

INTERNSHIP REPORT

Perspectives and experiences of stakeholders regarding the patient journey of children from two months to five years old with pneumonia in Mityana, Uganda

PRELIMINARY RESEARCH FOR IMPLEMENTATION OF THE CHILDREN'S RESPIRATION RATE MONITOR (CHARM)

Msc. Management, Policy Analysis & Entrepreneurship in Health and Life Sciences

Marthe Luitjens

STUDENT NUMMER

2535110

COMMISSIONING PARTY

Healthy Entrepreneurs

ECTS + COURSE CODE SPECIALIZATION

30 ECTS + AM_471121

DATE

06-07-2019

VU SUPERVISOR

Ona Ilozumba

ATHENA SCIENCE SHOP

Colophon

Title: Perspectives and experiences of stakeholders regarding the patient journey of children from two months to five years old with pneumonia in Mityana, Uganda: Preliminary research for implementation of the Children's Respiration Rate Monitor (ChARM)

Key words: patient journey, childhood pneumonia, diagnostic tool, Uganda

Author: Marthe Luitjens

Commissioning organization: Healthy Entrepreneurs

On-site supervisor: Tosca Terra

VU supervisor: Ona Ilozumba

July – 2019

Course code: AM_471121

This internship report was established in cooperation with the Athena Science Shop.

Athena Institute

Faculty of Science
VU University Amsterdam
De Boelelaan 1085
1081 HV Amsterdam
The Netherlands



Preface

This report 'Perspectives and experiences of stakeholders regarding the patient journey of children from two months to five years old with pneumonia in Mityana, Uganda: Preliminary research for implementation of the Children's Respiration Rate Monitor (ChARM)' is part of the second internship of Management, Policy Analysis, and Entrepreneurship in Health and Life Sciences at the VU university. The research is commissioned by Healthy Entrepreneurs in collaboration with Philips Healthcare and written by M.G. Luitjens. Therefore, the ownership of this report belongs to Healthy Entrepreneurs. This research contributes to the effective and sustainable implementation of the ChARM in Mityana, Uganda, as part of the 'Doctor@Distance' pilot. Gratitude goes to T. Terra and O. Ilozumba for supervision and guidance during the execution of this research. © 2019 M.G. Luitjens.

Summary

Pneumonia is the leading cause of mortality of children under the age of five. In Uganda the mortality burden under five year is 16.2%. Pneumonia is easily treatable with antibiotics and can be prevented with low-cost medication and care (WHO, 2011). In Uganda, Village Health Team members provide healthcare at the community level. VHTs are able to diagnose and treat mild pneumonia by counting the respiratory rate per minute of a child using an 'Acute Respiratory Infection' timer. However, low accuracy of this method is encountered due to difficulties, such as losing count, multiple actions at once, and a noisy environment. A probable consequence is misdiagnosis which could result in under- or overtreatment. Therefore, the need for the development of simple-to-use and standardized technologies in pneumonia diagnostics arose.

The technology company 'Philips Healthcare' developed the Children's Respiration Rate Monitor (ChARM). The current preliminary research was conducted in order to contribute to an effective and sustainable implementation of the ChARM in Mityana, Uganda. Therefore, this study's research objective was to make recommendations for the implementation of a new pneumonia diagnostic tool by understanding the stakeholders perspectives and experiences regarding the patient journey of pneumonia of children from two months to five years old. The research question that was answered is: "What are the perspectives and experiences of stakeholders regarding the patient journey of pneumonia of children from two months to five years old?"

This research was based on the 'Model of pathways to treatment'. This adjusted conceptual model contains five phases: the appraisal phase, help-seeking phase, diagnostic phase, pre-treatment phase and follow-up phase. The model supported the exploration of the current patient journey of pneumonia of children from two months to five years, the contributing factors to this patient journey and the barriers and opportunities for implementation of the ChARM.

The research was conducted by a mixed-method approach with a sequential exploratory design. The qualitative data was gathered for exploratory purposes followed by the quantitative data to support and validate the qualitative data. The qualitative data contributed to an in-depth understanding of the perspectives and experiences of the stakeholders on the patient journey. These insights were obtained by conducting 17 semi-structured interviews with stakeholders, including caretakers and healthcare professionals. Quantitative data was gathered mainly to explore possible contributing factors to the patient journey. This was obtained by means of a 'Knowledge, Attitude and Practice' survey which was conducted among 50 caretakers.

The research has observed the following main findings. The appraisal phase started after detecting the first symptoms of pneumonia within the child. This phase showed poor knowledge of caretakers regarding danger signs of pneumonia. The first step was often to self-medicate, with use of herbal medicines or by consulting a drug shop. In the help-seeking phase various factors related to money, were indicated to delay this phase, including the distribution of decision-making power, awareness of future medical bills, attempt to self-medicate and distance to health centres. In the diagnostic phase the interviewed healthcare professionals reported that the higher the level of the healthcare facility, the more diagnostic tools were available and the more examinations could be

executed. However, a difference was found among healthcare professionals in used tools, executed examinations and guideline-use. This was mentioned to lead to inconsistency of used diagnostic criteria of pneumonia which could explain the finding that diagnoses of pneumonia are rarely made. Furthermore, in the pre-treatment phase a possible tendency was observed in which medication is always prescribed, even without an identified illness. In addition, the statements of healthcare professionals regarding the provided information regarding pneumonia was not in line with the statements of caretakers about the received information. The last phase showed that a follow-up appointment was always requested according to healthcare professionals, however caretakers indicated to have never received such a request.

The discussion showed that little knowledge of caretakers regarding pneumonia and poor recognition of danger signs of pneumonia are linked to a delay the appraisal and help-seeking phase. In addition, knowledge could improve treatment adherence and the interaction with Village Health Team members, which could stimulate seeking medical assistance at the community level. Furthermore, lack of money was found to be a major contributing factor to the patient journey. Therefore, during implementation of a new intervention it should always be considered that even when free healthcare is available, healthcare costs always remain prohibitive for families. Also, in Uganda poor implementation and adherence to guidelines was found. To improve the quality of care and therefore the outcome of pneumonia in children under five, utilization of guidelines and reliable diagnostic tools should be strengthened. In addition, literature acknowledged that the linkage between quality of care and standard prescription of medication should be breached by making the right diagnoses and moving towards limited access to effective treatment in order to combat antimicrobial resistance.

Several strengths were identified that contributed to the quality of this research. Internal validity was strengthened by recording the interviews which assisted in recollection of statements. Investigator triangulation was conducted by an Ugandan researcher, which prevented wrongful interpretations due to differences in background. Furthermore, the credibility of the results was increased by methodological triangulation which in combination with triangulation of sources resulted in rich data as various stakeholders were included in the research. However, limitations were encountered as well. The study setting of this research demanded the use of a translator. This could have led to data being lost in translation. In addition, a social desirability bias and recall bias of respondents should be taken into consideration. Furthermore, the inclusion criteria of the purposive sampling did not include an actual diagnosis of pneumonia for the child. As last, the sampling strategy of the survey was insufficient as the sample size was too low. Therefore, future research should conduct the same survey with a sufficient sample size to be able to execute tests regarding significance.

This research has shown various opportunities and barriers for the implementation of the ChARM. Therefore, this research contributes to an effective and sustainable implementation of the ChARM to provide a more accurate and reliable diagnostic process at the community level. This has resulted in the following recommendations: sensitization of the community including disease information and increasing help-seeking at the community level; comprehensive consideration of the revenue model; training of VHTs and establishing a step-by-step plan for VHTs regarding diagnostics of pneumonia.

Table of content

Preface	3
Summary	4
Abbreviations	8
1. Introduction.....	9
2. Contextual background	11
2.1 Health situation: Uganda.....	11
2.2 Pneumonia in Uganda	12
2.3 Health Organisation in Uganda: Healthy Entrepreneurs	12
2.4 Children’s Respiratory Rate Monitor (ChARM).....	14
2.5 Stakeholders.....	14
3. Theoretical background.....	16
3.1 The model of pathways to treatment.....	16
3.2 Sub-questions.....	18
4. Methods	19
4.1 Study setting.....	19
4.2 Study population and sampling strategies	19
4.3 Data collection	20
4.4 Data analysis.....	21
4.5 Ethics.....	21
5. Results	23
5.1 Demographics KAP survey	23
5.2 Patient journey.....	24
5.2.1 Appraisal phase	24
5.2.2 Help-seeking phase	27
5.2.3 Diagnostic phase	29
5.2.4 Pre-treatment phase.....	31
5.2.5 Follow-up phase	33
6. Discussion	34
6.1 Main findings.....	34
6.2 Comparison with literature	34
6.3 Strengths, limitations and future research	36
7. Conclusion and recommendations	38
8. Acknowledgements.....	39
9. References	40
10. Appendix	49

10.1 Threshold respiratory rates	49
10.2 Interview guideline	50
10.2.1 Healthcare professional	50
10.2.2 VHT	54
10.2.3 Caretakers with child who suffered from pneumonia.....	58
10.2.4 Caretakers with a healthy child	62
10.3 Informed consent form.....	66