ORIGINAL RESEARCH

Primary care nurses in a local Belgian setting: Responding to healthcare needs of people with disabilities

Hannelore Storms *[1], Neree Claes[1,2,3]

[1] *Faculty of Medicine and Life Sciences, University Hasselt, Hasselt, Belgium*
[2] *vzw Wit-Gele Kruis Limburg, Genk, Belgium*
[3] *vzw Stijn dienstencentrum Sint-Gerardus, Diepenbeek, Belgium*

Received: December 5, 2016 **Accepted:** January 16, 2017 **Online Published:** February 14, 2017
DOI: 10.5430/jnep.v7n7p44 **URL:** http://dx.doi.org/10.5430/jnep.v7n7p44

ABSTRACT

Background: Given the worldwide evolution to deinstitutionalize care for people with a disability (PD), the importance of having care services, for instance as offered by primary care nurses (PCN), to deliver necessary care to PD can only be emphasized. European data (from 2014) show a relatively high percentage of PD in Belgium (16.2%) using home care services provided by primary health care providers (PCN, general practitioners. . .). Moreover, satisfaction levels regarding these services are among the highest in Europe. The objective of this research was to gain insight into the needs of PD regarding nursing care, based on PCN's experiences.

Methods: Between September and December 2015, a questionnaire – drawn up by a multidisciplinary team (4 general practitioners and 20 PCN) – was distributed electronically to 1547 PCN working in primary care in the Belgian region Limburg. Open-ended questions of this questionnaire were analyzed using techniques developed for qualitative data analysis. PCN were asked to report about (1) mental and behavioural problems, (2) medication policy, (3) swallowing problems, (4) monitoring of nutritional status and (5) any other needs arising in the care for PD.

Results: Comments of 588 PCN were generated (response rate of 38%). Besides the (routine) tasks of PCN, the impact of PD's and informal caregivers' behaviour on PCN's working environment were mentioned, particularly regarding medication policy, swallowing problems and nutrional status monitoring. PCN's collaboration with PD and their informal caregivers is often reported about in relation to respectively PD's limited ability to communicate or to understand PCN and informal caregivers behaving in a counteracting way, not following through PCN's advice. Additionally, PCN report about consulting and activating other healthcare professionals in the interest of PD's. Overall, PCN mentioned tasks in all facets of PD's lives: from the expected nursing care and far beyond.

Conclusions: Besides providing nursing care, PCN are also helping with different tasks related to daily living. This "beyond standard" - care enhances the likelihood of PD to keep on living in their homes for a longer period of time. PCN seem to play a crucial role in activating other healthcare professionals to meet the healthcare needs of PD. More extensive research should be carried out to gain insight in healthcare needs of PD and the challenges PCN come across in their care for this population. Findings can be used to align pre-qualification training and education of (future) PCN with the (unmet) needs of PD.

Key Words: Disability, Nursing care, Unmet needs

* **Correspondence:** Hannelore Storms; Email: hannelore.storms@uhasselt.be; Address: Faculty of Medicine and Life Sciences, University Hasselt, Hasselt, Belgium.

1. INTRODUCTION

People with disabilities (PD) often receive formal care from primary care nurses (PCN), both in their homes and in residential care facilities. A broad range of nursing care, from assisting with activities of daily living (ADL), for instance taking care of PD's personal hygiene, to complex wound care and managing medication, is delivered to PD. In their care for PD, nurses do not only pursue optimal health, their assistance often contributes to the independence of PD, in particular when they are able to keep on living in their own homes, because of nursing staff's interventions. Given the worldwide evolution to deinstitutionalize care for PD, the importance of having care services, for instance as offered by PCN, to deliver necessary care to PD can only be emphasized.[1] The reliance on primary care services in order to provide PD with necessary care is also true for Belgium: in 2014, 264,602 PD (<65 years old) were registered nationally; 129,021 of them living in the northern, Dutch-speaking part.[2–4] Despite efforts of the government to provide necessary care for PD in a community-setting, in 2013, approximately 21,518 PD (16%) registered in the northern part of Belgium, were waiting to receive care.[2–4] To compare, in the neighboring country, the Netherlands, healthcare for PD is more accessible and waiting lists are almost non-existing. As stated in a report from 2014, of the approximately 184,000 PD, 4,836 PD (2.6%) do not receive care of their choice.[5–7] Because primary care has shown to decrease mortality and is associated with positive health outcomes for PD, hampered accessibility of (Belgian) primary care would be problematic.[8–14] Taking into account European data (from 2014), the percentage of PD using home care services provided by nurses in Belgium is relatively high: about 16.2% of PD in Belgium, compared to 3% in other European countries; compared to 28% of people with difficulties in ADL in Belgium. Moreover, satisfaction levels regarding these services are among the highest in Europe: about 90% of PD report to be satisfied.[15]

Although this shift away from institutions was initially instigated by a cost-managing point of view – in order to reduce government expenditures on a broad range of care institutions, the movement towards more community-based services can also be approached from a participation-enabling perspective. Examplary is the PD-activating policy measure of assigning a budget for personal support to PD. With this budget PD can, whilst living in the community, 'buy' support to help them to live outside an institutionalized setting.[16] As care for PD is shifting towards primary care,[1] these community services are not always adapted to respond to this evolution. Primary care professionals are expected to address healthcare needs of PD, although feeling insufficiently educated (on prevalence of pathologies presented in PD, on how to respond to behavioural problems, on not knowing how to communicate with PD).[17–20] However, in correspondence with European data presented earlier, PD and their family caregivers are satisfied with the quality of care they receive.[21, 22] In order to gain insight in how PCN respond to healthcare needs of PD, this research examined nursing care delivered by PCN working in the Belgian region Limburg in PD's homes as well as in residential care facilities.

2. METHODS

A questionnaire was developed by a multidisciplinary team of 4 general practitioners (GPs) and 20 PCN during several meetings. Topics deemed relevant according to experts' opinion were addressed in both closed-ended and open-ended questions. In this research, only the open-ended questions on care needs of PD as presented to PCN, were analyzed. More specifically, PCN were asked to report about (1) mental and behavioural problems, (2) medication policy, (3) swallowing problems, (4) monitoring of nutritional status and (5) any other needs arising in the care for PD.

Data were gathered between September and December 2015, using purposive sampling: the questionnaire was distributed electronically to GPs and PCN working in home and residential care in Limburg, a region in Belgium. All self-employed PCN in the region and all PCN working for the regional nursing organization were send an email with a hyperlink to the questionnaire, respectively via the umbrella organization of self-employed PCN and the regional nursing organization. To analyze the quantitatively gathered responses to open-ended questions, techniques for qualitative data analysis were used.

3. RESULTS

3.1 Characteristics primary care nurses (PCN)

Findings in this study represent voluntary comments of 588 of the 1547 PCN who were send a questionnaire. 47.1% PCN (41.7%) were aged being between 46 and 60 years old. For the majority of PCN (64.6%) all three types of disabilities (physical, intellectual and combined) are represented in their patients. If PD can rely on a family caregiver 67.3% PCN have contact with at least half of these family caregivers.

3.2 Thematic analysis

Analysis revealed a broad variation in themes, beyond the four themes proposed in the open-ended questions. Moreover, themes are sometimes interrelated.

In Table 1, codes resorting under theme "mental and behavioural problems" can be found. Mental problems were categorized as: low mental age; memory problems; psychiatric problems (psychosis, paranoia, bipolar, hallucinations,

suicidal (attempts), self-mutilation, hearing voices, attention and concentration deficits. . .) and emotional problems (anger, frustration [because of not being able: to express themselves; to move], blaming others, feeling alone/socially isolated, crying, feeling blue, feeling not taken seriously, not being open to change). Behavioural problems were described form both PD's point of view: aggression (verbal versus non-verbal; in general, towards caregiver or health-care professional; because of: being fixated; paranoia); being resistive; anger outbursts; biting; and PCN's point of view: how to react to certain behavior; how to contribute to proper behavior.

Table 1. Mental and behavioural problems

Mental problems	Behavioural problems
• low mental age	Patient behaviour
• memory problems	• aggression
• psychiatric	➢ verbal versus non-verbal
➢ psychosis	➢ towards caregiver versus in general
➢ paranoia	➢ as a result of:
➢ bipolar	o being fixated
➢ hallucinations	o paranoia
➢ addiction	• attention seeking
➢ compulsory behaviour	• destructive
➢ suicidal (attempts)	• being resistive
➢ self-mutilation	• anger outbursts
➢ hearing voices	• biting
➢ attention and concentration deficits	• improper sexual behaviour
• emotional	PCN's opinions and questions
➢ anger	• how to react to certain behaviour
➢ frustration because of not being able:	• how to contribute to proper behaviour
o to express themselves	
o to move	
➢ blaming others	
➢ feeling alone/socially isolated	
➢ crying	
➢ feeling blue	
➢ feeling not taken seriously	
➢ not being open to change	
• coping	
➢ difficulties accepting condition/disability	
➢ difficulties accepting decline in health	
➢ difficulties accepting having to depend on others	

Note. PCN = primary care nurses; PD = people with a disability.

Medication policy were coded based on different medication management phases (preparation, administering, supervision, management, safeguarding, formal registration of medication actions) or by the most important actors (care institution, educators in institution, informal caregivers/family members, PCN) (see Table 2); problems with medication from a patient's point of view were primarily reducible to: not being able to prepare or put in place medication, not understanding how medication should be taken correctly, no insight in disease or how medication would help; being non-adherent in general; problems with medication encountered by PCN were: unavailability of medication; incorrect medication overview; unawareness of (extent) of other parties involvement in medication.

Codes representing themes "swallowing problems" and the "monitoring of PD's nutritional status" are portrayed in respectively Table 3 and Table 4. In Table 5 codes resorting under "tasks performed by PCN", as an emerging, additional theme, are listed. An overarching figure (see Figure 1) illustrates the collaboration of PCN with other health-care professionals as well as with PD's and their informal caregiver regarding mentioned themes. Moreover, PCN addressed several topics related to the struggles PD, in their opinion, experience: difficulties in communicating and understanding as well as related to functioning independently from others. In Table 6, these topics are described, as well as a few 'overlapping' themes.

Table 2. Medication policy: who manages what?

Medication handlers	Medication management					
	Preparation	Administering	Supervision	Management	Safeguarding	Formal registration medication actions
Care institution				X		
Educators in institution		X				
Informal caregivers/family members	X	X	X	X		
Primary care nurses	X	X	X	X	X	X

Table 3. Swallowing problems encountered by primary care nurses (PCN) in their care for people with a disability (PD)

Swallowing problems

- Underlying conditions
- Triggered by
  - solid food
  - liquids
  - medication
- Patient (disability-related) behavior
  - improper chewing
    - reason not specified
    - bad teeth
  - coughing
  - nausea
  - bedridden
  - wrong sitting position
  - brushing teeth
  - eating gluttonous
  - refusing thickners
  - refusing to sit up straight
- Informal caregiver behavior
  - family feeds bedridden patient orally when prohibited
  - uninformed about causes of swallowing problems
  - not knowing how to react on choking
  - not knowing how to adapt to swallowing problems
  - informal caregiver instructs patient when difficulties swallowing (medication)
- Supportive tools and adjustments
  - adjusted drinking cups
  - straws
  - thickners
  - mixed food
  - food cut into pieces
  - liquefy food
  - crushing food
  - total parenteral nutrition
  - percutaneous gastrostomy probe
- Problems situated in PD's home
  - eating/drinking too much
  - eating/drinking unadjusted
  - eating/drinking forced
- PCN inform and consult
  - informs informal caregiver about adjusting patients' positioning when drinking
  - consults dietician for advice
- PCN's opinions and questions
  - not enough time to spend with patients
  - useful to be able to give tips regarding swallowing problems to
    - patients
    - informal caregivers
  - how to react on choking
  - how to adapt to swallowing problems
  - wondering which types of food are (not) allowed
- Not responsibility of PCN
  - follow-up by dietician

Note. PCN = primary care nurses; PD = people with a disability

Table 4. Monitoring nutritional status (malnutrition/ obesity)

- PCN follow-up
  - ➢ follow up weight of PD
  - ➢ checking food intake
  - ➢ checking liquids going in & out
  - ➢ probe checking
- Nutritional status
  - ➢ underweight
    - resulting from
    - o lesser appetite
    - o refusal to eat
    - o forgetting to eat
  - ➢ overweight
    - resulting from
    - o medication
    - o too little exercise (sometimes disability related)
    - o eating too much
- Patient behaviour
  - ➢ PD refusing to eat
  - ➢ refusing to drink
    - o because inability to go to restroom (disability related)
  - ➢ not following up on diet
  - ➢ forgetfulness
  - ➢ dependability
- Informal caregiver behavior
  - ➢ feeding PD too much
- PCN inform and consult
  - ➢ food and sugar
  - ➢ food and obstipation
  - ➢ food and diarrhea
  - ➢ proteins and wound care
- Problems situated in PD's home
  - ➢ eating too much
  - ➢ eating too little

Note. PCN = primary care nurses; PD = people with a disability

4. Discussion

Findings presented in this research provide insight in the complex care needs of PD based on the experiences of PCN in the Belgian region Limburg. To date, few studies have been investigating how PCN respond to the needs of PD. The results presented in this study should be interpreted through the eyes of this group of healthcare professionals working in the field.

Besides the (routine) tasks of PCN, the impact of PD's and informal caregivers' behaviour on PCN's working environment, were also reoccuring themes in PD's medication policy, swallowing problems and the monitoring of PD's nutritional status. This is an indication that collaborating with PD and their family or friends is a crucial part of PCN's work. Two perquisites for a successful collaboration, which are brought up by PCN themselves, were PD's capabilities to communicate as well as being able to understand what they are told. Focusing on medication policy, PCN are involved from start to end, but some of the medication management tasks are reported to be carried out by informal caregivers or staff of the care institution where PD are residing. Collaboration in this context consists of monitoring medication intake and informing PD and their informal caregivers about the (importance of) proper use of medication. Consequently, relating to PD's behaviour, a majority of PCN refer to PD being non-adherent: this can be intentional or unintentional. The latter is contributed to not having insight in the necessity of medication or not being able to correctly use medication, which was sometimes related to the (mental) disability. An overlap also exists when considering PD's nutritional status: obesity is reported by a majority of PCN in relation to a bad physical health and limited exercise, which is also mentioned to correlate with the immobilizing disability of PD in some cases. Collaboration in this context is being conceived of as informing both PD and their informal caregivers about healthy lifestyle choices and helping them with strategies to cope with their specific situation. Summarizing the impact of informal caregiver behaviour, it often comes down to PD's informal network not following through instructions of healthcare professionals in general, and of PCN in particular: administering medication incorrectly, feeding PD in a potentially swallowing problem enhancing position, overfeeding PD are a few examples.

An apparent theme in this research is the omnipresence of PCN in all daily life activities of PD. Their care for PD covers much more than just delivering nursing care: they are asked to help with the mail, to pick up groceries or medication and they are being consulted by PD and/or their informal caregivers when seeking medical or practical advice. Although providing a broad range of nursing care is inherent to PCN's routine practices, going the extra mile is probably an important aspect contributing to PD's ability to keep on living in their own homes. PCN's assistance can help PD and their informal caregivers to achieve some degree of independence.

Often, PCN see themselves acting as a liaison towards other healthcare professionals or services (see Figure 1). For example, PCN follow up on medication, because of seemingly incorrect medication overviews, by consulting general practitioners and – some of them – a pharmacist. In case of swallowing problems, speech therapists as well as dieticians are contacted by PCN; when monitoring PD's nutritional status appealing to dieticians is mentioned by a lot PCN.

Table 5. Tasks of primary care nurses (PCN) regarding medication policy, personal hygiene care, nursing care

Medication	**Advising PD & informal caregivers**

• Preparing
• Putting in place
• Administering
• Medication intake
  ➢ checking
  ➢ guiding
• Supervising
• Safeguarding
• Formal registration
  ➢ administered medication
  ➢ administrator medication
• Informing PD about proper medication use
• Interprofessional consultation
	Questions about
	• Administration
	• Finances
	• Reimbursements
	• (pricing of) supportive tools
	• Personal assistance
	• Housing adaptation
	• Holiday/leisure activities
	• Availability care facilities

Nursing care	**Interprofessional consultation**
• Washing & bathing • Dressing • Feeding • Toileting • Transferring • Mobility	Consulting for advice • general practitioner • dietician • pharmacist • speech therapist Arranging appointments • general practitioner • dietician • physiotherapist • cleaning help Contacting services regarding • failing bed • failing wheelchair
Assisting in daily activities	**Referral**

• Picking up groceries
• Picking up medication
• Mail
  ➢ emptying postal box
  ➢ checking for important mail
  ➢ explaining content of mail
• Opening curtains
• Preparing meals
• Emptying trashcan
	• Diabetes educator
	• Dietician
	• General practitioner
	• Pedicure
	• Pharmacist
	• Physiotherapist
	• Speech therapist
	• Specialist

Note. PD = people with a disability

Moreover, PCN are often expected to answer questions about certain procedures and practicalities - for instance regarding reimbursements, supportive tools for PD and its pricing or the availability of care facilities – which they react upon by making referrals or by trying to inform PD and their informal caregivers correctly. PCN's involvement in a network of healthcare professionals of various disciplines would enable them to "shared" the workload amongst all members of the network.[23] In our opinion, PCN are (too frequently) expected to take the initiative to make referrals instead of other healthcare professionals being more proactively involved in the care for PD. Based on the generated comments, no statements can be made about how PCN feel about their role as a liaison. However, given previous research demonstrating care professionals valuing collaboration with other services,[24] this study might be an opportunity to debate about interprofessional collaboration and (shared) responsibilities amongst healthcare professionals.

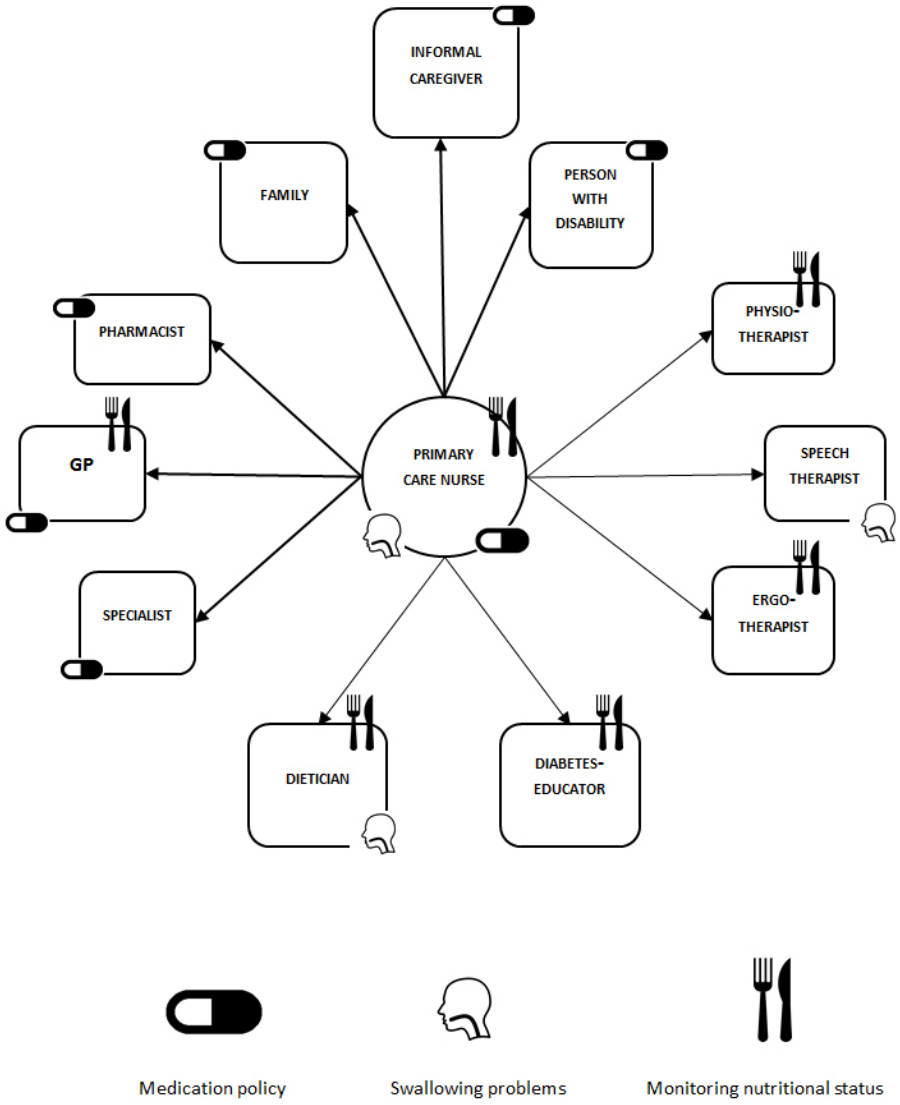

Figure 1. Primary care nurses (PCN) play a central role in the coordination of care regarding medication; swallowing problems; nutritional status for people with a disability (PD)

For their own professional development, PCN would like to know more on ways to deal with their patients: for instance, on how to prevent or act upon swallowing or behavioural problems. PCN are likely to be confronted with challenging behavior when delivering care to PD: depending on the study, prevalence of challenging behavior varies, from 5% up to 15% of people with an intellectual disability in Emerson's et al. research;[25] and a point prevalence of 41% in the research of van Schrojenstein.[26] Given this likelihood and PCN's reported need for more education on this topic, addressing this hiatus would not only help to make them less insecure in dealing with PD, but it would most likely improve quality of care PD receive.

This study can have important implications for nursing education and clinical practice of nurses and other healthcare professionals delivering care and support to PD and their informal caregivers. Being aware of the problems faced by PD, nurses should be educated to be able to act upon PD's healthcare needs. This might result in teaching nurses the necessary skills to provide (specific) care themselves, as it might also mean that PCN need to be better informed about other disciplines or are supported to make good referrals. This is obviously also necessary for other healthcare professionals involved in the care for PD. Focus should be on the pre-qualification training of nurses as well as other healthcare professionals.[27] The extension of the Belgian pre-qualification training for nurses from 3 to 4 years, would be an opportunity to adjust the curriculum in correspondence with healthcare needs of PD as experienced by nurses working in the field, for instance by incorporating more (practical)

courses. Involving PD in the education of nurses in training would be one way of exposing them to this group of patients. In a similar way as the projects of Bollard et al. and Smith et al., this might improve student nurses understanding and knowledge of PD.[28, 29] Moreover, professionals as well can receive training - in multidisciplinary groups - to experience (in)accessibility of care through the eyes of PD. A review of Hemm et al. has shown the potential to develop on the job training, which can be deployed in different settings (home care as well as residential care).[30]

Table 6. Other needs of care arising in daily practice of primary care nurses (PCN)

Struggles of PD

- Communication
  - Patients cannot express themselves
    - difficulties finding the right words
    - primarily/only non-verbal communication
  - Patients are not able to speak
  - Confusing conversations
  - Need for simplicity in language used to communicate with patients
  - Patients have been taught sign-language in
- Understanding
  - Patients do not understand certain situations
  - Patients do not understand instructions
  - Patients do not understand what is being asked from them
  - Patients need a lot of explanation
  - Different ways to explain things are necessary (on children's-level)
- Patients' ability to cope independently
  - Depending on support from others
  - PCN having to stimulate patients to act within their abilities
  - Reliance on technical aids

Overlapping themes

- Unhealthy behavior, resulting from
  - Limited physical health
  - Little to no physical exercise
  - Too much food intake
- Unintentional medication non-adherence, resulting from
  - Mental disability
  - Limited understanding of medication
    - instructions
    - insight in its necessity to improve one's condition

OR

  - Physical disability
  - Limited ability to prepare or to put in place medication

Note. PCN = primary care nurses; PD = people with a disability.

Because the presented results derive from open-ended questions, descriptive statistics are not relevant. However, these types of questions are a way of getting valuable and in-depth information. Unfortunately, question posing might have been influential: by primarily asking for problems, the limited responses on things going great could be explained. The list of generated themes is non-exhaustive and should be regarded as such: the primary goal was not to generalize findings, but to get an idea of PCN's experiences regarding healthcare needs of PD. This research was based on a purposive sample of PCN in one Belgian region because of the access to all email addresses of these PCN, both self-employed or work-

ing for the regional nursing organization, and the interest in these PCN's experiences in order to give some insights into the nursing care and the challenges PCN face in their care for PD. Although participants are representing a subset of PCN, there is no indication their experiences are specific for those working in this region or with a certain subsection of PD. However, these hypotheses were not tested, findings should therefore be interpreted cautiously. More quantitative data derived from the same sample are published elsewhere. However, all results should be interpreted prudently because of lacking data on non-responses.

5. Conclusion

Findings presented in this research indicate assistance of PCN in all facets of PD's lives. PCN provide nursing care and perform different tasks related to daily living as well: checking mail, picking up groceries, helping out with paper work regarding technical aids, reimbursements... Because of this "beyond standard" -care provided by PCN, PD are capable to achieve a certain level of independence and they are likely to keep on living in their homes for a longer period of time. PCN work closely together with PD and informal caregivers. Moreover, in an interdisciplinary context, PCN seem to play a crucial role to activate other healthcare professionals to meet the healthcare needs of PD.

Conflicts of Interest Disclosure

The author declares that there is no conflict of interest.

References

[1] Doostan D, Wilkes M. Evidence-based case review: Treating the developmentally disabled. West J Med. 1999; 171: 92-96. PMid:10510655

[2] Vlaams Agentschap voor Personen met een Handicap. Vlaams Agentschap voor Personen met een Handicap [Flemish Agency for People with a Disability]. Available from: http://www.vaph.be/vlafo/view/nl/204713-en.html Accessed 25 Sep 2015

[3] Vlaams Agentschap voor Personen met een Handicap. Zorgregierapport. [Care management report] Gegevens 31 december 2014-Tweede jaarhelft 2014.

[4] Directorate-General People with a disability. Jaarverslag 2014 In goede handen [Annual Report 2014. In good hands].

[5] Intrakoop, Verstegen accountants en adviseurs, Marlyse-Research. Jaarverslagenrapport 2014 Sectorrapport gehandicaptenzorg. [Annual report analysis 2014. Sector report care for people with a disability.].

[6] Zorginstituut Nederland. Tabellen toegankelijkheid. Wet langdurige zorg [Tables accessibilty. Act long-term care]. 2015; 33.

[7] van den Berg M, de Boer D, Gijsen R, et al. Zorgbalans 2014. De prestaties van de Nederlandse gezondheidszorg. [Balance of care. Health care performancy in the Netherlands]. Bilthoven. 2014.

[8] World Health Organization. World report on disability. World Heal Organ. https://doi.org/10.1016/S0140-6736(11)60844-1

[9] Scottish Government. Strengthening the commitment. The report of the UK Modernising Learning Disabilities Nursing Review.

[10] McGrath A. Annual health checks for people with learning disabilities. Nurs Stand. 2010; 24: 35–40. PMid:20865946 https://doi.org/10.7748/ns.24.50.35.s47

[11] United Nations. Convention on the Rights of Persons with Disabilities.

[12] Scheepers M, Kerr M, O'Hara D, et al. Reducing Health Disparity in People with Intellectual Disabilities: A Report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. J Policy Pract Intellect Disabil. 2005; 2: 249-255. https://doi.org/10.1111/j.1741-1130.2005.00037.x

[13] Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Milbank Q. 2005; 83: 457-502. PMid:16202000 https://doi.org/10.1111/j.1468-0009.2005.00409.x

[14] Starfield B. Primary care: An increasingly important contributor to effectiveness, equity, and efficiency of health services. SESPAS report 2012. Gac Sanit. 2012; 26: 20-26. PMid:22265645 https://doi.org/10.1016/j.gaceta.2011.10.009

[15] Europe. European comparative data on Health of People with disabilities Task 6: Comparative data and indicators ANED 2014.

[16] Townsley R, Ward L, Abbott D, et al. The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report. Acad Netw Eur Disabil Expert. 2010; 52.

[17] Lennox N, Diggens J, Ugoni A. The general practice care of people with intellectual disability: barriers and solutions. J Intellect Disabil Res. 1997; 41: 380-390. PMid:9373818 https://doi.org/10.1111/j.1365-2788.1997.tb00725.x

[18] Baxter H, Lowe K, Houston H, et al. Previously unidentified morbidity in patients with intellectual disability. Br J Gen Pract. 2006; 56: 93-98. PMid:16464321

[19] Lennox N, Van Driel ML, van Dooren K. Supporting primary healthcare professionals to care for people with intellectual disability: a research agenda. J Appl Res Intellect Disabil. 2015; 28: 33-42. PMid:25530572 https://doi.org/10.1111/jar.12132

[20] Wilkinson J, Dreyfus D, Cerreto M, et al. "Sometimes I feel overwhelmed": Educational Needs of Family Physicians Caring for People with Intellectual Disability. Intellect Dev Disabil. 2012; 50: 243-250. PMid:22731973 https://doi.org/10.1352/1934-9556-50.3.243

[21] Cardol M, Dusseljee J, Rijken M, et al. Huisartsenzorg voor mensen met een verstandelijke beperking. Huisarts Wet. 2011; 54: 354-8. https://doi.org/10.1007/s12445-011-0177-x

[22] Morrison EH, George V, Mosqueda L. Primary care for adults with physical disabilities: Perceptions from consumer and provider focus groups. Fam Med. 2008; 40: 645-651. PMid:18830840

[23] McColl MA, Forster D, Shortt SED, et al. Physician experiences providing primary care to people with disabilities. Healthc Policy. 2008; 4: e129-47. https://doi.org/10.12927/hcpol.2008.19989

[24] Phillips A, Morrison J, Davis R. General practitioners' educational needs in intellectual disability health. J Intellect Disabil Res. 2004; 48: 142–149. PMid:14723656 https://doi.org/10.1111/j.1365-2788.2004.00503.x

[25] Emerson E, Kiernan C, Alborz A, et al. The prevalence of challenging behaviors: A total population study. Res Dev Disabil. 2001; 22: 77-93. https://doi.org/10.1016/S0891-4222(00)00061-5

[26] van Schrojenstein Lantman-de Valk HMJ, Walsh PN. Managing health problems in people with intellectual disabilities. BMJ. 2008; 337: a2507. PMid:19064601 https://doi.org/10.1136/bmj.a2507

[27] Hahn JE. Addressing the need for education: curriculum development for nurses about intellectual and developmental disabilities. Nurs Clin North Am. 2003; 38: 185-204. https://doi.org/10.1016/S0029-6465(02)00103-2

[28] Bollard M, Lahiff J, Parkes N. Involving people with learning disabilities in nurse education: towards an inclusive approach. Nurse Educ Today. 2012; 32: 173-177. PMid:22036270 https://doi.org/10.1016/j.nedt.2011.10.002

[29] Smith P, Ooms A, Marks-Maran D. Active involvement of learning disabilities service users in the development and delivery of a teaching session to pre-registration nurses: Students' perspectives. Nurse Educ Pract. 2016; 16: 111-118. PMid:26527058 https://doi.org/10.1016/j.nepr.2015.09.010

[30] Hemm C, Dagnan D, Meyer TD. Identifying training needs for mainstream healthcare professionals, to prepare them for working with individuals with intellectual disabilities: a systematic review. J Appl Res Intellect Disabil. 2015; 28: 98-110. PMid:25266406 https://doi.org/10.1111/jar.12117