

Lessons from the daily life of a dialysis patient: the ergotherapeutic lens

Tiana Meeus, Veneta Mihailov, Louise Poelman, Stephanie Van Duyse, Eline Van Samang, Laura Vereecken,
Prof dr Patricia De Vriendt



We are indebted to:

- all patients
 - Dr Valerie Neiryndck
 - Mrs Ingrid Varendonck
 - Mrs Sigrid Desmet -
Van Damme
 - Mrs Tamara Leune
 - Prof dr Wim Van Biesen
-

Introduction







- Working till old age
- Purposeful physical activities
- Build in their daily life
- Reason for being
 - 'plan de vida' in Costa Rica
 - 'Ikigai' in Japan



Meaningful daily activities

- Working till old age
- Purposeful physical activities
- Build in their daily life
- Reason for being
 - 'plan de vida' in Costa Rica
 - 'Ikigai' in Japan



Population based study of social and productive activities as predictors of survival among elderly Americans

Thomas A Glass, Carlos Mendes de Leon, Richard A Marottoli, Lisa F Berkman

Harvard University
School of Public
Health, Department
of Health and
Social Behavior,
Boston, MA 02115,
United States

Thomas A Glass,
assistant professor
Lisa F Berkman,
professor and chair

Rush Institute for
Healthy Aging,
Rush-Presbyterian-St
Luke's Medical
Center, Chicago, IL
60612, United
States

Carlos Mendes de
Leon,
associate professor

Yale University
School of Medicine,
Department of
Internal Medicine,
Geriatrics, DC 023,
New Haven, CT
06504, United
States

Richard A
Marottoli,
associate professor

Correspondence to:
TA Glass tglass@hsph.harvard.edu

BMJ 1999;319:478-83

Abstract

Objectives To examine any association between social, productive, and physical activity and 13 year survival in older people.

Design Prospective cohort study with annual mortality follow up. Activity and other measures were assessed by structured interviews at baseline in the participants' homes. Proportional hazards models were used to model survival from time of initial interview.

Setting City of New Haven, Connecticut, United States.

Participants 2761 men and women from a random population sample of 2812 people aged 65 and older.

Main outcome measure Mortality from all causes during 13 years of follow up.

Results All three types of activity were independently associated with survival after age, sex, race/ethnicity, marital status, income, body mass index, smoking, functional disability, and history of cancer, diabetes, stroke, and myocardial infarction were controlled for.

Conclusions Social and productive activities that involve little or no enhancement of fitness lower the risk of all cause mortality as much as fitness activities do. This suggests that in addition to increased cardiopulmonary fitness, activity may confer survival benefits through psychosocial pathways. Social and productive activities that require less physical exertion may complement exercise programmes and may constitute alternative interventions for frail elderly people.

or musculoskeletal strength. We examined the relation between survival and three types of activities separately: social, productive, and fitness. While several previous studies provide tentative evidence for a link between social activities and mortality,^{7,8} no study has examined the impact of social and productive activities on the risk of mortality among elderly people independent of physical activities.

The exact mechanisms through which activity acts on health and survival are not known, although several mechanisms have been suggested. Activity has been found to be associated with more optimal lipid metabolism,⁹ high density lipoprotein concentrations,¹⁰ and glucose metabolism.¹¹ It also seems that inactivity is associated with a greater likelihood of behavioural risk factors for cardiovascular disease, including obesity, poor diet, and smoking.¹² Whether psychosocial mechanisms associate aspects of activity also contribute advantage enjoyed by more active known. Recent evidence suggests factors may influence some of variables, raising questions as to whether activity may operate through these mechanisms.^{13,14} Social activities have been shown to be associated with severe cardiovascular mortality including pressure,¹⁶ and presence of coronary artery disease.¹⁵ This study contributes to a growing gerontology that recognises the importance of engagement and productive activity of successful ageing.¹⁸

Key messages

- Little is known about predictors of survival among elderly people
- Physical activity is clearly good for health, but the potential benefits of social activities have not been studied
- Social and productive activities are as effective as fitness activities in lowering the risk of death
- Enhanced social activities may help to increase the quality and length of life

Research Article

An investigation into the role and meaning of occupation for people living with on-going health conditions

Carolynne White, Primrose Lentin and Louise Farnworth

Department of Occupational Therapy, School of Primary Health Care, Faculty of Medicine, Nursing and Health Sciences, Monash University, Frankston, Victoria, Australia

Background/aim: In Australia and internationally, more people are developing on-going health conditions (chronic illnesses) in which their daily occupations are implicated in both the onset and management of the condition. This article investigates the role and meaning of occupation from a client-centred perspective. It presents one aspect of a broader study that aimed to inform occupation-based practice for people living with on-going health conditions.

Methods: This study used an emergent, mixed methods design. A total of 16 adult participants, with one or more on-going health conditions that impacted on their participation in occupations, were interviewed using two semi-structured interviews. Narrative data were analysed using grounded theory methods which included coding, memo-writing and constant comparison. A theoretical understanding, consisting of four categories and a core concept, was constructed through the data analysis.

Results: Occupation fulfils four distinct, but interrelated, roles for people living with on-going health conditions. Engaging in occupation can reveal, explain, manage and overcome on-going health conditions. The core concept, 'occupation empowers', integrates the different roles of occupation and reflects the meaning of occupation for people with on-going health conditions.

Conclusions: This study contributes a theoretical understanding of the roles and meaning of occupation that is grounded in the experiences of people living with on-going health conditions. These findings extend our understanding of human occupation, and highlight the importance of narrative techniques to support occupation-based practice and empower people living with on-going illness.

KEY WORDS chronic illness, client-centred therapy, empowerment, human activities.

People's activities and occupations are implicated in the onset and management of on-going health conditions (chronic illnesses) (Australian Institute of Health and Welfare (AIHW), 2012a; World Health Organisation (WHO), 2011). Occupational therapy, with its focus on promoting health and well-being through occupation (World Federation of Occupational Therapists, 2011), is uniquely positioned to address the growing burden of on-going health conditions. However, an in-depth understanding of the relationships between human occupation, health and illness is required to support occupation-based practice with this client population. This article investigates the roles and meaning of occupation for people living with on-going health conditions.

Occupation can manage health conditions and identity

Participants managed their health conditions through their choice of occupations and activities. Their occupational choices were informed by their personalised understanding of illness and combined with medical, complementary and traditional treatment approaches. For example, while in hospital receiving medical treatment for second degree burns, Sean self-administered pranic healing techniques to promote health and 'fast track' his recovery. In addition to their on-going health conditions, many participants were more susceptible to acute infections and described occupational strategies to prevent illness. For example, Bea chose not to get a flu vaccination due to her sensitivity to medications. However, Bea protected herself by avoiding crowded, enclosed spaces and taking '[whisky], the medicine of my mother's Scots ancestors'. Participants often made choices between the occupations in which they did, and did not, engage to manage on-going health conditions and maintain general health and well-being.

Through their choice of occupations, participants also managed the personal and social impacts of their conditions. The experience of on-going illness and its treatment caused profound disruption to participants' lives and sense of self. For example, Wendy first experienced the symptoms of an arteriovenous malformation while playing the flute to her daughter. After experiencing fatigue and seizures following neurosurgery, Wendy chose not to resume this occupation as she did not want to discover 'yet another damaged bit'. In contrast, Keshini immediately returned to hairdressing after undergoing chemotherapy for breast cancer. In styling a hairpiece for herself, Keshini avoided unwanted sympathy from people and maintained a positive outlook by 'pretend[ing] I'm a normal person'. In choosing occupations to conceal their health conditions from themselves and others, participants protected and maintained their identity.

Occupation can overcome health conditions

Participation in activities and occupations enabled participants to overcome the challenges created by their health condition. Rather than 'give in' to their illness, participants' focus shifted from engaging in occupations to manage their illness, to those that enabled them to 'get on with life'. For participants, like Giovanna, this involved resuming participation in familiar occupations. After being diagnosed with MS, Giovanna became depressed and did not want to do anything. However, when she realised that by doing nothing "I'm not only killing myself but I'm killing my family", Giovanna resumed mothering occupations such as cooking meals and taking her children to school with new meaning. For other participants, overcoming their health condition involved pursuing goals with a renewed sense of determination and urgency. As Melanie explained, "because of the health conditions, I'm... going to have a ticking time bomb essentially so I need to get my act together and [go travelling] before it gets too hard and too late."

Often, engaging in valued occupations, such as leisure or social activities, involved participants' weighing up the benefits of the occupation against the risks to their health. For Sean, going to the pub 'for a few beers' was a regular social occupation, yet he found that after drinking alcohol, the lymphoedema in his leg became denser, which restricted his movement. Rather than stop participating in valued occupations that impacted negatively on their condition, participants adapted the occupation to minimise the risk. For example, by going to the pub once a week, Sean minimised the risk to his health, while maintaining his social connections. For many participants, continuing to engage in valued occupations, or pursuing goals set prior to the onset of their condition, represented a triumph of self over their health condition.

Aim:
gaining insight in the daily life of
the dialysis patients

their daily functioning
their quality of life and influencing factors

Mixed method study

- Quantitative study
 - Cross sectional
 - Survey
 - Consecutive sampling
 - 4 dialysis centres,
 - 18+,
 - dialysis since 3 months,
 - exclusion: dementia, other cognitive or communicative impairments that prohibit patients from understanding the questions, foreign languages and acute admissions (min. 3 weeks)

Assessment
protocol

Demographic data

The number of
hospital admissions

Comprehensive
Geriatric Assessment
(CGA)

Groninger Frailty
Index

Amnestic
Comparative Self
Assessment (ACSA)
for Quality of Life

EQ-5-D

BIA for
independence in
Activities of Daily
Living (ADL)

EORTC QLQ-C30

Mixed method study

- Qualitative study
 - Cross sectional
 - In depth interviews
 - Heterogenous purposive sample:
 - 4 dialysis centres,
 - 18+,
 - dialysis since 3 months,
 - exclusion: dementia, nursing home residents
- Fenomenological hermeneutical analysis (Lindseth & Norberg, 2004)

Results of the quantitative study

All participants (n=140)

Participants

Male: 92 (65,70%)

Female 48 (34,30%)

Age: 72,32 (14,24; 24-95)

>65: 111 (79,30%); <65: 29 (20,70%)

Risk for depression: 25 (17,90%)

Daily functioning of the dialysis patients

Independence
in self care
(basic-ADL)

ICF-qualifiers b-ADL



- | | | |
|--------------|--|-----------|
| XXX.0 | NO problem (none, absent, negligible,...) | 0 – 4% |
| XXX.1 | MILD problem (slight, low,...) | 5 – 24% |
| XXX.2 | MODERATE problem (medium, fair...) | 25 – 49% |
| XXX.3 | SEVERE problem (high, extreme,...) | 50 – 95% |
| XXX.4 | COMPLETE problem (total,...) | 96 – 100% |

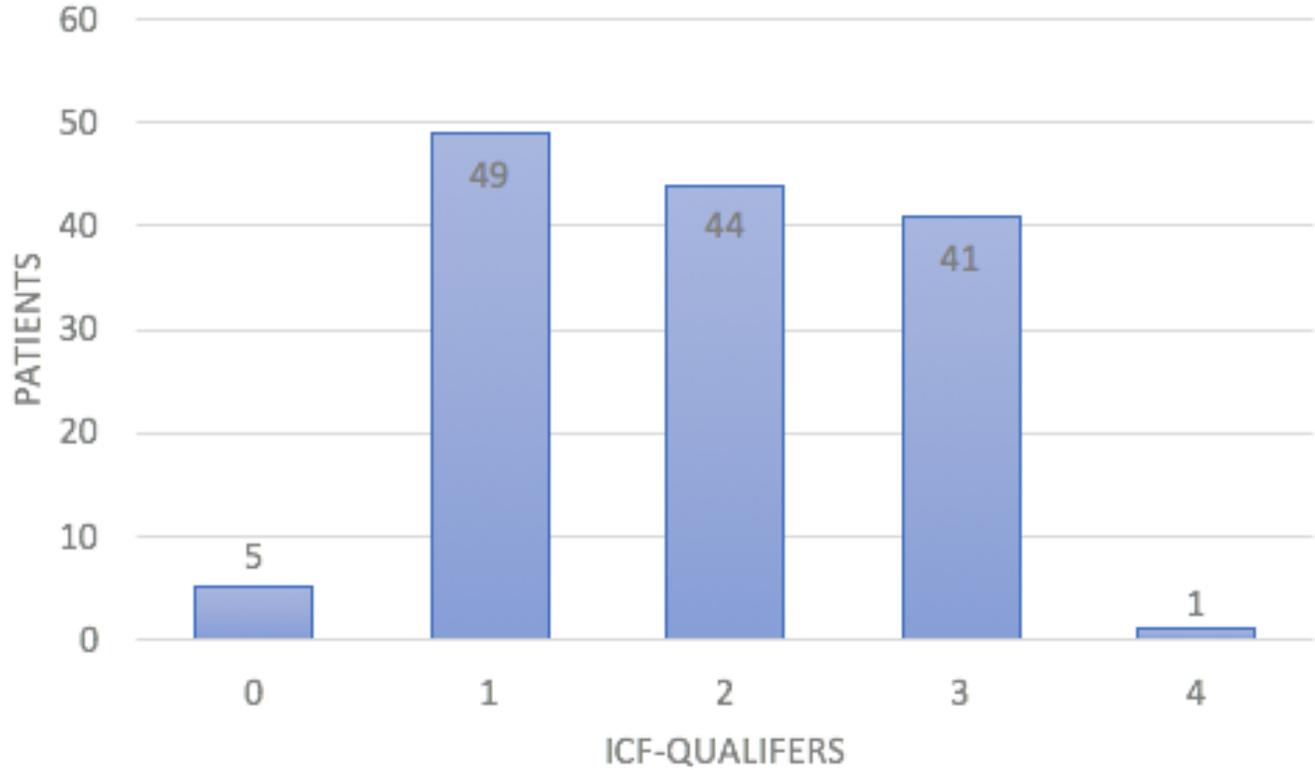
Independence
in household
activities
(instrumental
ADL)



XXX.0	NO problem (none, absent, negligible,...)	0 – 4%
XXX.1	MILD problem (slight, low,...)	5 – 24%
XXX.2	MODERATE problem (medium, fair...)	25 – 49%
XXX.3	SEVERE problem (high, extreme,...)	50 – 95%
XXX.4	COMPLETE problem (total,...)	96 – 100%

Independence
in hobbies,
leisure,
etc.(advanced
ADL)

ICF-qualifiers a-ADL

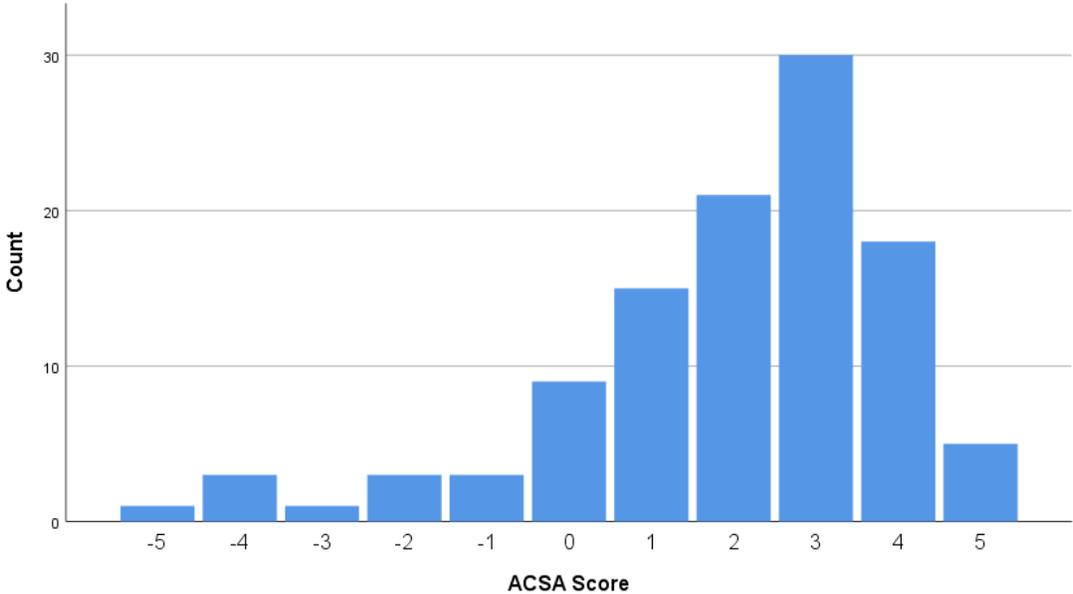


- XXX.0 NO** problem (none, absent, negligible,...) 0 – 4%
- XXX.1 MILD** problem (slight, low,...) 5 – 24%
- XXX.2 MODERATE** problem (medium, fair...) 25 – 49%
- XXX.3 SEVERE** problem (high, extreme,...) 50 – 95%
- XXX.4 COMPLETE** problem (total,...) 96 – 100%

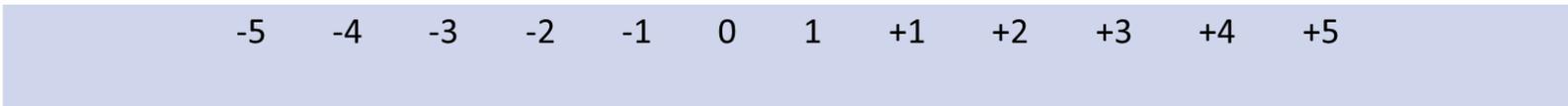
Quality of life of the dialysis patients and influencing factors

• ACSA - QoL-score: 1,97 ($\pm 2,05$; -5 +5)

Quality of Life
ACSA
(Bernheim & Buyse, 1984)



Ask the client: “Indicate down here how you felt during the last two weeks. On the scale, +5 means ‘as well as the best period in my life’ and -5 means ‘as bad as the worst period in my life’”.
Note the answer of the client.



➤ explaining 31,30% of the variance

Significant predictors of QoL: the ACSA-score ($p < 0,05$)

Cognitive Functioning Score (EORTC QLQ-C30)
80,33 (24,43; 0-100)

Usual Activities Score (EQ5D)
1,90 (0,60; 1-3)

Number of hospitalisations:
1,04 (1,00; 0-6)

Subjective health (EQ5D VAS)
60,52 (19,14; 4-100)

Frail (Groninger Frailty Index):
77,5% = frail
5,85 (2,57; 1-13)

Participants $\geq 65y$ (n=111)

Results of the qualitative study



Participants
(n=27)

Male: 12 (44,44 %)

Female: 15 (55, 56%)

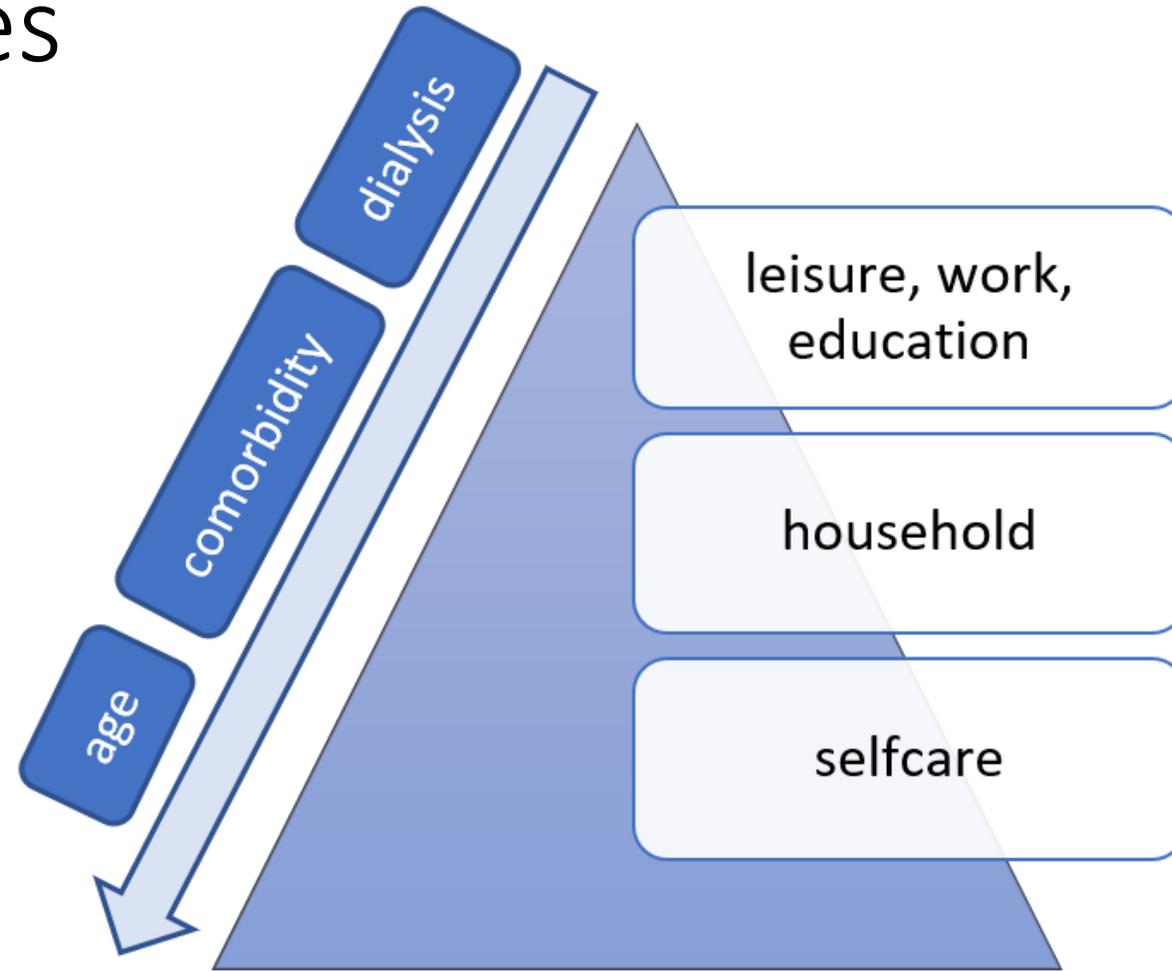
Age: 24-87 y

>65: 7 (25, 93%); <65: 20 (74,07%)

Dialysis: 4-90 months

Transplantation waiting list: 6

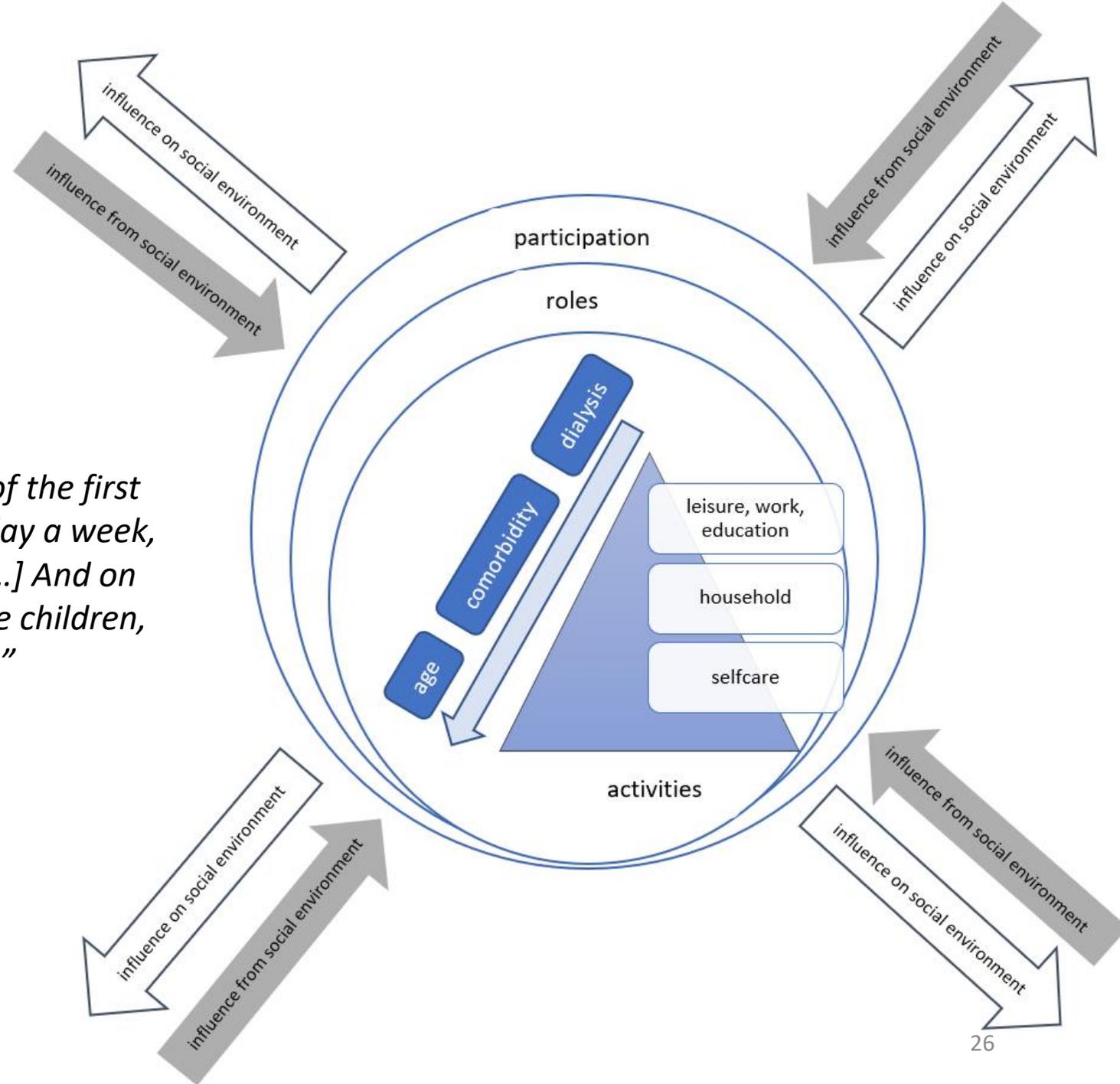
Daily Activities



Daily Activities

“I have four grandchildren and I always took care of the first two. Now I can only pick them up from school one day a week, Thursday, the day on which I don’t have dialysis. [...] And on Wednesdays I used to cook for my daughter and the children, and now she cooks, the roles are reversed.”

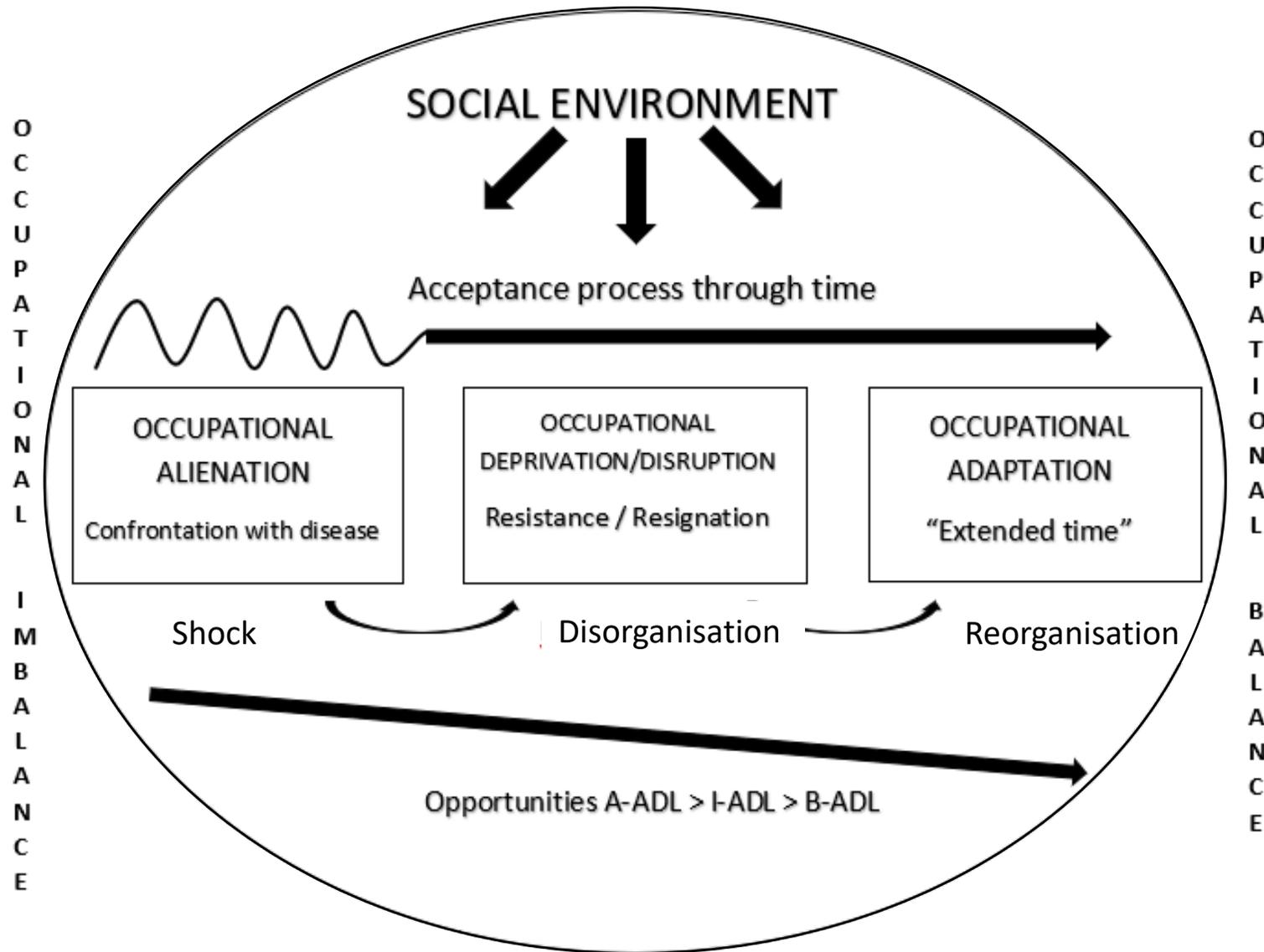
– woman, 71 years old –



Quality of Life

- Factors influencing QoL seemed to be
 - The decline in functioning and in social relations
 - Besides the time consuming dialysis, physical complaints
- Decrease in QoL from the moment dialysis started compared to 'before' dialysis
- Increase in QoL after a few months of dialysis through (beginning) acceptance of the dialysis

Adaptation process over time



The needs of dialysis patients

- Practical information about the impact on their daily life: how does it affect their work situation and how can they cope with the uncertainty of fatigue?
- How to deal with the changed future perspective and their roles: can they still be a parent, will they be able to work, ...?
- A wish for honest and raw information about life after transplantation.

“You need to be happy with what you have. That’s why it’s so hard for me to see the meaning of life, because you have to give up so much for something you didn’t want.”

– woman, 26 years old –

Implications for practice

- QoL and impact on daily life and social environment influence patients self-management abilities and treatment adherence (Kang & Stenfors-Hayes, 2016; Morton et al., 2012; Rosina, Crisp & Steinbeck, 2003)
- Patients should be coached in self-management: need for sufficient knowledge of coping strategies and time- and energy-management to maintain their meaningful activities and participation (Borell, Lilja, Svidén en Sadlo, 2001; Gemmel et al., 2016; Letchmi et al., 2011)
- Medical management and (to less extent) emotional management is supported
- Role management is almost not supported

Implications for practice

Occupational therapists can help:

- **Role management: adaptation of activities and environment -> maintaining activities and finding new ones -> higher QoL** (Chau et al., 2003; Mariotti & Rocha de Carvalho, 2011; Wells, 2015)
- **Implementing energy- and time-management strategies in their daily lives** (Chau et al., 2003; Mariotti & Rocha de Carvalho, 2011, McQuoid, Jowsey, & Taulikar, 2017)
- **Helping family members understand the impact of dialysis and reducing their stress** (Chau et al., 2003; Rote, Angel & Markides, 2014)

Take home messages

- Person centred care: take time to really listen what bothers the patients and matters and frame your recommendations in this context (O'Hare, 2017)
- Need for honest and raw information about 'daily life' after transplantation and during (pre)dialysis
- Supported (adapted) work (return to work) and education: refer patients to organisations (Hodac-Pannekeet et al., 2011)
- Attention for family members and their problems (Belasco, Barbosa, Bettencourt, Diccini & Sesso, 2006; Coleman, Piles & Poggenpoel, 1994)

Dialysis adds days to life,
occupational therapy adds life
to days

References

- Belasco, A., Barbosa, D., Bettencourt, A. R., Diccini, S., & Sesso, R. (2006). Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *American Journal of Kidney Diseases*, 13(48), 955-963.
- Borell, L., Lilja, M., Svidén, G. A., & Sadlo, G. (2001). Occupations and signs of reduced hope: An explorative study of older adults with functional impairments. *American Journal of Occupational Therapy*, 55(55), 311–316.
- Chau, K. F., Chak, W. L., Wong, M. K., Choi, K. S., Wong, K. M., Chan, Y. H., ..., & Li, C. S. (2003). *Rehabilitation of patients with end-stage renal disease*. Geraadpleegd op 3 mei 2019 via <http://www.fmshk.org/database/articles/771.pdf>
- Coleman, C., Piles, C., & Poggenpoel, M. (1994). Influence of caregiving on families of older adults. *Journal of Gerontological Nursing*, 20(11), 40-49.
- Davison, S. N., & Jassal, S. V. (2016). Supportive Care: Integration of Patient-Centered Kidney Care to Manage Symptoms and Geriatric Syndromes. *Clinical Journal of the American Society of Nephrology*, 11(10), 1882–1891. doi: 10.2215/CJN.01050116

References

- Gemmel, L. A., Terhorst, L., Jhamb, M., Unruh, M., Myakovsky, L., Kester, L., & Steel, J. (2016). Gender and racial differences in stress, coping and health-related quality of life in chronic kidney disease. *Journal of Pain and Symptom Management*, 30(52), 806-812. doi: 10.1016/j.jpainsymman.2016.05.029
- Kang, H. & Stenfors-Hayes, T. (2016). Feeling well and having good numbers: renal patients' encounter with clinical uncertainties and the responsibility to "live well". *Qualitative Health Research*, 25(26), 1591-1602. doi: 10.1177/1049732315591484
- Letchmi, S., Das, S., Halim, H., Zakariah, F. A., Hassan, H., Mat, S., & Packiavathy, R. (2011). Fatigue experienced by patients receiving maintenance dialysis in hemodialysis units. *Nursing and Health Sciences*, 13(1), 60–64. doi: 10.1111/j.1442-2018.2011.00579.x
- Mariotti, M. C., & Rocha de Carvalho, J. G. (2011). Improving quality of life in hemodialysis: impact of an occupational therapy program. *Scandinavian Journal of Occupational Therapy*, 18(18), 172-179.
- McLaughlin, K., Jones, H., VanderStraeten, C., Mills, C., Visser, M., Taub, K., & Manns, B. (2008). Why do patients choose self-care dialysis? *Nephrology Dialysis Transplantation*, 23(12), 3972-3976. doi: 10.1093/ndt/gfn359

References

- McQuoid, J., Jowsey, T., & Talaulikar, G. (2017). Contextualising renal patients routines: everyday space-time contexts, health service access, and wellbeing. *Social Science & Medicine*, 53(183), 142-150. doi: 10.1016/j.socscimed.2017.04.043
- Morton, R. L., Snelling, P., Webster, A. C., Rose, J., Masterson, R., Johnson, D. W., & Howard, K. (2012). Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. *Canadian Medical Association Journal*, 184(5), 277–283. doi: 10.1503/cmaj.111355
- Rosina, R., Crisp, J., & Steinbeck, K. (2003). Treatment adherence of youth and young adults with and without a chronic illness. *Nursing and Health Sciences*, 5(5), 139-147.
- Rote, S., Angel, J. L., & Markides, K. (2014). Health of elderly Mexican American adults and family caregiver distress. *Research on Aging*, 36(37), 306-331. doi: 10.1177/0164027514531028
- Wells, S. A. (2015). Occupational Deprivation or Occupational Adaptation of Mexican Americans on Renal Dialysis. *Occupational Therapy International*, 22(4), 174–182. doi: 10.1002/oti.1394