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Supporting families in health care systems – what do we know?

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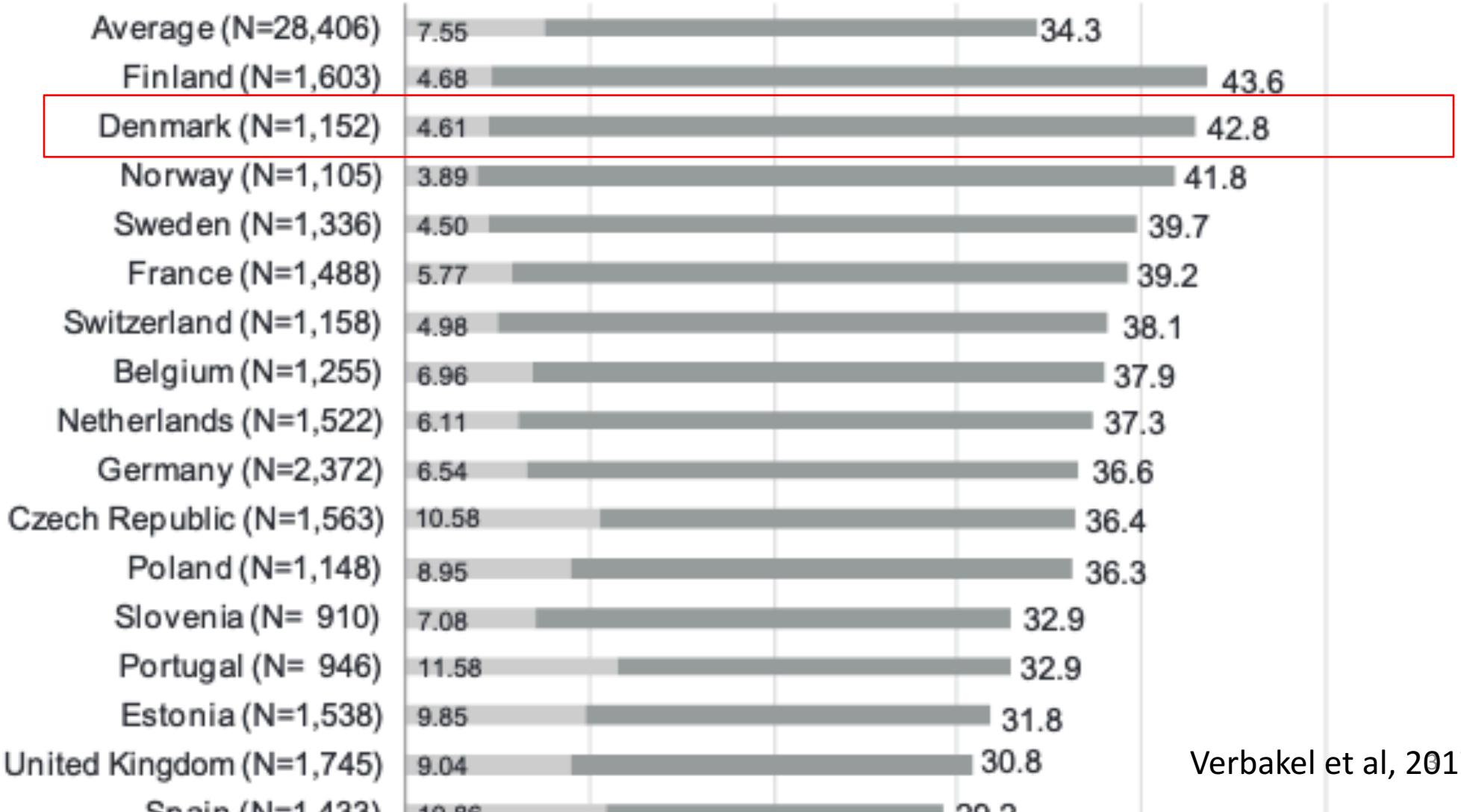
Families are in charge

Informal caregiving in Europe

Informal Caregiving in Europe



Verbakel et al, 2017

		n	Informal caregivers[a] %	Intensive caregivers[a] %	Generosity of formal long-term care provisions	Family care norm	Need for care
Austria	AT	1671	22.0	5.4	−0.36	0.37	12.81
Belgium	BE	1575	38.7	6.2	0.42	0.47	12.05
Czech Republic	CZ	1962	35.0	8.8	−0.62	0.50	12.13
Denmark	DK	1398	43.3	4.7	0.49	0.18	11.89
Estonia	EE	1876	31.5	9.2	−0.55	0.48	13.04
Finland	FI	1922	44.0	4.9	0.18	0.16	12.04
France	FR	1758	38.8	5.9	0.24	0.55	11.79
Germany	DE	2838	35.2	6.2	−0.02	0.39	12.54
Ireland	IE	2140	25.6	8.9	−0.60	0.44	10.80
Lithuania	LT	2064	20.4	6.8	−1.24	0.39	12.53
Netherlands	NL	1781	36.5	6.1	1.30	0.30	11.69
Norway	NO	1354	40.2	3.8	0.76	0.26	12.78
Poland	PL	1494	35.7	8.8	−1.70	0.68	12.57
Portugal	PT	1129	34.4	11.0	−1.41	0.81	12.22
Slovenia	SI	1113	33.1	5.6	−0.03	0.57	13.53
Spain	ES	1745	29.2	9.9	−0.54	0.68	10.82
Sweden	SE	1640	38.8	4.2	1.50	0.29	12.17
Switzerland	CH	1439	38.0	5.0	0.85	0.41	12.42
United Kingdom	UK	1995	30.2	8.6	−0.27	0.37	12.35
Mean			34.24	6.85	−0.08	0.44	12.22
Standard deviation			6.51	2.13	0.87	0.17	0.67
Minimum			20.41	3.75	−1.70	0.16	10.80
Maximum			43.97	10.98	1.50	0.81	13.53

Verbakel et al, 2018

Informal caregiving and formal provision of care

- family care norms not related to the likelihood of informal caregiving.
- family care norms positively related to intensive informal caregiving.
- generous long-term care provisions increases likelihood of informal care.
- less generous long-term care increases intensive caregiving, but lowers caregiving over all.

- CAVE: policy shifts to lower formal care could reduce informal caregiving over all.
- Caregivers who give “a little each”may be more sustainable for health care systems

Verbakel, 2018

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Families‘needs in health care

Understanding amongst patients , carers and professionals

Patient and Carer	Professionals
Economic hardship	Poor priority setting
Complexity associated with managing co-morbid conditions	Compliance failure
Competing demands inherent in balancing illness and its management with the desire to lead a normal life	Low health literacy resulting in poor motivation

Yen et al, 2011

During hospitalization

- Families feel overlooked and ignored;

- But provide:
  - Active presence
  - Protector
  - Facilitator
  - Historian
  - Coach
  - Voluntary caregiver

→ better knowing the patient

(McAdam, Arai & Puntillo, 2008; Mahrer-Imhof, Fröhlicher, Hofmann, 2006)

ICU

- 3.9% of families refused participation in care
- 13.8% provided care spontaneously
- 58.5% had symptoms of anxiety
- 26.2% had symptoms of depression
- 77.2% of patients had a favorable perception of family participation in care.

Garrouste-Orgeas et al, 2010

- Family members report diminished
  - family functioning
  - emotional well-being
  - communication
- Family members emotional support needs neglected by nurses

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Strengths and resources used by Australian and Danish adult patients and their family caregivers during treatment for cancer

E. Coyne, RN MN Hons PhD Senior Lecturer [a,*], K.B. Dieperink, RN, MCN, PhD, Postdoc [b], B. Østergaard, RN, MSc, PhD Associate Professor [c], D.K. Creedy, RN PhD. Professor of Perinatal Mental Health [d]

ORIGINAL ARTICLE

WILEY Journal of Clinical Nursing

Family functioning and perceived support from nurses during cancer treatment among Danish and Australian patients and their families

Karin B. Dieperink MCN, PhD, RN, Postdoc[1] | Elisabeth Coyne PhD, MN, RN, Senior Lecturer[2] | Debra K. Creedy PhD, RN, Professor[2] | Birte Østergaard MSc, PhD, RN, Associate Professor[3]

Family members

- No choice to become a caregiver
- Little information
  - What to expect
  - How to manage medication
  - How to perform ADLs
  - How to seek asstiance

Grimmer, 2004

- Well informed family members felt more prepared to provide care than less informed family members (M = 2,478, SD = 0,75 vs. M = 2,11, SD = 0,72 ; t(102) = 2,301, p = 0,02)

Originalarbeit

Die Zufriedenheit mit der Austritts-planung und die Informiertheit von Angehörigen beeinflussen die Bereitschaft, Pflege zu übernehmen

Katharina Weiler*[1], Yvonne Wittwer*[2], Daniela Händler Schuster[3] und Romy Mahrer-Imhof[4]

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[4] Nursing Science & Care GmbH, Winterthur

Weiler, Wittwer, Händler Schuster, Mahrer-Imhof, 2019

Family involvement

- Improved communication between health care providers and families
  - Length of stay
  - Resource utilization
  - Psychological disturbances

Ris,Schnepp &Mahrer-Imhof, 2019; Bauer, Fitzgerald, Haesler & Manfrin, 2009; Black, Boore & Parahoo, 2011

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What to do?

Aim of family intervention

1. Improve outcomes for person with the disorder or illness by improving family engagement and effectiveness in handling the challenges associated with the problem
2. Improve the well-being of the caregiver as well as reduce stress and negative outcomes of caregiving.

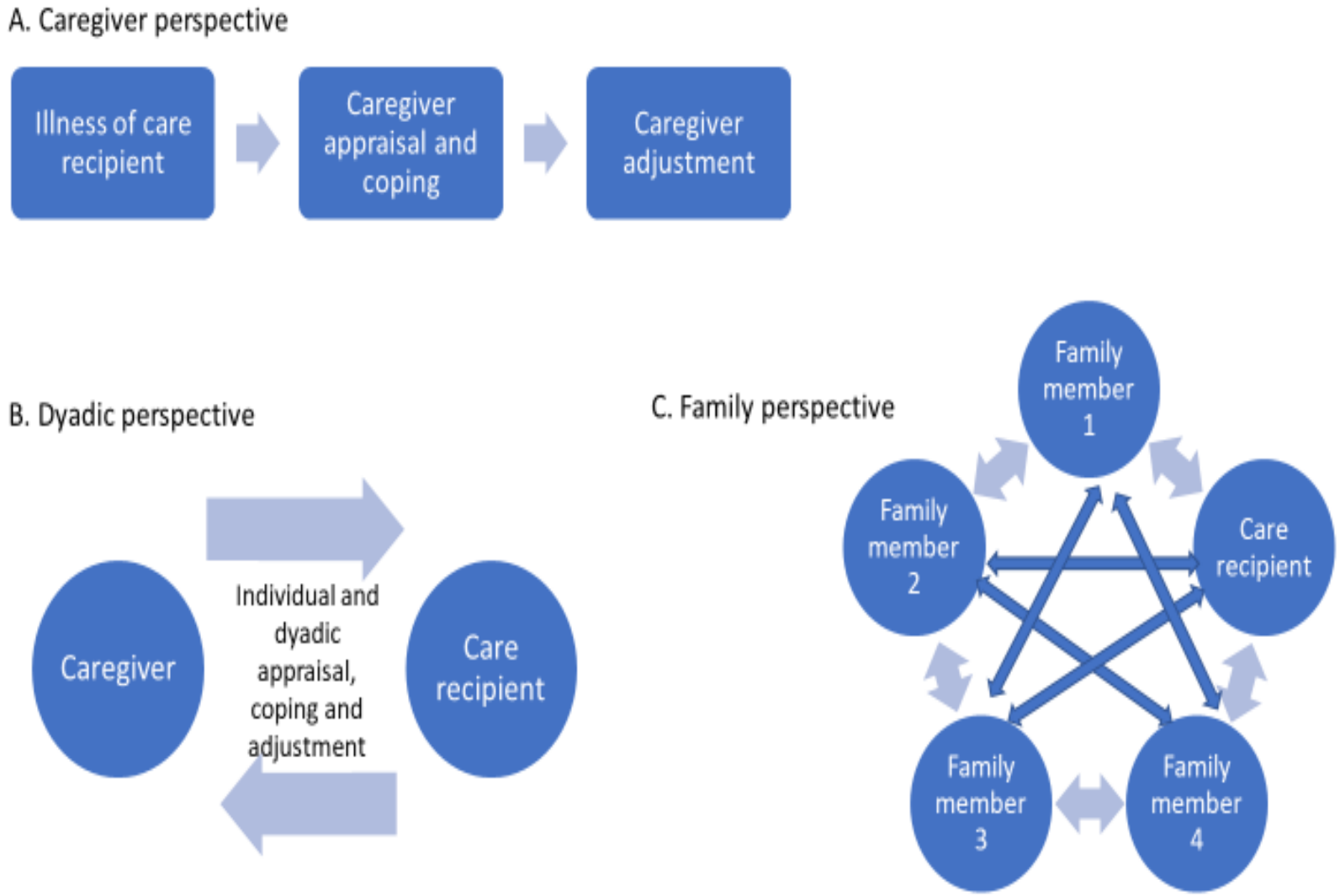
Diverse professionals can utilize general family interventions

American Psychological Association; 2019

Kind of interventions

- **Individual consultation for the patient**
  - Patient-focused intervention
    - Empowerment
    - Self-care management
    - Autonomy vs dependency
- **Individual consultation for family caregivers**
  - Family member-focused intervention
    - Empowerment
    - Self-care management
    - Reducing burden
- **Group consultation for family as system**
  - Family-focused intervention
    - Psychoeducational intervention
      - Mutual empowerment
    - Relationship based interventions
      - Alleviate stress in family relationships

Figure X. Simplified conceptual models of the caregiver perspective, the dyadic perspective and the family perspective



Original by K.Dieperink

Family interventions

- Psychoeducational intervention
  - inform patients and family members about the disease and about how the disease affects their lives;
  - increasing knowledge about the disease and improving self-management
- Relationship-based intervention
  - address relationships and go beyond education
  - directly improve family functioning with respect to health

Hartmann et al, 2010;
Mahrer-Imhof &Bruyland, 2014

Family nursing therapeutic conversations

- Intervention:
  - Individual or family sessions (3 over 6 to 12 weeks)
- Topics:
  - gaining a family perspective on living with heart failure
  - Most prominent problem and issues to discuss at meeting
  - tailored to individual family situation
- Outcomes:
  - Patients health-related QoL, Self-care, depression
  - Family members

Ostergaard et al, 2018

Effect of family nursing therapeutic conversations on social support, family health and family Functioning among outpatients with heart failure and their close family members: A randomised multi-centre trial.

Birte Østergaard , Romy Mahrer-Imhof , Mahdi Shamali, Birgitte Nørgaard, Bernard Jeune, Karen Steenvinkel Pedersen and Jørgen Lauridsen, under review

ELSEVIER

Patient Education and Counseling

Volume 101, Issue 8, August 2018, Pages 1385-1393

Effect of family nursing therapeutic conversations on health-related quality of life, self-care and depression among outpatients with heart failure: A randomized multi-centre trial

Birte Østergaard [a, c], Romy Mahrer-Imhof [b], Lis Wagner [a], Torben Barington [c], Lars Videbæk [d], Jørgen Lauridsen [e]

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What to build?

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Guest Editorial

Prioritizing Family Health of Older People in Europe: Current State and Future Directions of Family Nursing and Family-Focused Care

Journal of Family Nursing
2019, Vol. 25(2) 163–169

DOI: 10.1177/1074840719852547
journals.sagepub.com/home/jfn
SAGE

Garcia-Vivar, C., Arstedt-Kurki, P., Brodsgaard, A., Dieperink, K. B., Imhof, L., Konradsen, H., Luttik, M.L., Mahrer-Imhof, R., Ostergaard, B.,& Svavarsdottir, E. K.

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Capacity building : Prioritizing family health....

1. Develop a common, interdisciplinary understanding of family care.
2. Identify core outcome measures and research methods suitable for use in the context of family-focused care.
3. Develop a model for family care to guide knowledge and improve methods targeted at family care that focuses on independent living and empowerment.
4. Develop evidence on best practices of educational and supportive family nursing/family-focused interventions for families caring for their family members.

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Family Focused Healthcare Research Center (FACE)

I am wishing you all the best!

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