SD), Median (*n*)**	**Min.–max.**	**Mean (SD), Median (*n*)**	**Min.–max.**	**Min.-max. [95% CI], Median[a] (*n*)**
Dignity	91.42 (13.49) 97.40 (*n* = 35)	49.90–100.00	85.53 (13.61) 89.80 (*n* = 32)	33.90–92.90	−36.90–39.00 [−9.30, −4.00] −7.10 (*n* = 31) *p* = 0.002
Privacy	84.50 (15.92) 94.20 (*n* = 32)	49.80–99.40	88.54 (9.82) 92.00 (*n* = 35)	53.20–96.20	−7.80–32.10 [−3.40, 5.80] 0.50 (*n* = 31) *p* = 0.183
Physical	77.94 (25.88) 92.50 (*n* = 35)	10.50–100.00	92.37 (13.29) 97.50 (*n* = 35)	50.00–100.00	−28.50–83.00 [0.00, 8.50] 3.25 (*n* = 34)
Social	75.77 (26.68) 91.00 (*n* = 33)	24.67–100.00	91.94 (11.71) 96.83 (*n* = 36)	58.00–100.00	−3.33–62.00 [0.00, 22.33] 4.33 (*n* = 33)
Psychological	93.01 (12.88) 99.25 (*n* = 36)	47.00–100.00	94.50 (7.17) 97.50 (*n* = 36)	69.00–100.00	−20.00–47.50 [−1.00, 0.25] 0.00 (*n* = 36)
Informational	88.51 (16.36) 95.33 (*n* = 36)	33.00–98.00	78.98 (13.50) 84.83 (*n* = 36)	26.33–87.33	−48.33–33.33 [−11.33, −9.50] −10.67 (*n* = 36)
Autonomy	70.62 (25.12) 79.85 (*n* = 32)	19.50–100.00	85.05 (14.38) 90.70 (*n* = 34)	46.00–100.00	−29.00–71.20 [2.20, 20.00] 10.20 (*n* = 30) *p* = 0.003
Information	66.44 (28.71) 70.75 (*n* = 33)	0.00–100.00	78.20 (22.43) 85.00 (*n* = 35)	10.00–100.00	−52.50–84.50 [1.25, 12.75] 7.62 (*n* = 32)
Decision-making	71.95 (27.23) 79.83 (*n* = 33)	0.00–100.00	90.19 (13.25) 96.17 (*n* = 35)	48.50–100.00	−22.17–99.67 [1.67, 28.33] 9.25 (*n* = 32)
Symptoms diminishing functioning	76.15 (19.56) 83.59 (*n* = 29)	11.94–96.65	83.76 (20.20) 93.62 (*n* = 32)	3.29–97.35	−90.06–85.41 [1.12, 10.35] 5.68 (*n* = 26)

(Continues)

TABLE 2 (Continued)

Variables	Baseline		3 months		Change in the follow-up
	Mean (SD), Median (*n*)	Min.-max.	Mean (SD), Median (*n*)	Min.-max.	Min.-max. [95% CI], Median[a] (*n*)
Social environment	94.80 (8.73) 98.25 (*n* = 35)	60.00–100.00	95.14 (5.60) 96.50 (*n* = 25)	81.75–100.00	−10.62–23.12 [−3.13, 0.25] −0.88 (*n* = 24)
Significant others	94.46 (11.55) 99.25 (*n* = 35)	38.75–100.00	94.40 (8.93) 97.75 (*n* = 36)	64.50–100.00	−27.00–41.25 [−1.00, 0.00] 0.00 (*n* = 35)
Health professionals	95.13 (7.22) 98.25 (*n* = 35)	66.00–100.00	94.58 (6.10) 95.50 (*n* = 25)	77.00–100.00	−14.00–7.75 [−4.25, 0.00] −0.88 (*n* = 24)
Self-empowerment	82.25 (17.24) 85.60 (*n* = 35)	37.60–100.00	90.87 (9.54) 94.50 (*n* = 36)	64.60–100.00	−25.20–48.80 [0.60, 11.80] 5.40 (*n* = 35)

[a]Because of the small sample, statistical significance was calculated with Wilcoxon signed rank test only for the main variables of the dimensions of the ethical pathway.

situational factors at both measurement points. Social environment was perceived as rather stable in the post-stroke time period (median −0.88), and it was perceived as the highest of the life situational factors at both measurement points. Self-empowerment was perceived to be increased (median 5.40).

The associations between the dimensions of the ethical pathway and the life situational factors

Only few associations were detected between the dimensions of the ethical pathway and furthermore, between the dimensions and the life situational factors (Table 4). Dignity had a low positive correlation with overall autonomy and a medium positive correlation with decision-making by the participant, and a medium positive correlation with psychological privacy, but not with overall privacy. Privacy had a medium positive correlation with autonomy, including a medium positive correlation with decision-making by the participant, and a low positive correlation with information received. Autonomy had a low positive correlation with dignity and a medium positive correlation with overall privacy, including a low positive correlation with social privacy, psychological privacy, and informational privacy. Autonomy had a low negative correlation with social environment of health professionals.

DISCUSSION

Here, the novel concept of ethical pathway was shown as providing insight into the realisation of values and their possible changes as perceived by IwS during acute care and the recovery trajectory. Although there is a well-planned care pathway to treat and care for IwS from the onset of stroke to support recovery [2], IwS may perceive the realisation of values as threatened along the care pathway (e.g. 6). In this study, the ethical pathway of IwS showed variation in the post-stroke time, seen in the dimensions of the ethical pathway, including dignity, privacy, and autonomy. Next, the results are discussed in relation to previous study findings. However, this is conducted with the awareness that evaluating the perceived realisation of values is challenging and there are differences in the evaluation methods between the studies. Furthermore, the ethical pathway is a novel concept and therefore, it is possible to relate only parts of it to previous literature.

Perceived dignity showed a descending course in the ethical pathway. IwS have also described challenges in the realisation of their dignity in previous studies [10, 11], although these have focused on hospital and rehabilitation

TABLE 3 Examination of the changes on participant and item level.

Dimension-level examination **Variables**	**Perception increased in (*n*) participants**	**Perception decreased in (*n*) participants**	**No change in (*n*) participants**
Dignity ($n=33$)	6	27	—
Privacy ($n=35$)	19	16	—
Physical ($n=34$)	22	7	5
Social ($n=35$)	23	6	6
Psychological ($n=36$)	12	16	8
Informational ($n=36$)	3	33	—
Autonomy ($n=33$)	26	7	—
Information ($n=33$)	25	8	—
Decision-making ($n=34$)	24	8	2
Item-level examination	Contents of the most increasing/decreasing items (*n* participants)		
Variables	Note: the higher score of each item indicates more referable result		
Dignity	Increasing: Acknowledged in each situation in an appropriate manner [10] Being in the mercy of others [10]		
	Decreasing: People being mean for one [34] Being considered unpleasant by other people [34] Being diminished as a human being [33] Being stigmatised based on the health problem [32]		
Privacy	Increasing: Decided self when being in contact with other people [20] Forced being around other people [20]		
	Decreasing: Being inquired information not relevant for the situation [33] Being scared people revealing one's personal information to other people [32]		
Autonomy	Increasing: Enough information of the impact of stroke to the future [25] Enough information of the impact of stroke to the daily living [24]		
	Decreasing: Enough information of stroke care [10] Deciding self about the care of stroke [10]		

settings. The findings of this study suggest that the challenges in perceived dignity realisation continue beyond the rehabilitation phase. The challenges have been recognised to be associated with the life situational factors of symptoms diminishing functioning, social environment, and self-empowerment [11]. In this study, these associations were not confirmed. However, in the item-level examination, there were items whose scores decreased in the majority of the participants (Table 3). Previously, IwS have described challenges in participation in public life [22] and social situations [23], and the findings of this study suggest either IwS confronting disrespectful behaviour or their sensitivity to observe negative elements in other people's behaviour and interpret them as disrespect. Van Gennip et al. [41] have described seriously ill patients' dignity to be dynamic and both formal and informal caregivers as having important roles in dignity improvement. This study underlines the importance of special attention to respectful behaviour towards IwS, not only on the part of caregivers but also more broadly on the part of the general public and professionals in all public services.

Perceived informational privacy had a descending course in the ethical pathway. During the time of the data collection, there was a data breach in a Finnish private health care organisation that was widely reported in the media. In this study, informational privacy was measured with three items, one of which focused on data security systems. However, on the item-level examination, the descending course of informational privacy did not focus on this item. Instead, the scores of the items focusing on

TABLE 4 Correlation analysis among the changes in the ethical pathway and life situational factors in the follow-up period.

Dignity r_s (p)	Privacy r_s (p)	Autonomy r_s (p)
Privacy −0.11 (0.582)	Dignity −0.11 (0.582)	Dignity 0.44 (0.026)
Physical privacy −0.18 (0.363)		
Social privacy −0.05 (0.813)		
Psychological privacy 0.56 (0.001)		
Informational privacy −0.17 (0.357)		
Autonomy 0.44 (0.026)	Autonomy 0.58 (0.002)	Privacy 0.58 (0.002)
Information 0.21 (0.288)	Information 0.42 (0.028)	Physical privacy 0.23 (0.233)
	Decision-making 0.50 (0.006)	Social privacy 0.48 (0.011)
Decision-making 0.56 (0.002)		Psychological privacy 0.43 (0.017)
		Informational privacy 0.40 (0.031)
Symptoms diminishing functioning 0.24 (0.302)	Symptoms diminishing functioning −0.18 (0.415)	Symptoms diminishing functioning −0.13 (0.554)
Social environment 0.02 (0.920)	Social environment −0.32 (0.171)	Social environment −0.32 (0.170)
		Significant others 0.09 (0.625)
Significant others 0.30 (0.109)	Significant others 0.00 (0.991)	Health professionals −0.47 (0.036)
Health professionals 0.00 (0.994)	Health professionals −0.42 (0.067)	
Self-empowerment −0.05 (0.813)	Self-empowerment 0.08 (0.651)	Self-empowerment 0.25 (0.196)

other people's behaviour decreased in the majority of the participants (Table 3). As the participants were all at home at the time of the second measurement, the finding suggests that IwS wish for more sensitivity from people when asking about their condition, but it also suggests that IwS fear that people will reveal details of their condition to others. In literature, privacy of IwS has been described as lacking [24], but there is a very limited amount of detailed information about the areas where privacy is lacking; therefore, this study provides new knowledge on the topic.

Perceived autonomy had an increasing course in the ethical pathway during the 3 months post-stroke. In the literature, IwS autonomy has been described as decreased immediately after the stroke [24]. Together, these illustrate the curve of autonomy in an individual's health career described by Thompson et al. [16], where the degree of autonomy declines in the case of health crisis but improves alongside with the recovery. IwS' perceived information received was lower than decision-making by the participants. In a previous study, IwS reported receiving information, but the timing was not favourable for information processing [42]. In another study, the quality of the information provided to IwS was evaluated as incomplete [43]. As this study focuses on IwS perceptions, the finding suggests that IwS received too little information or that the timing to process the information was not favourable.

Dignity, privacy, and autonomy are theoretically seen as being related to each other (e.g. 44, 45) but they are also studied separately (e.g. 33, 35, 36). In this study, these represent the dimensions of the ethical pathway and the results indicate some significant associations between these. Autonomy seems to correlate with both dignity and privacy, while no significant correlation was found between dignity and privacy. This is an interesting finding, which is not in line with previous studies (e.g. 46). The result can indicate the central role of autonomy in the ethical pathway, or may be related to the small sample size and this finding needs further research to evidence.

In this study, the participants with severe stroke, including symptoms such as disorientation or reduced

consciousness, were excluded in the recruitment process. This selection was made consciously, as we saw important to hear the voice of patients and to collect the data from IwS themselves. Among the participants, during the follow-up time, none received professional home care and relatively few received rehabilitation. In the recruitment process, an evaluation of the severity of the stroke was not conducted, but it seems that the study included individuals with mild stroke, instead of mild and moderate stroke. It is possible, the inclusion and exclusion criteria were too tight to include individuals with moderate stroke or they were not willing to commit themselves to the follow-up study. In the future, to recruit individuals with moderate stroke to a follow-up study, it is vital to review the recruitment procedure.

Although, it seems that the study did not include individuals with moderate stroke, the study provides new knowledge. Individuals with mild stroke have described stroke as a shock and causing feelings of vulnerability. At the same time, they feel relief for having a mild stroke but consider it challenging to adjust to the new life situation after stroke [47]. As hospital patients' adjustment to a new situation has been described to be associated with a dimension of the ethical pathway [48], the descending courses in the ethical pathway may represent low adjustment to stroke. Adjustment to stroke is described as occurring alongside with the care pathway [42] but also extending beyond it [42, 47] across all stroke severities [42]. The adjustment is illustrated as a process which is neither straightforward nor identical for all individuals, although some similar themes [42] and time series may be recognised [49]. IwS have described multiple unmet needs related to, for example, health professionals and health care services [50], and these are additionally recognised as important in the adjustment process [42]. Therefore, individually tailored and correctly time provided information and rehabilitation could support IwS adjustment, and possibly, the perceived realisation of the ethical pathway.

The novelty of ethical pathway is in the illustration of the changes of realisation of values as perceived by IwS in post-stroke time (Table 2). The realisation of IwS dignity, privacy, and autonomy were at varying levels in the first measurement (70.62–94.42) but the variations narrowed down to minor differences in the second measurement (85.05–88.54). Although it could be argued, at least at the second measurement point, that the level of the perceived ethical pathway is rather high, the numbers point out that the dimensions of the pathway are perceived incompletely by most participants. As it would be favourable to perceive the ethical pathway at its highest, dimensions with higher scores and an increasing course should also be carefully considered in health care organisations to maximise the ethically high-level care and care pathways of IwS.

In this study, the realisation of values perceived by IwS were studied using the concept of ethical pathway. The results show the dynamic nature of the perceived realisation in first three post-stroke months. Although this is not identical for all IwS, most of the IwS did not perceive the ethical pathway as being in its ideal state. Ethical competence is stated as fundamental in the competence areas of European nursing students [51]. However, in the literature review of healthcare professionals' competence in stroke care, health professionals' ethical competence was not detected as a competence area in stroke care [52]. In the future, it is vital to give more visibility to health professionals' competence to encounter IwS with a high ethical stance in clinical practice.

This study had some limitations. The sample size was rather small. The criteria for participants were tight, limiting the number of suitable participants. Furthermore, because IwS are in a vulnerable position and in challenging life situations [47], they may not be eager to commit themselves to follow-up study. This was acknowledged in the planning phase of the research by making the participation as fluent as possible for IwS. Care of IwS is challenging and time-requiring, which may have limited the contact persons' commitment to the recruitment process. Although the researchers put serious effort into maximising the success of the recruitment process, the sample size remained small. Moreover, among the small group of participants, there was individual variation in the perceived realisation of values (Table 2). However, the study provides preliminary evidence of the existence of an ethical pathway of IwS with knowledge for the care of this vulnerable patient group. The data collection took place during the COVID-19 pandemic. As it had a major impact on clinical practices [53], it may have affected to the received care. Thus, it may have also affected to the perceptions of the participants as during the pandemic, for example, social contacts were highly restricted, also in the care environments. Furthermore, the pandemic restricted the already challenging recruitment of participants even further. However, systematic evaluation of the possible effects of the COVID-19 pandemic on the participants' perceptions was not conducted nor was the study design changed during the recruitment.

The instrument used in this study was new. Because of the small sample size, psychometric evaluation of the instrument was not conducted and it is obvious that the instrument requires full psychometric evaluation in the future. However, the instrument was developed diligently and operationalising the dimensions was based on the literature. Furthermore, the content and the logic of the instrument were assessed and the clarity of the instructions and the instrument and the relevance of the items were evaluated. As the dimensions of the ethical pathway may be understood in multiple ways (e.g. 33), a clarification of

each item was given in the instrument. In the future, to support the ethical realisation of the care pathways of IwS, there is a need for research focusing on individuals with more severe stroke and individuals receiving home care. It is also important to consider whether the ethical pathway comprises the three dimensions presented in this study or whether additional ones should be included. In the future, to illustrate the ethical pathways more broadly, the ethical pathway should be studied with other patient groups with long-term health problems. Before that, the EPIS instrument should be revised and renamed to fit for these health problems.

CONCLUSIONS

Ethical pathway describes the changes in the perceived realisation of values. In this study, the ethical pathway was considered dynamic for IwS in the first three post-stroke months. Most participants perceived the dimensions of the ethical pathway to be incompletely realised, and therefore, all dimensions need special attention and improvement in health care. Dignity and informational privacy had descending courses. Based on the most decreasing items of these scales, this seems to be related to the social environment. Although the results suggest that IwS perceive themselves as vulnerable in relation to the social environment, it cannot be confirmed whether this considers their close ones and health professionals, or other people.

AUTHOR CONTRIBUTIONS

All the authors have made adequate intellectual contribution to justify authorship. The conception and design were made by Sunna Rannikko, Riitta Suhonen and Helena Leino-Kilpi. The acquisition of data was made by Sunna Rannikko. The data analysis was made by Miko Pasanen. The interpretation of data was made by Sunna Rannikko, Riitta Suhonen, Miko Pasanen and Helena Leino-Kilpi. The article was drafted or revised critically of intellectual content by Sunna Rannikko, Riitta Suhonen, Miko Pasanen and Helena Leino-Kilpi. Final approval of the version to be published is made by all the authors.

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CONFLICT OF INTEREST STATEMENT

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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