



Hemispatial neglect following stroke: Developing an assessment tool and identifying viable clinical interventions

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* Collaborators

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- * Haukur Hjaltason, dr. med., Neurology, Landspítali, The National University Hospital of Iceland
- * Björn Þorsteinsson, dr. phil, Faculty of Humanities, University of Iceland
- * Þóra B. Hafsteinsdóttir, RN, PhD, University Medical Center Utrecht, Holland
- * Dan Zahavi, dr. phil, University of Copenhagen, DK
- * Árni Kristjánsson, Neuropsychologist, University of Iceland

* My motivation



* Structure

- * General introduction to stroke
- * Complexities of hemispatial neglect
- * Summarize contents, results, and contributions



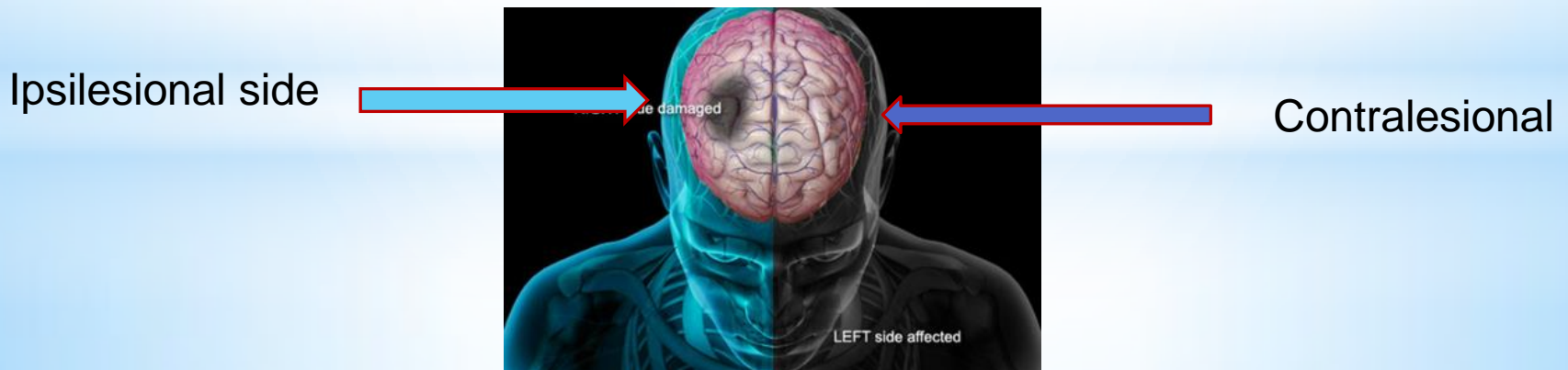
* Stroke

- * The leading cause of long-term disability (Go et al. 2013; Miller et al. 2010)
- * Fourth leading cause of death in the world when considered in isolation from other cerebrovascular disorders (Go et al., 2013)
- * Incidence of first stroke in Iceland is ~ 144 per 100 000 person (Hilmarsson et al. 2013)
- * Causes interference with normal healthy life and life quality
- * Stroke units are effective – specialized interdisciplinary approach (Stein et al., 2009)
 - * Decrease mortality (25%), shorter hospital stay (30%), increase likelihood of discharge to home (30%) (Johansson, 2011; Jorgensen et al. 1995; Langhorne and Duncan, 2001)



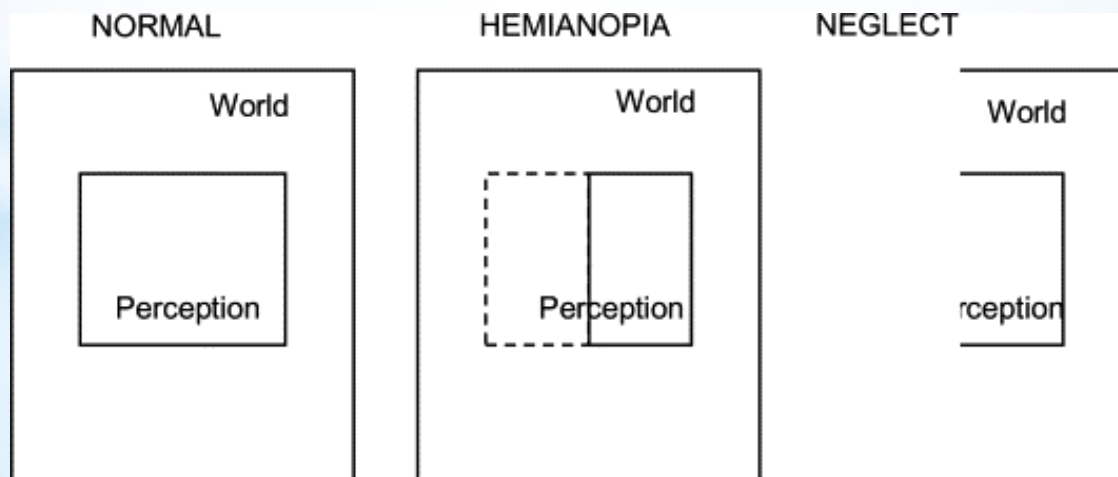
* Meaningful stroke rehabilitation

- Stroke effects the relation with others, the environment and existential possibilities (Carel, 2012; Stein et al. 2009)
- Phenomenological research have contributed to an understanding of the challenges of “being a stroke survivor” (Hafsteinsdóttir et al. 1997; Lawrence, 2010; McKeivitt et al. 2004)
- Sparse amount of qualitative research exist on patients who have difficulties with providing rich descriptions of their experiences. These descriptions have mainly been found in stroke survivors with damage to the left brain hemisphere (apraxia and aphasia) (Arntzen et al. 2013; Bronken et al. 2012a,b; Kirkevold 2007; Nyström, 2009; Sundin et al. 2002)



* Complexities of neglect

- * Defined as: “*Neglect is the failure to report, respond, or orient to meaningful or novel stimuli presented in a portion of space when this failure cannot be accounted for by either an elemental sensory or motor defect*” (Heilman, 2009, pg. 201)
- * Neglect occurs approximately in half of those who have suffered a stroke in the right brain hemisphere (Azouvi et al. 2002; Bowen et al. 1999)
- * It is estimated that 79-82% of patients with neglect are dependent on assistance from health care professionals after hospital discharge (Appelros et al., 2003)



* Defective symptoms

* Defective symptoms – loss of function or absence of behaviour or response

1. **Perceptual neglect** – problems with “input”

2. **Motor neglect** – problems with “output”

3. **Personal neglect**

4. **Representational/imaginary neglect**

* Transposition of left sided event into the right (Allosthesia)

* Ignorance and unconcern regarding personal disabilities (Anosognosia)



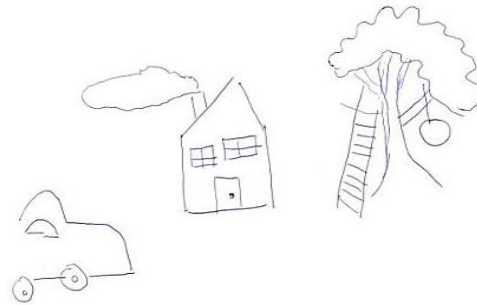
Crooked spectacles

Shaved only to the right

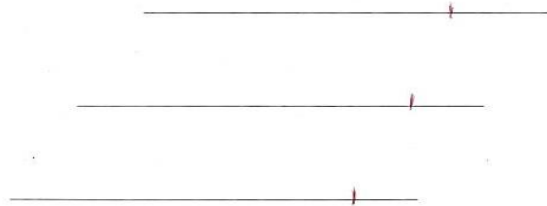
* Defective test solutions



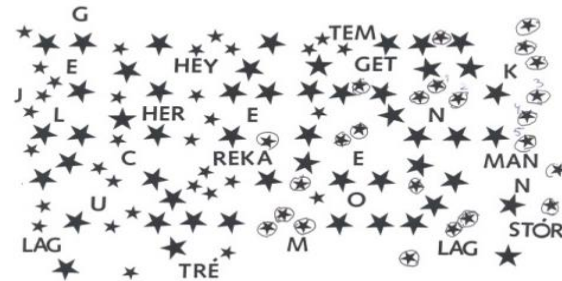
a. Original drawing



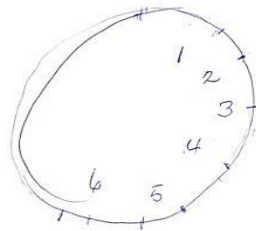
b. Patient copying



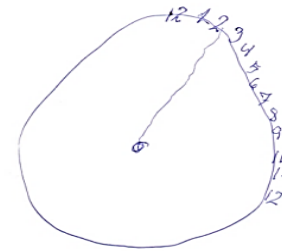
c. Line bisection



d. Star cancellation



e. Clock drawing



f. Clock drawing

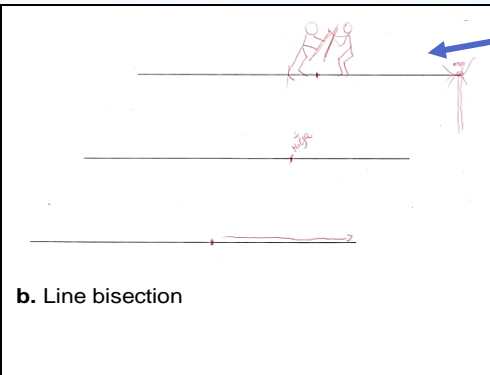
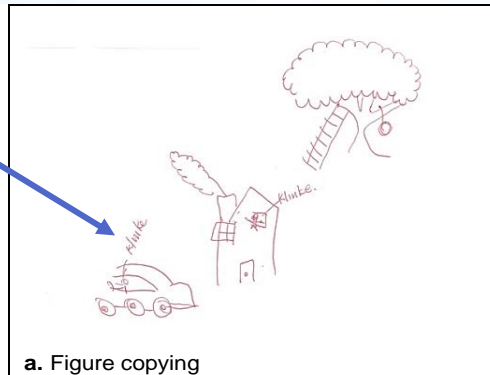
* Productive symptoms

* Productive symptoms – generation of “new” but non-reality-fitting behavior (Bottini et al., 2009)

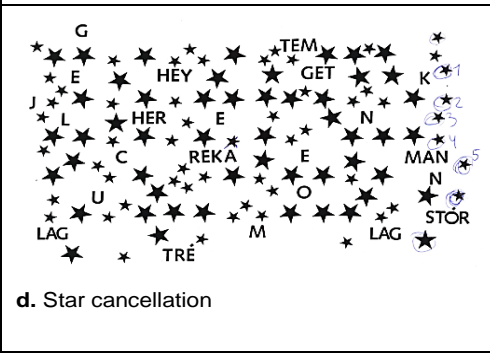
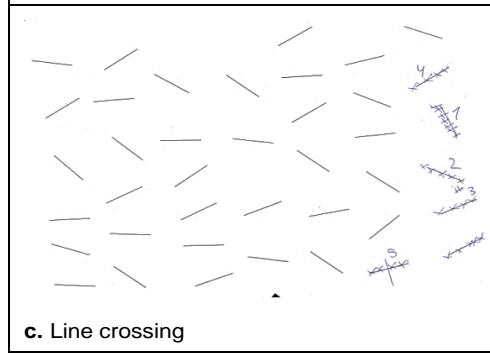
1. Delusions with regard to own body (Somatoparaphrenia)

2. Inappropriate iteration of behaviour or experience (Perseveration)

Adding graphic details

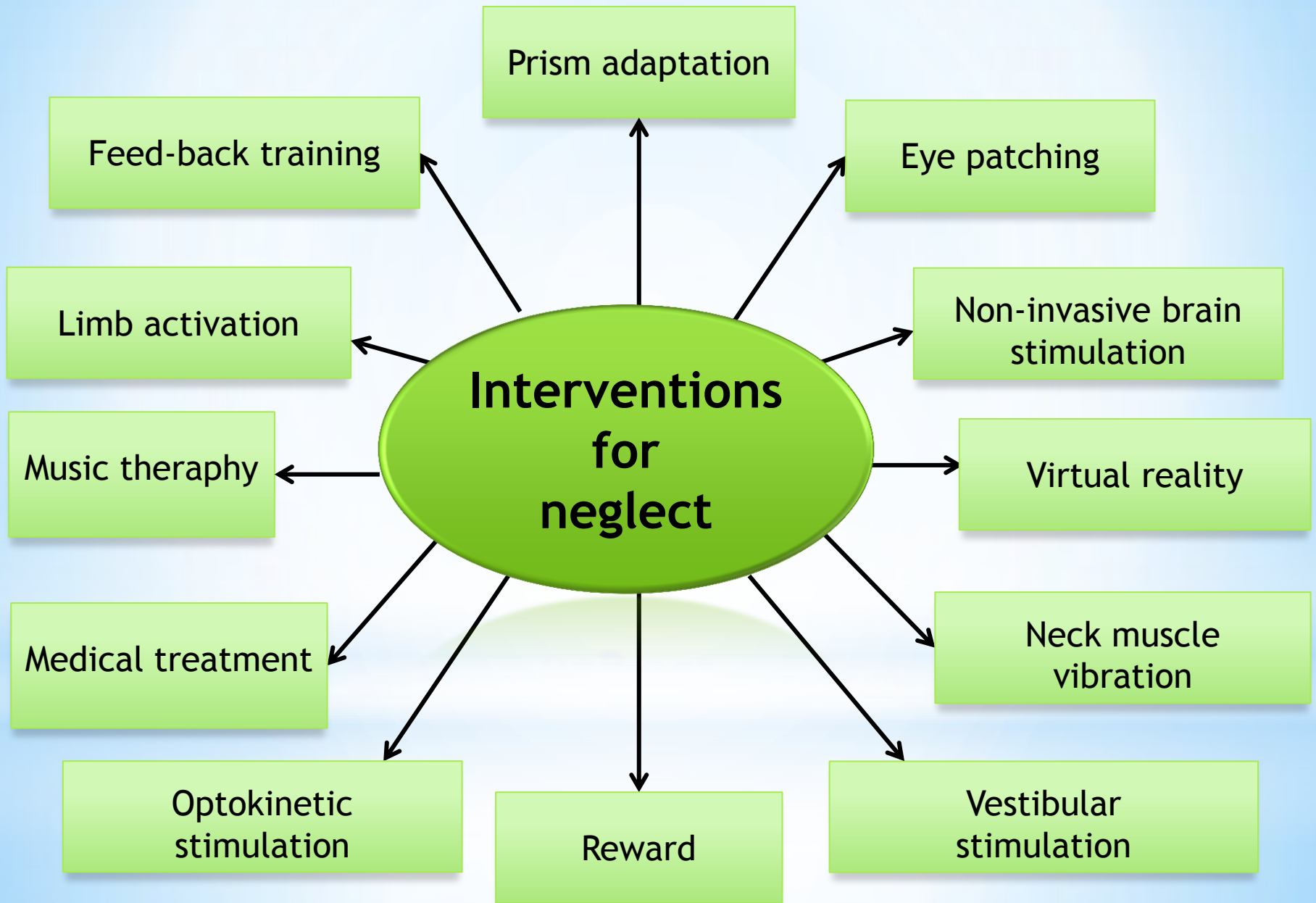


Repeatedly canceling the same target(s)

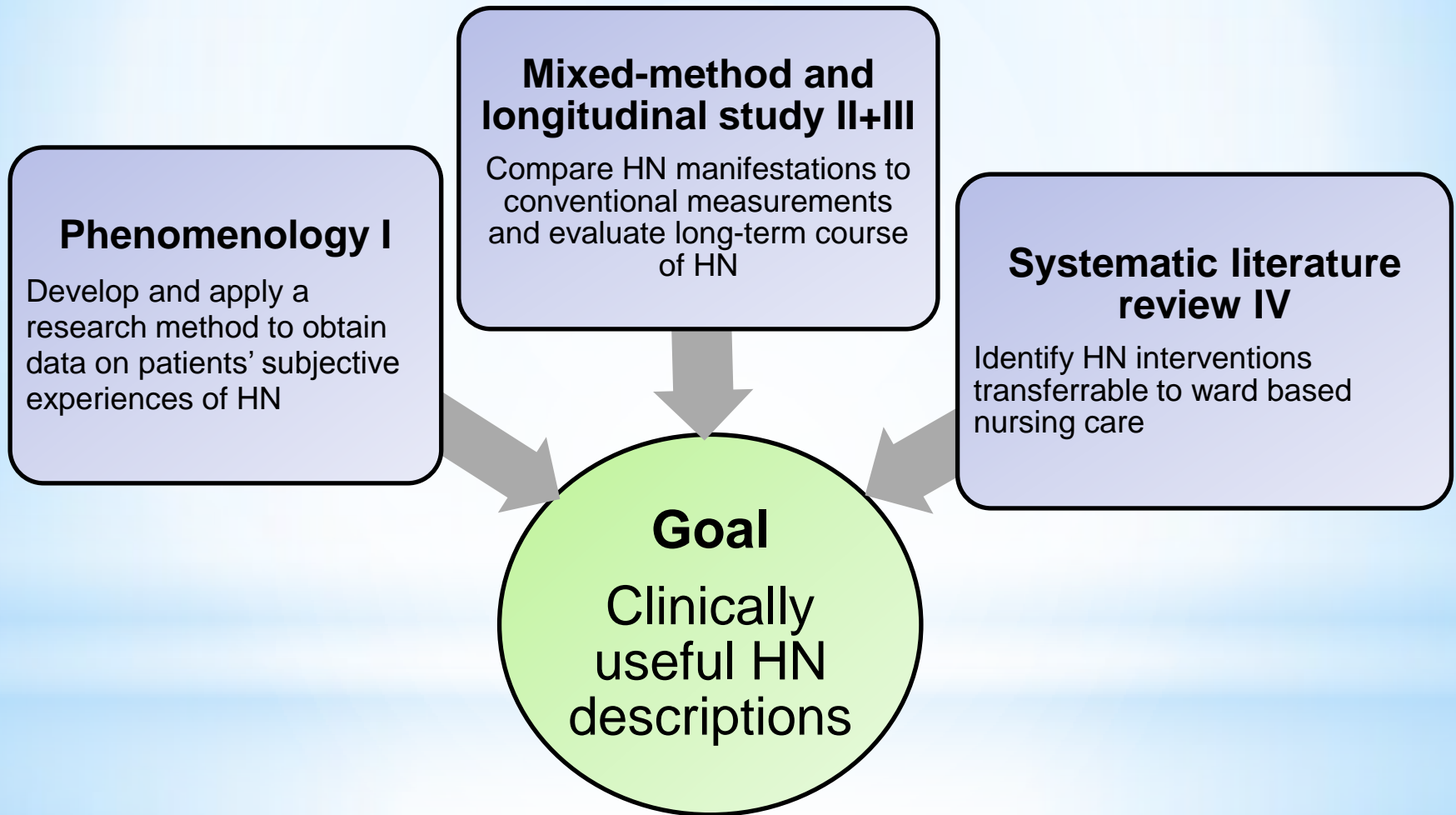


* Why this project was launched

- * Provide clinical useful descriptions of neglect that helps to address complex challenges in rehabilitation
- * Few studies exist on patients' subjective experiences of neglect
(Tham et al. 2000; Tham & Kielhofner 2003)
- * Nurses under-document neglect, reporting it only in 17.6% of instances
(Chen et al. 2013)
- * Identification of neglect is a prerequisite for interdisciplinary team approach
- * Neglect may be masked by other stroke problems, therefore clinicians should be aware of how neglect can be concealed



*Presentation of four papers



*Participants

A total of 2428 admission screened from January 2012 – September 2014

out of which 564 had stroke, 79 first right hemisphere stroke

A total of 29 patients fulfilled the eligibility criteria and were enrolled within 21 days after stroke

Paper I

Within 21 days following stroke

12 participants

Paper II

Within a month after discharge and more than 3 months after stroke

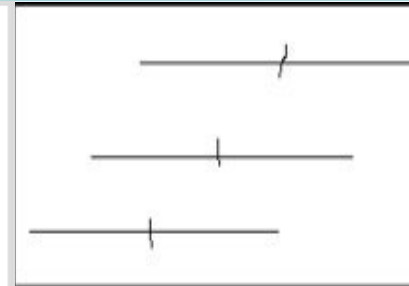
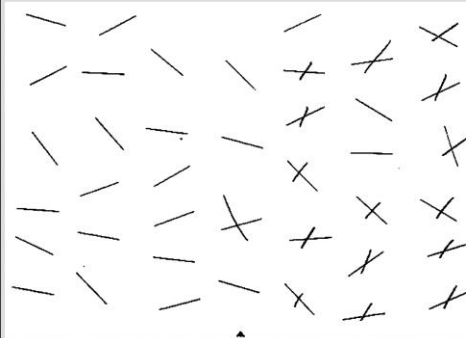
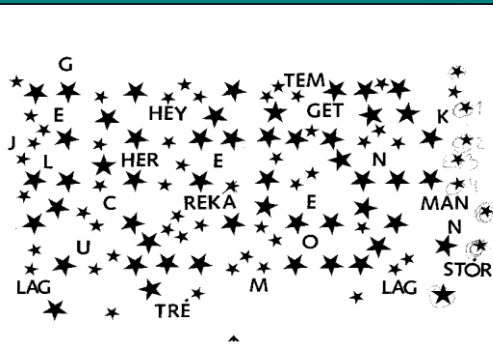
15 participants

Paper III

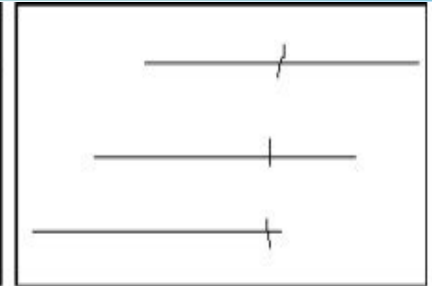
Longitudinal data from within 21 days following stroke until discharged

23 participants

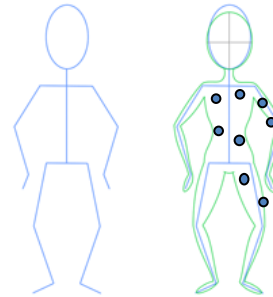
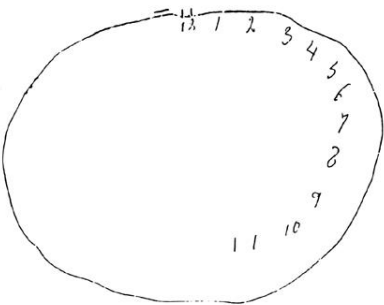
* Data collection



A. Normal line bisection



B. Highly impaired line bisection



Catherine Bergego Scale (CBS):

Behavioral manifestations e.g.;

- Grooming
- Shaving
- Eating food
- Collisions

- * Qualitative data: Observations and informal interviews, tape recorded in-depth interviews, observation of how patients solved paper-and-pencil tests
- * General stroke severity - National Institute of Health Stroke Scale (NIHSS)
- * Crude measure of ADL - Katz

Paper I

Phenomenology

- Apply a phenomenological research method to describe how neglect alters patients' experiences

* Paper I

“Getting the Left Right”: The Experience of Hemispatial Neglect After Stroke

Marianne E. Klinke^{1,2}, Dan Zahavi³, Haukur Hjaltason^{1,2},
Björn Thorsteinsson¹, and Helga Jónsdóttir¹

Qualitative Health Research

1–14

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Purpose: Explore how neglect affect the patient’s experience of self, other and world within the first month following stroke

Design: Phenomenological study

Sources: 12 consecutive patients with neglect (8 women), age 36-76 years ($M=61$ years). 4-8 hours of clinical observation. Transcribed interviews, field notes and observations

Analysis: Phenomenological analysis - significant statement and occurrences identified. Triangulation in collaboration with co-authors

*Method in paper I

Experience	Incorporation
Situation	What happened? The researcher describes the situation and contexts/environment in which the situation occurred Were there any distracting/motivating elements present?
Subjective dimension	Prior experiences, thoughts, feelings, anticipations of the patient are sought. The researcher might, for example, ask: How do you feel about this situation? Can you describe how you reacted/felt while this was going on? Have you experienced another similar situation that you could describe for me? Has this situation changed? Can you describe how this affects you? How did you experience the environment? Can you describe what you observed in the environment? Do you feel that anything is missing compared to how it was before – can you provide details on that? The researchers' actual observations from multiple daily common activities are used to explore further into the subjective dimension
Others' dimension	Identification of pathological affordances. How did the researcher see the situation compared to the patient's perspective? Here might also be included the perspectives of other persons who have experienced the problems related to neglect in proximity
Intersubjective dimension	Co-formation of meaning between the researcher and patient. The researcher engages naturally in important/meaningful activities to see/experience the immediate implicit response related to daily life

*Results of paper I

Getting the Left Right

Misconceiving own body and surroundings

- Dreamlike, unreal experience of the left
- Failing to recall disabilities in spontaneous action
- Limited view of surroundings
- Difficulties locating oneself in space
- Left/right transpositions
- Lack of illustrations to describe neglect
- Strange bodily sensations
- Feeling of wholeness in spite of loss

A Surreal Awareness of the Left

Brittle attention

- Fluctuating insight into disabilities
- Discrepancies in perceived reality
- Filling in missing parts
- Troubled left memory
- Increased difficulties when fatigued
- Physical difficulties co-occurring with high attentional requirements

Pursuing the left and generating stability

- Emotionally salient stimuli
- Personalizing the left
- Explicit statements and intellectualization
- Easier to attend to concrete, meaningful tasks
- Blocking out confusing stimuli
- Strategies to feel like oneself

Emergence of a Different World

Bewildering responses

- Unexpected reactions and corrections
- Feeling strangeness in other people
- Sense of aloneness and loss
- Vulnerability to corrections
- Discovering neglect with disappointments
- Self-alienation when not trusting one's own experiences



* Surreal awareness of the left

* Misconceiving own body and surroundings

“How would you feel if you were told that you were only seeing half of the world, although you feel as though nothing is missing? That you really need to look carefully to the left, how would you do that?”



* Brittle attention

Another patient failed to remove her shirt before showering. When her attention was drawn to the soaked clothes, she showed comprehension:

“I do not seem to be in control of anything hanging onto here [pointing at her left arm]”

This insight, however, quickly tapered off to a point where she minimized the difficulties. When requested to describe how she had managed to shower later the same day, the prompt reply was:

“Fine—this was no problem”



* Emergence of a different world

* Pursuing the left and generating stability

“I often try to explain to myself that something is wrong by imagining that my body is like the body of inseparable Siamese twins

—when I move, I need to pay attention to my twin—we are part of the same body even

though we are different. I cannot feel my twin in the same way as I feel me. I find it helpful to remember my twin by saying it out loud... somehow this makes the paralysis more real, more a part of me”



* Bewildering responses

“I feel like I’m at a huge get-together with my family and friends, but I am the only person who is drunk”



Paper II and III

Mixed method and longitudinal study

- Contrast conventional HN tests with clinical observations and patients' experiences after discharge from rehabilitation
- Describe the course of HN from early stroke until after hospital discharge and to identify sensitive screening instruments that can be used for bedside HN identification
- Determine the difference between the researcher's and patients' assessments of HN over time

*Paper II

Hemispatial neglect in stroke patients after discharge from rehabilitation to own home: A mixed method study

Marianne E. Klinke^{a,b,*}, Haukur Hjaltason^{b,c}, Thóra B. Hafsteinsdóttir^{a,d}, Helga Jónsdóttir^a.

- Purpose:** Explore usefulness of conventional neglect tests, and contrast findings with daily challenges encountered by patients after discharge from rehabilitation to home
- Design :** Mixed method prospective study
- Sources :** 15 participants with persistent neglect < 1 month after discharge to own home (eight females), age 36-84 ($M=65$). Mean time from stroke 164 days. Catherine Bergego Scale, Star Cancellation and Figure Copying, observations and interviews
- Analysis:** Qualitative data; content analysis. Quantitative data; non-parametric statistics. Data presented in a “mixing matrix” and integrated by “following threads”

Relationship between researchers conventional scoring on the CBS and results of deductive scoring of the same items, based on natural observations and interviews

CBS		N	Median	Mean	Std. Deviation	Std. Error Mean	Wilcoxon (Z)	p-value
Total neglect score on CBS	Researcher	15	5	5,87	4,207	1,086	-3,311	0,001
	Observations	15	8	9,27	3,494	,902		
Groomin and shaving the left part of the face	Researcher	15	0	,53	,640	,165	-1,732	0,083
	Observations	15	1	,73	,594	,153		
Wearing the left sleeve or slipper	Researcher	15	1	,67	,617	,159	-1,890	0,059
	Observations	15	1	1,00	,655	,169		
Eating food from the left side of the plate	Researcher	15	0	,33	,617	,159	-1,000	0,317
	Observations	15	0	,47	,743	,192		
Cleaning the left side of the mouth after eating	Researcher	15	0	,67	,816	,211	-1,000	0,317
	Observations	15	1	,73	,799	,206		
Spontaneous leftward gaze orientation	Researcher	15	0	,53	,743	,192	-2,236	0,025
	Observations	15	1	,87	,743	,192		
Knowledge of the left part of the body	Researcher	15	1	1,00	,655	,169	-3,000	0,003
	Observations	15	2	1,60	,507	,131		
Auditory attention	Researcher	15	0	,33	,724	,187	-2,828	0,005
	Observations	15	1	,87	,640	,165		
Collisions to the left	Researcher	15	1	1,07	,884	,228	-2,640	0,008
	Observations	15	2	1,73	,458	,118		
Finding way towards the left	Researcher	14	0	,50	,760	,203	-2,000	0,046
	Observations	14	1	,79	,699	,187		
Finding left-sided personal belongings	Researcher	15	0	,27	,594	,153	-1,732	0,083
	Observations	15	0	,47	,640	,165		

Neglect problems which were not accounted for in the CBS

CBS - ● Traditional scoring		✓ problem identified from content analysis	
●	✓	✓	1. CBS
●	✓	✓	2. CBS
●	✓	✓	3. CBS
●	✓	✓	4. CBS
●	✓	✓	5. CBS
●	✓	✓	6. CBS
●	✓	✓	7. CBS
●	✓	✓	8. CBS
●	✓	✓	9. CBS
●	✓	✓	10. CBS
3	8	5	Total traditional score CBS*
8	12	8	Total score from content analysis
Content analysis Category 1. Unpredictable nature of neglect			
✓	✓	✓	Adverse consequences
✓	✓	✓	Fluctuations and clumsiness
✓	✓	✓	Lack of faith in own abilities
Content analysis Category 2. Other daily neglect behaviour/challenges			
✓	✓	✓	Reading/watching television
✓	✓	✓	Eating/preparing food
✓	✓	✓	Dependence when going out
✓	✓	✓	Missing/dropping items
Content analysis Category 3. Safety issues			
✓	✓	✓	Driving
✓	✓	✓	Falling
✓	✓	✓	Cooking/kitchen
✓	✓	✓	Underestimating neglect
✓	✓	✓	Being left alone
Content analysis Category 4. Conditions enhancing neglect			
✓	✓	✓	Many distractors/
✓	✓	✓	Adverse effects of medication
✓	✓	✓	Tiredness or fatigue
✓	✓	✓	Fever, other illness or pain
✓	✓	✓	Orienting in (new) environment
✓	✓	✓	Things not in the right place
Content analysis Category 5. Conditions diminishing neglect			
✓	✓	✓	Eliminating distracting factors
✓	✓	✓	Being well rested
✓	✓	✓	External cueing:
✓	✓	✓	Structure in the environment

Illustrative quotation(s) and observations**Catagory**

“I have a little box of pills where they are divided into ‘mornings,’ ‘afternoons,’ ‘evenings,’ and ‘nights’ I have a tendency of beginning the other way around and emptying my evening pills first (which are to the furthers right)”

“I know that I am not supposed to come near the stove, not cook, warm up food or anything like that. But when I walk around by myself I start doing some stuff here maybe – cleaning up the dishes, and then one thing leads to another and then I forget that I am not supposed to cook. My family is very concerned about this. Actually I am very worried about this as well. I keep forgetting”

Safety

Driving, falling, cooking/kitchen, inability to be home alone or when mobilizing outside the home

“I got the flu the other day, had a fever and suddenly I was colliding into everything. I thought that I had had another stroke. Usually I do not feel the neglect. But then I suddenly encountered the same problems as during rehabilitation”

“When I get tired in this way, or have a headache then I become clumsy and bump into stuff “

Conditions enhancing neglect

Differences between qualitative and quantitative readings of Figure Copying



A. The figure that the participants were required to copy



B. Obvious neglect solution



C. Hidden neglect

*Paper III

Hemispatial neglect in stroke: course and sensitivity of diagnostic tasks

Marianne E. Klinke^{a,b,*}, Haukur Hjaltason^{b,c}, Guðný Bergþóra Tryggvadóttir^d, Helga Jónsdóttir^a.

- Purpose:** Describe the clinical course of patients with moderate to severe HN, the sensitivity of clinical diagnostic tasks, and agreement between researcher's and patients' neglect assessment
- Design :** Longitudinal study, data collection at; t1: sub-acute stroke, t2: during rehabilitation, and t3: after discharge
- Data :** 23 patients. CBS used as a benchmark for neglect. Diagnostic tasks: Star cancellation, line crossing, line bisection, modified fluff test, figure copying, and clock drawing
- Analysis:** Descriptive statistics; demographic data and clinical variables. Spearman's rho; correlate neglect on CBS with diagnostic tasks . Sensitivity of diagnostic tasks; case-by-case matrix . ANOVA for difference in the researcher's CBS scores compared to patient' over time. Description of patterns within and between cases

Characteristics	Time 1. Sub-acute stroke		Time 2. Rehabilitation		Time 3. After discharge	
CBS (n, %)						
No HN	0	(0)	0	(0)	3	(13.0)
Mild HN	0	(0)	11	(47.8)	15	(65.2)
Moderate HN	16	(69.6)	10	(43.5)	2	(8.7)
Severe HN	7	(30.47)	2	(8.7)	3	(13.03)
Items NIHSS (n, %)						
Partial gaze palsy	4	(17.4)	0	(0)	1	(4.3)
Hemianopia, partial	10	(43.5)	11	(47.8)	9	(39.1)
complete	5	(21.7)	5	(21.7)	5	(21.7)
Left arm/ motor						
Drift	0	(0)	7	(30.4)	7	(30.4)
Some paralysis	12	(52.1)	9	(39.1)	10	(43.4)
Total paralysis	11	(47.8)	6	(26.1)	4	(17.4)
Left leg/motor						
Drift	4	(17.4)	10	(43.5)	12	(52.2)
Some paralysis	15	(65.2)	7	(30.4)	6	(26.1)
Total paralysis	4	(17.4)	5	(17.4)	3	(13.0)
Sensory loss						
Mild/moderate	15	(65.2)	14	(60.9)	14	(60.9)
Severe	2	(8.7)	0	(0)	0	(0)
Hemi-inattention						
Mild	9	(39.1)	16	(69.9)	16	(69.6)
Severe	14	(60.9)	4	(17.4)	2	(8.7)
Ambulates with (n, %)						
Independent	0	(0)	2	(8.7)	2	(8.7)
Cane	0	(0)	5	(21.7)	6	(26.1)
Walker	6	(26.1)	4	(17.4)	7	(30.4)
Wheelchair	17	(73.7)	11	(47.8)	8	(34.8)
Others	0	(0)	1	(4.7)	0	(0)
Katz index (n,%)						
Full function	0	(0)	4	(17.4)	11	(47.8)
Moderate depend.	3	(13)	8	(34.8)	7	(30.4)
Severe depend,	20	(87)	11	(47.8)	5	(21.7)
Discharged to (n, %)						
Same home	-		-		15	(65.2)
Supported resid.					4	(17.4)
Nursing home					4	(17.4)

* Sensitivity of Diagnostic Tasks

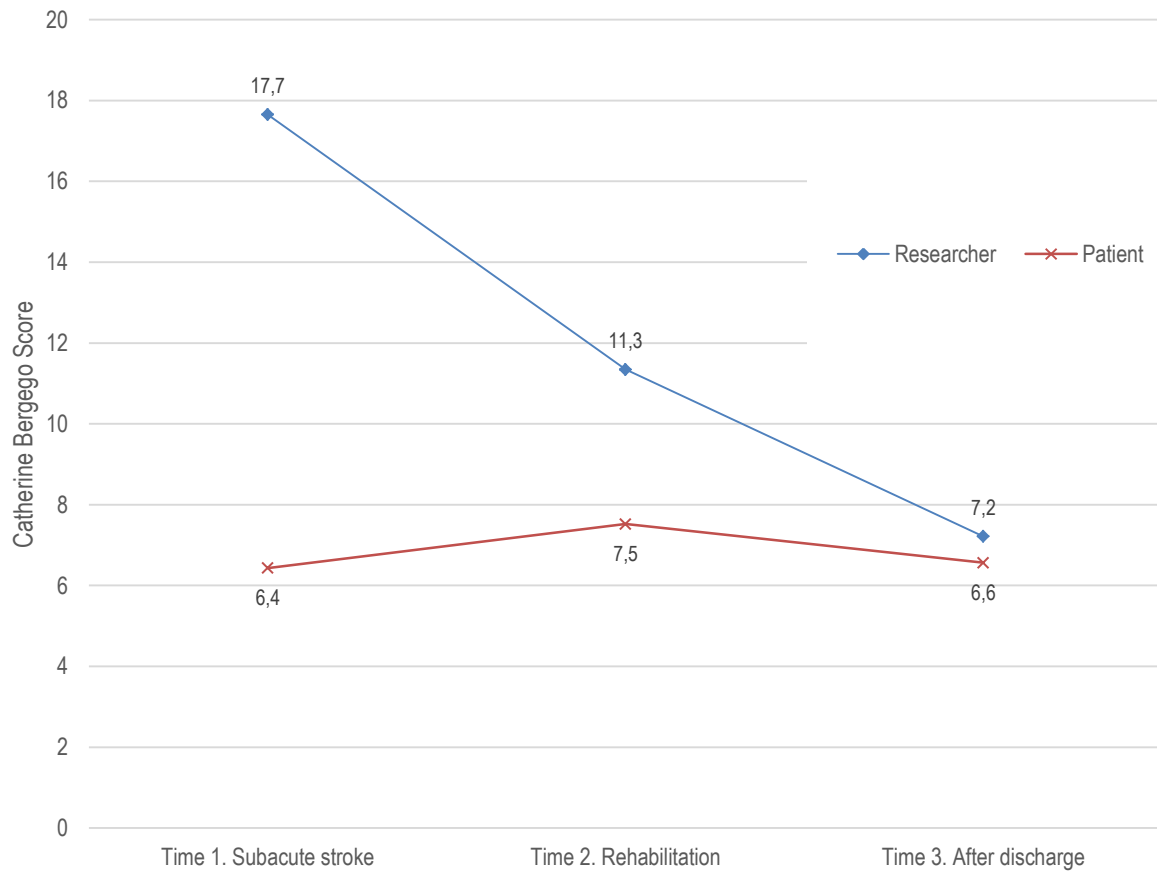
N	T1 Subacute phase						T2. Rehabilitation						T3. After discharge					
	SCT	LC	LB	CDT	FC	Fluff	SCT	LC	LB	CDT	FC	Fluff	SCT	LC	LB	CDT	FC	Fluff
1	+	+	+	+	+	+	+	N	+	+	+	N	+	+	+	+	+	N
2	+	N	+	+	+	+	N	N	N	N	+	N	N	N	N	N	N	N
3	+	+	+	+	+	+	+	N	N*	+	+	+	+	N	N	N	+	+
4	+	+	N	+	+	N	N	N	N	+	+	+	N	N	N	+	+	N
5	+	+	+	+	+	N	N	N	N	N	N	N	N	N	N	N	N	N
6	+	+	+	N	+	+	+	N	N	N	+	+	N	N	N	N	+	N
7	+	+	N	+	+	+	+	N	+	+	+	+	+	N	N	+	+	N
8	+	N	N	+	+	N	+	N	N	N	+	N	N	+	N	N	+	N
9	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	N	+	N
10	+	+	N	N	+	+	+	N	N	N	+	+	+	N	N	N	+	N
11	+	N	N	N	+	N	+	N	+	N	+	N	+	N	+	N	+	N
12	+	+	+	+	+	+	N	N	N	N	+	N	N	N	N	N	+	N
13	+	+	N	+	+	+	+	N	N	N	+	N	+	N	N	N	+	N
14	+	+	N	N	+	+	+	+	N	N	+	+	+	N	N	N	N	N
15	+	+	+	N	+	+	+	+	N	N	+	+	+	N	N	N	+	N
16	+	+	+	N	+	+	+	+	N	N	+	N	-	-	-	-	-	-
17	+	+	+	+	+	+	+	+	+	N	+	+	+	+	+	+	+	+
18	+	+	+	+	+	+	+	+	+	+	+	+	+	+	N	+	+	+
19	+	+	N	+	+	N	+	N	N	+	N	N	-	-	-	-	-	-
20	+	+	N	+	+	N	+	N	N	+	+	N	-	-	-	-	-	-
21	+	+	+	+	+	+	+	N	N	+	+	+	+	+	+	+	+	+
22	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
23	+	+	+	+	+	N	+	N	N	N	+	N	+	N	N	N	N	N
%	100	87	61	74	100	70	83	26	30	43	91	52	70	35	30	35	80	25

Unidentified
0%

Unidentified
4%

Unidentified
9%

* Difference in patients' and researcher's assessment



Paper IV

Systematic literature review

- Identify neglect interventions transferrable into ward based nursing care

* Paper IV



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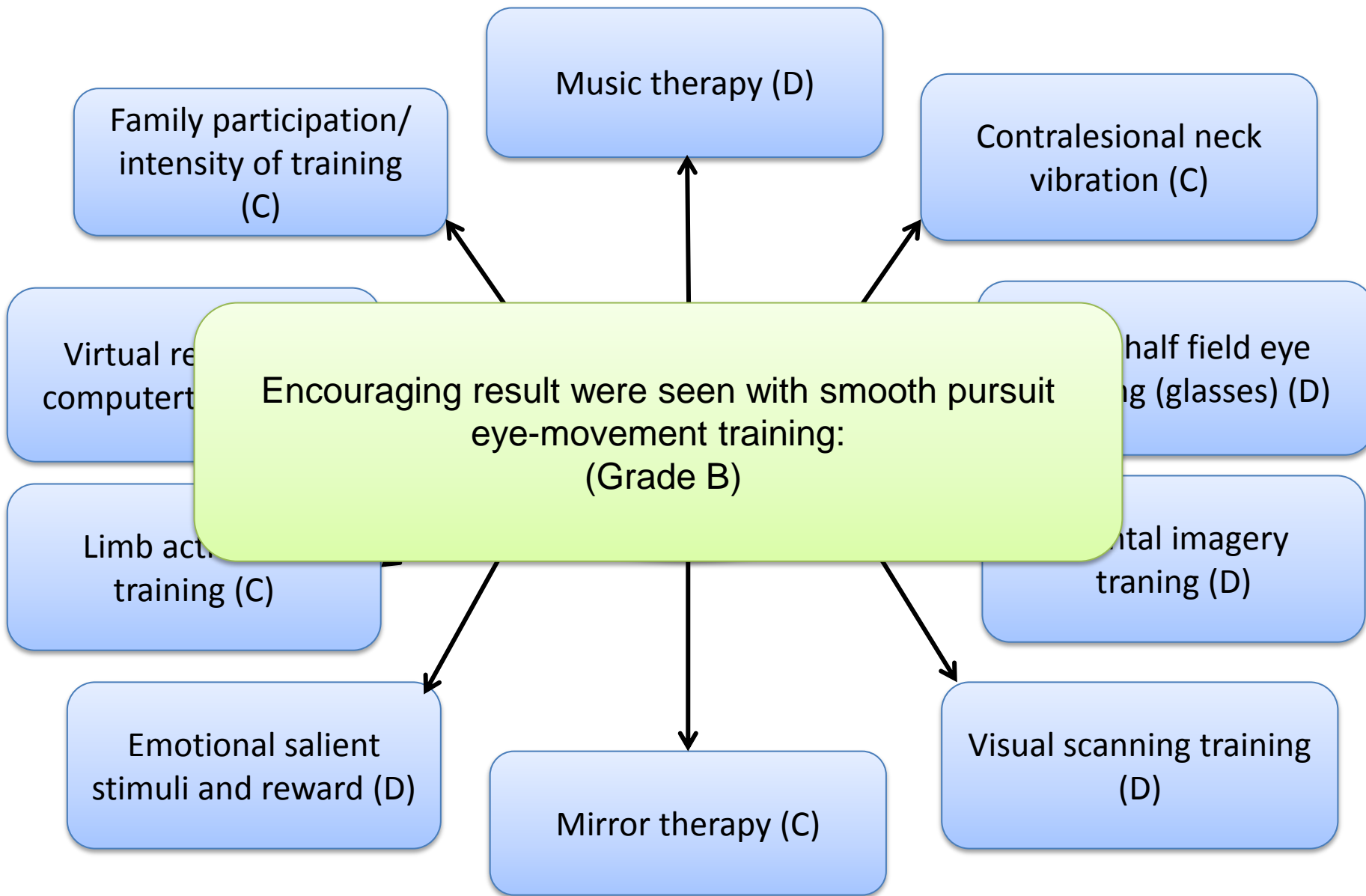
Review

Ward-based interventions for patients with hemispatial neglect in stroke rehabilitation: A systematic literature review



Marianne E. Klinke^{a,b,*}, Thóra B. Hafsteinsdóttir^{a,c}, Haukur Hjaltason^{b,d}, Helga Jónsdóttir^a

- Purpose:** Identify rehabilitation interventions that can be integrated into ward-based nursing for patients with neglect
- Design:** Systematic literature review, 2006-2014
- Sources:** Cochrane Controlled Trials Register, PubMed, CINAHL and PsychINFO. Additional search; selected journals, reference lists, and citation tracking. 41 studies included
- Analysis:** The JBI Reviewers' Manual and adherence to the PRISMA statement. Interventions were given recommendation grades for implementation (Grades A to D)



Encouraging result were seen with smooth pursuit eye-movement training:
(Grade B)

Family participation/
intensity of training
(C)

Music therapy (D)

Contralesional neck
vibration (C)

Virtual re
computert

half field eye
training (glasses) (D)

Limb acti
training (C)

mental imagery
training (D)

Emotional salient
stimuli and reward (D)

Mirror therapy (C)

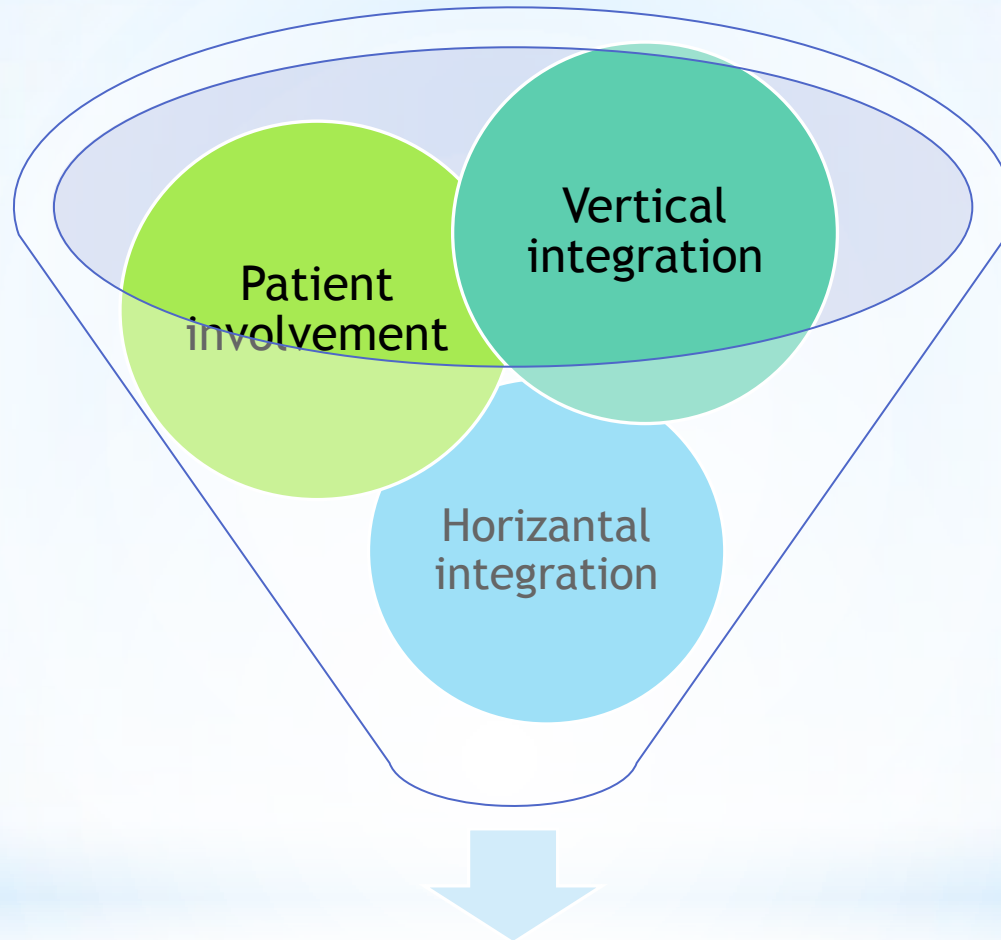
Visual scanning training
(D)

* Highlights paper I-IV

- * Patients' uses of possibilities in unique circumstances provides insight into their capacities and need for support
- * The star cancellation and figure copying were the most sensitive diagnostic tasks to screen for neglect. Sensitivity might be enhanced with qualitative readings
- * Neglect should be assessed even in seemingly recovered patients
- * Important to inform patients and relatives about conditions that enhance and diminish neglect and how deterioration can be prevented
- * Proposes 11 interventions for neglect

*What this thesis adds to previous knowledge

- Increases comprehension of the burden of neglect:
 - Wide-ranging impact that neglect has both on the stroke survivor and his/her surroundings
 - When patients with neglect improve he/she might not experience relief - they may experience themselves more disabled
 - The importance of continuity of care and specialized follow-up and support, even after discharge to home
 - Importance for development of complex assessment
 - Draws forth the need of nurses taking a more (pro)active role within the interdisciplinary stroke team



Management of neglect

* Implication for research - three stage follow up

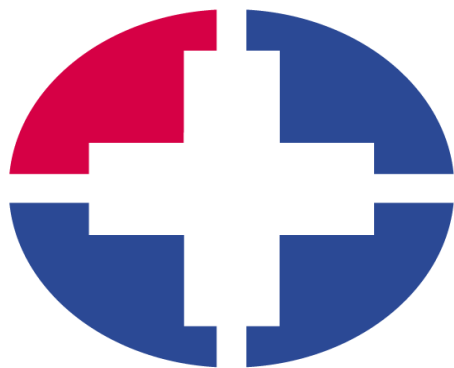
- Developing an assessment tool that pinpoints relevant daily life challenges that patients with neglect are confronted with, is a prerequisite for mobilizing outcome measures that have clinical significance
- **Stage I:** Validating the star cancellation as a ward based screening procedure for neglect identification
- **Stage II:** Developing and validating a neglect assessment instrument
- **Stage III:** Examining effects of two interventions; emotional cueing and Smooth pursuit eye movement training SPEMT

*The take home message...

- Neglect is not always obvious (as seen with the man and dog)
- Identification depends heavily on professional knowledge of the array of clinical manifestations
- Incorporation of diagnostic tools and development of clinical tools are needed to optimize detection of neglect and synergistic application of interventions to promote health and safety

Drawing by Federico Fellini (1920-1993)
suffered his first stroke in August 1993





LANDSPÍTALI
HÁSKÓLASJÚKRAHÚS



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 - The University of Iceland, doctoral grant
 - The Icelandic Nurses Association, research and science fund
 - Ingibjörg R. Magnúsdóttir research fund

*Strenghts and limitations

- Selection of participants - all with moderate to severe neglect at inclusion - homogeneous sample
- 29 participants out of 564 patients with stoke
- Validated and reliable tool to confirm neglect severity - Catherine Bergego Scale
- Quantitative use of tests to identify neglect were supplemented with “real life observations”
- Rigorous study of phenomenology as a part of the thesis program
- Multi professional experts
- Methods used to assess neglect are pertinent for nurses in clinical care
- Interventions identified are applicable in clinical practice