Hijlkema et al., J Sleep Disor: Treat Care 2019, 8:1
DOI: 10.4172/2325-9639.1000225

Journal of Sleep Disorders: Treatment & Care

Research Article A SciTechnol Journal

Measuring Pain Relief through Actigraphy in People with Intellectual Disability

Tejo Hijlkema[1]*, Sylvia Loos[2] and Geert Jaap Welsing[3]

Abstract

Information about reliable pain detection in people with intellectual disabilities is scarce. Pain (acute as well as chronic) has a great influence on daily activities and is often under-recognized. Chronic and acute pain also severely influences the quality and duration of sleep. Lack of sleep negatively influences chronic pain.

There is no research about the influence of pain on sleep in people with Intellectual Disability. Yet we think there is a link between sleep and pain (we had no reason to assume there is no link between the two). We measured sleep in people with Intellectual Disability at an institution in the Netherlands. All the participants had pain or chronic pain or were suspected of having chronic pain. We measured sleep using actigraphy and we assessed the pain of participants with suspected pain using the Rotterdam Elderly Pain Observation Scale (REPOS) or the Checklist Pain Behavior (CPG) for children.

A sleep problem was found in all the measurements and this was confirmed using the REPOS or CPG for the group with suspected chronic pain. There were 25 participants included in this research. After treatment (with analgesics for 68%) most participants experienced improved sleep. There was a significant improvement in the entire group in sleep efficiency, sleep latency, hours of sleep and/or WASO (waking after sleep onset).

Although the group is small, our outcomes suggest that there is a strong relationship between chronic and acute pain and sleep in people with Intellectual Disability. Actigraphy can be used with the REPOS and the CPG to confirm suspected pain and to measure the effect of the intervention. Suspected pain can also be confirmed by actigraphy.

Keywords

Actigraphy; Intellectual disability

Introduction

Nineteen percent of the general population in Europe has chronic pain. This prevalence is 18% in the Netherlands [1]. According to the International Association of the Study of Pain (IASP), pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described as such damage. Pain is always subjective [2], or physical or mental suffering. A state of localized or general discomfort which ranges from mild distress to acute agony: usually caused by injury to a part of the body or disturbance in the normal condition of a part of the body [3].

People with Intellectual Disability (ID) have a greater risk of experiencing pain than the general population [4]. Pain might be under-recognized and under-treated, especially in those who cannot communicate about their pain [5]. There is a greater risk of pain in people with ID because they have more painful conditions, such as coeliac disease [6] than controls, the prevalence of age-related painful conditions increases with the increase in life expectancy [7], and some syndromes imply a higher risk of musculoskeletal disorders than in the general population [4]. A significant proportion of people with ID and chronic pain experience limitations in several aspects of daily living [8]. One of the limitations is not being able to sleep properly. One of the health problems which influences the quality and duration of sleep is pain, and sleep problems in turn greatly influence pain [9-11].

Sleep is very important to our daily functioning. A lack of sleep can result in a range of health and psychiatric problems. Recent research shows that depressions could be the result of poor sleep in people who are evening types [12]. An increased risk of developing cancer also results from poor sleep. Furthermore, there is an association between sleep problems (short sleep duration) and the development of obesity in children and young adults [13]. There is also a greater risk of diabetes in people with short sleep and long sleep problems [14]. The prevalence of sleep problems in the general population in Western Europe is 31% [15]. The prevalence of sleep problems in people with ID is higher, up to 86% [16,17]. People with ID are therefore likely to have more health problems as a result of sleep problems and could have more pain complaints. We define sleep problems as problems with falling asleep and/or waking during the night, for a period of longer than one month and at least three times a week.

Is pain relief through pain treatment measurable in sleep using actigraphy?

Method

Participants

One residential home in the central Netherlands participated in this research. Its nightshift policy was that care is only provided during the night when the residents are awake. About 900 residents live there in units of one to eight. Each unit has a psychologist and a physician responsible for the care and treatment of the residents.

This residential organization has a professional sleep team to deal with sleep problems. The team is multidisciplinary: two sleep specialists, one physician, a physiotherapist, a member of the night shift and a psychologist.

If a psychologist or physician suspected that a resident was suffering from a sleep problem, they would report this by completing a registration form. Sleep problems were suspected on the basis of the number of naps taken during the day, periods of wakefulness during the night or problems falling asleep, challenging behaviour or physical problems. Following registration one of the sleep specialists would conduct an intake interview. The following items were discussed:

- What are the complaints?
- Is there sufficient light during the day?

***Corresponding author:** Tejo Hijlkema, MSc, Avans University of Applied Science, Breda, The Netherlands,Tel: 31642920858; E-mail: t.hylkema@zonnet.nl

Received: January 02, 2019 **Accepted:** March 18, 2019 **Published:** March 29, 2019

doi: 10.4172/2325-9639.1000225

- Is the bedroom dark?
- Does the resident have a specific syndrome? (some syndromes have a risk of more sleep problems or there could be pain)
- Is there a suspicion that the resident has pain?
- Is there sufficient arm movement to wear an Actiwatch?

We measured a total of 200 residents. A group of 25 residents had pain or were suspected of pain or pain had not been considered as a possibility. All the participants (N=25) were included. The mean age was 46 (range 4-70). The age level of ID, any co-morbidity and the level of locomotor disability are presented along with gender in Table 1.

Instruments and procedure

We used the Actiwatch (type AW2) manufactured by Philips for both the baseline measurement and the effect measurement. This is an objective and relatively non-invasive method of measuring rest-activity patterns based on body movement. The associated software (Philips actiware 6.0.6) estimates the sleep period. The outcome measurements from the Actiwatch were: time in bed, time to get out of bed, hours in bed, hours of sleep, sleep latency (the time it takes to fall asleep) sleep efficiency (total sleep time/time in bed multiplied by 100), WASO (time awake after sleep onset). The Actiwatch is a small, lightweight wristwatch [18]. Studies have shown that the Actiwatch is a valid instrument for measuring sleep [19,20]. The epoch length was 1 minute in the current study, and the Actiwatch was worn for 14 days. Instruction was given before each measurement. The Actiwatch had an event marker which was pressed at bedtime and when getting up in the morning. One of the sleep specialists calculated the measurements and drew up a report, including advice to improve sleep. Chronic or acute pain was obvious to the daily caregivers in 15 cases, and these residents had already received pain relief medication, but only when necessary or 1000 mg paracetamol three times a day, without receiving medication for the night. If pain was suspected or the caregivers were unaware whether there was pain, a pain measurement was performed using the Rotterdam Elderly Pain Observation Scale (REPOS) [21] or in one case the Checklist Pain Behaviour (CPG), [22,23]. The REPOS is validated for acute and daily pain in non-communicative impaired elderly, but unable to express pain by self-report. It consists of ten behaviours to be scored as present (1) or absent (2). These behaviours are panicky, panic attack, moaning, groaning, sounds of restlessness, verbal expressions, breath-holding, faltering respiration, body part movement and anxious look. The CPG (Checklist Pain Behavior) is very similar to the REPOS, except that there are three items in addition: sad look, crying/sobbing and tears. The pain measurements were performed by members of the pain team. This team consists of daily caregivers trained to conduct this measurement. A REPOS observation was performed for nine of the participants and a CPG observation for one (participant 14). That participant was too young for the REPOS observation. All the participants for which a REPOS or CPG observation was performed scored above five, which indicates strongly suspected pain. After the sleep measurement and the observation or clinical observation to detect the possibility or presence of pain, the advice was discussed with the psychologist involved with the resident and with the caregiver team. A control measurement was taken after implementation of the advice.

Results

Actigraphy was performed after the intake and a REPOS measurement was performed at the same time in 14 cases, and a CPG

Table 1: Characteristics of the participants.

Participant	Gender	Age (Years)	Level of intellectual disability	Level of locomotor disability	Co-morbidity	Type of intervention
1	Female	23	Severe	Moderate	Epilepsy	Haptotherapy
2	Male	63	Moderate	Severe	None	Analgesic
3	Male	53	Profound	Severe	Epilepsy	Laxation
4	Female	34	Profound	Severe	Epilepsy	Analgesic
5	Female	45	Moderate	Moderate	None	Other activities
6	Male	43	Severe	None	Down syndrome	Laxation
7	Male	25	Severe	None	Autism	Analgesic
8	Male	41	Profound	Severe	Martsolf's syndrome	Analgesic
9	Female	70	Severe	Moderate	Osteoporosis	Analgesic
10	Male	61	Profound	Severe	Epilepsy	Other bed
11	Female	68	Moderate	Moderate	Osteoarthritis	Analgesic
12	Male	51	Profound	Moderate	Down syndrome	Analgesic
13	Male	59	Profound	Severe	Angelman syndrome	Laxation
	Male	4	Profound	Severe	None	Analgesic
15	Female	45	Profound	Moderate	Epilepsy	Analgesic
16	Male	50	Moderate	None	Autism	Analgesic
17	Female	56	Severe	None	None	Activation
18	Male	34	Profound	Severe	Hydrocephaly	Analgesic & orthotics
19	Male	60	Severe	None	Gout	Analgesic
20	Male	59	Profound	Severe	Scoliosis	Analgesic
21	Male	48	Profound	Severe	Blind	Activation
22	Female	37	Profound	Severe	None	Analgesic
23	Female	31	Profound	Severe	Reflux	Analgesic
24	Male	48	Profound	Severe	Osler-weber-rendu	Analgesic
25	Male	56	Profound	None	Epilepsy	Analgesic

doi: 10.4172/2325-9639.1000225

in one case. (T and T0). After that the psychologist and physician provided their recommendation. If reflux was suspected, a further observation was performed, and treatment followed. If reflux was not found and pain was only suspected, treatment followed. An analgesic was prescribed in most (68%) cases. In general (82%) this was paracetamol. Paracetamol is a proven painkiller for chronic or acute pain [24-26], though it is only prescribed in 18% of cases in the general population with chronic pain in Europe [1]. A NSAID was prescribed in one case.

After six to eight weeks, we performed a T1 measurement with actigraphy. We observed a positive result in one or more of the sleep parameters measured in all participants (Table 2). We observed no significant improvement in time in bed, which can be explained by the fact that the focus of this study was on only on pain and not on good sleep hygiene (Table 3).

Table 1 presents the interventions implemented to provide pain relief. There was no pain relief medication involved in four cases. Two participants (17 and 21) were made to perform activities because their pain was caused by a lack of movement during the day. Participant one received haptotherapy which is a form of massage. This complementary form of care is very common in the Netherlands and it helps to provide pain relief. One participant (5) was given other activities, so that she could get more rest.

Discussion and Conclusion

This is the first study performed with a valid objective instrument to measure the effect of treatment. The Actiwatch (AW2) is not only a valid instrument in sleep interventions [18] but can be useful as an instrument in other inventions such as pain treatment interventions. This offers a much broader view on sleep and provides an even greater awareness that sleep is influenced by physical conditions. This seems very logical, because sleeping with pain is difficult. We do not know yet whether people with ID react in the same way to pain as people without ID. This question is difficult to answer. What we did observe is that pain is often underestimated or that pain is recognized after the failure of a series of behavioural interventions. If pain is suspected, the next step is pain measurement, which was difficult for caregivers. This was partly because they were not familiar with the pain assessment instruments and partly because caregivers find it difficult to assess pain objectively. Many pain signals were referred to as behavioural problems, which meant that many interventions initially targeted behaviour, which did not achieve any improvement.

Table 2: Sleep improvement results.

Participant	Hours of sleep T0 (h:min)	Hours of sleep T1 (h:min)	Sleep efficiency T0 (%)	Sleep efficiency T1 (%)	Sleep latency T0 (min)	Sleep latency T1 (min)	WASO T0 (h:min)	WASO T1 (h:min)	Hours in bed T0 (min)	Hours in bed T1 (min)
1	70.5	86.4	13	4	151	71	10:53	10:41	7:42	9:10
2	62.5	68.7	11	19	149	84	9:34	7:55	5:58	5:53
3	77.1	84.3	79	37	66	53	11:16	11:00	8:42	9:16
4	85.9	93.2	22	2	44	30	11:27	11:07	9:52	10:22
5	87.2	95	19	3	45	25	10:30	10:21	9:14	9:49
6	66.2	73	141	46	52	63	10:22	9:12	6:52	6:42
7	90.3	88.5	13	31	39	37	9:37	10:21	8:42	9:11
8	80.2	80.8	24	25	50	67	10:14	9:34	8:12	7:44
9	84.2	89.6	20	5	43	41	11:46	12:53	9:52	11:34
10	35.9	68.7	109	77	77	54	12:27	12:25	9:14	8:46
11	83.5	86.9	13	9	56	52	7:43	8:22	6:28	7:17
12	46.8	59.4	176	123	89	108	10:39	10:18	5:02	6:08
13	62.2	71	27	39	172	128	10:56	10:36	6:47	7:37
14	60.7	60.7	43	54	181	142	11:53	11:54	7:13	7:14
15	60.8	66.8	34	72	62	33	10:06	10:05	5:58	6:39
16	76.4	77.3	12	8	103	52	10:11	10:04	7:03	7:47
17	92.2	91.6	4	5	37	35	11:14	9:46	10:21	8:57
18	71.2	94.8	45	3	29	15	10:29	10:09	7:13	9:55
19	58.7	60.2	82	65	169	165	10:29	10:09	6:07	6:06
20	73.7	90.7	31	14	45	31	10:45	10:17	7:59	9:06
21	59.2	84.8	172	19	105	58	12:24	9:30	7:15	8:03
22	55	89.8	13	6	164	27	10:05	10:36	5:32	9:26
23	83	87.6	20	9	68	43	11:23	10:08	9:26	8:53
24	65.7	70.7	29	50	110	65	9:33	9:55	6:17	8:01
25	39.5	67.8	92	79	98	76	11:15	9:31	4:25	6:28

Table 3: Average sleep improvement (standard deviation).

	T0	T1	sig. (<0.05)	T-Values
Sleep efficiency index	70.6 (14.6)	81 (11.6)	0.000	-4.65
Sleep latency	49 min. (52)	29 min. (31)	0.024	2.423
WASO	87 min. (51)	59 min. (37)	0.002	3.576
Hours in bed	10:42 (1:01)	10:27 (1:11)	0.195	1.336
Hours of sleep	7:44 (1:34)	8:29 (1:35)	0.009	-2.875

There was no focus on somatic problems and/or interventions. Only after behavioural interventions failed to achieve their expected result, was further investigation performed on somatic problems. When pain was measured and found, active investigation was performed to discover the cause of the pain. It was remarkable that some pain behaviour was described as 'normal' or 'this is behaviour he/she has had for years' by caregivers. We also noticed that the severity of the mental and locomotive disability can subjectively distort a caregiver's expectation that a resident could be experiencing pain. For instance, pain relief is almost never provided after an epileptic fit. Only after actigraphy and the assessment of epilepsy during the night, and once awareness that this could cause pain was understood, was a pain measurement performed and a high pain score found. Further research should be conducted to produce guidelines for pain relief after an epileptic fit. Many people with ID have regular or daily epileptic fits and there is hardly any recognition of pain after a fit. We overlook the signals of pain and people with ID have to live longer with pain than is necessary.

The Actiwatch is used in many residential facilities in the Netherlands so its specific use in measuring the effects of pain treatment can be broadly implemented.

We observed that a wider range of interventions can be performed to relieve pain in people with Intellectual Disability. Although paracetamol is used very widely, Complementary and Alternative Medicine (CAM) was used in only one case. Haptotherapy, which is a CAM intervention, worked very well for participant 1. CAM could be used more often in care. In the Netherlands there is a lack of knowledge on using CAM in the care for people with ID.

The REPOS has been proven as a good instrument to measure suspected pain in people with ID, although the REPOS was designed for the elderly. We did not perform second REPOS as a control because the instrument is not made for use in an intervention study.

Asking about pain or suspected pain in the actigraphy intake obtained a response rate of 12.5% of people with sleep problems with pain or suspected pain. We think this is a very low rate and that there are many more people with ID who have pain. Further research should be performed to find how many people with ID have pain. There is also a need for more research into using CAM with people with ID and pain, and even more with people with ID and sleep problems.

References

1. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D (2006) Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. Eur J Pain 10: 287-333.
2. Merskey H (1991) The definition of pain. European Journal of Psychiatry 6: 153-159.
3. Barret N (1994) Blackwell's dictionary of nursing. Blackwell Science Ltd, Oxford, United Kingdom.
4. Knegt NC, Scherder EJA (2011) Pain in adults with intellectual disabilities. Pain 152: 971-974.
5. McGuire BE, Daly P, Smyth F (2010) Chronic pain in people with disability: Under-recognised and under-treated? J Intellect Disabil Res 54: 240-245.
6. Roizen NJ, Patterson D (2004) Downs syndrome. The Lancet 361: 1281-1289.
7. Boerlage AA, Valkenburg AJ, Scherder EJA, Steenhof G, Effing P, et al. (2013) Prevalence of pain in institutionalized adults with intellectual disabilities: A cross sectional approach. Res Dev Disabil 34: 2399-2406.
8. Walsh M, Morrison TG, McGuire BE (2011) Chronic pain in adults with an intellectual disability: Prevalence, impact, and health service use based on caregiver reports. Pain 152: 1951-1957.
9. Moldofsky H (2001) Sleep and pain. Sleep Med Rev 5: 385-396.
10. Ghaly M, Teplits D (2004) The Biologic effects of grounding the human body during sleep as measured by cortisol levels and subjective reporting of sleep, pain and stress. J Altern Complement Med 10: 767-776.
11. Edwards RR, Almeida DM, Klick B, Haythornthwaite JA, Smith MT (2008) Duration of sleep contributes to next-day pain report in the general population. Pain 137: 202-207.
12. Chan JWY, Lam SP, Li SX, Yu MWM, Chan NY, et al. (2014) Eveningness and insomnia: Independent risk factors of non-remission in major depressive disorder. Sleep 37: 911-917.
13. Nielsen LS, Danielsen KV, Sorensen TIA (2011) Short sleep duration as a possible cause of obesity: A critical analysis of the epidemiological evidence. Obes Rev 12: 78-92.
14. Anothaisinatwee T, Reutrakul S, Cauter van E, Thakkinstan A (2015) Sleep disturbances to traditional risk factors for diabetes development: Systematic review and meta-analysis. Sleep Med Rev 30: 11-24.
15. Leger D, Poursain B, Neubauer D, Uchiyama M (2008) An international survey of sleeping problems in the general population. Curr Med Res Opin 24: 307-317.
16. Didden R, Sigafoos J (2001) A review of the nature and treatment in individuals with developmental disabilities. Res Dev Disabil 22: 255-272.
17. Doran SM, Harvey MT, Horner RH (2006) Sleep and developmental disabilities: Assessment, treatment and outcome measures. Ment Retard 44: 13-27.
18. Hylkema T, Vlaskamp C (2009) Significant improvement in sleep in people with intellectual disabilities living in residential settings by non-pharmaceutical interventions. J Intellect Disabil Res 53: 695-703.
19. Gironda RJ, Lloyd J, Clark ME, Walker RL (2007) Preliminary evaluation of the reliability and criterion validity of the actiwatch-score. J Rehabil Res Dev 44: 223-230.
20. Lichstein KL, Stone KC, Donaldson J, Nau SD, Soeffing JP, et al. (2006) Actigraphy validation with insomnia. Sleep 29: 232-239.
21. Herk R, Dijk van M, Tribboel D, Baar F, Wit de R, et al. (2009) The rotterdam elderly pain observation scale (REPOS): A new behavioral pain scale for non-communicative adults and cognitive impaired elderly persons. Journal of Pain Management 1: 367-378.
22. Duinvoorden HJ, Tibboel D, Koot HM, van Dijk M, Peters JW (2006) Pain assessment in profound cognitive impaired children using the Checklist Pain Behavior: Is item reduction valid? Pain 126: 147-154.
23. Terstegen C, Koot HM, de Boer JB, Tibboel D (2003) Measuring pain in children with cognitive impairment: Pain response to surgical procedures. Pain 102: 187-198.
24. Nikles JC, Yelland M, Del Mar C, Wilkinson D (2005) The role of paracetamol in chronic pain: An evidence-based approach. Am J Ther 12: 80-91.
25. Hansen J (2001) Increased breast cancer risk among woman who work predominantly at night. Epidemiology 12: 74-77.
26. Luojus MK, Letho SM, Tolmunen T, Erkkiä AT, Kauhanen J (2014) Sleep duration and incidence of lung cancer in ageing man. BMC Public Health 295: 1-7.

Author Affiliations Top

[1]*Avans University of Applied Science, Breda, The Netherlands*

[2]*Nyx Zorg Voor Slaap, Amersfoort, The Netherlands*

[3]*University of Utrecht, Utrecht, The Netherlands*