

Appendix 2. Details of the articles

Author; year; country	Title	Informant s; number of participant s (N)	Study aim	Disease; category of seizures; intellectua l level; age	Design; method ology	Information needs identified for formal/inf ormal caregivers
Baca, Barry and Berg (2018, USA)	The epilepsy transition care gap in young adults with childhood onset epilepsy.	Informal caregivers (parent proxy or patients); N=308	To assess the extent to which epilepsy transition discussions occurred (prior to the patients' 18 th birthday) in the transition to adulthood	Epilepsy/epilepsy and ID Category of seizures not specified 14,6% had IQ<70 Patients aged 18 years or older	Quantitative; longitudinal study; Structured interviews and telephone interviews	Formal caregiver versus: -A need for professionals to initiate a transition discussion between the patient, family/local caregiver and neurologist

/medical formal caregivers in transition to adulthood.

- The need to identify barriers to successful delivery of effective information in transition is critical to build effective future care models.

Bar, Ghobeira, Azzi, Ville, Riquet, Touraine, Chemaly and Nabbout (2019, France)

Experience of follow-up, quality of life, and transition from paediatric to adult healthcare of patients with tuberous sclerosis complex.

Informal caregivers (family members and

To explore the experiences with medical follow

Tuberous Sclerosis Complex and epilepsy

Quantitative; Multicentre

Formal caregivers:
-A need to optim

patients); N= 60	w-up and transi tion	(debut < 16)	survey	<p>use transition programs to increase continuity of information between professionals particularly for patients with cognitive and psychiatric impairment.</p> <p>- A need for information related to the risk of developing symptoms from benign</p>
		<p>Epileptic spasms or focal seizures in 98 % of patients</p>		
		<p>Approx. 80 % had cognitive impairment</p>		
		<p>Patients aged 18 years or older</p>		

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heart, the
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may
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treatment.

<p>Bellon, Pfeiffer, Maurici (2014, Australia)</p>	<p>Choice and control: How involved are people with epilepsy and their families in the management of their epilepsy? Results from an Australian survey in the disability sector.</p>	<p>Informal caregivers (family caregivers and patients); N=171 and N=118 respectively</p>	<p>To explore the involvement in developing an epilepsy management plan</p>	<p>Epilepsy and ID Category of seizures not specified 18 % had various degrees of ID Patients</p>	<p>Quantitative; Multicentre online survey</p>	<p>Informal caregivers: Family caregivers and patients need to be involved in writing epilepsy management plans in order to</p>
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					aged 18 years or older	ensure patient-centred care.
Both, Holt, Mous, Patist, Rietman, Dieleman, Hoopen, Vergeer, de Wit, de Heus, Moll, van Eeghen (2018, The Netherlands)	Tuberous sclerosis complex: Concerns and needs of patients and parents from the transitional period to adulthood.	Informal caregivers (parents and patients); N=12 and N=16 respectively	To explore the concerns and care needs in the transition	Tuberous Sclerosis Complex	Qualitative; Semi-structured interviews	Formal caregivers: -The need for professional caregivers that includes the family caregivers and the patient's comprehensive needs. -The need for patient-centred, multi
					32,1 % (9 patients) had mild ID (IQ: 55-70)/	
					17,9 % (5 patients) had moderate ID	

(IQ: 40 – 55)/ 7,1% (2 patients) had severe ID (IQ: 20 – 40)	disciplinarily information exchange in transitions to adulthood.
Patients aged 18 years or older	-The need for well-informed professionals concerning possibility of seizures, side-effects of medication, tumour growth, TSC-associated neuropsychiatric disorders (TAND).

Informal caregivers:

The need for peer-support groups for parents.

<p>Buelow, Mc Nelis, Shore, Austin (2006, UK)</p>	<p>Stressors of parents of children with epilepsy and intellectual disability.</p>	<p>Informal caregivers (parents); N=20</p>	<p>To explore sources of parental stress</p>	<p>Epilepsy and mild ID</p> <p>Category of seizures not specified</p> <p>All participants had mild ID (IQ = 55-75)</p> <p>Patients aged</p>	<p>Qualitative; Semi-structured interviews</p>	<p>Formal caregivers:</p> <p>-The need for interaction between school and parents concerning issues like communication, transitions, child safety, and social issues.</p>
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9-16
years

-The need for information/skills concerning behavioural problems, and the handling of seizures.

Formal and informal caregivers:

-The need for sufficient information concerning the child's diagnosis/treatment.

Deepak, Obe, Attavar (2012, UK)	Administration of emergency antiepileptics in staffed care homes for people with intellectual disabilities in High Wycombe: survey of staff training status	Formal caregivers (staff and managers of nursing homes); N= not specified	To determine the training status and - need of staff in nursing homes regarding emergency antiepileptic medication	Epilepsy and ID	Quantitative; Survey and telephone interviews	Formal caregivers: -The need for seizure stopping training for formal caregivers in nursing homes. -The need for multidisciplinary collaboration and communication between professionals in various levels of care involved in
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managing people with intellectual disabilities and epilepsy to ensure provision of safe and effective care.

<p>Desnous, Goujon, Bellavoine, Merdariu, Auvin (2011, France)</p>	<p>Perceptions of fever and fever management practices in parents of children with Dravet syndrome.</p>	<p>Informal caregivers (parents); N=20</p>	<p>To study parents' experiences of managing fever in their child</p>	<p>Dravet syndrome</p>	<p>Quantitative; Survey</p>	<p>Informal caregivers: -The need for parent guidance related to appropriate handling of fever. -The need for addressing parental</p>
				<p>Category of seizures not specified</p>		
				<p>ID level not specified</p>		
				<p>Patients' mean</p>		

				age 4,7 years		anxiety regarding fever.
Gordon, Valiengo, Proenca, Kurcgant, Jorge, Castro, Marchetti (2014, Brazil)	Comorbid epilepsy and psychogenic non-epileptic seizures: How well do patients and caregivers distinguish between the two.	Informal caregivers (family caregivers and patients); N=25 and N= 24 respectively	To explore how patients and informal caregivers distinguish between epileptic and psychogenic non-epileptic seizures (PNES)	Epilepsy and ID Generalized seizures in 16,7 %/ Seizure activity in focal-temporal lobe in 66,7 %/ Seizure activity in focal-non temporal lobe in 4,2 %/ Nonclassified in 12,3 % and	Qualitative; Interviews and video - electroencephalography (VEEG) containing the patients' epileptic seizures and PNES.	Informal caregivers: -The need for (parental) information/education in order to be able to distinguish between PNES and an epileptic seizure and thus treat the seizures properly.

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Jensen, Liljenquist, Bocell, Gammaitoni, Aron,
Galer, Amtmann (2017, USA)

Life impact of caregiving for severe
childhood epilepsy: Results of expert
panels and caregiver focus groups.

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				and expert panel); N=not specified	specified	ID level not specified	care with patient-centered information provided by the parents/family caregivers	
						Patients aged 18 years or older		-The need for a measure that assesses all of the relevant domains necessary to consider the informal caregiver burden.

Kehyayan & Hirdes (articles: 2018 & 2019, Canada)

2018: Profile of persons with epilepsy receiving home care services.

Informal

To describe

Epilepsy

Quantitative

Informal

	caregivers (family members and patients); N=5665	be and understand the needs of patients in home care	and ID	e; Survey	caregivers:
2019: Care needs and health care burden of persons with epilepsy receiving home care services.			Category of seizures not specified		-The need for information and skills in caring for a family member with epilepsy. This includes the handling of seizures, medication, nutrition, the prevention of injury from falling in a seizure, the training of ADL functions and how
			27,2% had intact cognition/		
			47,7% had mild impairment/		
			11,6% had moderate impairment/		
			13,4% had severe impairment		
			Patients aged		

60 years or older to handle psychological and/or behavioural difficulties.

-The need for information regarding how to cope with stress for family caregivers.

<p>McGrother, Bhaumik, Thorp, Hauck, Branford, Watson (2006, UK)</p>	<p>Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications.</p>	<p>Informal caregivers (family caregivers); N=620</p>	<p>To determine the prevalence of epilepsy and associated difficulties in</p>	<p>Epilepsy and ID Category of seizures not specified</p>	<p>Mixed methods; Medical patient register and interviews</p>	<p>Formal caregivers: -The need for multidisciplinary collaboration and information</p>
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				adults with ID	All participants had moderate to severe ID (IQ<55)	Patients aged 18 and older	<p>n exchange (social services, educational agencies, health professionals, family caregivers, and the voluntary sector).</p> <p>-The need for specialists with knowledge related to epilepsy, associated difficulties and ID.</p>
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Nolan, Camfield and Camfield (2008, Canada) Coping With a Child With Dravet Syndrome: Insights From Families Informal caregivers To describe Dravet Syndrome Qualitative ; **Formal**

vers (parents); N=24	potential coping strategies to improve the daily life of parents	syndrome	Interviews	caregivers:
		Category of seizures not specified		-The need for an emergency department protocol for the handling of prolonged seizures to support the various professional caregivers involved in the treatment of the child.
		ID level not specified		
		Patients aged 24 or younger		-The need for teachers to call parents, not asking siblings

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participation in peer-support groups.

<p>Schultz (2013, UK)</p>	<p>Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care</p>	<p>Informal caregivers (parents); N=7</p>	<p>To describe parental transition experiences</p>	<p>Epilepsy and ID</p> <p>Category of seizures not specified</p> <p>All participants had severe to profound ID (IQ <40)</p> <p>Patients aged 18 and older</p>	<p>Qualitative Interviews</p>	<p>Formal caregivers</p> <p>-The need to develop transition programme for adolescents with cognitive impairments in particular</p> <p>Formal and informal caregivers:</p> <p>-The need for easily accessible and easily</p>
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understandable information about the diagnosis and the safe handling of seizures.

Informal caregivers:

-The need for information on how to navigate in the health care and social services.

-The need for information from

peers

<p>Thomsen, Linehan, Glynn, Kerr (2013 & 2014, UK and Ireland)</p>	<p>2013: A qualitative study of caregivers ' and professionals' views on the management of people with intellectual disability and epilepsy: A neglected population.</p>	<p>2013: Mix: Informal caregivers (family caregivers); N=38/formal caregivers (professionals and paid caregivers) N=59 and N=16 respectively</p> <p>2014: Informal caregivers (family members); N=48</p>	<p>2013: To study the impact of epilepsy and evaluate the available treatment</p> <p>2014: To examine the impact on caregivers</p>	<p>Epilepsy and ID</p> <p>Category of seizures not specified</p> <p>ID level not specified</p> <p>Patients aged 17 or younger</p> <p>38,1%</p> <p>(24 patients)/ patients aged 18 years or older</p>	<p>Quantitative; International online survey</p>	<p>Formal caregivers:</p> <p>-The need for patient-centred information (medical and personal history) to meet the care demand in a safe way.</p> <p>-The need for training in administering (acute) medications.</p> <p>Informal</p>
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12,7 %	caregivers:
(8 patients)	-The need for optimal medical information (including routine medicines) as well as to reduce concerns (psychological stress) during medical consultations. -The need for optimal collaboration of services for the profe

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<p>Vallenga, Grypdonck Tan, Lendemeijer-and Boon (2007, the Netherlands)</p>	<p>Improving decision-making in caring for people with epilepsy and intellectual disability: an action research project.</p>	<p>Mix: Informal caregivers (family members) / formal caregivers (professional caregivers); N: not specified</p>	<p>To improve decision-making regarding risks</p>	<p>Epilepsy and ID Category of seizures not specified ID level not specified Patients' age not</p>	<p>Qualitative ; Interviews and observations</p>	<p>Formal caregivers: - The need for information and skills in risk management associated with the persons' epilepsy and overall functi</p>
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-The need for increased dialogue with the patient and the family members as a precondition for shared decision-making.

- The need for a more systematic approach among the professional caregivers, oriented to individual client

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ID = intellectual disability, PNES = psychogenic non-epileptic seizures