

Master's Thesis

The extent to which healthcare professionals apply patient-centred care among low health literate patients and the role of healthcare professionals' familiarity with low health literacy and perception of organisational support.

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Abstract

Background – Patient-centred care (PCC) is concept often used by healthcare organisations, leading to improved organisational and patient outcomes. PCC is often described using 8 dimensions: (1) respect for patient preferences, values and needs; (2) information, education and communication; (3) coordination and integration of care and services; (4) emotional support; (5) physical comfort; (6) involvement of family and close others; (7) continuity and transformation from hospital to home; and (8) access to care and services. Understanding health related information and receiving appropriate PCC, is a challenge for patients with low health literacy (LHL) and thus there is a challenge for healthcare professionals to provide PCC among this group of patients.

Aims – This study is the first to explore the provision of PCC among LHL patients from the point of view of the healthcare professional. The aim of this study is to assess the extent to which healthcare professionals apply PCC in LHL patients and what role familiarity with LHL and organisational support play in this.

Method – Data of 320 healthcare professionals was gathered by an online survey. Percentages of familiarity and average scores of PCC (dimensions) and Organisational support were measured. Regression analyses were performed to examine whether healthcare professionals who are familiar with LHL and/or receive more support from their organisation score differently on PCC and its subdimensions. Remaining questions, about if and what additional steps healthcare professionals take among LHL patients and about suggestions for improvements in terms of organisational support for providing PCC among LHL patients, were analysed by placing answers in categories and by counting categories with the most responses.

Results – 52% of the healthcare professionals was not familiar with LHL. The mean score of all 8 dimensions of PCC was 3.71 on a 5-point scale. Most of the healthcare professionals (84,1%) indicated that they take additional steps or activities when dealing with a patient with LHL, like simplifying the information, providing additional information or asking whether the patient has understood the information. The mean score for organisational support was 3.61 on a 5-point scale. Organisational support was found to be a significant positive predictor variable for overall PCC ($\beta = 0,26$; $t(153) = 6,96$; $p < 0,001$) and each individual dimension. Healthcare professionals claim their organisation could better support them in delivering PCC to LHL patients by allowing more time with the patient and providing more education. Familiarity was only found to be a positively significant predictor for the dimension Emotional support and a negatively significant predictor for the dimension Access to Care.

Conclusions – Healthcare professionals do provide PCC to LHL patients in a certain extent, but improvements are still possible, mainly in the dimensions Information, education and communication and Access to care. Organisational support is an important predicting variable in Overall PCC and in every individual dimension of PCC. Most healthcare professionals claimed they need more time with the patient (e.g. by recruiting more colleagues) and needed more education provided by the organisation. Organisations can take these results into account when developing new healthcare policies on improving PCC provision among LHL patients.

Table of contents

Introduction	4
Theoretical framework	7
Patient-centred care	7
Health literacy	8
Low health literacy and PCC.....	9
Familiarity with LHL	11
Organisational support to perform PCC	12
Conceptual model.....	13
Methods	14
Study design	14
Data collection.....	14
Respondents	14
Measures.....	14
Data analysis.....	16
Validity and reliability.....	17
Results	18
Familiarity with low health literacy	18
Patient centred care delivery	19
Organisational Support.....	20
Correlations between PCC, Familiarity and organisational support	21
Regression analysis: Testing the hypotheses.....	22
Regression analysis: PCC dimensions.....	22
Discussion and Conclusion	24
Discussion of the results.....	24
Strengths and Limitations.....	28
Conclusion.....	29
Acknowledgement	29
Literature	30
Appendix 1. Online Survey	37

Introduction

Patient-centred care (PCC) is a trending topic in healthcare. PCC is a concept in which care is empathic and responds to the needs, values and preferences of each individual patient and where patients are informed decision-makers regarding their own healthcare (IOM, 2001). The Picker Institute believes that patient needs are the reason for the existence of hospitals and healthcare professionals, and thus that patient needs are what healthcare provision is all about (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). Therefore, they have defined 8 dimensions for PCC, which were later adopted by the Institute of Medicine (IOM) as key objectives for health care improvement: (1) respect for patient preferences, values and needs; (2) information, education and communication; (3) coordination and integration of care and services; (4) emotional support; (5) physical comfort; (6) involvement of family and close others; (7) continuity and transformation from hospital to home; and (8) access to care and services (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993).

These dimensions of PCC point out the importance of the quality of the relationships between care professionals and the patient and their families. Healthcare professionals are required to be mindful, informative and empathic, which changes their role traditionally characterised by authority to a role that is characterised by partnership, consensus and empathy (Epstein, 2011). This change in the role of the health care provider is critical when implementing PCC practices to ensure better clinical outcomes and increased patient satisfaction and well-being (Rathert, Wyrwich & Boren, 2013).

Healthcare professionals can learn to provide patient-centred care and to be an attentive and receptive listener (Oates, Weston & Jordan, 2000). Learning this is not only about acquiring skills, but also about understanding what it means to be a responsive partner to the patient. Patient-centred communication is found to be related to positive perceptions of patients' received care (Oates Weston and Jordan, 2000). A requirement for this positive perception of care is that the patient needs to obtain, process and understand the information provided by the healthcare provider in order to be able to participate in their care and make well informed (shared) decisions about their care (Coulter & Ellins, 2007). Understanding health related information can be a challenge for people with low health literacy (LHL) (Friedman, Hoffman-Goetz, & Arocha, 2006; Peter et al., 2007; Van Dijk et al., 2014; Van Weert, 2017).

Health literacy can be defined as the ability to understand and act upon health information (IOM, 2004). Individuals with LHL are more likely to misunderstand health information (Friedman, Hoffman-Goetz, & Arocha, 2006; Van Dijk et al., 2014; Van Weert, 2017) and therefore experience problems following medical advice (Davis et al., 2006). Almost 30% of Dutch adults have insufficient or limited health literacy (Heijmans, Brabers & Rademakers, 2019). It appears that this group of people is less likely to seek care and has poorer physical and mental health and shorter life expectancy (Wolf, Gazmararian, & Baker, 2005). Consequently, a relationship is found between LHL and higher degree of hospitalisation, poor adherence to therapy, higher medication and treatment errors and a reduced use of preventive services (Kindig, Panzer & Nielsen-Bohlman, 2004; Lindquist et al., 2012; Van Beusekom et al., 2016). Regarding PCC, patients with LHL are less likely to report their communication and relationship with their healthcare organisation as patient-centred and are less satisfied with their care (Wynia, Matthew & Chandra, 2010; Altin & Stock, 2016)

Recent research revealed that many Dutch healthcare professionals have never heard of low health literacy (Roodbeen et al., 2020). Their familiarity with health literacy can influence their ability to provide PCC to patients with LHL (Altin & Stock, 2016). When the healthcare provider recognises LHL in a patient, he can adapt the way of providing PCC, such as adapting the provision of information to the patient's health knowledge or engaging the help of the patient's family. Unrecognised LHL can cause problems in communication between healthcare professionals and patients, which in turn leads to dissatisfaction, diminished patient safety and autonomy, discontinuity of care and it hinders shared decision making (Vermeir et al., 2015).

Even when healthcare professionals do recognise a patient with LHL, they still seem to find it difficult to make complex information comprehensible to these patients (Roodbeen et al., 2000). Brach et al., (2012) recommended that organisations offer training in dealing with patients with low health literacy where health workers learn how to recognise LHL and apply best practice communication strategies. In recent years, attention to LHL has grown. This is reflected in government and municipal policies, but also within healthcare institutions (Murugesu et al., 2018). Initiatives have been developed to help carers better cope with LHL, such as tools and the development of education for healthcare professionals (Heijmans et al., 2016). For example, Van der Giessen et al. recently developed a training program (Erfo4all) for healthcare professionals (van der Giessen, 2020). Evaluation of this program showed “ a significant increase in self-assessed awareness of the prevalence and impact of limited health literacy and in healthcare professionals’ self-efficacy to recognize limited health literacy and to communicate effectively with patients with limited health literacy” (van der Giessen, 2021, p. 91).

The organisation can thus help healthcare professionals to provide adequate PCC. When organisational support is lacking, PCC can often not be properly applied (Shaller, 2007). Fix et al. (2018) also recognised the major role the healthcare organisation plays in the performance of PCC. According to them, the organisation must provide an organisational plan to introduce PCC throughout the organisation, including every patient group. It is important that the policy makers invest in PCC to make it possible for healthcare professionals to put it into practice. After all, the healthcare professionals are the ones who actually implement and execute PCC (Fix et al., 2018). This means that the organisation must allow sufficient time for health professionals to recognise LHL patients and adapt the care to them so that patients with LHL can be offered PCC. Healthcare professionals should also be offered training in how to properly apply PCC to these patients. This kind of regulations within an organisation play a role in the extent to which a healthcare professional is able to actually practise PCC.

This study will focus on Dutch health care professionals and the extent to which they perform PCC when providing care to LHL patients. Since most research on PCC has focused on the patient's perspective, this study focuses on healthcare professionals' perspectives of five different healthcare professionals: nurses, nursing specialists, care givers, general practitioners and medical specialists. Insights from these healthcare professionals could reveal where they may need guidance or support in order to provide adequate PCC care to LHL patients.

The aim of this study is to assess the extent to which healthcare professionals apply PCC in LHL patients and what role familiarity with LHL and organisational support play in this. Therefore, the main question of this paper is: To what extent do Dutch healthcare professionals apply patient-centred care when providing care to low health literate patients and is this associated with familiarity and organisational support? The results can be taken into account when making decisions about health care policies regarding to PCC among LHL patients. The results of this study will show where there is still room for improvement in the provision of PCC to LHL patients.

Theoretical framework

Patient-centred care

PCC is a concept that originated with Edith Ballint's (1969) concept of "understanding the patient as a unique human being". After that healthcare organisations started to apply this concept in their own way in healthcare (Santana et al., 2018). Central to PCC is the importance to see the patient as a person. This requires a more holistic approach to care that includes wellbeing, the context of the patient and their individual preferences and beliefs (Ekman et al., 2011). By "context" it is meant that a patient's history and individual strengths and weaknesses are taken into account. Furthermore, PCC goes beyond the patient himself; families and informal carers are also involved in the care. PCC assumes that the patient is capable of deciding what they need and want (Lutz and Bowers, 2000). The goal of PCC is therefore to inform patients with appropriate health advice so that they themselves can make informed decisions.

In 1987, the Picker/Commonwealth Programme for Patient-Centred Care started to investigate the needs and concerns of patients, which resulted in the identification of dimensions that are still widely used today to give shape to PCC. In this study these 8 dimensions of PCC by the Picker Institute will be used as theoretical foundation (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993):

1. *Respect for patient preferences, values and needs.* Treating individuals with respect, keep individuals involved and informed, and focus on the person's quality of life.
2. *Information, education, communication.* Providing complete information to individuals regarding their clinical status, progress, and prognosis; process of care; and information to help ensure their autonomy and their ability to self-manage, and to promote their health.
3. *Access to care.* Ensuring access to reliable healthcare settings and services. This includes physical access to care, but also the approachability of healthcare.
4. *Emotional support.* Providing support in relieving fear and anxiety related to the patient's health statute, the impact of their illness on themselves and others (family, caregivers, etc.) and the financial impacts of their illness.
5. *Physical comfort.* Enhancing individuals' physical comfort during care, especially with regard to pain management, supporting the activities of daily living and a supportive care environment (e.g. privacy, cleanliness, comforts, accessibility for visits).

6. *Involvement of family*. Recognising and respecting the role of the patient's family and friends in the patient's healthcare experience by accommodating the individuals who provide the person with support during care; respecting the role of the person's advocate in decision making; and supporting family members and friends as caregivers, and recognizing their needs.
7. *Coordination of care*. Coordinating and integrating clinical and patient care and services to reduce feelings of fear and vulnerability. Care coordination is about care professionals working together to provide PCC.
8. *Continuity and transition*. Continuity of care is about the patient experiencing the care as coherent and interconnected. Alleviating concern about the person's ability to self-manage after discharge by providing enough information regarding medication, physical restrictions and, coordinating ongoing treatment and providing access to supports on an ongoing basis (e.g. social, physical, financial).

Rathert, Wyrwich and Boren (2013) conducted a systematic review which showed that the 8 dimensions of PCC lead to better patient satisfaction, patient clinical outcomes (e.g. survival and wellbeing) and organisational outcomes (reduced healthcare resource needs and costs). To achieve these positive outcomes, PCC must be applied in a personalised way that is appropriate to each individual patient.

Health literacy

During the past decades, there has been an emphasis on the role and responsibility of the patient in healthcare. Accompanied by this, there has been a growing interest in the concept of health literacy (Nutbeam, 2000). Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (IOM, 2004, p. 20). Research has shown that health literacy plays a role in maintaining and improving health and could lead to health inequalities (van der Heide et al., 2013). Relationships are identified between low health literacy and poorer general state of health, higher degree of hospitalisation, poor adherence to therapy, more medication and treatment errors and a reduced use of preventive services (Kindig, Panzer & Nielsen-Bohlman, 2004; Lindquist et al., 2012; Van Beusekom et al., 2016). Almost 30% of Dutch adults have insufficient or limited health literacy (Heijmans, Brabers & Rademakers, 2019). Studies often showed the association between low education and low health literacy (Adler & Newman, 2002; Nielsen-Bohlman & Kinding, 2004; Paasche-Orlow et al., 2005; Cavanaugh et al., 2010). However, given the definition of health literacy, in which a person lacks knowledge specifically in the field of health, poor health literacy is also relatively common among high educated people (Van der Heide et al., 2013).

Limited health literacy could negatively affect patient experiences of communication quality in a healthcare organisation (Wynia & Osborn, 2010). To address health literacy related problems, experts suggested improving patient communication by employing a few techniques like: slowing down; using nonmedical language; reducing the amount of information; repeat information; use the teach back technique and create a shame free environment (Kountz, 2009). However, it appears that these strategies are not used often enough by care professionals, even when they are familiar with health literacy and the communication techniques (Turner et al., 2009). According to care providers, the most important reason is the limited time to discuss information combined with the amount and complexity of the information.

Low health literacy and PCC

Each dimension of PCC should be applied in a way that is appropriate for patients with LHL.

Respect for patient preferences, values and needs

Healthcare professionals should understand that patients with LHL may have different preferences, values and needs. For example, preferences in the way health-related information is provided. Many health materials are often written at levels exceeding the reading abilities of patients with a LHL (Parker, 2000). Visually supporting this information increases the ability of patients with a LHL to understand the provided information (van Dijk et al., 2016). This in turn helps these patients to be sufficiently informed and thus involved in decision making about their own healthcare (Coulter & Ellins, 2007).

Information, education, communication

Healthcare professionals should adjust their communication and health information to abilities and preferences of the LHL patients (Roodbeen et al., 2020). Adjusting information and communication to the needs of the patient ensures their autonomy and ability to self-manage and promotes their health (Vermeir et al., 2015). To address health literacy related problems, patient communication can be improved by: using nonmedical language, reducing the amount of information, repeating information or using the teach back method to check if the patients has understood the provided information (Wynia & Osborn, 2010; Kountz, 2009).

Access to care

In addition to being related to understanding and applying health information, health literacy is also related to the competency to access health-related information. The reduced access to health related information lowers the chance of understanding, appreciating and applying the health information (Sorensen et al., 2012). Assessing the need for care also seems difficult to people with LHL, but factors such as transparency and information about treatments can make care more accessible (Levesque, Harris & Russell, 2013).

Emotional support

LHL patients may experience anxiety when learning about a serious disease, which keeps them from engaging with health information (Papen, 2009). LHL is also a source of shame for patients (Parikh et al., 1996). It appeared that patients find it difficult to admit having difficulty in understanding health information. This embarrassment stops patients from asking for help to understand, read and decide on their care and creates feelings of inadequacy, fear and a low self-esteem (Parikh et al., 1996). Health care professionals should create a fear- and shame-free environment, which is considered to be an important part of emotional support (Kountz, 2009).

Physical comfort

Pain management is an essential aspect of physical comfort. Healthcare professionals might need to pay extra attention to pain management among patients with LHL because they tend to have poor knowledge of the use of pain medication (Devraj, Hemdon & Griffin, 2013). Furthermore, poor knowledge about pain medication is associated with poor compliance, making effective pain management more challenging (Robinson, 2000).

Involvement of family and friends:

It is the responsibility of the healthcare professionals to involve family and friends of the patient (Roodbeen, 2020). The social network of a patient with LHL can have a positive and supportive role in understanding and using health information (Roodbeen et al., 2020). A relative or friend with an adequate level of health literacy can help this patient in making health-related decisions (McQueen et al., 2007) or motivate a person with LHL to seek care when needed (Rolink et al., 2020).

Coordination of care

Every healthcare provider in the organisation should recognise and be aware of the patient's LHL in order to be able to tailor their communication and care to this patient in order to provide patient-centred care (Mora-Pinzon et al., 2019). A proper coordination of care will ensure that information is equally accessible at all stages of care and the same information is provided by the various healthcare professionals, which is a prerequisite for providing appropriate PCC (Roodbeen, 2020).

Continuity of care

All healthcare professionals of different organisations involved in the healthcare of the same patient, should be aware of the LHL of the patient. Research also suggests that appointing a single care coordinator has a more positive perceived care coordination of LHL patients (Mora-Pinzon et al., 2019). Care coordinators facilitate navigation of the healthcare system, which may be especially helpful to patients with LHL during and after treatment. Using a care coordinator can address problems in care that result from LHL like increased care utilisation, worse healthcare outcomes and lower satisfaction with healthcare (Mora-Pinzon et al., 2019).

Familiarity with LHL

In order to apply PCC in a way that is best for patients with LHL, a health care provider should be aware of the LHL of the patient. However, low health literacy is not always easily recognized. Research with physician assistants shows that they could identify 28% of the patients with low health literacy (Bass et al., 2002). Patients are often ashamed of their LHL and do not like to share it with others (Parikh et al., 1996). LHL is hard to recognise for healthcare professionals because patients use well-practiced coping mechanisms or avoidant behaviour (Johnson, Moser & Garwood, 2013). Patients use excuses ('I forgot my glasses') or postpone decisions ('I'll read it at home') (Parikh et al., 1996). Nevertheless, there are also signalling factors for LHL. For example, a patient who often arrives late or not at an appointment, who does not fill in forms properly, or who tells an incoherent story and keeps asking the same questions (Havers & Engels, 2019). In addition, healthcare professionals actively involve the patient in every question and to pay attention to the patients' surprise or confusion rather than assuming they understand the information correctly (Havers & Engels, 2019). It is up to physicians to recognise and then respond appropriately to these signalling factors.

Being familiar with the patient's LHL enables the healthcare professional adjust the provision of care. For example, when being familiar with LHL, the healthcare professional can use appropriate communication tools. They often try not to use medical jargon, and offer tailored care by repeating and summarising the provided information (Roodbeen et al., 2020). Using the right communication skills can save time and effort and improve patient satisfaction and health outcomes (Stocks, 2009). However, without being familiar a patient's LHL, healthcare professionals will not be able to adapt their care to the specific needs of this patient, which is a prerequisite for applying PCC (Roodbeen et al., 2020). It is often assumed that being familiar with LHL is one of the criteria for achieving the desired PCC (Noordman et al., 2019). However, this effect of familiarity with LHL on PCC does not seem to have been investigated before.

Organisational support to perform PCC

The fact that a healthcare provider is familiar with a patient's LHL does not mean that they can necessarily apply PCC to this patient. (Shaller, 2007; Turner et al., 2009). Santana et al. (2018) created a framework that emphasises the structure of the healthcare system and the context in which care is provided. This framework shows that the structure and context of care (necessary materials, healthcare resources and organisational characteristics) is the basis for PCC. This basis influences the interaction between patients and healthcare professionals, which in turn is related to patient outcomes. Structural domains are needed first in order to facilitate processes and influence outcomes appropriate to PCC (Santana et al., 2018). The creation of structural domains include creating a PCC culture across the continuum of care, co-designing educational programs and providing a supportive and accommodative environment (Santana et al., 2018).

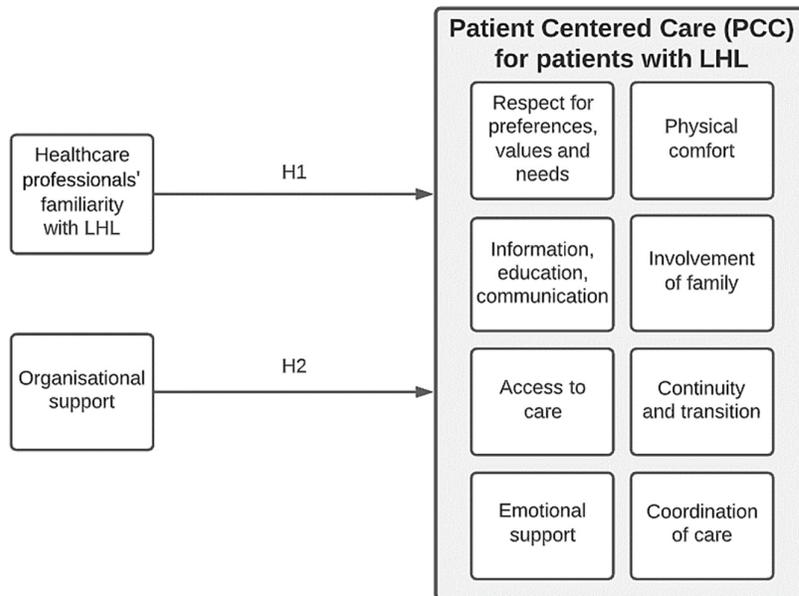
Providing PCC requires knowledge of clinical practice, communication and developing relationships with patients, their families and other professionals. But if there is insufficient focus on PCC in education, and a lack of coordination and collaboration among healthcare professionals, this will hinder the implementation of PCC practices (Pelzang, 2010). According to Pelzang (2010), “this implies that the implementation of PCC requires a planned and coordinated approach, with sufficient staff, efficient teamwork, and adequate education of healthcare professionals” (p. 917). So in order to provide tailor-made PCC to LHL patients, healthcare professionals must be given the opportunity by the organisation to actually implement these practices. Providing PCC can be very time consuming, especially when patients are in need for some extra attention, like LHL patients. Organisational support in terms of time management is therefore required (Shaller, 2007; Hower et al., 2019). Moreover, health care professionals indicate that their organisation could also support them in terms of checklists, risk profiles, workshops and seminars in order to be able to provide PCC (Hower et al., 2019). Santana et al. (2018) also suggested some options that would allow healthcare professionals to deliver PCC, including standardised PCC training for health care professionals and stimulating teamwork.

Conceptual model

Based on this theory, a conceptual model is created that represents the expected association between the concepts included in this study (Figure 1). This conceptual model leads to two hypothesis, which are numbered in figure 1.

- H1. Health care professionals who are familiar with the concept LHL are expected to score higher on PCC performance around patients with LHL compared to healthcare professionals who are not familiar with the concept LHL.
- H2. The more organisational support health care professionals perceive to apply PCC practices, the higher they are expected to score on PCC performance around patients with LHL.

Figure 1. Conceptual model. Arrows indicate an expected association. Numbers in this figure correspond to the numbers of the hypotheses.



Methods

Study design

This study focused on healthcare professionals and the extent to which they apply PCC among patient with LHL and what role familiarity with LHL and organisational support for PCC play in this. Data gathered by an online survey was mainly quantitative, obtained by closed-ended questions. In addition, some open questions were used to explain the results from the quantitative data.

Data collection

The distribution of the online survey and the collection of the data was done in cooperation with I&O Research. This research company is engaged in independent research and additional advice for the government and public organisations. I&O Research has a large online panel consisting of more than 28,000 active panel members. This random sample is created by actively acquiring panel members through random sampling from population registries, which prevents selection bias. Because many background characteristics and additional profile characteristics of the panel members are known and up to date, it is possible to draw representative samples or to approach a certain selection for research, as care professionals were approached in this study.

Respondents

The target group of this survey were different types of healthcare professionals in the Netherlands: professional carers, nurses, specialised nurses, general practitioners and medical specialist. In total, 502 health care professionals were invited to fill in the questionnaire. It was checked at the beginning of the online survey whether the healthcare professionals performed one out of the five suggested professions. Respondents who did not meet this requirement were unable to complete the survey. In total, 320 healthcare professionals completed the survey. This sample included 92 professional carers, 194 nurses, 18 specialised nurses, 11 general practitioners and 27 medical specialists.

Measures

Healthcare professionals' familiarity with LHL

The online survey started by asking healthcare professionals if they were familiar with the concept LHL (yes/no). A definition of LHL was then provided to ensure that the health care professionals had a good understanding of the concept before completing the remaining questions in the survey. They were then asked whether, after reading the definition of LHL, they were familiar with the concept and whether they found it easy to recognise a patient with LHL.

To gain some insight into how healthcare professionals deal with patients with LHL, an open-ended question asked whether, and if so, what extra steps the healthcare professional takes when providing care to a patient with LHL. This question was asked at the beginning of the online survey so that the statements or questions in the questionnaire could not influence their answers. Appendix 1 contains an overview of all the questions in the survey.

Patient centred care

Questions to measure the performance of PCC were based on the instrument of Cramm and Nieboer (2019). This instrument is validated with a Cronbach's alpha of 0,88. For this survey, questions were minimally adjusted to make the questions applicable to LHL patients. The dimension Information, education and communication consisted of 5 questions, the dimension Family and friends contained 3 questions. The remaining dimensions included 4 questions. A 5-point Likert scale ranging from "strongly agree" to "strongly disagree" was used for questions regarding the 8 dimensions.

An additional closed question with five possible answers was added to the dimension 'information, education and communication' in order to gain more insight into which of the five proposed communication techniques healthcare professionals use when communicating with an LHL patient (avoiding medical terms, adapting the amount of information, repeating the information, letting the patient repeat the information in their own words, visualising the information). Experts have suggested that professionals can improve communication with LHL patients by employing these techniques (Kountz, 2009).

Organisational support to perform PCC among LHL patients

In total, 6 closed questions about the perception of organisational support were asked using a 5-point Likert scale. Healthcare professionals were asked about the perceived organisational support for performing PCC in general and for performing PCC among LHL patients. These two questions are based on the Planetree designation self-assessment tool, of which a part focuses on the support the organisation provides to healthcare professionals to deliver PCC (Planetree, 2014). Healthcare professionals are also asked whether sufficient education is offered by the organisation about PCC and LHL. These questions are based on the health environment review where questions belonging to the theme 'Staff skills building' focuses on education on literacy offered by the organisation (Rudd & Anderson, 2006). The last two closed questions regarding organisational support were related to time provided by the organisation. The healthcare professionals were asked whether they are given enough time to determine whether they are dealing with an LHL patient and whether they are given enough time to pay extra attention to an LHL patient. In order to better interpret these answers, an open question is asked to assess if and what improvements healthcare professionals suggest in terms of organisational support for providing PCC among LHL patients.

Data analysis

Data was analysed using SPSS (IBM SPSS Statistics version 24.0). Based on the data, it is not possible to identify the respondent or to identify the organisation in which the respondent works, which guarantees anonymity.

The data analysis started with the analysis of all closed questions. First, the percentage of health professionals who were familiar with LHL and the percentage of health professionals who indicated taking extra steps or activities were examined. In order to measure the extent to which healthcare professionals apply PCC in LHL patients, the average scores of the dimensions will be used as well as an overall score of PCC, taking all eight dimensions together. An average score was also calculated for organisational support, taking all six closed questions together. For both the PCC and Organisational support scores, it applies that higher scores indicate better PCC provision and a better experience of organisational support.

After calculating percentages and averages of the three concepts, there will be an exploratory analyses of the correlations between PCC and familiarity with LHL and organisational support. Next, regression analyses will be performed to examine whether healthcare professionals that are familiar with LHL and/or receive more support from their organisation score differently on PCC and its subdimensions. Before conducting the analysis, there was tested if the data met all the corresponding assumptions for a regression analysis. Using a scatter diagram, it was checked whether the dependent and independent variable had a linear relationship. By means of a P-P plot it was concluded that this assumption was met. While analysing the correlations between the independent variables, the assumption of multicollinearity was checked. With no correlation of 0.7 or higher, all of the variables were used in the regression analysis. Outliers were checked by means of a scatterplot, where the values for residuals should be between -3 and 3. This assumption was met. The residuals of the regression should follow a normal distribution. Compliance with this assumption was confirmed by means of a histogram.

In the regression analysis, the Overall PCC or a score from one of the separate dimensions served as the dependent variable. The main independent variables in the analysis are familiarity with LHL and organisational support. In addition, age, gender and education will also be added to the model as control variables. For the variable education, dummy variables were created because this variable consists of 3 categories (low, high, medium). If the regression coefficient of a variable is not significant ($p > 0,05$), it will be removed from the final model.

Regarding to the answered obtained from the open-ended questions, a summary will be made. During the analysis, these answers were placed in categories. For example, for the suggestions of healthcare professionals for more organisational support, a category 'providing more education' was created that included answers such as the need for workshops, training and education.. Categories that count the most responses will be reported.

Validity and reliability

To ensure that questions in the online survey are stated clearly and properly understood, the questionnaire was tested among 5 health care professionals external to the research panel before officially sending it to the panel members. They were instructed to point out ambiguous questions or statements. Based on their comments, two ambiguities were removed from the questionnaire by rewriting the questions.

Reliability of the concepts

The reliability of the concepts will be measured in order to see if similar items are related. This internal consistency of the questions within each PCC dimension is measured using Cronbach's alpha, where a minimum reliability of 0.7 is desirable, but a value between 0.6 and 0.7 is also considered as an acceptable level of reliability (Ursachi, Horodnic & Zait, 2015). A low value ($\alpha < 0.6$) of alpha could be due to a low number of questions, poor inter-relatedness between items or heterogeneous constructs (Tavakol & Dennick, 2011). Results of the internal consistency are presented in table 1. All concepts have reliabilities above 0.6 and are considered acceptable. The reliability of the PCC dimension Information, education and communication is just below the critical value of 0.6 and therefore considered acceptable and included in the analyses.

Table 1. Reliability per concept.

Variable	Number of items	Cronbach's alpha
Patient centred care dimensions	8	0,80
Respect for patient-preferences, values and needs	4	0.65
Information, education and communication	5	0.57
Access to care	4	0.66
Emotional support	4	0.75
Physical comfort	4	0.65
Family and friends	3	0.79
Coordination of care	4	0.77
Continuity and transition	4	0.73
Organisational support	6	0.87

Results

Respondents

In total, 320 of the 502 invited care professionals completed the questionnaire, which lead to a response rate of 64%. The majority of the sample were women (85,3%) and nurses (60,6%) or professional carers (28,8%). The average age was 49, with a minimum age of 19 and a maximum age of 73. A full description of the sample can be found in table 2.

Table 2.Characteristics of the healthcare professionals (n = 320).

Sample characteristics	N (%)
Sex	
Male	47 (14,7)
Female	273 (85,3)
Education (highest level followed)	
Low	19 (5,9)
Medium	127 (39,7)
High	174 (54,4)
Health care profession	
Professional carer	92 (28,8)
Nurse	194 (60,6)
Specialised nurse	18 (5,6)
General practitioner	11 (3,4)
Medical specialist	27 (8,4)
Mean (Min – Max)	
Age	47,9 (19 - 73)

Familiarity with low health literacy

When asked about their familiarity with LHL, 52% (166 out of 320) of the healthcare professionals indicated that they had never heard of the concept LHL. After providing the definition of LHL, only 15,9% stated they never heard of LHL. 73% of respondents (strongly) agreed that they often have to deal with patients with LHL and only 38% (strongly) agreed that they do find it easy to recognise a patient with LHL.

Most of the healthcare professionals (84,1%) indicated that they take additional steps or activities when dealing with a patient with LHL. Table 3 lists the most frequently mentioned additional steps that healthcare professionals claim to take when dealing with a LHL patient. The most frequently mentioned additional step, mentioned by 77 healthcare professionals, was simplifying the information. Healthcare professionals want to communicate at a level that the patient can understand, sometimes referred to as ‘Jip en Janneke taal’, which is a simple, understandable language consisting of easy to understand sentences and containing few difficult words.

Some healthcare professionals indicate they provide more information to LHL patients, while others indicate they dose the information, meaning they provide the patient with less information at once. In addition, some professionals mention they are willing to take extra time for more verbal explanation or ask the patient if the information they have given is understood by the patient. There are healthcare professionals that check the patient's understanding by having the patient repeat the information given.

Table 3. Additional steps that healthcare professionals undertake when dealing with a LHL patient

Additional steps when dealing with LHL patients	Frequency of reporting
Simplifying the information	77
Providing additional (verbal or reading) information	52
Asking whether the patient has understood the information	40
Involving family/caregiver	37
Using visual aids	32
Repetition of information	31
Writing out information/giving a disease- or treatment-based leaflet	30
Having the patient repeat the information	26
Involving the team/colleagues	19
Calling in other disciplines	19
Dosing information	13

Patient centred care delivery

The mean score of all 8 dimensions of PCC was 3.71 on a 5-point scale (sd = 0,40). The results for each individual dimension of PCC are shown in Table 4. The highest score was obtained on the dimension 'respect for patient preferences, values and needs' with an average of 4.13 (sd = 0,52). The lowest score was obtained on the dimension 'Access to care' with an average of 3,08 (sd = 0,68).

Table 4. Average scores on Overall PCC and the dimensions of PCC (n = 320).

Dimension	Mean	SD
Overall PCC	3,71	0,40
Respect for patient preferences, values and needs	4,13	0,52
Emotional support	3,93	0,53
Physical comfort	3,90	0,51
Family and friends	3,85	0,66
Coordination of care	3,79	0,67
Continuity and transition	3,74	0,70
Information, education and communication	3,55	0,51
Access to care	3,08	0,68

Organisational Support

The mean score for organisational support was 3.61 on a 5-point scale (sd = 0,72). Healthcare professionals were asked how their organisation could better support them in delivering PCC to LHL patients. Almost half of the healthcare professionals (155 out of 320) did not submit any suggestions for how the organisation could provide them more support. Caregivers who did not make any suggestions for improvement did not score significantly differently on organisational support. Of the care providers who did offer suggestions, some indicated that there is already a lot of attention for LHL within their organisation. The remaining healthcare professionals indicated how the organisation could support them more in providing PCC in LHL patients. An overview of the most mentioned improvements are listed in table 5.

The point for improvement that was mentioned most often was time. These professionals indicated that they had not enough time to check whether they were dealing with an LHL patient, or that they did not have enough time to adapt their care to this patient. They also said that the workload was too high and that there was too much focus on performance and administration.

A lack of time was mentioned several times in combination with a lack of financial resources. There was said to be no money to pay extra attention to LHL patients. One medical specialist even called this 'very disappointing'. Health insurers played a major role in the answers: the organisation should put pressure on health insurers, as they determine how much time can be spent on the patient.

In addition to needing more time, care professionals indicate that there is a shortage of staff. Most professionals would like to have more staff so they have to see fewer clients in a day and therefore have more time to offer PCC to an LHL patient. In addition, there were a number of care professionals who felt that they would benefit from the deployment of a specific person in the organisation who is trained to deal with low (health) literacy.

Finally, 42 health care professionals indicated that the organisation could offer more training on how best to provide PCC to LHL patients. Recognition and awareness were the main goals of these trainings. Examples of training included: training in different methods of explanation, the use of case studies and periodic workshops for new staff to keep them up to date. A nurse mentioned that her organisation focuses on training in topics that the healthcare professionals request, and that this is not always the same as topics that are important to the patient.

Table 5. Organisational support improvements mentioned by healthcare professionals.

Improvements	Frequency of reporting
Allowing more time with the patient	62
Providing more education	42
Employing more staff	22
Providing other tools	9
Increasing financial resources	6

Correlations between PCC, Familiarity and organisational support

The correlations between the main variables are shown in Table 6. Overall PCC and Organisational support have a positive significant relationship ($r = 0,49$), while Familiarity is not significantly related to Overall PCC or Organisational support. This means that only the perception of caregivers about receiving organisational support seems to play a role in the extent to which they provide overall PCC to LHL patients.

Looking at the individual dimensions for PCC, the relationship with Organisational support is positively significant for all dimensions (r ranges from 0.20 to 0.52). With regard to Familiarity, there appears to be a negatively significant relationship with the Access to care dimension ($r = -0.22$) and a positively significant relationship with Emotional support ($r = 0.13$).

Table 6. Pearson Correlations between main variables used in the regression analysis (N=320).

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Overall PCC	-	-	-	-	-	-	-	-	-	-	-
2. Familiarity with LHL	0,033	-	-	-	-	-	-	-	-	-	-
3. Organisational support	0,491*	0,019	-	-	-	-	-	-	-	-	-
PCC dimensions											
4. Respect for patient preferences, values, needs	0,635*	0,085	0,284*	-	-	-	-	-	-	-	-
5. Information, education and communication	0,617*	0,041	0,232*	0,284*	-	-	-	-	-	-	-
6. Access to care	0,499*	-0,219*	0,244*	0,061	0,257*	-	-	-	-	-	-
7. Emotional support	0,780*	0,137*	0,242*	0,539*	0,366*	0,196*	-	-	-	-	-
8. Physical comfort	0,683*	-0,025	0,301*	0,586*	0,263*	0,126	0,589*	-	-	-	-
9. Family and friends	0,695*	0,056	0,195*	0,467*	0,204*	0,067	0,625*	0,512*	-	-	-
10. Coordination of care	0,614*	0,021	0,409*	0,235*	0,212*	0,254*	0,330*	0,310*	0,271*	-	-
11. Continuity and transition	0,691*	-0,029	0,524*	0,274*	0,318*	0,330*	0,368*	0,359*	0,351*	0,559*	-

* = $p < 0,005$

Regression analysis: Testing the hypotheses

A multiple regression with overall PCC as dependent variable and Familiarity with LHL and Organisational support as explanatory variables and age, sex and education as control variables was significant, $F(1.154) = 7,370$; $p < 0,001$. However, the regression coefficients of age, sex, education and familiarity were not significant. Therefore, using backward elimination, variables that were not significant ($p > 0,05$) were removed stepwise from the analysis. The final model contained only the significant variable Organisational support. This new model with overall PCC as the dependent variable and only Organisational Support was again significant ($R^2 = 0,241$; $F(1.153) = 48,50$, $p < 0,001$). The predicted increase in score on PCC is 0.26 per point of score on organisational support ($\beta = 0,26$; $t(153) = 6,96$; $p < 0,001$). Returning to the hypotheses formulated at the start of this study, H1 is rejected, as Familiarity is not a significant predictor for the overall PCC score. There is a significant association between Organisational support and PCC, and therefore H2 is accepted. A higher score of organisational support leads to an increase in each of the PCC dimensions.

Regression analysis: PCC dimensions

In order to gain more insight into the significant relationship between the score on PCC and familiarity, the score on organisational support and the control variables, regression analyses were performed per dimension of PCC. Similar to Overall PCC, Organisational support is a significant positive predictor variable in each individual dimension of PCC. This means that a higher score of organisational support, lead to an increase in each of the PCC dimensions. Despite the fact that Familiarity was not a significant predictor variable for Overall PCC, Familiarity did turn out to be a significant positive predictor variable for the dimension Emotional Support. Familiarity was found to be a negatively significant predictor for the Access to Care dimension. This means that healthcare professionals who are familiar with LHL score higher on Emotional Support and lower on Access to care than healthcare professionals who are not familiar with LHL.

Significance of the control variables also differed per dimension. Sex turned out to be a positive significant variable for the PCC dimension Physical comfort, indicating that female healthcare professionals score higher on this dimension than male professionals.. Age was a significant positive variable in the dimensions Respect for patient preferences, values and needs, and physical comfort, and a negative significant predictor variable in the dimension Access to care. This means that older healthcare professionals score higher on the dimensions Respect for patient preferences, values and needs and Physical comfort, but lower on the dimension Access to care. Education appeared to be a negatively significant variable only in the dimension Coordination of care, meaning lower educated healthcare professionals score higher on this dimension than medium and high educated healthcare professionals. The results are shown in table 7.

Table 7. Results regression analyses for the Overall PCC score and each individual dimension.

Dependent variable	Variable	β	p	F	df	p	R ²																																																																																																											
Overall PCC	Constant	2,82	<0,001	48,50	1.153	<0,001	0,24																																																																																																											
	Support	0,26	<0,001					1. Respect for patient preferences, values, needs	Constant	3,13	<0,001	18,31	2.317	<0,001	0,10	Support	0,20	<0,001	Age	0,01	,005	2. Information, education and communication	Constant	2,96	<0,001	18,02	1.319	<0,001	0,23	Support	0,16	<0,001	3. Access to care	Constant	2,13	<0,001	11,89	3.222	<0,001	0,14	Familiarity	-0,32	<0,001	Support	0,24	<0,001	Age	-0,01	,012	4. Emotional support	Constant	3,50	<0,001	13,05	2.317	<0,001	0,28	Support	0,18	<0,001	Familiarity	0,14	,015	5. Physical comfort	Constant	2,58	<0,001	14,23	3.316	<0,001	0,35	Support	0,21	<0,001	Sex	0,18	,015	Age	0,01	,021	6. Family and friends	Constant	3,21	<0,001	12,63	1.318	<0,001	0,20	Support	0,18		7. Coordination of care	Constant	2,81	<0,001	21,50	3.281	<0,001	0,43	Support	0,36	<0,001	Education (medium)	-0,31	,042	Education (high)	-0,37	,011	8. Continuity and transition	Constant	2,04	<0,001	68,48	1.181
1. Respect for patient preferences, values, needs	Constant	3,13	<0,001	18,31	2.317	<0,001	0,10																																																																																																											
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Discussion and Conclusion

Discussion of the results

The extent to which PCC is applied among LHL patients

This study examined to what extent Dutch healthcare professionals apply patient-centred care when providing care to LHL patients and if this is associated with familiarity and organisational support. Healthcare professionals generally scored reasonably well on providing PCC in patients with LHL in this research, with the highest score obtained on the dimension Respect for patient preferences, values and needs and the lowest score on Access to care. All averages are comparable with scores found in previous research (Cramm and Nieboer, 2019) examining PCC in general. This is an interesting finding, because research has shown that LHL patients experience their communication as less patient-centred compared to patients with adequate health literacy (Wynia & Osborn, 2010). This could mean that there is a difference between how healthcare professionals think they provide PCC to LHL patients and how these patients actually experience it.

The results of this study also showed that most healthcare professionals (84%) take extra steps when they are dealing with an LHL patient. They simplify the information, check whether the patient has understood the information (simply by asking or using the teach-back method), involve the family or a caregiver in the care, use visual aids or dose the information. These additional steps are in line with Kountz's (2009) recommendations for effective strategies to improve patient understanding and Roodbeen et al's (2020) findings among hospital physicians and nurses.

Some healthcare professionals indicate that they dose the information, but many more indicate that they actually give more information to LHL patients. And while dosing information is often recommended in the literature (Kripalani & Weiss, 2006; Kountz, 2009; Oates, 2009; Hersh, Salzman, Snyderman, 2015), providing too much information is seen as a communication technique that does not seem appropriate for LHL patients (Mayeaux et al., 1996; Kripalani, 2006; Kickbusch, 2008), because this can decrease a patient's understanding of the material (Mayeaux et al., 1996). This means that many healthcare professionals use a communication technique that is counterproductive for LHL patients. Organisations and education should create awareness among healthcare professionals about which methods to use among LHL patients.

Only a few healthcare professionals mentioned they visualise the information for patients with LHL, while research shows that this is a very effective way of attracting a patient's attention and improving the patient's memory and understanding (Kountz, 2009). Many researchers therefore strongly recommend the use of visual information among LHL patients (Entwistle & Williams, 2008; Meppelink, 2015; Pratt & Searles, 2017; Schubbe et al., 2020). There are many visual communication materials

available today that healthcare professionals can use to convey understandable information to LHL patients (Murugesu et al., 2018; Noordman et al., 2019; Oosterveld, Noordman & Rademarkers, 2019). Recent research shows that healthcare professionals are often unaware of the existence of these visual communication materials (Roodbeen et al. 2020). This corresponds to the healthcare professionals in this study, of whom few say they use visual materials. Organisations and educators could make healthcare professionals aware of the existence of these tools in order to improve communication with LHL patients.

The role of familiarity with LHL in providing PCC to LHL patients

Approximately half of the healthcare professionals (52%) indicated that they had never heard of the concept of LHL. This is consistent with research by Roodbeen et al. (2020), in which they found that healthcare professionals were often not familiar with the concept health literacy and confused the concept with limited literacy. A smaller group of healthcare professionals (26.7%) indicated that they found it difficult to recognise this group of patients. The difficulty of recognising these patients was also demonstrated in the study by Bass et al. (2002), in which physician assistants only recognised 30% of all patients with LHL. Healthcare professionals tend to overestimate patients' literacy level, as revealed in research among primary care physicians (Kelly & Haidet, 2007).

Even though many healthcare providers are not familiar with the concept of LHL, the results showed this has little effect on Overall PCC scores. However, awareness of LHL did play a significant role in the dimensions of Access to care and Emotional support, showing that familiarity increases emotional support, while decreasing access to care. A link between Familiarity and emotional support was also recently demonstrated in a qualitative study. Interviews showed that some healthcare professionals aware of the LHL of patients adapt their communication by empathising with the patient (Roodbeen et al., 2020). They do this by asking the patient about feelings and emotions and in doing so, they create an 'openness' by showing genuine interest, which is similar to creating a shameless environment, a component of the PCC dimension emotional support. Assessing a patient's health literacy and understanding is important because patients with LHL may not know what to ask or may not feel comfortable asking questions (Cohen et al., 2013). Organisations that focus on making healthcare professionals aware of LHL can expect an increase in PCC provision in the Emotional support dimension.

Healthcare professionals scored lower on the dimension Access to care when being familiar with LHL. A possible explanation would be that health professionals who were familiar with LHL were more aware that Access to Care is not always arranged properly for this group of patients (Schwartzberg, VanGeest, & Wang, 2005), and therefore scored lower on this dimension. Further research will have to show whether this is the correct explanation or whether there is another underlying reason.

The role of organisational support in providing PCC to LHL patients

On average, healthcare professionals scored 3.61 (sd = 0.72) for organisational support. Regression analysis showed that scoring higher on organisational support had a positive effect on providing PCC to LHL patients, and on each of the separate dimensions. These results are consistent with the literature and the hypotheses established in the theoretical framework. Santana et al. (2018) already showed that structural processes within an organisation were necessary in order to influence outcomes appropriate to PCC.

The influence of support was strongest in the dimensions Continuity and Transition and Coordination of care. This is in line with Pelzang (2010), who showed that a lack of coordination and cooperation between healthcare professionals would hinder the implementation of PCC within an organisation. To avoid this barrier to PCC implementation, the organisation can offer more support to the care professionals. Organisations trying to improve continuity and coordination of care could use a care coordinator. “Care coordinators oversee multidisciplinary teams, provide information to multiple providers and participate in the monitoring and evaluation of care delivered” (Mora-Pinzon, 2019, p. 6). This intervention may be costly initially, but navigating patients through the care system can be very helpful for patients with LHL (Mora-Pinzon, 2019). Furthermore, a care-coordinator is associated with a decrease in healthcare costs by decreasing duplication of services and the use of inappropriate resources. This in turn leads to better healthcare utilization and better outcomes. (Robinson-White et al., 2010).

According to a large part of the healthcare professionals, support from the organisation to apply PCC among LHL patients could be improved. The most frequently mentioned improvements were allowing more time with patients and offering more education about LHL and PCC. The importance of organisational support in terms of time management had previously been mentioned in research (Shaller, 2007; Coleman, 2011; Lambert et al., 2014; Coelho, 2018; Hower et al., 2019; Roodbeen et al., 2020; van der Giessen et al., 2020). In Coelho's (2018) study, a large proportion of care providers stated they needed more training in recognising and managing LHL, which is similar answers of healthcare professionals in this study.

Lack of time with the patient is seen by health professionals as a reason for not being able to take LHL into account during the consultation (Murugesu et al., 2018). In addition, it has been shown that more time for a consultation is a strategy for supporting patients with LHL in palliative care (Chou, Gaysynky & Persoskie, 2015) and that more time is mentioned by patients as a prerequisite for effective shared decision making (Oosterveld, Noordman & Rademakers, 2019).

The lack of time was often mentioned in combination with a lack of staff. This lack of staff means that healthcare professionals have to see more patients, and therefore have less time per patient. Buerhaus et al (2005) stated that needing more time and human resources is a core disadvantage of PCC. According to them, a consequence of this is that healthcare professionals are in a hurry to listen to the patient's concerns. A shortage of healthcare staff leads to routines that hinder the development of PCC in hospitals (Kelly, 2007). It can undermine the ability of healthcare professionals to provide physical and emotional support and respect patient preferences (Institute of Medicine, 2001; West, Barron, Reeves, 2004).

Although the organisation could support healthcare professionals in providing PCC among LHL patient by allowing more time with the patients, it appears that when healthcare professionals are planning more time, tension is generated between healthcare professionals and the hospital management (Roodbeen et al., 2020). Therefore, the real contribution to PCC of giving healthcare providers more time to deal with LHL patients will need to be investigated in future research, to enable the management of the healthcare organisation to make an informed choice on adjusting time management.

If the organisation wants to improve the provision of PCC, it can also support healthcare providers by offering (more) training on PCC and LHL. This is in line with research of Roodbeen et al. (2020), where healthcare professionals also suggested education for increasing their communication skills among LHL patients. Initiatives have already been developed to help healthcare professionals deal with LHL (Heijmans et al., 2016). For example, the Erfo4all training program trains healthcare professionals to be aware of the prevalence and impact of LHL and helps them recognize and communicate with these patients (van der Giessen, 2021). Centres of expertise in the Netherlands such as Pharos and Nivel also offer training and information to better deal with LHL.

Studies also mentioned that healthcare professionals are in need for more training on PCC (West, Barron & Reeves, 2004; Foster et al., 2019). Education in PCC is important because a lack of focus on PCC in education will hinder the implementation of PCC (Pelzang, 2010). Trainings have also been developed for healthcare professionals to provide more PCC (e.g. Towle & Godolphin, 2013; Burton et al., 2016; Noordman et al., 2019; Skovlund et al., 2020). Towle & Godolphin (2013) investigated the effect of an interprofessional workshop developed by advisory groups of community members, students and teachers. This led to a successful patient-centred educational intervention where the patient is the teacher. In the study by Noordman et al, 2019, a three-day training course was developed for healthcare professionals to improve patient-centred communication and empathy. This training consisted of presentations and literature on the basic principles of PCC, practising with actors and reflecting on videos of recorded conversations during practice. Trained professionals showed significant improvement in showing empathy and in communicating about the diagnosis.

However, given the fact that many healthcare professionals still indicate that they need more education on PCC and LHL, it seems that these education initiatives are not being used by healthcare organisations. Organisations appear to be unfamiliar with these education programmes and training courses, or consciously choose not to use them. This study suggests the importance of organisational support in improving PCC provision among patients with LHL and thus the importance and necessity of time management and education about LHL and PCC for healthcare providers.

Strengths and Limitations

The present study complements the existing literature on PCC delivery. This study is the first to explore the provision of PCC among LHL patients from the point of view of the healthcare professional. This study is therefore unique, but also relevant because almost 30% of Dutch adults have insufficient or limited health literacy (Heijmans, Brabers & Rademakers, 2019). In addition, this study confirms that organisational support can improve the delivery of PCC to LHL patients, also shown in previous studies on patients in general (Shaller, 2007).

This study has a relatively high response rate (64%) with a diverse sample, identifying five different healthcare professions. However, this study did not include differences in healthcare professionals. The majority of respondents were nurses (60.6%) and professional carers (28.8%), and as there were few respondents in the other three professional groups, it was not possible to look at differences in professions. The other three professions had too few respondents to analyse the difference between the groups. However, it is interesting to look at this because research shows that professionals differ in providing PCC (Cramm & Nieboer, 2019). It is therefore not inconceivable that there are also differences between different healthcare professionals in the application of PCC among LHL patients. Future research can focus on one profession or can ensure that enough data is collected from the various professions.

Professionals of different type of organizations can also differ in providing PCC (Cramm & Nieboer, 2019). Therefore, a limitation of this study is that there was no data collected on the type of organisation in which the healthcare professionals carried out their profession. This means that no distinction could be made between, for example, a nurse working in a hospital, in a nursing home, or in another type of organisation. Assuming there are differences between the professions in different healthcare organisations, information about the type of organisations would make the results easier to translate into practices for distinct organisations. Future research should take into account the type of healthcare organisation where the healthcare professional works.

The concept of familiarity with LHL was measured in these studies with a dichotomous outcome (yes/no). However, there are studies that measure familiarity using a scale. For example, the study by Morgan et al. (2008) measured familiarity with original Medicare using a 4-point scale (very familiar, familiar, unfamiliar, very unfamiliar). The study of Gefen (2000) used a 7-point scale, ranging from strongly agree to strongly disagree. More healthcare professionals indicated to be familiar with LHL after reading a definition. A possible reason for this can be the healthcare professionals may be somewhat familiar with the term LHL itself, but choose not to indicate being familiar with it because they are not convinced they know the exact definition. Further research should take into account that the use of a scale would provide a better understanding of the actual familiarity of healthcare professionals with the concept of LHL.

Conclusion

To conclude, healthcare professionals do provide PCC to LHL patients in a certain extent, but improvements are still possible, mainly in the dimensions Information, education and communication and Access to care, which scored below the average of the overall PCC score. However, healthcare professionals did undertake extra steps when providing care to a LHL patients. Healthcare professionals being familiar with LHL did not have any effect on overall PCC provision, but did in the dimensions Access to care and Emotional support. Organisational support seems to be an important predicting factor in Overall PCC and in every individual dimension of PCC. In order to improve the organisational support, and thus the provision of PCC among LHL patients, most healthcare professionals claimed they need more time with the patient and needed more education provided by the organisation.

Organisations can take these results into account when developing new healthcare policies on improving PCC provision among LHL patients. Time management need to be considered and education can be implemented in order to focus on the Information, education and communication dimension, where healthcare professionals learn how best to provide information to and communicate with LHL patients, as well as how to recognise LHL patients.

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Appendix 1. Online Survey

Selection questions

1. Do you currently practise any of the following professions?
 - Nurse
 - Nursing specialist
 - Caregiver
 - General practitioner
 - Medical specialist

2. Do you have regular contact with patients during your work?
 - Yes
 - No

Health professionals' familiarity with health literacy

1. Have you ever heard of the concept 'low health literacy'?
 - Yes
 - No

People with low health literacy have difficulty in finding, understanding and applying information about their health. One in three Dutch people over the age of 16 has limited health skills. These can be either highly or less educated people.

2. Now that you have read what 'low health literacy' means, were you already familiar with this concept?
 - No, not at all
 - A little
 - Yes, very well

From here, all questions will be answered using a 5-point Likert scale:

Strongly disagree – disagree – neither agree nor disagree – agree – strongly agree.

3. I often deal with patients with low health literacy.

4. I find recognising a patient with limited health skills easy.

5. Are there any particular steps or activities that you undertake extra when dealing with a patient with low health literacy? If so, please describe these steps or activities

Respect for patient-preferences, values and needs

6. I treat patients with low health literacy with dignity and respect.
7. Healthcare for patients with low health literacy is aimed at improving their quality of life.
8. I give special consideration to the preferences of patients with low health literacy.
9. I give extra help to patients with low health literacy in deciding what is the right healthcare for them.

Information, education, communication

10. Patients with low health literacy can easily access their medical records.
11. Patients with low health literacy are in control of their own care.
12. I help patients with low health literacy take charge of their care.
13. During my work, I try to discover to what extent patients with low health literacy are familiar with medical terms.
14. I am prepared to give extra help to patients with low health literacy to help them understand all health information.
15. I use one or more of the following conversational techniques when communicating with patients with limited health skills.
 - Avoiding medical terms
 - Adapting the amount of information
 - Repeating the information
 - Letting the patient repeat the information in their own words
 - Visualising the information

Access to care

16. Healthcare facilities are easily accessible for patients with low health literacy.
17. The directional signs (signs with route numbers, etc.) within your organisation are easy to understand for patients with low health literacy.
18. Scheduling an appointment is easy for patients with low health literacy.
19. Care is accessible for patients with limited health skills.

Emotional support

- 20. I pay extra attention to the emotions of patients with low health literacy about their situation.
- 21. I involve family in the emotional support of patients with low health literacy.
- 22. I pay extra attention to the concerns of patients with low health literacy about the impact of their health on their loved ones.
- 23. I create an embarrassment free environment for patients low health literacy.

Physical comfort

- 24. I pay extra attention to pain management of patients with limited health skills.
- 25. I take into account the preferences of patients with low health literacy regarding support with their daily needs.
- 26. I give patients with low health literacy adequate privacy.
- 27. I do extra checks to make sure that patients with limited health skills follow the prescribed treatment/advice.

Family and friends

- 28. I involve family members in decisions about the care of patients with low health literacy.
- 29. I pay extra attention to relatives in their role as carers of patients with low health literacy.
- 30. I pay attention to the needs of family and friends of patients with low health literacy.

Coordination of care

- 31. Patients with low health literacy only need to tell their story or concerns once. I am well informed.
- 32. I am informed by other colleagues about the situation of patients with low health literacy.
- 33. My colleagues and I work together as a team to provide care to patients with low health literacy.
- 34. My colleagues inform me about a patient's low health literacy..

Continuity and transition

35. When transferring patients with low health literacy to another healthcare provider, there is communication about their low health literacy.
36. When patients with low health literacy are transferred, they are properly informed about where they are going, what kind of care they will receive and who their contact person will be.
37. Patients with low health literacy receive expert advice on care and support when they return home.
38. Patients with low health literacy are assigned one care coordinator.

The focus of patient centred care is not on the disease, but on being human, on functioning, on the life situation and on the lifestyle. Patient-centred care is characterised by good communication with the (different) care providers and participation in decision-making on the treatment.

Please indicate to what extent you agree with each of the following statements, where 1 is for strongly disagree and 5 for strongly agree.

Perception of received organisational support to perform PCC optimally among patients with Low health literacy.

39. My organisation supports me in providing patient-centred care.
40. My organisation offers sufficient education about patient-centred care.
41. My organisation supports me in providing patient-centred care to patients with low health literacy.
42. My organisation provides sufficient education about patient differences in health literacy.
43. Within my organisation, I am given enough time to determine if I am dealing with a patient with limited health skills.
44. Within my organisation, I get enough time to pay extra attention to a patient with limited health skills.
45. How can your organisation better support you in delivering patient-centred care to patients with limited health literacy?