PHYSICAL EXERCISE IN CHILDREN WITH INTELLECTUAL DISABILITIES AND EPILEPSY – A QUALITATIVE STUDY ON NURSES' PERSPECTIVES

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S.A.W. (Suzanne) Leijten, RN 3870030 Final version 04-07-2014 Utrecht University **Clinical Health Science** Nursing Science, UMC Utrecht **Master Thesis** I.E. (Irina) Poslawski PhD, RN Kempenhaeghe, Heeze L.M.C. (Laura) Gottmer-Welschen, PhD Prof. A.P. (Bert) Aldenkamp, PhD I.Y. (Francis) Tan, MD International Journal of Nursing Studies Harvard 2000-5000 COREQ M.C. (Marijke) Kars PhD, RN Vancouver 3493 300/298

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INTRODUCTION

Children with intellectual disabilities (ID) and epilepsy have an increased risk for developing osteoporosis due to a combination of antiepileptic drugs and oftentimes impaired physical mobility.^{1,2} This risk increases when there is a possible nutritional deficiency due to liquidised diets or an impaired metabolism and/or when genetic conditions with an increased fracture risk are present.³ The World Health Organization (WHO) recommends regular physical exercise to be part of lifestyle interventions directed at patients at risk of developing osteoporosis.^{4,5} Caspersen and colleagues^{6(p128)} describe physical exercise as 'physical activity that is planned, structured, repetitive, and purposive in a sense that improvement or maintenance of one or more components of physical fitness is an objective'. Prevention and management of osteoporosis by physical exercise seem most worthwhile in childhood, because then the skeleton is most susceptible to the benefits.^{4,5,7}

Results of several studies evaluating the effect of physical exercise on bone health in small subsamples of children with ID showed at least modest positive effects.^{3,8-11} Unfortunately, two systematic reviews focussing on children with ID concluded that these children lack in physical exercise.^{12,13} Patients with epilepsy are often excluded from physical exercise due to fear of high risk of injury.¹⁴ Of all epilepsy patients, institutionalized patients exercise the least.¹⁴ Based on this knowledge, it is proposed children with ID and epilepsy lack in physical exercise. Moreover, a vast distance was seen in general recommendations suggested by the WHO and required actions in care practice.

The various physical exercise interventions to improve health in persons with ID, that have been put forward, are found impractical and are not integrated in current care models.¹⁵ Earlier interventions (e.g. treadmill interventions, fitness and standing programs) appeared to be time-consuming, unsustainable, or expensive.¹⁵⁻¹⁷ To ensure practicality of new interventions, early attention to the implementation opportunities and the likely response of the target group are recommended.¹⁸ Hence, there is a need for understanding of factors influencing physical exercise in intellectually disabled care to design feasible interventions.¹³

A review of Frey, Stanisch and Temple¹³ described a lack of studies centring on factors influencing physical activity in children with ID. A systematic review of Bodde and Seo¹⁹ of both quantitative and qualitative studies on factors influencing physical activity in adults with ID found transportation issues, financial limitations and lack of awareness of options to exercise. Other salient barriers included negative supports from caregivers and authority figures (e.g. teachers, coaches and parents) and lack of clear policies for engaging in regular activity in residential and day service programs.¹⁹ It is expected that the influencing factors of this review are not simply generalizable to children with ID and epilepsy. These children have

significant differences in support needs due to the combination of childhood, severity of ID, epilepsy and oftentimes impaired mobility.²⁰

Because of their need for support from others in their daily lives, the perspective of caregivers on facilitating exercise participation and adherence needs to be further explored.¹³ Nurses are considered to be important stakeholders. They usually take on the largest part of 24-hour care and have experience working with children with ID and epilepsy.³ Therefore, they can contribute to the development of effective intervention strategies.²¹

PROBLEM STATEMENT, AIM, AND RESEARCH QUESTION(S)

Physical exercise in children with ID and epilepsy is complicated. Given the importance placed on physical exercise to be part of prevention and management of osteoporosis^{4,5}, it is an area that warrants examination. Involvement of users and thinking in terms of practicality at an early stage, improves the chance of successful implementation of an intervention.¹⁸ This qualitative study aimed to obtain insight into nurses' perspectives on factors that directly or indirectly influence physical exercise in these children. These findings contribute to the design of a feasible physical exercise intervention to prevent and manage osteoporosis. Two questions were formulated to address both needs and requests of care, and practicality of an intervention:

- What, according to nurses, influences the feasibility of physical exercise by children with ID and epilepsy?
- 2. What, according to nurses, influences effective implementation of physical exercise interventions in care for children with ID and epilepsy?

METHODS

DESIGN

A generic qualitative approach was used, implying that not one specific qualitative methodology guided the study.²² Qualitative methods can provide insight and in-depth understanding of needs, perspectives and constraints of stakeholders during the design phase of interventions.^{21,23} To ensure clarity in this generic qualitative study, notation of the researchers' positions, distinguishing method and methodology, explicit approach to rigor, and the researchers' analytic lens were provided, as recommended by Caelli, Ray and Mill.²²

RECRUITMENT AND SAMPLE

Nurses were recruited from two child residential units at Kempenhaeghe, an academic centre for epileptology, sleep medicine and neurocognition in The Netherlands. The staffs cared for children from six to twenty years, with moderate to profound ID, all with a complex form of epilepsy (Table 1). Initially, all 48 staff members received an invitation e-mail using their manager. Of the 20 respondents, 12 Registered Nurses became participants. Inclusion of at least 12 participants is recommended when trying to achieve maximum variation.²⁴ Purposive sampling included participants with a range of characteristics that might influence nurses' perspectives (gender, residential unit, education, working experience and size of labour agreement). Participants received an e-mail with an information letter and a brief demographic questionnaire. Scheduling of interviews was at a time convenient for participants at a quiet location at the residential units. The sample consisted of ten female and two male nurses, working with an experience range of 2-40 years. Six participants were nurses without a Bachelor of Nursing Degree, five had a Bachelor of Nursing Degree and one nurse had a Master's Degree (Table 1).

[Table 1: participants' characteristics]

DATA COLLECTION

This study used face-to-face, semi-structured interviews. This enabled contact with nurses involved to an extent that is necessary to grasp what is going on in the field.²¹ Educational heterogeneity of nurses could hinder equal contribution in focus group interviews.²⁴ One researcher (SL) conducted all 12 interviews of approximately one hour, between January and April 2014. To ensure reliability, a semi-structured topic list guided the interviews, based on literature and discussions with experts (LGW and YT). Table 2 shows the first question, topics and a selection of questions on the topic list. Participants were also encouraged to raise issues that were relevant to them but not included in the topic list. Prior to data collection, the topic list and interview style were tested in two pilot interviews. These interviews, with nurses caring for similar children, are not included in the study. All interviews were recorded using digital audio equipment. Recordings were safely locked away after verbatim transcription. The interviewer wrote field-notes summarising the interviews and highlighted key issues up soon after each interview. The interviewer presented verbatim transcribed and anonymised interviews to participants and asked them whether they verified the information in order to achieve member validation for credibility of results.²⁴

[Table 2: topic list]

DATA ANALYSIS

Analysis was part of a cyclic process of data collection and data analysis. This process in turn guided future data collection and sampling of participants. The analyst team consisted of three researchers (SL, LGW, AA). Two researchers (SL, LGW) both independently coded two transcripts to check intercoder agreement. Meaningful segments were 'active' coded in line with Charmaz.²⁶ One researcher (SL) developed a codebook in a two-part process: (1) preparation of the coding work, using only paper and pencil and (2) the actual coding process, using the qualitative software program QSR NVivo 10. This process is based on the Qualitative Analysis Guide of Leuven (QUAGOL).²⁷ Given the importance of feasibility of a new intervention, subsequently, the seven domains of the Tailored Implementation for Chronic Diseases checklist (TICD-checklist)²⁸ were used as theoretical concepts. The TICD-checklist is a tool for identifying factors influencing improvements in health care practice, including patient factors, with focus on providers (Appendix 1).²⁸ This more deductive approach allowed systematic exploration of factors influencing physical exercise in the data.

The analyst team attempted to achieve consensus on the interpretation by discussing the condensing of codes into categories. One data analyst (SL) checked interpretations against existing data and new material. Initial categories were discussed after seven and twelve interviews in the multidisciplinary research team Chronic Epilepsy and ID of Kempenhaeghe. This fostered a higher level of conceptual thinking in the analysis process.²⁹ Different interests in this research project brought new input into the discussion, because of different professional and personal knowledge, experience and baggage. The method employed constituted researcher triangulation and increased depth and reliability of analysis.

Data collection was finished after clarity on definition and properties of each category. Saturation was reached on a conceptual level. Given the complexity and number of variables saturation was not reached in detail.

ETHICAL CONSIDERATIONS

The Medical Ethics Committee and Scientific Research Committee of Kempenhaeghe approved the study. Data collection was in accordance with the Declaration of Helsinki.²⁵ All participants gave written informed consent to be interviewed and audio recorded. The interviewer promised confidential handling of the data and affirmed this by signing the confidentiality agreement on each consent form. Participants were free to terminate their participation at any point.

RESULTS

Nurses were asked to provide their perspective on factors influencing the feasibility of physical exercise in children with ID and epilepsy and effective implementation of physical exercise interventions in care. Since children's needs, beliefs, motivation, behaviour and preferences are incorporated in patient factors in the TICD-checklist, all factors were organised into seven categories, based on the domains of the TICD-checklist: (1) child factors, (2) individual nurse factors (3) intervention factors, (4) professional interactions, (5) incentives and resources, (6) capacity for change and (7) societal factors. Table 3 shows a selection of quotes supporting the categories.

CHILD FACTORS

All nurses reported the importance of children's characteristics in physical exercise. Furthermore, these characteristics affected their drive to perform exercise interventions. Children's severity of epilepsy, disability level, impaired mobility and behaviour problems were commonly cited complicating factors. Most nurses indicated children's characteristics demand focuses on fall risk and use of restraints. Additionally, some children had contraindications on physical exercise, because it provokes seizures.

Playing is considered one of the most natural ways for children to be physically active by nurses interviewed. Sensory stimuli also play a significant role in current care practice. Mentioned physical exercise interventions are e.g. dancing, multi-sensory stimulation, hydrotherapy and equine-assisted therapy. Although all children generally like physical exercise, many nurses indicated children's needs and preferences are child, situation and content specific. Nurses reported children's fluctuating health and mood determine perspectives, motivation and wishes of children. Some perceived it as harder to promote physical exercise in children without preference of physical activity.

All nurses repeatedly indicated that the children particularly need clarity. According to them, this means that the content of an intervention, its performer, the environment and communication about the physical exercise must be clear to them. They reported lack of clarity could cause stress, resistance and problem behaviour. In addition, most nurses indicated that according to children, the performer of an intervention should be a person who knows performing exercise interventions in this specific target group, aligning the interventions at the varied levels and perspectives of children.

INDIVIDUAL NURSE FACTORS

Many nurses reported that focus on nutrition, supplements and medications in multidisciplinary care last year, caused attention to the risk of osteoporosis. More than half of the participants referred to importance of physical exercise to benefit overall health and wellbeing. All nurses suggested experts should give them more information and education. Education should include information about the importance and benefits of physical exercise. Some nurses mentioned the need for information about how to tailor interventions to individual needs, and ways to monitor physical exercises to make them safe and enjoyable. The expert could be a physiotherapist, physician or researcher. Nurses proposed both on-and off-the-job training of performing adequate interventions. Further, performance should at least temporarily be guided by movement experts to ensure correctness, but preferably prolonged. Some nurses mentioned the need for continued attention to physical exercise during and after implementation.

Nurses mentioned they all strive for best possible care for this vulnerable group. Therefore, they assumed physical exercise would get priority if they were more aware about importance and benefits. Wellbeing, measured by observable comfort and enjoyment in children, encourages nurses in performing essential interventions. However, children's fluctuating health and mood created doubt among nurses about feasibility of compliance to recommendations.

Physical exercise interventions are not incorporated in nurses' daily routines. Nurses described that they currently have a supporting role, but exercising is usually attributed to movement experts. Many nurses would like to improve care; however, they perceived few opportunities. They already felt demonstrating maximum effort to integrate physical exercise in care. Lack of time in their schedule is the most frequently cited barrier to change. Two nurses indicated that current opinions are based on present limitations of children and care, rather than on potential.

INTERVENTION FACTORS

Several nurses described the need for ability to try out and evaluate new interventions with children in the residential environment, because impacts could be unpredictable in this target group. Moreover, they declared that performing physical exercise interventions can conflict with precautions for fall risk, maintaining balance in activity/rest and preventing behaviour problems. Additionally, they reported that benefits of interventions should be clear for nurses to promote adherence. This first includes enjoyment and subsequently maintenance or progress in children's physical capabilities.

PROFESSIONAL INTERACTIONS

According to nurses, personal care plans only include physical exercise interventions in case of problems with the musculoskeletal or motor skills. They reported that physical therapists planned individual interventions in current care. Nurses, as well as activity therapists, supported and performed instructed interventions. Several nurses indicated that monitoring bone health should be particularly a physician's task. They agreed that integration of new interventions in personal care plans and/or daily schedules could support effective implementation. Additionally, the electronic patient record could contribute to accurate multidisciplinary transfer of information about physical exercise.

Care is discussed monthly in multidisciplinary team meetings. Many nurses indicated that the child psychologist is most influential in determining multidisciplinary care. Some nurses felt implementation would be successful, if interventions were commanded by the child psychologist. A few nurses reported that enhanced coordination of interventions by a movement expert could also be a facilitator.

INCENTIVES AND RESOURCES

Nurses' assessment of availability of resources varied from limited to practically sufficient. Some nurses mentioned need for extra (play) equipment, facilities, supporting staff and transport, but also making more effective use of existing resources. A few nurses reported that use of volunteers is complicated because of the complexity in guiding these children.

CAPACITY FOR CHANGE

Most nurses indicated that care has been shifted, due to the use of the current pedagogical approach instead of the former medical model. Higher educated nurses pronounced that this approach increases opportunities to perform physical exercise interventions in addition to personal care, due to an increased attention to wellbeing. Nurses caring for children with severe or profound ID indicated that, even now, personal care requires considerable time.

All nurses reported that the willingness to think in solutions to change is present at the caregiving staff. They emphasized most nurses still have other priorities, like daily living assistance and non-patient dependent tasks. Some nurses indicated that formal inclusion of attention to physical activity to residential or organisational vision could increase performance of interventions. Members of one team named instant feedback as a tool to achieve desired behaviour.

SOCIETAL FACTORS

Almost all nurses mentioned that they experience a significant decline in the national health care budget. This reduces opportunities to organize structural, supervised activities for exercise promotion at the residential units. They named financial incentives would greatly increase possibilities.

Most nurses emphasized parents' voluntary participation in care. A few nurses mentioned some parents are involved in residential care and/or motivated to perform instructed interventions at home. Except for one group, most children stayed home during weekends. Some nurses described the segregation between life on the group and at home. They reported that information transfer would be necessary to continue interventions in weekends.

[Table 3: quotes]

DISCUSSION

This study identified a range of factors influencing physical exercise in children with ID and epilepsy from nursing perspective. Insight into children's needs and requests for care, in addition to insight in existing practices offers a point of departure for outlining the specific aspects and actions associated with physical exercise interventions.^{22,23}

Once influencing factors have been identified, it is important to prioritise them based on importance and amenability. Something that is important, but difficult to change, may not be a good use of resources compared with something that is important and easier to change.²⁸ For instance, limited budget and staff resources are relatively established facts. Children's fluctuating health and mood are also critical issues, but hardly amenable to change; epilepsy will affect practicality of interventions due to risk of falling and side effects of antiepileptic drugs. However, some of the factors, such as lack of awareness, knowledge and skills, may explain the lack of success in previous studies trying to evaluate physical exercise interventions in children with ID to promote bone health.^{3,8-10} Heller and colleagues found the carer's perception on benefits of physical exercise were positively related with higher levels of participation.³¹ A study of Tohil and Laverty³ found awareness and feedback sessions improved knowledge and skills, although exercising in persons with severe ID or more physical disabilities remained difficult.

Value was given to the practice and experiential knowledge of nurses. This study used proxy reports of nurses to explain diversity and complexity of children's needs and requests for care specific to physical exercise. Proxy reports are useful in case persons with ID have limited verbal skills.¹⁹ Nurses especially mentioned that children's characteristics and

preferences require tailored and flexible interventions. This corresponds with a qualitative, focus group study by Temple and Walkley³⁰ using proxy reports. They found caregivers assigned barriers to internal characteristics of adults with ID. Unlike the majority of adults with ID in their study³⁰, children with ID and epilepsy generally like physical exercise within their physical capabilities.

Care was taken to maximize sampling variation, as far as personal characteristics and the contextual variables are concerned. A clear definition of characteristics of nurses and the population they work with, as recommended by Frey, Stanish and Temple, improves replication of the study and clear interpretation of results. Nurses' sensitivity to some factors differed, depending on their education level, presence of behavioural and mobility problems and disability levels on their residential group. For example, nurses with a bachelor's degree referred more often to care innovation by nurses rather than by other disciplines.

A primary limitation of this study was that no model was created, because the focus of the TICD-checklist is identifying of completeness and grouping influencing factors of practice logically.²⁸ However, although the categories are described separately, in reality they are intertwined. Nurses' narratives reflected this interrelationship, although the topic list was divided in two themes. This is consistent with findings of the review of Bodde and Seo.¹⁹ They found studies using health promotion models describing context and intervening conditions of physical activity in adults with ID. Better understanding of relationships between the influencing factors could support intervention strategies.¹³

Data analysis explored which influences are important to the feasibility of a new intervention. Findings can also facilitate tailoring more effective change interventions.³² For instance, it should be noted that physicians, child psychologists and psychical therapists were considered as experts; with some nurses stating they would follow any given guideline of an expert. In the light of this knowledge, professional interaction needs attention in implementation. Insight in influencing factors can facilitate evaluation and reporting of tailored interventions.³² This will support implementation at practice, practitioner and child level. Eventually, this will improve clinical outcomes.³³

CONCLUSION AND RECOMMENDATIONS

This study provides an overview of factors influencing physical exercise in care for children with ID and epilepsy. Interviews with involved nurses confirmed that physical exercise in practice is complicated. However, designers of a new physical exercise intervention may consider some of these factors in order to increase feasibility. The results show that child factors, both characteristics and preferences, ask for flexibility and tailoring of a new physical exercise intervention to individuals, subgroups or local circumstances at residential units. Furthermore, individual nurse factors, particularly awareness, knowledge and skills, and professional interaction are critical issues contributing to feasibility.

Although this study provided a rich and in-depth insight in factors influencing physical exercise in children with ID and epilepsy, other studies would be informative for practice. The sample was limited to nurses. However, it is valuable to replicate this study with other stakeholders in care practice, because their perspective could differ greatly in nature. Parent reports can also contribute to effective intervention strategies.¹⁸ After the design phase, an ongoing dialogue with stakeholders and a qualitative field study in the test phase of a new intervention will ensure rooting within actual experiences rather than opinions.²¹

REFERENCE LIST

- Aronson E, Stevenson SB. Bone health in children with cerebral palsy and epilepsy. Journal of Pediatric Health Care 2012;26:193–9
- Bergqvist AGC, Schall JI, Stallings VA, Zemel BS. Progressive bone mineral content loss in children with intractable epilepsy treated with the ketogenic diet. American Journal of Clinical Nutrition 2008; 88(6):1678-1684.
- Tohill C, Laverty A. Sunshine, diet and mobility for healthy bones an intervention study designed to implement these standards into the daily routine in an at risk population of adults with intellectual disability. Journal of Intellectual & Developmental Disability 2001 09;26(3):217-231.
- 4. World Health Organization. Prevention and Management of Osteoporosis. Technical Report Series, No. 921. Geneva: WHO Marketing and Dissemination, 2003.
- 5. World Health Organization. WHO scientific group on the assessment of osteoporosis at primary health care level. WHO, 2004.
- Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Reports 1985 Mar-Apr; 100(2):126-131.
- 7. Ondrak K, Morgan D. Physical activity, calcium intake and bone health in children and adolescents. Sports medicine 2007; 37(7): 587-600.
- González-Agüero A, Vicente-Rodríguez A, Gómez Cabello A, Ara I, Moreno L, Casajás J. A 21-week bone deposition promoting exercise programme increases bone mass in young people with Down syndrome. Developmental Medicine & Child Neurology 2012; 54(6): 552-556.
- Hemayattalab R. Effects of physical training and calcium intake on bone mineral density of students with mental retardation. Research in Developmental Disabilities 2010 May-Jun;31(3):784-789.
- Reyes ML, Hernandez M, Holmgren LJ, Sanhueza E, Escobar RG. High-frequency, lowintensity vibrations increase bone mass and muscle strength in upper limbs, improving autonomy in disabled children. Journal of Bone and Mineral Research 2011 Aug;26(8):1759-1766.
- Ward K, Alsop C, Caulton J, Rubin C, Adams J, Mughal Z. Low magnitude mechanical loading is osteogenic in children with disabling conditions. Journal of Bone and Mineral Research 2004;19(3):360-369.
- Newacheck PW, Strickland B, Shonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C, Fox H, Arango P. An epidemiologic profile of children with special health care needs. Pediatrics 1998;102(1):117-123.

- 13. Frey G, Stanish H, Temple V. Physical activity of youth with intellectual disability: review and research agenda. Adapted physical activity quarterly 2008;25(2):95-117.
- Ellertsen B, Eriksen HR, Motovsky DI. H 5 Exercise and epilepsy. In: Motovsky DI, Loyning Y, editors. The neurobehavioral treatment of epilepsy. 1st ed. New Jersey: Lawrence Erlbaum Associates, inc; 1993. p. 177-203.
- 15. Schijndel-Speet M van, Evenhuis H, Empelen P van, Wijck R van, Echteld M. Development and evaluation of a structured programme for promoting physical activity among seniors with intellectual disabilities: a study protocol for a cluster randomized trial. BioMed Central Public Health 2013;13:746-746100.
- 16. Bergström H, Hagströmer M, Hagberg J, Elinder L. A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomised controlled trial. Research in Developmental Disabilities 2013;34(11):3847-3857.
- 17. Elinder L, Bergström H, Hagberg H, Wihlman U, Hagströmer M. Promoting a healthy diet and physical activity in adults with intellectual disabilities living in community residences: design and evaluation of a cluster-randomized intervention. BioMed Central Public Health 2010;10:761-761.
- 18. Grol R, Wensing M. Implementatie. 3rd ed. Amsterdam: Reed Business; 2011.
- 19. Bodde AS, Dong-Chul. A review of social and environmental barriers to physical activity for adults with intellectual disabilities. Disability and health journal 2009;2(2):57-66.
- 20. Bowley C, Kerr M. Epilepsy and intellectual disability. Journal of Intellectual Disability Research 2000;44(5):529.
- 21. Gamel C, Grypdonck M, Hengeveld M, Davis B. A method to develop a nursing intervention: the contribution of qualitative studies to the process. Journal of Advanced Nursing 2001;33(6):806-819.
- 22. Caelli K, Ray L, Mill J. 'Clear as mud'. Towards a greater clarity in generic qualitative research. International Journal of Qualitative Methods 2003. 2(2)1–23.
- 23. Meijel B van, Gamel C, Swieten-Duijfjes B van, Grypdonck M H F. The development of evidence-based nursing interventions: methodological considerations. Journal of Advanced Nursing 2004;48(1):84-92.
- 24. Holloway S, Wheeler I. Qualitative research in nursing and healthcare. 3rd ed. Oxford: Wiley-Blackwell; 2010.
- 25. Declaration of Helsinki. Ethical principles for medical research involving human subjects. Journal of Indian Medical Association 2009;107(6):403-405.
- 26. Charmaz K. Construction Grounded Theory: A Practical Guide through Qualitative Analysis. 1st ed. London: SAGE publications ltd.; 2006.

- 27. Dierckx de Casterlée B, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. International Journal of Nursing Studies 2012;49(3):360-371.
- 28. Flottorp SA, Oxman AD, Krause J, Musila NR, Wensing M, Godycki-Cwirko M, et al. A checklist for identifying determinants of practice: a systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice. Implementation Science 2013 Mar 23;8:35-5908-8-35.
- 29. Boeije H. Analysis in Qualitative Research. 1st ed. London: Sage Publications; 2010.
- 30. Temple VA, Walkley JW. Perspectives of constraining and enabling factors for healthpromoting physical activity by adults with intellectual disability. Journal of intellectual & developmental disability 2007;32(1):28-38.
- 31. Heller T, Ying Gs, Rimmer J, Marks B. Determinants of exercise in adults with cerebral palsy. Public health nursing 2002;19(3):223-231.
- 32. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. British Medical Journal 2008 Sep 29;337:a1655.
- 33. Jäger C, Freund T, Steinhäuser J, Aakhus E, Flottorp S, Godycki Cwirko M, Lieshout J van, Krause J, Szecsenyi J, Wensing M. Tailored Implementation for Chronic Diseases (TICD): a protocol for process evaluation in cluster randomized controlled trials in five European countries. Trials 2014;15:87-87.

TABLE 1.

Characteristics of the participants (N=12) and setting

Characteristics	Ν						
Gender	Gender						
Male	2						
Female	10						
Highest level of nursing education							
No Bachelor of Nursing Degree	8						
Bachelor of Nursing Degree	3						
Master's Degree	1						
Employment status (%) [*]							
50-75	4						
75-100	8						
Total work experience (years)							
<10	3						
10-20	4						
>20	5						
Work experience current residential group (years)							
>5	5						
5-10	3						
>10	4						
Work site nurses							
Residential unit 1	7						
Residential unit 2	5						
Age children residential units							
5-10	10						
10-15	15						
15-20	17						
Gender children residential units							
Male	25						
Female	17						
Classification of intellectual disability children							
Moderate	6						
Severe	19						
Profound	17						
Mobility Children							
Ambulant	14						
Partly wheelchair dependent	13						
Wheelchair dependent	15						
Day care children							
Activity therapy	20						
Special needs education	22						

100%=36 hours

TABLE 2.

Topics and selection of questions on the topic list

Opening question

What are your experiences with physical exercise interventions in this target population?

Theme 1

Feasibility physical exercise by children with intellectual disabilities and epilepsy (nurse is used as proxy)

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	1.	Children's preferences	1.	What physical exercise do children in your group prefer?
	2.	Frequency	2.	How often do children in your group like to exercise?
	3.	Duration	3.	How long do you think it is pleasant to exercise for these children?
	4.	Performer	4.	Who will children choose as performer of physical exercise interventions?
	5.	Facilitators	5.	What helps these children in physical exercise?
	6.	Barriers	6.	What hinders these children in physical exercise?

Theme 2

Requisites for implementation of physical exercise in daily care

1.	Current physical exercise interventions	1.	What physical exercise interventions are used in daily practice?
2.	Opportunities in current care	2.	What opportunities do you see to improve physical exercise in your group?
3.	Implementation in current care	3.	What influences performing physical exercise interventions in daily practice?
4.	Facilitators feasibility	4.	What helps performing physical exercise?
5.	Barriers feasibility	5.	What hinders performing physical exercise?
6.	Intended result	6.	What should be the result of physical exercise interventions?
7.	Required disciplines	7.	What disciplines should be part of multidisciplinary prevention and management of deterioration in bone health?
8.	Performer	8.	What discipline(s) should be the performers of physical exercise interventions in these children?
9.	Nurses' role	9.	What is/should be the role of nurses in physical exercising?
10.	Requisites nurses	10.	What do you need to support physical exercising?

TABLE 3.

Factors influencing physical exercise in children with intellectual disabilities and epilepsy

INFLUENCING	ILLUSTRATIVE QUOTES*
FACTORS	
Child factors	A nurse caring for children with profound ID** spoke about a child's fluctuating health influencing performance of physical exercise interventions: 'One day a child is very dopey due to seizures and medication, and the other day he feels totally happy. You should actually be able to anticipate to his needs of the moment. That would be the finest, '(P1) A nurse caring for children severe to profound ID and behavioural problems spook about the need for clarity in children: 'I think predictability supports children in physical exercising. They should be aware of the next activity and what they can expect. A fixed order in the activity and a well-known instructor supports them in physical exercising.' (P9)
Individual nurse factors	A nurse pronounced the lack of knowledge and skills in nurses impede performance of physical exercise interventions: 'A bit of knowledge and understanding might be missing in people. Implementation of interventions depends on valuation of importance. This determines whether a colleague chooses to perform physical exercise interventions or chooses to draft a personal care plan.' (P7) Another nurse mentioned specific knowledge and skills for the complex target group: 'Some professionals have better skills to read the children's body language as other professionals. It depends on how often you care for these children. When a child stays on the residential group for five years, you can better interpret the child, than if you have never seen it.' (P3)
	A nurse caring for young children with mild to severe ID indicated visible enjoyment motivated her and her colleagues to perform exercises: 'When we see children are having fun, we tent to persevere. When I see a child smiles and is comfortable, I really enjoy stimulating physical exercises. I actually plan regular quality time for the kids during my shift' (P12) One of the nurses spoke about nurses' current professional behaviour: 'Our starting points are a child's disabilities and poor physical condition, while we do not see a child's abilities to increase health status. Currently, nurses feel they abuse a child by offering a standing program. Nurses only want comfort for children, while I think comfort and development perfectly fit. First, a girl could not sit in an active position for three minutes. Nurses judged an intervention to achieve a more upright and active sitting position was a big challenge; they believed she was not able to improve. After a lot of practice she can already sit for ten minutes. Success motivated them to persevere in
Intervention factors	<i>difficult moments</i> '. (P5) A nurse caring for children with mild to severe epilepsy explains severe epilepsy entails careful risk assessment that influences physical exercise:

	'One child always had seizures while swimming. Then you'll be thinking: exercise is fun, but is it worth doing? The risk is significant in the pool. I think the risk certainly is important. Children like to play in the playground, but I experienced once a child fell because of a seizure.' (P5)
Incentives and resources	A nurse caring for children with severe and profound ID spoke about the lack of human resources: 'I have a lot of ideas, but then sufficient staff should be available. When we would have more staff, we would have more time to exercise with children. We spend little time on exercising. I think it should be more. But time is scarce due to children's vulnerable health that asks a lot of care of our limited staff.' (P2)
Capacity for change	A nurse caring for children with behaviour problems explains current attitudes in nurses: <i>'I think we are on the right track to give physical exercise more</i> <i>attention, but we could do more. Recently, I had to work during the</i> <i>holiday period. Colleagues told me in the face-to-face handover at</i> <i>nursing shift change that they did not support children in physical</i> <i>exercise. I expressed my deep indignation. It is my opinion that we</i> <i>have extra time for children during holiday periods. At that moment, I</i> <i>point out my colleagues on their attitude' (P9)</i>
Professional interactions	A nurse of the only non-closed group spoke about the role of other disciplines to enable more physical exercise: 'Physical therapists or movement therapists should develop and supervise physical exercise interventions. They are educated to guide children in physical exercising. Furthermore, they are able to adjust exercises. Nurses do not have specialised knowledge of physical exercise. Our role would be supporting activities because of seizures and behaviours. (P6).
Societal factors	A nurse caring for children with mild to severe ID recounted about the effect she noticed of decline of the health care budget: 'I tried to organize judo, because the children were very enthusiastic after a clinic last year, but every time I hear there is no longer budget for such things.' (P10)

^{*}Quotes have been translated and slightly edited to increase readability.

**ID=intellectual disabilities

NEDERLANDSE SAMENVATTING

Titel: Lichaamsbeweging door verstandelijke beperkte kinderen met epilepsie - kwalitatieve studie naar het perspectief van verpleegkundigen.

Inleiding: Lichaamsbeweging zou onderdeel moeten zijn van preventie en behandeling van osteoporose bij verstandelijke beperkte kinderen met epilepsie. Beweeginterventies blijken echter vaak onpraktisch. Het al in een vroeg stadium betrekken van de gebruikers en denken in termen van uitvoerbaarheid dragen bij aan de ontwikkeling van haalbare beweeginterventies. Verpleegkundigen zijn belangrijke betrokkenen in de zorgpraktijk. *Doel en onderzoeksvragen:* Deze kwalitatieve studie beoogde inzicht te krijgen in factoren die lichaamsbeweging door deze complexe doelgroep beïnvloeden vanuit verpleegkundig perspectief. Twee onderzoeksvragen werden vastgesteld:

- 1. Wat beïnvloedt volgens verpleegkundigen de haalbaarheid van lichaamsbeweging door kinderen met een verstandelijke beperking en epilepsie?
- Wat beïnvloedt volgens verpleegkundigen de effectieve implementatie van beweeginterventies voor kinderen met een verstandelijke beperking en epilepsie?
 Methode: Twaalf semigestructureerde interviews vonden plaats met verpleegkundigen van

twee woonafdelingen van een centrum voor epilepsiewoonzorg in Nederland. De basis van de analyse van de getranscribeerde interviews was de Qualitative Analysis Guide of Leuven. Zeven domeinen van de Tailored Implementation for Chronic Diseases checklist waren theoretische concepten bij de analyse.

Resultaten:

In de verhalen van verpleegkundigen kwamen zeven hoofdcategorieën van beïnvloedende factoren voren: kinderfactoren; individuele factoren bij de verpleegkundige; interventiefactoren; professionele interacties; stimulansen en middelen; vermogen tot verandering; maatschappelijke factoren.

Conclusie: Deze studie geeft een overzicht van factoren die lichaamsbeweging door verstandelijk beperkte kinderen met epilepsie beïnvloeden. Met een aantal van deze factoren kan bij de ontwikkeling van een nieuwe beweeginterventie rekening gehouden worden. Kinderfactoren, zowel hun kenmerken als wensen, vragen op een flexibel inzetbare interventie, op maat gemaakt per individu, subgroep of lokale omstandigheden. Om de haalbaarheid te vergroten is aandacht nodig voor individuele factoren bij de verpleegkundigen, in het bijzonder bewustzijn, kennis en vaardigheden, en de professionele interactie rondom lichaamsbeweging.

Trefwoorden: lichaamsbeweging; verstandelijke beperking'; epilepsie; kinderen; interventie

ENGLISH ABSTRACT

Title: Physical exercise in children with intellectual disabilities and epilepsy - A qualitative study on nurses' perspectives

Background: Physical exercise should be part of prevention and management of osteoporosis in children with intellectual disabilities and epilepsy. However, physical exercise interventions often prove impractical. To develop feasible interventions, early thinking in terms of practicality and involvement of users is requested. Nurses are considered to be important stakeholders in care.

Aim and research questions: This qualitative study aimed to obtain insight in nurses' perspectives on factors that influence physical exercise in this complex target group. Two research questions were formulated:

- 1. What, according to nurses, influences the feasibility of physical exercise by children with intellectual disabilities and epilepsy?
- 2. What, according to nurses, influences effective implementation of physical exercise interventions in care for children with intellectual disabilities and epilepsy?

Method: Twelve semi-structured interviews were conducted with Registered Nurses of two units of a centre for residential epilepsy care in The Netherlands. Data analysis of verbatim transcribed interviews was based on the Qualitative Analysis Guide of Leuven. Seven domains of the Tailored Implementation for Chronic Diseases Checklist were theoretical concepts in the analysis.

Results: Seven main categories of influencing factors emerged from nurses' narratives: child factors; individual nurse factors; intervention factors; professional interactions; incentives and resources; capacity for change; societal factors.

Conclusion: This study provides an overview of factors influencing physical exercise in children with intellectual disabilities and epilepsy. Some of these factors can be taken into account in the development of a new intervention. Child factors, including characteristics and preferences, ask for flexibility and tailoring of an intervention to individuals, subgroups or local circumstances. Furthermore, individual nurse factors, particularly awareness, knowledge and skills, and professional interaction are critical issues contributing to feasibility.

Keywords: Physical exercise; Intellectual disability; Epilepsy; Children; Intervention

APPENDIX 1.

TAILORED IMPLEMENTATION FOR CHRONIC DISEASES (TICD) CHECKLIST²⁸

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
1. GUIDELINE FACTORS • Recommendation					
Quality of evidence supporting the recommendation	How confident we are in the estimates of effects	What is the quality of the evidence supporting the recommendation and has it been assessed appropriately?	The quality of the evidence that supports the recommendation may not be clear or may not be judged appropriately	Clearly and accurately communicate the quality of the evidence; Don't invest resources in implementing recommendations for which there is low quality evidence	Critical review of the guideline using GRADEi
 Strength of recommendation 	How confident we are that the desirable effects of adherence to the recommendation outweigh the undesirable effects	What is the strength of the recommendation, has it been assessed appropriately, and are the implications of the strength of the recommendation clearly communicated?	The strength of the recommendation may not be clear or appropriate, or the implications of a weak recommendation may not be clearly communicated2	Clearly communicate the implications of the strength of the recommendation	Critical review of the guideline using GRADEii
• Clarity	The clearness of the target population, the settings in which the recommendation is to be used and the recommended action	Is the recommended action (what to do) stated specifically and unambiguously? Is sufficient detail provided to allow the targeted healthcare professionals to perform the recommended action?	The recommendation may be ambiguous, lack sufficient detail or be longwinded	Clearly communicate a specific and unambiguous action with sufficient detail about how to do it to allow the targeted healthcare professionals to perform the recommended action	Critical review of the guideline using the GuideLine Implementability Appraisal (GLIA) iii
Cultural appropriateness	The extent to which the recommendation is suitable in the social context where it is being implemented	Is the recommendation culturally appropriate?	The recommendation may not be congruous with customs or norms in the context where they are being implemented	Adapt the recommendation so that it is congruous; Communicate the recommendation in a way that is more congruous	Reflexion; Interviews or focus group discussion with targeted healthcare professionals and with patients

1 The examples are presented as barriers that might hinder implementation of a recommendation. However, factors can also be facilitators that could be capitalised on to help implement a recommendation. 2 I.e. it may be implied that a weak recommendation is not important rather than that clinicians should be prepared to help patients to make decisions that are consistent with their own values.

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Accessibility of the recommendation	How accessible the guideline or recommendation is	Is the guideline or recommendation accessible	The guideline may be long or poorly written; The recommendation may be buried in the guideline or one of a long list of recommendations; The guideline may not be available in a format (e.g. electronically) that appeals to the targeted healthcare professionals	Provide a concise guideline with easily identifiable recommendations in a format that appeals to the targeted healthcare professionals	Critical review of the guideline using the GuideLine Implementability Appraisal (GLIA) iii
Source of the recommendation	The organisation(s) and people that made the recommendation	Do the organisation(s) and people who made the recommendation have credibility with the targeted healthcare professionals?	The organisation or people that made the recommendation may lack credibility with the targeted healthcare professionals	Ensure that the recommendation is made or endorsed by an organisation and people that have credibility with the targeted healthcare professionals	Ask targeted healthcare professionals about their perceptions of the credibility of the organisation and people who made the recommendation
Consistency with other guidelines	The extent to which the recommendation is consistent with recommendations in other guidelines with which the targeted healthcare professionals might be familiar	Is the recommendation consistent with recommendations in other guidelines with which the targeted healthcare professionals might be familiar?	Conflicting recommendations may be confusing	Explain the reasons for conflicting recommendations to the targeted healthcare professionals	Examine the reasons for conflicting recommendations iv
Recommended clinical intervention	ion				
• Feasibility	The extent to which the recommended clinical intervention is practical	Is the recommended clinical intervention feasible for the targeted healthcare professionals?	The recommended clinical intervention may not be practical in some settings or may be perceived as not being practical	Ensure that the clinical intervention is practical; Provide necessary assistance to make it more practical; Address misperceptions of its practicality	Ask targeted healthcare professionals; Pilot test use of the clinical intervention in the targeted settings
Accessibility ty of the intervention	The extent to which the recommended clinical intervention is accessible	Is the recommended clinical intervention accessible?	The recommended clinical intervention may not be accessible in some settings	Ensure that the clinical intervention is accessible; Make it more accessible	Routinely collected data; Survey people in the targeted settings
Recommended behaviour					
Compatibility	The extent to which the recommended behaviour fits with current practices	Is the recommended behaviour compatible with existing practices?	The recommendation may disrupt the current work flow	Information or education that helps the targeted healthcare professionals to fit the recommended behaviour into their current practice	Focus group discussion with targeted healthcare professionals
• Effort	The amount of effort required to change or adhere	How much effort is required to adhere?	Adherence may require a substantial effort	Reduce the effort required, provide assistance or provide motivation	Interviews or focus group discussion with targeted healthcare professionals



Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
• Trialability	The ability to try out the recommended behaviour	Is it possible to try out the recommended behaviour?	The targeted healthcare professionals may be reluctant to change their behaviour if they cannot first try it out in conducive circumstances	Provide the targeted healthcare professionals the opportunity to try out the behaviour; e.g. at an educational meeting or with a simulated patient	Interviews or focus group discussion with targeted healthcare professionals
Observability	The degree to which benefits of the recommended behaviour are visible	Are the benefits of adhering to the recommendation observable?	The targeted healthcare professionals may have doubts about the benefits of adhering to the recommendation	Provide feedback, information or education regarding the benefits of adhering to the recommendation	Interviews or focus group discussion with targeted healthcare professionals about their perceptions of indicators of adherence or outcomes that can be measured
2. INDIVIDUAL HEALTH PROFES	SSIONAL FACTORS				
Knowledge and skills Domain knowledge	The extent to which the targeted	What knowledge or expertise	Exports and pop exports may	Change the mix of professional	Boutingly collected data regarding
Domain Knowledge	healthcare professionals have pre-existing knowledge or expertise about the targeted condition	what they need to know to adhere and to what extent do they have that knowledge or expertise?	have different educational needs; Implementing a recommendation based on new knowledge may require targeted efforts to disseminate that new knowledge	skills in the targeted teams or organisations; Tailor educational strategies to the level of expertise of the targeted healthcare professionals; Targeted dissemination of new knowledge	human resources for health; Interviews or focus group discussion with targeted healthcare professionals
Awareness and familiarity with the recommendation	The extent to which the targeted healthcare professionals are aware of and familiar with the recommendation	Are the targeted healthcare professionals aware of and familiar with the recommendation?	The volume of information, time needed to stay informed, and guideline accessibility	A dissemination strategy that is tailored to reach the targeted healthcare professionals	Survey, interviews or focus group discussion with targeted healthcare professionals
Knowledge about own practice	The extent to which the targeted healthcare professionals are aware of their own practice in relationship to the recommended practice	Are the targeted healthcare professionals aware of the extent to which they are adhering to the recommendation?	The targeted healthcare professionals may not be aware of their own performance	Audit and feedback	Audit and survey, interviews or focus group discussion with targeted healthcare professionals
Skills needed to adhere	The extent to which the targeted health professionals have skills that they need to adhere	What skills are needed to adhere and do the targeted health professionals have those?	The targeted health professionals may not have the necessary skills	Educational strategies with opportunities to practice necessary skills	Interviews or focus group discussion with the targeted health professionals

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Cognitions (including attitudes)					
Agreement with the recommendation	The extent to which the targeted healthcare professionals agree with the recommendation	Do the targeted healthcare professionals agree with the recommendation? If not, why?	The targeted healthcare professionals may interpret the quality of the evidence or its applicability differently, may not think the recommended intervention is cost-effective, or may lack of confidence in the guideline developer	Educational strategies that address the reasons for disagreement; A local consensus process	Survey, interviews or focus group discussion with targeted healthcare professionals
 Attitudes towards guidelines in general 	The perceptions that the targeted healthcare professionals have regarding guidelines in general	How do the targeted healthcare professionals view guidelines in general?	The targeted healthcare professionals may perceive guidelines as being oversimplified or cookbook, lacking sufficient flexibility or adaptability, restricting their autonomy, or not practical	Use strategies that do not depend on the targeted healthcare professionals' attitudes towards guidelines; Educational strategies that address negative attitudes towards guidelines; Design guidelines to address legitimate concerns	Survey, interviews or focus group discussion with targeted healthcare professionals
Expected outcome	The extent to which the targeted healthcare professionals believe that adherence with the recommendation will lead to desired outcomes	Do the targeted healthcare professionals believe that adherence with the recommendation will lead to desired outcomes?	The targeted healthcare professionals may not believe that adherence with the recommendation will lead to desired outcomes	Information or educational strategies that provide compelling evidence; Audit and feedback	Survey, interviews or focus group discussion with targeted healthcare professionals
Intention and motivation	The extent to which the targeted healthcare professionals intend to adhere and are motivated to do so	Do the targeted healthcare professionals intend to adhere? Are they motivated to adhere? What concerns do they have about adhering to the recommendation?	The targeted healthcare professionals may not intend to adhere; They may not be persuaded to change their behaviour due to inertia or their stage of change3	Local discussion and consensus; Discuss resistance; Provide good arguments why adherence is important; Involve opinion leaders; Strategies that are tailored to the stage of change of individuals in the targeted healthcare professional v	Survey, interviews or focus group discussion with targeted healthcare professionals
Self-efficacy	The targeted healthcare professionals' self-perceived competence or confidence in their abilities	Do the targeted healthcare professionals believe that they are capable of adhering to the recommendation? If not, why?	The targeted healthcare professionals may lack confidence in their ability to adhere	Skills training; Feedback; Education or counselling to change the targeted healthcare professionals' self-assessment of their competency	Interviews or focus group discussion with targeted healthcare professionals

3 Stages of change include contemplation, planning and undertaking actions, and appraising the outcomes of those actions. Individuals in different stages may be motivated by different factors.

Determinante	Definitions	Questions	Examples of enseifin factors1	Examples of related	Mathada for identifying the
Determinants	Demnitions	Questions	Examples of specific factors i	implementation strategies	determinants
Learning style	The preferred ways in which the targeted healthcare professionals learn	What types of continuing education do the targeted healthcare professionals prefer?	Continuing education strategies that do not fit with the preferences or routines of the targeted healthcare professionals may not be effective	Selection of continuing education strategies that fit with the preferences and routines of the targeted healthcare professionals	Survey, interviews or focus group discussion with targeted healthcare professionals
Emotions	The extent to which emotions affect adherence	Do the targeted healthcare professionals have emotions that facilitate or hinder adherence?	Adherence may be hindered by a lack of satisfaction, frustration, empathy or a lack of empathy, stress or burnout, cognitive overload or tiredness, or anticipated regret or fear	Strategies to increase satisfaction or reduce dissatisfaction; Strategies to reduce stress	Interviews or focus group discussion with targeted healthcare professionals
Professional behaviour					
Nature of the behaviour	Characteristics of the behaviour, including: frequency of performance for a patient, frequency of performance for a population of patients, the degree of habit or automaticity, whether it is within a sequence of other behaviours that have to be performed, and whether it is performed by one person or by different people	What do people currently do? Who needs to do what differently when, where, how, how often and with whom?	The targeted healthcare professionals may need to break a habit, establish a new habit, or be prompted to do something that is not routine	Modification of the context to prompt the new behaviour; e.g. reminders, changes in layout or equipment	Interviews or focus group discussion with targeted healthcare professionals
Capacity to plan change	The extent to which the targeted healthcare professionals have the capacity to plan necessary changes in order to adhere	What changes do the targeted healthcare professionals need to plan in order to adhere? Do they have the capacity to do this?	The targeted healthcare professionals may lack time or skills to plan necessary changes	Extra resources, support or aids to assist with planning necessary changes; Provide feasible objectives for change, an inventory of typical problems and solutions	Interviews or focus group discussion with targeted healthcare professionals
Self-monitoring or feedback	The extent to which the targeted healthcare professionals have the capacity for self-monitoring or feedback to reinforce adherence with the recommendation	Is self-monitoring or feedback of adherence with the recommendation needed? If so, do the targeted healthcare professionals have the capacity for this?	The targeted healthcare professionals may relapse to previous behaviours or forget to adhere; They may lack necessary ongoing support or resources to maintain adherence	Monitoring, feedback, reminder systems; Integration of the recommendation into routine care plans or local protocols; Provide necessary resources, support or rewards	Interviews or focus group discussion with targeted healthcare professionals
3. PATIENT FACTORS					
Patient needs	Real or perceived needs and demands of the patient	What are the targeted healthcare professionals' perceptions of the needs and demands of patients? How do those perceptions correspond with actual patient needs and demands?	Patients may make demands that hinder adherence; The targeted healthcare professionals may have misperceptions of patients' needs or demands	Patient education materials; Provide the targeted healthcare professionals with accurate information about patient needs and demands	Interviews or focus group discussion with targeted healthcare professionals and with patients

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Patient beliefs and knowledge	Patients' beliefs or knowledge or ability to learn, or the targeted healthcare professionals' ability or perceived ability to inform or teach patients necessary knowledge and skills	What are the targeted healthcare professionals' perceptions of patients' knowledge or ability to learn, or the targeted healthcare professionals' ability or perceived ability to inform or teach patients necessary knowledge and skills? How do those perceptions correspond with actual patient knowledge and ability to learn?	Patients may have beliefs that hinder implementation of the recommendation; Patients may lack necessary knowledge or skills; The targeted healthcare professionals may lack confidence in their ability to adequately educate patients; The targeted healthcare professionals may have misperceptions of patients' beliefs, knowledge, skills or ability to learn	Patient education materials; Train the targeted healthcare professionals to provide patient education; Shift responsibility for patient education; Provide the targeted healthcare professionals with accurate information about patients knowledge, skills or ability to learn	Interviews or focus group discussion with targeted healthcare professionals and with patients
Patient preferences	Patients' values in relationship to professional values or those in the recommendation	Do the targeted healthcare professionals perceive patients to have values that are different than their own or those in the recommendation? How do those perceptions correspond with actual patient values?	Patients may have values that are different than those of the targeted healthcare professionals or those in the recommendation; The targeted healthcare professionals may have misperceptions of patient values	Change the recommendation if it is based on values that are different from those of the targeted patients; A decision aid for patients to help them clarify their values; Provide the targeted healthcare professionals with accurate information about patient values	Interviews or focus group discussion with targeted healthcare professionals and with patients
Patient motivation	The targeted healthcare professionals' ability or perceived ability to motivate patients to adhere	Do the targeted healthcare professionals perceive difficulties motivating patients to adhere? How do those perceptions correspond with actual patient motivation?	Patients may not be motivated to adhere; The targeted healthcare professionals may have misperceptions of patients' motivation	Provide the targeted healthcare professionals with aids or strategies to motivate patients; Shift responsibility for motivating patients; Provide the targeted healthcare professionals with accurate information about patients' motivation	Interviews or focus group discussion with targeted healthcare professionals and with patients
Patient behaviour	Patient behaviours that motivate or demotivate adherence with the recommendation	Do the targeted healthcare professionals experience patients behaving in ways that discourage them from adhering?	Patients may behave in ways that hinder adherence (e.g. they may not adhere to recommended treatment or they may under or overuse health services)	Provide targeted healthcare professionals with strategies for coping with patient behaviours that are demotivating	Interviews or focus group discussion targeted healthcare professionals and with patients

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
4. PROFESSIONAL INTERACTIO	NS				
Communication and influence	The extent to which the targeted healthcare professionals' adherence is influenced by professional opinions and communication	Is the targeted healthcare professionals' adherence influenced by professional organisations, professional networks, prevailing norms (opinions of colleagues) or opinion leaders (or champions or other influential people)?	Opinions and communication among professionals may hinder adherence	Engage professional organisations in guideline development or a consensus process; Obtain endorsement of the recommendation by professional organisations or opinion leaders; Identify champions to promote implementation of the recommendation	Interviews or focus group discussion with targeted healthcare professionals
Team processes	The extent to which professional teams or groups have the skills needed to adhere and interact in ways that facilitate or hinder adherence	What skills do targeted professional teams or groups need to have? Do they have those skills? Do they interact in ways that facilitate or hinder adherence with the recommendation?	Teams may lack necessary skills; They may interact in ways that hinder adherence	Organise teams in which roles are defined and they have a shared goal	Interviews or focus group discussion with targeted healthcare professionals
Referral processes	Processes for transferring patients and communication between different levels of care, between health and social services, and between the targeted healthcare professionals and targeted patients	What referral processes and communication is needed between different levels of care, between health and social services, and between the targeted healthcare professionals and targeted patients? What changes are needed to adhere?	Poor communication; Inappropriate referrals	Structured referral sheets; involvement of consultants in primary care educational activities; Tailored patient information; Patient-held medical records	Interviews or focus group discussion with targeted healthcare professionals and with patients; Observation
5. INCENTIVES AND RESOURCE	S				
Availability of necessary resources	The extent to which the resources that are needed to adhere are available	What resources are needed to adhere, including: financial and human resources, facilities, equipment and supplies, and technical capacity? Are they available?	Necessary resources may not be available	Provide the necessary resources; Reduce the need for additional resources or their cost; Task shifting	Routinely collected data regarding resources; Interviews or focus group discussion with targeted healthcare professionals and managers
Financial incentives and disincentives	The extent to which patients, individual health professionals and organisations have financial incentives or disincentives to adhere	What financial incentives and disincentives do the patients, individual health professionals and organisations have to adhere?	There may be financial disincentives that hinder adherence	Remove or modify the financial disincentives; Provide financial incentives	Interviews or focus group discussion with targeted healthcare professionals and with patients

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Nonfinancial incentives and disincentives	The extent to which patients, individual health professionals and organisations have nonfinancial incentives or disincentives to adhere	What nonfinancial incentives and disincentives do the patients, individual health professionals and organisations have to adhere?	Disincentives or a lack of incentives for health professionals - e.g. personal recognition or appreciation (from managers, colleagues or the community), continuing education (opportunities to participate in educational activities), working conditions (facilities, equipment or security), career development (possibilities to specialise or be promoted), management (working relationship with managers) – can hinder adherence	Remove or modify disincentives; Provide incentives	Interviews or focus group discussion with targeted healthcare professionals and with patients
 Information system 	The extent to which the information system facilitates or hinders adherence	How does the information system facilitate or hinder adherence?	Limitations of the information system may restrict the ability of the targeted healthcare professionals to adhere, e.g. it might not be possible to identify patients in need of follow-up or recall	Improve the information system; Provide appropriate incentives to record needed information	Interviews or focus group discussion with targeted healthcare professionals and managers
Quality assurance and patient safety systems	The extent to which existing quality assurance or patient safety systems facilitate or hinder adherence	How do the existing quality assurance or patient safety systems (or the lack of these) facilitate or hinder adherence?	Limitations or lack of quality assurance or patient safety systems may hinder adherence	Establish or improve a quality assurance or patient safety system; Adapt implementation strategies to work within the constraints of the existing systems	Interviews or focus group discussion with targeted healthcare professionals and managers
Continuing education system	The extent to which the continuing education system facilitates or hinders adherence	How does the continuing education system facilitate or hinder adherence?	The continuing education system may hinder adherence	Modify the continuing education system; Adapt implementation strategies to work within the constraints of the existing system	Interviews or focus group discussion with targeted healthcare professionals and managers
Assistance for clinicians	The extent to which clinicians have the assistance they need to adhere	Do clinicians have the assistance they need to adhere, such as checklists, patient information, decision aids, decision support or clinical supervision?	Clinicians may not have assistance needed to help them adhere	Provide needed assistance, such as checklists, patient information, decision aids, decision support or clinical supervision	Interviews or focus group discussion with targeted healthcare professionals

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants		
6. CAPACITY FOR ORGANISATIONAL CHANGE							
• Mandate, authority, accountability	The mandate, authority and accountability for making necessary changes	What organisational changes are needed and who has the mandate and authority to make necessary changes? Who is accountable, to whom and how?	It may not be clear who has the mandate or authority to make changes; There may be a lack of accountability	Allocate or reallocate authority to make relevant decisions; Monitor organisational changes; Formally appoint implementation leaders; Use external change agents; Formal agreements regarding accountability; Increase transparency	Interviews or focus group discussion with targeted healthcare professionals and managers		
Capable leadership	The extent to which clinical leaders or managers are capable of making necessary changes	What changes require leadership or management? Are there leaders or managers with the necessary capacity (including knowledge, project management, other necessary skills and time)? Are they engaged and is their leadership or management style suitable?	Leaders or managers may lack awareness or familiarity with the recommendation; They may not have the necessary capacity; They may not be engaged; They may not have a suitable style	Engage leaders or managers in designing and implementing the implementation strategy; Provide external support or training for managers and leaders; Shift or allocate leadership or management responsibilities to someone with a suitable style	Interviews or focus group discussion with targeted healthcare professionals and managers		
Relative strength of supporters and opponents	The extent of support and opposition to necessary changes	Who supports and who opposes necessary changes?	Opposition to changes may hinder necessary changes	Engage and persuade opponents; Engage and capitalise on supporters; Facilitate dialogue, understanding of conflicting perspectives and achievement of a consensus	Interviews or focus group discussion with targeted healthcare professionals		
Regulations, rules, policies	The extent to which organisational regulations, rules or policies facilitate or hinder necessary changes	How do internal and external organisational regulations, rules or policies facilitate or hinder necessary changes?	Organisational regulations, rules or policies may hinder necessary changes	Change the regulations, rules or policies; Make adaptations to enable adherence to the recommendation within the existing regulations, rules and policies	Interviews or focus group discussion with targeted healthcare professionals and managers		
Priority of necessary change	The relative priority given to making necessary changes	How are the necessary changes prioritised relative to other priorities?	The necessary changes may be a low priority	Persuade those responsible to change their priorities; Accept the current priorities and work within those constraints	Interviews or focus group discussion with targeted healthcare professionals and managers		

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Monitoring and feedback	The extent to which monitoring and feedback are needed at organisational level and available to sustain necessary changes (including evaluations of improvement programs)	Are monitoring and feedback needed to sustain necessary changes? If so are they available?	Monitoring and feedback may be needed and not available	Use external support to provide monitoring and feedback; Establish required monitoring and feedback	Interviews or focus group discussion with targeted healthcare professionals and managers
Assistance for organisational changes	The extent to which external support is needed and available for necessary changes	Is external support needed to achieve necessary changes? If so is it available?	External support may be needed and not available	Provide the needed external support	Interviews or focus group discussion with targeted healthcare professionals and managers
7. SOCIAL, POLITICAL AND LEG	AL FACTORS				
Economic constraints on the health care budget	Limits on the total healthcare budget or its growth	Do economic constraints on the healthcare budget facilitate or hinder changes?	Economic constraints may hinder necessary changes if they entailed a substantial increase to the healthcare budget	Pragmatic consideration of what is feasible; Gradual change; Shifting resources from elsewhere in the healthcare budget; increasing the healthcare budget	Interviews with managers, policymakers and stakeholders
Contracts	The extent to which contracts may affect implementation of necessary changes	Do contracts facilitate or hinder implementation of necessary changes?	Contracts with service providers or enforcement of contracts may not be adequate to ensure implementation of necessary changes	Improvements in contracts, including provision for enforcement	Interviews with managers, policymakers and stakeholders
Legislation	The extent to which legislation may affect implementation of necessary changes	Does legislation (or regulations) facilitate or hinder implementation of necessary changes?	General legislation (e.g. regulating government contracts or working conditions) or health care legislation (e.g. licensing health professionals) may be hinder necessary changes	Modify the option so that it is not in conflict with legislation or modify conflicting legislation	Interviews with managers, policymakers and stakeholders
Payer or funder policies	The extent to which payer or funder policies may affect implementation of necessary changes	Do payer or funder policies facilitate or hinder implementation of necessary changes?	Payer or funder policies may hinder necessary changes	Negotiate with payers or funders to allow or support changes	Interviews with managers, policymakers and stakeholders
Malpractice liability	The extent to which malpractice liability may affect implementation of necessary changes	Do real or perceived risks of malpractice complaints facilitate or hinder implementation of necessary changes?	Perceived or real risks of malpractice complaints may hinder necessary changes or adherence	Provide accurate information to correct misperceptions; Provide support to reduce the risk of inappropriate malpractice complaints	Interviews with managers, policymakers and stakeholders

Determinants	Definitions	Questions	Examples of specific factors1	Examples of related implementation strategies	Methods for identifying the determinants
Influential people	The extent to which influential people may affect implementation of necessary changes	Do influential people (outside of the targeted healthcare organisations) facilitate or hinder implementation of necessary changes?	Influential people may be opposed to necessary changes	Engage and persuade opponents; Engage and capitalise on supporters; Facilitate dialogue, understanding of conflicting perspectives and achievement of a consensus	Interviews with managers, policymakers and stakeholders
Corruption	The extent to which corruption may affect implementation of necessary changes	Does corruption facilitate or hinder implementation of necessary changes?	Corrupt behaviour may hinder necessary changes and adherence	Increase transparency and accountability; decrease incentives or factors that motivate corruption	Interviews with managers, policymakers and stakeholders
Political stability	The extent to which political stability may affect implementation of necessary changes	Does political stability or instability facilitate or hinder implementation of necessary changes?	Political changes may hinder necessary changes	Engage stable politicians, civil servants or leaders	Interviews with managers, policymakers and stakeholders

I Guyatt GH, Oxman AD, Kunz R, Vist GE, Falck-Ytter Y, Schunemann HJ, and the GRADE Working Group. What is 'quality of evidence' and why is it important to clinicians? BMJ 2008; 336:995-8.

ii. Guyatt GH, Oxman AD, Kunz R, Falck-Ytter Y, Vist GE, Liberati A, Schunemann HJ, and the GRADE Working Group. Going from evidence to recommendations. BMJ 2008; 336:1049-51.

iii. Shiffman RN, Dixon J, Brandt C, Essaihi A, Hsiao A, Michel G, O'Connell R. The GuideLine Implementability Appraisal (GLIA): development of an instrument to identify obstacles to guideline implementation. BMC Medical Informatics and Decision Making 2005; 5:23.

iv. Oxman AD, Glasziou P, Williams JW. What should clinicians do when faced with conflicting recommendations? BMJ 2008; 337:a2530.

v. Groll RPTM, Bosch MC, Hulscher MEJL, Eccles MP, Wensing M. Planning and Studying Improvement in Patient Care: The Use of Theoretical Perspectives. Milbank Quarterly 2007; 85:93-138.