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Article *in* Journal of Nursing Education and Practice · March 2016

DOI: 10.5430/jnep.v6n7p109

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ORIGINAL RESEARCH

Care, communication and educational needs of primary care nurses to treat disabled patients

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Received: December 18, 2015

Accepted: February 9, 2016

Online Published: March 16, 2016

DOI: 10.5430/jnep.v6n7p109

URL: <http://dx.doi.org/10.5430/jnep.v6n7p109>

ABSTRACT

Introduction: In the northern part of Belgium, 21,518 of 129,021 disabled patients (DP) were waiting to receive residential care. Due to waiting lists for DP, Belgian government promotes a shift towards primary care. This shift results in specific needs for primary care professionals (general practitioners, primary care nurses [PCN] and informal caregivers). The objective of this research was to detect nursing care, communication and educational needs of PCN to treat their DP and their informal caregivers.

Methods: A questionnaire was constructed by a multidisciplinary team of primary care professionals (4 general practitioners and 20 PCN) in different consensus meetings. Disabilities are defined as physical and/or intellectual impairment. The questionnaire was sent electronically to participants. Analysis is performed using SPSS 22.0.

Results: 1547 questionnaires were mailed, 617 PCN responded (response rate = 40%). PCN are delivering care to 16 patients (+/-10) of which 5 DP (+/-6). 408 PCN have contact with at least half of informal caregivers. Most PCN (n = 582) report overburdening of informal caregivers due to an overload of tasks (72%). Personal hygiene and administering medication are most frequent administered care. Communication with DP and primary health care professionals is evaluated as very good. Most reported educational needs are dealing with behavioral problems (84%), functional loss (84%) and acquired brain injury (74%). There is no significant difference in educational needs of PCN nursing exclusively at home versus at least in residential care facilities.

Conclusion: PCN prefer education on dealing with behavioral problems, which corresponds to previous studies. An educational program can be designed to ensure PCN have necessary skills to ensure high quality care for DP and a reduced overburdening of informal caregivers.

Key Words: Education, Primary care, Nursing care, Physical disability, Intellectual disability

1. INTRODUCTION

In Belgium, 264,602 disabled patient (DP) are registered, 129,021 of them are living in the northern, Flemish part.^[1-3] The care for DP is organized by the Flemish Agency for persons with disabilities, called VAPH (“Vlaams Agentschap voor Personen met een Handicap”). This agency facilitates participation, integration and opportunities for persons with

disabilities in all domains of social life in order to achieve maximum autonomy and quality of life for DP. This agency subsidizes residential care facilities and services; assistive aids and customized accommodation to improve the daily life of the DP; personal-assistance budget for disabled persons who prefer living at home. In 2013, 21,518 DP (16%) were waiting to receive residential care or a personal-assistance

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budget. Despite efforts of the Flemish government to provide necessary care for DP in a community-setting, there are still long waiting lists for both facilities and personal-assistance budget.^[1-3] In the Netherlands, health care for DP is more accessible than in Belgium. Waiting lists are almost non-existing as is stated in a report: in the beginning of 2014, of the approximately 184,000 DP, 4,836 DP (2%) do not receive care of their choice, only 72 were critically waiting for care.^[4-6]

Due to the waiting lists, Belgian government promotes a shift towards primary care. Primary care in Belgium is provided by general practitioners, primary care nurses (PCN) and informal caregivers. Deliverance of primary care has shown to have important positive effects on health outcomes and mortality for DP.^[7,8] Although primary care is highly accessible in Belgium, this shift to primary care results in specific needs for primary care professionals. Primary care is not organized to adequately respond to this evolution and action has to be taken. Primary care professionals are suddenly confronted with the specific needs of DP and have limited knowledge or experience with nursing care that DP require. To provide DP with the necessary care, it is often needed to rely on informal caregivers. This care is complementary to formal care.^[9] The role of informal caregiver can be very demanding.^[10-12] To prevent overburdening of the informal caregiver with the care for their family member or friend, the emphasis should always be on formal care.

To assure DP have access to primary care, it is important that health care professionals' needs are addressed. Research shows that primary care providers are often not educated about care for DP, are unaware of the way to react to specific behaviour or do not know how to communicate with DP.^[13-17] A lack of knowledge can cause anxiety and PCN might feel overwhelmed and be more reluctant to treat someone with a disability.^[16,18] This need for more knowledge is also perceived by some informal caregivers.^[19,20] As PCN are the first contact with primary care, it is necessary they feel secure when being consulted by a DP and/or their informal caregiver.^[21] Failure to assess the needs of DP, results in restricted access to necessary care for this vulnerable group, possibly leading to a worsening of their health problems.^[22]

The objective of this research was to detect nursing care, communication and educational needs of PCN to treat their DP and take care of their informal caregivers.

2. METHODS

A questionnaire was drawn up by a multidisciplinary team of primary care professionals (4 general practitioners and 20 PCN) in different consensus meetings. The questionnaire

was made in Qualtrics online survey software and mailed as a hyperlink to the participants. In order to maximize participation, key figures distributed the electronic version of the questionnaire to PCN. Targeted PCN were both PCN who are self-employed and PCN working for a nursing organization. The latter operate in a home care setting, which includes residential care facilities. Response rate of these PCN was checked weekly and reminders were sent to non-responders. Self-employed PCN received one reminder two weeks after the initial mailing.

The objective of this research was to detect nursing care, communication and educational needs of PCN to treat their DP and take care of their informal caregivers. Therefore, following topics were addressed: characteristics of PCN (4 items), DP (6 items) and informal caregivers (8 items); nursing care (10 items), educational needs (18 items) and communication with DP (4 items) and other health care professionals (3 items). Disabilities are defined as a physical and/or intellectual impairment. These can be congenital or non-congenital, for instance: Down syndrome, oxygen deprivation at birth, acquired brain injury due to trauma or to disease, spina bifida, muscular diseases. Sensory disabilities and impairments attributed to the normal ageing process in the elderly are excluded.

Descriptive analysis of data was undertaken using SPSS Statistics 22.0: mean with Standard Deviation is calculated. A case-controlled comparison between PCN working exclusively at home and those at least working in a residential setting was carried out. A Chi-square analysis with 5% level of significance was performed to compare groups. Respondents with missing values for one or more variables were excluded from the analysis that included those variables.

3. RESULTS

3.1 Primary Care Nurses (PCN), Disabled Patients (DP) and Informal Caregivers

In total, 1547 questionnaires were mailed, 617 primary care nurses (PCN) responded, representing a response rate of 40%. 146 PCN did not fully complete the questionnaire. Figure 1 shows the age distribution of our respondents. Internal consistency reliability (Cronbach's alpha) of sub-scales: 0.751 (problems experienced by informal caregivers; 5 items), 0.827 (nursing care; 10 items), 0.766 (education about supportive tools and relevant procedures; 8 items).

PCN are on average delivering daily care to 16 patients (+/-10), with a mean of 5 DPs (+/-6). The mean distribution of disability is 1/3 physical, 1/3 intellectual and 1/3 mixed disability. 341 PCN take care of DP exclusively at home. 45% of participated PCN take care of patients at home and

in residential care facilities: most of these patients are physically disabled. Informal caregivers of DP living at home, are in decreasing order: partners, parents, children, brother/sister and friends. Only 27 PCN have no contact with an informal caregiver and 408 PCN have contact with at least half of the informal caregivers. Most PCN (n = 582) report an overburdening of informal caregivers due to following problems: overload of tasks (72%), acceptance problems of the disability (56%), difficulties to find suitable care for DP (48%) and difficulties in their communication with DP (44%).

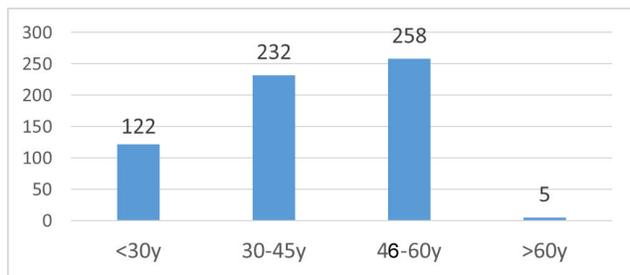


Figure 1. Age distribution of primary care nurses (n = 618)

3.2 Nursing care

In decreasing order, the following clinical problems are raised by DP: physical problems (88%), medication management (73%), mental- and behavioural problems (70%),

follow-up of nutritional status (malnutrition or obesity) (50%) and swallowing problems (31%). Table 1 shows the most frequently provided nursing care for DP at home and in residential care facilities. 96% of PCN administer frequently personal hygiene care to DP and the least frequent administered care is the use of a urinary catheter to drain and collect urine from the bladder.

Table 1. Percentage of PCN frequently or seldom nurse this type of care (n = 617)

	Frequently	Seldom
Personal hygiene care	96%	4%
Administering medication (+/-injections)	75%	25%
Wound care		
42% Stoma (gastro-colon-urethra)	55%	45%
34% Post-operative		
24% Decubitus		
Enema administration	31%	69%
Use of a urinary catheter to drain and collect urine from the bladder	15%	85%

3.3 Communication with DP and other health care professionals

Communication with DP is evaluated as good to excellent by 93% (n = 436) PCNs. Miscommunication is reported by 7% PCN and is attributed to: low intellectual capacities (n = 23), no tools to communicate (n = 18) or cultural differences (n = 7). Quality of communication of PCN with primary health care professionals is shown in Figure 2.

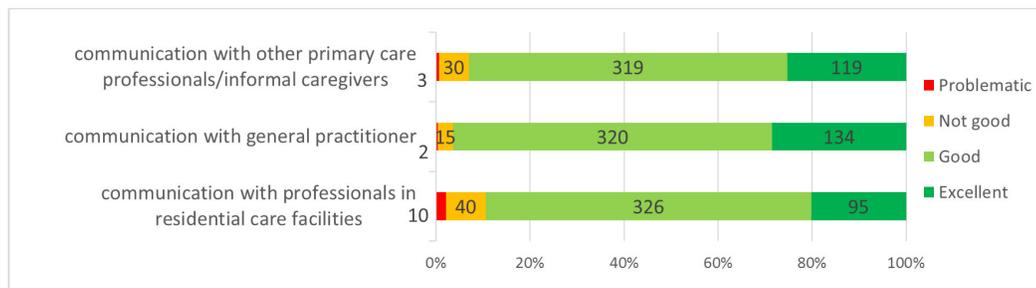


Figure 2. Evaluation of the communication with primary health care professionals (n = 463)

3.4 Educational needs

Most frequently reported educational needs concern: dealing with behavioral problems (84%), functional loss (84%) and acquired brain injury (74%). Table 2 shows the educational needs of PCN (exclusively) at home and in residential care facilities.

Regarding actions resorting under the organization of the Flemish Agency for persons with disabilities (VAPH) unsatisfactory knowledge is reported by a significant number of PCN: 81% mention a need for education about the personal-

assistance budget, 80% about the procedure for admission in residential care, 73% about the Flemish Agency for persons with disabilities and 62% about the existing residential care facilities. There is also inadequate knowledge on supportive tools to improve communication (89%), living at home (24%), activities of daily life (23%) and mobility of DP (11%).

4. DISCUSSION

Due to the shifting paradigm, primary care services face important challenges in providing DP with the necessary

health care. Research shows that DP report unmet needs as a result of hampered accessibility.^[22-25] DP's needs are often unrecognized because of unawareness or lacking knowledge of health care professionals.^[13-16] To ensure best quality of care for DP, health care professionals' needs should be addressed. Therefore, this research examined PCN's nursing care, communication and educational needs, enabling them to treat their DP and to take care of their informal caregivers. Findings demonstrate the need for additional education about ways to deal with behavioral problems and functional loss, as well as the need for more information about measures available to DP (such as communication tools) and knowledge on the role of DP expert organization "VAPH".

Table 2. Educational needs of PCN caring for DP: home-setting (n = 264) versus home & residential care facilities (n = 207)

	Home	Home & residential care	χ^2 (1, N = 471) = χ^2 -value, P-value*
Dealing with behavioural problems	218 (82%)	180 (86%)	0.38, p = .53
Dealing with functional loss	202 (76%)	172 (83%)	2.30, p = .130
Acquired brain injury	187 (71%)	157 (76%)	0.60, p = .440
Muscle diseases	184 (70%)	166 (80%)	0.08, p = .781
Muscle rigidity and -spasticity	168 (64%)	148 (71%)	1.02, p = .312
Epilepsy	165 (62%)	146 (70%)	0.38, p = .535
Cerebral palsy	159 (60%)	130 (62%)	0.02, p = .893
Relational problems (sexual needs)	147 (55%)	134 (64%)	1.45, p = .228
Socio-emotional age	128 (48%)	129 (62%)	2.90, p = .089
Down syndrome	119 (45%)	135 (65%)	3.53, p = .06

*significance < .05

The majority of PCN participating in this study are taking care of DP at home. There was no overrepresentation of PCN caring for DP with a specific type of disability. Moreover, there was no significant difference in educational needs between PCN taking care of DP exclusively in a home-setting, compared to PCN treating DP both at home or in residential care facilities.

As reported by PCN, informal caregivers are overloaded with tasks and need some support in their coping with the disability of their beloved-one, as well as with finding care facilities for DP. As PCN frequently report about their need of additional education on dealing with behavioral problems and functional loss, providing PCN with the necessary skills will not only improve their clinical practices, but will also allow them to give guidance to informal caregivers regarding

coping strategies. Presumably, addressing PCN's inadequate knowledge on the role of the Flemish agency for persons with disabilities ("VAPH"), would make them capable to share this knowledge with DP and their informal caregivers and might, if necessary, steer them into the direction of alternative care solutions, while waiting for admission in care facilities of their choice. The usage of alternative, more formal care could decrease the overburdening of these informal caregivers.

Despite difficulties with accessing suitable care, communication between PCN and both health care professionals and DPs is reported to go well. Although communication was not objectively measured, it is reassuring that no problems are reported as (multidisciplinary) health care information exchange is crucial for high quality care.^[26-28] Despite the majority of PCN communicating well with DP, miscommunication is mostly attributed to characteristics associated with the disability. This shows the importance of informing PCN accordingly: as DP might have problems understanding and communicating, sometimes as part of their disability, PCN should have clinical knowledge to foresee these obstacles. Moreover, PCN should be trained to employ strategies in order to engage DP in their treatment.^[29-31]

Focusing on the educational needs, there is no significant difference between PCN who do (not) exclusively treat PD at home. When interpreting these data, it is important to take into account that these 'groups' of PCN were constructed and compared in a case-controlled, retrospective manner. Both groups of PCN prefer additional education about dealing with behavioral problems and with functional loss, followed by information on acquired brain injury (exclusively home) or on muscle diseases (home and residential care facilities). These results are not surprisingly as they correspond with previous research reporting about health care professionals' inadequate clinical knowledge on the specific disability, secondary conditions and associated (to be expected) behavior, as well as insecurities about strategies to respond to DP and their 'peculiar' behavior.^[13-18, 32-34] As research of Emerson *et al.* reports, prevalence of challenging behavior varies depending on the study, from 5% up to 15% of people with an intellectual disability.^[35] Research of van Schroyen *et al.* states a point prevalence of 41% in people with an intellectual disability with the most prevalent type being problem behavior.^[36] This kind of behavior is often categorized as the (only) indicator of a medical problem, although underlying psychiatric problems are more frequently the cause.^[36] Unfortunately, Bates *et al.* also report about nurses lacking knowledge with regard to mental health issues.^[37] Consequently, it is likely PCN will come across 'challenging behavior' in their daily practice. Similar findings about diffi-

cult interaction are presented in research about educational needs of general practitioners^[17,33] and of health care professionals working in a hospital setting.^[38] Because of the likely confrontation with challenging behavior when working with DP and because of frequently reported inadequate knowledge on coping strategies, the National Institute for Health and Clinical Excellence (NICE) as well as a group of Canadian experts developed guidelines to advise (primary) health care professionals about best care practices for this population.^[39,40]

4.1 Limitations

This study provides insight into the needs of PCN regarding nursing care, communication and educational needs in the care for DP. The questionnaire was validated by a multidisciplinary group of health care professionals working with DP in a primary care setting. Face validity was assessed, as well as Cronbach's alpha for the majority of subscales. Moreover, findings must be interpreted prudently, as selection and response bias is possible. Findings are limited to the needs of PCN working in one geographic area. Research was intended to collect valuable, in-depth information from this specific group: consequently, maximum participation of this one organisation (employing about 1,500 nurses) was pursued. Although it might have reduced selection bias, participants were not randomized because of the descriptive, explorative scope of the research. The objective of this research is not to generalize, although this would – to some extent – be justified, as certain needs reported in this research are similar to previous studies.^[16,18] Despite the questionnaire being distributed broadly in the targeted region, there is potential response bias if only PCN with a specific interest participated: for instance, PCN who encounter problems in their care for DP or who feel inadequately trained. Because there are no comparable data from non-respondents, this remains unclear. Results might also be influenced by the (varying) level of expertise among PCN: this was not registered. Moreover, due to limited data, no distinction could be made in educational needs based on type of disability of DP receiving care from PCN. However, despite this potential bias, every need for additional education should be addressed as PCN who feel unsure might become reluctant to provide health care services to PCN.^[16,18]

4.2 Recommendations

By identifying opportunities to improve PCN's education, this research is a first step to address the unmet needs of DP. Based on the concerns raised by PCN, an educational program can be implemented. However, to ensure DP are getting the best quality of care, a more structural approach is advised. Focus should be on the pre-qualification train-

ing of nurses (and health care professionals in general).^[41] There is no necessity to create a new curriculum: elaborating on existing topics, with specific consideration for the needs of patients with a physical and/or intellectual disability can fill in the gaps nurses reported in this research. A project of Bollard *et al.*, aiming at exposing (mental health) nurses to DP by involving these patients in their nurse education, showed to be beneficial to the students as they improved their knowledge of disabilities, as well as their understanding of the need for different ways to communicate with DP.^[42] As the pre-qualification training for nurses (in Belgium) will be extended from 3 to 4 years, this would be an opportunity to adjust the curriculum to incorporate more (practical) courses with regard to nursing care needs of DP. An approach similar to Smith *et al.* can be pursued: teaching students from the point of view of service users and their experiences in trying to get access to necessary health care might be an innovative and intriguing way to educate health care professionals.^[43]

Moreover, a review of Hemm *et al.*^[25] shows that it is feasible to design a training package that can be deployed in different settings and consequently for different profession groups. Therefore, it would be interesting to develop multidisciplinary, on the job training to tackle common, everyday challenges that professionals, working in residential facilities, as well as PCN, are confronted with in their care for DP.^[44]

In general, educational programs should include more topics regarding mental health, because mental health has an influence on the physical state of PD and PCN report to be more anxious dealing with behavioral than physical problems.^[45-48] One recommendation of World Health Organization is stated to illustrate the importance of mental health care (46): "Certain skills and competencies are required to effectively assess, diagnose, treat, support and refer people with mental disorders; it is essential that primary care workers are adequately prepared and supported in their mental health work". This statement also applies to people with physical and/or mental disability: investing in proper education will equip PCN with the (clinical) knowledge and skills to deliver nursing care to their DP to the best of their abilities.

5. CONCLUSIONS

Primary care Nurses are important partners in providing primary care to disabled patients (DP). This study provides guidance in identifying PCN's concerns and needs to improve nursing care in both in DP's home as in residential care facilities. To ensure best quality of care for DP, needs of PCN regarding nursing care, communication and education should be addressed. PCN prefer additional education about ways to deal with behavioral problems, functional loss and

information on supporting measures for DP. These acquired skills might, in turn, resolve the overburdening of informal caregivers.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no competing interests.

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