



*Demenz Support Stuttgart
Zentrum für Informationstransfer*



End-of-life care for people with dementia – an evaluation of two innovative approaches in Luxembourg

20th Alzheimer Europe Conference “Facing dementia together”

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Care-Oases: Target Group

- people with dementia in (highly) advanced stages of their condition
- strong need of (physical) long-term care
- severely impaired verbal communication skills
- strong impairment in terms of (independent) mobility
- reliance on third parties with regard to the fulfillment of social/psychological/spiritual needs



Care Oases: Main Focus

- living in a community (6-8 persons in one room together)
- constant presence by a staff member (during daytime)
- need-oriented interactions
- amelioration of suffering and pain management
- reduction of fear/anxiety



Care Oases: spatial setting

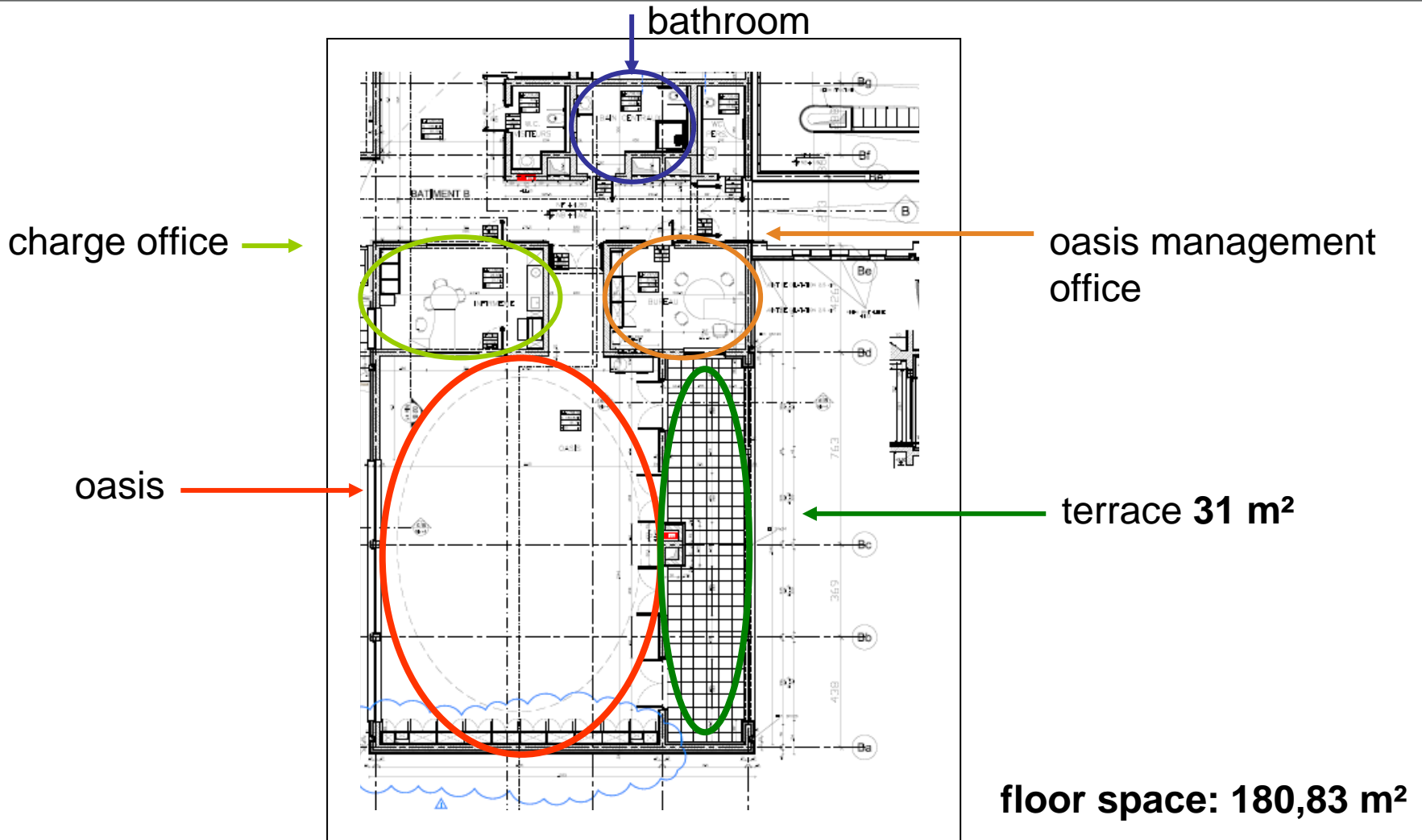
- common space with table and chairs
- individual space with nursing bed and blinds
- a kitchen with equipment to keep food warm
- a therapeutic space, e.g. a water bed
- a specially equipped bathroom
- access to a garden / outdoor area
- a room for retreat



Evaluation: nursing homes with oases in Luxembourg

	„Beim Goldknapp“ - ALA	Centre Pontalize - CHNP
<ul style="list-style-type: none"> • newly built homes • start • conceptual model • size of care oasis • organizational unit • target group • provision of food / meals 	<ul style="list-style-type: none"> • 120 places • 09/2007 • Sonnweid oasis (CH) • 12 inhabitants (max.) • living unit (24 persons) • persons in late stages of their dementia • food / meals prepared / cooked in the kitchen of the living unit 	<ul style="list-style-type: none"> • 145 places • 07/2007 • Sonnweid oasis (CH) • 6 inhabitants (max.) • living unit (19 persons) • persons in late stages of dementia, apallic syndrom, craniocerebral injury and hemiplegia • food prepared in central kitchen

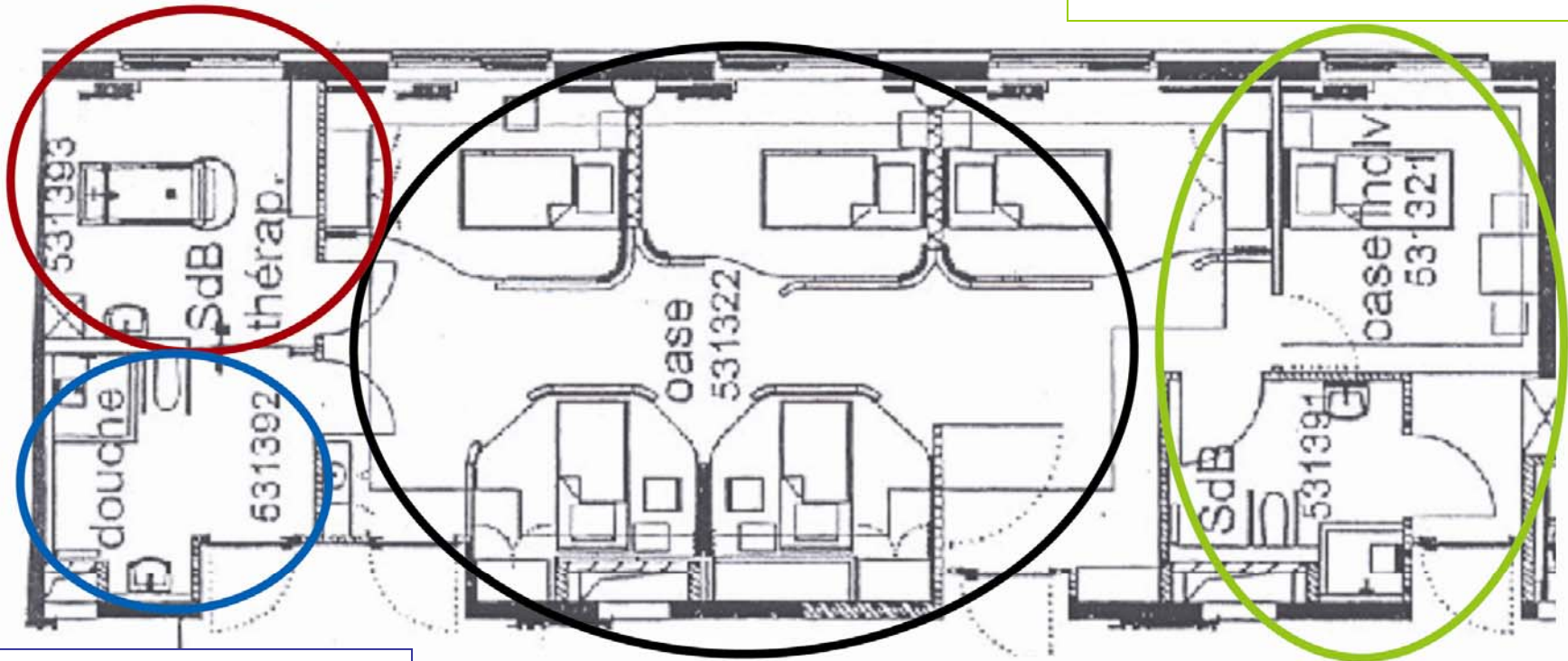
ALA care oasis – floor plan



CHNP care oasis – floor plan

bathroom 10,7 qm

single room



bathroom 8,2 qm

Oasis 85,37 qm

Care oasis: realization in terms of construction and design



ALA: up to 9 inhabitants



CHNP: 5 inhabitants

privacy – community – comfort - therapeutic offers

Care oases in Luxembourg: evaluation 4/2008 - 3/2010

➔ longitudinal comparative study with control group

Objectives

- approach to quality of life of those living in the care oases (assessment)
- comparison of their quality of life with that of (compatible) persons living in other care settings („domestic community“/Hausgemeinschaft, classical residential unit)
- evaluation of the care oasis from the point of view of family members and care staff
- account of strain experienced by care staff

Data base

research method	total data base
Partially structured interviews	71 interviews - ca. 4260 min.
digital recording of (contact) time	4.639:26 h unadjusted data 3.541:67 h adjusted data
burn out inquiry of care staff	92 questionnaires - 3 measuring points
participating observation	18 days of observation
Satisfaction with Care at End-of-Life in Dementia Scale (Volicer et al. 2001)	19 questionnaires
Inhabitants' quality of life and well-being: diagnoses, medication, Barthelindex, NPI, CMAI, Quality of Life in late stage dementia	continuous document analysis, 6 measuring points per home/facility
Environmental factors (light, acoustics, indoor temperature and air quality, photo documentation)	4 measuring points per home/facility

Sample: 17 family members (aged 35-83); 48 staff members (aged 19-58)

ALA: sample residents

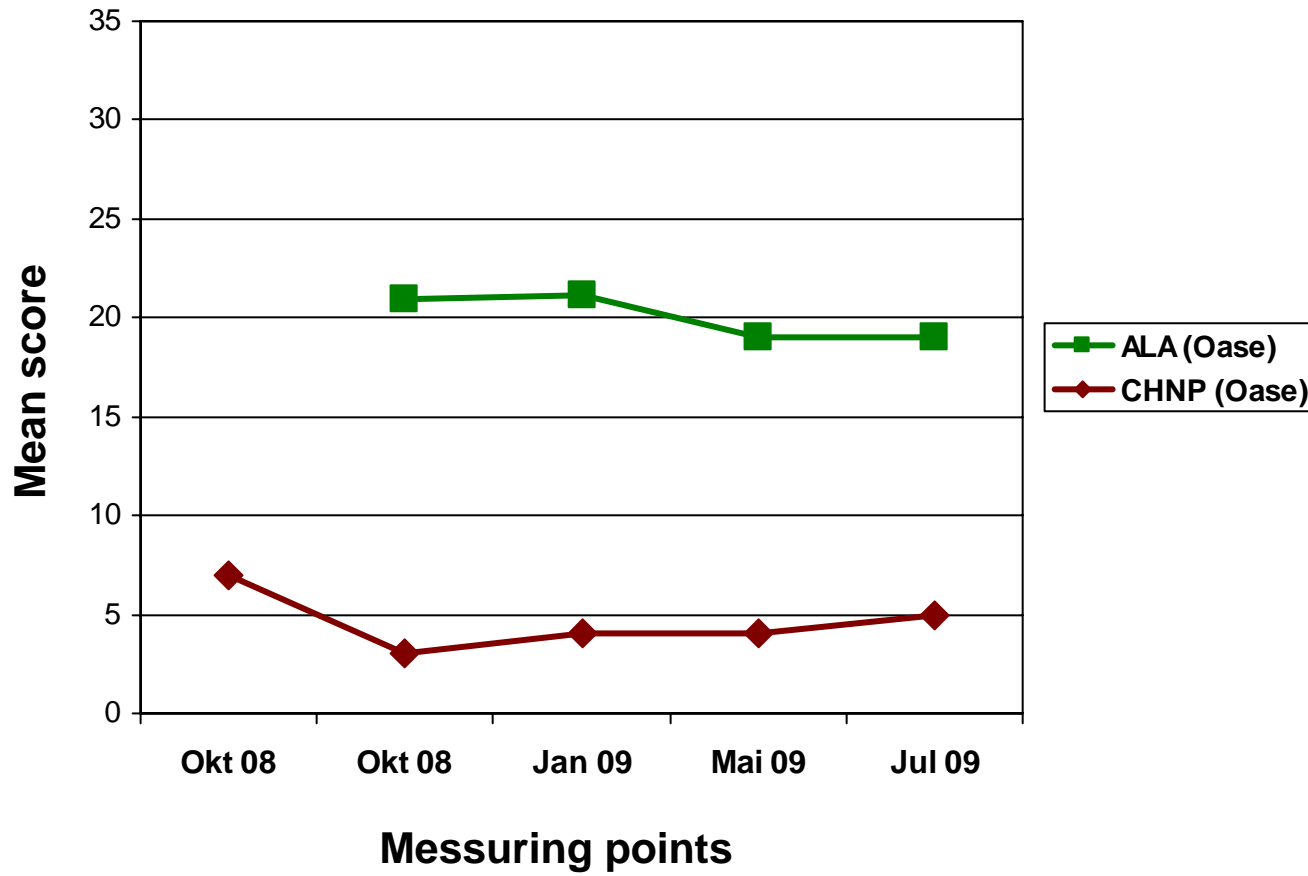
	care oasis	control group
sex	4 women, 2 men	3 women, 3 men
age	66-86; mean: 77,7	70-89; mean: 81,4
diagnoses	alle residents: DAT (dementia of the Alzheimer's type); multimorbidity	DAT (dementia of the Alzheimer's type); senile dementia (1 person); multimorbidity
MMST	6 residents = 0 points .	4 residents = 0 points 1 resident = 2 points 1 resident = 3 points
FAST	moderate to very severe cognitive Impairments (scale 6-7)	moderate to severe cognitive impairments (scale 5-6, 1 x 7a)
care/week	1267,11 min.	1107 min.

CHNP: sample residents

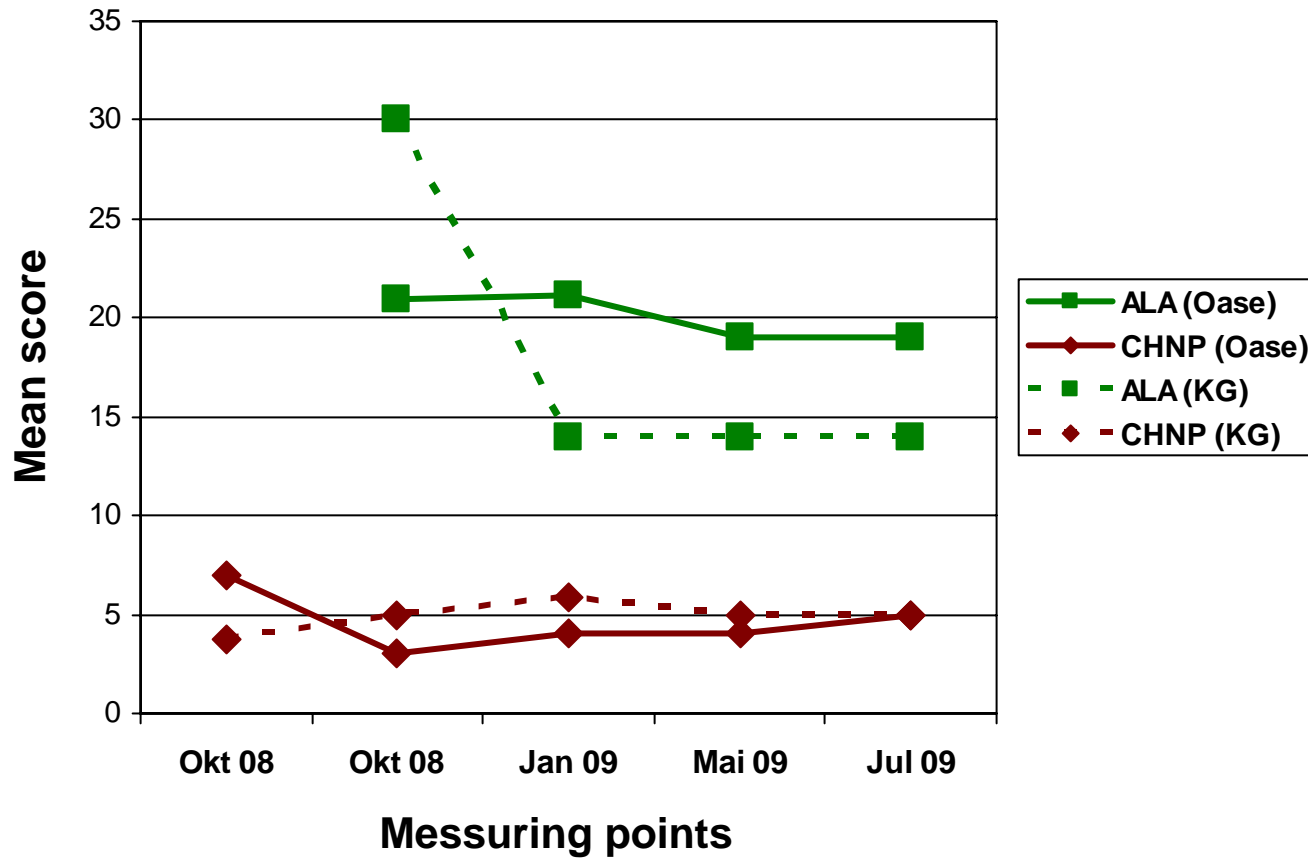
	care oasis	control group
sex	4 female, 1 male	2 female, 4 male
age	67-89; mean: 78,0	63-93; mean: 76,3
diagnoses	4 residents DAT; 1 resident dementia of another type,	Dementia due to cerebro-organic changes, mult morbidity
MMST	4 resident = 0 points 1 resident = 8 points	4 residents = 0 points 1 resident = 12 points 1 resident = 17 points
FAST	severe to highly severe cognitive impairments (scale 6 – 7)	severe to highly severe cognitive impairments (scale 6 – 7)
care/week	1453,2 min.	1663,3 min.

➔ Out of 145 residents, 13-15 fulfilled standards for oasis admission

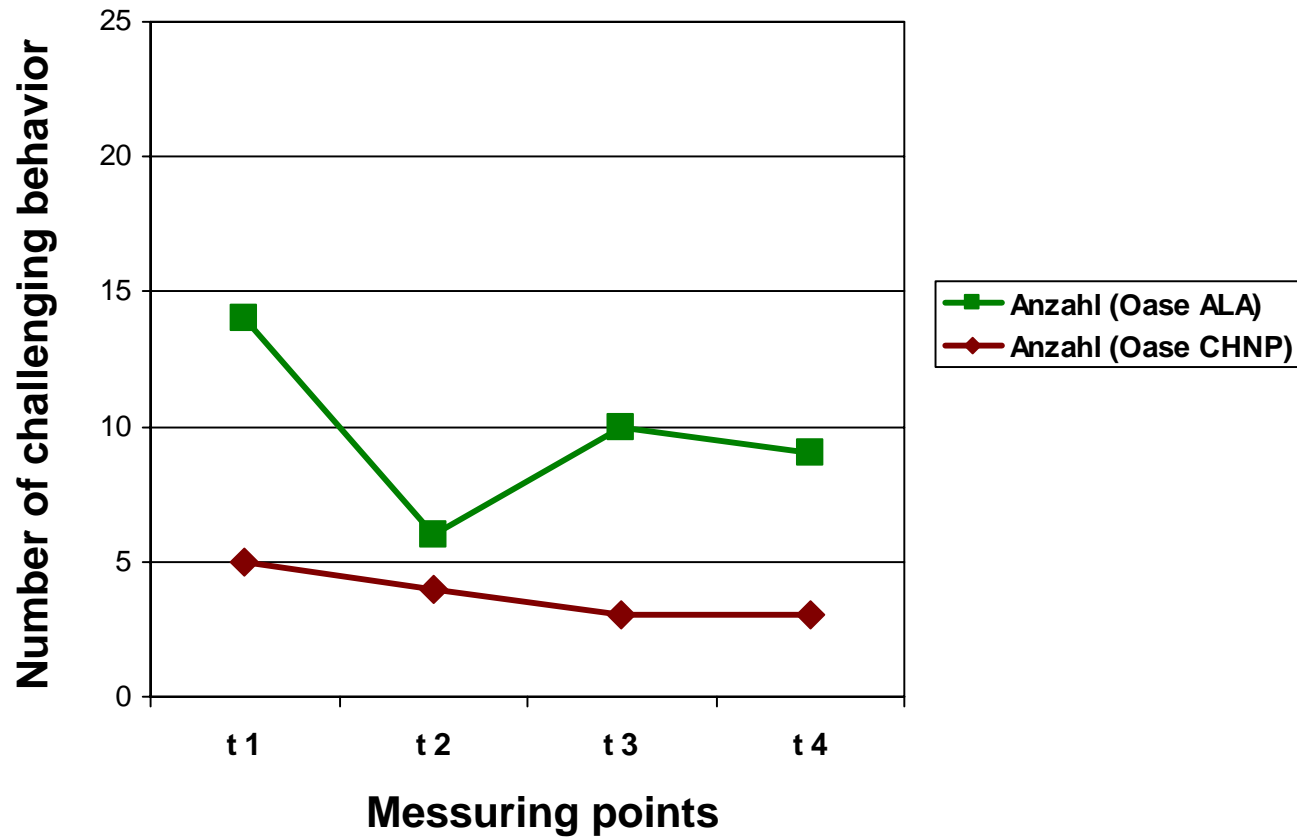
Barthel – compare both oases



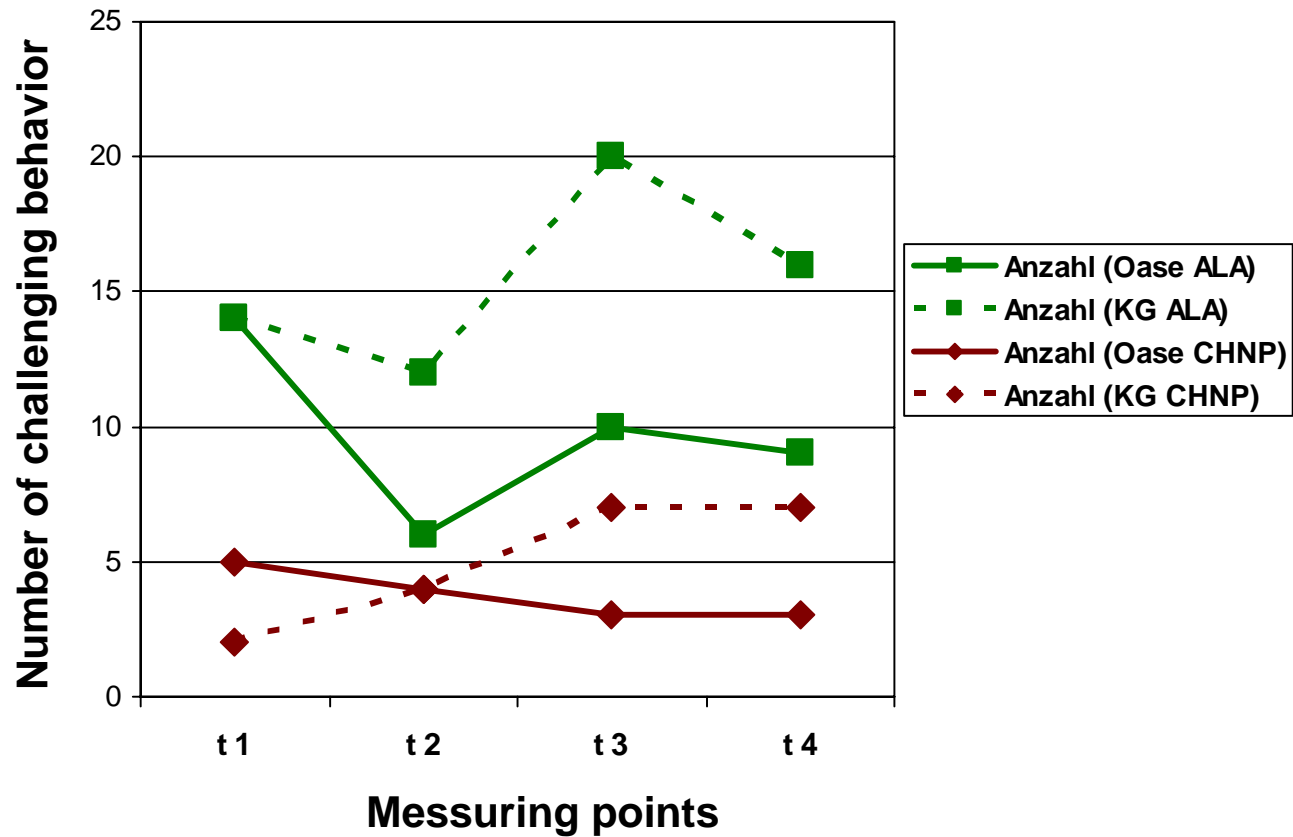
Barthel – compare both oases and control groups (KG)



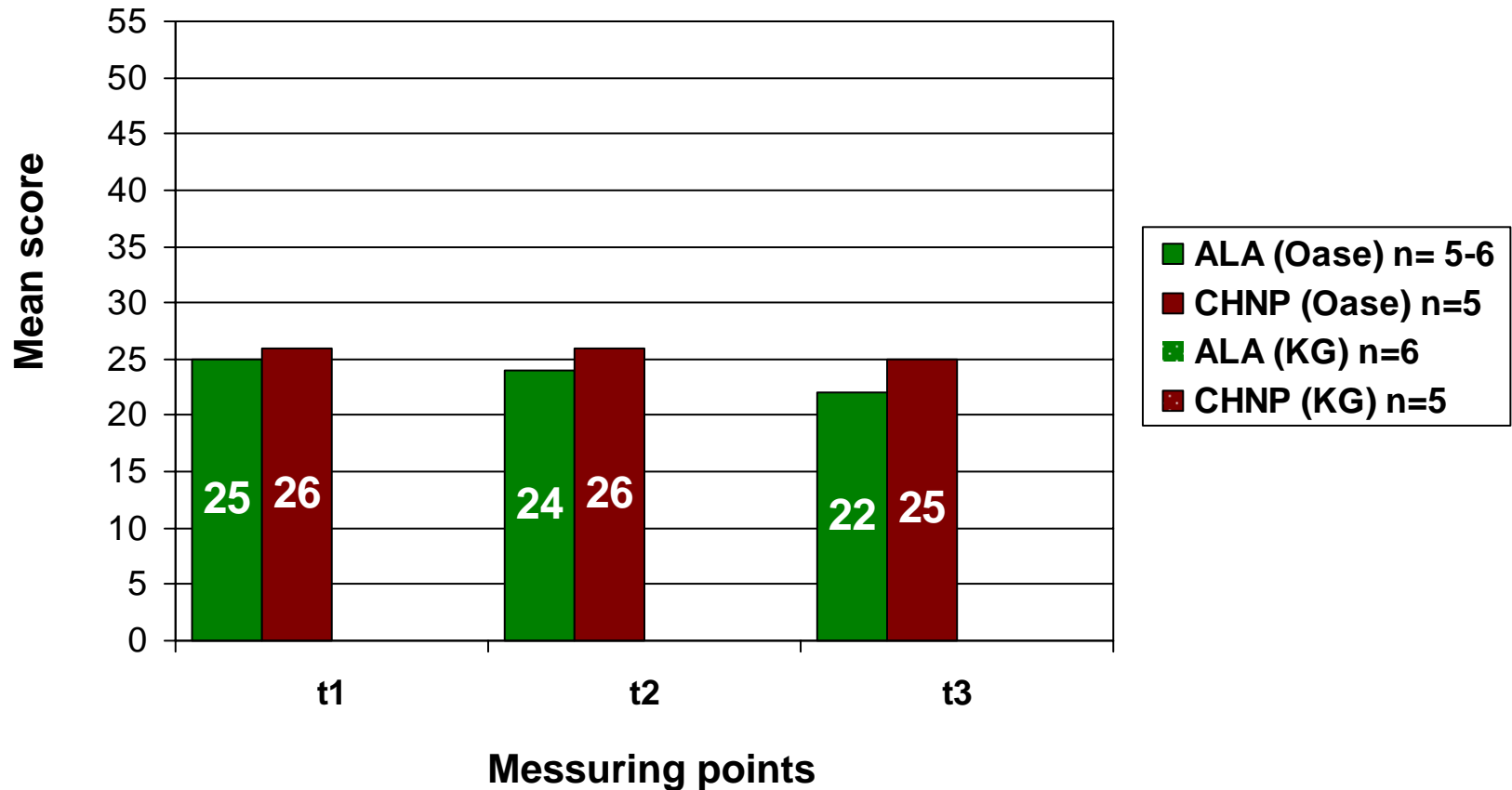
CMAI – compare both oases



CMAI - compare both oases and control groups (KG)

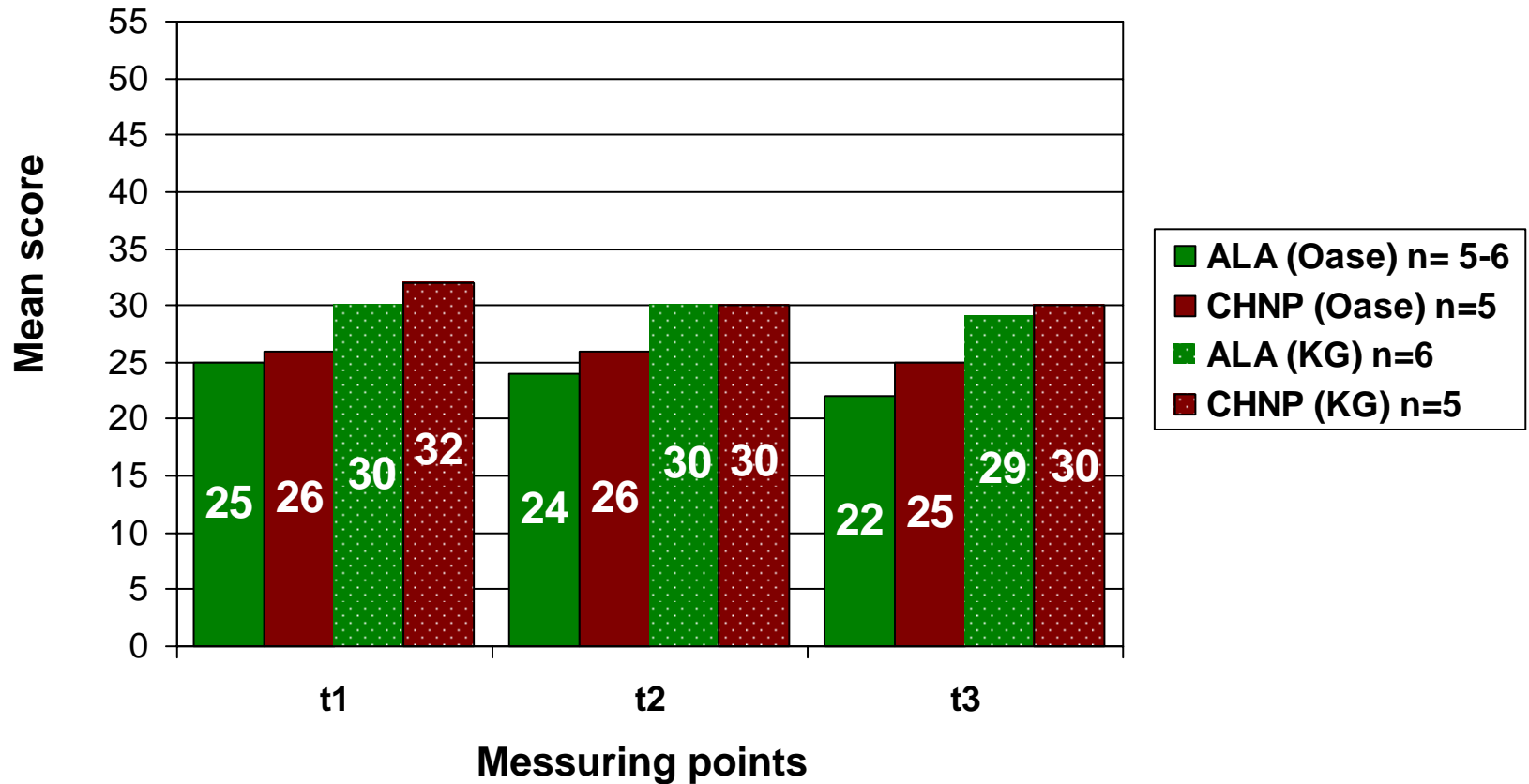


QUALID – compare both oases



11 points = best score for quality of life

QUALID – compare both oases and control groups (KG)



11 points = best score for quality of life

Autonomous
choicel

Well-being and behaviour-related competence

improved
nutritional
situation

improved level
of alertness

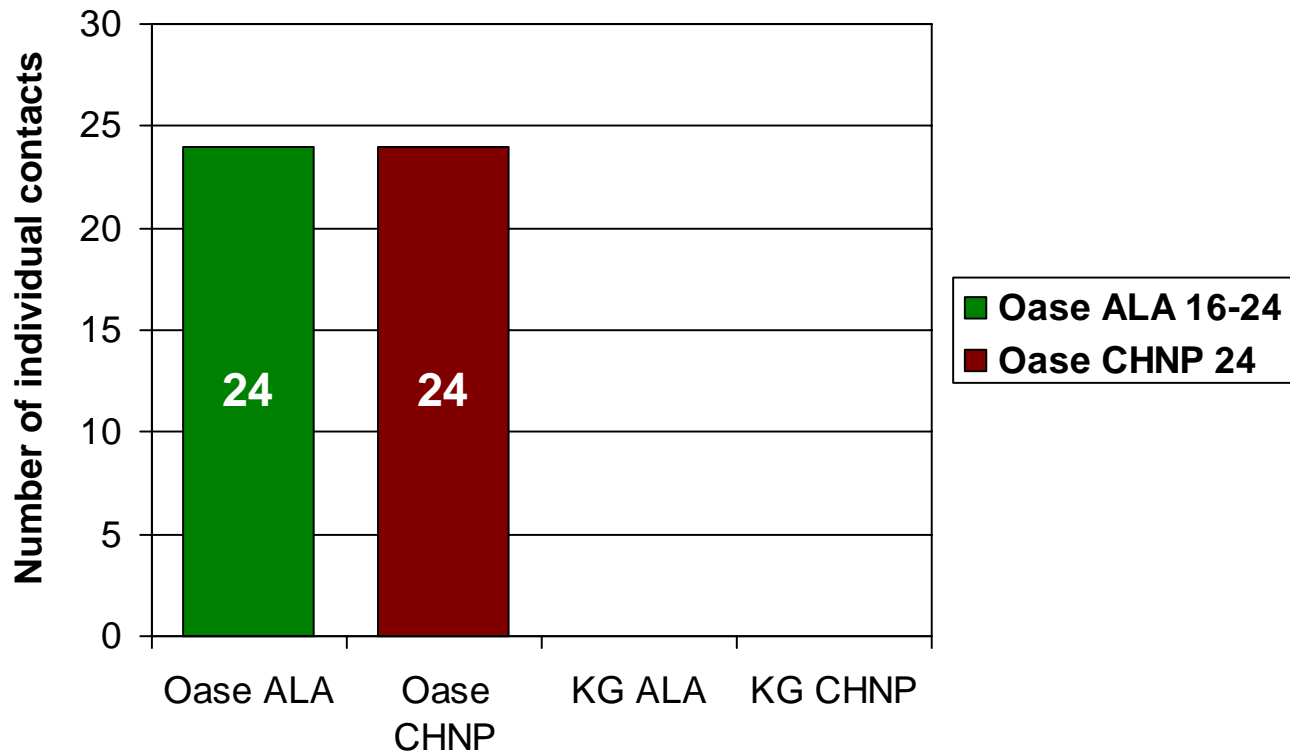
increased
frequency
of interacton

Improved
relaxation
and sleep

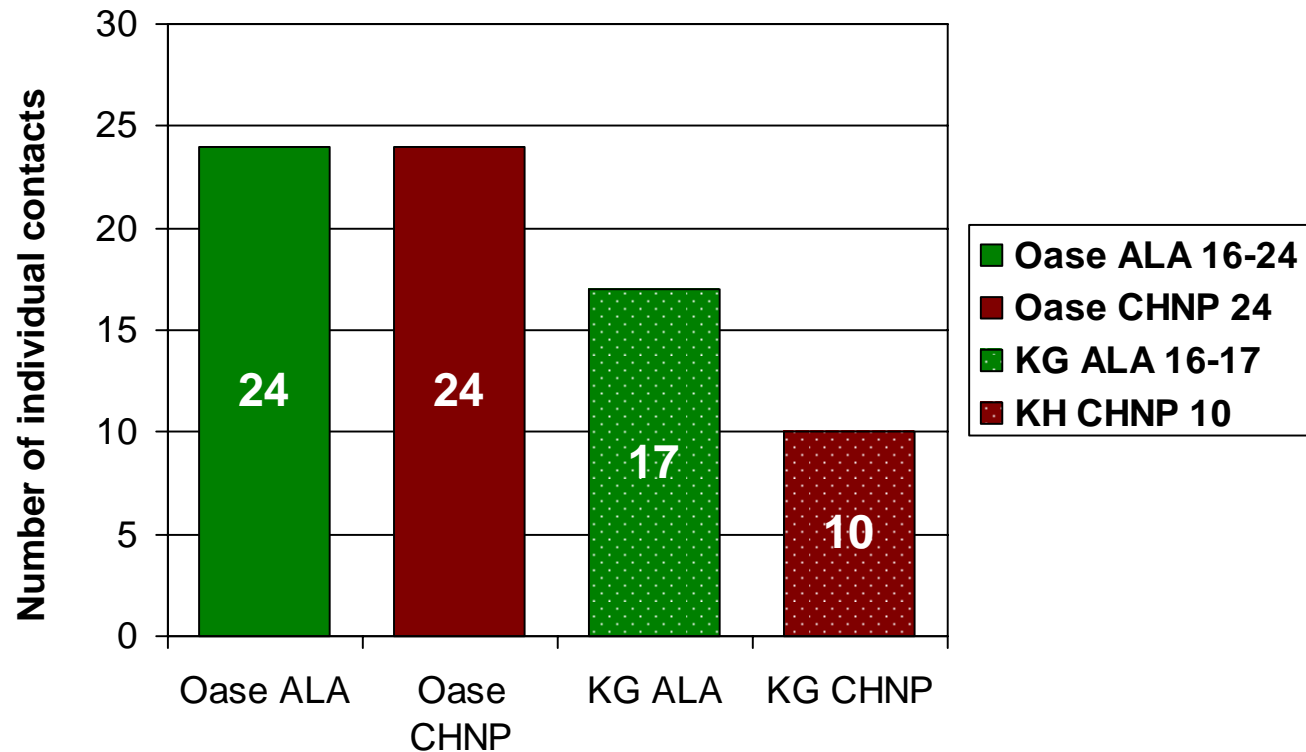
reduction of
challenging
behaviour

Perspective of family members and care staff

DIGI – compare frequency of contact of both oases



DIGI – compare frequency of contact



➔ Staff presence facilitates need orientation

- **Comparability between the two facilities**
 - target groups differ
 - difference in terms of staffing in oasis
- **Comparison between care oasis and control group**
 - staffing
 - Course of the disease impacts on behaviour (dementia-related degradation processes; improvement effects after apoplectic stroke);
- **Observations with regard to care oasis residents**
 - heightened level of alertness
 - positive changes in development of body weight
 - reduction of states of fear/anxiety
 - more contact between care staff and residents

Thank you for your attention



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