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**PELVIC ORGAN PROLAPSE MANAGEMENT  
IN NEPALESE WOMEN:  
AN EXPLORATION OF FACTORS EFFECTING  
QUALITY OF LIFE AND IMPLICATIONS FOR  
POLICY AND PRACTICE**

**Anjana Dongol Singh**

**PhD**

**2019**



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POLICY AND PRACTICE**

**Anjana Dongol Singh**

**A thesis submitted in partial fulfilment of the  
requirements of Northumbria University for the  
degree of PhD Research undertaken in the School  
of Health and Life Science.**

**2019**



## ABSTRACT

Pelvic organ prolapse (POP) is a major reproductive health problem in developing countries like Nepal. The government has addressed the problem by initiating free surgical camps. However, different issues related to the paternalistic mode of management raise questions about the effectiveness of this approach. For a successful outcome, the problem needs to be assessed and treated considering different quality of life (QOL) domains. In order to arrive at a solution to manage POP in Nepal that places the person at the centre of care (person-centred care, PCC), multiple ways of understanding the effectiveness are needed which include the voices of women and the voices of clinicians.

A qualitative methodology, based on an interpretivist approach was used in this study. This study explores the views of women who experienced POP management together with the clinician's views involved in the management of POP. The impact of POP, on QOL before and after its management forms the central focus for evaluating effectiveness. Fourteen one-to-one interviews and two focus group discussions were conducted. Narratives were obtained from the women about the experiences of living with POP as well as life after its management. Similarly, narrative accounts of POP management were obtained from the clinicians. These narratives from the two groups of participants were analysed using the framework analysis technique.

This thesis highlights that the position of women in society was an important factor contributing to the development of POP amongst Nepalese women. Poverty, lack of education and socio-cultural disempowerment together with lack of access to a health care facilities were associated factors leading to delays in seeking timely health care. POP has been found to hamper the QOL for women significantly. The physical domain was the main domain effected above all other domains. Correction of physical symptoms was found to be associated with an improved QOL for women. The favoured clinical initiatives taken for the treatment of POP, though paternalistic, seemed successful as surgery for POP was found to be associated with an improvement in QOL for the majority of women. However, the management approach needs to be refocused on PCC in order to improve the overall lives of the women. Such a shift to PCC will require practice development at every level of its management. There is an urgent need to develop knowledgeable and skilled manpower both in curative and preventive care of POP. Integration of preventive aspects of POP management, within the government health care system, is a key factor if sustainable improvements are to be achieved.



## Table of contents

| Content  | Page |
|--|------|
| ABSTRACT   | i    |
| TABLE OF CONTENTS  | iii  |
| ACKNOWLEDGEMENTS   | ix   |
| DECLARATION  | x    |
| LIST OF ABBREVIATIONS                                    | xi   |
| <b>SECTION ONE: THE PROBLEM IN CONTEXT</b>               |      |
| CHAPTER 1: INTRODUCTION                                  | 1    |
| 1.1 Introduction   | 1    |
| 1.2 Background   | 2    |
| 1.3 Context of the study                                 | 3    |
| 1.4 Researcher's reflexivity                             | 7    |
| 1.5 Researcher's motivation for doing this study         | 9    |
| 1.6 Practice issues underpinning the need for this study | 10   |
| 1.7 Aim and objectives                                   | 11   |
| 1.8 Research questions                                   | 11   |
| 1.9 Uniqueness of the study                              | 12   |
| 1.10 Outline of the chapters                             | 12   |
| 1.11 Summary   | 14   |
| CHAPTER 2: NEPAL IN CONTEXT                              | 15   |
| 2.1 Introduction   | 15   |
| 2.2 Geography  | 15   |
| 2.2.1 Geographical regions of Nepal                      | 15   |
| 2.3 History and political landscape                      | 17   |
| 2.4 Administrative structure                             | 18   |
| 2.5 Nepalese society                                     | 18   |
| 2.5.1 Culture of marriage                                | 19   |
| 2.6 Economic overview                                    | 20   |
| 2.6.1 Basic infrastructure                               | 21   |
| 2.6.1.1 Water supply                                     | 21   |
| 2.6.1.2 Livestock management                             | 22   |
| 2.6.1.3 Household energy                                 | 22   |
| 2.6.1.4 Electrification                                  | 22   |
| 2.6.1.5 Transportation                                   | 23   |
| 2.7 Education for girls and women                        | 23   |
| 2.8 Health education in schools                          | 24   |
| 2.9 The health care system                               | 24   |
| 2.9.1 Human resource for health (HRH)                    | 26   |
| 2.9.2 Private hospitals                                  | 27   |
| 2.9.3 Medical colleges                                   | 27   |
| 2.10 Health financing system in Nepal                    | 27   |
| 2.11 Maternal health services                            | 29   |
| 2.11.1 Effect of financial incentive on maternal health  | 30   |
| 2.12 Family planning services                            | 31   |
| 2.13 MDG and Nepal                                       | 32   |

|   |  |    |
|---|--|----|
| 2.14                                      | Summary  | 33 |
| <b>SECTION TWO: EXPLORING THE PROBLEM</b> |  |    |
| <b>CHAPTER 3: LITERATURE REVIEW</b>       |  | 34 |
| 3.1                                       | Introduction   | 34 |
| 3.2                                       | Reproductive morbidity in low-income countries       | 34 |
| 3.2.1                                     | Women's position in Nepal                            | 35 |
| 3.2.2                                     | Early marriage                                       | 37 |
| 3.2.3                                     | The need for sons                                    | 37 |
| 3.2.4                                     | Access to health care                                | 38 |
| 3.2.5                                     | Health seeking behaviour                             | 39 |
| 3.2.6                                     | Family planning service utilisation                  | 41 |
| 3.3                                       | Magnitude of pelvic organ prolapse                   | 42 |
| 3.3.1                                     | Causes for the development of POP                    | 42 |
| 3.4                                       | Pelvic organ prolapse and Nepal                      | 43 |
| 3.4.1                                     | Factors influencing the development of POP in Nepal  | 44 |
| 3.4.1.1                                   | Child birth  | 44 |
| 3.4.1.2                                   | Heavy physical work                                  | 45 |
| 3.4.1.3                                   | Migration and workload                               | 46 |
| 3.5                                       | Effects of pelvic organ prolapse                     | 46 |
| 3.5.1                                     | Bulge  | 47 |
| 3.5.2                                     | Pain   | 48 |
| 3.5.3                                     | Urinary problems                                     | 48 |
| 3.5.4                                     | Bowel problem  | 49 |
| 3.5.5                                     | Sexual function                                      | 49 |
| 3.5.6                                     | Psychological effects                                | 50 |
| 3.6                                       | Physical assessment of pelvic organ prolapse         | 51 |
| 3.7                                       | Assessment of quality of life                        | 52 |
| 3.7.1                                     | Assessment of PQOL                                   | 53 |
| 3.8                                       | Management of pelvic organ prolapse                  | 55 |
| 3.8.1                                     | Nonsurgical management                               | 55 |
| 3.8.2                                     | Surgical management                                  | 56 |
| 3.8.3                                     | Prevention of POP                                    | 57 |
| 3.9                                       | Government approach to improving the quality of care | 59 |
| 3.10                                      | Quality of life after surgical management            | 60 |
| 3.11                                      | Qualitative studies exploring QOL                    | 62 |
| 3.12                                      | Medical Paternalism                                  | 64 |
| 3.13                                      | Person-centred care                                  | 66 |
| 3.14                                      | Practice development                                 | 67 |
| 3.15                                      | Summary  | 68 |
| <b>CHAPTER 4: METHODOLOGY AND METHODS</b> |  | 70 |
| 4.1                                       | Introduction   | 70 |
| 4.2                                       | Conceptual framework                                 | 70 |
| 4.3                                       | Philosophical assumption underpinning ontology       | 72 |
| 4.4                                       | Philosophical assumption underpinning epistemology   | 73 |
| 4.5                                       | Selection of methods                                 | 74 |
| 4.5.1                                     | Data collection methods                              | 74 |
| 4.5.2                                     | QOL tool for this study                              | 76 |
| 4.5.3                                     | Tools for data collection                            | 77 |

|        |   |     |
|--------|---|-----|
| 4.5.4  | Data analysis method  | 78  |
| 4.6    | Sampling  | 79  |
| 4.6.1  | Purposive sampling  | 79  |
| 4.6.2  | Snowball sampling   | 79  |
| 4.6.3  | Location of research sites  | 80  |
| 4.7    | Participant recruitment   | 81  |
| 4.8    | Plan of the study   | 82  |
| 4.9    | Ethical considerations  | 84  |
| 4.10   | The need for a pilot study  | 87  |
| 4.10.1 | Learning from the pilot study   | 88  |
| 4.11   | Data generation for main study  | 90  |
| 4.11.1 | Recruitment of the first group of participants who had experienced POP surgery  | 90  |
| 4.11.2 | Recruitment of second group of participants who were involved in POP management | 94  |
| 4.11.3 | Sampling matrix   | 95  |
| 4.11.4 | Data collection   | 97  |
| 4.11.5 | Reflexive perspective   | 98  |
| 4.11.6 | Transcription and translation   | 98  |
| 4.11.7 | The framework analysis  | 100 |
| 4.12   | Ensuring rigor  | 103 |
| 4.12.1 | Credibility   | 103 |
| 4.12.2 | Transferability   | 104 |
| 4.12.3 | Dependability   | 105 |
| 4.12.4 | Confirmability  | 105 |
| 4.13   | Limitation of the research  | 105 |
| 4.14   | Summary   | 106 |

### **SECTION THREE: FINDINGS**

|   |  |     |
|---|--|-----|
| CHAPTER 5: FACTORS: CONTRIBUTING TO POP DEVELOPMENT | 107  |     |
| 5.1   | Introduction   | 107 |
| 5.2   | Position of women in the society                             | 107 |
| 5.2.1   | Early marriage   | 107 |
| 5.2.2   | Need for a son   | 108 |
| 5.2.3   | Hard physical work   | 110 |
| 5.3   | Poor health care facilities                                  | 112 |
| 5.3.1   | Poor delivery practice                                       | 112 |
| 5.3.2   | Poor family planning services                                | 115 |
| 5.3.3   | Death of children  | 116 |
| 5.4   | Summary  | 116 |
| CHAPTER 6: PROCESSES: UNDERSTANDING POP MANAGEMENT  | 117  |     |
| 6.1   | Introduction   | 117 |
| 6.2   | Delays in seeking health care                                | 117 |
| 6.2.1   | Ignorance of POP and its treatment                           | 117 |
| 6.2.2   | Position of women in the family                              | 118 |
| 6.3   | Understanding the interlinked elements within POP management | 125 |
| 6.3.1   | Training manpower, limitations at different level            | 126 |
| 6.3.1.1   | Screening of women   | 126 |
| 6.3.1.2   | Assessment before treatment                                  | 126 |

|   |   |            |
|---|---|------------|
| 6.3.1.3   | Poor follow up  | 128        |
| 6.3.1.4   | Time limitations  | 130        |
| 6.3.2   | Government shortcomings: surgical camp opportunities      | 131        |
| 6.3.2.1   | Camp infrastructure                                       | 131        |
| 6.3.2.2   | Opportunities to participate                              | 132        |
| 6.3.3   | Monitoring and supervision: manpower issues               | 134        |
| 6.4   | Summary   | 138        |
| <b>CHAPTER 7 : IMPACTS: QOL AND POLICY CHALLENGES</b> |   | <b>139</b> |
| 7.1   | Introduction  | 139        |
| 7.2   | Impacts after POP development                             | 139        |
| 7.2.1   | Physical domain   | 139        |
| 7.2.2   | Social domain   | 145        |
| 7.2.3   | Psychological domain                                      | 148        |
| 7.2.4   | Economical domain   | 150        |
| 7.3   | Impacts after POP management                              | 151        |
| 7.3.1   | QOL: Returning to relatively normal life after treatment  | 151        |
| 7.3.2   | QOL: Inadequate post-operative care                       | 156        |
| 7.4   | QOL: Management improvements                              | 159        |
| 7.4.1   | Improving existing policy                                 | 160        |
| 7.4.1.1   | View from a clinician working in a medical college        | 163        |
| 7.4.1.2   | View from a clinician working in a Government hospital    | 165        |
| 7.4.1.3   | Views from clinicians working in a private hospital       | 166        |
| 7.4.1.4   | View from the clinician about managing in zonal hospitals | 166        |
| 7.4.2   | Upgrading knowledge and skills for care management        | 169        |
| 7.4.3   | Expanding preventive approach beyond health care          | 173        |
| 7.5   | Reflexive perspective                                     | 174        |
| 7.6   | Summary   | 175        |
| <b>SECTION FOUR: ADDRESSING THE PROBLEM</b>           |   |            |
| <b>CHAPTER 8: DISCUSSION</b>                          |   | <b>176</b> |
| 8.1   | Introduction  | 176        |
| 8.2   | Validation of research topic                              | 176        |
| 8.3   | Women, at the individual level                            | 178        |
| 8.3.1   | Factors contributing to POP development                   | 178        |
| 8.3.2   | Reflexive perspective                                     | 182        |
| 8.3.3   | Process for understanding POP management                  | 183        |
| 8.3.3.1   | Barriers in accessing health care                         | 183        |
| 8.3.4   | QOL and policy changes                                    | 185        |
| 8.3.4.1   | The physical domain                                       | 185        |
| 8.3.4.2   | The social domain   | 186        |
| 8.3.4.3   | The psychological domain                                  | 186        |
| 8.3.4.4   | The economic domain                                       | 187        |
| 8.3.4.5   | Life following management                                 | 188        |
| 8.4   | Health care organization level                            | 189        |
| 8.4.1   | Factors contributing for POP development                  | 189        |
| 8.4.2   | Process for understanding management                      | 192        |
| 8.4.2.1   | Screening   | 192        |
| 8.4.2.2   | Assessment  | 193        |
| 8.4.2.3   | Management  | 195        |

|   |  |     |
|---|--|-----|
| 8.4.2.4                                   | Post-operative care and follow up of patient                   | 197 |
| 8.4.2.5                                   | Monitoring and supervision                                     | 199 |
| 8.4.3                                     | QOL and policy changes   | 200 |
| 8.4.3.1                                   | Upgrading knowledge and skills                                 | 200 |
| 8.4.3.2                                   | Strengthening infrastructures                                  | 201 |
| 8.4.3.3                                   | Expanding preventive approach                                  | 202 |
| 8.4.3.4                                   | Medical prevention of POP                                      | 202 |
| 8.4.3.5                                   | Safe delivery practice   | 202 |
| 8.4.3.6                                   | Post-delivery care   | 203 |
| 8.4.3.7                                   | Reducing multiple childbirth                                   | 204 |
| 8.5                                       | The government level   | 205 |
| 8.5.1                                     | Factors contributing for POP development                       | 205 |
| 8.5.2                                     | Non-medical prevention   | 206 |
| 8.6                                       | Summary  | 207 |
| CHAPTER 9: CONCLUSION AND RECOMMENDATIONS |  | 209 |
| 9.1                                       | Introduction   | 209 |
| 9.2                                       | Overall key conclusions  | 209 |
| 9.3                                       | Impact of POP from QOL perspective                             | 209 |
| 9.4                                       | POP management and its weakness                                | 210 |
| 9.5                                       | An approach for prevention of POP                              | 212 |
| 9.6                                       | Practice development   | 213 |
| 9.7                                       | Post script  | 214 |
| 9.8                                       | Contribution to knowledge                                      | 214 |
| 9.9                                       | Dissemination of results                                       | 216 |
| REFERENCES                                |  | 217 |
| APPENDICES                                |  | 249 |
|   | Appendix 1: Invitation letter                                  | 249 |
|   | Appendix 2: Information sheet                                  | 251 |
|   | Appendix 3: Consent form                                       | 257 |
|   | Appendix 4: Ethical approval letter                            | 261 |
|   | Appendix 5: Amendment request form                             | 262 |
|   | Appendix 6: Ethical approval letter from Kathmandu University  | 263 |
|   | Appendix 7: Schedule visits at data collection sites           | 264 |
|   | Appendix 8: Impression about visits                            | 266 |
|   | Appendix 9: Informed consent sample                            | 274 |
|   | Appendix 10: Example of verbal consent                         | 275 |
|   | Appendix 11: Topic guide                                       | 276 |
|   | Appendix 12: List of tables                                    | 279 |
|   | Appendix 13: Pilot findings                                    | 285 |
| LIST OF TABLES                            |  |     |
|   | Table 4.1 The sampling matrix: Women participants identity     | 95  |
|   | Table 4.2 The sampling matrix: Clinician participants identity | 96  |
|   | Table 1: POP prevalence in Nepal                               | 279 |
|   | Table 2: List of Nepal's central hospitals                     | 281 |
|   | Table 3: List of Nepal's regional hospitals                    | 281 |
|   | Table 4: List of Nepal's sub-regional hospitals                | 282 |

|  |     |
|--|-----|
| Table 5: List of Nepal's zonal hospitals                           | 282 |
| Table 6: List of Nepal's major district non-governmental hospitals | 283 |
| Table 7: List of Nepal's medical college hospitals                 | 284 |

## LIST OF FIGURES

|   |     |
|---|-----|
| Figure 1.1: Normal female pelvic anatomy and POP                          | 2   |
| Figure 1.2: Paternalism in POP management                                 | 10  |
| Figure 2.1: Map of Nepal  | 16  |
| Figure 2.2: Organogram of Department of Health Services                   | 25  |
| Figure 3.1: Comparisons of commonly used grading systems                  | 51  |
| Figure 3.2: Pessary in position   | 56  |
| Figure 4.1: Map of Nepal showing location of research sites               | 81  |
| Figure 4.2: Access on the way to Manekharka                               | 93  |
| Figure 4.3: The stages of framework analysis                              | 100 |
| Figure 4.4: Triangulation   | 104 |
| Figure 8.1: Conceptual model for POP management                           | 177 |
| Figure 9: Team involved for recruitment of participants at Manekharka     | 267 |
| Figure 10: Women carrying heavy load at Manekharka                        | 267 |
| Figure 11: Sharing information to participants at Manekharka              | 268 |
| Figure 12: Sharing women's reproductive health related issues in Dhading  | 269 |
| Figure 13: Sharing women's reproductive health related issues in Janakpur | 272 |

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## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

The ethical clearance for the research has been approved and granted by both the School Ethics Committee and Kathmandu University School of Medical Sciences.

Name: Anjana Dongol Singh

Signature:

Date: 4<sup>th</sup> June 2019

## **List Abbreviation**

|       |   |
|-------|---|
| AFR   | Adolescent Fertility Rate                   |
| AHW   | Auxiliary Health Worker                     |
| AMA   | American Medical Association                |
| ANM   | Auxiliary Midwife Nurse                     |
| BMI   | Body Mass Index                             |
| BSP   | Biogas Support Program                      |
| CAC   | Comprehensive Abortion Care                 |
| CBS   | Central Bureau of Statistics                |
| CMA   | Community Medical Assistant                 |
| CPR   | Contraceptive Prevalence Rate               |
| CRADI | Colorectal Anal Distress Inventory          |
| DHOS  | Department of Health Services               |
| DHS   | Demographic Health Survey                   |
| DPHO  | District Public Health Offices              |
| ECD   | Early Childhood Development                 |
| FA    | Framework Analysis                          |
| FCHV  | Female Community Health Volunteers          |
| FGD   | Focus Group Discussion                      |
| FHD   | Family Health Division                      |
| GDP   | Gross Domestic Product                      |
| HA    | Health Assistant                            |
| HP    | Health Post                                 |
| HRQOL | Health Related Quality Of Life              |
| ICC   | Interclass Correlation Coefficient          |
| ICH   | International Conference on Harmonisation   |
| IUCD  | Intra Uterine Contraceptive Device          |
| IEC   | Information, Education and Communication    |
| INGO  | International Non-Governmental Organization |

|       |  |
|-------|--|
| LMP   | Last Menstrual Period                        |
| MBBS  | Bachelor of Medicine and Bachelor of Surgery |
| MCH   | Maternal and Child Health                    |
| MD    | Doctor of Medicine                           |
| MDG   | Millennium Development Goal                  |
| MMR   | Maternal Mortality Ratio                     |
| MOHP  | Ministry of Health and Population            |
| NAMS  | National Academy of Medical Science          |
| NCP   | Nepal Country Profile                        |
| NDHS  | Nepal Demographic Health Survey              |
| NDP   | Nepal Demographic Profile                    |
| NER   | Net Enrolment Rate\                          |
| NESOG | Nepal Society of Obstetrics and Gynaecology  |
| NFHS  | Nepal Family Health Survey                   |
| NGO   | Non-Governmental Organization                |
| NMR   | Neonatal Mortality Rate                      |
| PAC   | Post Abortion Care                           |
| PCC   | Person Centred Care                          |
| PD    | Practice Development                         |
| PFDI  | Pelvic Floor Distress Inventory              |
| PFIQ  | Pelvic Floor Impact Questionnaire            |
| PHC   | Primary Health Care Centre                   |
| POP   | Pelvic Organ Prolapse                        |
| POPQ  | Pelvic Organ Prolapse Quantification System  |
| PPE   | Pre-Primary Education                        |
| PQOL  | Prolapse Quality Of Life                     |
| QOL   | Quality Of Life                              |
| SBA   | Skilled Birth Attendant                      |
| SDIP  | Safe Delivery Incentive Programme            |

|        |  |
|--------|--|
| SHP    | Sub Health Post  |
| SMP    | Safe Motherhood Programme  |
| TFR    | Total Fertility Rate   |
| UDI    | Urinary Distress Inventory                                       |
| UNDP   | United Nation Development Programme                              |
| UNESCO | United Nations Scientific, Educational and Cultural Organization |
| UNFPA  | United Nations Family Planning Association                       |
| USI    | Urodynamic Stress Incontinence                                   |
| VDC    | Village Development Committee                                    |
| VVF    | Vesico-Vaginal Fistula   |
| WHO    | World Health Organization  |
| WHOQOL | World Health Organization Quality Of Life                        |



## **Chapter 1: Introduction**

This chapter introduces the significant, reproductive morbidity related problem of pelvic organ prolapse (POP) and its prevalence in Nepal. The impact of POP, quality of life (QOL) issues for women and the available intervention strategies are presented. The chapter then debates the challenges facing clinicians and women in the management of POP. The cultural, economic and policy gaps in its management are highlighted. In the ensuing critical discussion, the justification for the study: to improve the QOL for women, emerges. This chapter further presents the aim, objectives and research questions then it concludes giving an outline of the thesis structure.

### **1.1 Introduction**

Pelvic organ prolapse is considered as one of the common reproductive health-related morbidities in developing countries. The causes and risk factors for POP are complex and deeply embedded in the social, cultural, and economic conditions of women. POP is prevalent among younger women in Nepal (Gurung and Rana 2007; Dangal 2008). This thesis will explore the impact of a male dominated society in rural Nepal which limits women to household and agricultural activities and complicates women's rights when making independent health seeking decisions. Power over many aspects of life and especially in health, resides with men and the in-laws. This situation means that women with POP endure the problem for significant periods of time, which inevitably impacts upon their quality of life (Pradhan 2007).

The Government of Nepal has recognised POP as a major health problem (UNFPA 2007). This recognition led to a decision to offer curative surgical treatment through mobile surgical camps. These mobile clinics have undoubtedly improved access to treatment for women with POP in the rural areas; however the QOL for women following this treatment is questioned and explored in this thesis. The theoretical framework of the study questions the appropriateness of care based on the premise of medical paternalism. Medical paternalism dominates the physician-patient relationship and is defined as a philosophy that certain health decisions are best left in the hands of those providing healthcare (Surgeon's Medical Dictionary 2012).

This study aims to find ways to improve the management of POP. It seeks to improve the QOL for women by taking an interpretivist approach to gain in depth understanding of the problem through the perspective of those who are related with POP management, and make recommendations for change based upon those findings. This research represents the different journeys of the two participant groups; women who have experienced POP and surgical management and the clinicians involved in providing surgical management. The narratives were obtained from both groups. The women participants who had experienced POP management explained the effect POP had on their lives before and after surgical intervention. Another group of participants, the clinicians involved, discussed their management and the need for a change of approach in order to improve the QOL for women. In order to explore a range of a care experiences throughout the country the study was undertaken in three different regions of Nepal.

## 1.2 Background

Pelvic organ prolapse (POP) is defined by the International Continence Society as the descent of one or more of the anterior vaginal wall or the posterior vaginal wall, to the apex of the vagina (cervix/uterus) or vault (cuff) after hysterectomy (Abrams et al. 2002). POP is a common reproductive morbidity for women worldwide. In a report on a women’s health initiative, 41% of women age 50-79 years showed some degree of POP in high and low income countries (Hendrix and Clark 2002). Global prevalence is estimated to be between 2 and 20% and the life time risk of requiring prolapse surgery in women is 11% in developed countries by the age of 80 years (Oslen and Smith 1997). This rate has been projected to increase over the following two to three decades (Nygaard and Bradley 2004).

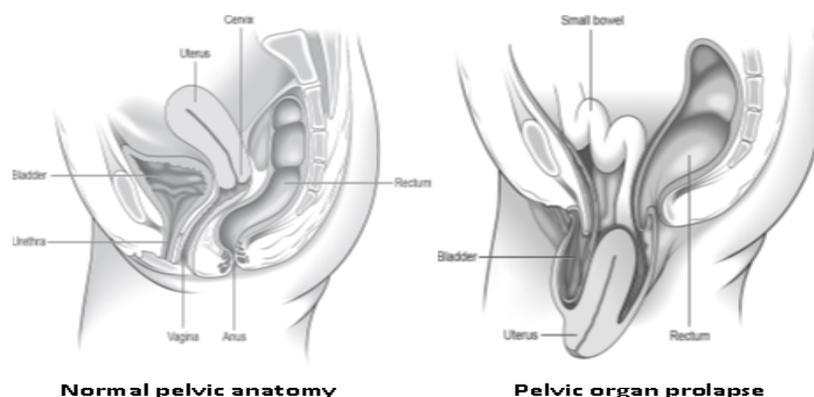


Figure 1.1: Normal female pelvic anatomy and pelvic organ prolapse. Source: RCOG, patient information leaflet on POP (Published in March 2013)

POP is one of the leading reproductive health problems in Nepal. Particularly among women in rural Nepal POP is prevalent in all ethnic groups and in all ecological zones and development regions. About 600,000 women of reproductive age group suffer from prolapse and among them 200,000 women are in need of immediate treatment (UNFPA 2007). The incidence of POP in Nepal is distinct because unlike high-income countries where it is predominantly seen in women of post-menopausal age group, it is seen more in the reproductive age group. In Nepal, studies have estimated that as many as 51% of uterine prolapse cases first occur in women between the age of twenty and twenty four years (Pradhan 2007). POP occurs after the first delivery in 30.4% of women and after second delivery in 62% (Shah 2010). However, the factors that give rise to prolapse in earlier reproductive age group are poorly understood in Nepal. The most significant factors associated with the onset of POP are heavy work and lifting heavy weights during the postpartum period (Bodner et al. 2007).

### **1.3 Context of the study**

The study is situated in the context of reproductive morbidities in the low-income country of Nepal. Nepal has been facing challenges related to maternal morbidity and mortality for many decades. The maternal mortality ratio (MMR) has been taken as a sensitive indicator of maternal health and became a huge concern globally. The Government of Nepal has begun to take the issue seriously and has committed to improve the situation by launching a range of priority programmes to improve the MMR. Detail on the different priority programmes is presented in the literature review chapter. Nepal experienced a decline in MMR from 539 to 239 per 100,000 live births between 1996 and 2016 (NDHS 2016). Despite progress in MMR, POP a leading maternal morbidity, has not been taken into account and remained a persistent concern throughout the country. The magnitude of POP in Nepal is described in the literature review chapter. At the beginning of the millennium, morbidity from POP became a huge concern in Nepal due to its high prevalence. The Government recognised POP as a leading reproductive morbidity for women in Nepal and are now recommending free treatment to protect the reproductive rights of women (UNFPA, 2007).

Advocate Prakash Mani Sharma (Shah 2010) highlighted the high incidence of POP and mentioned that in the absence of proper protection of reproductive health, POP may constitute a violation of women's rights. Nepal's Supreme Court proclamation in the case of Prakash Mani Sharma v. Government of Nepal was the foremost government legal initiative,

nationally or internationally, which acknowledged POP to constitute a violation of women's reproductive rights. No government prior to this had initiated such action or designated a targeted campaign to address POP (Shah 2010). Nepal has the distinction of being the only country internationally to initiate a government campaign to address POP problems.

The Government has shown its commitment by creating a fund for the provision of free POP surgery services to women in need. A strategic plan for prolapse management was instigated by the Ministry of Health and Population (MoHP) who developed a national service guideline for the management of POP in the year 2008 (Family Health Division 2008). Service guidelines have focused on different aspects of management which include screening, management and follow up. Other aspects include distribution of funds, monitoring and supervision, and samples of reporting forms and criteria to be fulfilled before contract agreement is reached with health service providers. The guidelines also contain checklists for monitoring and requirements for providing services (Family Health Division 2008). The mobile surgical camps for POP treatment represent one approach to provide operative services to rural, remote and underserved populations in Nepal. However, the strategic plan offered care which was almost similar for all women. This shows that the Government's decision appears to have been to avoid the potential litigation for violation of women's reproductive right rather than being based on person-centred care with an aim of improving the QOL for women. The Institute of Medicine highlighted the dimensions of person-centred care as: respect for patients' values, preferences, and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support relieving fear and anxiety; and involvement of family and friends (Institute of Medicine 2001).

Following the Government initiative, MoHP made the burden of POP a high priority for both prevention and management. The Government of Nepal set a target for free surgery of 20,000 women in the years 2008-10 and a target of 13,000 for the years 2011-12 (Clinical protocol 2012). The Government provided a budget for vaginal hysterectomies at the beginning of the programme, as the singular option of choice for POP treatment (Family Health Division 2008). The Government aimed to achieve the target within a short period of time. To fulfil the target, mobile surgical camps began in various parts of the country both in central and peripheral health facilities. Surgical camps in the context of Nepal refer to surgery for POP by an expert team within a specified time period time, in a specified place. Following the

Government direction, service provider groups were an easy solution to meet the target in the specified time period by providing curative management i.e. surgery focused on doing vaginal hysterectomies (surgical removal of uterus by vaginal route) in the surgical camps. When providing similar types of care for every woman without considering the grade and symptoms of POP, there is a chance of either under or over correction which may lead to further health care problems for the women. Social, cultural and economic constraints often prevent women from seeking care a second or subsequent time. This situation is often not understood by the clinicians or the policy makers when designing treatment plans. The agreement, based upon medical paternalism engages clinicians to provide a single way of treating women irrespective of their specific needs or evidence-based practice. The additional motivating source involved the money-per-case payment, which may have influenced the clinicians' decision making on the best treatment for each woman. Such action adds complexity to the situation because whilst hitting the target, it could be argued that the widespread surgical intervention may have missed the point, if it has failed to improve the overall health of women. This paternalistic approach created personal discomfort for the researcher as a clinician, involved in a programme that did not necessarily, she believes, always improve women's health.

Though the POP management programme is purported to be for prevention and treatment, the preventive approach of bringing awareness to populations and using conservative management (using vaginal pessaries), has not been taken seriously. Nepal is not a rich country. It has to depend upon foreign aid in order to provide interventions on major health issues. Every penny spent on improving the health of women also influences the health of families. The researcher has concerns that a prevention approach, which could have been possible from the same budget at the same time, has not been seriously considered. This situation raises the question of whether approaches to improving the lives of Nepalese women, from a political perspective or that of other decision making groups, is a worthy investment. Sustainable approaches to the prevention of POP, rather than short-term surgical activities, need to be explored. Hence, this study arises from the need to explore the issues from different viewpoints.

The approximate cost for POP management through the vaginal route is around twenty thousand Nepalese Rupees (Rs) (£1 equal to Rs 130). POP surgery is performed at government permitted hospitals and mobile surgery camps free of cost to the patient. The

proposed dates and places of camps are generally decided by consensus of district-based stakeholders. Information about the camps is provided to people in the respective district from different sources such as print, radio and word of mouth. All the team members are given specific duties for the various management activities during the camp period so as to conduct camp surgery in a systematic way i.e. registration, history taking, examination, investigation, operation and post-operative care. Proper assessment of the woman, considering her age, parity, symptoms and degree of prolapse is important in deciding the most appropriate mode of management. The researcher, being a clinician, feels there can be a marked deficiency in proper pre-operative assessment of women undergoing prolapse surgery, especially when treating patients in large numbers. Such shortcomings can either result in inappropriate treatment or the failure of surgery inviting many other negative consequences including poorer QOL with ongoing health complications.

Conducting surgery outside the hospital environment, where routine surgery is not the norm, increases the chance of facing difficulties i.e. difficulties in the infrastructure, required eligible manpower, required instruments. Routine assessment, monitoring and supervision are essential requirements in giving quality care. Although guidelines are provided for the supervision and monitoring of care, there is no formal committee or review board to examine the potential benefits or harm that result from the surgical camps' interventions. Evaluation of the effectiveness of the current approach is therefore a high priority for many reasons; to justify public spending on a health issue, to ensure the intervention is effective from the perspective of those who are affected by it, and that alternatives or additional elements are considered in future policy.

Authors, like Rana, who is a gynaecologist and Subedi, an anthropologist have expressed their dissatisfaction about the surgical camp approach to POP management (Rana 2006; Subedi 2010). Rana (2006) in her editorial article claimed that around 16-22 surgeries are performed daily on average, by 2-3 doctors in a hectic schedule which can start at 6am and go on until 8pm. Staff nurses work as first assistants and 2-3 parallel operating tables are managed simultaneously by a single anaesthetist. Rana, raised the issue about reproductive rights, and asked why Nepalese women receive a service which is below the national standard. Nepalese women, it would appear, have to make stark choices between living with prolapse, or risk death from the surgery (Rana 2006). Although she mentioned the mortality issue related to POP surgery it has yet to be explored.

Short-term surgical camps have become the subject of much debate because of their transient nature and doubtful long-term effects on the health status and development of the local population (Seabrook 2012). Unknown groups of clinicians from different parts of the country gather in a place hoping to provide some medical or surgical treatment to needy populations. Counselling and advice relating to complications and aftercare, when treating many people at the same time, are seldom included. Whilst some benefit from the surgical treatment, the majority need further follow-up, and will never have the opportunity to see the same group of clinicians again. Subedi (2010) mentions in his study the difficulties women face in getting treatment, the problems they face after treatment when returning home and the difficulties they face due to the development of complications after surgery. He complained about the lack of mechanisms for post-discharge consultation following POP surgery and demanded a clear-cut monitoring system to keep track of the patients in order to find out the outcome of the surgery (Subedi 2010). Some recent studies, however, in the field of QOL for women after surgery reported surgical intervention as being beneficial to women suffering from POP (Chhetry et al. 2012; Dhital et al. 2013; Tamang et al. 2014).

The researcher in her clinical practice comes into contact with women who face various types of difficulties after undergoing surgery for POP in the surgical camps. Women expressed a wide range of dissatisfaction regarding place, persons and procedures. Regarding place; because of the temporary sites, women reported failure to locate an appropriate venue when they needed help and advice following surgery. Regarding person; women said they never knew the surgeon's name nor knew when they would be able to see him or her again. Regarding procedure; women rarely knew what had actually been done and were ignorant of what needed to be done in the future.

The researcher offers a short reflective account before presenting the motivation for her study. Throughout this study, the researcher will be writing in the third person but while sharing and reflecting on elements of her personal PhD journey, she will write in the first person.

#### **1.4 Researcher's reflexivity**

I am Dr Anjana Dongol Singh, a Nepali woman, gynaecologist and obstetrician working in Dhulikhel Hospital, Kathmandu University School of Medical Science, Nepal. Since I

started my medical career I have developed an interest in women's health issues. I completed my M.B.B.S. (Bachelor in Medicine and Surgery) in the year 1999. Since then I have voluntarily been involved in women's health education in different parts of the community within Kathmandu Valley. My interests were nurtured by inspiration from my father Mr Ram Bahadur Dongol, who is social worker and was president of our ethnic community. Since I became a doctor, improving women's health by providing health education has become a part of my life. I came to understand the value of communication and sharing knowledge which is lacking in Nepal health care due to lack of education. Another part of my learning was the significance of and need for counselling women.

I joined Dhulikhel hospital in the year 2006 soon after completing my M.D. (Master's degree in Gynaecology and Obstetrics). A key reason for joining Dhulikhel Hospital was its philosophy of 'Quality health service for the poor'. It is an independent, not for profit, non-government institution. Dhulikhel Hospital is also the university hospital for all the medical programs run with the collaboration of Kathmandu University. It has extended health services in different parts of Nepal, called outreach centres; in areas where people can't reach hospital health services. Clinicians will travel to them in their remote places to provide health care services. The hospital at present has 20 community outreach centres around its periphery. The hospital has managed to attract and collaborate with different hospitals and universities worldwide. It has become a platform for experts as well as students to come and share experiences, knowledge and skills. I have had an opportunity to work in the management of POP with gynaecologists from the Netherlands and Australia on several occasions. These experiences have further helped me to improve my knowledge and skill in the field of POP management.

My involvement in prevention, management and follow of patients with POP started in 2006. I was one of the novice clinicians involved in a follow up program after POP management in rural Nepal. This work on the follow up of prolapse surgery in rural Nepal was published in 2008 along with the Dutch clinicians (Schaaf et al. 2008). I published my second article about renal impairment among patients with pelvic organ prolapse in a tertiary care centre in 2013 (Dongol et al. 2013). My interest in POP gave me wider understanding about the health status of women living with POP in Nepal.

Within my clinical practice in hospital and community centres, I have maintained an interest in looking after women's health. I was actively involved with my colleagues to establish our hospital as a main Skilled Birth Attendant (SBA) training site for the Kavre district. We have, so far, completed training for 25 batches of SBAs (10-12 participants in each batch). This is a significant step towards the prevention of POP.

My interest in post-surgical morbidity grew as a consequence of working in the community outreach centres and following-up women operated both in hospital and in camp settings. I noticed a difference in the women who underwent management in the camps as opposed to hospitals. My personal observation was that despite receiving surgical treatment in camps the women were still experiencing problems and frustrations because of their symptoms. They were confused about the surgical procedure. They did not know what had been done in the operation and to whom they could turn for help after the surgery. From experience, it appeared that those who were operated upon routinely in hospitals have expressed high satisfaction and complained significantly less compared to those operated upon in the surgical camps. This raised questions regarding the current surgical camp approach. I started exploring the possible solutions to improve the health status of women who suffer from POP. This encouraged me to enrol for the PhD in order to explore and research in depth ways to improve the health status of women with POP.

### **1.5 Researcher's motivation for doing this study**

For the current study, the researcher has been motivated by the following:

- High prevalence of POP among Nepalese women
- Observing women living with POP for long periods of time
- Difficulty in accessing health care
- A need for surgical camps in Nepal
- Government initiated management for POP
- Debate over the utility surgical camps
- Offering similar care for all women with different symptoms and degree of POP
- Lack of the Government enthusiasm in expanding the preventive approach
- Understanding the limitations that leads to poor health care services

## 1.6 Practice issues underpinning the need for this study

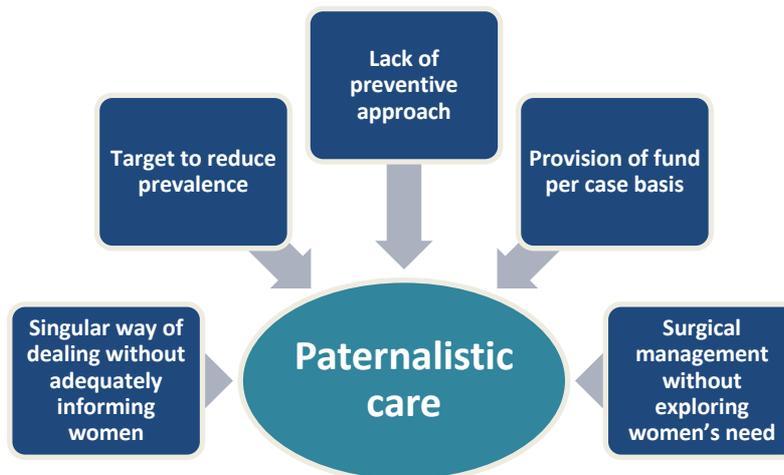


Figure 1.2: Paternalism in POP management

The high prevalence of POP among Nepalese women, stimulating the Government initiative to manage POP, led to a paternalistic care approach with targets only focussed on reducing the prevalence; the lack of a preventive approach and the dominance of a single way of dealing with these women by providing similar treatment for every woman without exploring the women's individual needs and priorities. The paternalistic care was influenced within this patriarchal society because women lack a voice and have less decision making power. The theoretical framework based upon issues with medical paternalism was the prime concern in this study.

The researcher as a clinician was happy for the initiative taken by the Government but was not happy with the paternalistic approach when dealing with the women. The researcher wanted to explore alternative models of care. For that she has had to question the notion of paternalism and whether person-centred care could be a way forward. With a person-centred care approach to improve women's QOL this study emphasizes the need for a practice development initiative. Practice development can be defined as:

*'A continuous process of improvement toward increased effectiveness in person-centred care, through the enabling of nurses and healthcare teams to transform the culture and context of care'* (McCormack 1999: p.256).

In order to move towards person-centred care, the adoption of a singular way of knowing which reflects the medical perspective cannot be sufficient to understand the situation. To achieve multiple perspectives on the issues associated with POP and surgical management, information is required from the different groups of people involved, which include the voices of women and those of clinicians. This key principle has informed the conceptual framework for the study, which is presented in the methodology chapter.

### **1.7 Aim and Objectives**

This study explores women's and clinicians' views on their experiences of POP and its management in Nepal. The study is underpinned by the following aim and objectives:

Aim:

To understand women's and clinician's perspective on the perceived impact of surgical management amongst Nepalese women who experience POP in order to make suggestions for policy and practice improvement

Objectives:

1. To explore the women's and clinician's experience of POP before and after surgical management from physical, psychological, social and economic QOL perspectives;
2. To analyse the factors that need to be considered during POP management to improve women's lives
3. To make recommendations for changes in policy and practice

### **1.6 Research questions**

In order to address the aim and objectives the following research questions were posed. These further justify the rationale for the methodology for this study.

- What are the QOL issues for women before and after management of POP?
- How can the management of POP be improved in order to enhance the QOL for Nepalese women?

## **1.9 Uniqueness of the study**

The researcher believes that it is very important to explore the range of difficulties women face before, during and after surgical intervention. This knowledge can better inform and evaluate the effectiveness of the current surgical management programmes. The dearth of information regarding women's experiences about the given management demands a study which investigates post-surgical morbidity and QOL issues for women after the management of POP. Generally a patient-oriented view is elicited or a medical view is sought with objective information in order to assess effectiveness. In this study, women's voices were listened to and provided subjective narratives of experiences which have rarely been heard before in Nepal.

In order to gain multiple perspectives on the management of POP the researcher identified the need to also listen to the clinician's. The study aims to identify possible solutions from the clinicians who are involved in POP management. The uniqueness of this study is that it explores POP from these different viewpoints. The different views from the participants will be integrated using a framework analysis technique. The literature is devoid of studies which bring both clinician's and women's viewpoints together in order to construct multiple meaningful perspective on POP management. Through this study, the researcher seeks to justify the need for a change in practice in order to improve women's QOL.

## **1.10 Outline of the Chapters**

### **Chapter 1 – Introduction**

Chapter One presents an introduction to the thesis, the researcher and the participants. This chapter discusses the background to the research topic drawing attention to the context of POP as the most common reproductive morbidity in rural areas of Nepal. The initiative taken by the Government for its management was presented, followed by the motivation for doing this study. An outline of the thesis chapters concludes this section.

### **Chapter 2 – Nepal in context**

Chapter Two presents an overview of Nepal. The geographical distribution, the culture and socioeconomic status of the people living in Nepal, and its health care system within the context of reproductive morbidities, is presented here. The broader, national picture provides

the context for women's health and factors that contribute to the development of POP and is the setting for its management challenges.

### **Chapter 3 – Literature review**

Chapter Three presents the literature relevant to the topic, both historic and current, on different aspects of POP and its management. It is important to show the difference in POP's aetiology, effects and management between high and low-income countries. The distinctiveness of a high prevalence in the reproductive age group will be shown. Analysis of the effectiveness of the Government initiative for pop management in context of QOL improvement is reviewed in this chapter.

### **Chapter 4 - Methodology**

Chapter Four provides the philosophical assumptions underpinning the study to explore QOL for women who have experienced POP management. This chapter begins by providing a conceptual framework. Then it presents the research plan which includes the choice of methods for data collection, the participants, and the analysis process appropriate to answer the research questions. It also describes the ethical issues considered during the research process.

### **Chapter 5, 6 and 7- Findings**

The findings in this study are divided into three different phases and each phase is presented in a different chapter. Chapter Five presents the findings about the factors for the development of POP. Factor reflects the phase of life with POP. The mechanism phase is presented in Chapter Six which explores the mechanism for understanding ongoing management. Chapter Seven presents impacts which reflect elements of life after management. The evidence for change in practice to improve the QOL for women living with POP is presented.

### **Chapter 8 – Discussion**

Chapter Eight discusses the entire project. Links between the original research question, methodology and findings are critically considered with respect to the current body of knowledge. The conclusion offers suggestions for further exploration, policy and practice development.

## **Chapter 9– Conclusion and Recommendations**

Chapter Nine begins by presenting the key findings. It is followed by a separate conclusion and recommendation sections elicited from the research findings on impact of POP from QOL perspective, an approach for prevention of POP and on POP management, its weakness and need for practice development. This explores the status of management policy and guides the need for change in existing policy. This chapter then reflects on the contribution to knowledge from the study. Finally, it concludes by presenting emerging ideas for further development beyond this project in the post script.

### **1.11 Summary**

This introductory chapter has introduced POP as one of the major causes of reproductive morbidity in Nepal. The challenges faced by women after developing this problem have been emphasised. The government response to reduce the prevalence of POP is presented, demonstrating the prioritisation of a singular-way of dealing which does not include the perspective of women. This highlights paternalism in the current management of POP. The drive behind conducting this study has been presented along with the aim, objectives of the research and concluded by presenting the outline of the thesis structure. The next chapter Nepal in context highlights the relevant aspects of the country and its challenges related to women's reproductive morbidity.

## **Chapter 2: Nepal in context**

### **2.1 Introduction**

This chapter presents a brief geography, history and political landscape of Nepal. The culture and socioeconomic status of the people and the health care system are then addressed. This exposition will signify the different factors responsible for the development of reproductive morbidities like POP. It provides an understanding of the challenges across different dimensions when accessing health care, in which QOL related issues following the development of POP and its management are embedded. This explains the importance of understanding both context and culture for PCC. The three geographical regions within which the study is carried out are introduced. The rationale for choosing three different regions will be presented in the methodology chapter. The online resources of Google, Hinari, and the WHO webpages were used to search for the country profile, Nepal demographic health survey, world bank report and health care system in Nepal.

### **2.2 Geography**

Nepal is a relatively small landlocked country, situated in the northern hemisphere, occupying only 0.03% and 0.3% of total land area of the world and Asia respectively. Nepal has an extreme topography with altitude ranging from 70 to 8848 metres (m) and a climate which varies from tropical to polar. The country stretches from east to west with a mean length of 885 kilometres (km) (longitude 80° 04' East, to 88° 12' East) and widens from north to south with a mean breadth of 193 km, (latitude 26° 22' North, to 30° 27' North) covering a total area of 147, 181 square km. Nepal, borders to the north with China and to the east, west and south with India (Country Profile: Nepal 2005).

#### **2.2.1 Geographical regions of Nepal**

Nepal is divided laterally across the country into three east-west ecological zones:

The southern ranges, the Terai (flat land: lowest 70 m above sea level), covers approximately 23% of Nepal's total area and borders with India (east, west and south). The transportation and communication facilities are more developed in this region than other two regions. It is the main agricultural region and the most densely populated area within Nepal.

The middle range, the Hill (1000 to 4000 m in altitude), covers approximately 42% of the total area and consists of mountains, hills, valleys and lakes. Kathmandu valley which contains the capital city of Nepal lies in this region. The transportation and communication facilities are more developed than in the mountains. The population distribution in the hills varies with fairly dense population in the valleys but notable lower population numbers above higher altitudes.

The northern range, the Mountain region (more than 4,000 m in altitude) covers nearly 35% of the total area. Because of the harsh terrain, transportation and communication facilities in this region are very limited and only about 7 percent of the total population lives here (Ministry of Health and Population 2012).

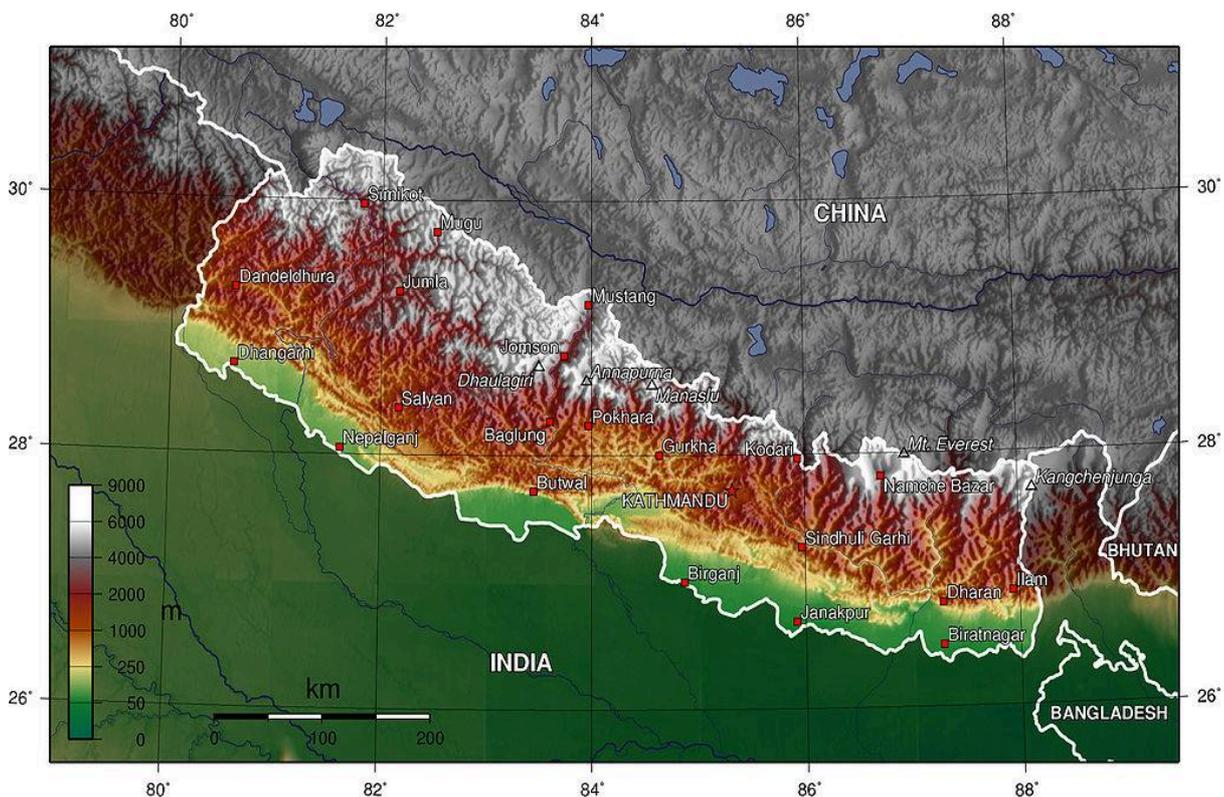


Figure 2.1: Map of Nepal. Source: [www.undp.org.np/.../dcr96/developmentmap.htm](http://www.undp.org.np/.../dcr96/developmentmap.htm)

2009

Nepal's rugged terrain prevents people travelling especially in the hill and mountain districts where the links are made by poor or non-existent roads. Nepal's road network and quality are among the lowest in South Asia. More than one-third of its people live at least a two hours walk from the nearest all-season road; 15 out of 75 district headquarters are not

connected by road. In addition, some 60% of road networks and most rural roads are not operable during the rainy season (The World Bank 2009). In order to access health services people travel for hours or even days mostly without transportation. The limited geographic access makes transportation difficult which prevents people using health services in the remote areas (Simkhada et al. 2006).

### **2.3 History and political landscape**

The history of Nepal goes back thousands of years. Shah dynasty continued ruling Nepal since the years 1765 until 2006. The democratic reformation took place in the year 1990 which brought multiparty democracy with the king as a constitutional monarch (Country Profile: Nepal 2005). In early 1996, the Nepal Communist Party (Maoist) launched a movement based on dissatisfaction with a democratically elected government. The mass movement of April 2006 in Nepal ended a 10 year armed conflict, restored parliament and the democratic process and initiated a peace movement. However, a period of armed conflict between the years of 1996-2006, further limited the use of health services (including maternal health services) through increased barriers to travel and security (Thapa and Sijapati 2003; Wagle et al. 2004).

Nepal has undergone a major political transformation since 2006. An interim constitution was drafted, and the restored parliament dissolved to cover the way for an interim legislature and interim government. The Nepal Communist Party joined the democratic competition, and a constituent assembly election was held in April 2008 to devise a constitution to manage the root causes of the conflicts affecting the nation. King Gynandra was dethroned on 28<sup>th</sup> May 2008 and the Nepalese constituent Assembly declared Nepal a republic and abolished the monarchy. The ruling seven-party alliance announced substantive structural reforms such as the declaration of the country as secular and federal, civilian control of the Nepal Army, nationalization of royal property, and empowerment of the prime minister as head of state. Currently, the Nepal government is a multi-party system within a republican framework (Country Profile: Nepal 2005). Finally, the Nepalese citizens got the new constitution of Nepal on 20<sup>th</sup> September 2015 by former honourable President Mr. Ram Baran Yadav. This has brought hope to the citizens for political stability, development of the nation for improving poverty and inequalities.

The struggle for human rights in Nepal for freedom, rights and social opportunities still remains unfinished. As mentioned in human rights report (2013) the most significant problems were exacerbated by the country's continuing delay in promulgating a permanent constitution; the absence of transitional justice mechanisms; and failure to implement court order arrests of military personnel, Maoist and other individuals accused or convicted of human rights violations as a result of the country's 10 year of insurgency remain at large. Although there are different issues related to violence against children, at the level of society the discrimination and domestic violence against women remains a serious problem along with dowry-related deaths. The human right issues at the level of society provide an important insight into the position of women whose voices are not heard. Discrimination against people with disabilities, some ethnic groups, and people with HIV/AIDS also exists in Nepal. There are some restrictions on worker's rights, and forced, bonded labour. However, child labour remains a significant problem in Nepal. The sex trafficking of adults and minors also remains a serious problem (Human Rights Report 2013). The newly constituted assembly was expected to improve human rights in Nepal related to freedom, rights and social opportunities. However, time will tell about such improvements.

#### **2.4 Administrative structure of Nepal**

Administrative and politically, Nepal is divided into 7 development regions, 14 administrative zones, which are, in turn, divided into 75 districts. Each district has been further divided into Village Development Committees (VDC) (3913 VDCs in total) and 58 municipalities as front-line administrative units. Each VDC is further divided into 9 smaller political units called wards. The purpose of VDC is to organize village people structurally at a local level and to create a partnership between the community and the public sector for improved service delivery systems (NDHS 2016).

#### **2.5 Nepalese society**

The country's total population is estimated to be 29,033,914 (Nepal Demographic Profile 2016). The age structure of this population is 32% in the range of 0-14 years, 22.6% of 15-24 years, 34.9% of 25-54 years and 5.5% of 55-64 years. The growth rate of population is 1.24% compared to 1.35 per annum in the year 2011. There are 19.9 births for every 1000 population. The life expectancy at birth in the year 2013 according to World Bank report was 68 years which was previously only 62 years in the year 2000. The urban population is

about 17% of total population and it is estimated that there is an annual rate of change to increase in urbanization of 3.62% (World Bank 2013).

There are 125 ethnic groups in Nepal. The population distribution of ethnic groups includes 16.6% Chhettri, 12.2% Brahmin, 7.1% Magar, 6.6% Tharu, 5.8% Tamang, 5.0% Newar, 4.8% Kami, 4.4% Muslim, 4% Yadav and 2.3% Rai. Despite high social diversity, the state imposed a single Hindu religion (followed by 81% of population). All together there are 123 languages spoken throughout Nepal but Nepali as mother tongue is spoken by only 44.6% of the population (Central Bureau of Statistics 2012).

### **2.5.1 Culture of marriage**

Marriage forms the basis of family formation and is an important determinant of fertility. Early marriage is still the norm in Nepal. The age of marriage depends on ethnicity and also the different regions. Women living in the mountains tend to marry later than women from the Hilly and Terai regions (Aryal 2008). In poorer families the girl child is meant to provide the traditional contributions in the household like domestic work, caring for younger children and tending domestic animals. Daughters are considered to be an economic burden to the family. The parents want to shift the expense of rearing by giving away the daughters to another family. Women are thus encouraged to marry early because of lack of alternatives to marriage, such as education and female employment outside the family (Aryal 2008). Marriages in Nepal are mostly arranged by family members with decisions made for their economic survival strategies. In some parts of Nepal there is a culture of dowry paying. The payment will be increased according to the girl's age. To avoid a larger investment, the family are likely to marry off their daughters early (Lloyd et al. 2005).

Marriage coexists with high rates of workforce participation. Data from longitudinal analysis using the Nepal's Living Standards Survey (2012) show the influence of household poverty on early marriage, schooling and work outcomes. According to the study, in rural areas, all marriages are early compared to urban areas (Nepal's Living Standards Survey 2012). Early marriage deprives girls of education. According to Bajracharya and Amin's (2012) study, girls who delay marriage remain in school for longer whilst those who marry early withdraw from school earlier. Educated girls participate in the workforce. This gives them autonomy to decide on marriage and encourages girls to delay marriage (Bajracharya and Amin 2012). Thus, education lets women attain improved communication levels and

along with associated autonomy of the individual women gain empowerment to make decisions for themselves and for other family members. Attaining higher education and developing autonomy is still not possible in the rural context of Nepal. As they are not empowered, women's voices are not listened to, which makes them destined to live with the problems they develop.

## **2.6 Economic overview**

Nepal is one of the low-income countries in the world, with about one-quarter of its population living below the poverty line. The Gross Domestic Product (GDP) per capita in Nepal was recorded to be \$ 409.04 in 2013 with growth rate of 3.8% (from 2004 to 2012). The GDP composition includes 38.1% in agriculture, which is the mainstay of the economy, providing a livelihood for three-fourths of the population. Because more than 70% of the farmers are subsistence in nature, thus they are not contributing much to GDP. However, they have to depend on agriculture for their very existence and livelihoods (World Bank 2013). Political uncertainty hampers industrial activity and inevitably impacts upon the economy of Nepal. The challenges to Nepal's economic growth include its landlocked geographic location, acute power shortages, labour unrest and its susceptibility to natural disaster (Bergner 2014). The April 2015 earthquake has destroyed lives and livelihoods as well as buildings and infrastructures. The challenges to health services, in its aftermath are immense.

More than half of the impressive reductions in poverty in Nepal over the past two decades have been directly attributed to robust remittance income. Remittances sent mainly from male family members from different parts of the world equate to at least 25% of GDP and possibly over 33%, growing at an average of 24% over the past 10 years. Money is sent home through an effective system of Money Transfer Operators, remittances make crucial contributions to national financial stability and also to household finances. Over 55% of households are receiving remittance income in Nepal (Jones and Basnett 2013). Labour migration and remittances thus are strong drivers of poverty reduction, and the most realistic hope for inclusive growth in Nepal in the near future. Every year, more than 4 million Nepalese travel abroad for work. The number of migrant workers is increasing at an average of 47% between 1999 and 2009. Migrants find employment in India, the Gulf nations, Malaysia and elsewhere. Migration is common across all geographic regions, ethnic and social groups, and with high participation across all wealth quintiles as well (Ministry of

Labour and employment 2014). However, the loss of male population and subsequent increase in the work load for women remains an issue which will be further discussed in the literature review chapter.

Nepal at the moment is struggling to achieve the Sustainable Development Goals (SDGs). The first SDG goal among the seventeen is to eliminate poverty. Despite the efforts to address the most marginalized and vulnerable people in society by enhancing their livelihoods and improving their access to basic services, wide disparities persist at a national level between rural and urban areas. The NDHS (2016) stated that one third (34%) of the population is under age of 15 and 31% of the houses are headed by women. In children under the age of 5, 36% have stunted growth, 10% are wasted, 27% are underweight and 1% is overweight. A total of 48% of households in Nepal are food secure and have access to food year around while 52% are still deprived of access to food during the year. Low literacy rates (11% of men and 31% of women have no education) leave a large part of the young population (14% of men and 33% of women) unskilled and unemployed (NDHS 2016).

### **2.6.1 Basic infrastructure**

The presented headings below reflect the work load for women. This has been presented to understand and correlate how a lack of basic infrastructure is contributing to the development of POP amongst Nepalese women.

#### **2.6.1.1 Water supply**

All people have the right to access to drinking water but the burden placed on women's time and work load by inconvenient water sources is well recognized in Nepal. It was found that village women spent more than two hours per day collecting water from nearby water resources (Millennium Development Project 2002). The Government of Nepal ambitiously targeted the Ninth Plan Period (1997-2002) to provide basic water supply facilities to all (100%). The progress was only 29.94% in water supply sector. The Government of Nepal has signed up to the MDGs, under which it needs to achieve 73% drinking water coverage by 2015. The 2016 report showed that improved drinking water supply facilities were available to about 95% of the population (NDHS 2016). The access to water supply is limited to drinking water; however water is basic for all household activities including livestock. This suggests there is still a need to increase coverage and to provide safe water supplies to

underserved populations in remote areas. It is vital to achieve widespread coverage to reduce the work load of rural women.

#### **2.6.1.2 Livestock management**

Agriculture is the main source of livelihood for the people of Nepal. Livestock rearing is a part of farming by rural communities. Nutrients for the farm come from animal manure and leaf material. This study confirms that the other major contributing factor to the work load for women was livestock management. Women spend three to six hours every day with livestock management (Regmi 2003). The Nepal Living Standard Survey (2011) stated that roughly 70% of the country's households collect fodder for their livestock. Around 57% collect from their own land, 23% from the forest and 20% from unspecified places.

#### **2.6.1.3 Household energy**

Nepal relies heavily on traditional energy sources to meet its energy requirements. Almost 87% of Nepal's total energy needs are met by traditional biomass fuels (fire wood, agricultural residue and animal dung); fire wood accounts for about 75% of total energy. The remaining portion of energy (12%) demand is met by commercial sources and less than 1% from alternative sources in fiscal year 2008/2009 (Water and Energy Commission Secretariat 2010).

Collection of fire wood from nearby available forests is generally a daily responsibility for rural women. Lack of transportation leads women to carry heavy loads on their backs often over several kilometres. Heavy work every day for prolonged periods is associated with the development of pelvic organ prolapse. A study by BSP conducted in 1992 estimates that almost 75% of rural women and a large number of children, mostly girls allocate 20% of their work time to collecting firewood (Bajgain and Shakya, 2005).

#### **2.6.1.4 Electrification**

Nepal has the potential to generate huge amounts of energy from hydropower projects. The country however at present was only able to produce less than 650 Mega Watt (MW) of electricity. The Government adopted Hydropower Development Policy of 2001 aimed at attracting local and foreign investment. The objectives were to generate electricity at low cost by utilizing water resources, to link electrification with economic activities, to render support and develop the rural economy and to develop hydropower as an exportable commodity. The targets for 2017 were to develop hydropower electricity up to 2,035 MW

to meet the projected domestic demand. The Integrated Nepal Power System will achieve electricity supply to 50% of households, 12% by isolated (Micro) hydro systems and 3% by alternative energy with a per capita electricity consumption of 160 Kilo Watt (KW). These improvements are expected to solve social problems by eliminating poverty and improving the quality of life (Sovacool et al. 2011). Unfortunately the scheme was delayed by the sudden and devastating effects of earthquakes and an unstable government.

#### **2.6.1.5 Transportation**

In Nepal, road transport has a major role and has been a priority in order to gain the overall development and socio-economic transformation. There are 15 National Highways and 51 feeder roads totalling 8000 km. The government plans to increase the length to 12000 km by the year 2017. Still Nepal has a very low road density of 6.39 km per 100 sq km indicating poor accessibility to various parts of the country. As most of the rural land transportation in the mountain and hilly regions is affected during the rainy season, air transportation though costly has been a major transportation system option. Across the country, 47 airports operate with schedule flights (Gairhe 2013).

#### **2.7 Education for girls and women**

Illiteracy has historically been a challenge for Nepal. The Government emphasized the importance of early childhood development (ECD) and pre-primary education (PPE). Nepal has made excellent progress in primary education: from just 64 percent in 1990, the net enrolment rate (NER) at primary level reached 95.3% in 2013 (Nepal Millennium Development Goals 2013). The problem of illiteracy was found to be worse among women; according to a study in 1997 only 15-20% of the women could read and write (Skar and Cederroth 1997). The NDHS report shows, irrespective of efforts to increase literacy levels by mutually acting, both from the Government and non-government sectors, the adult literacy rate, for the population aged 15 and older is just 63% and the gap between women and men illiteracy is wider still. In rural areas 47% of women and 26% of men have no education as compared to urban areas where 35% of women and 17% of men have no education. (NDHS 2016).

Girl's education has always been a serious concern in Nepali society. The girl from the under-privileged community, because of poverty, will not get the opportunity either to go to school or continue her education at secondary level. Gender parity remains in favour of boys at the

secondary level. A girl's responsibility is rooted in daily household tasks as she is expected to assist in the rearing of younger siblings, fetch water and collect wood for fuel. The concept of spending money, as an investment, on girls who will leave home after marriage is still met with strong disapproval (UNESCO 2013).

People in Nepal are becoming more aware of the power of education and are trying to improve education levels. According to a recent study by the Ministry of Education, female literacy rate in 2013 has increased to 47% from 37% since 2009 (Ministry of Education, 2013). Government and various non-governmental organisations are making efforts to improve literacy levels. Women, when educated, bring more changes to education levels in the family. Improved literacy in women is seen as more likely to improve youth employment which can be an effective measure to reduce poverty in the family. This further enables the necessary changes in the health status of the family and community. Access to education is a means to reduce gender inequalities and to improve overall health status. The focus on girls' education continues to be the single most effective measure to reduce poverty (Country strategy for development cooperation with Nepal 2014; World Bank Report 2000).

## **2.8 Health education in schools**

Health education in Nepal is provided from the basic level of school education in order to reduce morbidity related to a lack of knowledge of various types of communicable and non-communicable diseases. Primary level education (grade 1-5) includes personal hygiene, environmental sanitation, food and nutrition, disease prevention and first aid, health services and the impact of smoking and narcotic drugs. The objectives are: to develop positive attitudes to personal hygiene; the hygienic environment of home; school and community; to adopt preventive measures for communicable diseases; to make a habit of selecting nutritious food; to adopt safety measures in daily activities; utilise health services available in the community and realize the bad effects of narcotic drugs and smoking (Ministry of Education and Sports 2008).

## **2.9 The health care system**

The Ministry of Health was established in 1956 and its first priority was to control communicable diseases. Four major vertical projects were initiated at the beginning, namely Malaria Eradication (1958), Leprosy and Tuberculosis Control (1965) and Small Pox Eradication (1967). The family planning programme was converted into the family planning

and maternal child health hoard in 1968. Following the eradication of small pox the immunisation programme was expanded in 1977 (Rai et al. 2001). The ministry underwent a major reorganization in 1987; all vertical projects were integrated under the public health division. Simultaneously, five regional health directorates and 75 district public health offices (DPHOs) were established.

### Organogram of Department of Health Services (DoHS)

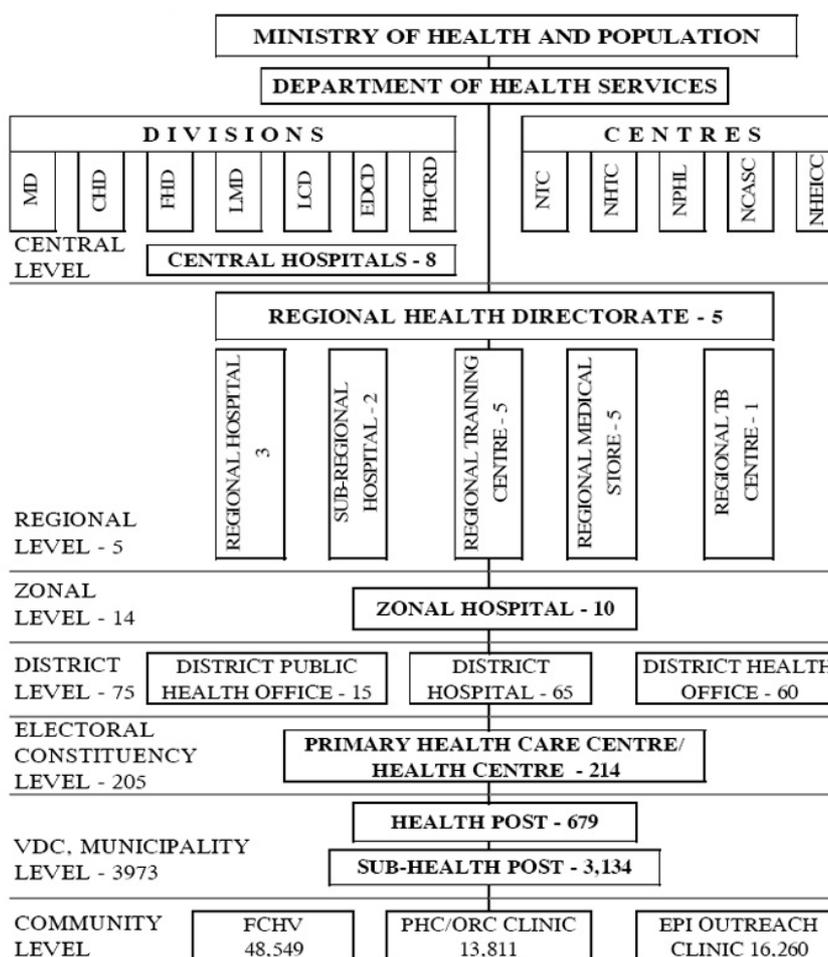


Figure 2.2: Organogram of DoHS, Reference taken from DoHS Annual Report 2012/13

The curative health services including POP management are provided through central, regional, sub-regional and zonal hospitals. The activities chiefly directed to inpatients, are carried out under the direct supervision of medical doctors and include: services of medical

and paramedical staff, services of laboratory and technical facilities, including radiologic and anaesthesiology services, emergency room services, provision of operating room services, services of family planning centres, pharmacy services, food and other hospital services, with accommodation. There are a total of 10 central level hospitals, 5 regional and sub-regional and 10 zonal hospitals in Nepal. Figure 2.2 presents the detailed organisational structure of the Ministry of Health. The list of central, regional and zonal hospitals will be presented in appendix 12, tables 2, 3, 4 and 5.

The primary health care and other services provided by vertical projects are delivered through health posts. In 1991 there were 816 health posts managed by DPHOs with a staff of three to five professionals. Under the 1991 health policy it was decided to create a new tier of sub-health posts to improve health care, each was staffed by a female maternal and child health worker, auxiliary field worker and a village health worker (Rai et al. 2001). Difficulty in getting access to the hospitals due to various reasons means that most of the citizens living in rural areas depend for healthcare upon the primary health care services.

The outreach services are delivered in rural areas through village health workers (VHW) and female community health volunteers (FCHV). VHW are field based staff who are trained for 90 days in PHC. They conduct household visits, provide basic treatment and medicines, keep a good record of pregnant women and all children under five, provide tetanus toxoid injections for pregnant women, make referrals when necessary and provide health education. They motivate communities for family planning. The FCHV are mainly involved in motivational aspects of health provision, delivery of first aid services and resupply of contraceptive pills and condoms within their ward of residence. FCHV are trained for 24 days at DPHO. They work under supervision of village health workers and health post staff. They are expected to promote and utilize the services and encourage the adoption of preventive health practices through mothers groups. Married women able to read and write are eligible for the post (Acharya and Cleland 2000).

### **2.9.1 Human resources for health (HRH)**

The overall sectorial policy planning and management of health care in Nepal is prepared and regulated by the Ministry of Health and Population (MoHP). Under the MoHP, the Department of Health Services (DoHS) coordinates all administrative activities of health service delivery under its administration department in Nepal, such as logistics, training,

public awareness and quality enhancement. The MoHP manages officer level recruitment, while the Regional Health Directorate (RHD) manages below the officer level. In the health sector, the Public Service Commission (PSC) recruits all levels of health staff and the department, regional and district authorities of the MoHP are responsible for their deployment (Karki, 2012).

### **2.9.2 Private hospitals**

There are all together 301 private hospitals in Nepal. Central Bureau of Statistics (CBS) (2013) report identified that 214 are private, 54 are community and 33 others. Though private hospitals aim to provide easy access for the general public, the CBS report shows that these hospitals have been established mostly in major urban or urbanising areas. The health services in deprived rural areas have not benefitted much by the privatisation of services. According to the ecological belt distribution the greatest number of private hospitals are in the Hill region (148), followed by the Plain region (144) with fewest in the Mountain region (9) (Central Bureau of Statistics 2013). The list of major district NGO Hospitals is presented in appendix 12, table 6.

### **2.9.3 Medical colleges**

There are a total of 19 medical colleges in Nepal. Like other private hospitals, most of the medical colleges are also established in urban and urbanising areas. Besides the National Academy of Medical Sciences, Patan Academy of Health Sciences and B.P. Koirala Institute of Health Science, there are eight medical colleges each under the affiliation of Tribhuban University and Kathmandu University (Nepal's Medical Colleges 1013). The list of medical colleges in Nepal is presented in appendix 12, table 7. There are approximately one thousand doctors produced in Nepal every year. In order to provide the secondary and tertiary medical care services and medical education, many private medical colleges were established in different parts of Nepal including some of the rural areas making access easier for the general public. As community health programmes are a part of the medical programme, the medical college focus on preventive as well as curative health compared with other private hospitals.

## **2.10 Health financing system in Nepal**

The Government of Nepal, community based health insurance and households use different ways of paying for health service use. There is no perfect provider payment mechanism available in Nepal. Government funds are mainly allocated to public providers. The

Government of Nepal pools funds from various financing sources (tax and non-tax revenue, and pool funds from external development partners) and pays providers (hospitals, health posts, sub-health posts, primary health care facilities, etc.) through the health sector budget managed by the MoHP (the main financing agent), mainly on historic basis. Only about more half of the resources (53%) for health are pooled by Nepal's health financing system. Non-pooled resources consist mainly of out-of-pocket expenditure; under this method of payment every patient has to pay their own expenses with no support from others to mitigate the financial risk. The WHO estimated that total health expenditure in Nepal reached 6% GDP in 2013 compared to 5.8% of Nepal's GDP, around \$25 per capita in the year 2009, of which out of pocket expenditure represented approximately 47% of the total health expenditure. In Nepal, the Government capacity to regulate unfair pricing is weak. This prevents people from accessing health service as they cannot afford prices established by the market. In order to improve the access to health care there is a need to design a mechanism to reduce out-of-pocket expenditure and to generate the financial resources in a prepaid manner so that no direct payment is required at the time of service utilisation (Ministry of Health and Population HSSP 2012).

In order to provide primary health care as fundamental right, the Government of Nepal introduced the provision of free health service programmes through district level health facilities from October, 2007. The aim was to promote utilisation of basic health services particularly within the reach of poor and excluded groups. The policy was implemented in January 2008 through existing health facilities financed by the Government resources. During 2008/9 period, basic health services were provided to the general public through 100 government hospitals, 207 Primary Health Care Centres (PHC), 679 Health Posts (HP) and 3,114 Sub Health Posts (SHP). Primary health care was also provided by 14,366 Primary Health Care Outreach Clinic (PHC/ORC) sites. These services were further supported by 48,604 Female Community Health Volunteers (FCHV) (Central Bureau of Statistics 2008).

Under the free health service scheme, the Government of Nepal provides up to 40 essential medicines free through district level health facilities. The Logistic Management Division under the Department of Health Services (DHOS) is responsible for procurement and distribution of drugs throughout the country through its service outlets. Currently, there are central and district level drug procurement and distribution arrangements. The drug availability in health facilities include contraceptives, maternal and child health

commodities, and selected essential drugs after the implementation of the free health care policy (Department of health Services 2014). However, barriers are emerging following the implementation of free health services related to the sustainability of the programme and the maintenance of the quality of care due to financial and human resource constraints.

### **2.11 Maternal health services**

Maternal morbidity and mortality is a huge concern in Nepal. According to 1996 Nepal Family Health Survey (NFHS), the maternal mortality ratio (MMR) was 539 per 100,000 live births. Around three quarters of maternal deaths were due to direct obstetric causes because of haemorrhage, sepsis, unsafe abortion, obstructive labour and hypertensive diseases, two thirds occurred after delivery, and about one third occurred during pregnancy (Family Health Division 1996).

High levels of maternal mortality and morbidity in developing countries including Nepal are partly due to the non-availability of services and partly due to poor utilisation of health services. The poor utilisation of health care also depends on socioeconomic and demographic factors. To address these issues, the Government of Nepal drafted a National Safe Motherhood Plan of Action for the period 1994-1997 and launched its Safe Motherhood Programme (SMP) in 1997. It was recognised as a priority programme in Nepal for the period of five years (1997-2002). Various interventions like Clean Home Delivery Kits to reduce maternal and neonatal sepsis and tetanus were being mass produced for purchase by families at an accessible price, National Maternity Care Guidelines had been published, IEC materials developed and printed to improve the utilisation of maternal health care during that period. The National Safe Motherhood Plan (2002-2017) formed a basis of the current Safe Motherhood and New Born Health Long Term Plan.

With a sense that the SMP had yet to be effectively launched, the Government of Nepal launched the Aama Surakchha Karyekram (within Safe Motherhood Programme) that includes two components: the safe delivery incentive programme (initiated in 2005) and free delivery service (initiated in January 2009). The safe delivery incentive programme provides; (a) cash payment to women who give birth in a public health facility; (b) exemption from user fees, the transportation fare for those residing in the least developed one third of districts; and (c) a financial incentive to the health workers for providing the delivery service.

The results of 2006 Demographic and Health Survey indicate that MMR has been reduced to 281 per 100,000 live births, which was still more than double the target (Ministry of Health and Population 2006). Targeting to reduce MMR to 134 per 100,000 live births by 2015, the policy of Skilled Birth Attendants (SBA) 2006 was initiated by the government. The goal was to reduce maternal and neonatal mortality and morbidity by ensuring availability, access and utilisation of skilled care at every birth. A SBA can be doctor, nurse or ANM working in the field of MCH. The World Health Organization (WHO) defines a SBA as:

*'An accredited health professional such as a midwife, doctor or nurse who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate post-natal period, and in the identification, management and referral of complications in women and newborns'* (WHO, 2005).

Starting in 2009, the government of Nepal has been implementing the "free delivery service" which includes free delivery care for uncomplicated, complicated and caesarean section births at all health facilities capable of providing these services, including all public health and a number of private facilities across all 75 districts (Ministry of Health and Population 2012).

### **2.11.1 Effect of financial incentive on maternal health**

A World Bank study for MoHP (2006) demonstrated that the cost of emergency obstetric care is a major barrier to access to services. These findings became the subject of policy interest and policy concern around SBAs. A key component of the government effort in maternal health is to increase the coverage of women who deliver in the presence of a skilled health professional so that complications are recognised in time and managed properly. The Government of Nepal introduced the Safe Delivery Incentive Programme (SDIP) in 2005 which has been explained above. Poor individuals have a low demand for health care. To increase the demand and use of services the health facilities must be available and accessible to people. This programme was initiated to bring change in health seeking behaviours. SDIP is targeted towards poorer families. Utilisation is the key to health service and immunisation coverage (Department of Health Service 2006).

The goal of SDIP is to reduce maternal mortality and morbidity in line with the Government of Nepal's commitment to the Millennium Development Goals (MDG). Karki studied the

impact of SDIP in the Karnali district of Nepal and found that maternal health service utilisation increased due to SDIP. There has been a substantial increase in the proportion of women giving birth under the assistance of health workers and SBAs. The delivery by health workers increases from 18 percent in 2005/6 to 46 percent in 2010/2011 and delivery by SBAs increased from 15 percent in 2007/8 to 31 percent in 2020/2011 (Karki, 2012). Increase in the number of SBA is expected to improve outcomes for women. Government of Nepal set targets for the number of births with skilled attendants to rise to 60% by the year 2015 (Ministry of Health and Population 2012).

SDIP was also found to be positively associated with quality care in hospitals and primary health care centres. In resource poor settings, inappropriate health infrastructures and low quality of care will impede the success of SDIP. The magnitude of the effect of SDIP depends on the extent of its area of implementation. Though there is limited coverage of the programme related to awareness and implementation, service utilisation increased by 4 percent as a result of SDIP (Jackson and Hanson 2012).

## **2.12 Family planning services**

The utilisation of family planning services is indirectly associated with maternal morbidity. The family planning programme in Nepal was started in 1959. Initially the services were centred on Kathmandu and only limited services were available in the peripheral regions. His Majesty's Government began providing family planning services integrated with maternal and child health (MCH) activities in 1965 and in 1968. The government established a semi-autonomous family planning and MCH Board under whose umbrella the Nepal Family Planning and Maternal Child Health Project was established (Regmi 1997).

The Nepal Family Planning and Maternal Child Health Project established clinics in district health institutions all around the country. It was soon realised that the expansion of family planning services would be limited if the services were restricted to health institutions. The family planning services were integrated with health services and are available at all the government health institutions. In the early 1990s, the Government decided to operate sub-health posts at the VDC level, to ensure that each VDC would have at least one health institution. There has also been a tremendous increase in the number of International Non-Governmental Organizations (INGO) and Non-Governmental Organizations (NGO) providing basic family planning services in Nepal.

Though the family planning service is integrated within a general health system of Nepal, there are still some groups of people whose family planning needs have not been met yet. The unmet family planning need is high among married adolescents, residents of rural areas, hill and mountain regions and certain ethnic groups (Shrestha et al. 2012). There is a great need to improve access to meet the family planning needs in the rural areas. Currently, temporary family planning methods (male condoms, pills and injectable contraceptives like Depo Provera) are provided free of cost on a regular basis through health posts, sub health posts, primary health care clinics, periphery level health workers and volunteers. Further discussion on different factors related to reproductive morbidity will be presented in literature review chapter.

### **2.13 Millennium Development goals (MDGs) and Nepal**

In September 2000, the United Nations implemented the MDGs to reduce poverty and improve social development by 2015. Nepal has committed to the policies in achieving the MDG's. By the end of year 2015 most of the targets were achieved, some were partially achieved and some were unfinished.

Nepal has made good progress on reducing extreme poverty (Goal 1) within MDG period. The extreme poverty dropped from 33.5% to 16.4% by the year 2013 thereby achieving the target. In universal primary education (Goal 2), the net enrolment ratio improved to 96.6 and the literacy rate (15-24years) to 88.6%. However, educational disparities still persist. Though the performances of girls are better than boys, the girls drop out of school early due to socioeconomic reasons. The final status report stated that the share of women's engagement in wage employment increased to 44.8% irrespective of gender inequality. Nepal fully achieved the targets under MDG 4, the infant mortality rate reduced to 33/1000 live births, under 5 mortality rate reduced to 38/1000 live births. However, Nepal could only partially meet Goal 5, reducing MMR and other reproductive health indicators. MMR reduced to 258 in 2015. The reduction in MMR was associated with a fall in fertility rate, increased use of maternal health service and contraceptives. The unfinished agendas need be addressed in the planning and implementation of the Sustainable Development Goals (SDGs) (Nepal and the Millennium Development Goals 2016).

## **2.14 Summary**

The aim of this chapter is to provide an important contextual and cultural background to the different factors responsible for the development of POP. An introduction to the three geographical regions presents the context within which the study was carried out. The socioeconomic picture together with infrastructure underpins the challenges women face when determining and seeking health care and offers insight into why Nepalese women often suffer for prolonged periods that may affect their QOL following POP. The health care system information provides an important understanding of the care contexts within which women's health is managed. The MDGs portrayed within reach are those of elimination of extreme poverty, improvement education and health in Nepal. Additional discussion on POP, its magnitude, management and QOL related issues will be presented in the following literature review chapter.

## Chapter 3: Literature review

### 3.1 Introduction

POP has been widely researched regarding its aetiology, assessment and management. For a comprehensive search on POP and its management different online resources were accessed. These included PubMed, Medline Plus, Google Scholar, Hinari and WHO webpages. Key words, phrases, topics of choice and subject headings were utilized in the search. Over a thousand articles were searched and 314 were referred to in this study. The results were refined by limiting the time frame to literature from 1973 to 2014. Most of the literature identified and used was between 2000 to 2014. This chapter starts by presenting the context for reproductive morbidity in low-income countries. The literature shows the magnitude of POP worldwide and in Nepal. The development of POP in Nepalese women is explained. This is followed by an explanation of symptoms, different approaches to assessment and available modes of management in order to critique the intervention strategies. The policies in relation to existing literature on medical paternalism co-relating to government policy on POP management are presented. Health seeking behaviour is then critiqued from a professional decision making standpoint. QOL is explored through the literature on current clinical management. This chapter ends by discussing practice development and its role in attaining person-centred care.

### 3.2 Reproductive morbidity in low-income countries

Reproductive morbidity reflects the relationship between illness, the reproductive system and a women's status. A WHO working group defined reproductive morbidity as

*"Any morbidity or dysfunction of the reproductive tract, or any morbidity which is a consequence of reproductive behaviour including pregnancy, abortion, childbirth or sexual behaviour and may include those of a psychological nature" (WHO, 1989: p.2)*

Three categories of reproductive morbidity and its subcategories were distinguished: obstetric morbidity (i.e. direct, indirect and psychological maternal morbidity); gynaecological morbidity (i.e. direct, indirect and psychological morbidity of the reproductive system, including sexually transmitted diseases); and contraceptive morbidity

(i.e. local and systemic morbidity caused by modern or traditional fertility regulation). Reproductive ill health accounts for 33% of the total disease burden in women as compared to 12.3% for males (WHO 1995).

Maternal mortality lies within obstetric morbidity and Nepal has been facing challenges related to maternal morbidity and mortality for many decades. The National Reproductive Health Strategy for Nepal was elaborated in 1996 to facilitate the implementation of the Cairo Action Programme within the existing health care system (Department of Health Services 1996). Eight important components were outlined. Reduction of maternal mortality ranks first on the international public health agenda and this issue has become a priority in many low income countries including Nepal. MMR reflects the status of women, their access to health care and the adequacy of the health care system in responding to their needs. In a country like Nepal, statistics of MMR and other related reproductive morbidity go beyond measuring levels i.e. 539 per 100,000 live births (Department of Health Services 1996). They are considered to represent only the 'tip of the iceberg' suggesting that a much greater number of women suffer from reproductive morbidities.

### **3.2.1 Women's position in Nepal**

Nepal is a patriarchal society and all institutions ranging from education to the legal system and even health services are strongly influenced by these norms and values. Men are considered as the primary decision makers in the family in Nepal. Generally Nepalese women have three main responsibilities: reproduction and child bearing, house hold maintenance and income generation (Radl et al. 2012). Following marriage, a daughter-in-law is expected to perform domestic duties under the supervision of her mother-in-law. The mother-in-law is considered to be the primary decision maker in matters relating to child rearing and health care of the family (Dali et al. 1999). The traditional roles within decision-making prevent women coming forward with health problems. Research on women's autonomy in decision-making on health care, and its determinants in 3 South Asian countries i.e Nepal, Bangladesh and India, using nationally representative surveys showed that 72.7% of women's health care decisions were made without their participation in Nepal (Upul and Gunawardena 2009).

In Nepal, female children are discriminated against from early childhood, and this continues into their adult reproductive life and beyond. Discrimination in feeding and use of health

care for women is influenced by the culture which results in female malnutrition. The National Demographic Health Survey showed that 18% of women of reproductive age are undernourished with body mass index (BMI) < 18.5 kg/m<sup>2</sup>. The survey results also showed that 35% of women of reproductive age, between 15-49 years, are anaemic (Ministry of Health and Population 2011). Malnutrition is a major risk factor for poor birth outcomes in Nepal.

The power imbalance between the mother-in-law and daughter-in-law in matters relating to childbirth is most prevalent in rural areas. Simkhada et al. (2010) in their qualitative study on the role of mothers-in-law in antenatal care decision making, found that with some slight exceptions the influence is mostly negative. This is due to their lack of education, the prioritisation of household duties, their reliance on their own past experiences rather than evidence-based practices, scarcity of resources and the power relation between mother-in-law and daughter-in-law (Simkhada et al. 2010). Though the younger generation is more aware of the importance of care during pregnancy, delivery and after birth, they are not always able to convince the older family members of the need for such care. The older family members view birth as a normal, inevitable fact of a woman's life and therefore they see no need for special arrangements before, during and after delivery. The fear of abandonment by family members leads women to hide their problems and live their lives in silence. These culturally embedded practices increasingly aggravate the situation for women with POP (Subedi 2010).

Furuta and Salway (2006) studied women's household positions when receiving skilled antenatal and delivery care under four indicators. The indicators were; 1) involvement in decision making about their own health care and about large household purchases, 2) their employment, 3) their control over their own earnings and 4) their discussion of family planning with their husbands. Only 25% of women reported being involved in final decisions either alone or with others regarding their own health care. The majority of women involved in final decision making on health lie in the over 35 age group. A woman's position in the household is highly related to the use of health care services and women's secondary education was also strongly associated with the greater use of health care (Furuta and Salway 2006).

### **3.2.2 Early marriage**

Early marriage is still culturally accepted in Nepal. The country's laws allow marriage after 16 years with consent from the parents and 18 years without parental consent (Country Profile Nepal 1985). Irrespective of law a large proportion of Nepalese women get married before the age of 15 and the majority of them give birth before the age of 20; this, according to Aryal (2005a) ranks Nepal highest among Asian countries for early marriage and childbearing (Gubhaju 2002; Aryal 2005a). Data from a sample survey conducted in the Palpa and Rupendehi districts in rural Nepal show the median age of marriage to be 17 years. The median age at marriage, according to educational attainment was 16 years in the uneducated group and 19 years when educated to intermediate level (Aryal 2007). A statistical exploration of early marriage in South Asia in the year 2005 evidenced 48% of young women was married before age of 18 (UNICEF 2005). Early marriage is considered as a family norm and presided over by culture and religion.

Low socioeconomic conditions are responsible for the increased incidence of early marriage. Such low socioeconomic conditions are also associated with low levels of literacy, low self-esteem of girls and unemployment along with early marriage, early childbearing, less contraceptive knowledge and use, sexual abuse and assault (Bajracharya and Amin 2012). The age of marriage is negatively related to fertility. Women who marry early are more likely to have their first child at a young age and give birth to more children because of a longer exposure to the risk of pregnancy and childbearing thus overall contributing to the development of POP (Dangal 2006).

The cultural of early marriage and early childbearing have a tremendous influence on the occurrence of POP. The underdeveloped pelvis in younger adolescents leads to more difficulties in childbirth when compared to adults or mature adolescents with more fully developed bone structures (Patchauri 1986). There is, therefore, a higher chance of complications related to pregnancy and delivery, such as obstructed labour and its sequels, vesico-vaginal fistula (VVF) and POP in these young adolescents (Dangal 2006).

### **3.2.3 The need for sons**

Nepal has been classified as having considerable levels of son preferences since the world fertility surveys first documented the phenomenon in 1980. Though daughters are desired,

sons are very highly prized because they continue the family name, can perform funeral rituals and are expected to provide support in old age (Karki, 1992).

Though Nepal has multiple cultures and religions, the majority of people follow Hinduism. Hinduism suggests a religious preference for the son. Basu et al.'s study suggests that Hindu families are more likely to target sons than are non-Hindu families. (Basu et al. 2010). The utility of having a son also arises from the important religious functions that only sons can provide, though both sons and daughters are required to perform certain religious functions (Dharmalingam 1996; Leone et al. 2003). For some of the ethnic groups sons are of value because of the cultural sanction of bringing economic reward during marriage. The marriage of a son provides additional household help from the daughter in law as well as economic reward in the form of dowry payments (Dharmalingam 1996).

Though women are not responsible for determining the sex of a child people blame women for not giving birth to a male child. Women are only accepted by their husbands, family and society after giving birth to a boy (Radl et al. 2012). The impact and determinants of sex preference in Nepal was studied by Leone et al., where they expressed a view that having a son is fundamental to being accepted by the community. In rural areas the only certainty that women are likely to have is after having a son (Leone et al. 2003). To gain acceptance, women keep on giving birth irrespective of the problems which are associated with childbirth. Yamaguchi defined the stopping rule: couples continue child bearing until they reach their desired number of sons (Yamaguchi 1989).

### **3.2.4 Access to health care**

There is no universally accepted definition of access to health services. Peters et al. (2008) mentions it as the timely use of service according to need. Donnel categorized an access in four dimensions: availability, geographic accessibility, affordability and acceptability (Donnel 2007). According to the institute of medicine, access to health care in America is a term for a broad set of concerns that centre on the degree to which individuals and groups are able to obtain the necessary services from the medical care system. Access to care and barriers to care are often used interchangeably. Barriers to care provide targets for policy intervention. Barriers may be at the level of the individual, their social environment or at the health care organization level (Albrecht et al. 2000). The Nepal in context chapter further elaborated the higher barriers to health care in rural areas.

### **3.2.5 Health seeking behaviour**

Karkee et al. (2013) reported that despite the Government's serious commitment to deliver maternity services in public health facilities, their utilisation is still very low in rural areas (31.6%) compared to urban areas (71.3%). Following a review of 21 articles from Nepal they identified factors that affected the use of delivery facilities in rural areas and impeded women from utilising maternity services. They placed these factors under four headings; socio-cultural, perceived need/benefits of skilled attendance, physical accessibility and economic accessibility (Karkee et al. 2013). This is similar to the Donnel's four dimensions of access. Karkee et al.'s review stated that traditional belief and customs, low status of women, long distance to facilities, low levels of health awareness and women's occupation tended to impact negatively on service uptake (Karkee et al. 2013). Shaikh and Hatcher's study in Pakistan on health-seeking behaviour also supports Karkee's findings. Shaikh and Hatcher divided the causes for poor utilization of primary health services into poor socioeconomic status, lack of physical accessibility, cultural beliefs and perceptions, low literacy levels of the mothers and large family size (Shaikh and Hatcher 2005).

The factors affecting the use of delivery facilities in Nepal were also studied by Wagle et al. (2004) and Baral et al. (2012). Both studies explored utilisation of maternal health services depending upon the socioeconomic status of women and geographical location. According to Wagle et al. (2004), socioeconomic standing of the household was a strong predictor determining the place of delivery, and a distance of more than one hour, low education, multi-parity, early marriage and not seeking antenatal care in the present pregnancy were associated with a high risk of home delivery. Geographical diversity as mentioned in chapter Two, hill and remote mountain locations make access extremely difficult. Transportation facilities in rural areas are very limited because of the harsh terrain (Wagle et al. 2004). Baral et al. (2012) suggested that the government should give priority to women from lower socioeconomic groups by providing different community interventions, establishing more health facilities in remote areas, and improve access to the facilities. However, these suggestions, whilst valid and essential elements, to improve of access to health, have not been taken as a priority by the government. As Donnel (2007) mentioned the singular element of the availability of health service is not enough to improve health care, other elements (physical accessibility, affordability and acceptability) need to be addressed too.

A study in Bangladesh showed that rural, younger, poorer and less educated mothers were significantly less likely to seek antenatal, delivery and postnatal care compared to their counterparts in Bangladesh who were women living in urban areas, older, wealthier and better educated (Anwar et al. 2008). A project on maternal schooling and reproductive change in Mexico, Nepal, Zambia and Venezuela showed associations between women's schooling and changing levels of child survival and fertility. Several factors such as older age at marriage, more frequent use of maternal and child health services and contraception, greater exposure to public health as well as family planning messages in the mass media have been shown to improve health in educated mothers (LeVine et al. 2004). A study conducted in Nepal on education and its association with the utilisation of health services found that education is positively associated with maternal health service utilisation. Women who had completed higher secondary level were found to have greater decision-making power in relation to health issues (Acharya et al. 2010; Sharma et al. 2007).

Kyomuhendo (2003) found that education alone may not be sufficient to improve health care seeking behaviour. Despite education and decentralization of health services there has not been an increase in the utilisation of emergency obstetric services by women in Uganda. Women's care seeking behaviour is not simply the result of individual preferences but conditioned by community poverty, norms and traditions (Kyomuhendo 2003). This view is supported by Jejeebhoy and Sathar (2001) who mentions that autonomy is not enhanced by education if traditional factors remain strong in the community. Furthermore Futura and Salway's study stresses that financial and geographical accessibility of the services are not the only important factors in utilisation of health care; but women's position in the household, led by educational attainment, also play an important role in health care uptake in Nepal (Futura and Salway 2006).

Hogen et al. (1999) argued that paid employment raises women's economic status and empowers them to make decisions about their health. Employment increases awareness and provides new ideas, behaviour and opportunities through interaction with other people outside home and community (Hogen et al. 1999). But, Futura and Salway (2006) reported that there is no correlation with employment and use of health care systems in Nepal. Most of the women who work belong to poor families in rural areas and work to sustain the family with no control over the use of their earnings. Working women are less likely to receive maternity care because of time constraints that reduce their opportunities more significantly

than those who do not work in rural areas. However, those who were working in the service sectors were found to utilise maternal health care more (Futura and Salway 2006).

From the literature it is clear that use of health care facilities is strongly linked to the position of women in the family. In order to improve the women's status and to change the dominant patriarchal culture, education is a means for empowering women. If empowered, they have better communication skills and where they don't have knowledge they will be able to find out from others and make decisions for their own health and family. Educated women will use obvious means to influence family decisions. Thomas concluded that women with better comprehension skills may be better able to access and assimilate information in the community. They are likely to be better informed than their peers and therefore better able to use community services effectively (Thomas 1999). The reproductive health indicators related to empowerment include the ability to decide when to get married, when to have children, and being able to control the number of pregnancies and births. Utilisation of maternal health services and empowerment of women are closely associated with the prevention of POP.

### **3.2.6 Family planning service utilisation**

Family planning is a priority programme of Nepal. However, according to a UNFPA report only less than half of married women of reproductive age use any family planning methods. Additionally, 26% of rural women want to time or space their pregnancies, but have an unmet need for family planning. This unmet need for family planning in Nepal is higher among women with low income and living in the most remote areas (UNFPA 2010). However, the report does not mention the reasons behind these unmet needs irrespective of the provision of family planning services being free of cost in all government health centres in Nepal. Unmet need may be either due to difficulties in accessibility or acceptability of the family planning service by women living in rural areas.

A study exploring family planning service uptake indicates that the influence of couple discussions on contraception is limited. Women seem to adopt other women's choice of contraception in the community. However, couples do discuss the adoption of family planning in Nepal (Sharan 2002). Family planning discussion in a couple depends on the age and the number of children. Women having fewer children and those in the early reproductive age group were less involved in the decision making than those women who

had more than two children and were of the mid reproductive age group (Furuta and Salway 2006). The poor utilization of family planning services by women increases the probability of giving birth to many children which is likely to effect the prevalence of POP.

### **3.3 Magnitude of POP**

POP is one of the enduring major reproductive morbidities that affect women worldwide. The problem of uterine prolapse has been described in the oldest documented medical literature, the Egyptian Papyri, where it is written:

*“Of a woman whose posterior, belly, and branching of her thighs are painful, say thou as to it, it is the falling of the womb”* (Kahun papyrus ca. 1835 B.C.E.; Cited by Downing, 2012 p. 1).

The global prevalence of POP is estimated to be between 2-20% (WHO 1995). The mean prevalence of POP was 19.7% in the Indian subcontinent (Walker and Gunasekera 2011). In a report on a women’s health initiative, 41% of women age 50-79 years showed some degree of POP in high and low-income countries (Hendrix and Clark 2002). POP is the leading indication for hysterectomy in post-menopausal women and accounts for 15-18% of procedures in all age groups (Kesharvarz et al 2002). In the United States, data presented in 2001 identified that on average 200,000 women undergo surgical repair for prolapse each year (Subak and Waetjen 2001).

#### **3.3.1 Causes for the development of POP**

Female POP is a common condition that is said to be multi factorial in aetiology. Jelovsek and Christopher (2007) mention clearly the established and potential risk factors for POP. The established risk factors are vaginal delivery, advancing age and obesity. The potential risk factors are other obstetric factors that lead to damage of the pelvic floor where there will be loss of vaginal or uterine support such as pregnancy, forceps delivery, and young age at first delivery, prolonged second stage and delivering a large baby vaginally. Some other potential risks are the shape of the bony pelvis, family history of prolapse, race or ethnic origin, occupation entailing heavy lifting, constipation, connective tissue disorder, previous hysterectomy and selective oestrogen receptor modulators (Jelovsek and Christopher 2007).

According to the Oxford Family Planning Study ‘increasing vaginal parity was the strongest risk factor for POP in women younger than sixty years (Mant et al 1997). Hendrix and Clark in the Women’s Health initiative mentioned single childbirth was associated with raised odds of uterine prolapse but every additional delivery, up to five births, increased the risk of worsening prolapse by 10-20% (Hendrix and Clark 2002). Incidence of POP increases with maternal age following menopause because of hormone deficiency. Lack of oestrogen weakens the structures and tissue that holds the pelvic organs in place, causing them to fall. The prevalence has been found to increase by 40% with every decade of life (Swift, 2006). In the women's health initiative, women in the USA age 60-69 years and 70-79 years had higher risk of POP than those of 50-59 years (Hendrix and Clark 2002). Women who are overweight (BMI 25-30; odds ratio 2.51, 95% confidence interval 1.18 to 5.35) or obese (>30; 2.56, 1.23 to 5.35) are at high risk of developing prolapse (Swift, 2003). Some evidence suggests that inherited or genetic factors can play a part in development of POP. The risk of POP was found to be 1.4 times higher in those with a family history of prolapse or hernia (McLennan et al. 2008; Lince et al. 2012).

### **3.4 POP and Nepal**

POP is one of the most widespread reproductive health problems in Nepal. A high prevalence of POP has been documented over the past thirty years in Nepal. About 600,000 women of reproductive age suffer from prolapse and among them 200,000 women are in need of immediate treatment (UNFPA 2007). A descriptive study on Reproductive Morbidity in Nepal showed one in four women reporting to clinics complained of POP. The prevalence rates in different parts of Nepal are presented in the appendix (Appendix 12 Table 1).

POP was commonly thought to occur in the postmenopausal stage of life following hormone deficiency (Swift et al. 2003), but research in Nepal shows that POP can occur at a much younger age and may present shortly after the first childbirth. In a study by UNFPA, 25% of POP was among women less than 35 years of age. The overall mean age of onset was found to be 27.9 years and mean duration of suffering was 7.8 years. Almost one in every third woman noted POP after their first childbirth; because of the tendency to return early to physical work. Women therefore become symptomatic for longer which hampers their quality of life over a greater time span (Gurung and Rana 2007; Dangal 2008; Pant and Joshi 2007).

### **3.4.1 Factors influencing the development of POP in Nepal**

The prevalence of POP has been found to be different in high and low-income countries. The literature from Nepal suggests that POP develops in early reproductive age groups (Gurung and Rana 2007; Dangal 2008; Pant and Joshi 2007). The factors that give rise to prolapse in Nepal in the early reproductive age groups are poorly understood, though the most significant factors associated with the onset of pelvic organ prolapse are child birth and heavy physical work, especially lifting heavy weights during the postpartum period (Bodner et al 2007).

#### **3.4.1.1 Childbirth**

Childbirth is regarded as an established risk factor in the development of POP (Jelovsek and Christopher 2007). During the delivery of the child, over stretching of the perineum may tear pelvic connective tissue and Levator muscle tissues causing permanent changes in the integrity of pelvic support, which leads to prolapse of all three compartments (Quiroz et al. 2010). One epidemiological study concludes that parity is the strongest risk factor for the development of prolapse. When compared with nulliparous women, the risk of prolapse from vaginal delivery was 8.4 times more likely for a woman having two children. Every additional delivery up to five births increased the risk of worsening prolapse by 10-20% (Mant et al. 1997).

Most of the studies confirm that vaginal delivery leads to damage of the pelvic floor and establishes a cause for POP. However, in relation to childbirth, a study by Handa and colleagues seems more applicable in the context of Nepalese women to establish reasons for the development of POP. Their study concluded that pregnancy and delivery contribute to pelvic floor injury through different mechanisms. At the time of pregnancy, compression and stretching play an important role in pelvic floor dysfunction. During delivery stretching, nerve injury, muscle tearing, connective tissue disruption or a combination of all or some of these contribute to pelvic floor dysfunction (Handa et al. 2010). The damage to the pelvic floor muscle and the nerve injury along with the heavy work women do soon following delivery, increases the intra-abdominal pressure which further stretches the pelvic floor before it heals completely. POP at an early reproductive age group for Nepalese women can be explained by these factors which makes the prevalence different from high-income countries. A study by Gurung and Rana (2007) found that early return to work, within a week following delivery, is a significant factor along with the early age of marriage,

unattended delivery, home delivery and incorrect bearing down efforts during labour. Additional reasons for increases in intra-abdominal pressure were excessive coughing, sneezing, climbing hills, the presence of mass in the abdomen and constipation (Gurung and Rana 2007).

#### **3.4.1.2 Heavy physical work**

Women in Nepal work an average of 11-16 hours a day, much higher than the global average, and 3.1 hours more than men (UNDP 2004). Housewives, who undertake substantial physical work, are more likely to have prolapse than professional /managerial women. The people with occupations in which heavy lifting is required, have a high chance of undergoing surgical procedures for pelvic organ prolapse (Chiaffarino 1999). Studies show that in rural Nepal, women's work burden is 12-22% greater compared to men's (UNDP 2004). Heavy lifting is a daily norm for the majority of women in Nepal. Agriculture is the most prevalent occupation of the women and with it comes a significant amount of heavy lifting along with daily activity. Repetitive heavy lifting increases intra-abdominal pressure and can cause considerable damage to structural tissues that suspend organs in the pelvic cavity and lead to POP development (Shrestha et al. 2009).

Women in Nepal typically do not alter their workload during pregnancy because of a common belief that work during pregnancy makes delivery easier. Women therefore keep working until immediately before labour (Shah 2010). Nepali women were found to resume work in the field and household duties soon after delivery. A study in Tribhuban University Teaching Hospital showed that 78.79% of the respondents worked one week after delivery (Shrestha et al. 2009). A study in Sirah and Saptari districts of Nepal demonstrated that 40% of the women start light working from 12-14<sup>th</sup> day following delivery and 26% of women start heavy work within 15 days. Lack of adequate rest after childbirth can aggravate the development of POP. A total of 37% of women with uterine prolapse mentioned that the cause of their prolapse was working hard soon after delivery and 32% said it was due to lack of care following delivery (Pradhan 2007). A recent study in Nepal by Thapa et al. identified that women who have taken rest for fewer than 42 days after delivery were more prone to develop POP than those who had rested for longer periods of time (Thapa et al. 2014).

### **3.4.1.3 Migration and workload**

Labour migration is a major livelihood strategy for many households in Nepal. Labour migration from Nepal rose significantly over a six year period from 219,965 in 2008/09, increasing annually to reach 521,878 in 2013/14 (Ministry of Labour and Employment 2014). Migration has both a negative as well as a positive impact on the family. The negative impact is related to the loss of manpower in the family where agriculture is the mainstay. When members of the family leave to work abroad it is expected that the work load will be redistributed among the remaining members of the household, especially the women. A study from China showed that migration leads to a decrease in the families overall work and local income, but an increase in agricultural work by women (Mu and Walle 2011).

A study by Maharjan (2010) related to migration in Nepal showed that when the remittances are high; the migrants' households demonstrated a reduced priority in agriculture. The tendency was for the household to increase leisure time in the family, this was more marked in males than females. Therefore, when the remittances are high, physical workload reduces among the household members. However, when the remittances are low, the migrants' households continue to give priority to the agriculture sector despite migration. This pattern leads to an increased work load on those left behind. Work load is gender biased, with women taking a higher share compared to men (Maharjan 2010). Hence, the workload of women remains high even with the improved economy of the family. However these studies do not mention subjective wellbeing following the migration of the male population. Gartaula and colleagues in their study in Nepal regarding wellbeing of the women left behind in migrant households, mentioned that additional income from remittances increased their objective wellbeing by improving living conditions, education, health and insurance against sudden expense, but it may not have increased their subjective wellbeing (Gartaula et al 2012).

### **3.5 Effects of POP**

Many parous women have some degree of POP but this rarely results in severe morbidity or mortality, rather it causes symptoms that affect women's daily activities and QOL (Jelovsek and Christopher 2007). Davis and Kumar suggests that although rarely life threatening, the symptoms are embarrassing and if left untreated can precipitate social isolation, sexual inhibition, restricted employment and leisure opportunities, and potential loss of independence (Davis and Kumar 2003).

Women with prolapse suffer many physical symptoms ranging from mild to severe and include bulge, pain, urinary, bowel and sexual symptoms (Barber 2005; Mouristen 2009). Ellerkmann and colleagues assessed 237 women for pelvic organ prolapse and noted 63% with bulge symptoms, 73% had urinary incontinence, 86% urinary urgency or frequency, 62% voiding dysfunction and 31% faecal incontinence (Ellerkmann et al. 2001). Though Ellerkmann et al. mentioned the symptoms separately among 237 patients, the symptoms may present in any combination which can be difficult to predict for the patients. Symptoms originating from one anatomical area are likely to affect other pelvic organs or areas. Women are likely to present with a combination of pelvic floor problems including bulge, pain or discomfort, vaginal laxity, voiding dysfunction, faecal incontinence and sexual dysfunction because of shared relationships of the physiological mechanisms involved in maintaining normal pelvic floor function (Davis and Kumar 2003).

Prolapse symptoms depend on the stage of POP and the probability of symptoms increases with the severity of the stage (Kristen et al. 2008; Swift et al. 2003). Swift et al. assessed symptoms and pelvic organ support in 477 women presenting for their routine gynaecological check-up. The women with POP with the leading edge of the prolapse beyond the hymeneal remnants in the vagina have increased symptoms, which may help define symptomatic POP and only the most severe symptoms are likely to be presented by the women (Swift et al. 2003). As the management of POP depends upon the symptoms and the severity of stages the different symptoms and stages will be presented.

### **3.5.1 Bulge**

The most common symptom of prolapse is bulge and is acknowledged by patients with severe prolapse as the presence of a vaginal bulge that can be seen or felt. Bulge or mass protruding or herniation symptoms that have been attributed to worsening pelvic organ prolapse include sensation of bulging or protrusion in the vagina, a sensation of 'something falling out' of the vagina, seeing or feeling a vaginal or perineal bulge, pelvic pressure, fullness and heaviness (Barber 2005).

The development of the symptom of bulge is posture dependent and diminishes or disappears when lying horizontal. Ross and colleagues mentioned, physical activity can lead to an increase in the degree of prolapse during examination (26%). Most women reported

worsening vaginal lump (54%) and pelvic heaviness (41%) following an increase in physical activity (Ross et al. 2009). In Nepal women do strenuous physical activity as a part of their routine daily work, according to Bonitti et al., 80-89% and according to Shrestha et al., more than 85% of women with POP face problems associated with bulge i.e. difficulty with lifting, sitting and walking (Bonitti et al. 2004; Shrestha et al. 2014).

### **3.5.2 Pain**

Women with prolapse are more likely to report pain, pressure and heaviness compared to women with normal vaginal support. Reddy et al. reported that the pain in advanced prolapse was significantly bothersome and interfered with daily activities (Reddy et al. 2011). The symptoms of low back pain and groin pain were very common among women with any degree of prolapse. From the total numbers, 48% of the subjects responded positively to pain questions and 33% of these reported this as a bothersome problem. This symptom was found to increase with the worsening of the prolapse (Swift et al. 2003). Another prospective cohort study that investigated the symptoms and severity of prolapse reported that 44% of the subjects complained of pelvic pain, and of those subjects experiencing pain, 69% reported that the pain had a negative impact on their quality of life. However, Ellerkmann et al. failed to establish a relationship between pelvic pain and the severity of prolapse (Ellerkmann et al. 2001).

### **3.5.3 Urinary problems**

The pubocervical ligament supports the anterior vaginal wall, bladder and urethra. Loss of this support results in urethral hypermobility and cystocele formation, which is thought to contribute to development of stress urinary incontinence. Stress incontinence coexists in prolapse particularly when the prolapse is mild. In a severe degrees of prolapse, stress incontinence is less likely but symptoms of obstructed voiding are more likely, such as urinary hesitancy, intermittent flow, weak stream, feeling of incomplete emptying, the need for manual reduction for urination and in rare cases urinary retention (Hendrix and Clark 2002).

Romanzi et al. evaluated lower urinary tract symptoms and urodynamics in 60 women with varying degrees of anterior vaginal wall prolapse. Women with grade 3 or 4 cystocele were significantly more likely to have symptoms of voiding dysfunction than those with lesser degrees of prolapse. Seventy two percent of women with advanced prolapse had objective

evidence of urethral obstruction and 86% of women with lesser degree of prolapse demonstrated urodynamic stress incontinence (Romanzi et al. 1999). Between 23-50% of women with advanced prolapse without symptoms of urinary incontinence develop urinary leakage after reduction of the prolapse. These women are said to have potential or occult incontinence and are thought to be at greater risk of developing a new onset of stress urinary incontinence.

#### **3.5.4 Bowel problems**

Defecatory symptoms are linked with posterior vaginal wall prolapse. Women with POP complain of symptoms related to bowel dysfunction; these include a feeling of incomplete emptying, straining, need to apply digital pressure to start or complete defecation (Ellerkmann et al. 2001). The association between bowel symptoms and prolapse was studied by Fialkow et al. and they found that difficulty with stool evacuation and the need for manual assistance with defecation were more common in women with posterior vaginal wall prolapse than other symptoms such as incomplete defecation, faecal incontinence and bowel movement (Fialkow et al. 2002). Though according to Bradley and colleagues, bowel symptoms are common in women with POP, but they found that the symptoms do not increase as the prolapse increases in severity (Bradley et al. 2006).

Asfaw et al. studied the association between pelvic and defecatory symptoms in women with POP. The prevalence of posterior vaginal wall prolapse was higher in the pain group compared to the no pain group. Age adjusted analysis of individual bowel symptoms showed that pain with bowel movements, faecal urgency, sense of incomplete evacuation and splinting with bowel movements were significantly associated with the presence of pelvic mass. The significantly associated bowel symptoms were straining with bowel movements and sensation of tissue bulging through the rectum. All symptoms of defecatory dysfunction, except incontinence of solid stool, were associated with the presence of pelvic pain (Asfaw et al. 2011).

#### **3.5.5 Sexual function**

The existing evidence suggests that in general, women with POP have similar rates of sexual activity as similarly aged women without POP (Weber et al. 1995). A third of sexually active women with POP complain that their prolapse interferes with sexual function (Barber et al. 2002; Weber et al. 2000). The Ellerkmann and colleagues study mentioned that impairment

of sexual activity was moderately associated with worsening prolapse in all three vaginal compartments with apical prolapse being the most pronounced (Ellerkmann et al. 2001). However, in a comparison using a validated sexual function questionnaire, no difference was noted in frequency of intercourse, libido, vaginal dryness, dyspareunia, orgasmic function or overall sexual function between the two groups. Furthermore, a high level of sexual satisfaction is reported in women with POP who are in an intimate relationship (Weber et al. 1995).

A study in Nepal showed discontinuation of sexual activity by 74% of the women with POP for various reasons, for example no sexual desire because of age, pain and difficulties during sexual intercourse, conflict and separation with spouse and fear of spousal awareness of POP (Shrestha et al. 2014). Many women reported that if they decline sex due to pain or are unable to engage in sex altogether, they experience violence and marital rape from their husbands who often threaten to take new wives or abandon them. When women are divorced by their husbands as a result of POP, returning to their parents' home is often not an option, leading women to resort to working as domestic servants, sometimes even in the home of their former husband and his new wife. In a study carried out by the Beyond Beijing Committee (BBC) 31.8% of the respondents reported that their husbands remarried after the development of the wife's prolapse problem (Shrestha et al. 2009). Another study evaluated the impact of uterine prolapsed surgery and showed that the husband remarried in about 9.3% of cases. Of these women, 17% reported that POP was responsible for their husbands seeking a second marriage and 9% reported the development of the husband's negative attitude due to POP (Chhetry et al. 2012).

### **3.5.6 Psychological effects**

Following the development of POP women remain silent and live with their problem because of traditional beliefs regarding genital issues. The fear related to the stigma of abandonment prevents women from disclosing POP. In Nepal disclosure of the problem may result in a woman being hated by her husband, family and community. Some women fear their husband will take a second wife while many women fear the condemnation of their mother-in-law, the matriarch of the family unit. They may not be able to fulfil their daily routine activities and in the worst case scenario, they are treated as outcasts by their family and society (Palm 2013).

Women with POP have higher depressive symptoms compared to women without prolapse. Although their work load, compared to men's is greater, women's illnesses still rank lower among family priorities, particularly when the condition is not life threatening. Such obstacles result in a delay in treatment which may detrimentally affect women's mental health. Those who were illiterate and those who were separated from their husbands had higher depression scores (Dhital et al. 2013).

POP may increase symptoms of depression and anxiety and may impact upon health behaviour, symptom burden and QOL. The first study investigating depressive symptoms in women with POP found that women seeking treatment for POP have a seven times higher prevalence of depressive symptoms compared to controls without prolapse (Getti et al. 2010).

### 3.6 Physical Assessments of POP

Pelvic examinations define the extent of the prolapse and establish its effect in different compartments (anterior, apical, posterior) and so help to decide the mode of management. The best possible management is chosen following the assessment based upon the grading and symptoms presented.

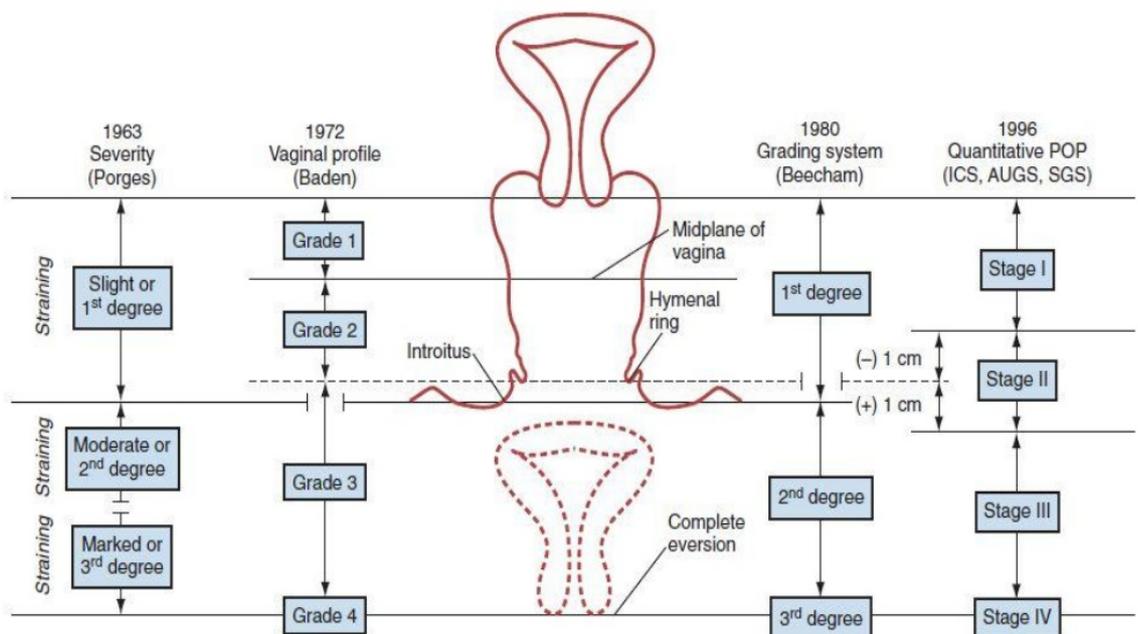


Figure 3.1 : Comparisons of commonly used grading systems. Source: Mouristin (2005)

The Baden Walker system classified Grade I as when the cervix descends half way to the hymen from the Ischeal spines; Grade II, when the cervix descends to the level of the hymen; Grade III, when the cervix descends outside the hymen and Grade IV, when the uterus is completely out of the hymen (Baden and Walker 1992).

Several prolapse grading systems exist (see figure 3.1), but the only system that has been robustly tested for both inter-observer and intra-observer reliability is the pelvic organ prolapse quantification system (POPQ). This POPQ system defines the extent of prolapse by measuring the descent of anterior, posterior, and apical segments of the vaginal wall relative to the vaginal hymen. This is a site specific system designed for quantifying, describing and staging pelvic support as well as enhancing clinical and academic communication (Baden and Walker 1972; Hall et al 1996). However, POPQ is considered time consuming and impractical for clinical settings. The simplified POPQ (S-POPQ) was designed in order to make POPQ user friendly. S-POPQ is based on examination of four areas, the anterior and posterior vaginal walls, the apex and the posterior fornix (Swift et al. 2006).

### **3.7 Assessment of quality of life (QOL)**

The WHO defines Quality of life as:

*'The individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'* (WHOQOL, 1997, p. 1).

Perception of QOL varies from person to person. The concept of the QOL of an individual is multidimensional. Considering this, various attempts have been made to design different components for QOL assessment. Descriptions of QOL struggle with the components of 'living', including emotional well-being or distress, social relationships or functioning, financial concerns, physical functioning or limitations, health status and/or spiritual well-being (Swenson and Clinch 2000). In recent years there has been a broadening of focus in the measurement of health beyond traditional health practices. The impact of disease and related health interventions on quality of life aspects form key parts of such evaluations.

The WHO's initiative to develop a QOL assessment in health care stemmed from the need to promote a holistic approach to health and health care. The structure of the WHOQOL-100 was developed by the WHOQOL group together with fifteen international field centres so that it could be applied to all aspects of health. In order to reflect the multi-dimensional nature of the QOL the structure is divided into 6 broad domains. A total of twenty four facets are covered within each domain producing a total of 100 items in the assessment. The broad domains are: physical; psychological; levels of independence; social relationships; environmental and spiritual (WHOQOL 1993; Power et al. 1999).

The administration of WHOQOL-100 tool was found to be very lengthy for practical use. Hence, WHO developed the WHOQOL-BREF, which is an abbreviated version of the WHOQOL-100. It is based on a reduced domain structure and contains only twenty six questions. The reduced domains include physical, psychological, social relationships and environmental aspects (WHOQOL-BREF 1996).

### **3.7.1 Assessment of prolapse quality of life (PQOL)**

Guidelines for Prolapse QOL (PQOL) have been proposed by the International Continence Society, Urodynamic society, American Urological Association and WHO International Consultation on Incontinence (Barber 2005). The main domains in these quantitative research guidelines are general health perceptions, prolapse impact, role limitations, physical and, social limitations, personal relationships, emotions, severity and sleep /energy measures. However, only a few validated questionnaires are available which record both symptoms and the QOL. Improvement in symptoms and QOL are two important parameters for successful management of pelvic organ prolapse problem (Barber 2005).

Digesu et al. (2005) tried to establish the importance of evaluation of symptoms and validate a questionnaire to assess symptoms and their impact on QOL of women with POP. All women participants underwent PQOL questionnaire before their hospital visit for examination. Their study found that 45% of the asymptomatic women had stage II POP and should be considered 'normal'. After finding this the authors concluded that asymptomatic prolapse is common and the presence of prolapse does not always require treatment (Digesu et al. 2005). They confirmed previously reported data where subjects usually become symptomatic when the prolapse extends beyond the hymen (Swift et al. 2003) and concluded that surgical indication should be based on individual symptoms rather than the degree of

prolapse when choosing the mode of management (Digesu et al. 2005). Though Digesu and colleagues tried to assess the patient by focusing on her symptoms, the study failed to include the patient's needs in order to make it more patient-centred when choosing the appropriate care-procedure. However, Arbel mentioned that comprehensive discussion of the management options according to the patient's need helped to define the aim of the procedure. Understanding the patient's needs is imperative for the surgeon to offer the appropriate procedure and achieve optimal results (Arbel 2005).

Srikrishna et al. (2008) studied QOL evaluation in POP, investigating the relationship between physician and patient-assessed QOL using the PQOL questionnaire. In that study patients with symptomatic prolapse were recruited and asked to complete PQOL and blinded with respect to patient's responses elicited by the physician. When the results were analysed it confirmed that QOL outcomes, based on the physician's perspective, may not be valid. Analysis estimated the interclass correlation coefficient (ICC) to measure different domains. The ICC was found to be lowest in the domains of emotion, sleep and energy. Patients tend to report higher subjective distress when completing questionnaires than when answering similar questions at medical interview. Srikrishna and colleagues did not mention why patients failed to report their distress in medical interview. However, they presumed physicians might not correctly estimate the impact that POP symptoms have on patients' QOL (Srikrishna et al. 2008). This difference of views shows the importance of qualitative studies to evaluate PQOL subjectively rather than objective evaluation which returns less valid results.

Chan (2012) utilised the Pelvic Floor Distress inventory (PFDI), Pelvic Floor Impact Questionnaire (PFIQ), Short Form-36 (SF-36), and POP Quantification system in their urodynamic study to investigate symptoms and QOL issues for women with POP. Chan, in this study assessed the factors that affect women's decisions on treatment choice. The study found that urinary impact was more associated with impairment of QOL than colorectal-anal symptoms. Subjective feelings of the prolapse affecting walking or daily activities was greater in the stage III/IV group. The factors associated with choosing surgical treatment were complications from vaginal pessary, urodynamic stress incontinence (USI), stage of prolapse and pelvic organ prolapse distress inventory (POPDI). But, the QOL, as indicated by pelvic organ prolapse impact questionnaire (POPIQ) was not found to be a significant factor. This study also demonstrated the advantages of using qualitative methods

to evaluate QOL for women following POP development. Another study by Srikrishna et al. (2008) utilised both quantitative and qualitative methodologies. The quantitative analysis of PQOL suggested that the main area of concern was the impact of the prolapse on women's lives and personal relationships while qualitative analysis suggested that women were most affected by the actual physical symptoms of prolapse.

### **3.8 Management of POP**

POP is responsible not only for physical morbidity, but also has implications for economic, social, psychological, occupational, domestic and sexual function (Digesu et al. 2005). Hence, there is no doubt that its management needs to address all these aspects. Considering the patients' needs, priority and expectations, a person centred approach, rather than paternalistic approach should be advocated for its management. POP is a condition where spontaneous regression has been shown to occur. If the patient is not symptomatic, then there is no need for active treatment beyond education, counselling and monitoring over time (Handa et al. 2004; Digesu et al. 2005).

#### **3.8.1 Non-surgical management**

The use of vaginal pessaries is the only currently available non-surgical intervention for the management of POP (Cundiff and Weidner 2000). The use of pessaries for the treatment of genital prolapse dates back prior to the days of Hippocrates and their use has been documented in early Egyptian papyruses. Pomegranates were inserted as remedies for prolapse. In the middle ages, linen and cotton wool soaked in different potions were used (Shah et al. 2006). Over 200 forms of pessaries have been developed in the past, of which approximately 20 types are still in use. The two basic working mechanisms for pessaries are supportive and space filling. The most prominent form is the ring pessary (Vierhout 2004). The pessaries can be inserted manually by the woman herself or with the help of a health worker after examination for suitability of pessary use by gynaecologists. The contraindications and likelihood of non-compliance with follow-up should not be overlooked (Guideline for pessary use 2012).

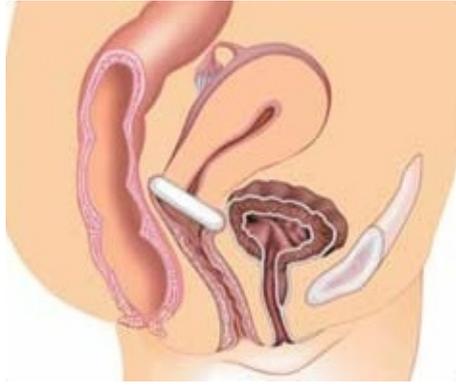


Figure 3.2: Pessary in position. Source: Guideline for pessary use 2012 p25.

The major indication for a pessary is the presence of a symptomatic prolapse when surgery is not yet possible. Women with prolapse during pregnancy and immediately after pregnancy during the puerperium, prolapse in elderly with multiple co-morbidities, prolapse with decubitus ulcer to promote healing, prolapse in the childbearing age group expecting a child soon and those waiting for surgery are all candidates for use of a pessary (Kumar and Malhotra 2008).

The advantage of using a pessary prior to surgery is that it allows the gynaecologists to determine whether or not surgery will be successful in providing relief of symptoms. The common complications of a pessary are irritation in the vaginal mucosa giving rise to discharge, formation of ulcers, bleeding and foul smelling odour. Other serious complications are the formation of a fistula urethrovaginal anteriorly, rectovaginal posteriorly and incarceration of the pessary. All serious complications are due to use of the same pessary for a duration of over three months (Vierhout 2004).

### **3.8.2 Surgical management**

According to Jelovsek and Christopher (2007), women with symptomatic POP are candidates for surgery. Treatment can be categorised into reconstructive and obliterative techniques. Reconstructive surgery corrects the symptomatic prolapse and maintains vaginal sexual function. Surgery can be done by vaginal, laparoscopic, abdominal or a combined route. However, the preferred route for prolapse surgery is via the vagina in 80-90% of patients (Jelovsek and Christopher 2007). Surgery usually involves a combination of repairs to address the typical combination of defects involving the vagina, apex and perineum. Surgical procedures for POP are anterior vaginal repair (anterior colporrhaphy), posterior

vaginal repair (posterior colporrhaphy), Apical vaginal repair (Vaginal hysterectomy, Manchester Fothergill's repair), Enterocele repair (McCall's Culdoplasty) and hysteroplexies (Puri and Malhotra 2009).

Nowadays surgical mesh to correct the prolapse is in use. Although this may have side effects such as mesh erosion and infection, dyspareunia and recurrent vaginal discharge; all of which would usually require removal of the mesh (Milani et al. 2005). The life time risk of repeat surgery was reported as 29% in 1997 (Oslen and Smith 1997) and this rate was projected to increase over the next two to three decades (Nygaard and Bradley 2004).

Obliterative procedures (Colpocleisis) are less frequently undertaken. They are used only in women who are elderly, sexually inactive or medically compromised to improve the quality of their life. The disadvantage of obliterative procedures is the elimination of the potential for vaginal intercourse (Barber 2007).

Vaginal vault prolapse is a complication following hysterectomy and has a negative impact on women's QOL due to associated urinary, ano-rectal and sexual dysfunction. Though it can happen after abdominal hysterectomy the incidence after vaginal hysterectomy increases fivefold. Vault prolapse is likely to result from poor supporting structures, increased intra-abdominal pressure due to any cause, poor tissue healing and poor surgical technique which further requires surgical correction (Uzoma and Farag 2009; Parikh 2005). The repeat surgery is not usually an option in poor countries like Nepal.

### **3.8.3 Prevention of POP**

The prevention of POP is possible but needs a multi-sectoral approach. The causes have been reviewed above highlighting the different sectors involved. Some are health related while others are non-medical related to culture, socioeconomic status, geography, women's status and lack of empowerment and governing systems. Prevention of POP by avoiding multiple child birth, improving girl's education and avoiding early marriage, and improving utilisation of family planning methods have been reviewed earlier in chapter Two. The literature reviewed below are mainly health related, however, the issues related to reproductive morbidities are also relevant to preventive approaches.

Improvement of women's health status especially during and after delivery is essential. Lavy et al. (2012) mentioned all obstetricians should make efforts to minimise the insult to the pelvic floor while conducting vaginal delivery. He advised that women who are at risk of developing pelvic floor dysfunction should be identified, but this is difficult and should be based on consideration of biometric maternal parameters, fetal size, and genetic background. Changes in the practice are needed such as avoiding the use of forceps and routine episiotomy where possible to avoid pelvic floor dysfunction (Lavy et al. 2012).

Piya and colleagues suggested approaches to prevent prolapse which included the avoidance of bearing down before full dilatation of the cervix, avoiding a long second stage by appropriate use of episiotomy, avoiding heavy weight lifting and especially heavy work during the puerperium, reducing the number and frequency of child births together with avoiding smoking (Piya et al. 2003). Additionally, provision of good antenatal care, delivery in a health facility by skilled hands, early ambulation, pelvic floor exercises post-partum and improved postpartum care can also prevent prolapse (Kumar and Malhotra 2008). A cohort study of primiparous Australian women found episiotomy is associated with the least morbidity due to pelvic floor dysfunction (Bell and Rane 2014). A Cochrane review of conservative prevention and management of POP states that treatment should consist of advising women's lifestyles, helping them to identify the muscles, and teaching the use of correct muscle techniques in strength training of the pelvic floor muscles (Hagen and Stark 2011). The randomised control trials identified that supervised pelvic floor muscle training reduce symptoms and grade of POP (Braekken et al. 2010). All these preventive strategies to reduce POP are not easy in the context of Nepal since the majority of deliveries take place at home which suggests a priority to improve the health centre delivery by skilled hands.

Many PQOL studies, (Rana 2006; Dhital et al. 2013; Tamang et al. 2014, Chhetry et al. 2012) mention that prevention should be a priority now. Development workers in the field of public health know that medical practitioners are beginning to appreciate that the only sustainable way to reduce the incidence of POP requires going beyond the medical causes, to the sources of the problem. For real and sustained impact, development and medical responses need to work in tandem taking into consideration the socioeconomic practices and contexts that affect women's reproductive health (Younis et al. 1993). However, the culture of utilizing a multidisciplinary approach in order to reduce POP has yet to become the norm in Nepal.

The family plays an important role in the prevention of POP. Next to a husband, the mother-in-law seems to be the most important member of the family who can support the health of younger women. However mothers-in-law may claim that when they were younger, they had to work even harder than their daughters-in-law and uterine prolapse was simply a part of their lives. Such beliefs will not support the necessary behaviour change. Family interaction and open communication are two things repeatedly mentioned as effective methods within prolapse prevention (Radl et al. 2012). However, women in rural areas communicate less frequently with family members and are less involved with decision making for themselves and the family during the early years of their marriage. According to one study in Nepal women's decision making depends upon the length of marriage and the number of children they have. There was significant improvement in women's decisions on their own health care and large purchases after attaining the age of thirty five years (Futura and Salway 2006). Women's autonomy and utilisation of health care was studied by Self and Grabowski (2012). The more autonomous women are within the household, the greater influence they have in the allocation of resources for health care as compared to those who only work on the land. Better educated women who are employed outside the home, in non-agricultural activities are more likely to see a doctor (Self and Grabowski 2012).

### **3.9 The Government approach to improving the quality of care**

A strategic plan for prolapse management was developed by the Ministry of Health and Population through a national service guideline for the management of POP in 2008. Service guidelines focus on different parts of POP management and include screening, treatment and follow up. The other aspects relate to funding, monitoring and supervision, samples of reporting forms, criteria to be fulfilled before contract agreement with service providing health organizations, checklists for monitoring and requirements for providing services (Family Health Division 2008). The clinical protocol containing guidelines for prevention and management of POP was prepared in Dec 2012 to improve the quality care delivered by all levels of health workers throughout the country (Clinical Protocol 2012).

The clinical protocol differs from the national service guideline. The former is clearly paternalistically influenced. Although the programme is for the benefit of the women, it fails to understand that each patient is an individual. It is the duty of the health care provider to

adequately inform women about potential problems and offer a wide range of options for assessment, management and follow up.

### **3.10 QOL after surgical management of POP**

PQOL after surgical management has been studied in different places. Hirata et al. (2004) in their study in Japan evaluated QOL and efficacy of surgical repair in patients with POP postoperatively. After surgery, restoration of the bladder base was confirmed in all patients by urethrocytography. The postoperative QOL was assessed three times by mailing a QOL questionnaire in 52 cases and was repeated for at least two years. After this the researchers concluded that following surgical repair, women achieved improved results with both post-operative disease specific and health related QOL (Hirata et al 2004). The follow up of patients, assessing their situation 3 times over two years is possible in a country like Japan. However, in a low-income country like Nepal, follow-up studies are only possible with difficulty because of the prevailing culture, lack of technology and the geographical challenges when accessing health care.

Mobile surgical camp services began in the remote areas many years ago. These were introduced to reduce the prevalence of POP and the related magnitude of morbidity. Palm (2013) reported that whilst programmes have treated women with POP in the past, there has been little or no follow up care. Many INGOs set up health camps, treat, take promotional pictures for their own purposes and leave, with no tracking of outcomes (Palm 2013). The studies have found that there is scant evidence on post-operative problems or follow up of the women which provide insight into their health condition after surgery. Rana highlights in her study that women have had to be flown or driven in cases of dire emergency arising from lately detected postoperative complications like significant hemo-peritoneum or undiagnosed vaginal vault hematoma (Rana 2006). Rana's work further demonstrates the need for a detailed study of the women following POP surgery. The following studies highlight the objective impressions of QOL for women after management in surgical camps.

An impact evaluation following uterine prolapse surgery in Nepalese women was carried out by Chhetry et al. (2012). The study was conducted in eight districts to examine the status and problems for women who have undergone prolapse surgery. Both qualitative and quantitative methods were used to examine the issues. Among a total 646 women who underwent surgery, the majority (317) had surgery in a health centre while the others were

treated in government and or non-government hospitals. Their study showed that health camps for POP surgery were more beneficial to women in remote districts, especially those who can't afford treatment. The majority improved their health status after surgery. Only 4% reported that their health status had diminished. In interviews 10% rated their health as below average. The results showed an incidence of post-surgery problems and these were highest following camp surgery (15.1%), low in non-governmental hospitals (11.1%) and lowest in (10.1%) in government hospital surgery. Those who faced problems developed these within a week of discharge from hospital (Chhetry et al. 2012). However, the researcher failed to co-relate the health status of the women before surgery and the economic status of women whose health status worsened. Exploration of the factors responsible for poorer outcomes will be one of the major components for this study.

Dhital et al. (2012) conducted a longitudinal study in selected central and peripheral hospitals in Nepal where POP surgery was carried out free of cost. They used the WHOQOL-BREF, a 26 item abbreviated version derived from WHOQOL-100 to measure the QOL. The four domains included physical, psychological, social and environmental health. A Nepali version of the scale has been validated for use in Nepal. Dhital and colleagues (2012) compared these different domains with women with POP and without POP. This showed that PQOL is poor in women after the development of POP. Among 206 women who have completed the baseline study, 68 women were lost to follow up, with 9 missing persons data. One hundred and seventy seven cases were analysed for follow up at 6 weeks which showed that all domains of QOL progressively improved. However, the study failed to be able to generalise results because of the number of cases lost to follow up. Therefore the authors cannot say whether all those who underwent surgery have improved QOL and they are unable to mention definite factors responsible for loss to follow up. Though efforts were made to explore the QOL for women after surgery at 3 and 6 months, the study does not mention the different problems women faced following surgery. If they had been highlighted they could be of help in finding factors that hamper QOL after surgery (Dhital et al. 2012).

The recent study by Tamang et al. (2014) looked at the impact of surgical intervention on health related QOL for women suffering from uterine prolapse. The women who had surgery for POP were provided with a questionnaire based on pelvic floor distress inventory PFDI-20 and pelvic floor impact questionnaire PFIQ-7 and pre-operative assessment about the condition of POP. The analysis showed that PFDI-20 scores were higher in women with IV

degree POP and the QOL for these women drastically improved after surgery. The response to the urinary distress inventory (UDI-6) was shown to be better than that in the Colorectal-Anal Distress Inventory (CRADI-8).

In conclusion, though these studies have showed that camp surgery is beneficial for rural women by demonstrating improvement in their QOL. However, they fail to address the women who had poor QOL after surgery. The weakness in these studies is that they have evaluated only the outcomes of those who agreed to participate after surgery; ignoring the large numbers of women who dropped out (Dhital et al. 2013; Tamang et al. 2013; Chhetry et al. 2012). As Subedi mentions, there is need for clear-cut monitoring systems to keep track of patients who have undergone surgery. He observed that the ones who face complications were absent from follow up studies (Subedi 2010). The evidence presented begs the question: had the initiatives been person centred; might women have had an improved quality of life?

### **3.11 Qualitative studies exploring QOL**

There are multiple reasons that impinge on the QOL, especially after suffering from chronic illness. Various social, cultural, geographical and economic factors affect the QOL which vary from country to country. These factors will also change between high and low-income countries. Access to health depends upon an availability of the service, which must be accessible to patients, who can afford the cost and who are able to accept the provided treatment. There may be different reasons behind not seeking health care (Karkee et al. 2013). For the clinician, the issue regarding delay in seeking health care is often the reason why women suffer for so long without seeking help. It becomes important to discover the reasons from the women's perspective, why health care is not accessed after the development of prolapse.

Some qualitative studies have attempted to explore QOL elements for women. With an objective to elucidate the experience of living with POP and its impact on daily life prior to surgical intervention, a qualitative study was conducted in Sweden by an urogynecologist (Pakbaz et al. 2010). In-depth, semi-structured interviews were conducted with 14 women before surgical treatment. Two different categories identified were, obstacles and facilitators to seeking health care. The main obstacles described by the participants were lack of information and confirmation of the problem itself. Deficiency of knowledge about prolapse

and a feeling of shame were important factors behind the delay in seeking health care. Pakbaz et al. mentioned that information about prolapse should be easily accessible to improve opportunities for women to learn about their condition which, in turn, will help to overcome one obstacle in seeking health care. Women's behaviour, when applying coping mechanisms, also contributes to delays in seeking health care. The main facilitators constituted feeling sexually unattractive with impaired physical ability due to a prolapse (Pakbaz et al. 2010). The reasons uncovered by Pakbaz et al.'s (2010) study, although within a high income country context, may well be valid for different places. However, the author of this study observes that if levels and availability of information in a high-income country like Sweden are problematic, then the issue will be much greater for low-income countries like Nepal.

Women's experiences and health care-seeking practices in relation to POP, in a hill district of Nepal, were studied by Shrestha et al. (2014). They mention perceived barriers to accessing health care which included shame. Women, they report, were unable to share their problem with others and especially with male health workers. The second reason for the delay in seeking health care was because childbirth was perceived as a normal event for women and therefore care was unnecessary. Such traditional positions are seldom challenged as women lack education and empowerment. The fear of discrimination within their communities was expressed as yet another reason for hiding the problem which inevitably leads to delays in seeking help (Shrestha et al 2014). Delay in treatment remains a huge concern for Nepali women. From the literature on the duration of suffering, Nepalese women report more distress compared to women from other countries (Gurung et al. 2007; Dhital et al. 2012; Shah 2010). It is likely that all the factors that cause delay in seeking and receiving health care coincide with the very factors that hamper a woman's QOL.

Another qualitative study of women's preferences for the treatment of pelvic floor disorders was conducted in the United Kingdom (UK) (Basu et al. 2010). Semi-structured interviews were conducted based on women's perceptions of each treatment and the factors that lead them to find treatments. Their views were analysed thematically using a comparative method derived from grounded theory. Among a total of 16 women who were interviewed, the problem of POP was found to be less bothersome than stress urinary incontinence. The surgical solution appears to be more acceptable for POP as women can forget their symptoms and carry on as before. However, women were unsure about treatment and less willing to risk potential complications even for a higher chance of long term success. They reported

the need for careful exploration of women's hopes and expectations before embarking on treatment to achieve successful management (Basu et al. 2010).

Basu and colleagues study reports the preference for treatment of pelvic floor disorder in the UK, where various alternatives of conservative and surgical management are available and can be accessed easily in health centres near to where women live. Such evidence from high income countries, although useful, may not be applicable in low income countries where women live in areas remote from health care facilities. All the dimensions related to access are applicable to women in rural areas which lead to poor utilisation of the health care facilities. The Nepalese Government provides free surgery for women with POP. As this intervention is not always available to them, women are bound to accept any sort of treatment provided without making choices. Even with this paternalistic provision of care, the evidence available for evaluation is based on objective studies which show improvement in QOL. There are limited published works on QOL improvement using quantitative methods and addressing the need for improvement in intervention management. To investigate the impact of surgery on women's lives, a qualitative study will add significantly to the body of knowledge. Subjective findings, comparing life before and after treatment, will contribute to the broader evaluation of ongoing management and will be useful in assessing the quality of care and, importantly, they will help to identify changes needed in health care delivery.

### **3.12 Medical paternalism**

Medical paternalistic in health-care decision making has its roots in the Hippocratic ideal of acting in the best interests of the patient, sometimes spelt out in terms of beneficence and non-maleficence. The physician, as a care taker of the patient's interest where medical decisions are concerned fails to involve the patient and may go against her wishes.

Allen Buchanan defined paternalism as:

*'Paternalism is interference with a person's freedom of action or freedom of information, or the deliberate dissemination of misinformation, where the alleged justification of interfering or misinforming is that it is for the good of the person who is interfered with or misinformed'* (Medical Paternalism, 1978:p.62).

He also describes that if a government lies to the public or withholds information from it, and if the alleged justification of its policy is that it benefits the public itself, the policy may

properly be called paternalistic. The medical paternalist model acts for another's good often against that person's will and was a dominant way of conceptualising the physician-patient relationship (Buchanan 1978).

There are different ways of viewing paternalism. Paternalism may not necessarily always be viewed as coercive. Some perceive it as such while others perceive the approach as superiority, domination, oppression and dogmatism. When characterised in this way it is also called authoritarianism. Paternalism and autonomy are two inversely varying parameters along a spectrum of independence. When autonomy recedes paternalism advances. This example of change can be observed in the American Medical Association (AMA) Code of Ethics itself along with the change of time and advances in autonomy of the people. The AMA Code of Ethics (1947) was absolutely paternalistic, calling for complete and unquestioned obedience from the patients:

*'The obedience of the patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous and even fatal'.*

However, a more modern version of AMA code is modest being more liberal on the rights of patients to make their own decisions:

*'The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment'.*

The AMA thus stated that physicians are to foster this partnership by providing information and allowing for autonomous decision making (Council on Ethical and Judicial Affairs 1990). Though there are benefits as well as harm in giving priority to both paternalism and autonomy, Komrad warns care givers about not being more paternalistic when autonomously chosen decisions may lead to disaster for the patient (Komrad 1983). However, the recommendation is to adequately share information providing, multiple options which includes advantages as well as disadvantages so that patients will be able to understand and contribute their knowledge in the decision making process.

According to Bridson et al, the evidence of a shift from paternalism can be seen in the changing face of informed consent. Such changes include the evolution of the person-centred model, which identifies the doctors and patients as equals, but with different expertise. This model encourages practitioners to explore the patient's individual needs and priorities because their beliefs, culture, occupation or other factors may have a bearing on the information they need in order to reach decisions (Bridson et al. 2003). Person-centred care has to be incorporated into the paternalistic model in order to provide meaningful, holistic health care.

### **3.13 Person-centred care**

Person-centred care (PCC) is dependent on knowing each patient as an individual. It connects to an ideal of respecting patients where patient's choice remains the authority over the decision as to what should be done. In contrast to medical paternalism, PCC allows patients not only to make choices, but to choose options contrary to medical advice depending upon their personal interests, as long as they are well informed by the health care professionals of all the risks and benefits. PCC gives room for the professional to reason over what is really in the patient's best interest, giving the patient an opportunity to critically assess their preference and the reasons around different sets of preferences and how they can be satisfied in the situation (Sandman and Munthe 2010). The promotion of authority for, and participation of, patients when making a diagnosis and choosing treatment has resulted in improved time allocation for care delivery, lower treatment costs, decreased hospitalization periods, and earlier discharge. Patient satisfaction in these studies is improved (Hobbs 2009; Epstein et al. 2010).

Barriers to PCC were studied by Esmacili and Salsali (2014). They identified three themes. The first theme was lack of a common understanding of teamwork. They point out that nursing staff believed that other health care workers (physicians, laboratory workers, radiologists etc) are also responsible for providing PCC. They recommended that it is essential for all members of the health care team to have a PCC perspective. The second theme was individual barriers and the third was organizational barriers. The second and the third themes had subthemes of lack of motivation, holistic view and experiences of model staff in the organisation. According to the authors, in order to provide PCC there is a need for a holistic view which focuses attention on the patients' and their families' needs, resolving problems both during hospitalisation and after discharge. Their study identifies a lack of up-

to-date knowledge which limits critical evaluation, planning, and clinical judgement, making assessment of PCC difficult (Esmaeili and Salsali 2014). The Epstein and Street study offers support stating that in order to provide PCC an increased quality at all levels of personal, professional and organisational relationships is required. Evidence-based practice and the use of up-to-date knowledge play a significant role in directing attention to the needs and preferences of the patients (Epstein and Street 2011).

Organisational support is equally important to facilitate PCC in order to provide appropriate working environments. In a study by Esmaeili and Salsali the barrier to PCC at the level of organisation was found to be a lack of manpower among nursing staff leading to a lack of time to address the workload (Esmaeili and Salsali 2014). Therefore, manpower though trained, can't expect to achieve the level to PCC. The alternative to PCC is to develop a PCC perspective as recommended by Esmaeili and Salsali for all members of the health care team. This requires great motivation.

Esmaeili and Salsali (2014) noticed injustice in the relationship between doctors and nurses as well as a lack of support from managers to motivate and create a suitable working environment. Creation of suitable working environments and motivating staff results in improved performance and improved patient satisfaction. The barriers found were limited mainly to individual and organisational levels and the recommendations they have made to provide PCC were mostly focused on practice development, however they do not mention specifically the concept of equal participation of all in a move towards PCC.

### **3.14 Practice development**

The concept of practice development (PD), based on patient need, was proposed by Mallett et al. (1997). They highlighted a link between professional development and practice development. Professional development is concerned with the skills, knowledge and values of the individual, whereas practice development reflects how those facets are used to advance quality PCC. If the organisational or national requirements for some change in practice is adopted, then individual professionals will need to acquire skills and knowledge in order to develop their practice. Practice development is needed to assist health and social care organisations, teams and individuals improve the quality of services they offer (McSherry and Bassett 2002).

PD is a continuous process of improvement toward increased effectiveness in PCC. McCormack (2010) reported, clinical PD appeared to be more about boundary management and service effectiveness. However, anything concerned with PD should be oriented around: process, place and people. The PD process is continuous and it has no clear beginning and no defined end. There is nothing as such to evaluate other than effectiveness in care. McCormack views PD as the essential process of clinical governance which is sustained by embedding the process into everyday practice. Organisations learn to value different methodologies that enable practitioners to 'own' these processes thus building the potential for their replication.

Changes in culture and transformation of ideas suggest that PD is more than simply finding better ways to provide health services and improve patient outcomes. Patient outcomes cannot be improved without staff development and education. Tackling development by recruitment and retention strategies while addressing recognition and reward are key PD traits. Dedicated independent facilitators enabling professionals to embrace PD in their roles and, ultimately, their publications are needed (McCormack 2010). McCormack mentions empowerment of health care professionals within practice development. However, he does not include the empowerment of patients without which the development of practice is incomplete. PD can be successful by enabling patients to identify shortcomings in the health care system and design innovative ways of delivering care (Pratt et al. 1999). Hence, the empowerment of patients along with the empowerment of health care professionals is equally important to achieve change in, and development of practice. This justifies the methodological approach adopted, and the uniqueness of this study as few previous studies have explored women's views on POP management and none have considered their views alongside those of clinicians.

### **3.15 Summary**

The literature review has addressed the issue of POP in Nepalese women. The position of women in Nepalese society, particularly in rural areas, their health care seeking behaviours. Lack of access to appropriate care during labour, ante and post natal care has been shown to be largely responsible for the development of prolapse. The previous chapter (Nepal in context) provided a wider picture of the challenges women face and their health related needs. The literature on effects of POP, assessment of the problem and management are from a predominately medical point of view. The limited literature related with QOL issues after

POP management were reviewed. The factors for improved management were further supported by the need to understand both women's and clinician's experiences in order to elicit holistic accounts of POP and its management. Findings from such an approach can usefully inform health care policy change through adopting a more PCC. It is recognised that within the traditionally patriarchal society of Nepal, the views of women are not necessarily heard in general, and specifically when the topic is one where shame and stigma militate against this. These issues inform the conceptual framework, methodology and method selected for the study and are explored further in the next chapter.

## **Chapter 4: Methodology and Methods**

### **4.1 Introduction**

This chapter begins by presenting and justifying the conceptual framework and philosophical assumptions of the study. The research design is then presented with the rationale for choosing a narrative method and congruent research methods. Framework analysis is justified and ethical issues are discussed. The chapter concludes by presenting the limitations of the study.

### **4.2 Conceptual framework**

Conceptual frameworks are the current version of the researcher's map of the territory being investigated and as the knowledge of the terrain improves, the map becomes correspondingly more differentiated and integrated (Miles and Huberman, 1994). Jabareen states that a conceptual framework is a network, or "a plane," of interlinked concepts that together provides a comprehensive understanding of a phenomenon or phenomena (Jabareen 2009).

The driving force behind this study was the government's initiative for the management of POP. Providing free surgery for women in different parts of Nepal focused on reducing the prevalence of POP. Considering the geographical difficulty of accessing health care and the position of women identified in the literature review chapter, this single approach to providing care is considered paternalistic and not acceptable due to the multi-dimensional causes of POP in the context of Nepal. Furthermore, as POP has various degrees which can present with a wide ranges of symptoms which require different management, one specific clinical intervention cannot address the range of issues needed to improve health status.

The researcher is a gynaecologist. Within her routine clinical practice she found that patients operated on in hospitals complained less at follow up than those who has been operated on in the surgical camps. This observation has been reflected on in the introductory chapter. The researcher observed this difference in her clinical practices both in hospital clinics and outreach centres where she followed up women after surgery for POP. This stimulated the researcher to think critically about the overall effectiveness of POP surgery and the impact of surgical intervention on the QOL of women after surgery. She questioned the rationale for camp-based surgery; whether it was to improve the health and QOL of women, or to

reduce the prevalence of the problem by only offering surgery without listening to and involving the women.

The researcher also recognised that during her practice and from her past research experience on the follow-up of prolapse surgery in rural Nepal, (Schaaf et al. 2008) women became disillusioned over the treatment provided and refuse to return to the clinic following the development of different types of complications. Following surgery women are expected to continue to fulfil the demands of the family and society as they did before the development of their prolapse. Development of complications after surgery means that women again face social and cultural embarrassment. These incidents led the researcher to question the notion of the paternalism on which the Government's care is based. In order to explore these concerns the views of women who experience POP management were important.

As noted in the literature review (Rana 2006; Subedi 2010; Palm 2013) some of the authors raised questions about the effectiveness of ongoing surgical care highlighting the weaknesses regarding supervision, monitoring and follow up after camp surgery in Nepal. Though their points of view were also against the paternalistic care and supportive of person-centred care, they failed to debate the gap in the paternalistic approach. This led the researcher to understand that she is not alone in her discomfort of the care provided to Nepalese women. This further stimulated her need to understand the views of the clinicians who are involved in the management of POP. Holistic and person-centred care will only be possible if the clinicians' concerns are explored and addressed, and can ultimately contribute to a sustainable way to change current POP management policy.

The researcher wanted to discover the reasons why person-centred care was lacking in areas where women were deprived of health care. With a belief that person-centred care should be the way forward she decided to take on the challenge through this study. In order to develop an understanding, it is important to acknowledge the professionals' views and to find out whether they are comfortable with changing the way they manage POP. Similarly, the views of the women who experienced POP and its management need to be heard. The multiple ways of knowing involved interpretation from two different groups of participants; with experience of POP management.

With a theory based upon the dominance of medical paternalism the conceptual framework has been designed to move towards person centred care. Conceptual frameworks possess ontological, epistemological, and methodological assumptions and each concept within a conceptual framework plays an ontological or epistemological role. The ontological assumptions relate to knowledge of the “way things are,” “the nature of reality,” “real” existence, and “real” action. The epistemological assumptions relate to “how things really can” and “how things really work” in an assumed reality. The methodological assumptions relate to the process of building the conceptual framework and assessing what it can tell us about the “real” world (Guba & Lincoln 1994).

### **4.3 Philosophical assumptions underpinning ontology**

The ontological assumptions are concerned with what constitutes reality in others worlds (Crotty 1998). Ontology relates to the nature of the reality of the subjective and multiple existences (Cresswell 2007). The development of the research strategy begins with researcher’s ontological position. The scientific paradigm believes that facts and rules can be identified by observation of cause and effect, and confirmed and verified through different measurements for describing objective reality (Guba and Lincon 1994). The researcher’s professional background as a medical doctor has influenced the researcher to prioritise the facts which usually inform objective understanding and present studies in the form of reports.

Quantitative researchers can explore patient outcomes by measuring how many patients are not concordant with a given treatment by simply highlighting the extent of a problem. As discussed in the literature review POP has been researched across all health care disciplines, particularly through a medical lens which utilises mainly a quantitative rather than a qualitative approach. Such studies focus on the possible treatments and outcomes from a clinical perspective (Dhital et al. 2013; Tamang et al. 2013; Chhetry et al. 2012). The objective realities created by some of these quantitative studies assert that the QOL for women after treatment of POP improves. However, the researcher contends that it is not possible to know if QOL improves significantly without knowing what a woman's QOL was before receiving the treatment. It is also important to discover the difficulties women face when trying to improve their QOL.

In any health-related issue where there are social, cultural and economic co-relations, the value of qualitative research becomes evident as it can better understand and co-relate different phenomenon. The researcher wants to explore and understand QOL from the standpoint of women as well as from clinicians. She contends that objective reality may inform but can't explain the situation in the same way as subjective realities. Creswell also states that many effects of illness and disabilities are observed from outside, however lived experience cannot be measured or observed by professionals. It can only be shared in the telling (Creswell, 2007). Qualitative research aims to explore the situation by asking what and how things happen. It is therefore relevant to use a qualitative methodology. The researcher obtained answers to the questions through the participants sharing or telling their experiences. Bryman argues that qualitative research is able to capture the client perspective of healthcare, and it enables professionals and providers to understand how clients perceive health services. Such findings are now used to influence health policy at a local and national level (Bryman 2001).

#### **4.4 Philosophical assumptions underpinning epistemology**

An epistemological position is a relationship between the researcher and those being researched which conveys how knowledge can be explained with reference to existing evidence in the specific context (Creswell 2007). Interpretive studies assume that people create and associate their own subjective and inter subjective meanings as they interact with the world around them. Interpretive researchers thus attempt to understand phenomena through accessing the meanings participants assign to them.

This work is inevitably influenced by the researcher's own personal and professional background, highlighting her epistemological position. In the study presented the researcher transcends her traditional, positivist roots to present as an interpretivist. Her epistemological position stimulated her to understand the context by utilising multiple ways of knowing. This stance is supported by King et al. who conclude that the strength and power of the interpretivist approach lies in its ability to address multiple realities (King et al. 1994). She believes that understanding what this means to women can only be obtained by understanding the women's experience. Similarly, understanding POP management in the context of Nepal can be aided by exploring the clinician's experiences. The research questions relating to women's experiences before and after management of POP together with the clinicians' experience of POP management belong to an interpretivist paradigm. In

order to address the research questions, the researcher proposed collecting experiences by interviewing the participants.

An interpretivist approach, helped to make sense of the work by understanding human life. Wiklund described Ricoeur's understanding, which is accomplished by dealing with the text 'as text' and thereby explaining meaning (Wiklund 2002). Though this study utilises philosophy behind the understanding of text, the researcher is aware that when understanding the text she will have to deal with multiple languages. Therefore, for this study knowledge is created through listening, interpreting and understanding the participants' views and ideas rather than by observing them. The meaning of the text gathered as data is then explained for the dissemination of new knowledge.

## **4.5 Selection of methods**

### **4.5.1 Data collection methods**

Women in Nepal live with POP for prolonged periods of time before they have treatment. Living with POP and undergoing treatment can be expressed as a narrative. Narration is one of the fundamental ways that people organize their stories, make sense to themselves of their past experiences and share those experiences with others. Through these exchanges people come to know, understand and make sense of their social world. In the context of illness, an illness narrative is the story the patients tell about the experience of their symptoms and suffering. It integrates the symptoms and consequences of illness into social reality. Narratives provide insight into what the important themes are and suggest ideas for further investigation (Gibbs 2007). Thus, a narrative method was a fitting way to obtain the information of women's experiences of living with POP.

The key features of narratives are that they are chronological, meaningful and social. The researcher plans to understand the effects on women following the development of POP and would further like to explore life after its management in order to evaluate the interventions. Elliot describes narrative as the discourses that organize a sequence of events into a whole so that the significance of each event can be understood through its relation to the whole (Elliot 2005). The narrative thus can best serve here as a data collecting method from the women participants.

Within clinical practice, in order to move towards a diagnosis, clinicians proceed with a history about the illness. Patients talk about their symptoms which helps the clinicians

consider possible related illnesses. Brody, emphasises the importance of illness narrative as a means by which doctors acquire a more detailed clinical picture of the patient. A medical practitioner must become knowledgeable of patients' narratives, not only to make a correct diagnosis but also in order to propose a treatment that is acceptable to the patient (Brody 1987). Narration thus is one of the most powerful forms for expressing suffering and experiences related to suffering.

In a country like Nepal, where problems related to genitalia are a taboo issue and where women have rarely been listened to, it was difficult as well as challenging to approach the subject directly by asking questions regarding experiences of POP. As the study shows women's experiences were collected by providing opportunities for the women to come forward with permission to talk about their POP problems. The narratives were expected to make women comfortable so that they will be receptive to the sequences the researcher wanted to understand. The advantage of being a female researcher cannot be denied here. The researcher accepts this as a positive situation as a male researcher would be less able to explore women's experiences with POP in depth.

Narratives can be obtained not only from the patient but also from other people involved with the illness. Situations where doctors, nurses and other medical professionals discuss the patient's illness are also narration. Some authors have suggested that narrative has a central place in medicine as a means of formulating and conveying clinical knowledge (Brody 1987; Hunter 1991). Narrative has been used in the health field to understand clinical practice and the experiences of the health professionals (Hyden 1997). By utilising the narratives different issues related to POP causes, consequences and management were explored from a second group of participants i.e. clinicians in order to find ways to improve practice. Narratives in this study allowed the clinicians to provide different voices on the procedures. All narratives were inevitably contextualised within particular social, cultural and political understanding to address the research questions.

What is called narrative has to maintain a sequence of beginning, mid and the end but maintaining such a sequence was difficult as clinicians may not like to share experiences in this way. The interview approach allowed the researcher to maintain a sequence during data collection. Where it was not possible to maintain the sequence she tried to interpret the data in such a way that sequence was identified. Wilcund et al. reports that narrative is an

interpretivists' approach because it is by narration that interpretations of the world are structured (Wilkund et al. 2002). It is an interpretation which complements the narrative understanding. Narratives are not just about telling stories but also allow for an understanding of theory. As the researcher planned to work with two languages, (Nepali and English) interpreting text in order to create understanding presented a particular challenge. Efforts were made to validate interpretations to create meaningful data with the women. Some of the words and the quotes which were difficult to translate were kept as spoken in the Nepali language in order to avoid the potential harm of losing meaning. The researcher's epistemological position herself was expected to eliminate bias in translation. The validity in terms of correct interpretation was presented as verbatim quotes and explained later by the researcher.

#### **4.5.2 QOL tool for this study**

Desigu et al. highlighted POP as a condition affecting women's QOL. He states that, depending upon patient's characteristic and socio-cultural influences, POP is responsible not only for physical morbidity, but also has huge implications for economic, social, psychological, occupational, domestic and sexual function (Digesu et al. 2005). The literature review discussed many standard tools available to measure QOL of individuals and also prolapse quality of life (PQOL) (Barber et al. 2005; Digesu et al. 2005; WHO 1993; WHO 1996) which the researcher felt were appropriate in quantitative studies. As development of POP is socially constructed, (Earth and Sthapit 2002) and considering the socioeconomic status and education level of women in the rural areas of Nepal the researcher planned to use only the components of WHOQOL-BREF domains for her study. Though it contains four major domains i.e. physical, social, psychological and environmental, for this study the environmental domain has been moulded to an economic situation as the surrounding environment depends on the economic status of the family. The study not only set out to explore QOL from the perspective of women, following the development of POP, but it also aimed to co-relate effects from all domains which quantitative studies were not able to show. Within the proposed qualitative study use of the QOL tool was necessary in order to evaluate associations as well as the effectiveness of the management provided. Evaluation of QOL issues enabled the researcher to make recommendations for change in policy and practice.

### **4.5.3 Tools for data collection**

The interviews gave the richest means of exploring the participants' experiences. The researcher planned to use one-to-one semi-structured interviews as well as focus group discussions with both groups of participants. The decision to use semi-structured interviews and focus group discussions as data collection methods was governed by both the researcher's epistemology and the study's aim and objectives which located the study design within the interpretivist approach. The rationale behind choosing different tools stemmed from fact that POP is a common problem among Nepalese women and although common is a sensitive as well as a taboo issue. The journey travelled by women with POP and its management issues were thought to be better captured by one-to-one interviews with women participants. Similarly, the views about past, ongoing and future management were elicited from the clinicians through one-to-one interviews. To make sense of a participant's world, the researcher explored it from the participant's own perspective.

As this study used a narrative method, unstructured interviews should have been utilised to collect the narratives. She has not used this as in unstructured interviews neither the question nor the answer categories are predetermined. As Minichiello describes, they rely on social interaction between the researcher and the informant (Minichiello 1990). The researcher chose semi-structured interview instead of unstructured ones for the women participants, POP is a sensitive issue. In order to focus on the key research question it was pertinent to use semi-structured interviews. Similarly, for clinician participants' the researcher wanted to collect narratives of their POP management journeys. She wanted to hear specifically what they do, how they work and what they would like to change. An unstructured interview approach, would not necessarily achieve these aims. It was best to maintain a focus by using open-ended questions. However, the researcher was aware of the strengths and weakness of structured, semi-structured and unstructured interviews (Zhang and Wildemuth 2009).

The researcher used focus group discussions with both groups of participants. Focus group discussions were underpinned by the study philosophy and were appropriate to answer the research questions. In the women's group, the focused discussions drew on the common issues that exist but were never spoken about. The topic being sensitive, the researcher was well aware of the possible harm to individuals and the ethical boundaries. From the clinician participants she expected to obtain information on the need to improve management via the focus group discussion and come up with recommendations to improve practice. By

questioning one another and showing different viewpoints the focus group clinicians could arrive at new ways of understanding problems.

#### **4.5.4 Data analysis method**

Qualitative data analysis is the range of processes where collected data is processed into some form of explanation, understanding or interpretation of the people and situations under investigation (Jacelon 2005). Qualitative researchers look for categories or themes from raw data to describe the phenomenon under study. In this study the researcher utilized the approach to understand the effectiveness of management provided to women suffering from POP. The study was not just aimed at finding out whether intervention is effective or not (as with a deductive approach) but rather it hoped to find ways to improve management. The framework analysis was adapted for use with deductive, inductive or combined types of qualitative analysis.

Framework analysis (FA) was developed in the 1980s by a social policy researcher in the UK for handling qualitative data. The intention was to produce an analysis with potential for actionable outcomes for real world investigators (Ritchie & Spencer, 1994). This approach was helpful especially with data derived from healthcare research. Its prime concern was to describe and interpret what was happening in a particular setting (Ritchie & Spencer, 1994).

The researcher chose this technique as it complemented the narrative data gathered from one-to-one semi-structured interviews and from the focus groups collected in the two different groups of participants. FA has a series of interconnected stages that enabled the researcher to move back and forth across the data until a coherent account emerged (Pope et al. 2000; Ritchie and Lewis; 2003, Swallow et al. 2003). The researcher could have used discourse analysis as an alternative approach as she was dealing with power imbalances at different levels between both the groups of participants with the aim of bringing about policy changes, but as mentioned above this study needed to interconnect different level of interpretations to give meaning to the data, therefore it was not used. The other key reason for the use of framework analysis was its ability to merge data from two different groups of participants. The researcher had to balance the views of women against the views of the clinicians. The epistemological perspective of this study explains the interpretivist approach with the intention of giving meaning to the data collected. The researcher interpreted two different ways of knowing by utilising framework analysis. Solutions then emerged which

informed person-centred care. While using this method the researcher was also aware of the limitations of FA. It was time consuming and needed to be undertaken in a committed fashion to allow all data to be considered and ensure a rigorous process (Gale et al. 2013; Ward et al. 2013).

#### **4.6 Sampling**

The selection of appropriate participants depended upon the aim of the study. Choosing research participants is an important step in any research project since it is rarely practical, efficient or ethical to study the whole population. The aim of qualitative sampling approaches is to draw a sample from the range of the population, so that the result of studying the sample can then be related back to the population. An appropriate participant number for a qualitative study is one that adequately addresses the research question. The collection of data continues until the researcher recognises a point of data saturation (Tuckett 2004). According to Marshall (1996), there are three broad approaches to selecting a sample for a qualitative study. They are purposive, convenient and theoretical sampling (Marshall 1996). Using the logic of emphasis on in depth understanding, a purposive sampling technique was applied in this study.

##### **4.6.1 Purposive sampling**

Purposive sampling is also known as judgemental sampling where investigator uses her judgement and prior knowledge to choose people for the sample who best serve the purposes of the study (Monette et al. 2005). This sampling technique involves selecting certain units or cases based on a specific purpose, rather than randomly. There are three broad categories of purposive sampling technique; sequential, comparability and special sampling. Sequential sampling involves the principle of gradual selection. Snowball sampling is one type of sequential sampling (Teddile and Yu 2007).

##### **4.6.2 Snowball sampling**

Snowball sampling is often used to find and recruit the hidden population that is not easily accessible to the researcher through other sampling strategies (Monette et al. 2005). Additionally, snowball sampling was felt to be an appropriate strategy where embarrassment may inhibit women participants from volunteering directly. Similarly, for clinician participants, this technique was appropriate as it was feasible to identify the participants from the contacts among the clinicians who have specific experience of POP management.

The logic and power of purposive sampling derive from the emphasis on in-depth understanding. This leads to selecting information rich cases from which one can learn a great deal about issues of central importance to the purpose of the research (Pattorn 2002). Creswell (2007) explains the concept of purposive sampling and states that it is the duty of the researcher to decide who should be sampled, how many people should be sampled, how many places to be sampled and what form of sampling should be used. The sample selected should be accessible, have knowledge of the issue that is going to be explored and must be willing to provide information (Creswell 2007).

Data saturation is the point at which no new information or themes are observed in the data. Therefore the required size of the sample is something that will only become clear as the study progresses (Keyes 2010).

#### **4.6.3 Location of the research sites**

The researcher selected all three regions in Nepal to collect data. There were a total of seven research sites within five districts. In the mountain region, Sindhupalchowk district which included two research sites i.e. Manekharka and Tipeni. In the hilly region, the Kathmandu district, Dhading district and Kavre district which included four research sites i.e. Dhading, Kathmandu, Dhulikhel and Dapcha. In the plains region, Dhanusha district which included one research site i.e. Janakpur.

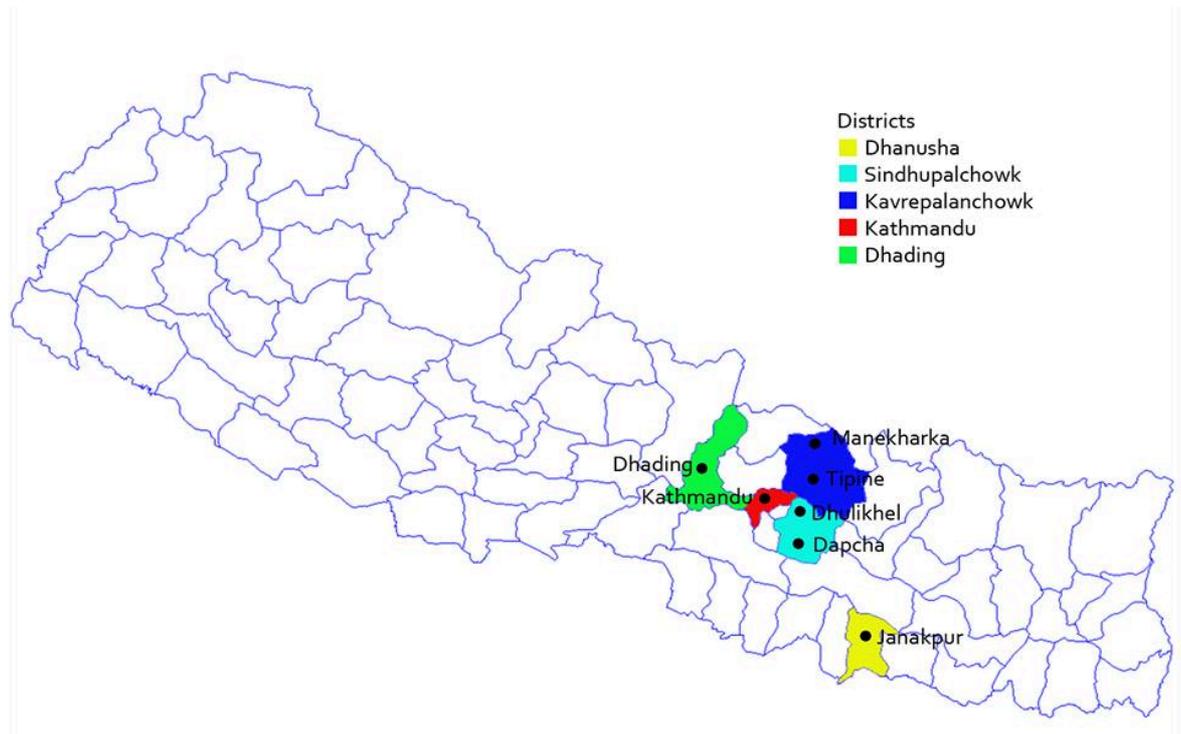


Figure 4.1: Map of Nepal showing location of research sites in 5 districts of Nepal

#### 4.7 Participant Recruitment

Though the sampling approach provided less practical guidance for estimating sample sizes prior to data collection, the researcher planned for ten participants with experience of POP management, from three different regions, for one-to-one interviews. Similarly, for the clinicians a similar, purposive (snowball) sampling technique was used. Ten clinicians who were involved in the management of POP and working in different parts of Nepal were recruited for the one-to-one interviews. This sample was reviewed to ensure that data saturation was achieved, within practical limits.

Focus groups usually employ such purposive sampling where the cases are not selected randomly but are selected as a group with similar experiences based on the research question (Robinson 1999). The researcher planned a separate group of participants for focus group discussions. A total of 10 women participants and 10 clinicians were recruited for the focus group sessions. However, not all participants were present at each group.

#### **4.8 Plan of the study**

The focus group method in health care organisations has become increasingly popular as it is a direct method of obtaining rich information within a specific social and professional context, where people consider their own views in relation to others (Robinson 1999). A successful focus group discussion relies heavily on the development of a permissive, non-threatening environment where the participants feel comfortable enough to discuss their opinions and experiences without fear that they will be judged or ridiculed by others in the group (Hennink 2007).

In the context of POP, a very common problem, the researcher planned to begin collecting data by approaching the women participants first via focus group discussion. The decision was challenging for the researcher because normally the voices of women from rural Nepal are not heard. However, from the researcher's previous clinical practice she was assured that women can speak about their problem if given the opportunity and were allowed to. With this confidence the researcher prepared women for FGD. The principle of 'homogeneity' according to Greenbaum was followed by not including the participants from diverse cultures, social status and hierarchical positions. This was necessary to avoid inhibition or situations where some participants are embarrassed to talk in front of people with whom they feel distant in terms of life experience and representation of the world (Greenbaum 1988).

FGD is an appropriate methodological tool to prompt the participants to articulate their shared and different experiences and produce relevant information. However, there are disadvantages such as: formation of ambiguous situations; unequal participation of all; incomplete analysis of the topic; obtaining polarised ideas; inhibiting innovative ones; activating defensive strategies to protect individuals in the group rather than them actually presenting themselves (Acocella 2012). The researcher recognises situations and will avoid such circumstances by giving adequate time to prepare and offer explanations to the participants in the FGD.

The first stage of data collection involved FGD with a homogeneous group of women who all had experienced POP management. Semi-structured questions were posed to the participants to facilitate the sharing of their common experiences. The questions explored their general knowledge about the causes, effects and treatment of POP and the barriers to treatment. The researcher had the opportunity to listen to shared and opposing views which,

as Gaiser mentions, may not emerge from interviewing women on their own (Gaiser 2008). However, it was planned that no questions would be asked which were too sensitive or difficult, to maintain the confidentiality for the individuals.

The second stage of data collection involved one-to-one in-depth, semi-structured interviews with the first group of women participants. Based on narratives; the individuals were encouraged to give accounts of their personal experiences before and after management of POP. POP being a common problem, it is a sensitive as well as an embarrassing and stigmatising issue. These stories enabled the researcher to make sense of the experiences within their POP journeys. However, the researcher was aware that to build trust with the participants and at all times ensure confidentiality and sensitivity, she needed to build rapport. Ryan and Dundon define rapport as a global term, involving the exchange of meaningful dialogue that captures how respondents interpret their social world. They mention a rule of thumb for eliciting superior quality data as: the better the quality of the relationship between interviewer and interviewee; the richer the quality of the data elicited (Ryan and Dundon 2008).

Similarly, the third stage involved one-to-one in depth, semi-structured interviews with the second group of participants, the clinicians. Narratives collect the metaphors or stories that individuals build to describe, explain and make sense of their experiences and serve as a way for the researcher to attain a richer understanding of participants' realities (Docherty and McColl 2003). The philosophy behind planning one-to-one interviews with the clinicians was to obtain the individual views about POP management to understand the situation more clearly. It was very important for the researcher to listen to the personal views from the clinicians about their ongoing management and to identify any gaps in management programmes which she anticipated they may not be able to voice in a group. In this way the researcher accessed the multiple realities of many clinicians' personal professional views. In one-to-one interviews, participants can elucidate their personal experiences, challenge the issues related to management and voice potential ways forward for policy improvement.

Finally, the fourth stage of data collection involved a focus group discussion with the clinicians who were involved in POP management. Clinicians working in different sectors were involved. This was done to promote a certain level of dynamism in the discussion and obtain rich data from their collective debate. This discussion was considered as another

important part of data collection. It was planned in such a way that the clinicians working in all sectors i.e. the Government, medical college, private hospitals were included with half of the participants having experience of surgical camps. The FGD was seen as appropriate with the clinicians so that uncertainties and unclear issues obtained from the one to one interviews related to the management of POP could be clarified and strengthened.

A topic guide (Appendix 11) was used to guide the discussion. The first two data collection stages explored the impact of POP on the lives of women. The range of experiences gleaned from the women reflected the research's first objective. The last two data collection stages explored the management situation and highlighted gaps in the management. The findings from these provided a platform from which possible actions could follow.

#### **4.9 Ethical considerations**

This research involved women who have experienced POP management. Data from the women were collected to explain their understanding of living with POP before and after intervention. The clinicians, involved in POP management were the second group of participants from whom management issues were elicited. A request to undertake the research was submitted to Northumbria University Ethics Committee and contained the well explained participant's rights and safety along with the research methods for collecting data and an explanation about the Data Protection Act. The Northumbria University Ethical Sub Committee (HCES) provided the authorisation for conducting this research in the year 2011 (Appendix 4). As the research was conducted in Nepal, mostly within the premise of Dhulikhel hospital catchment areas the researcher also obtained authorisation from the research section of Kathmandu University School of Medical Science, Dhulikhel Hospital in the year 2012 (Appendix 6).

The researcher is aware of the ethical standards of beneficence; non-maleficence; respect for autonomy and respect for justice (Brazier and Cave 2007). Any issue related to genitalia is a taboo issue in Nepal and the emotional reactions associated with research in POP may cause harm to some participants. The researcher made every effort to be ethically sound in her decision making and provide the participants with an understanding of their contribution, ensure their safety within the study through trust and openness between the research participants and her. Visiting participants several times before data collection during the recruitment process helped establish good relations.

Informed consent and confidentiality should minimize harm for research participants. The guidelines of the International Conference on Harmonisation (ICH 1996) for good clinical practice define informed consent:

*'A process by which a subject voluntarily confirms his or her willingness to participate in a particular trial, after having been informed of all aspects of the trial that are relevant to the subject's decision to participate. Informed consent is documented by means of a written, signed and dated informed consent form'* (ICH 1996).

The researcher assured participants of confidentiality in one to one interviews. However, she was aware that maintaining confidentiality for focus group discussion is not possible. Tolich, states that for focus groups, informed consent and confidentiality may uniquely manifest themselves as endemic ethical dilemmas for the researcher because of few ethical assurances (Tolich 2009). To avoid this, participants for the focus groups were made aware of these endemic ethical dilemmas (confidential personal matters may come out) in advance, to allow them to consent to share responsibility for any potential harm.

Informed consent was taken from all research participants. For educated clinicians, the researcher faced little difficulty in informing them of the study and obtaining consent in the form of a signature. For some of the women participants living in rural areas, who were uneducated, the researcher faced the difficulty of gaining written consent after informing them verbally. Informed consent of a verbal form was obtained from these participants. After obtaining the verbal consent the researcher wrote the name of participants on the consent form in front of them (Appendix 9). Some of these were recorded and later on transcribed and translated. An example of obtaining verbal consent is attached in Appendix 10. The research ethics committees were informed of the appropriateness of gaining verbal consent from the women who cannot read and write. Those participants who could write were asked to sign the consent form. This also helped the researcher to assess the level of education among the women in rural areas. The researcher was fully aware that she should avoid using negative language and risky situations. The researcher thus followed ethical procedures as outlined in the statement of informed consent to all participants and researcher was satisfied

that ethical considerations were fully respected. Throughout the entire process no complaints were made against the conduct of this research.

It is very important to know the possible impact, the potential risk of psychological and emotional distress or discomfort and conflict that may arise during the research process both to the participants and researcher. The researcher, at one time faced emotional distress in a woman; the data collection process was stopped temporarily and the researcher provided time and an appropriate environment for the participant to recover from the situation before continuing. The participants were not under any obligation and they were informed of their right to leave if they no longer wished to take part in the research.

One participant voiced emotional distress which was upsetting for the researcher. Ramos acknowledges that the benefit of the interview does not outweigh the harm to the participant during interview (Ramos 1989). In this instance the interview was stopped and the option for both continuation as well as discontinuation of interview was given. However, she once again explained how confidentiality would be maintained by anonymising her name so that people who read the research would not recognise her. With this trust, the interview proceeded. The researcher felt that the situation did not warrant terminating the interview completely.

The researcher being a clinician as well as researcher faced potential conflict. She would see these women as patients, but for the purpose of research, she tried her best to take off her clinician's duty during data collection. Throughout the recruitment process she continued her work as a clinician and continued to look after women as well as recruiting women participants. To present as researcher, in front of patients, she avoided wearing a white coat. This helped to explain that she was not working as a clinician at that time. On that particular day she would only deal with data collection for her research. However, she was also aware that while dealing with patient participants the interview session could also become a counselling or treatment session at some points. By creating a friendly environment and using simple language the researcher helped the participant understand the purpose of the research and the role of the researcher during recruitment. It was cross checked by the researcher herself to identify whether women understood the process or not. In this way the researcher was able to balance the situation.

Despite trying her best to present as a researcher, it was difficult for her to fully step outside her medical role at all sites. At one point, the researcher was asked to examine the women participants on the day of data collection. These women had been operated on in the camps and were facing problems but had never had a chance to see the clinicians after surgery. So, at the request of the gate keeper (community health in charge) the researcher needed to switch into her clinical role and examine them after completion of the data collection. The outcomes of the examinations are presented in the findings chapter. Holloway and Wheeler (2002) mentioned that such conflicts can arise when the researcher has a dual role of the care giver as well as researcher. In such instances where having a commitment to ensure the integrity of the research they state that researchers must acknowledge their obligations to their professional code: they have a duty of care to the patients (Holloway and Wheeler 2002). Though, the researcher here switched to being a clinician, she had the opportunity to explore the reasons for poor QOL after management of POP.

While dealing with the clinician participants, the researcher often had to avoid conflict when presenting herself as a researcher to her colleagues. She was able to negotiate her path by communicating with them about her role as researcher and the purpose of her research. While dealing with clinician participants many discussions about other prolapse related management issues were raised. The researcher was aware that conflicts can arise between the academic clinicians and clinicians in practice only. Such conflicts were more obvious in the clinicians' focus group discussion. Minor conflicts, however can be healthy in discussion with differences of opinion bringing interesting perspectives making the data richer. However, major and uncontrollable conflicts may emerge during the process; the researcher informed the clinicians beforehand about the possibility of having to stop the discussion. The researcher herself was determined to stop the discussion if such circumstances appeared.

Ethical issues relating to participant's confidentiality when using research assistants may arise. The researcher was well aware of this situation. To avoid breeches the research assistants were included in the research ethics and the aim and objectives. The research process integrity was therefore maintained.

#### **4.10 The need for a pilot study**

A pilot study refers to a mini version of the full-scale study and can also be known as a feasibility study. The specific pre-testing of a particular research instrument such as

questionnaire or interview schedule can be carried out (Van Teijlingen and Hundley 2001). The pilot study enabled the researcher, who had no previous experience of qualitative work, to develop confidence for the main study by enabling her to expose any difficulties during participant recruitment, data collection and analysis. The pilot study was very useful to ensure that the chosen approaches were appropriate for eliciting the data required to answer the research question. The sample selection criteria were similar to the main study group as described above. The participants of the pilot study were afforded the same ethical considerations (as described in the ethical consideration section of this chapter) as the main study group. The pilot, for this study involved a fewer number of participants but included both semi-structured interviews and a focus group. There was one focus group and two one-to-one semi-structured interviews with the women participants and two one-to-one semi-structured interviews with the clinician participants. The pilot study began in January 2012 and ended in November 2012. Analysis of the pilot data was carried out and preliminary findings were presented at the researcher's annual progression interview (Appendix 13 for pilot findings). The findings from the pilot study data were not included in the findings chapters. However, some of its findings have informed the discussion.

#### **4.10.1 Learning from the pilot study**

The researcher learned that recruitment of participants was not easy. Planning according to the different sites (mountain, hilly and plain regions) was required. The pilot study demonstrated to the researcher that visits to clinics are severely restricted during certain months of the year due to extremes in the climate. Another important revelation came from visits to the recruited centres. The patients had a routine day fixed for visiting outreach centres. For example: in a month either the last Friday of the month or the second Thursday of the month. The researcher learned that women would not turn up just to be part of the research on days other than routine visiting days. Therefore the researcher understood that her research must coincide with routine visiting days. Recruitment of participants as well as data collection took place on these days.

The patient recruitment process in Janakpur (plains) region was found to be more difficult than in other regions as no routine visits were scheduled. While visiting Janakpur the researcher also realised that language was a problem. She needed to recruit an assistant who could be helpful in data collection and analysis as well as in translation. Maithali, the third language was difficult to understand for the researcher and she had to completely depended

upon research assistant. For this reason the data collection from the women participants was kept on hold. From a personal safety point of view also this region was judged to be unsafe because of political activists. Finding patients who had already undergone prolapse management was another challenge in this region. Young women, around 35 years, may have had their uterus removed for other reasons, for example abnormal uterine bleeding or pelvic inflammatory disease. Because of these reasons the Plain region was held in reserve by the researcher. However from previous visits to several hospitals, clinic patients' details were found to have been recorded in a register. The assistant recruited was asked to review this list for the next data collection should more participants be needed.

Recruiting clinician participants was another challenge noted during the pilot. The researcher planned to collect data by inviting clinicians to her work place in Dhulikhel, however none of the clinician participants wanted to visit Dhulikhel for the interview. Data were then collected according to a mutually convenient place and time in clinician participants' working place. Pilot data were collected from clinicians who had only worked in the government hospital in Kathmandu. For the main study data collection, to gain a range of views, the researcher planned to interview clinicians working in different sectors (Government, medical colleges and private) and places.

The researcher learned that it was important to have one research assistant to help with data collection and analysis. On many occasions difficulty was experienced during data collection. For example, while conducting a one-to-one interview focusing on the interviewing she realised that she was unable to look after the tape-recorder, or note changing expressions and other non-verbal cues. For the focus group discussion with women, the researcher prepared a research assistant for data collection who was male. The reason for utilising male research assistant in pilot was for their availability in visiting different outreach centers and their background of public health with knowledge about data collection for qualitative research. However, as the assistant was male, the participants refused to allow him inside the room. Therefore, the researcher handled the entire discussion alone. In order to note who was speaking she was busy writing identification points along with the moderation. This possible gender issue was hidden to the researcher before commencing the pilot. The experience with this gender issue allowed the researcher to decide on recruitment of female research assistants for the main research. Staff nurses, who were familiar in qualitative research, were recruited as assistants. As the recruited research assistants were

familiar with qualitative research process, with minimal orientation they understood their role for this study. Their roles were for recruitment of participants, to help the researcher in data collection and for translation only. However, the research ethics committee was made aware and gave approval.

The researcher learned from the pilot that major changes in the prepared questions were not required. However, the decision to change the environmental domain among four major domains i.e. physical, social, psychological and environmental from WHO-BREF into economical domain was made after pilot study. The decision was taken because the surrounding environment depends on the economic status of the family. The pilot study suggested a need for modification in the technique of asking questions for the main study. As the researcher had no past experience of collecting data for a qualitative study she was restless at times and was busier talking than listening. Over time and with practice she however learned to listen and to moderate more effectively. After the pilot data collection, analysis techniques were applied. The researcher previously was prepared for narrative analysis with narrative data collection. However, the collecting method for narrative was found appropriate for the women but did not fit well for the clinicians'. Hence, to accommodate both groups of participant's data, a framework analysis method was chosen. This exercise provided more insight into the need to focus on the research aim and objectives during data collection and analysis. Although the pilot study was time consuming, the researcher learned that systematic improvements were necessary in each stage of the research process. Recruitment approaches, data collection methods and the analytical pathway benefitted from the preliminary work, thus enhancing outcomes from the main study.

#### **4.11 Data generation for main study**

##### **4.11.1 Recruitment of the first group of participants who had experienced POP surgery**

The researcher gained access to and approached the first group of women participants who had experienced POP surgery, via the gatekeeper, 'community in-charge' (Health assistant) at Dhulikhel Hospital as the researcher does not have direct, legitimate access to the potential participants. The community in-charge further recruited persons, in-charge in different places to help the researcher. The community in-charge along with the person in-charge at different centres was given explanations of the aim and objectives behind the study and the

importance of anonymity and confidentiality within research ethics. Following this induction, the research sites were determined according to the advice provided from the community in-charge. The researcher planned to recruit participants who had experience of POP management in a hospital as well as through surgical camps. This planning was changed after the pilot study because the participants for the pilot were all managed in hospitals so seemed satisfied with the service without many complaints and could not fulfil the aim and objectives of the study.

The research was conducted across three different sites: Manekharka, the mountain region; Dhading, the hilly region and Janakpur, the plain region. During the time of recruitment for the first group of women for the main study, a decision was made to include additional sites: In the mountain region, Tipeni, instead of Manekharka was identified because of difficulties in getting access to Manekharka during the rainy season. Tipeni lies in the same district and many women from there have been treated in surgical camps in different places. In hilly region, Dapcha was added along with Dhading because the women participants from Dhading had been previously used for the pilot study. The researcher cancelled a visit to the plain region in Janakpur to recruit the first group of women participants because of language problems, the unstable political situation and unreliable weather. However, for a later data collection stage the researcher managed to visit clinicians in Janakpur. The clinicians were identified to be fluent in Nepali language. Recruiting clinician participants from Janakpur for data collection was therefore possible for the main study.

Listing of participants who had undergone POP treatment according to the recruitment strategy was arranged by the person in-charge at different research sites, following instruction from the community in-charge at Dhulikhel Hospital. Throughout the process of recruitment and data collection the researcher was constantly in contact with the community in-charge and person in-charge at different research sites. However, researcher was informed by gatekeepers that those women who had not improved after going through surgery did not show interest in participating in the study. Here, the few initially interested participants were encouraged to bring women with similar POP histories to meet for possible inclusion in her project.

In the selected research areas, visits were made on the hospital visiting days except for the Tipeni where she attended on separate days. The reason behind visiting on these days was

to ensure the availability of patients and the health team which go together to work in the remote areas. The political situation, risky environments and access difficulties also contributed to her decision. The researcher tried to recruit participants on non-hospital visiting days but it proved unsuccessful. There were several reasons behind not being able to manage this. First, women were not sure that the team would arrive on non-hospital visiting days. Even after giving assurance, women were also afraid that their whole day would be wasted if the medical teams did not come. Their work at home was more important to them. Some women failed to convince family members that their presence was required at the clinic on a non-hospital day. Receiving information about the research and providing an interview was considered less important than their health check up or obtaining medicine. Lastly, the relatives could not understand why the hospital team should come just to talk to a wife or daughter in law? Sticking specifically to hospital visit days, the recruitment process was found to be very time consuming.

During the process of the recruitment, the researcher provided, with help from other team members, a health check-up and health education. She also provided information regarding POP except in Tipeni where unfortunately there were time constraints. The pictures taken during the recruitment period and data collection time are in Appendix 8. The researcher was able to invite the participants on the planned date and provide general information about the research. The information giving sessions, though consumed her time, helped her to build a rapport with the participants during data collection. The information sheets (Appendix 2) were read through for all women participants and handed over to interested women who took them home. For most women the researcher had to read through and explain the information sheet as they were unable to read. The researcher wanted to make sure that the women knew exactly what was being expected of them. The information sheet also emphasised that confidentiality and anonymity would be respected and maintained and the women would not be under any obligation. The researcher visited the participants several times before the actual data collection. Through these visits, planning for the focus group discussion and the one-to-one interviews were arranged. Once a woman had accepted the invitation and the researcher was sure that she understood the nature of the research, informed consent was taken. For the participants who could not sign the consent paper were provided only verbal consent. A sample of which is provided in Appendix 10.

In this real world project, the researcher was constantly encountering, and having to deal with, different situations. The following scenarios capture some of these encounters.

On 23<sup>rd</sup> March 2013 the researcher, along with her team, visited Manekharka, a research site in the mountain region. On her return two local men asked for a lift. As it was a hospital vehicle, with 6 staff along with a driver and the researcher's ten year old son permission was refused. But after 30 minutes three men appeared suddenly and started to attack the vehicle. The vehicle stopped and they began hitting the windows with sticks. One of the staff went to talk to them but they slapped him on his face which was very worrying. The staff member was called back to get on the vehicle which just managed to escape from the area. The matter was not reported to the police as the driver suggested that if future visits were to be made then could create problems to the hospital team.



Figure 4.2: An access on the way to Manekharka

In the month of April, 2013 a research site in the plain region, Janakpur was visited for recruitment and a planned visit the following month was arranged by the research helper from that region. The day before the planned visit, there was bomb blast, so the trip had to be cancelled. For the researcher's safety a single visit to interview the clinicians only was planned to take place in central Janakpur, in zonal hospital and around its periphery.

On 8<sup>th</sup> June Friday, a visit was made to Dhading. Two participants were to be available for interview. It had been raining for two days and in order to avoid a difficult river-crossing to

reach the site a short cut was taken. About 15 minutes from the health centre the road became very narrow and the staff had to disembark and help guide the driver across the road. Immediately after the vehicle had crossed a landslide blocked the road. The vehicle managed to reach the centre but unfortunately none of the participants appeared. The next visit was planned for July 13<sup>th</sup> 2013 when the long route was taken.

#### **4.11.2 Recruitment of second group of participants who were involved in POP management**

The second group of participants were the clinicians (gynaecologists) who were involved in the care and management of POP working in different health sectors of Nepal. The clinicians were recruited from the government hospitals, private hospitals and medical colleges from different regions. The recruitment process started in March 2013. Similar snowball technique was used in order to gain access. To make initial contact the researcher used Facebook messenger. During the process, once fully informed about the aim and objectives for research, other suitable clinician participants were suggested by some of the initially contacted participants. Through this medium telephone numbers and email addresses of possible participants were obtained. The invitation letter and information sheet were sent to the clinicians electronically. The researcher made further planning with the second group of participants for data collection via telephone. The clinician recruitment process was found to be more difficult than that for the patients. The clinicians were often unavailable and had serious time constraints. The researcher had to take leave of absence several times from her workplace for recruitment and data collection which was not very easy for her. Though there was difficulty in recruitment, once doctors accepted the invitation it was easy for them to provide informed consent. The researcher visited several hospitals in different parts of Nepal for recruitment and data collection. The interview sites were selected according to the convenience of the clinician participant. These were mostly their working places.

The recruitment of clinicians for the focus group discussion was a challenge for the researcher. She found it the most difficult aspect of recruitment for her study. The participants selected were from expert groups occupying good positions, mostly in the field of management, who could influence future policy. The aim of the study is to explore management policy and identify ways to improve it. It took researcher almost six weeks just to organise a convenient time and place for the two-hour session. Though, the time table and agenda were provided well in advance, for a variety of reasons not all those who had

agreed to attend could participate. The researcher had to be satisfied with only five participants in her focus group discussion. The sampling matrix in both groups of participants with their anonymised identity is presented below. The initial ‘W’ and ‘D’ represents woman and clinician respectively.

#### 4.11.3 Sampling matrix

##### Women participants

| S.N. | Name | Age | Place of residence | Interview | Suffering duration | Organization |
|------|------|-----|--------------------|-----------|--------------------|--------------|
| 1    | WBI  | 49  | Dhading            | OTO       | 11 years           | NGO Camp     |
| 2    | WRA  | 53  | Kavre              | OTO       | 13 years           | Govt. Camp   |
| 3    | WDK  | 54  | Dhading            | OTO       | 18 years           | Govt. Camp   |
| 4    | WCM  | 48  | Kavre              | OTO       | 6 years            | NGO Camp     |
| 5    | WTPA | 60  | Sindhupalchowk     | OTO       | 30years (approx.)  | Govt. Camp   |
| 6    | WTPB | 52  | Sindhupalchowk     | OTO       | 17 years           | Govt. Camp   |
| 7    | WRK  | 60  | Kavre              | FGD       | 30 years (approx.) | NGO Camp     |
| 8    | WSA  | 61  | Kavre              | FGD       | 30 years (approx.) | NGO Camp     |
| 9    | WIS  | 57  | Kavre              | FGD       | 20 years (approx.) | NGO Camp     |
| 10   | WSK  | 57  | Kavre              | FGD       | 18 years           | NGO Camp     |
| 11   | WMA  | 46  | Kavre              | FGD       | 11 years           | NGO Camp     |
| 12   | WMT  | 47  | Kavre              | FGD       | 17 years           | NGO Camp     |
| 13   | WHM  | 74  | Kavre              | FGD       | 23 years           | NGO Camp     |
| 14   | WNMT | 38  | Kavre              | FGD       | 13 years           | NGO Camp     |

Table 4.1: The sampling matrix: Women participants identity

### Clinician participants

| S.N. | Name | Age | Gender | Interview | Working at          | Place of working | Work experience |
|------|------|-----|--------|-----------|---------------------|------------------|-----------------|
| 1    | DTH  | 50  | F      | OTO       | Medical college     | Kathmandu        | 18 years        |
| 2    | DGG  | 51  | F      | OTO       | Medical college     | Kathmandu        | 21 years        |
| 3    | DYD  | 38  | M      | OTO       | Medical college     | Kathmandu        | 7 years         |
| 4    | DSS  | 41  | F      | OTO       | Government hospital | Kathmandu        | 9 years         |
| 5    | DRM  | 37  | M      | OTO       | Government hospital | Janakpur         | 7 years         |
| 6    | DPA  | 44  | M      | OTO       | Private hospital    | Janakpur         | 11 years        |
| 7    | DTS  | 43  | M      | OTO       | Medical college     | Kavre            | 9 years         |
| 8    | DRI  | 46  | F      | OTO       | Private hospital    | Janakpur         | 15 years        |
| 9    | DDA  | 48  | M      | FGD       | Private hospital    | Kathmandu        | 14 years        |
| 10   | DKC  | 56  | F      | FGD       | Medical college     | Kathmandu        | 29 years        |
| 11   | DPR  | 52  | M      | FGD       | Medical college     | Kathmandu        | 19 years        |
| 12   | DPR  | 64  | F      | FGD       | Medical college     | Kathmandu        | 34 years        |
| 13   | DMS  | 43  | F      | FGD       | Government hospital | Kathmandu        | 10 years        |

Table 4.2: The sampling matrix: Clinician participants identity

#### **4.11.4 Data collection**

The data collecting tool utilized for both groups of participants were focus group discussions and one-to-one semi structured interviews. The first group of participants (women participants) was planned to be complete before the second group of participants. According to the plan, the focus group discussion was to be followed by one-to-one semi structured interviews. However, the recruitment of participants for the focus group was time consuming as participants from the previous planned site Dhading had been used in the pilot study. Here, researcher decided to begin with the one-to-one interviews with the women as the recruitment process for the focus group discussion continued. The interviews continued even after completion of the focus group discussion.

With the second group of participants (clinicians), the researcher managed to organize one-to-one, in-depth semi-structured interviews followed by a focus group discussion as per plan. The final dataset includes a total of two focus group discussions and fourteen one to one interviews. The total duration of interviews was 1284 minutes. It was 600 minutes with the first group (women) and 684 minutes with the second group (clinicians). For women participants, the longest interview was 77 minutes and shortest was 44 minutes with average duration of 57 minutes for 6 one to one interviews. Similarly for clinician participants, the longest interview time was 80 minutes and shortest was 35 minutes with average duration of 63 minutes for 8 one to one interviews.

The interviews were conducted using a topic-guide (Appendix 11) which helped as checklist. Exploration was through providing informally, open-ended questions on the subject. For the women participants the questions explored the development of and their life with prolapse, their search for treatment and their lives following prolapse intervention. Similarly, for the clinicians, the topic guide explored their views on prolapse management, the present status of treatment and their plans for future improvements in the service for women.

All the interviews were digitally recorded using mini disc-recorder. Supervisors recommended this recorder for supervisory meetings at the beginning of the studentship. The researcher found this recorder very useful also for the supervisory meetings recording and to re-listening to discussions and events. The researcher had thought of using a video camera but found the mini disc-recorder more advantageous as it is a small, handy device and did not distract the attention of participants. The same recorder was used for all data collection.

For the one-to-one interview the researcher handled the recorder herself which included introducing the machine to the participant and switching it on and off during interviews. But, during focus group discussions, the handling responsibility was given to research assistants. The other recorder was borrowed from hospital to use in focus group discussion. It was returned after copying and deleting the data from the recorder. The research assistants also helped to make notes during the discussion process. In addition to the interview information, the researcher also used her notes from field visits and her reflexive diary (Appendix 8).

#### **4.11.5 Reflexive perspective**

The pragmatic point behind collecting the women's data first before speaking to the clinicians within a clinical environment was mainly because accessing women in rural areas in different regions was difficult. But on reflection listening to the women's stories first was found to be helpful for this study. It gave me an opportunity to listen to women speaking openly about their lives before and after POP management. By the time the clinicians' interview commenced a change in understanding of women's perspectives had occurred. Their stories had already started impacting on my view as I began realising how important the issues were to women. I felt lucky to be able to step outside my clinical position to explore what could be done by exploring POP from the women's point of view. This enabled me to gain understanding which would inform the interviews with the educated clinicians. The management of POP has a significant impact on women and their families. Identification of the position of women in society and relate it with their QOL by interviewing women first brought the richness in the data. If the clinician's data had been collected first, the research might have lost some of its richness.

#### **4.11.6 Transcription and translation**

The language used for collecting data was the local Nepali language (except for one). The researcher had to deal mostly with two (Nepali and English) languages. Although sometimes, she had to deal some phrase in an additional local language (Newari and Maithali) often which was further explained in Nepali by the participant themselves. Polkinghorne stated that qualitative research is considered valid when the distance between the meanings as experienced by the participants and the meanings as interpreted in the findings is as close as possible (Polkinghorne 2007).

Temple and Young (2004) mentioned the issues of translation are influenced by two factors: the epistemological position of the researcher and conditions related to specific language (Temple and Young 2004). For this study, the researcher was herself involved in data collection and translation (some from women's data and most of the clinicians data), she speaks the same Nepali language as the research participants which together reduced potential bias in translation during the process of knowledge creation. Edwards (1998) discussed the technique of back translation to ensure the agreement of correct version of text (Edwards 1998). However, this was not applied for its risk of losing useful meaning. The researcher was conscious about such processes where significant nuance and meaning could be lost or misrepresented. Translation therefore, was carried out directly keeping some of the Nepali words and phrases, which couldn't be or were poorly translated, as they appeared. For example, a participant explained her pain as 'khet ko bhus khadeko jasto' which was kept as it is as it cannot be directly translated into English. It means the pain is similar to that developed when rubbing the husk of rice onto skin, a kind of burning pain due to friction.

In the initial phase of data collection the researcher was involved in translation. She found the job very time consuming, taking nearly eight to ten hours for each interview. To reduce the time commitment this translation job was given to a research assistant. She translated the collected data and the researcher checked it. Even checking took four to six precious hours. While working with the first women's focus group, the researcher enrolled a community nurse who worked for the researcher as another research assistant. The assistant came from the same location (Dapcha) where the focus group discussion took place therefore, knew the participants well. She was involved in recruitment, helped the researcher in data collection and also transcription. The researcher herself was involved in translating the transcribed data after checking.

For the clinician participants, data collection started with one-to-one interviews and ended with their focus group discussion. Once again the researcher tried to transcribe the clinician's data to see differences from the women's interview transcription. However, this was time consuming and there was no difference noted from direct translation. Most of the data from the second group of participants had been translated by the researcher herself. One clinician participant gave the interview in English which the researcher found very easy to transcribe. In each case the researcher offered her understanding of the term in English. The first letter 'W' in provided name represents the women and 'D' represents clinician.

#### 4.11.7 The framework analysis

While involving two groups of participants to study a single subject and to accomplish the aim and objectives, the researcher needed a method which could merge the data. This was possible via a framework technique. Fig. 4.3 illustrates how framework technique been applied in this study. The following stages of framework analysis adapted from Swallow, Newton and Lottum (2003) were followed:

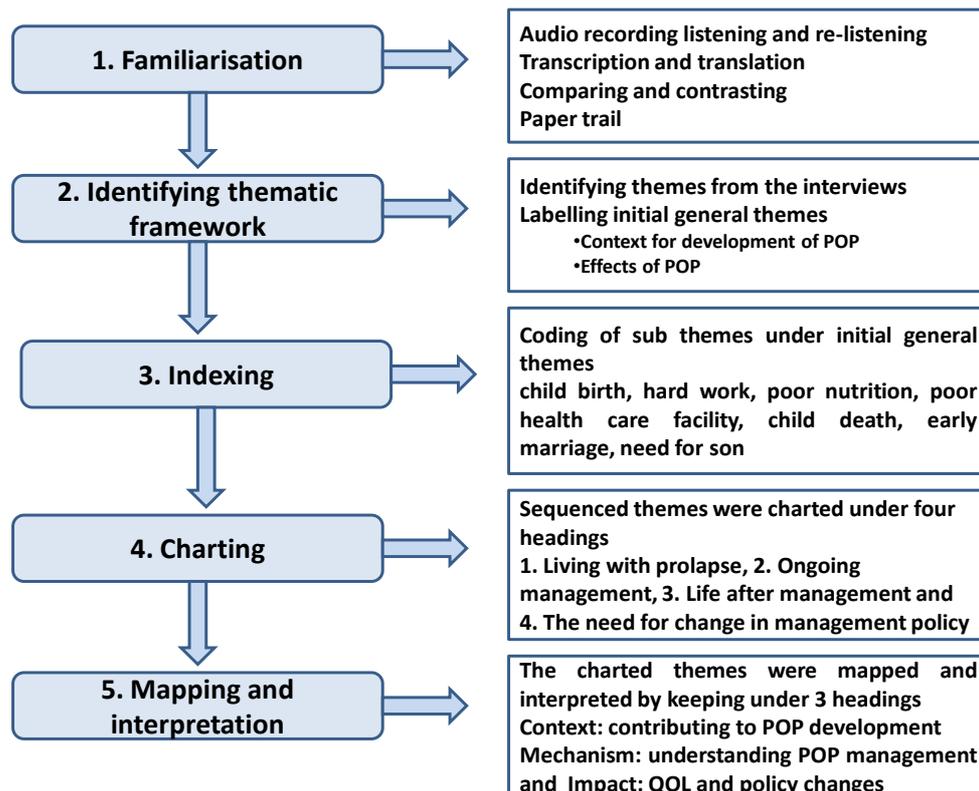


Figure 4.3 The stages of the framework analysis and example of its application. Adapted from Swallow, Newton and Lottum, 2003.

#### Stage one: Familiarisation (Immersing in data)

The researcher was immersed in all her data. To achieve familiarisation the following stages were carried out.

- Audio recording listening and re-listening
- Transcription and translation (one to three languages)

The detail about the transcription and translation has been described earlier in this chapter. The first translated data was sent to supervisor and feedback was collected before translating more. The researcher ensured that original meanings were kept intact by not translating words that were difficult to translate or had a different meaning following translation. Though it was kept untranslated the interpretation of similar meaning was provided and explained.

- Comparing and contrasting

This was done first within participants; among women participants and among clinician participants and then second across participants between the two groups (women and clinicians). It was started at the beginning looking for similarity and then negative cases were identified (those who had not improved even after management). This brought richness to the data making the researcher reflect on the possible reasons why there was no improvement even after treatment. Similarly, with clinician participants shared views were considered alongside dissimilar views within their management. The comparisons of views (about the surgical camps, personal experience of case management both in hospitals and in surgical camps) brought richness to the data analysis.

- Paper trail (field notes and reflective notes for each visit and impressions of interviews)

An audit trail was captured from the data obtained, the field notes, impressions about visits and the researcher's reflective notes. This further helped in interpretation of the data by clarifying what exactly participants wanted to explain. Her feeling from a reflexive perspective have been presented above in this chapter.

**Stage two: Identification of a thematic framework (abstraction and conceptualisation)**

- Identifying themes from the interviews

- Patients one-to-one interview and FGD
- Clinicians one-to-one interview and FGD

The identification of priori themes started at the time of data collection. Repetition of words such as home delivery, hard work, no health care facility for the development of POP; and mass, pain, discharge for the effects of POP. However, following familiarisation initially

women participants data and then clinician participants data were kept separately and looked at for similarity and dissimilarity. From there, initial general themes were identified, labelled and kept in order. For example 'context for development of POP', 'effects of POP' and 'seeking health care'. Identified initial general themes were ordered and separately assessed by coding the transcripts where sub themes were identified.

### **Stage three: Indexing**

- Identifying codes - Coding of sub themes was carried out from the transcripts. For example, the factors related with the context for developments were coded (child birth, hard work, poor nutrition, poor health care facility, child death, early marriage, need for son).
- Grouping codes were then utilized to identify key themes again like 'position of women in the society'.
- Identifying challenges (from both groups)
  - o Verbatim participant quotes
  - o Why these labels and where have they come from?
  - o Reflexive stance
  - o Critical friending (a very similar and a very opposite opinion on similar issue were identified and kept together, similar issue but lay and expert opinion were kept together. For example, similar and opposite opinion about availability and use of contraception and also its lay versus expert opinion).

The identified initial themes were ordered with verbatim quotes and separately assessed for the above points to bring the richness to data analysis.

### **Stage four: Charting**

The sequencing of the themes, both from the patients and clinicians, were used to create charts of data which could be easily read across the whole dataset. The charting was done in four stages:

- Living with prolapse
- Ongoing management
- Life after management
- The need for change in management policy

### **Stage five: Mapping and interpretation**

The themes obtained finally from charting were mapped by defining phenomena, creating typologies, finding associations, providing explanation, developing and defining strategies and finally interpreted by classifying and analysing under the three headings “Context: contributing to POP development”, “Mechanism: understanding POP management” and “Impact: QOL and policy changes”. The impact is based upon the outcome following development of POP and outcome following management. These three headings will be presented in the finding chapters, each as a different chapter.

### **4.12 Ensuring rigour**

Without ensuring rigour, qualitative research becomes an invalid fiction. Qualitative research findings are evaluated in terms of trustworthiness, which comprises credibility (in preference to internal validity), transferability (in preference to external validity), dependability (in preference to reliability) and conformability (in preference to objectivity) (Shenton 2004).

#### **4.12.1 Credibility**

Credibility deals with the question, 'How congruent are the findings with reality?' Lincoln and Guba (1995) argue that ensuring credibility is one of the most important factors in establishing trustworthiness. An important aspect of credibility is to present the data and the process of analysis in relation to the research questions. Credibility will be enhanced through reflection and discussion of the findings and presentation of the authentic voices of the participants.

Triangulation is one of the techniques to improve the credibility of findings and interpretation. Triangulation aims to gain information from three different directions. In this research to assure credibility, the researcher merged data obtained from the two different groups of participants collected via utilising different tools and utilised the reflexive notes about her experience and visits to explain the different issues within the subjects.

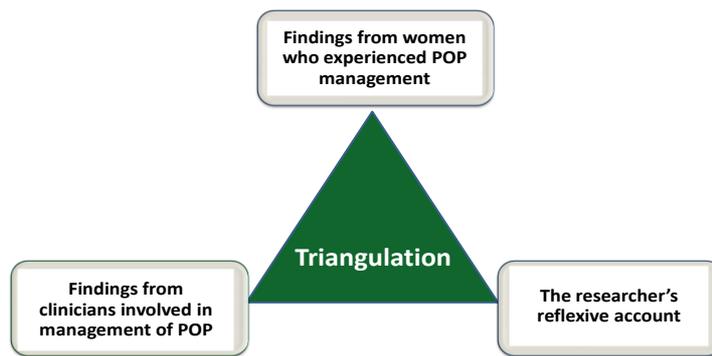


Figure 4.4: Triangulation in this thesis

#### 4.12.2 Transferability

Transferability is similar to external validity and is concerned with the extent to which the findings of one study can be applied to other situations. Since the findings in qualitative research are obtained from small numbers of individuals it is impossible to demonstrate that all the findings apply to other situations and populations. However, Stake (1978) suggests that each unique case is also an example in a broader group so the prospect of transferability should not be immediately rejected. Lincoln and Guba (1995) suggest that it is the responsibility of the investigator to ensure that sufficient contextual information of the study is provided to enable the reader to make a transfer and to have a proper understanding of it.

The researcher presents her findings in a way which will enable the reader to develop his or her own understanding. In this study the data from one clinician and two women's accounts were context specific. In the context of clinicians, the majority were advocating for institution-based surgery for patient safety. One clinician advocated the need for camp surgery for those who are living in extreme rural areas and are completely deprived of medical care. Although many women reported satisfaction following surgery, two were experiencing greater difficulty than prior to the intervention. Their voices have contributed to the themes indicating a need for change in POP management policy. This indicates the researcher's philosophy of listening to women to decide health care approaches which ultimately bring positive influences on QOL. Although the study is related to the management of POP, the emerging themes may well offer ideas for improvements in services in other health sectors, or for women in other developing countries.

#### **4.12.3 Dependability**

Dependability is a technique to show that, if the work were repeated, in the same context, with the same methods and with the same participants, similar results would be obtained or not. In order to address the dependability issue more directly, the processes within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessarily to gain the same results (Shenton 2004). The research report should include the research design and its implementation, the operational detail of data gathering and reflective appraisal of the project. These will be obtained by analysing data and comparing the findings with other research in the area. The researcher stepped back from her clinical role to seek clinicians' opinions on care. Critically analysing the current management of POP in Nepal is the aim of the research to identify how practice could be improved in order to make it more person-centred. Such in-depth coverage allows the reader to assess the extent to which proper research practices have been followed.

#### **4.12.4 Conformability**

The concept of conformability is the qualitative investigator's comparable concern to objectivity. Here, steps were taken to help ensure as far as possible that the work's findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. This was done by keeping all dialogue recordings and transcripts for confirmation. However, the researcher recognises that total objectivity is neither possible nor desirable. She is female, Nepali, has given birth and is a practising clinician in women's health. Her experiences and characteristics inform, and are informed by, her research.

#### **4.13 Limitation of the research**

The study population included women who have experienced POP management. The value of utilising these participants included the opportunity to gather information about POP from different phases from single participants. For example, experience of life without POP, experience of life with POP and experience of life after treatment for POP. The participants provided a wide range of experience across the different phases of their life. QOL they were currently experiencing and the need for changes in management policies were explored.

POP begins as a physical problem but has a social impact. This PhD project could have included other family members to gain opinions regarding POP management. However, they

were not utilised as the researcher saw potential difficulty in managing such a large range of qualitative data.

The researcher involved clinicians who had experience of POP management. She managed to collect data from clinicians working at different levels i.e. government hospital, medical college and private clinics. This provided a wide range of experiences in the field of management. The information obtained from clinicians involved in surgical camps in past days and those who were involved in the government initiated recent surgical camps was an additional strength of the study. A broader picture of care strategies, challenges provided more information on surgical camps.

Considering the aim of the study, the researcher perhaps should have included those involved in policy making. Those involved in policy making are not all gynaecologists by profession. The one clinician who is gynaecologist and involved in policy making was invited for FGD but couldn't attend because she was leaving the country. Her presence would have been of value. However, even in her absence those clinicians who participated in FGD were able to satisfy the researcher's desire to explore policy improvements. However, in the future for studies challenging health care policy level, the researcher recommends involving participants from that level.

#### **4.14 Summary**

This chapter presents the conceptual framework through which the research has been conducted. Underpinned by the aim and objectives it describes philosophical concepts and methodology of the research. The participant groups and their selection within this interpretivist project are explained. The qualitative interviews explore QOL issues for women suffering from POP. The narrative method used here is to gain insight into the QOL for women and answer the research questions through the data collecting tools of one-to-one semi-structured interviews and focus group discussions with women and their clinicians. A framework analysis technique was used to merge data gathered from different datasets. The intention was to identify areas of POP care and management which need to change so that women's lives, as well as their medical conditions, are improved. The next three chapters present the findings. Chapter Five presents the factors for development of POP, chapter Six presents the process for understanding the management and chapter Seven presents the findings on perceived impacts for improving care.

## **Chapter 5: Factors: Contributing to POP development**

### **5.1 Introduction**

In this chapter the findings from both groups of participants are presented. Data from one-to-one interviews and focus group discussions are included. The rationale behind an exploration of the factors is to understand the different background which contribute to women developing POP. Although many reasons, for example, exposure to smoke and the menopause were mentioned, the emergent themes from the combined findings leading to POP in Nepalese women were found to be the position of women in society and issues related to poor health care facilities. Many contributions from the women and clinicians are offered to support the themes.

### **5.2 Position of women in society**

This study shows that socio-cultural practices continue to influence the number of children women have. Giving birth to many children has been found to be associated with the development of POP. Early marriage, the strong preference for a son and women's hard physical work have been identified as sub-themes resulting in POP.

#### **5.2.1 Early marriage**

Marriage forms the basis of family formation and is an important determinant of fertility. The culture of getting married at an early age and its consequence of early and frequent childbirth was shared by many in both groups of participants. WDK is a woman living in a hilly area with her extended family. WDK was married at the age of 15 and became the oldest daughter-in-law. She explained that she was under pressure to become pregnant and deliver her first child in order to avoid social blaming. Culture demands that the first child is born to the oldest daughter-in-law. She describes her first delivery like this:

*WDK - "Now, at that time I was age of 17 years and I delivered my eldest son."*

*R - "First child?"*

*WDK - "Yes, delivered at the age of 17. After that, I did not menstruate umm, not menstruated but then when my older son was 1 year old, on Ashad 4<sup>th</sup>, I delivered another son."*

After her first delivery this mother gave birth to another child within a year without having any menstrual period. 'Ashad' is the third month according to Nepali calendar. The clinicians also identified that whatever the cultural reason for marriage, women who marry early are more likely to have their first child at a young age and give birth to more children. Cultural influences were strongly associated with early marriage. The clinician DRM, from the Terai region identified that if a young woman was not married early her parents would have difficulty in finding a groom when she was older. Another reason offered was that daughters are expected to leave home and potentially add an extra burden on the family if they remain.

WIS was an older woman aged about sixty who married early and soon started having babies. She explained the effect of early delivery on her body using her own experience:

*“Marriage at an early age causes weaknesses. That causes some problems. Then, our body being sano kathiko, inside, will be affected very much”*

Here, she uses the phrase ‘sano kanthiko’ which actually means ‘under-developed body’. She tries to explain that inside this under-developed body, when pregnancy and childbirth occurs frequently, damage to the body parts ensues, leading to prolapse. Clinician DGG also mentioned that adolescents have more difficulties in childbirth than adults. There is therefore, a greater risk of facing complications related to pregnancy and delivery in the future.

### **5.2.2 Need for a son**

The researcher found that there is still a strong family preference in Nepali society for male rather than female offspring. The association between the cultural preferences for a son in the family was mentioned by most of the women. WMA was a woman of around 45 years living in Dapcha. She was the youngest participant in the FG. Being the youngest she describes the demand for a son in the family:

*“There must be a son. That we came to know, doctor saab. Those who have daughters only, when the father dies the daughters can only cry huaa huaa. We have to do rituals in our cast during death but these can only be done by son. Don’ t we? If there is no son, there will not be anyone to do rituals then. Either dumb or disabled, it doesn’ t matter, but we need to have one son. I have seen this.”*

WMA was calling researcher 'doctor saab' here. What she explained here was after the death of parents only a son will be allowed to undertake the cultural rituals. In the absence of a son, the dead body may not be burnt. The phrase used 'huaa huaa' refers to the fact that if only a daughter is present she will be there only to cry, not to undertake the rituals. So, a son is culturally demanded in the family.

DRM explained how the culture of society exerts an influence on women:

*“It is because of culture. Besides culture, it is also the mentality in the society. If they don't have a son then they will be looked down upon. It is also said that if you don't have a son they may tell you that you don't, in fact, have children even. There is a word for it. Umm...nisantan they say that even.”*

He said that in the society where he is living, if a woman doesn't give birth to a son, even if she has a daughter, she will be considered infertile. The word 'nisantan' means infertile which actually describes those who don't have any children irrespective of regular unprotected coitus. Being infertile is socially stigmatising for women; so they keep trying to produce a son.

The second cultural reason, revealed in the study, driving the need for a son in the family relates to future aspects embedded in the culture, as DRM mentions:

*“Once the daughter gets married [in Terai], it is different than in the hilly region. In hilly region the women are more literate than here and they look after father and father in law, but in the Terai this is very rare. Once after getting married, there will not be anyone to take care of older parents. Even if there are 5, 6 daughters, they don't come back and look after parents. This is the culture here.”*

DRM mentioned that culturally in Terai, after daughters get married, they will only look after the in-law's family so they believe that only a son is finally responsible to look after his family in the future. He compares the cultural practice of looking after parents in an extended

family from different places and found that where women are educated, they look after in-laws as well as their own parents.

### 5.2.3 Hard physical work

Women in the rural areas have to work very hard each day. The study shows that their household activities include collecting fire wood, bringing grass for cattle, fetching water, cooking, cleaning, looking after the family, children and cattle and also doing field work. Heavy lifting for the different activities is the daily norm for the majority of women in Nepal. WDK shares her daily activities in this way:

*“I had to work. If I did not work, I will not have income. I didn't stay with in-laws, I stayed separately so I had to do all works myself. It's not like now, I had to work even in the evenings. If I couldn't finish work then I used to wake up at 3 o'clock in the morning to complete my tasks.”*

WDK was living in rural Nepal. People in rural areas were mostly farmers by occupation and they don't have much money. Hard work is required daily to sustain life. In contrast to WDK, WRP was living in an extended family and her views on the need for hard work are:

*WRP - “There will be younger brother-in-law, elder brother-in-law, elder sister-in-law, mother-in-law, father-in-law we have to make them all happy.”*

*R - “Make them happy by working?”*

*WRP - “Yes, make them happy by working hard. Ko bhanda ko kam everybody has to work hard equally.”*

According to WRP those who do not work as per the wish of the family it could become difficult for them to sustain their position in the family. In an extended family, women have to compete by working hard with other members in order to secure a good position in the family. The phrase used here ‘ko bhanda ko kam’ can only be loosely translated as ‘competition to prove who is better’. When explored further, other reasons for working hard, according to WRP, emerge:

*WRP – “It is like this, if you can't impress the in-laws, then they will ask for re-marriage of son and if husband is not impressed then husband will demand another marriage. If you can't impress parents-in-law, the husband will get angry. This is what the custom is. It was like this in those days, not like these days.”*

(laugh)

She explained that her struggle was simply to sustain the in-law's family. She also mentioned that she was not educated so didn't have another living alternative. She could only work hard and impress family members and contrasted her experience with the researcher who is educated and standing on her own feet.

The study reveals a strong association between frequent child delivery and hard physical work with increased rates of POP. When identifying the time that their prolapse developed most of the women mentioned that it was soon after delivery of their first child following resumption of normal work. It was also found that women typically did not alter their workload during pregnancy and resumed normal work soon after delivery. WDK, WRP, WTB and many other women shared similar stories about resumption of work following delivery. According to DTS, who is working in a hospital in the hilly region:

*“It’ s all because of many deliveries. And they also return to hard work too soon. They don't get any rest. When can they take rest? At an interval of one year she is giving birth again. After delivery also she doesn’ t get any opportunity to take rest.”*

The increased numbers of children are another reason for a woman's increased work load. She has no choice but to resume her daily chores soon after delivery.

The migration of men was another reason identified for the continued physical demands on women. This was explained by clinician DRM:

*“Because all the men are away that is also the reason why women have to work more at home. Money will come from the men, but if that person was still at home then there will be division of the work. Household work and field work they have to do it all. Men are not getting job [paid] so they are going abroad.”*

DRM sees migration as the consequence of unemployment. Women are compensating for the absence of men which adds an extra burden of work. DRI, however, justifies migration as being advantageous for the family although it does increase a woman's workload:

*“So, yes, as it happens, every coin has two sides. The man has gone outside to work but the money has increased. In fact I know that many of my patients tell me that their husbands have gone abroad but that they [husbands]tell them to go and see the doctor if you have any problem.[ …… ] but women are taking on more and more responsibilities and this makes them prone to more work. I think so.”*

According to her, the workload responsibilities increased due to the loss of manpower, but with the resulting increase in economic wealth there has been a change in access to and use of health care.

### **5.3 Poor health care facilities**

The study shows that through not having access to the health care services women are inevitably going to deliver many children, which in turn contributes to the development of POP. The sub-themes emerging from the analysis are: poor delivery practice; poor family planning services and the death of children.

#### **5.3.1 Poor delivery practice**

Delivery practice was found to be related to the development of POP in this study. Women participants were mostly between the ages of 40-70 years and most reported having home deliveries. The women participants WCM and WBI expressed that there was no culture during their pregnancies to visit a hospital for delivery. During their childbearing years the health facility was either not available or getting easy access to a clinic was difficult. They are bound, therefore, not to recognise a culture of hospital delivery. WIS explained about her time as follows:

*“It wasn't like now, going to hospital immediately for delivery of child. There was no way and also no vehicle. There was no facility like we have now. Because of that many women suffered. Now, this is one reason that women had to suffer and carry*

*this disease [POP]. See, there were no facilities and we lived in the place where there were no facilities.”*

WIS was nearly in her sixties during the interview and was referring to a time some 40 years ago. Even at present, despite the availability of health centres for delivery, getting access to the place is difficult during the rainy season. She expressed that if the health centres had been available and accessible she would have visited them for childbirth and that might have prevented her own prolapse problems. But the other woman participant WTA from Tipeni, the mountain region, who was almost of similar age expressed differing views on delivery in the health care centre:

*“It [Birth] is not in hospital, it is all at home not like now. In my time I delivered all babies at home. I come to hospital only for illness but delivery takes place at home.”*

WTA is a woman from the mountain region who lives near Manekharka. She wanted to express her beliefs about delivery, which according to her was a normal process which happens on its own and is not an illness. Only for illness should they seek health care. She was aware of the availability of health centres, but had not embraced the idea that delivery should take place there in order to prevent complications.

The findings show that women however wish to deliver with a trained attendant, most of the deliveries occur not only at home, but unsupervised and unattended. The woman participant WRP delivered her first child at age sixteen. She had never seen a delivery before. The conversation below reflects her first child delivery:

*R - “In which place did you deliver your child at home?”*

*WRP - “Near to house we have small pavement and near to that there is a vegetable garden and lawn. On the lawn nearby, I delivered there.”*

*R - “On lawn? … Your first child?”*

*WRP - “Yes”*

*R - “Your first child?”*

*WRP - “Yes, I delivered my first child on the lawn. Then I picked up my child and came to the main door and shouted for help. My mother-in-law came quickly and looked at my baby. Then cut the cord.” “The past talks...”*

*R - “Then she cut the cord?”*

*WRP - “No, I cut the cord myself.”*

*R - “You yourself”*

*WRP - “Yes, my mother-in-law taught me how to do it. And, then I cut it myself.”*

During the conversation WRP seems very confident and was feeling proud that she did it all by herself without much assistance and without compromising her daily activity.

The circumstances around conducting delivery were shared by some clinicians. According to them different sorts of malpractice were still apparent in some rural areas where traditional birth attendants, relatives or someone in the village conducts the delivery. DRI elaborates:

*DRI - “After delivery they do lots of massage. I mean whole body massage and sometimes they press the uterus with foot also”*

*R - “Ummn..”*

*DRI - “So, the traditional birth attendants, especially when the placenta has not come out, do massage. That massage can also give rise to the prolapse right? I have seen two cases of inversion of uterus because of the massage by the foot. Then I anticipate that if someone is massaging vigorously and you have just delivered; the chance of prolapse is very high. I see that most of the women who have a home delivery, when they come to me for some other cause, I also diagnose that most of them have cystocele and rectocele.”*

Cystocele is prolapse of urinary bladder and rectocele is prolapse of rectum. DRI’s statement about vigorous abdominal massage by foot after home delivery was also supported by DGG. According to clinician DRI, the quality of care given in the health care centre was not up to the mark:

*“In fact it is not a good thing to say, but I have seen in the hospital, nurses giving fundal pressure [……] when they are not bearing down well there is tendency to develop, number one. I think, number two, they don't identify prolonged labour at time. [……] I see cases of prolonged labour and obstructed labour. They wait for long, long time for delivery to happen.”*

DRI tried to explain that within health centres some still practice delivery in traditional ways which may aggravate the situation and lead to complications. The reasons for poor practice, according to her, are lack of knowledge and skills in the people involved in delivery and a lack of trained human resources.

### **5.3.2 Poor family planning services**

The non-availability of family planning devices, and possible lack of education to use any means leads to women to deliver many children. Participant WHM provides an emotional account:

*“I don’ t know. If I had known why delivering so many babies makes our body mar parera. We got no rest, nor stayed hygienic and clean. One baby cared for and then another will come along and then another to be cared for, followed by another. Then what to do? Because of not getting any family planning treatment. Now days, here, after giving birth to two they stop. At that time there was nothing to help us stop’ ‘*

She expressed that a family planning service was not available and that she did not have any knowledge of the options. Here, the phrase ‘mar parera’ means creating trouble in body by having many children. She was explaining that, with difficulty, she managed to look after several children then. She is now aware, however, that family planning is a reality for women of today, who can space their children and, more importantly, choose how many babies to have.

The other member in the FGD discussion said that she came to know about family planning methods only after the delivery of her 4<sup>th</sup> child. The medical facility was available during that time but was not easily accessible. The clinician group agreed that the family planning service had been provided in rural areas for many years but that it was not properly used.

### 5.3.3 Death of children

Poor health care facilities have been found to contribute to the death of children. Losing babies was found to be linked to the frequent pregnancies in this study. Among the women participants, it became apparent that most had experienced the death of a child in their family. One woman participant, WHM, tells a sad tale:

*“ It was all because of lack of health facilities. Yearly the death of children was due to lack of these. This much care delivered, that much care delivered. We never got to eat something good nor got to live healthy. Children didn’ t get better care neither did their mothers or others. Now, myself I have given birth to eight.”*

According to her, yearly child deaths were due to the lack of health facilities. Through giving birth frequently her health deteriorated and her children were also not getting proper care. If a health care facility had been available then at least she could have tried to prevent them from dying. The clinician participants DTS and DPP added that child mortality is high in Nepal. The women above went on to deliver many children hoping that some would survive to secure their and their family’s future. DTS explained that the days, when most deaths could be attributed to a lack of facilities, were now passed. Now, after 10-15 years, much has changed because of the increased availability of facilities and better training. Most of the morbidity and mortality related to children was preventable through appropriate, timely health intervention.

### 5.4 Summary

The socio-cultural contexts explored above demonstrate that the position of women is key to understanding the development of POP in Nepal. The socio-cultural practice for women to marry at an early age and the demands made on them to produce sons have a strong influence on childbearing trajectories. Poor access to family planning services aggravates a woman’s chances of spacing her children. High child mortality rates are another factor pushing women to deliver many children. Household labour must also be understood as an important factor. Women are destined to do hard physical work for a living. These contextual findings portray a Nepalese landscape wherein women lack empowerment. The lack of preventive measures makes women at greater risk of developing pelvic organ prolapse.

## Chapter 6: Process: Understanding POP management

### 6.1 Introduction

The aim of this chapter is to understand the processes involved in the management of POP in order to make recommendations which will address the QOL for women. After analysing both groups of participants' data, the two key themes associated with the process of care were: delays in seeking health care and understanding the interlinked elements within care management. These themes and their related sub-themes are presented together with supporting data from both the women and their care-providers.

### 6.2 Delays in seeking health care

Delays in seeking health care affect the QOL for women. They live with POP for long periods of time. The sub-themes identified were ignorance of POP and its treatment and the position of women in the family. These sub-themes, presented below, are in turn associated with the disempowerment of women.

#### 6.2.1 Ignorance of POP and its treatment

Though POP has been found to result in reproductive morbidity for women in the rural areas, many women participants were found to be unaware of the problem. WDK explained:

*“Yes, everybody used to develop [POP]. Cattle also develop the same problem. They used to say this and that it also affects women. We didn't know what the uterus was. I have never known about it. I used to ask myself ‘what happened to me?’ What happened to me? Later on I came to know it [uterus] is the same place where my son and daughter grew inside my body. Later on I realised. I had no idea before. Husband also did not know. .. I never dared to tell him about my problem this can be hard and this can be difficult. What to do then? I have to face.”*

WDK explains in lay terms that development of a bulge after delivery of a child was very common in their community. She was hoping that her mass would go back and she would be all right after a little time. However, she was not aware that the mass was her uterus. Similar to WDK, WIS and WMT also thought it is normal to develop some sort of descent of the womb after delivery. The clinician DGG recounted that for rural women POP is

perceived not as a woman's 'problem' but is understood as a normal phenomenon which happens to every woman after childbirth so they do not seek health care.

Knowledge about treatment was put forward as an open-ended question in the FGD and also asked individually during interviews. In the focus group held in Dapcha, a hilly region most of the participating women did not know about treatment so were living with POP. After the establishment of a health centre by Dhulikhel hospital in this remote place these women came to know about possible treatment. WMT said:

*“How would I know? If I had known there was treatment then would we sit by suffering like this? I thought it would be all right by itself but I became more and more affected the longer I suffered.”*

DGG supported raising women's awareness about treatment in rural areas like this:

*“For the awareness, after such a long time, I give credit to the camps. This credit comes from those who go to camps for prolapse or some other health camps. These actions have brought awareness. That and also the media maybe. The NGOs and INGOs have focused on prolapse more. UNFPA has one special focus on prolapse.”*

The camp is a temporary health care service provided in rural communities. According to DGG although such camps were for a short duration only (weeks), they brought awareness to the people about POP. National and international organizations are now involved in prevention and management of POP which brings additional benefits for women receiving treatment. Local FM radio helped in spreading the message in local languages which has been found to be an effective media to bring awareness to the people according to clinicians DYD and DRI.

### **6.2.2 Position of women in the family**

The position of women in the family is often responsible for a delay in seeking health care. Feelings of shame, family responsibility and financial dependency all coincide to increase delays in seeking treatment.

The women participants, hid the problem for long periods because they were ashamed and felt unable to discuss any problem related to genitalia. The commonly used term was 'Laaz' for feelings of shame. Some women WBI and WDK, for example, said that hiding their prolapse was due to fear of discrimination but also because of feelings of shame. WTA said:

*“He [husband] never asked before. Later on it [prolapse] was out while sleeping as well as standing. At that time he asked me ‘what happened to you’ ? Then I told him this happened and that happened. It is painful and there is difficulty when walking. Then he brought me here.”*

WTA was hiding the problem from her husband for ten years because she felt shame in sharing her difficulty. She said that the mass used to go back inside her while sleeping and was not much of a problem for her. WTA kept quiet for a long time until the mass remained outside even when sleeping. Her husband saw the prolapse and she then shared her problem with him. She was taken for health care after that. WBI and WRP also kept the problem hidden from their husbands as they felt ashamed. However, sharing the problem with their husband was found to be helpful for many women who were then able to seek care, except for a few who were not encouraged to go for treatment due to the expense. Similarly, sharing problems with other women, either with friends or family members, in matters maternal was also helpful. Women participants said they shared their problems with women. WBI shared her problem with friends first. She did not tell her husband, when asked why, she answered:

*WBI - “I felt ashamed, so didn't tell. I walked with friends to places and talked with them and told them what had happened. They used to tell me that maybe [the bulge] is uterus. Then I thought maybe it is. Otherwise I didn't know anything; how it had come out and what had happened.”*

*R - “Your husband never knew?”*

*WBI - “I told him later.”*

In the community women go out together to collect grass, fetch water, and to go to fairs to sell or exchange their products. WBI feels the women are similar (meaning have a similar

lifestyle) unlike those at home with husbands and in-laws who feel comfortable in sharing problems with each other.

A social barrier due to family responsibilities also prevents women from seeking health care. Many (WRP, WCM, WMA, WMT and WDK) mentioned not seeking health care earlier because of responsibilities for children. DGG, a clinician, shared an experience about family responsibility:

*“She will be daughter-in-law in a family. Mother-in-law will not allow her to go and another reason is that she may well be afraid to talk with her mother-in-law. Another reason is her children. Children will be small, looking after them doing this and that in the family means that they will not get time away from family. [……] whoever comes with prolapse are usually aged 40, 50. They will have grown up children with grandsons and granddaughters. After having grandsons and granddaughters, the mother will be having fewer responsibilities in the home [……] when responsibility of family is slowly reduced, she will then feel it is time for her operation. With that calculation, they usually come to hospital I think. Rather than coming in at age 20 or 30 years when they hardly ever come, though they had problem of prolapse for the last 20 or 30 years.”*

The low status of women has been identified as another barrier for seeking health care. However, often people don't seek health care simply because of lack of money.

WDK explains:

*“Yes... I have to suffer. But in my home we don't have much money.....then we don't have much to spend..... had to educate son and daughters..... I had to suffer.....even if I might die, I had to educate children so they won't have to do heavy lifting... then I cannot spend, spend more money... not doing operation won't relieve pain... but to do operation costs a lot and I don't have even Rupees 40 Where can I get this amount? (Pause) Rupees 40,000 is like... a crore [10 million]... then I was in such pain at that time... at that time, oh mother it was...”*

(Deep breath)

*“All that suffering was for lack of money?”*

*“Yes... It was for that.....what could I do?”*

(Pause)

WDK in conversation with her sister in law came to know that surgery cost Nepalese Rupees 40,000 (£250 approximately). She explained about not being able to afford surgery without great difficulty. She was in a dilemma. Without treatment she would continue to have problems, but there was no money to help her. She explained that when she remembers those days, her heart freezes and feels like a knot somewhere inside. She expressed that she had not dared ask either her father or mother for money for her treatment. Instead she hoped that she would not continue to live anymore. Finally, she got the opportunity to have free treatment.

The clinician participants also mentioned that although there are many reasons for delaying treatment the financial burdens play a major part in the delay in seeking health care. According to clinician DGG, she feels treatment costs are expensive in Nepal. Families cannot get credit and have no health insurance which leaves them fearful of not being able to afford treatment. She felt pity for Nepalese women who, because they are poor, are deprived of health services.

In contrast DTH mentioned:

*“Yes, it is because they don't have money. It was always that way. Now, the treatment is free of cost so, we have to think that they don't actually want to spend money. [.....] Maybe they want to spend the money on some other things, for example, owning cattle. They don't want to spend their money on prolapse surgery ”*

What she is addressing here is that women are not in a situation to afford treatment. Even if they have money to spend on treatment of POP they do not want to spend it that way. Women would rather wait for a surgical camp because nowadays they know about free surgical camps in the villages. DTH has enough clinical experience within the community. She feels the women's position in the household affects their use of health care services. According to clinician DTH:

*“Now, females are confined to the house. A male may go here and there. He can walk independently. For a female however, somebody has to bring them. [……] They themselves can't come alone and say they have prolapse and that they need treatment because they are dependent on others. Economically also they are dependent. They don't have money of their own so even if they know about treatment or have transportation how can they come? They don't have anything in their hands.”*

DTS another clinician described the position of women in rural communities as being the reason they were not able to seek care. DTS specifically identified lack of empowerment as the key factor that prevented the use of health care services. DTS explained the women's position in family:

*“That main thing is that it is in the economy. At homes, the husbands or mother-in-laws have main control of their assets or the cash. [……] There is no role for women in asset management or cash as such. If we can empower women, then if the husbands leave them, they are guaranteed that they will remain economically sound and will not be afraid of anybody. Wives always remain dependent on others. She is not secure for her future. If the husbands do bad things too it is out of question to talk against him.”*

According to DTS it is important for women to remain economically sound to gain power and maintain their position in the family, which will help them to become independent and take decisions for themselves.

The researcher presents three accounts from women who describe their health seeking journeys. Within each different story financial problems dominate. They each present ways for getting access to free treatment.

**a. WBI's story**

WBI's son was an army man. After she noticed something protruding from her genitalia she went to XX hospital located at place called Chhauni. From there she was sent to another hospital. There they gave her medicine for a watery discharge only. After taking the medicine

the watery discharge stopped. WBI said at the hospitals (Government) where money was not needed they made her wait and delayed getting treatment. This resulted in her uterus prolapsing further until there was a complete prolapse. WBI said:

*“ I had difficulty walking; difficulty sitting, then went to hospital. I went to Thapathali [name of a place] where my son took me from Mahankal [name of a place] Son had called there first so we went there. It was a government hospital and I was told to wait today, and I waited the next day. It didn't improve. Then I took the medicine [for discharge] and it was ok. Then I stayed quiet seeing what would happen. Then there was one woman down at home [neighbour who went and got treatment]. At that time 4, 5 women were taken in and they got treated. I knew this when they talked to me. Else, I didn't know what to do, where to go. If I had known, I would have gone earlier, when they had gone.”*

WBI then visited a third hospital located at a place called Thapathali where she was again asked to wait. She was fed up with the behaviour encountered in government hospitals and then left feeling helpless. Later, WBI came to know that other women in the village went for surgery free of cost. She communicated with them. The women who came back after surgery scolded her for not going for treatment. Then she made-up her mind to go. Along with one of her close friends she went and had the operation in a private hospital free of cost (funded by NGO). This story demonstrates the ongoing difficulty women have in getting access to health care.

The clinician DKC adds her supports to the situation, saying that patients are treated like dogs in government hospitals. They will not know where to go or what to do. They have to sit for long periods in dirty places. In cities even, there are no client friendly environments. So the middle-class families visit private clinics where they will be provided with respectful and dignified care and where they are more likely to have good outcomes.

#### **b. WRP's story**

WRP started experiencing discomfort after developing POP. Then she went to YY Hospital where she was provided with a ring pessary. She was taught how to remove and clean it and how to re-apply. When asked how she came to know about the ring pessary, she answered:

WRP - *“It was here in our village. There used to be the other women who had prolapse.”*

[.....]

WRP - *“I heard about it and when I asked them, they told me to go for treatment. Among friends we talk. What has happened to me I ask questions about.”*

R - *“Among friends, you talk?”*

WRP - *“Yes, after it started happening.”*

With this treatment, WRP was happy because the difficulties with prolapse disappeared and she could work comfortably once again. But, slowly she started to face difficulty with the pessary. After a few years she underwent surgery. She told of her surgical journey like this:

*“From here the team went to the health post. Health post in Dapcha [name of a place]. The team went from here. From here only. There was an advertisement. There, they were doing the operation. People from here with prolapse were asked to come for treatment. So we all went for treatment.”*

Shared information about surgery from health centres let WRP know more about the ongoing surgical camps. The health centre in the community is the place where all health-related activity is provided. This is the contact point for the different hospitals. According to WRP, the transportation fare was also provided. WRP was feeling a little reluctant to mention the transportation fare. The women with POP, from that area, were taken to and operated on in a hospital in Kathmandu and then sent back home with advice. However, they were disappointed that they didn't know the names of the doctors who treated them and were not given any opportunity to see them again.

### **c. WDK's story**

WDK kept on hiding the problem until her mother asked her about it; after seeing her blood stained clothes. She was then taken to a traditional birth attendant where she was provided with a ring pessary. She was comfortable with her ring pessary at the beginning but this became problematic later on. WDK knew about surgery but because of financial constraints

she couldn't afford to pay for treatment and lived with her prolapse for a long period of time. She shared her feelings after coming to know about free treatment:

*WDK - “One day I sat to cook rice. I was cooking rice and on the same day the radio was on. Then radio umnn, [...] announced ‘For all the ladies and sisters who don't know and have not thought about prolapse care, people from rural areas who are suffering from uterine prolapse please contact us. If they haven't been to Kathmandu, please contact us for treatment. We will do your operation. We have carried out this surgery on many women’ on radio”*

*R - “On radio?”*

*WDK - “Yes, after I heard that on radio I was jhalyassa bhaye ma then. They would do the treatment. Would do surgery”*

According to WDK, listening to the radio and hearing about free surgery was like a blessing for her. She was speechless listening to how women with POP can get free surgery. This unsolicited information came as a surprise to women are suffering from POP. The phrase used here ‘jhalyassa bhaye ma’ means waking up suddenly with surprise to hear something new and pleasing. The radio programme also announced that a foreign doctor had come to carry out the treatment. WDK felt happy because her dream of undergoing surgery was about to come true.

### **6.3 Understanding the interlinked elements within POP management**

The surgical camps at the beginning of the programme started in the health posts or in the schools (in remote places) but later on were set up in district or zonal hospitals and also in medical colleges. The sub-themes identified, in relation to management issues, were trained manpower: limitations at different levels, government shortcomings: surgical camp opportunities, monitoring and supervision: manpower issues. The quality of management was perceived to be associated with women’s quality of life.

### **6.3.1 Trained manpower: limitations at different levels**

#### **6.3.1.1 Screening of women**

The screening for surgical camps is provided by the nursing staff with the help of village health workers. DTH explained:

*“In camps there is time limitation. [……] it is difficult for us to look and evaluate and operate at the same time. So what tends to happens is there will be volunteers who screen patients with prolapse, asking them with some general questions. They don't examine patients. They visit each home asking who else has prolapse problem. They bring the names to the camp. After that, information about the camp will be given to those needing treatment. The nurse or ANMs examine in the first round and select patients and decide eligibility for surgery. They don't do PV [per vaginal] examination, rather they just look [at the prolapse] and select. Once there, we again examine patients to judge their need for surgery.”*

DGG and DYD also added that screening is done by the nurses working in a village, with the help of village health workers and local volunteers. Screening according to them starts a few weeks prior to the surgical camp. They advertise through media, local radio, banners or posters. For screening purposes, according to DYD, they train the manpower involved before setting up the camp. But DTH mentioned that though trained for screening, many other cases may be identified instead of POP (for example; cervical mass). She stresses the need for assessment before surgery and the need for training in screening.

#### **6.3.1.2 Assessment before treatment**

Before surgery in the camps it appears that clinicians are not properly assessing the patients individually, but in groups. DTH mentioned that though they, the clinicians know that every patient has to be assessed individually, this rarely happens due to time and manpower constraints. According to DYD, the screened patients will complete the basic preliminary examinations including investigations and they will be prepared for surgery.

WRP had her operation in one of the camps; she explained her experience of assessment like this:

*“After I went there they checked us at first. Then recorded my name...same. Then I went and stayed at my son's place. They asked us to come next day with an empty stomach. We could not even have tea. They said so and that was it, we left”*

The word ‘same’ is slang while talking. According to WRP, there were many people. Everything was happening at speed. She was quickly asked some questions. The clinician wrote down her responses and did a quick check-up. She has no idea who examined her. According to DYD, working in a hospital is a completely different experience from working in a camp. In a camp, there are many patients and very few clinicians

*“It is completely, totally different scenario in hospital than in camp. Assessment in hospital is very different from that done in the camp. There will be different levels of doctors in hospital. Starting from medical officer to the professor, a senior consultant; it is within this hierarchy that the patient will be assessed. [ .....] Not only the physical examination will be carried out, but how her quality of life is affected will also be assessed. We will assess her socioeconomic status and will be telling her the cost of treatment in hospital but that is different in the camp situation. The number of patients is very high in the camps.”*

DGG agreed with DYD that assessment in hospital is carried out in order to foresee the complications and decide on mode of management. Lack of proper assessment has led some clinicians to operate on complicated cases where the women have ulcers and infections. On the other hand, some women with POP were found to hide their problems for fear of being rejected for the free surgery. DTH encountered this story:

*“They don't talk about their problems. Even pregnant women don't tell. One woman lied about her LMP. She knew that she was pregnant. Multiparous women have a bulky uterus. We did operation on her. [.....] She knew but was not telling anyone because of the fear of rejection and not qualifying for free surgery. She had not told the doctor earlier and we were in some doubt and when we cut a section of her uterus after surgery there was a foetus inside.”*

In hospitals during normal sessions clinicians often did not take an in-depth history to assess women's other problems besides their physical ones. DRI, a female clinician from the Terai region, in contrast, prefers to assess women beyond their physical problems to decide on the mode of management. DPA is a male clinician also from Terai region, he thinks women from here are comparatively more conservative than women in the hilly regions and he can't assess beyond the physical even though he would like to. Instead DPA said his practice depends upon the locality and the social structures, which have made him, practice completely differently from the text book. He gave the following reasons for not assessing beyond the physical:

*“Now, not exactly, we don't go beyond the physical problem. [...]The other thing is, if we ask her questions about her social or sexual life as well as her physical problem they may be surprised and think why am I being asked these different things? If asked these other questions they may react differently. Why he is saying this? That is why we can only indirectly ask them”*

This male doctor recognises the difficulties faced when asking about POP induced physical difficulties in the Terai region. Male clinicians fear that probing beyond physical symptoms may be perceived negatively by the women and their family members. According to DPA, POP induced physical problems are mainly relieved through corrective surgery. When the physical problems are alleviated, then other associated problems, it is believed, will spontaneously improve.

### **6.3.1.3 Poor follow up**

Although the importance of follow up after treatment to prevent complications post-surgery was stressed by most of the clinicians; it was found that this was not happening. DTH shared her feelings:

*“Follow up should be there. It should be done by the one who was involved in the management at the beginning. That weakness [in the system] I feel every time. Recently I went to camp, I have done many operations but what happened to all those*

*women? How are their lives? How many of them developed vault prolapse? How many of them developed urinary problems? I want to know. This was never possible. I never got the chance to visit the prolapse camp site for a second time”*

DTH mentioned that it was not possible to have the same team providing follow up as it will not be economically viable for the government. Instead she suggested the need to train the local health manpower to follow up. This probably would be a better strategy. DYD describes the current follow up system:

*“For follow up after camp surgery, this is what we are doing. I have mentioned that we are working in the district hospital. In that district hospital we have taught medical officers what to look for during follow up. Till now we do only short-term follow ups. [ … … ] We have raised awareness, at medical officer level, that complications can happen and therefore we have to do this. After going back from surgical camp, we contact women by telephone. The medical officer will call directly when patient comes with complications. Some patients come with urinary retention, some with vault discharge, and some with secondary bleeding. If they come we find some are fine but some who are not doing well even after two or three days post hospitalization, we call them for better management here in Kathmandu.”*

Some women however, after surgery did not come for follow up even when asked to. DRM suggested this is because:

*“Lack of awareness is a factor but another reason is domination. I think here women are dominated by men. The men will say ‘now you have been already operated on, why do you need to go again?’ Husbands… they scold. Maybe because of that suppression they don't come.”*

Women who are operated on in the rural surgical camps were found to have less knowledge about follow up than those who had their operation in hospitals. WTA said:

*WTA – “I don’ t know much. I don’ t know who operated on me.”*

R - *“Haven’ t you asked?”*

WTA - *“I was about to die. It was said that if I’ m lucky then I will live, otherwise I may die; they said. That was told to my wife [was telling husband as wife because Nepali is second language for her]. I did not know about this. Who has done my operation? I don’ t know that.”*

R - *“Don’ t you feel like going and meeting them?”*

WTA - *“What to say? I may not recognize him or her. What would I do?”*

Though WTA was invited to come for follow up, she didn’t know where to go or whom to meet. Another participant WRP also mentioned that after surgery in a camp she never got an opportunity to meet anybody. WTB, the other women participant from the mountain region said she was called for follow up at the place where she had had her operation. She was even told not to go to the other centre if any problem developed. She said she didn’t know how to get there and couldn’t recognize the person who had operated. Women after surgery were found to visit nearby health centres following the development of problems.

DRI, practising in a rural area said that many patients who underwent surgery in camps land up in her clinic with many complications. The ones who had their operations in the final days of the camp seemed to get most of the complications. The women then ended up spending the same or more money managing the complications that was needed for the original surgery.

#### **6.3.1.4 Time limitations**

Both groups of participants mentioned the large number of women with POP participating in surgical camps in rural areas. WRP expressed her view about the camps like this:

WRP - *“Yes, there were many people. Many people at that time.”*

R - *“Many people?”*

WRP - *“On that day from morning around 8-9am they started to come and when our turn came it was almost 9pm. Finally, we were told that the operations would continue until the next morning. That whole night they were operating, on the day we had our operations.”*

WRP came for her operation without having tea even and waited the whole day with an empty stomach for her turn to come. Regarding the time and manpower constraints in camp surgeries, DYD said:

*“To carry out the surgical strategy for the existing cases of prolapse management in Nepal, there are only 10, 12 or 15 gynaecologists. If one doctor, let's say, carries out 10,000 operations in a year at the rate of 15 per day, then there will be 1 lakh 50 thousand [150,000] for surgery per year. Doing 10 thousand surgeries in a year, in his/her life time, is next to impossible”*

There are many gynaecologists in Nepal and most of them are female. However, only a few will travel to the remote areas to carry out surgical camps. There are many reasons for female gynaecologists to avoid being involved in surgical camps for example: risky journeys; accommodation problems and risky environments. DYD said that it is not possible to reach the government's target and explained the effect of the limited manpower:

*“Currently, we have to do many surgeries. The amount of work when we have to work beyond our capacity the quality of that work will be compromised. When done in the hospital, we have 2 routine days for surgery, and 1 day of rest. But in camp, if I have gone there for 5 days, I have to work every day at the same pace, from day 1 to day 5 [……] Rest is required but it is not possible in camp surgery. You can work out how many compromises we must make out there.”*

### **6.3.2 The Government shortcomings: surgical camp opportunities**

#### **6.3.2.1 Camp infrastructures**

DYD, the clinician participant who has experience of visiting camps in rural areas stressed the importance of health camps in rural areas:

*“If we can provide services on the women's doorstep; patient participation will be better, which is very important. For example, suppose I have screened and found 25 cases of prolapse and ask them to come to Kathmandu for free surgery; the*

*attendance will be less than 50%. Ten or eleven will come; the remaining fourteen or fifteen will not come for surgery. If we go to them, obviously more than 20 patients will attend and we can operate on them all. With this calculation; I can say that camp surgery is needed.”*

DYD was well aware of the position of women in families and their responsibilities that prevent them from leaving their homes for long periods of time. DGG expressed regret about camps that existed about 20 or 30 years ago; these were set up in health posts. She referred to them as inhuman treatment for women. DPA shared an experience at the first surgical camp in the Terai, which took place at JJ hospital. This is a small hospital where they managed to arrange four operating tables for four surgeons. There were 280 registered cases of POP. It was a huge success although failed to complete all registered cases. However, DPA mentioned that the activities fell short of medical ethics standards as all the protocols for surgery were not maintained. After surgery, patients were kept on the floor.

DYD was involved in a recent camp surgery in a district hospital.

*“The camps where I have been are mainly the district hospitals, where major surgeries were not routinely done. Only 2, 3 days prior to surgery we clean the OT and fumigate that area to keep it clean. We say for surgery, that patients should get a certain level of care, but that may not always be possible because of patient burdens, facilities within the infrastructure, and the instruments that we have which are not always up to the mark.”*

DYD recalled the struggle to carry out what had to be done while working in such temporary settings. Other clinicians involved in camp surgery also mentioned feeling insecure all the time.

### **6.3.2.2 Opportunities to participate**

The government approach to prevention and management of POP is largely based on contracting out to private sectors, who will carry out most of the work in the remote surgical camps. DGG commented:

*“Currently, what is happening is that government has given responsibility to NGOs and INGOs. It is more or less like a contract. INGO and NGO receive money and then sub contract to other smaller INGOs. The private sectors are told that they will get this much for doing a certain amount of surgery. It is like another contract. The more surgery done, in short period of time, the more money they get. They can earn much money. In five days finishing 100 operations compared to finishing 25, the amount is very different. That NGO who got paid benefitted and the ones doing the surgery also benefitted. However, the patient has not benefitted.”*

A personal interest in conducting surgical camps was evident in some people working at different levels. DYD gave an example of vested, political interests in the Ministry of Health who had no real view on POP surgery. Surgical camps in remote places were supported, after elections, in order to show that something was being done for the community. The intention of the district health officer is to demonstrate a commitment during his time in office to secure another higher post. The interests of the health care giving institutions, which may be governmental, NGO or a private body, and who take responsibility for the entire camp, lie in the hope of procuring further opportunities as DYD states:

*“Health care giving institutions report that they have organized camp in remote places. But they don’ t know that surgery should not take place in such areas. That they don’ t know at all. Other local people in the community say oh this organization is strong because they were capable to manage camps in very remote places. So, there is a vicious cycle. [……] Then the organizations give continuity to same health care giving institution. Because of these views conflicting surgery is taking place in such places.”*

DYD explained that health care giving institutions thus get the opportunity to conduct more surgical camps on the basis of past performance in the remote places, irrespective of knowledge of the risks involved with working in remote areas.

From the focus group discussion (FGD) data it became clear that the Government bypassed the Nepalese Society of Obstetrics and Gynaecology (NESOG) in handing the contracts to the private sector providers. The clinicians mentioned that while developing the directive for prolapse management in camps, the Government completely side-stepped NESOG. This

action is not acceptable as the POP management programme requires full NESOG involvement. The members of NESOG were blaming the Government who were not taking complete responsibility for the prevention and management programme along with its monitoring and supervision.

### **6.3.3 Monitoring and supervision: manpower issues**

Young gynaecologists tend to participate in the surgical camps in remote areas; senior gynaecologists do not participate much. DTH's view:

*“Doctors, after newly qualifying as gynaecologists want to go to surgical camps. I feel they should be more experienced before they go to camps. Here, it is just opposite. Experienced personnel don't go to camps. Those who have just graduated and who only know how to take a uterus out are going to the camp for gaining experience.”*

The clinician participants in the FGD referred to the directive which mentions that surgery for POP must be provided only by trained gynaecologists. However, many people from different faculties were found to be involved in the surgical camps.

*DDA - “Non-gynaecologists are also doing surgery that is why there is an issue”*

*DPR - “Surgeons are also doing POP work”*

*DDA - “Surgeons are also doing this work as are MBBS doctors [those who completed bachelor in medicine and surgery degree]”*

*DKC - “MBBS are doing operations. But from the poor patient's eye all doctors are same. How will they know who has MD [those who completed masters in obstetrics and gynaecology], who has training, who is MBBS. They won't know.”*

All the clinicians involved, it would seem, were doing camp work to earn money by removing the uterus and without being concerned about the consequences for that patient's future. DSS's comment illustrated this point. She saw women six months following surgery who had developed vault prolapse. According to her, these complications were because of the involvement of unskilled doctors who simply wanted to learn basic operation skills. They could be Nepali or from a foreign country. The clinicians demand a need to develop criteria

for doctors to be involved in a specific camp. They also propose that participating doctors should have either at least 5 years of experience or special training for surgery.

Among the clinician participants, some had been involved in camps, some were currently involved with government camps and some were not involved at all but gave their opinions regarding the present situation. DTH who has experienced camp surgery shared her experiences:

*“Camp surgery is done in very much compromised situation. Like in the hospital, we get neither instruments nor manpower. No proper space, no proper sterile conditions. What happens if there are complications? That sort of insecurity is always there. But you have to be prepared for everything. If something happens; then I'll do this or refer there. We have to be mentally prepared. Secure feelings when working in hospital will not be there in the camp. There are limitations of time as well. You have to finish a certain amount in one day, otherwise with so many people coming how can we go without treating them? Our conscience doesn't allow for that.”*

Clinicians experienced in camp surgery also mentioned time limitations while operating on women with POP. Clinician DRI, working as private practitioner in Terai region, was not happy with the surgical camp approach. The problem was aired:

*“[……] I don't think that that much care was being given or patients were not being properly evaluated because I am seeing many complications. From camps in remote areas this happens and women come with infections or have not had a proper repair done. They have all these problems. These are serious clinical aspects. Some women were refused operations, and it is not clear why they were denied surgery. So I don't think much care was being given in the camps.”*

Other clinician participants also agreed that the care provided to the patients was not adequate because of time constraints when dealing with so many patients. However, some of the clinician participants (DPR and DTH) mentioned the provision of ‘incentive per-case’ basis being a factor for inadequate care. HT compared work done when the incentive was provided per-day basis against per-case basis:

*“At one time it was never you do this much of surgery and you will get this much of money. Now this is the case. They get money according to the number of patients. One person operated on 200 cases [……] When we did the work, we were not under such pressure. We used to do it according to our capacity. [……] We never did more than 13 or 14 cases per person. That is reasonable I think. I can’ t think of doing 20-25 or 40 cases per day. How they can do this? I don't know. The patient is the patient, an individual patient. How can we perform as if in a factory? Again, each case is different.”*

DPR and DRI contend that money is a big motivator and in order to earn money, many surgeries are carried out in a day. DRI respected the competencies of surgeons who are able to perform so many surgeries but reflected on whether this would be the case without the financial incentive. DPR said:

*“How is it possible? Because anterior repair they are not doing, posterior repair they are not doing. Problem is money with each case. When I used to go for one day they paid 8 thousand.”*

The study also revealed that the managing organisation gave the names of women on the surgery list who had not had the surgery. DPA said that the error had happened because of lack of supervision and monitoring within the Government system. DSS and DTH told a similar story about a woman who came for follow up after surgery with her discharge paper suggesting a vaginal hysterectomy had been performed for her POP but when she was examined, nothing had been done to her. DMS pointed out the need for supervision and monitoring which was supported by most of the clinician participants to improve the quality of care.

The clinicians involved in camps agreed that though they look after patients following surgery, the main focus is the surgery. Many clinician participants (DRI, DGG, DPA) in the study asserted that the post-operative care was inadequate. DYD, a clinician, explained the scenario for post-operative care in camps like this:

*“Another thing is post-operative care, it is very pathetic. May be in the first 24 hours, it is not like hospital care, but still they get good care. Vital signs will be monitored one hourly or two hourly, they get IV antibiotics, IV fluids and get care, if vomiting occurs they receive care. But, from the second post-operative day, what happens is the 1<sup>st</sup> post-operative day patients will get priority. That day for her is 2<sup>nd</sup> post-operative day but on that day a new patient will come. So, in 2<sup>nd</sup> post-operative day they will be ignored; receiving less care. [……] The care giver will not get time to offer advice to them even. That scenario is also seen there.”*

WDK and WTB who had experienced camp surgery, explained that there were rooms in which there were many women who had undergone surgery. The doctors came to examine them in the post-operative room and after three days these women were discharged. DYD, a clinician, shared a story about poor post-operative care and tackling complications:

*“In RR district in the hysterectomy camp, one case which was operated in the morning started developing haemoperitoneum. The monitoring was not good. Staff were not aware of what to do when blood pressure drops. I was informed at one time in the evening only. Her abdomen was distended. I told them it has to be opened up and I should do a laparotomy. The difficulty I faced was whether structure was similar to RR hospital as this is district hospital. The basic equipment required for resuscitation was there. We used to take resuscitation instruments in adequate amounts with us too. When I was doing laparotomy there, medical officers from districts were there but not with our team. They don't have sufficient knowledge to help in operations. Along with 4 nursing staff I did the laparotomy. There was one bleeding vessel which was loose. I tied that and was able to save the patient. But, my problem was, though I had 4 nursing staff this was the first time all 4 had seen a laparotomy. That' s why they faced difficulties in helping me.”*

Lack of trained manpower at all levels is a significant issue in the management of POP. DYD asserted that when complications happen, all the blame falls upon the surgeon. As a result surgeons grow more concerned for the surgery than for pre and post-operative care.

## **6.4 Summary**

This chapter has presented an understanding of the reasons for delay in seeking health care from the women's standpoint together with process within POP management. Both elements are important drivers when planning improvements to policy. Perceived delays were found to be associated with poor socio-economic conditions of the family. Poverty prevents women from gaining education, which in turn, prevents women from becoming independent decision makers. Lack of understanding and empowerment was also associated with poor communication skills and acceptance of the need to seek health care. As a result, women suffer for prolonged periods of time which impacts upon their QOL. Discussions around the ongoing management of POP revealed a lack of trained manpower at different levels, and maintenance of appropriate standards, the effect of which brings major challenges for those who try to maintain quality throughout the care process. The Government is endeavouring to provide care to the women but there are problems over internal management responsibilities between different organizations. There are also weaknesses in supervision and monitoring which, if unaddressed, will further impede management quality. The next chapter addresses the impact following POP interventions. These are presented as challenges within QOL contexts and for policy development.

## Chapter 7: Impacts: QOL and Policy Challenges

### 7.1 Introduction

This chapter introduces the impact, across different QOL domains, after the development POP and following intervention. Management issues will then be presented. Finally, the chapter concludes presenting suggested policy changes with explanations of ways management could be improved. Each theme is supported by quotations from both the women's and clinician's contributions.

### 7.2 Impacts after POP development

The effects of POP on the QOL for women as identified by both groups of participants are presented below; based on different domains of QOL. However, the principal theme identified, the physical domain, negatively affects all other QOL domains for women.

#### 7.2.1 Physical domain

The physical domain includes bulge, pain and discharge from the mass. These physical factors were found to affect women's daily activities resulting in poorer QOL. The physical domain impacted upon other areas of their lives, including sexual, social, psychological and economical domains.

Having a bulge was the first symptom that women noticed after developing the problem. Discomfort and difficulty in walking were the two significant elements which almost all the participants mentioned as an effect of POP. WRK expressed her handling of the difficulty like this:

*“I knew something had fallen, something fell, I didn’ t know that it was prolapse. Water was not flowing in mine [vaginal discharge]. Now, I couldn’ t walk, couldn’ t eat, then walked two steps and pushed it back and again walked. I managed like that. Then when it was too much and I had the operation. It had come out completely.”*

WRK, a woman from the hilly region developed POP after the delivery of her eldest son. She lived with her prolapse for thirty years because she was unaware of the possible

treatment for the problem. According to WRK, all the time she could manage herself she resumed her daily work but she had surgery after the prolapse began aggravating her more.

Clinician participants also raised the issue of difficulties women face because of the mass and how they try different ways to obtain relief. According to DSS:

*“Somebody must have thought that a ring pessary was a bangle but they don't really know and tried to apply a bangle. Some had replaced the prolapse by applying a cloth like they do during their period. They said if they remove the cloth it [prolapse bulge] will fall down. I have seen that. The cloth was foul smelling. When asked about it, they said they apply it [cloth] daily, but they probably change it at intervals of three four days only.”*

The above statement describes the best coping option lay women have at their disposal to reduce their prolapse. The ring pessary used for conservative management is called ‘chura’ in the Nepali language which means ‘bangle’. Women in the village who have not seen a pessary but have heard of chura used their own bangles to push back the bulge. The presence of a bulge was found to be affecting the women’s routine daily activities of walking, sitting, urinating and defecating. These disturbances seriously hampered their QOL as their mobility is curtailed.

The findings from the study suggest that the QOL of women depends on their ability to work for the family, which relies on their mobility. Restriction of mobility has created different problems for women. According to WRP, POP hampered all her activities once she began having difficulty walking. She had problems carrying water, bringing grass for cattle, collecting firewood, working in fields etc. which were similar experiences to the others who developed POP. WDK, another woman participant, explained her feelings:

*WDK - “It used to stay out. If it was possible to cut it myself, I should have cut it out.”*

(laughing)

*R - “But you have not cut?”*

WDK - *“If I could. It used to hurt during that time. If I had cut - then it would be more difficult wouldn’ t it?”*

R - *“Uhhh...”*

WDK - *“I used to feel like that. I could have cut it entirely and thrown it away. I use to think those things from my heart several times. These thoughts used to come. I couldn't walk properly so what was I to do?”*

R - *“What used to happen?”*

WDK - *“It was difficult to walk in day time. It's like burning fire there... inside... inside a burning sensation. Again that rubber ring was there. That was still there inside then. I hadn’ t thrown it away. Later on, after throwing it away, it was even more difficult.”*

WDK being a woman from the hilly region needed mobility in order to perform her everyday work and her bulge was disturbing her. While she was explaining, it was clear that she really meant to cut the bulge entirely and throw it away because of the associated difficulties it had created. In contrast, she explains her comfort:

WDK - *“Now it was in the char pahar it gets better. It used to give me back pain at day and once I went to bed, it used to get better.”*

R - *“After sleeping it used to get better?”*

WDK - *“Yes, in the next char pahar it gives comfort. All right at night. I used to wait for night to come because for the feeling of comfort. I have to finish all my work during day time. At char pahar I used to have sound sleep.’ ’*

According to WDK throughout day she needs to work hard even with her prolapse and pain. She longed for the night to come. Here, the phrase ‘char pahar’ means a couple of hours at night. While sleeping, the bulge repositions itself and she obtains some comfort when lying down.

The women participants mentioned work which they need to do in a sitting position, for example cutting grass, cooking, washing, milking a cow or buffalo. Sitting, in the rural

context, means sitting mainly in a squatting position. While doing that the prolapse used to protrude and cause pain or disturb the posture itself. WMA shared her difficulties:

*“After it [prolapse] started falling out, I started facing many difficulties. [……  
]Now, if I sat for milking buffalo that prolapsed bag of bulge used to come out and lie on the floor. Once it is on the floor I can't get up and walk that easily. It is like the head of a child. Then I would put the bucket down, sit on it and push it back. When pushed back it makes a sound while walking like bhatta tatta. I was ashamed to stand in front of others.”*

WMA's husband was ill and was not able to help the family so WMA had been doing all the work. The above statement explains how she milks the buffalo, with difficulty, by sitting in a squatting posture twice a day. After repositioning the mass, the sound 'bhatta tatta' was heard. This sound like during passing flatus or wind from her bowel which made her feel embarrassed several times in front of others. Other concerns relating to the bowel were expressed by the women.

It has been found that food intake is associated with the POP. Many women participants (WCM, WRP, WNMT and WIS) mention aggravation when the bulge descends, bringing discomfort after taking a full meal. Some mention pain in their lower abdomen after a meal. According to WRK:

*“It was difficult. Even wished to I can't eat everything, it used to cause a burning pain. If I walked for some time, then I felt like not to have to walk. All my body starts getting weak. I couldn't walk then.”*

WRK like other women used to avoid having a full meal which made them feel weak. WCM mentioned that she can neither eat a full meal nor avoid eating as she cannot work with an empty stomach. Some women mentioned being more comfortable with an empty stomach. None of the clinician participants mentioned a relationship between taking food and aggravation of POP symptoms.

The study also reveals a relationship between the mass and difficulties in urination and defecation. Urinary problems are expressed by WMA:

*“When I went to urinate and sat down I couldn't pass urine and when I stood up urine used to flow like a tap”*

WMA experienced urinary problems. The urine flow was blocked while sitting and poured out, as if from a tap, once after standing up. Along with this problem she also frequently suffered from a burning sensation during urination. Similar complaints were expressed by WNMT and WSK. Combined with most of these physical discomforts the women tolerated varying degrees of pain.

The majority of women participants talked about pain following the development of a bulge. The symptoms of low back pain and pain in the lower abdomen were found to be very common among women. WRK likens her pain to her time in labour, similar to the pain giving birth to a baby. Her pain used to be at the front and at the back in her lower abdomen. WSA, another participant experienced similar pain. She shared the effect of her pain:

*“Back pain and pain in lower abdomen. Couldn't eat. I couldn't walk due to back pain. I had to clean house by sitting but I couldn't sit, so I had to do it standing. I had difficulty in walking due to backache.”*

WSA's pain was creating difficulty in her daily work. She shared the problem with her husband, hoping that he would tell her to seek treatment. Instead, he advised her not to apply any instrument in her body (invasive treatment) at this age. So she continued to live with her POP. WMA explained the nature of her pain:

*“Doctor, I feel like I' m on fire, burning, feeling like khet ko bhus khadeko jasto polne. Burn up to here, burning sensation deep inside.”*

WMA was referring to the researcher as ‘doctor’ again. The pain was a deep burning type. She used the phrase ‘Khet ko bhuskhandeko jasto polne’ which means the pain was like the friction caused deep inside like by rubbing husk of rice on the skin.

Women who had POP for a long period of time also complained about vaginal discharge. Some complained of a watery but many complained of a blood stained discharge. WNMT said it was very problematic for her because water used to flow out and wet her wherever she sat down. WMA explains:

*“It affected me doctor saab. Sometimes it feels like having menstruation. But it will not be there. While walking, because of friction from both thighs, it [blood] used to flow. One dhoti will be changed, then after some time another dhoti is needed. While walking, blood used to dribble. If I sit in the toilet it becomes all red. It used to give me burning pain, massive pain I used to have. It was like that”*

WMA explained the difficulty she had due to bleeding. The friction given by both thighs to the bulge while walking causes ulcers and the bleeding occurred there. ‘Dhoti’ is the cotton cloth women wear in the village. That cotton cloth will stick to the ulcer and when they tried to remove it the bleeding would start again. They needed to change the cloth several times a day. The bleeding was occasionally massive in amount, simulating menstruation. The clinician participant, DSS, mentioned that she had seen women in the village walking and dribbling blood drop by drop. In order to avoid friction they used to walk with their legs wide apart. Blood discharge can be understood as a portent for death, making the women fearful. According to DSS:

*“There is tremendous psychological effect. Following prolapse when they develop ulcers and bleed, they are afraid of cancer. They come with a fear, telling that they couldn't sleep the whole night. They come saying ‘I have cancer’ When examined, they are found to have prolapse with decubitus ulcer.”*

Women’s fear of cancer is one of the reasons for seeking health care in this study. The study findings show that the women participants experienced real difficulties when asked to share the sexual problems they faced with the development of POP. Instead, they shared other problems that came between husband and wife because of POP. These will be described under social domain. However, women reported having painful sexual contact in the study. WDK started to have pain during sexual contact after the development of prolapse. She couldn’t share this problem with her husband. The conversation below she did share:

*“When I told him, he said, ‘what would happen? I haven't done so harshly that causes pain’ . He was like that. It is not painful for him. He didn't feel pain, but I had. Nothing would happen to him. Then for them, only this sexual contact matters. Then he didn’ t leave me [force to have sex]. What feelings of mine matter to him···  
···? (pause) I’ m used to face such problems. What to do?”*

WDK said there was no love between her and her husband and she was only ‘needed’ for short periods of time for having sex. If she refuses sex then he used to beat her. According to clinician DPA, like WDK, many women face difficulties because of painful sex but they never speak out. It is in the culture that women will not raise their voice against their husband. DPA explains:

*“ After development of prolapse women develop difficulty in the body. [·····] Another thing is sexually related problems which will be there as well. They must be doing sex with difficulty. In our society, when husband tortures wife there are very few women who talks about it outside [the family]. Also at the age of 40 or 50 years, I don't think even 0.1% ladies will be talking against their husbands. They may report my husband is like this, he is not helping me. Up to this point, but saying that husband used to force me for sex or hit me, that does not happen. ”*

DPA agrees that following the development of POP along with different physical problems sexual problems also occur. The culture of the society will not permit women to complain about these difficulties outside the home. When the doctor referred to older women he was making the point that they will be very much dependent on their husband and family. They fear rejection so they keep quiet even when facing serious sexual problems.

### **7.2.2 Social domain**

The social domain in this study is divided into relationships within the family and relationships with the wider society. The relationships within the family are further divided into relationships with the husband and relationships with other family members.

The relationship between a husband and wife, although a private entity, sits better within the social domain. The study confirms that how society behaves towards women depends upon

how the husband behaves towards his wife. POP is associated with sexual problems. The study found that following the development of POP, husbands of many of the women participants turned their affections towards other women. A FGD clinician participant told a story about a woman from LL. DPR happened to visit her during one of the medical camps.

*DPR – “I would like to give a small example. I went to LL [name of place]. There I went for a general health camp. There came one patient with prolapse, 32 years old young lady with prolapse who was the mother of 6 children. She wrapped her prolapse at her waist as it was of size up to her knees. Her husband had left her because of this problem. When asked why he left her, said it was because of her prolapse. He has 6 children with his wife who has prolapse problem. Instead of seeking treatment for his wife he brought another wife and started living with her. I brought that woman to Kathmandu and operated and then sent her back home. That patient came to me after 9 months. At that time she brought a small pot of ghee.”*

*[.....]*

*“When I have asked why you have brought me this she said because of you my husband came back. If the prolapse has impacted this much; then there must be an effect on physical, mental, social - everywhere it has an effect. I have found this.”*

Development of POP hampers the relationship between husband and wife in many ways. Some were physically abusive, some deviate towards other women while some left their wives. DKC agreed that to maintain marital harmony sexual function is important and when the husband cannot get satisfaction he brings another wife. What is seen from the outside is that the husband-wife relationship is not good. The reality that the breakdown is because of the prolapse problem is neither recognised nor understood. Once a husband starts ostracising his wife, then everybody in the family will treat her in the same way in the rural area.

Most of the participants were part of extended families in this study. In rural communities to maintain the harmony between family members, women need to perform routine daily activities. WRP shared her experience of living in a big family:

*“If I can't make family members happy who will feed me? You are standing by yourself on your own feet; that is why you are happy. If not, then you have to make your family happy by working for a living.”*

WRP tried to explain that to sustain relations in the family, a woman needs to work hard. Here, she was telling the researcher that she is standing on her own feet which means earning enough to maintain her place as she can't do otherwise due to lack of education. She can't contribute to any other financial activities of the family; therefore she need to work hard for the family. Family relationships depended on the performance of her work. After developing POP, when they came to know about her problem, the reaction of WRP's family members was described:

*“What you developed [bulge] nobody has that. Of all people you are the one to develop the problem. Older people used to say this in the family. Many things are said when you have a problem. You don't know anything. But nowadays people will not have such problems.”*

The family members were not happy about WDK's problem and blamed her as if she is somehow personally responsible for her prolapse. They do not consider how she might have developed the problem and what could be done for her. Here, as the researcher was not from the rural area, DK was making it clear to her that she couldn't know what happens within families in rural areas. Aspects of relationships between family members after a woman develops prolapse was also been raised with the clinicians. According to DDA and DSS, the family relationship after the development of prolapse will deteriorate for the daughter-in-law. The family is not ready to accept that the woman's problem is because of the hard work they have to do for the family. Instead they begin to reject the woman; she becomes shunned by family and society.

People in rural areas live together in a society. Development of POP, in this study, is a very stressful situation for women. The women hide their problems from family members and other people for fear of discrimination and not being able to socialize.

*WBI - “Yes, maybe other people will see. What will other people say if they see it? I used to feel so deeply. How could this disease be caused? I felt tension, maybe I might die? What will others say if they see it [prolapse after death even]? Used to think that maybe they'll see it.”*

*(laugh)*

*R - “Why must it have happened?”*

*WBI - “Tension was not about maybe I will have this disease and I will die but was about what will others say if they see it? That person has this disease. Maybe they will say this has happened. Rather than tension of I might die of this disease, I was afraid of what others will say if they will see it.”*

The reason behind feelings of discrimination was linked to shame, as POP is a problem associated with the genitalia. WBI was very concerned about people knowing her problem. She was even worried that people might come to recognise the prolapse after her death. According to her, the fear of social discrimination is present in every woman. Her prolapse was not visible while walking, but while sitting. When it became obvious, in order to hide the mass while sitting, she used to push the mass tightly with cloth. Only then she would sit. Though women hide the problem from others for fear of discrimination, the study found that they felt free to share the problem with their friends rather than with their families. Many women mentioned comfort when sharing their problem with friends. The study also revealed that sharing helped the women find ways to seek treatment.

### **7.2.3 Psychological domain**

Psychological factors were not directly expressed by participants. However, from their stories, the researcher identified a range of stress-related issues that the women faced. These are presented here as psychological components.

Not knowing about POP was found to be a significant cause of stress for the women. Many women participants did not know what was happening as they developed their prolapse. Some thought that POP develops in all women after childbirth and will right itself later on. Women became stressed when they developed a prolapse. DKC, one of the clinician participant states:

*“Prolapse definitely affects quality of life of the patient. So far I think physically and mentally, may be both. One thing is they do not know what a prolapse is. When mass is coming out, they must be psychologically upset. That is one thing. Something is coming out, but what it is they will not know. In that sense they may be facing torture. They can't go to places. May be they can't afford treatment. The service is not accessible. There is no support from the family. That torture is there mentally in them.”*

According to clinician DPR, psychological problems are more prevalent in a young woman, as her family responsibilities will be greater compared to other family members. WDK explains her distress:

*“Family members used to tell me that I work, but why has this woman started working lato chadeko. They used to say this to me”*

WDK was unable to share her problem with the family and she became wearisome, her work monotonous. She started working even harder but without speaking. Here, ‘lato chadeko’ means working monotonously like a dumb person. Family members noticed this but nobody thought about to enquire why she had changed or whether she was upset or ill.

The clinician, WPA, mentioned that all problems are interlinked. When an adult female in the family are unable to work she must face physical, economic and social problems which, together contribute to psychological problems.

The development of suicidal thoughts and even attempting suicide was confessed by one of the participants. She had not shared these feelings with anyone previously. WDK described the moment she went to commit suicide:

*WDK - “Ummn at that time I felt why do I have to experience [all troubles] by living? Instead of suffering, it is better to die by hanging. I felt like that once.”*

*R - “Ooh!”*

*WDK - “Then once, heart said bring some poison. I have committed crime being a woman that I have to suffer so much. Tolerate husband's beatings. Now I can't be happy even if I die. Suicide means that a killer can never get happiness even after*

*death. Heart said living is similar to death for me. Then after that, that idea didn't work. I went. Then I saw that I have children and when they'll grow up, they may say that if I had lived till they grew then they would take me for treatment. If dead, they may say 'mother why did you killed yourself like that?' Then I said now this idea will never come again."*

Suicidal thought is a psychological phenomenon which WDK developed after a long period of suffering and seeing no alternative to get rid of her problem. WDK compared her life of suffering to hell. She was also pregnant at this time. She thought of taking poison first, and then changed her mind, to hang herself later. One morning, very early she went to hang herself. Just before the attempt she sat near the tree and smoked. Then she thought whether she could be happy even after killing herself as she has responsibility to raise many children. She thought that even her children would live with a question as to why their mother left them like that. Hoping to get treatment once the children grew up, she changed her mind about committing suicide.

#### **7.2.4 Economical domain**

The majority of the population in rural areas are farmers by occupation. The study shows that the contribution from women to income generation through their involvement in agriculture was significantly affected after the development of POP. This problem decreased their working capacity, which directly or indirectly decreased their income. WTPA explained the effect on the economy:

*WTPA - "He used to sit at home saying that this woman may die now. He never used to go to earn money also"*

*R - "Why"*

*WTPA - "Thinking that I may die"*

*R - "He didn't want to leave you. Wasn't it more difficult then?"*

*WTPA - "Don't know. We used to borrow and live in debt. Buy."*

WTPA is a woman from the mountain region. Her family don't have their own land. For their daily living they had to work for other people in the fields. WTPA's husband used to work and bring home enough money for one meal a day. This stopped after she became sick.

She was getting worse day by day. Her husband thought she was going to die so didn't want to leave her. This worsened their economic condition even more. The clinician also believed in a cyclic relationship between POP, hard work and poverty. Following sickness all productivity will be affected. DKC compared the difficulty when a family member becomes sick in her own family like this:

*“Somehow while talking about prolapse we also have to consider financial status. Simple people living in village. When one member of our family gets sick, how difficult it is for us being a doctor. Can we imagine how hard it is for them? One thing is their quality of life has been already deteriorating and for the treatment they have to add on other expenses. With that again their quality of life will be indirectly affected.”*

The people in the rural areas were of low economic status which forced them to work hard for a daily living, without having spare funds in hand in case of need. Alteration of their daily work adversely affected the economic condition.

### **7.3 Impacts after POP management**

Following treatment, the outcomes obtained were mostly positive (by women or clinicians or both). The theme identified as outcome following intervention was; returning to a relatively normal life for many women and for others. An undesired outcome was where inadequate post-operative care led to a poor QOL.

#### **7.3.1 QOL: Returning to relatively normal life after treatment**

Most of the study's participating women reported better QOL following surgery, irrespective of where the operation took place. They felt more comfortable after the removal or repair of the prolapsed uterus. Both conservative and surgical modes of management were found to improve the QOL for women by enabling them to perform their daily activities. Women suggest that they find happiness in being able to resume these activities. WRP, when she visited the hospital, was managed with a ring pessary at first. She commented:

WRP - “Yes, yes I was able to walk, I was able to work. I was told that it needed to be cleaned three monthly. Whenever I felt like it or in discomfort I use to clean and reapply. It was easy.”

R - “Uhhh”

WRP - “I used to visit at the time they ask me to”

R - “Uhhh”

WRP - “And I used to change the pessary and go. Like this it kept on going. For the last 2 years, I was not having too much discomfort, even before 2 years. Even after having so many children, big and grown up children, I had not faced too much discomfort, until last year. Not much discomfort. May be it was because I became used to it. I have to say.”

A ring pessary is a ring like device made of rubber. It comes in different sizes. The ring is applied via the vagina to support the uterus and hold it in position. It is used as a conservative management of POP. WRP used a pessary before she underwent surgical correction. She was having difficulties in performing daily activities because of a ‘mass’. Once it was repaired, she found herself strong enough to work for the family.

WDK was taken by her mother to seek care for POP with a traditional birth attendant who provided a ring pessary, called 'Kamani' in the local language and this means ‘a device to hold back’. WDK shared her experiences:

*“After placing that, it was easy to work. That is also my experience. Then I didn't feel any effects. I didn't feel any kind of effect. It was very easy after I inserted it. After that I stayed like that ...”*

Like WRP, WDK also reflected on her QOL, comparing the work she could perform before and after use of a pessary. Absence of the mass found to improve comfort when working which made her feel happy. Both of them found handling the pessary easy. WDK used to take it out during pregnancy and re-apply it later on after delivery. In her later years she faced some problems with a ring pessary:

*“Later on, with time, it used to break. Even inside it used to break. Even when broken we have to keep it in. It was changed, but again it used to break. Once a ring pessary was applied by traditional birth attendant, but it was of small size. She applied small one. Small one! It used to fall out frequently and didn’ t remain inside. It did not fit and again had to be replaced by a bigger one. In this way I developed an ulcer. Isn’t it? Wound inside uterus. Then, I was operated on, after 12-13 days.”*

WDK was re-using the pessary given to her but she was cleaning it every three months. She mentioned different problems associated with the application of the wrong sized pessaries. Following the development of an ulcer she sought surgical care. She compared and explained her experience of both modes of management like this:

*WDK - “Now after surgery I am fine. I am fine now.”*

*R - “Better after surgery than after ring pessary?”*

*WDK - “Better but at the time of ring pessary it was comfortable for that period. At that time I couldn't take enough food to give me a full stomach. I wondered what will happen after food. Now I can eat to a full stomach. I can eat. I can walk. I can walk. It is easy now. It is comfortable.”*

WDK found relief from her problems and explained that she was able to walk, repeating herself showing the importance of mobility in rural areas.

WCM was operated on in hospital following screening within an outreach centre. According to her, her surgery took a very long time. She was not sure whether she would survive it. However, she expressed her life satisfaction following surgery in this way:

*WCM - “I have felt this treatment is very good. Now after having surgery, [……] I am able to do everything. Can eat properly, can walk and can work. When the illness is in my body, how will others know? I am better now.”*

*R - “The problems that you had during your prolapse, do you think all those problems have gone?”*

*WCM - “It is not present now. I think it has all gone. It is better.”*

*(laugh)*

Surgery enabled her to achieve her daily activities. Her QOL had improved. Regarding her sexual problems, she mentioned that though intercourse occurs infrequently, it is no longer painful. She said that after surgery her 'body becomes better'.

Inability to take food due to pain and discomfort was expressed by many participants as one of the problems they faced following the development of a prolapse. This led to weakness that in turn impacted on their daily activity. Some of the participants (WDK, WCM and WBI) suggested there had been improvement in their food intake following surgery. According to WBI:

*WBI - "Everything is fine with me. It is better now."*

*R - "It is better. What has happened?"*

*WBI - "Let's say, it is not the same like before. Eaten food has been absorbed by body. It is better."*

WBI was very lean and thin because of her reluctance to take food when she had a prolapse. Once this was corrected with surgery she regained her appetite and is now feeling strong. The findings show how women's appetite improved after surgery, illustrating another indirect effect on their well-being.

DRI, a clinician from a rural area, has seen improvements in the QOL of some women after surgery. She expressed:

*"Oh yes definitely. I will say how many women I see for follow up, not after first follow up, but after their second visit. They have really got back to their normal life and say how happy they are; how they appreciate, how much they appreciate what we have done for them. So yes, definitely, a big yes there. Their QOL has definitely improved after the surgery"*

DRI has the opportunity to talk with the women after surgery, including those who had suffered symptoms for a long time. According to her, women felt relief from different symptoms, not immediately after surgery, but mostly by their second follow up which is

usually after one month. This clinician was enthusiastic in her description of the change in the women's QOL after surgery:

*“Oh yes, many differences. Like most of the operations that we do, many have been suffering for a long time, umm 10 years, 15 years. So they are really grateful and they are really happy. Their quality of life has improved. There they were not going anywhere. They were restricted, they could not do any work and now they are really happy.”*

Women showed their satisfaction after surgery by developing positive attitudes about the importance of prevention for women who had not developed POP and about the value of management for those experiencing POP. WTPB shared that when she had a prolapse she used to feel ashamed and did not share her problems with anybody. Consequently she suffered for a long time. Now, after surgery, she has learned the causes of prolapse and its aggravating factors and suggests that she can, at least, tell others who ask her about a prolapse. WTPB wished to tell the other women in the village who were also suffering from POP to go for treatment because it makes your body 'comfortable'. DDK didn't have knowledge of POP. In the statement below, WDK illustrates how she might have applied preventive measures if she had known:

*“We didn't know, so we carried loads. Then after development that couldn't be treated easily. [.....] Instead if I had known by carrying heavy loads this happens then I would have just cut a bit, cut grass and dig but not do both all day. I should have dug then cut grass a little bit for tomorrow or keep cutting grass then carry a bit home and tell son or granddaughter to bring it from that place. Then they will go and bring it. Then I don't have to do everything.”*

WDK had developed a positive attitude for other women. She said 'let no one suffer with POP'. For those who had already developed POP, she liked to tell them that they could have a better life following treatment. WBI, after surgery, developed similar feelings to those of WDK and prayed 'let nobody face the problem of POP'. She was advocating surgery to other women with POP. At home, WBI was found to be taking care of the female family members so that they didn't suffer from POP. She expressed her feelings for her daughter-in-law:

*“Have to care, after they [daughter-in-law] have said father and mother. It is similar, has happened so didn't let them wash clothes for long time. I cooked and gave her food to eat. Didn't let her work early. I had done work too early too hard after childbirth so I know that this might happen to her as well. It had happened to me but I say that no one else should have to face it again.”*

### **7.3.2 QOL: Inadequate post-operative care**

Whilst the participants above expressed positive benefits of surgery some others spoke of the development of post-operative complications. These may depend upon the care of the women after surgery. WTPA who came from a mountainous region, complained that her life after surgery was worse than before. After she underwent surgical intervention, she developed pain all over her body and became bed bound. Her problems were getting worse each day and WTPA felt that she was facing greater difficulties than when she had the prolapse.

*“Now I can't stand by myself. I can't walk. After coming back from operation I have not done anything.”*

*“It has been more difficult. If tried to get up suddenly; I can't even get up. If I want to walk; I can't walk. I can't die even. Now sir you have to look me over. What can you do? Even when I want to die, I can't die.”*

WTPA received her treatment in a surgical camp. She recounted that money was not required for surgery at that time. She was in doubt that as money was not required for her surgery, the treatment might not be effective. Here, the participant was calling the female researcher ‘sir’ as these data were collected in the mountain region, where doctors have high status i.e. as a man. The participants from here were operated on in the camps. After surgery she was not followed up by any doctors. She was told by the health post staff that a doctor would come to ask about the prolapse problems. She was asking the researcher for help for her problem.

The researcher, during the process of recruitment, in order to gain rapport with the participants discussed POP and examined patients. Once the participants were ready for

interview, on data collection day, she only collected data. But, in this place in the mountain region, there were time limits to build a rapport. WTPA was interviewed first and then, as a matter of respect and professional care, she was examined. This action clearly meant that the boundary between researcher and clinician had been crossed. The researcher felt bound to examine some patients at the request of health post nurses and the women who attended. WTPA was examined along with some other women who had undergone surgery in the camp. During the examination of WTPA, the length of vagina was noticed to have been made very short, about four centimetres only.

WMT was another woman participant who faced problems after surgical correction. After surgery she went to stay in her mother's place for one week and then came back home.

*“For me, after returning from my mother's place, for others there was no need [for medicine] after operation but for me, eight to nine hundred rupees went on medicine only. I got an infection. This much amount [pus] had come out.”*

According to WMT, she developed an infection after returning from hospital. She came back from her mother's place sooner than planned because there was no other woman to work in her house. She resumed her work soon after surgery.

*“For me, I had to come and cook when I could barely walk. Nobody stayed home and a buffalo delivered. Daughters have not stayed. Couldn't lift Gagri from the Kua. It was not like these days when we can get water everywhere. Anyhow, water must be brought for cooking, even by crawling with the help of a stick.”*

The word ‘Gagri’ is the pot to collect water. And, ‘Kua’ means a water collecting place. Following the infection WMT experienced difficulties of pain upon walking, sitting and working. She had a discharge and an infection which was so severe the volunteer health workers at Tepeni told her that she would die with ‘developing maggots inside her body’. WMT described a rotten smell from her own body. Despite this, WMT continued her normal work and later on, the operated part prolapsed again. She said previously when there was prolapse she would use a pessary and she would be comfortable, but now following the further vault prolapse, she could not even bend forward, sit, walk to work. She regretted

having surgery but her neighbour, WHM, who also attended the focus group, blamed her for her problem:

*“If you look after yourself before, then it will be useful later. If we care for our bodies at that time, we won't have to face problems like this. Would we have to face problem like this?”*

For some of the women, the period following surgery had been the most difficult time with inadequate rest associated with the development of complications, leading to further deterioration in QOL. This particular scenario was also highlighted by the clinicians. It is not only the surgery, but rest and care after surgery that are important factors for better outcomes and for securing a better quality of life in the future.

The women receiving camp surgery were found to be discharged sooner than those in hospitals, sometimes they were discharged on the third day post-surgery. The period following surgery according to some of the participants was the most difficult phase. Most of the women from the rural areas needed to be able to stay with relatives living closer to the hospital than their own home, which may be situated in a far-away village. Post-surgery they needed to stay with these relatives for at least a few days before travelling to their own homes. WTPB shared her experience:

*“After operation it was very difficult. I was staying inside my room for a month. After a month only I went home. [……] It was very difficult for me. The time when I was in hospital I was comfortable. [……] I had difficulties actually during that time. Then, only later on, after a month, I went back home. I reached home at around evening. After three days there I went for check-up. Santa sister told me I had a wound infection and it was all rotten. She said why had I not come earlier? Then I was given medicine. She has given me ointment and the medicine to clean.”*

The distance from the home of WTPB to Kathmandu where she received surgery, was nearly 80 km. Some of this terrain has roads that are difficult to traverse even for vehicles. To avoid this difficulty WTPB stayed in a relative's place near the hospital for a few weeks, tolerating all the pain and discharge exuding from the operated site. As she was staying in a distant

relatives' place, she did not feel able to complain about her problems. She expressed her current satisfaction four years after surgery, but complained of pain in her lower abdomen, backache and weakness after surgery. Apart from these complaints, she compared her past difficult life with her present one and explained that life had become very easy after her operation.

Some participants experienced difficulties upon returning home after surgery:

*WBI - "I had to be carried home. Had headache and vomiting. [.....] I was just ... sleeping, taking up two person's seats. Didn't reach home, on the day we travel. Returned after staying at Thankot."*

*R - "Ummn...."*

*WBI - "Stayed in hotel, I was kept there and couldn't get a taxi by searching, nothing by searching. Because I didn't get one, I stayed in hotel at Thankot. Then next day, in morning, I called people from home and they came and carried me home. . And after I came home I didn't like to eat for 4 - 5 days. Then I started to eat, little by little."*

Although some of the participants benefitted from the camp surgery, most recounted facing difficulties with the journey back home. In contrast those who were able to take a rest after surgery reported a better QOL. WHM achieved nearly six weeks of rest by staying in Kathmandu with relatives. WSA returned home after 20 to 22 days following surgery after staying at relative's house and then had further rest for nearly 20 more days at home. Life after surgery was better for both WHM and WSA. The clinician participant, DKC, also mentioned an association between the development of complications and inadequate rest post-surgery.

#### **7.4 QOL: Management improvements**

Policy makers and clinicians gained insight from listening to women, their experiences of POP recounted in this study offer useful insights into how care pathways could be made more person-centred. Management improvement themes identified in this phase are: improving the existing policy; upgrading knowledge and skills for management, and expanding a preventative approach, beyond health care.

#### 7.4.1 Improving the existing policy

The sub-themes identified from the data relate to treatment according to need, surgical site selection prioritising women's safety, flexibility in utilization of funds, and effective monitoring and supervision of the management programme.

Treatment depending upon need after thorough assessment was recommended by most of the clinicians in this study rather than the direct surgical approach. Various opinions were aired in the focus group:

*DKC - "If there is a minor degree prolapse then you can educate and teach pelvic floor exercises. Provide her with food advice, advice to prevent further repeated child birth, or have institutional delivery if we can do it. This will prevent further progression. Her quality of life will be improved. If she has a major 3<sup>rd</sup> degree or 4<sup>th</sup> degree then she has to undergo surgery."*

*DDA - "That should not be treated with ring pessary."*

*DKC - "If can't do surgery then we can put in a ring pessary. It will also improve her quality of life."*

DKC (clinician) was working in a teaching hospital but had previous experience of rural health care. DKC asserts that family members must be involved in prevention and treatment, through education in order to improve the QOL for women.

Another clinician, DRI, suggests that treatment should not only be based on the degree of the prolapse. The symptoms produced by it may need to be considered when managing the problem:

*"So I suppose women may have marginal problems. They may have only cystocele and rectocele but, after all, these are as debilitating as a uterine prolapse."*

The suggestion is for an evaluation of prolapse severity based on degree, as well as consideration of symptoms and correction depending upon the woman's needs; rather than providing the same treatment for all women.

Protocol is a code of behaviour for performing certain tasks. In this study, many clinician participants felt the need for a comprehensive management protocol which they should all follow. DGG highlighted its importance:

*"For proper care, government should make a protocol. There should be one standard for treatment. Somebody is doing this, others are doing that. Some said posterior repair is not done. Camp post repair is not done. What is its significance, nobody knows. That's why one standard protocol should be made and we all follow that. That should be the evidence based standard. And should be followed"*

DTH mentioned the first draft of a protocol for prolapse management which was prepared by The Nepalese Society of Obstetricians and Gynaecologists (NESOG) for the Government. This protocol was discussed in the focus group. The clinicians did not know whether the protocol has been followed up or not.

*DPR - "We have already prepared guidelines, spending so much time on it. It should be followed. It includes information about hospitals and camps. For hospitals, there is not much to be done. It is basically for camps. Which medications? Who will do operations? What should be done? We have national guidelines that should be followed up. In Nepal, when will they be followed up?"*

DPR mentioned that according to the prepared guidelines the criteria state that gynaecologists should carry out surgery only after having five years of experience. Each day they are allowed to do only ten cases. She is not sure whether clinicians are following the guidelines. She suggested that the researcher should consult the guideline.

The number of patients to be managed in the camps has been found to be one of the reasons for poor quality of service. The limitations imposed by infrastructure and manpower, together with a shortage of the necessary instruments further increased the poor quality of service. A limit to the number of operations per day is needed if quality of care is to be improved. DCK explains about tissue handling in surgery:

*"Skilled doctors do stepwise surgery. Just saying that one case will earn this much money doesn't mean that you increase number of operations. To do many they will do dangdung. There should be gentleness respecting tissue while handling it. That also comes. Steps can be missed, if in a hurry while just trying to finish. It is without thinking of the long-term effects."*

DKC spoke about doing too many operations in a day, which she thinks happens because of the money; as the incentive is provided per-case. The phrase 'dangdung' means doing haphazardly. What she tried to explain here is that while performing surgery, one has to be very selective in choosing a case and planning management. There is a need to think through the effects that may arise later. The consequences of not repairing the prolapse properly were explained by DPR, who also works in a teaching hospital, but is regularly involved in the camps:

*"Now vault prolapse factor we have mentioned. Complete procedentia will occur if we are not given adequate time and do not repair properly. Patient is having chronic cough and operated on immediately. Patient, if she resumes work very soon after surgery may experience vault prolapse."*

There are many reasons why complications develop following surgery. The surgeon should not add to these by doing too many operations beyond his or her capacity. DKC mentions the weakness of government policy in not limiting the number of cases:

*"Basically, when doing every day cases, there should be a limitation of numbers. When going to the family planning camp, there is a rule to do 25 operations per day, not more than that. Now we are doing 100 cases per day, I am astonished."*

Along with DKC, the other participants in the focus group also emphasized the need to limit the number of surgical cases to improve the quality of care.

Surgical camps are designed for rural communities and basically provide a service in very remote areas, where women are deprived of health care. DDA who was involved in camp surgeries explains:

*"Other is surgical management. In surgical management, hospital-based and camp-based. If we have to target rural areas, camp-based surgery should be done. It must be done regularly in big hospitals; in medical college also it must be done regularly, in zonal hospital, in peripheral medical colleges plus a camp base where patients cannot reach hospital. They should do surgery there."*

According to DDA, there should be camp-based surgery targeting people living in very remote places and at the same time surgery should continue in hospitals where they have the capacity to perform this work, in zonal hospitals and medical colleges. But, DRI expressed some concern:

*"What I will say is first of all those camps that are organized in remote areas in school buildings or in a, I mean any big buildings that they can get, is not the proper way of doing things. I mean as a doctor you can think that surgery means it should be done in an operation theatre [.....] so, in my view the government should, I mean, not only government, I mean like UNFPA or whoever is giving funds for this, they should all ensure that operations are all performed in an operating theatre. In the proper operation set up, alright?"*

From the study, the preferred place for management was in well-equipped hospitals. Here, well-equipped means equipped with manpower, infrastructure and instruments. UNFPA means the United Nations Family Planning Association.

Regarding the location for surgery, different opinions regarding people and venues depended upon the clinician's practice.

#### **7.4.1.1 View from a clinician working in a medical college**

DGG, who is working in a government medical college and has experience of surgical camps, offered her opinion:

*"Now, after some time, the place where I have served was in an institution, for example in BB medical college. I have been there three times in camps. Whenever*

*you say medical college, it means a little better equipped place, monitoring will be better. Intra-operation care also, if something happens then you will be able to manage. That is one of the reasons why I say it must not be done in health posts or in schools.*

There are many medical colleges in different parts of Nepal. The Government should consider providing a budget and make medical colleges responsible for conducting treatment free to the patient. If surgeons are prepared to travel and provide services in different parts of Nepal, then locating care in medical colleges will be a better option compared to camps. Other clinicians, working in teaching hospitals, concurred with DGG. DKC said:

*“In hospitals there will be screening, treatment and follow-up. If done in hospital the care is not compromised like in camps. When everything is possible then people develop faith and feel that they are in safe and secure hands. This is the advantage doing operations in the hospital.”*

She added the need for the Government to develop and implement a public/private partnership. According to DKC, the Government releases very few funds for initiatives involving private organisations:

*“For the patient, what is private and what is public? They go everywhere. [……] Private medical college charge is almost similar to that of government hospitals. Where to go depends on the choice of the patients. If government hospital is giving a service, then private medical colleges also need to provide that service. In the name of public private partnership”*

She feels this demand is genuine, comparing the cost and quality of care provided from medical colleges. The other clinician, DPR, expressed additional benefits to giving the responsibility to medical colleges. There will be an opportunity for students to learn about POP and through this increased knowledge, the work load for those clinicians going into camps will also be shared and reduced.

#### 7.4.1.2 View from a clinician working in a government hospital

The Safe Motherhood Programme (SMP) is a Government initiated programme to improve delivery outcomes through using skilled hands. The women coming for delivery don't have to pay for their treatment. Women are also provided with transportation costs depending upon the region. The clinicians working in the Government hospitals asserted that they have greater workloads because of the SMP. Their time was consumed mostly managing obstetric cases with little time for managing gynaecological surgeries. However, they were managing to provide outpatient services for gynaecological cases regularly.

According to DRM, the Government should open centres for POP management in different parts of Nepal. He explains:

*"What will happen with one centre? It has to be opened in different places. Say for example in Janakpur. [.....] Like we have for cancer centre. There is CAC and PAC centre. [.....] So if there will be one centre, instead of getting confused with many places, they go to a particular place and get treated properly. If women come to a clinic there will be many patients. Whom they see like normal then they will become more stressed."*

CAC is a comprehensive abortion care centre and PAC is post abortion care centre where women come for different types of abortions. If there is to be a centre for POP treatment separately, then according to DRM, it will encourage the patients to attend because this is providing care specifically for women with POP.

A similar opinion was expressed by other clinician participants. DSS said irrespective of having a desire to do regular POP surgery in a Government hospital, she can't do it. She argued that if there was a special POP management centre, patients would receive all sorts of care including counselling together with advice on everything women needed for POP management. Staff would, through working in the same field, gain more confidence in all aspects of POP care.

#### **7.4.1.3 View from a clinician working in a private hospital**

The clinician DPA, who has a private practice, offered a different opinion about where and by whom POP management should be provided;

*“Patient should be provided with many options. If she likes to have her treatment in private nursing home, with same money, we should motivate them [……]. With permission from government they should permit the work and it should be possible there. If I want to do it according to government, they should allow me to do so according to the mechanism of government, at the same cost……”*

According to DPA, when treatment is made free of cost by the government, permission should be given to all who can manage POP by providing funds to the gynaecologists, even if they work in a private set up. The advantage he explained:

*“Then patient will have easy availability. They also have their right to choose. Some patients may feel I will directly go for surgery. [……] If we do it in that way it will be beneficial for patients. They can choose which doctor they find good. They can go to them.”*

DPA mentioned the women’s right to choose the clinician for her care. To date, the Government has not allowed this freedom for a patient to choose the place and the person for her treatment. DPA demands that the Government should provide opportunities for private practitioners too.

#### **7.4.1.4 View from the clinician about managing in zonal hospitals**

The zonal hospitals in different parts of Nepal have been taken as an option for the management of POP, rather than in rural surgical camps. The clinician working in the Janakpur district felt that the Government should identify the places where the service can be provided and that at these places there should be an investment in infrastructure, equipment, training and manpower. A one off investment, which mean that the service could then be provided for a long period of time.

DYD comparing surgery at different places said:

*“What I have advised is to do it in the centre. In different places, we have 14 zonal hospitals. It is not difficult for them to cover 75 districts. Let's collect patients and do surgery everyday or on an alternate day. The patients who have come, if we were able to manage them in a good set up, then obviously the outcome of treatment will also be better and we can decrease morbidity and mortality related to prolapse.”*

DRI also suggested that the Government should routinely manage POP surgery in zonal hospitals. She argued that the reason this is not sanctioned is the lack of trained manpower and the lack of a culture of transferring the trained manpower to different places.

The study found that many women with POP are rejected for surgery if they have associated co-morbidities condemning them to live with dual (or more) problems. Women having associated co-morbidities tended to hide the problem for fear of rejection. Across different regions of Nepal, the Government is providing incentives to perform surgery. The findings suggest that a solution to this problem is to maintain a certain level of flexibility in the utilisation of the funds for the women with co-morbidities. DRI states:

*“So, suppose government is giving 15,000 for a surgery and a women requires 25,000 then 10,000 has to be found by that person or whoever is doing the surgery or which organization it is, could top up that. So, even if the doctor thinks that this women should stay for longer period here and I should provide some other care to her besides this, then that person is forced to send that women [……] You will restrict your treatment to vaginal hysterectomy. And then you will refer her for all the other things which will end up costing money. So if we have treated someone and they need some other treatment, the government should be flexible in that. Ok, you can take care of that and we will do that.”*

According to her there should be a special budget for handling complicated cases and these should be referred to the tertiary care centres for further management and the Government should take responsibility for the treatment costs.

The Government provides money for vaginal hysterectomy only and for this reason the uterus may be removed as a treatment with, or sometimes without, pelvic floor repair. Clinician participant DRI has suggested that the government needs to be flexible in providing money for different types of surgery when managing POP.

*"I think government should in fact change the policy and then make it like providing funds for all types of pelvic organ prolapse ok? There is, I know there is, a good chance there will be over correction. Like some women may not be in that much need of that operation, but because of the money involved they are getting operated on. [……] May be we will be able to control the numbers we are operating on and limit services."*

Monitoring and supervision in surgical camps was found to be weak in the study. According to DDA, monitoring and supervision are everybody's responsibility. Although it is everybody's responsibility, he has noticed it is better where there is access to a nearby health facility:

*"Government has provided incentives to deliver [babies] in a nearby health facility and has increased services. Then we could apply that here. If facilities are provided nearby the service will improve. In that nearby place, to maintain the quality, monitoring must be there. The provider should do this and the donor, who provides money, should also do."*

Whereas DKC feels that when the Government has provided funds for a service then responsibility to monitor and audit the service remains with the Government. On responsibility for monitoring and supervision, she says:

*"Sometimes the Government should also take an initiative. How should it be done? It is up to them. If they [the Government] have made guidelines, national guidelines, they should be followed up. Whether one is followed or not should be monitored by somebody. Because of lack of audit, this all becomes a mess. It is needed to maintain quality"*

DDA mentioned if the Government is not able to take responsibility for maintaining quality then it should be handed over to another body like NESOG. DKC added:

*"Government should either make one committee or do as Dr DDA mentioned. They have to give responsibility to the society in a sub-contract. Then all the expenditure will be within the society, monitoring will also be done; training will be done for needy people. So, the professional society can do these things. But government should give sub contract. Government will not be able to do this alone. What can governments do? Easier way is to give contract to the professional society."*

#### **7.4.2 Upgrading knowledge and skills for care management**

The high prevalence of POP in Nepal is mentioned by both groups of participants. The findings also suggest that getting accurate data on prevalence may be difficult. There is, however a need for screening at a national level in order to plan the care management of women with POP. The two key issues identified in the screening and follow up processes are the utilisation of local manpower through training and for clinicians to prepare appropriate manpower by training gynaecologists.

DRI, who had previously worked in a government hospital but was now working in a private clinic, provided an example of the utilisation of manpower:

*"We will have to think about the grass root levels, like in the health post and the sub health post, where there are no doctors most of the time. These are the other people who are looking after these women. So, if you train them, like you know there is a very good example about the Gates..., Bill Gates foundation. They have trained auxiliary health workers in many parts of India to do a speculum examination. Just to see the condition of the cervix so that early identification of carcinoma cervix can be made. [.....] So, we can do something like that. We can train these people, like even those birth attendants, they can be trained how to identify cystocele, rectocele, early decent, so that referral can be made."*

Rural people get access to health care from health posts or sub health posts where Health Assistant (HA), Auxiliary Health Workers (AHW) or Community Medical Assistants

(CMA) and Auxiliary Nurse Midwife (ANM) run the service. They remain in contact with the people via voluntary health workers and do door-to-door visits, raise health awareness, carry out immunization and the provision of medication for the promotion of health. DPR (Clinician) found that these health workers are the main mediators who can be helpful in screening. She said:

*"To make it effective we can train nurses by teaching them about 1<sup>st</sup> degree, 2<sup>nd</sup> degree POP they can then detect. The study which they have done by AR it is not by doctors. Nurses and lay men. May be they were trained. I don't know about the education. For screening purpose nurses can be trained. More so if trained to skilled birth attendant level, then they know more."*

DPR emphasized the need for such health workers to receive the training to become skilled birth attendants. They are responsible for child delivery which could provide dual benefits through carrying out screening and also spreading preventative advice. Similar advice is offered by YD, that is, if local manpower is harnessed for screening it can also be used for follow up.

Surgery in the mobile camp setting is not always risk free and there is a greater chance that patients will develop complications. Follow up care is essential but it is not happening because of lack of trained manpower. DTH said that she wanted to return to the place where her surgery was performed, but she never had the chance. DTH comments:

*"It must happen there. Now, at different times, different levels of people should go and do regular follow ups. Or we should appoint people from that place only. One person from that place can be given all the responsibility to follow up all the prolapse patients and if anything happens then they should report to a certain centre. That system will be better. Otherwise, the same camp team going there just for follow up will not be economically possible. All the travel expense and all."*

The government has separated the budget for the follow up of patients, as transportation costs and health personnel costs are lower when compared to the surgical costs, according to DYD, clinician. A similar opinion was mentioned by DRI in relation to follow up care:

*“That is not happening much because it is; you know again, (laugh) I will say it is because of incentives, because the whole team is getting incentives. Ask someone to do it, that person is expecting an incentive and if the money is not forthcoming they don't bother to take care of those women. Then they say if a woman gets complications they go to the local health post...”*

When performed in hospitals and medical colleges, the follow up care after mobile camp surgery was found to be better. DYD explained that it is more advantageous to operate in hospitals for patients and for service providers too. They train medical officers in the hospital for post-operative care and how to recognise complications early. This has helped improve quality of care:

*“With them, even after leaving from surgery, we contact them by telephone. They will call directly and report that a patient came with this, has this complication, what should I do? Some come with urinary retention, some with vault discharge, and some with secondary bleeding. If they come, some are fine and some are not fine. Even after two or three day's hospitalisation, for them we call in Kathmandu and have managed them well.”*

One finding suggests that the funds provided for each surgery became a key motivator for the involvement of different groups of clinicians. For those groups of gynaecologists who are recently qualified, surgical camps become the place to learn skills and gain in competency to practice in hospitals. DDA asserted:

*“When working in camp base, quality matters come after training them. Not immediately after graduating at least they will not make vagina short. If so, then they will complain of dysparunia. They cut and cut and there will be no vagina left. At least they leave something for suspension of vault prolapse, backside for enterocele. They can do at least a modified coldoplasty.”*

What he explains is that with the novice gynaecologists, though they are keen to work, their lack of skills increase the chance that they may create complications for the patients.

Because senior gynaecologists are not normally going to the surgical camps, who should be allowed to perform surgery was a topic of discussion in a focus group. The findings suggest management must be the responsibility of gynaecologists but there is a need to train the gynaecologists in quality care aspects. As DDA suggests:

*DDA - "For doing CAC we need to train you and give certificate. Then vaginal hysterectomy is not a joke. MBBS is also doing, surgeons are also doing, and Americans are also coming and cutting. British are also coming and cutting. This should not be done." [.....] "They should be trained. Government can introduce a package for a week or 10 days. OBGYN doesn't need much."*

*DSS - "There are less certified people"*

*DPR - "OBGYN also at least working for 5 years"*

*DKC - "Yes 5 years"*

*DDA - "When going to the rural camps they go as boss, not as supervisor. In hospital there will be supervisors. I am there and above me somebody will be there. Like mam said"*

DDA was persistently asking about training for gynaecologists, that they should be provided with competency based training. He feels it is needed for the present situation.

DRI also agreed:

*"Yes all the zonal hospitals should be doing surgeries and it should be mandatory. I think it should be mandatory for all the surgeons, gynaecological surgeons. To do this will be a part of your job description; that you will be doing this surgery. What is happening is not all surgeons are doing these operations possibly because they are not trained in vaginal hysterectomies. Here comes the need for training. Those who are already operating can train the junior manpower so when they are not doing this work, the second line of people will do the operations"*

Clinician DYD also believes there is less manpower to perform the operations. According to him, training manpower improves the likelihood of being able to perform surgery.

### 7.4.3 Expanding preventive approach beyond health care

Most of the clinicians mentioned the importance of prevention. According to DTH they are treating one case here, but at the same time, because of a lack of preventative approach, another ten had already developed the problem. According to DGG, like many other programmes, free POP treatment was launched but many people didn't know about it or how long it would last. Prolapse remains a major problem for women suggesting that the Government would be better advised to focus more on preventative aspects.

The findings show that the medical approach can contribute to prevention of POP. However there is a role for a multi-sectorial approach in the prevention of POP. For example, improvements in education, transportation, water supply and agriculture. DRI knows that prevention needs a multi-sectorial approach but explains the advantages of a medical approach:

*"So, as I told you earlier, prevention is a very, very, very long process. It will take a lot of years but then, yes, your efforts should be in all the fields. In contraceptive field, in the hospital delivery field, motivation of the women to deliver in the hospital and training of the traditional birth attendants or may be safe vaginal delivery so that all the precipitating factors of uterovaginal prolapse is restricted [...]"*

DTH reinforces the realities for rural women who have to collect water from distant wells every day. Being clinicians, it is not possible to tell these women not to collect water as it can give rise to POP. They need wood for cooking. Doctors can't tell them not to carry loads of wood. In these situations, in rural Nepal, DTH said prevention is not possible until the socioeconomic status of the family is improved. DGG emphasises that if prevention is the focus, then education has to start with family and community.

DYD mentions that the Government should understand POP as a national burden and focus on prevention. Programmes, like the Safe Motherhood Programme, could be designed for prevention of POP. DKC's view:

*"It should be taken country wide, well-organized and in a well-planned way. Where to give advice and how to give it has to be on an ongoing basis. It should not be like a one year project and then finished. You have to make your programme sustainable"*

*so that the Government should keep it on their agenda. The Government should incorporate this programme in their own systems, in their organizations. It should be incorporated in their regular activity. So that the budget will be separate for this. Let's say reproductive health awareness programme. One of the components could be prolapse. Isn't it? If done in such a way all awareness programmes will run in all 75 districts."*

The Kegel exercise in post-partum care for prevention of POP is not practiced routinely. DKC mentioned that the main key issue is the integration of a prevention approach in the Government health care system which may lead to many changes throughout Nepal. Prevention of POP should also be included in Skilled Birth Attendants' training in post-partum care.

### **7.5 Reflexive perspective**

My role in this research journey is as both insider and outsider. I am a woman, a daughter, a daughter-in-law, a wife, a mother and last but not the least, a clinician and a researcher. I cannot pretend to be separate from the study and remain only a researcher. In many places I see myself as one of the participants because while participants were telling their story and while dealing with data for analysis I found myself in the middle, between both groups of participants. Being a clinician I stepped outside of my clinical duty and tried to understand the issues around POP from different viewpoints. However, in several conversations with the clinician participants I found myself judging others' work and trying to justify my own work compared to theirs. This has helped me understand my work in a better way. Whatever is to be done has to be done for the benefit of the patient.

In this research journey, following patient recruitment and data collection, I noticed changes in my own behaviour while dealing with patients. I understood the importance of women's priorities and started listening to my patients more than I did before. I was frequently criticized by my supporting staff who felt that I was working slower when examining patients. I was not comfortable knowing the remaining patients were waiting outside for long periods of time but at the same time I was happy to be able to look after my patients better and to the level of my own satisfaction. I was, on reflection, changing myself and enjoying adopting a person-centred approach.

## **7.6 Summary**

Following development of POP, the physical aspects of a woman's life were found to be the most affected. The physical domain inevitably impacts on all other areas of her life. The different symptoms POP produces have a significant effect on the mobility of women which is fundamental to their role in the rural family. A woman's QOL depends upon her ability to work for the family. Following treatment, correction of physical problems helps to correct aspects across other domains spontaneously and enables women to return to a relatively normal life. However, those women who are still living with poor QOL after treatment were found to be those with inadequate post-operative care. Improvement in care management can come from modifying the existing policy, prioritizing women's safety and upgrading manpower knowledge and skills. Holistic POP management requires multi-sectorial involvement at different levels and expanding the preventative approach must move beyond health care. The themes from the three findings chapters are expanded and linked to the body of literature in the next chapter.

## **Chapter 8: Discussion**

### **8.1 Introduction**

This chapter begins by presenting a validation of the research topic. The exploration of the POP problem and its management was developed through three different strands. The first strand narrated factors for the development of the problem, the second strand explained the process of understanding the management approaches and the final one relates to improvement in management and its perceived impact. The conceptual model based on these strands will be presented as an outcome of this research at three major levels: Individual, Health care organizational and the Government level. The discussion chapter will follow the pattern of the conceptual model.

### **8.2 Validation of research topic**

This research explores the experiences of Nepalese women who have undergone treatment for pelvic organ prolapse (POP). The theoretical basis for the study emerges from, and is informed by, the perceived traditional, paternalistic way of managing POP by offering surgery without addressing the women's needs and priorities. The Government approach for women suffering from the problem was by developing a programme for both prevention and management of POP. This research has taken forward the need to explore the impact of surgical management on the QOL for women. The conceptual framework discussion in Chapter Four provides the holistic landscape from and through which the researcher seeks to improve POP management policy.

Chapter Two, Nepal in Context, provides a discussion around the socio-cultural and geographical factors associated with the development of POP and highlights the challenges related to its development and management. The magnitude of the problem and its effects are presented in the Literature Review chapter. A significant omission in the literature is a lack of information regarding women's QOL before and after medical intervention. The researcher identified some quantitative studies, which utilized tools to measure the QOL for women after management. However, few studies employed qualitative methods, which gave additional credence to the chosen methodology for this study.

A narrative method was used in this study for data collection. The interpretivist approach taken for the study helped the researcher to corroborate the topic by bringing views from both groups of participants i.e. women who underwent management and clinicians who were involved in the management of POP. The findings obtained from both groups of participants provide useful insights for better holistic proposals to address the current situation. The framework analysis technique helped to merge the data from the two different study groups and offered combined solutions (Ritchie and Lewis; 2003, Swallow et al 2003). Though the research topic explores factors effecting QOL, only the components of QOL (physical, social, psychological and economical) were utilised here to ascertain the impact of POP management and to gather support for change to the care policy; from a traditional paternalistic mode of care to person-centred care.

The analytic journey, guided by the conceptual framework of the POP problem and its management, developed three different strands. The first relates to the various factors for the development of the problem, the second strand embraces the process for understanding the management approaches and the final one relates to perceived impacts for improved management. The conceptual model as an outcome of this research for POP management is presented below in Figure 8.1. The Discussion Chapter follows this pattern, being presented under three major headings at Individual, Health care organizational and the Government level.

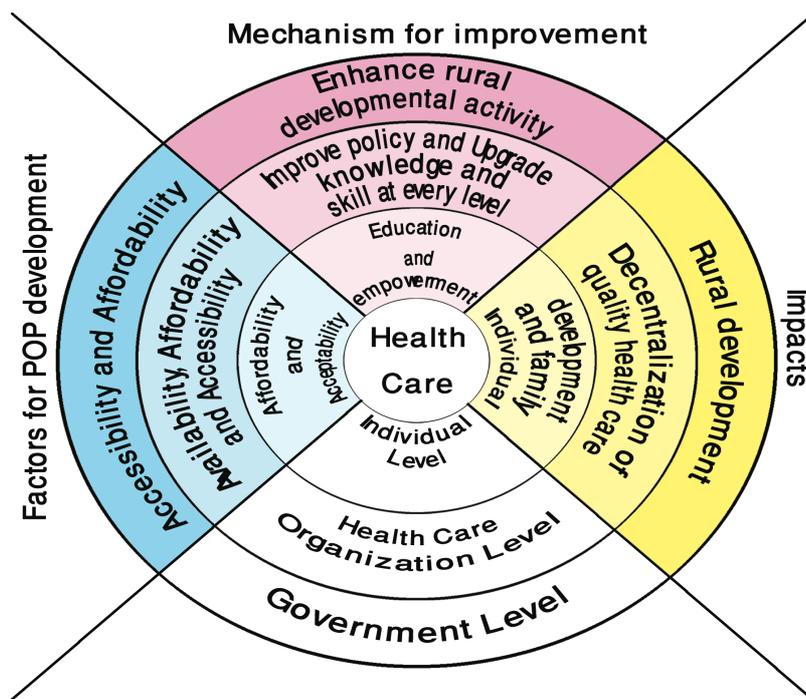


Figure 8.1: Conceptual model for POP management

### **8.3 Women, at the individual level**

The position of women was presented in the previous chapter. The factors for the development of POP are discussed from a QOL perspective at the individual level.

#### **8.3.1 Factors contributing to POP development**

In this research the circumstance in which POP may develop was given a high priority. The literature suggested that development was related to the clinical risk factors (Jelovsk and Christopher 2007). The additional literature from Nepal further reinforced the reality that aetiology is mostly associated with the childbirth and the hard work that women are performing especially soon after giving birth (Bodner et al 2007; Shah 2010). The Nepal in context chapter highlighted the socioeconomic, geographical and political factors that contribute further to POP. However, the identified themes from this study suggest that the factors for development of POP, related to the position of women in Nepali society which in turn is deeply embedded within the socio-cultural and economic conditions. This understanding, supported by the findings identified an impact that there is a need to improve the position of Nepalese women.

Access to health care in relation to acceptability and affordability, was an identified barrier within the individual level, which resulted in women delivering their children at home. The participants' view was a consequence of their culture; they explained that there is no culture of going to hospital to give birth. Though every woman has a right to give birth under the supervision of a trained attendant, however, most of the deliveries of babies take place, unattended and at home. The older family members in this study emphasized home delivery as the norm. Though some women knew of the potential for negative outcomes following unsupervised childbirth, they were not able to speak up and demand an assisted health care delivery because of their position in the family. These views are similar to those in Simkhada et al. (2010) study on the role of the mother-in-law in antenatal decision making. Subedi (2010) also comments on the power imbalance between the mother-in-law and daughter-in-law in making decisions related to child birth. The younger generation of women has failed to convince the older family members of the need for expert care during pregnancy and childbirth. The older family members from their experience accept birth as normal and therefore there is no need for special arrangements before, during and after delivery. A contradictory finding, regarding a woman's choice of unsupported home delivery is that gaining acceptance in the in-law's family (Simkhada et al. 2010) took priority over the

mother and her baby's safety. The women showed great courage by delivering alone, trying hard not to disrupt the routine daily activities. Women are keen to establish a positive impression, acting bravely to gain acceptance and maintain their position in the family, especially from mothers-in-law and other family members.

This study reaffirms that women in Nepal begin childbearing early, the majority in their teenage years following marriage. Jelovsek and Christopher mentioned in their study that early marriage is negatively associated with fertility. A young bride will have many fertile years and, inevitably she will give birth to many children which is an established risk factor for the development of POP (Jelovsek and Christopher 2007). The tradition of giving away daughters as soon as they are old enough was found to be strongly linked to family poverty. The cost burden of raising a female child is reduced when they are married at an early age and leave home to live with their husband's family. This finding supports Aryal's study where the parents wanted to shift the expense of rearing a girl by giving away their daughter to another family. Following attainment of marriageable age parents were marrying off their daughters irrespective of levels of education and work (Aryal 2008). Mensch found that in some parts of Nepal where dowry payments are still the norm, the payments increase according to a girl's age; so parents marry off their daughters early (Mensch 2005). Early marriage deprives a child of her education and prevents her involvement in other socio-economic developmental activities. They will be dependent upon other family members for living. Bajracharya and Amin (2012) mention that low levels of literacy are associated with low self-esteem for girls, unemployment and early marriage. This study therefore encourages a change in early marriage practices through advocating full access to education for girls through their teenage years.

The cultural demand for sons was found to be another reason for having many children. Leone et al. (2003) identified three major factors for giving preference to sons. They are economic, cultural and religious. The only certainty for a women's sustained status in the family stems from having a son (Leone et al. 2003). This study shows that tradition was found to be important for two reasons. First, strong cultural beliefs, especially through Hinduism, provide a religious sanction behind the son preference. The rituals following the death of a parent can only be performed by a son. The second reason for son preference is for the future economic security of the family. According to culture within Nepalese society, sons, not their daughters, look after the parents following marriage. Thus, parents see their

future security in a son, giving priority to male children. This study showed that in some parts of Nepal the demand for a son is so high that women have been considered infertile even when they have given birth to girls. Such favouritism and prejudice against a daughter further disempowers her.

Another significant factor contributing to the development of POP is the hard physical workload of women. Most of the rural women are poor and not educated; therefore they don't have access or the means to earn money. So, a married woman has no option other than to use her strength for household activities in order to gain acceptance and maintain position in the family. The report from UNDP on Nepalese women's work hours in rural areas shows it to be higher than the global average and 3.1 hours more than men (UNDP 2004) and in percentage work burden is 12-22% greater (Earth and Sthapit 2002). A women's responsibility related to workload in the family was found to be influenced by socio-cultural practices. The study shows how cultural norms demand that women work for the family. The mother-in-law is freed from all the routine household work after the arrival of a daughter-in-law. This shift in labour roles enables the mother-in-law to gain power, which she would not have enjoyed during her own years as a daughter-in-law. Radl et al (2012) underestimated the role of the mother-in-law since they are women and were at one time in the same situation. However, he compensates somewhat by affirming the strong patriarchal influence of the culture.

The findings also confirm that most of the women participants resumed their work soon after child birth. A study in Nepal showed that 78.79% of the respondents returned to work within one week of giving birth (Shrestha et al. 2009). Thapa et al. identified that women in Nepal who have rested less than 42 days after giving birth are more prone to develop POP (Thapa et al. 2014). At the level of the individual, the findings related with the position of women challenges the need to bring change in the culture. Change of culture though is difficult but not impossible with improved socio-economic status. The hard work associated with poor infrastructure development related issues will be further discussed at the Government level.

The results from this study show that the factors contributing to the development of POP underlie a the need to improve the position of women in society and so improve women's QOL. The key issue identified from the findings was related to poor education of girls. Improving literacy, can be a driver of change required for emancipation. The MDG's target

to improve the overall literacy rate to 88.6% is challenged by the educational disparity between boys and girls, in particular girls dropping out of education early (Nepal and the Millennium Development Goals 2016). The proposed target in the Sustainable Development Goals (SDG) 4 for 2030 includes 100% enrolment and completion of primary education, 95% in grade one to reach grade eight, and 90% attending secondary education. SDG 5 aims to achieve gender equality and empowerment of women and girls including the elimination of wage discrimination for similar work (Sustainable Development Goals 2015). Girls and women when educated will bring changes within the family and slowly influence society and thus facilitate cultural change. Education allows women to be involved in all the developmental activities, which will improve the family economy. Women will then be equally able, as men, to contribute to family matters, including economic ones. Such participation by women will improve their position in society. The value of daughters when recognized will probably help to delay the marriage of daughters and reduce the demands for sons. This study therefore, strongly advocates the importance of educating girls. The power of education, the researcher perceived is expressed below in her reflexive note.

Lack of education was also related with lack of autonomy and decision making power for self, poor social networking and developmental activities which is probably why women are denied opportunities to discuss and understand POP. The position of women and the consequences of poor education were found to stimulate paternalistic management. For example in the study, women were in a situation where they were bound to accept the surgery provided because they were not in a position to decide or influence what they actually needed. The change to where the women choose the mode of treatment that is best for them, in the context to POP management, is vital as developing person-centred care calls for equal participation of care giver and care taker. For the development of emancipatory practice, there has to be progressive change at an individual level along with the health care organisational level. This will be discussed further at health care organisation level.

Presenting an understanding about the position of women in Nepal is important for clinicians and policy makers to make them aware of the current situation. Inadequate understanding of the position of Nepalese women may have contributed for the failure of the preventive approaches within the government initiated prevention and management programme. The study challenges and questions the established programme for its consequences and advocates change in the design of the prevention programme. The government recommend

the involvement of maternal health care providers in the prevention of POP. However, after understanding the position of women this study suggests several changes are needed for emancipation to occur. A multidisciplinary approach for example that involves public health practitioners and anthropologists along with maternal health care providers in improving the preventive approach as suggested in Global Health Law (Gostin 2014). In short, women's QOL will be improved when POP is not there.

### **8.3.2 Reflexive perspective**

I am a Nepali woman, a daughter who was brought up in a family where educating a daughter was a priority. Being a wife, a daughter-in-law and a mother, I was never restricted in pursuing my education and my career. My work in the outreach centres outside Kathmandu valley taught me that Nepal is not just Kathmandu where 90% of all health care resources are available; where as 85% population still lives in the villages. My PhD journey helped me to understand in-depth the real status of Nepalese women. I came to realise that economic problems are directly linked to illiteracy and vice versa. Lack of education leads families to become subsistence farmers and prevents opportunities to generate the kind of income possible from professional occupations. The alternative approach often taken, in order to control the economy within family was to not educate children, but marry off daughters and avoid their health care and other expenses. Illiteracy or poor education was found to be associated directly with poor communication which, in turn, severely compromises a woman's autonomy in this patriarchal society. It was and is obvious to me that women were and are not able to ask for professional health care at the time of need. They are destined to suffer more health problems and have poorer quality of life than their male peers.

Economic development with access to finance can enable income-generating activities amongst women in rural areas of Nepal. I have seen the change in women (illiterate mostly) who are involved in micro-finance programmes launched by Dhulikhel hospital in different community outreach centres. The vision of such scheme was, and is, to provide women access to finance and raise health awareness during their monthly meeting held in the outreach health centres. The change I observed was the level of communication increased in the women who participated in the scheme. Along with financial independence and health awareness, women were noticeably gaining confidence and were motivated towards health care for themselves and their families. The progress made by small changes among illiterate women is an example of how incremental development can be achieved. Upgrading

women's position comes from, and in turn, further promotes, improved access to knowledge and the economy. As women remain the backbone of every family, educating girls is fundamental to societal and eventually cultural change in Nepal.

### **8.3.3 Process for understanding POP management**

The findings from this study suggest that POP development and delays in seeking health care are both associated with affordability and acceptability at an individual level. Chapter Two provided an overview of the deprived socio-economic status of rural areas in Nepal. The literature reviewed reaffirms low economic status as the most persistent barrier to accessing health care. Health seeking behaviour varies greatly between developed and developing countries, depending upon the economic status of the family (Chamberland et al 2007).

#### **8.3.3.1 Barriers in accessing health care**

The time in a woman's life, when she is likely to develop POP, lies usually in her early married years, accomplishing her many family responsibilities and giving birth to the required number of children. The findings reveal the significance of her responsibilities; she gives up any consideration for her own body and health. Mothers spend money on their children's education rather than their own health. They want their children to be able to earn money from less hazardous, physical work, which will give rise to fewer health problems later. The women only attained some power in the family after the children had grown up. It is only at this stage in her life that a woman may be able to present her health problems to the family and ask for funds to seek medical help. Although the delay in seeking treatment is deeply rooted in the financial situation of the family, the study reports a contradictory finding; where a family was capable of affording surgery for the woman, they were reluctant to use their own funds because of the possibility of free surgical camps. Women wait, often for long periods, for the surgical camps to come to their area so that they can use their money for other things. This delay implies that women in rural areas cannot afford surgery for the management of POP. Free surgery, as a blessing for a poor woman, is presented in chapter six in WDK's story. Therefore, the other message from this study is that there is still a need to continue the government-initiated free treatment of POP in order to improve women's situation.

The other reason, emerging from this study, as to why women do not address their POP problems is fear of discrimination from the family and wider society. Following the development of POP, a woman will fear rejection, for reasons which may include not being able to satisfy her husband to not being able to work for the family. On the one hand, if she reports her prolapse she would need money to correct the problem, but she has no direct access to funds; on the other hand, her anxieties stem from the possibility (or reality) that she will be rejected and she will have nowhere to go. Women therefore hide their POP from their husbands and family. These fears of rejection are similar to findings from a study by Shrestha et al. (2014) who reported women hiding their problems due to feelings of shame and fear of discrimination and rejection from family and wider society.

The researcher had previously thought that men must surely know about their wives' POP but chose not to bring their wives in for treatment for various reasons. Husbands were, she believed content to let them suffer for long periods. This study confirms that such a view has been found to be both unfair and unhelpful. Actually, it is women who hide the problem and consequently, suffer on their own. This finding brings a new, rich element to the understanding of Nepalese women's health seeking behaviour. The verbatim reports from women participants WTA and WBI related to strategies for hiding their problems has been presented in chapter six under the heading 'Position of women in the family'. This is again not true for all women; as some women's lives further deteriorated after the husband came to know about the problem. For some husbands, negative responses were associated with financial implications, while for others, sexual relations became difficult and they started considering taking another wife. This study supports women's reluctance to talk about their prolapse to their family, wider society and health care workers. To improve the situation for women to come forward with their POP problem, the study suggests an intervention in the form of an awareness programme on POP prevention and its management. This will help to identify the hidden numbers in the population who are still suffering and being denied treatment. Involvement of a multidisciplinary approach is crucial to the success of any awareness intervention. The health care providers (village health workers) working closely with the community are the potential body who can influence change in society by bringing better understanding of POP. The government should support their involvement so that public awareness is raised within communities. The following discussion will explain the QOL issues for individuals who develop POP and their experience of management.

### **8.3.4 QOL and policy changes**

Development of POP rarely resulted in mortality but the morbidity associated with the development of symptoms has been found to interfere on the lives of women through its impact on their daily activities. The adverse effects of POP on the women's QOL can be understood across a range of domains. However, the findings from the study show that it is in the physical domain where the heaviest impacts are to be found. Other domains, for example, social, psychological and economical are affected due to the prolonged duration of physical suffering.

#### **8.3.4.1 The physical domain**

Women with POP tended to be aware of the problem following the development of a bulge (mass protruding into vagina). The early phase is experienced as discomfort, which later on results in severe difficulties for the woman. The analysis based on clinical interviews also suggested that women were most affected by the actual physical symptoms of prolapse (Srikrishna et al. 2008).

POP affects the mobility of women creating difficulties in walking, sitting, eating and urinating. These difficulties were further exacerbated by the development of pain, discharge and sexual problems. An account from WDK *“If it was possible to cut it myself, I should have cut it out”* reveals the extent of one woman's suffering more clearly. The findings show that the inability to perform daily activities needed for the family effect a women's position and were associated with discrimination and rejection from the family and society. A women's ability to work in the family is therefore strongly related to women's QOL. Clinicians also mention physical problems of POP as giving rise to other associated problems i.e. social, psychological and economic. According to them, once physical problems are corrected other associated problems should resolve spontaneously. Hence, the physical aspects of POP symptoms are considered the most important domain in this study. These are interwoven with the other main domains as discussed below. Therefore, the key message for the clinician involved in the management of POP is that there is a need to assess the physical domain thoroughly so that all associated problems will be addressed during management. The clinicians should understand the fact that both over and under-correction are harmful for the patients.

#### **8.3.4.2 The social domain**

The findings within a social domain perspective are presented under the headings of relationship with husband, family and society. The position and value of a woman in Nepalese society according to this study depends upon her role and acceptance in the family, which she gains from her hard work and this, in turn, depends upon the treatment and value of the woman by her husband. These relationships all impact upon the QOL for women. Women therefore, find happiness in working. Their QOL is enhanced where they are able to work hard, have children and maintain family harmony. Women suffering from POP were found to have fewer expectations beyond these desires.

In this study, it was found that sexual problems associated with POP effect the marital harmony of the couple which directly affects QOL for women. Many women experienced punishments as their husbands left them or started seeing other women and some faced problems because of physical assaults. The account of a clinician participant who reported a story of a woman from LL, a mother of 6 children at age of 32 who was left by husband, well illustrates the social domain in Chapter Seven. Therefore, this recommends that the treating clinicians preserve sexual function during surgery to improve womens QOL. A study in Nepal found 74% of women discontinue sexual activity after the development of POP for various reasons such as pain, difficulty during sexual intercourse, fear of spousal awareness and separation (Shrestha et al. 2014). However, other studies using validated sexual function questionnaires found less impairment of sexual activity with the development of POP (Ellerkmann et al. 2001.; Weber et al. 1995). This explains the need for qualitative as well as quantitative research to further understand the ‘reality’ of living with POP.

#### **8.3.4.3 The psychological domain**

People suffering from POP are 7 times more likely to have psychological problems (Getti 2010). The literature evaluating the psychological domains utilised validated questionnaires to identify the extent of effect. However, this study attempted to identify the causes behind the development of psychological problems in women suffering from POP. Among the identified reasons, the most common one is not understanding the problem but facing continual daily difficulties. These are further aggravated by an inability to share problems of genital origin. The shame forces a wife to hide her problem, even from her husband. The

majority of women participants felt unable to disclose their POP and quoted ‘*I felt ashamed, so didn't tell.*’ However, shame related to fear of discrimination and rejection from the husband and family weigh heavily on their minds. Hiding the problem from their family, however strong their reasons may be, will mean that they will be treated normally and will be expected to do all their usual daily chores. Continuing to work hard and rest little will not only increase the prolapse burden but also make them unhappy. The findings show that not being able to share the problem but having to work is associated strongly with the development of psychological problems. These findings could not emerge through the quantitative method alone. A woman who confessed to an attempt to commit suicide expressed an extreme example of a psychological problem in the study in the findings, Chapter Seven. This provides a strong message that there is a need to identify women who are suffering from POP. The solution explained within “barriers in accessing health care” of raising public awareness to this problem hidden among the population applies here.

#### **8.3.4.4 The economical domain**

Prolapse is considered a product of poverty but after its development it further invites economic decline. After the development of prolapse, women were not able to perform daily activities as before. A study show that 82% of women reported experiencing reduced family income following POP development (Shah 2010). However, this study explored the relationship between POP and the economy. It was evident from the findings that rural people work to earn food rather than for money. WTPA's husband worked to bring home one meal every day. This could not happen after she became sick. Her incapacity worsened their situation which was made even worse when the family went hungry. Therefore, the economy is significantly affected as the living of the entire family is interrupted.

Women contribute in almost equal levels to men, to the household economy, in rural communities. The work burden compared to men is higher. This study stresses that women’s work, though not directly involved in moneymaking, deals with daily living and is significantly related to POP as supported by Shrestha et al. (2009). Lack of access to money (cash in hand) means women depend completely on their husbands and family. Without money, treatment is not possible (apart from infrequent free surgical camps). They are not able to demand money for any health related problems. The inability to pay for treatment

left women suffering for longer periods of time and living with increasingly poorer quality of life. Because of this women often said in their accounts that they lived without hope.

#### **8.3.4.5 Life following management**

The study findings showed that the main problem for the women was the bulge (i.e. mass coming out). The other physical symptoms for example pain, discharge and sexual problems were all associated with the development of a bulge. Hence, both conservative as well as surgical management correcting the bulge were found to improve their symptoms. A study by Hirata et al. reports that both post-operative disease-specific and health related QOL improved significantly when compared to the base line condition but demanded further follow up and more cohorts to confirm this data (Hirata et al. 2004). Correction of the physical symptoms were found to correct problems in the other domains. Most of the women returned to a relatively normal life soon after bulge correction. According to Getti et al. surgery led to a dramatic improvement not only in the condition specific QOL but also in depressive symptoms (Ghetti et al. 2010). Likewise, this study demonstrates that those women whose physical ailments were corrected completely were achieving a comparatively better QOL than those whose physical problems were not corrected. The finding also revealed that those who developed complications and those whose physical problems were not corrected after surgery, were still living with poor QOL.

Resumption of work soon after surgery was evident in women living in rural areas. Women finally felt comfort following surgery after a long period of suffering. The sense of well-being led to a new urge to work as hard as before. Some women had a feeling of satisfaction when working but for others working was a necessity especially after surgery in order to make the family happy. On the other hand the majority of family members expected women to resume their work. To fulfil the family demands, women returned to work soon after surgery without knowing the possible consequences such as development of infection and vault prolapse as mentioned in the Literature Review (Uzoma and Farag 2009; Parikh 2005). Understanding the issues related to the early resumption of work following surgery is another important finding of which clinicians need to be made aware. Ignorance of a women's key work role offers an explanation as to why, irrespective of the clinician's effort; rural women's QOL seldom improves after management. Knowledge sharing around the consequences of hard work soon after surgery for POP is lacking. Therefore, this study advocates a need to improve both post operative care and care counselling. These approaches

would include maintaining hygiene, rest for at least six weeks and a nutritious diet post-operatively. Rather than individual counselling, this study suggests that family counselling within the Nepalese context would be of more value.

Another finding from the study, which is unique to other follow up studies, was that only those women who got better after treatment participate in follow up appointments. The women who faced problems after surgery tended not to participate in any other medical activities including follow up. When facing problems after surgery women did not feel able to tell their family members that they were again suffering the same symptoms. Financial constraints in the family prevent women from seeking health care for recurrent problems. The reason for patients not participating was due to a loss of faith in the clinicians, and so they were hesitant to return for check-ups. Hence, taking data only from women who are successfully treated and who participate in follow up checks cannot conclude that QOL improves after POP surgery. Any future study related to QOL should focus on the reasons behind dropouts from follow up clinics in order to find out the actual outcome.

#### **8.4 Health care organization level**

The overview of factors contributing to POP development in relation to health care organizations has been presented in a previous findings chapter. This further discussion will be on factors contributing for POP development at the health care organizational level and the possible solution for their prevention and management through understanding ongoing management. This provides direction for policy change in the management of POP.

##### **8.4.1 Factors contributing for POP development**

Poor access to health care facilities was one of the themes identified from the study, which gave rise to POP. The dimensions of access (Donnel 2007) at the health care organization level are availability, physical accessibility and affordability. Nepal's health care system, as outlined in the Nepal in Context Chapter, is underdeveloped. Health care facilities are still very limited in rural areas when compared to urban and urban natured settlements. The literature related to maternal and child health reaffirms the poor health status of Nepalese women; their problems of access to health care and the adequacy of the health care system in responding to their needs (Department of Health Services 1996). The findings also showed that child death in rural areas is common due to the unavailability of health care facilities. Clinician participants agreed that lack of health care was found to be related to child

morbidity and mortality. Under five mortality rate in the year 1990 was 142/1000; in the year 2000 it was 82/1000 live births which reduced to 40/1000 live births in the year 2013 (World Bank 2013). The time when most participants in the study were giving birth was around 1990 when there was a high under five mortality rates. The impact of infant and child mortality on fertility was identified from the study findings. Parents were found to insure themselves against possible child death by having more children than they would otherwise want without knowing the consequence of POP. This reality is consistent with the findings from a study carried out in Ethiopia and other countries with high fertility rates as the need to replace the lost indexed child, (Lindstrom and Kiros 2007). Nepal has made significant progress in achieving the MDG for child mortality rate. However, the SDG 3 target seeks to promote healthy lives and well being by reducing preventable deaths of newborns and children to less than 1% (Sustainable Development Goals 2015).

Along with the poor-availability of health care facilities, the study findings show the lack of trained manpower at different levels across maternal health care services as a contributor to the development of POP. The non-availability of trained manpower inevitably leads to women having more home deliveries. Home deliveries are mostly assisted by traditional birth attendants or family members, especially mothers-in-law where malpractice, sadly, is dominant as shown in the findings. Evidence of malpractice was also found in some remote health centres. This brings serious attention to the need of training the manpower to improve the quality of care. Acharya and Cleland (2000) report that MCH coverage is higher in high quality health posts than in lower quality health posts and argues for investment on the quality of health posts rather than increasing their number. However, this study suggests need to improve access to health care service by improving both the number of health centres and trained manpower so that every birth is assisted by skilled hands. Irrespective of the current efforts, the Government is still facing the challenge of making access to health care services easy. The further recommendation is for the Government to continue providing SBA training in order to produce the required number of trained health care providers. The solution regarding trained manpower will further be discussed in medical prevention section under the heading of safe delivery practice.

The choice of a home delivery was also found to be due to a lack of money to cover the costs of a health facility delivery. The report from the pilot study showed that even where there was a health facility, home delivery remained the norm (Appendix 13). People were simply

put off by the expense. They felt that their limited funds were better directed to other areas of their lives. Hence, in order to increase health facility deliveries, huge socio-economic barriers have to be overcome. The health financing system provided a free health service through district level health facilities from October 2007 (Ministry of Health and Population 2012). This has improved access by improving the affordability.

Physical accessibility was another reason identified by women in rural areas for not seeking a health facility delivery. Physical accessibility includes place of residence, distance to the physical facility and the availability of transport. Wagle et al., in their cross sectional study, showed that a distance of more than one hour is associated with increased risk of home delivery (Wagle et al. 2004). This study also showed that physical accessibility was a major barrier in seeking health care irrespective of the availability of health centres. Geographical diversity as mentioned in Chapter Two, hills and remote mountains with poorly constructed roads made access extremely difficult. These aspects make transportation facilities in rural areas very limited. This requires the attention of the Government to develop future policy to improve physical accessibility, and should direct the building of roads in rural areas where access is really a problem. The Government is now committed with its plans to achieve the relevant SDG. The target is to increase road density from the current 0.44km/km<sup>2</sup> to 5km/km<sup>2</sup> by 2030 (Sustainable Development Goals 2015). Thus physical accessibility is likely to improve.

The Organogram of Nepal's Department of Health Services is presented in Chapter Two 'Nepal in Context'. There are 1,689 health posts with 2,127 sub-health posts. The Government has launched different maternal health related programmes to improve the access to health for all. The study findings and the report from the Ministry of Health and Population (2012) signified that there has been improvement in the utilization of maternal health services over the last decade. However, access remains in doubt as some recent studies (Baral et al. 2012; Dahal 2013) have described inadequate utilization of maternal health services. They suggested the need for government to give priority to women from lower socioeconomic groups in the rural areas by adopting a different community intervention. However, the finding identified barriers related to acceptability as a challenge for women, irrespective of improvements in the availability and affordability of services. The responsibility of health care workers to raise people's awareness and encourage acceptance of health services has been discussed above.

### **8.4.2 Process for understanding management**

The Government initiated a campaign to address POP by providing funds for free surgical treatment at hospitals as well as in surgical camps. At some places women were screened and taken to hospitals for surgery while in others the surgical team provide treatment in situ depending upon the remoteness. The overall management of POP care including screening, assessment, management and post-operative care through to follow up are discussed below. The findings are discussed in relation to relevant literature together with the National Service Guideline and Clinical Protocol.

#### **8.4.2.1 Screening**

The prevalence of POP, in different parts of Nepal is presented Appendix 7, Table 1. However, there are no actual statistics available from the whole country. The researcher, as a part of her work, visited outreach clinics in different parts of Nepal. In some parts, where access was difficult, the prevalence was notably higher. The government launched the POP prevention and management programme, which aimed to lower the prevalence of POP. Without knowledge of the actual base-line prevalence, it is difficult to calculate the remaining prevalence and need for further intervention. The findings from this study suggest a need to identify POP from the hidden population through a national survey so that the actual picture of its prevalence can be presented to the Government. Once comprehensive data are available, it will be easier to plan and run management programmes.

Although the service guidelines mentions the requirement of at least one doctor, two staff nurses and one counsellor of ANM level; this study found that these manpower levels were not being achieved. The doctors were seldom involved in screening. The first round of screening was done by community health workers, the second round by nurses and a woman's eligibility was only assessed in the third round, where doctors would evaluate and screen the patients before performing surgery. Clinicians mentioned the lack of manpower is challenging. To be involved in screening, evaluation, surgery and follow up at the same time in the POP surgical camps was not possible for them. Health workers, therefore, at different levels were utilized to screen the patients.

The findings suggest that screening of POP has to be done by community health workers to bridge the gap between the community and the health centre. The aim of the screening camp is to identify women suffering from POP who need treatment. However, identifying those

who are not symptomatic but would benefit from preventive awareness to avoid developing POP should also be the objective. The National Service guideline mentions provision of awareness of POP as part of the screening process. However, the study identified that the health workers involved in screening lacked sufficient knowledge of POP and its management. The pilot study findings showed cases of poor screening when the health workers found it difficult to reject patients. Similarly, when the clinicians faced difficulties during treatment, they observed that the development of complications was more often associated with poorly screened cases (Appendix 13). From the researcher's experience, in her clinical practice, poorly screened women from the community were mostly not in need of surgical correction and were rejected for surgery. This apparent positive outcome has an unintended negative impact for women who then lose faith in the community health worker. The training of health workers involved in screening is a priority to improve their knowledge and skill and is a recommendation of the study.

#### **8.4.2.2 Assessment**

Assessment includes comprehensive history taking, examination and investigations in order to come to a diagnosis and that will allow choice of an appropriate mode of management. Pelvic examination shows the extent of the prolapse and establishes the involvement of different segments. The thorough assessment of the patient is a time consuming process but an important indicator for management (Jelovsek and Christopher 2007). Different approaches for assessment have been reviewed in the Literature Review Chapter. The Clinical Protocol outlines assessment methods; findings from this study show differences in the assessment of patients in hospital and those seen in mobile surgical camps; irrespective of the eventual place of surgery. In hospital based management the assessment happens at different levels before deciding the final mode of treatment. In the camps, although every clinician participant said that assessment of each patient took place prior to surgery, time constraints and lack of manpower, meant that assessments were often superficial. Inevitably, doctors tended to choose the same mode of management for most women which may not have been appropriate for all.

The findings also show that the clinicians' assessment focuses on the woman's physical problems and rarely extends to any social or emotional difficulties she may have. Most of the clinicians believe that once the physical problem is solved, the other related symptoms will disappear. However, some clinician participants recounted going beyond the purely

physical assessment; to encompass social, psychological and sexual problems in their assessment. According to these clinicians, such investigations enabled them to decide on an optimal mode of management, and avoid women undergoing unnecessarily over or under correction, which would have its own consequences later on. For example, if social factors are excluded from assessment, a woman may have a hysterectomy for her POP even if her family is not yet complete. Her husband may well then seek another wife to bear him children, which further compromises her quality of life.

The study found that women hide other health problems in case they are rejected for POP surgery, which they know, is free-of-cost. They do not want to miss a possible solution to their long-suffering problem. In such situations, there is a greater risk of experiencing complications during or after surgery. The clinician participants provided a telling example of operating on an already pregnant uterus. The scenario from surgical camps in rural settings also reveals that camps are seldom equipped with adequate manpower, drug and equipment to overcome complications. Under such circumstances, although time consuming, proper assessment becomes mandatory in order to avoid complications. The general idea obtained from assessment, which policy makers should know, is about the requirement of trained manpower for effective assessment. The identified solution from the study is training the health care providers apart from clinicians, working at community level within the surgical camp site. The benefit is not only for screening and assessment of patients and selecting for surgical management but also for post-operative care and future follow up. The present study demands further research to explore outcomes of post-operative care and follow up of patients by trained health care providers.

Thorough assessment helps in identifying multiple co-morbidities during screening. Chronic disorders like POP are likely to be associated with co-morbidities. If these are diagnosed then the women affected are less likely to be selected for surgery. Sadly, under the current health system, they are not referred for other management and their future health remains uncertain. A study at Nepalgunj Medical College showed that among 937 cases of POP, 305 cases were rejected because of various complications. The majority of the rejected cases were suffering from anaemia, hypertension and chronic obstructive pulmonary disease (COPD) (Sah et al. 2010). These women face dual problems and have a poorer QOL than those who have POP only. The findings from this study suggest a need for flexibility in the Government's budget manage such cases of co-morbidity. The National Guideline

prescribes funds to manage complications but does not mention managing prolapse with co-morbidity. Policy makers need to be made aware of such conditions and prioritise these women for treatment in tertiary care centres; where POP can be effectively managed alongside other pathologies.

#### **8.4.2.3 Management**

While exploring the day-to-day management around POP; major weaknesses were found. Poor quality management results from a funding system provided on a per case basis. Operating on so many women per day supports Rana's finding. The researcher's personal discomfort as mentioned in the in Chapter One was found to be supported by her and the researcher therefore wanted to raise the issue about reproductive rights together with Rana (Rana 2006). As a clinician, the researcher was aware of the time required for each surgery for POP treatment. Therefore, demands the need to be explicit in the guidelines for sufficient time to be given to each surgery. However, the research findings evidence the weaknesses of the approach which suffer from a shortage of trained manpower and a lack of monitoring and supervision.

The financial incentive provided to the service provider, as in the guideline, is provided on a per-case basis. This 'per-case' approach motivates service providers to operate on as many women as possible each day. Clinician participants compared the advantage of a 'pay-per-day' approach meant that though fewer patients had surgery they received better treatment, which also considered the severity and symptoms of their POP. However, the clinician involved in the current camp surgery reported operating on many patients each day because of insufficient trained manpower to meet the need in rural and remote areas of Nepal. Clinicians who participated in this research and went to surgical camps said they only attended for short periods and that they were expected to complete a certain number of cases. Furthermore, failure of the National Service Guideline for the management of POP to mention the maximum number of surgeries per day has exacerbated the situation. Through this research, the researcher recommends that Government sets a maximum number of surgeries a surgeon can perform per day in the Guidelines and to make all who are involved in management of POP aware of this number.

Worrying findings from the study identified that the financial incentives, motivated inappropriately skilled manpower to be involved in POP treatment. Ideally, gynaecologists

should be managing POP, but others such as general practitioners, surgeons and even medical officers (under-graduate doctors) were found to be operating. The failure of the national Guideline to state who should carry out the operations, a lack of trained doctors, educated and skilled enough to perform POP surgery and a lack of monitoring and supervision at a time of management by the Government have all exacerbated the situation. The recommendation to Government is to specify explicit within the Guidelines, the criteria for the surgical teams' qualifications. Secondly, as a part of practice development there is need for gynaecologists to be updated on a regular basis to ensure they are knowledgeable and skilled enough to deal with POP management.

The financial incentives initially were based on curative management via vaginal hysterectomy. Clinicians who are experts in managing POP face a dilemma. Should they follow what the Guideline stipulates and deal paternalistically, or use their expert knowledge to assess and optimally manage each case of POP. Whilst, most of the women screened were undergoing similar kinds of treatment, improper treatment for some may mean that they will continue to suffer later. Family members expect compensatory work from her after her treatment because they are not aware about problems post-surgery. As she has already undergone surgery for the problem she cannot demand further treatment. Women would benefit if the funds were issued according to a range of treatment needs. More recently there has been a change in the National Guideline (2012) giving flexibility in funds for anterior or posterior compartmental defect management along with apical. The findings from this study offer further evidence for a much needed person-centred approach where women are offered various treatments according to their needs. In order to provide person-centred care the service providers need to gain adequate knowledge and skills regarding POP and its management options.

Seabrook states that short-term medical camps are currently the subject of much debate within the global health community because of their transient nature and uncertain long term effects on the health status, poverty and development of the local population. Her findings uncover a number of problems and ethical implications such as duplication of effort, lack of follow up, and non-compliance with government regulations (Seabrook 2012). The clinicians cited the complication of haemorrhage as a frequent problem, which, if not managed quickly can lead to a woman's death. While working in compromised situations, if the manpower do not have the necessary skills, complications are more likely to develop.

The findings from this study demonstrated that those who received treatment from the tertiary care hospitals showed improved quality of life over those who were managed in the camps. The development of infection was found to be more common in those women who were operated on in rural camps than those who had their operations in hospital. The researcher feels that the surgical camps, although they have demonstrated benefits, are not and never can be a sustainable intervention programme for the management of POP. There is a need for pre-surgery preparation, by assessing the skills of the person involved in the management of POP. If the necessary skills are not apparent then the stakeholders must take responsibility and set up training programmes. Trained manpower will not only improve surgical outcomes for women but also enable better follow up care.

#### **8.4.2.4 Post-operative care and follow up of patients**

Findings from the study suggest that post-operative care in the camps was virtually non-existent. Limitations of time, infrastructure and manpower mitigated against good post operative care and follow up provision. The camps are planned for a certain period and therefore will be utilised maximally to provide curative management through surgery. The post-operative care is severely limited to either a medical officer or other health workers who were not trained and were not able to diagnose complications in time. The chief surgeon is a 'one-man-army' in the camp, taking all responsibility for the patients in their treatment process. When complications happen, the chief surgeon must assume all responsibility and act accordingly. Therefore, their focus goes mainly into surgery rather than pre-operative assessment and post-operative care. The National Service Guideline (2008) proposes post-operative care for 5-7 days, in the camps. However, findings show that patients are discharged before 5 days. The most common reason for early discharge is the unavailability of adequate space and beds for post-operative care in rural camps.

Although follow up of patients after six weeks, has been made mandatory the findings from this study shows that this is not happening. The researcher, in her clinical practice, identified a wide range of dissatisfaction when following up women from surgical camps regarding place, persons and procedures; this was supported from her research findings. The temporary sites meant women failed to locate the venue for follow up. Regarding person; women did not know who had operated on them. The women's wish to meet with the clinician is presented further in the next paragraph. Regarding procedure; women rarely knew what had actually been done to them. The researcher supports the women's right to know and

recognise the person who is going to treat her. The step in which the involved clinicians, introduced themselves and explained what they were going to do to the individual was missing. The clinician participants cited other clinicians involved in the surgery as the problem. An account of a clinician DRI, '*treating clinician don't attend for follow up care once the camp is over*'. She works in a remote area and sees many patients with different complications. Subedi, states the need for a clear-cut monitoring system to keep track of patients who have undergone surgical procedures, especially the ones who could face complications (Subedi 2010). The monitoring system though in existence was found weak in reality. Here, all the evidence about the compromise happening with time and trained manpower suggests strictly the need for the monitoring system to be followed up by the government, this will further discussed under the next heading.

The women participants who do not receive good post-operative care developed many sorts of complications. The most difficult period for women identified from this study was the period within the first few weeks following surgery when they were discharged home. Because of the lack of transportation facilities and difficult access issues women often walk long distances over many hours. Such exertion immediately after surgery was found harmful for women. Following the development of complications, many women turn to private practitioners. Women wished to meet the doctor who had carried out their operation, but this opportunity was never offered. The study found a strong association between post-operative care and the QOL for women. Those who received good care following surgery developed fewer complications and went on to have a better QOL. Women who reported poor or non-existent follow up care tended to develop complications soon after surgery, which led to a poorer quality of life later on. This finding could not be explored in a quantitative study alone. Utilisation of a mixed methods approach, both quantitative and qualitative allowed the actual picture to be seen.

After being involved in this study and visiting several outreach centres for follow up clinics, the researcher found that it is those women who made good recoveries after surgery, who tended to come forward for check-ups more readily than those who did not. During the recruitment process and data collection it became apparent that the women who came forward to participate were more often those whose life improved after surgery. There were very few participants, who reported poorer QOL after surgery. Though the ones whose symptoms were not improved, whilst difficult to recruit, have brought richness to the study

by providing an actual picture of the difficulties they faced before, during and after POP management. The clinician participants gave similar accounts of women who developed complications after surgery tending not to come for any follow up. To support this claim, further research need to be carried out to exploring the reasons for drop out in follow up, and identify the gaps in management. The actual picture of QOL following surgical management then becomes acceptable. In the researcher's view, the main reason behind women's dissatisfaction was the single approach of dealing with the problem without involving the women or providing adequate information about the problem, but just offering management as per the guideline without respecting women's autonomy for decision making. If a person-centred care approach had been offered, there would be high probability for satisfaction.

#### **8.4.2.5 Monitoring and supervision**

The lack of monitoring and supervision within POP management across all levels was criticised by the clinician participants. The surgical camps, in the remote areas, have their own benefit to the patients and the service providers. Participation was found to be higher when the health service (surgical camps) were taken to the women. The monetary incentive provided for patient transportation was actually not needed and the funds could have been better used elsewhere. The service providers benefitted as they were remunerated well for the surgical camps in rural areas. However, compromise was inevitable within the process of POP camp management because of limitations of time, infrastructure and manpower. The level of compromise and the feeling of insecurity while working in camp has been explained in the finding chapter by a clinician participant DTH. The management programmes in camps, therefore, require regular monitoring and supervision as part of quality care demands. For future reference, after getting trained manpower at different levels it is presumed that the monitoring will be more systematic and effective.

Lack of trained manpower and infrastructure for management of POP together with the high prevalence of POP among Nepalese women instigated the surgical camps in remote areas. The opportunities for securing a contract to conduct the surgical camps were found to be highly politicised. Personal interests worked across different sectors so the clinicians themselves had doubts about the quality of care and demanded proper monitoring and supervision. A recent study on the impact of surgery for POP in Nepal recommends improving the quality of health camps, care, supervision, monitoring and follow up. They suggested for proper implementation of the National Guideline and Clinical Protocol,

effective counselling and better co-ordination among the stakeholders (Chhetry et al. 2012). As the prevention and management is a national program, it could have been better to identify the manpower and infrastructure beforehand which was not done. However, the researcher is hopeful that with practice development, the quality of care delivered by all involved in POP management will improve and therefore reduce the need for supervision and monitoring.

### **8.4.3 QOL and policy changes**

The difficulties women face before, during and after management of POP highlighted in this study have identified the challenges inherent in the management policy and further advocate the need for an improvement in the national policy. The several changes identified from all levels in this study call for the need to develop emancipatory practice. This study suggests three main changes. The first one is related to upgrading the knowledge and skills of the people who are involved in the management of POP at all different levels, the second requires strengthening infrastructure and the third is expansion of the preventive approach beyond the health care level.

#### **8.4.3.1 Upgrading the knowledge and skills**

Lack of knowledge and skill among service providers prevents offering treatment options to women. The management policy reflects a lack of investment in manpower who are knowledgeable and skilled enough to manage POP care in Nepal at different levels. New trained manpower and improved training of the existing human resource is required. For screening, post-operative care and for follow up, community health workers were identified as key staff to be provided with education and training in POP and its management. From these developments screening, assessment, conservative management and prevention will become more effective. The lack of counselling and communication skills identified among service providers may be improved with improved knowledge.

The gap in the knowledge and skills of the gynaecologists and the policy which dictates dealing with all patients in the same way supported paternalism. As a part of practice development, the study affirms the need to empower gynaecologists. Therefore, the Government should take up this message for the future preparation of skilled and knowledgeable manpower for management of POP. The options are to provide of competency based training in masters programs; to improve the number of trained and

certified gynaecologists; and by giving competency based training to gynaecologists already in practice; these approaches are possible ways forward to fulfil the demand in tertiary care centres throughout Nepal. This action will not only help to improve the number of competent gynaecologists for POP management but also reduce the need for monitoring and supervision. Following competency based training, the gynaecologists themselves become motivated to and involved in POP prevention and management.

#### **8.4.3.2 Strengthening infrastructure**

Another barrier to providing quality care while managing POP, was related to lack of infrastructure. The main recommendation from this study to the Government is for a long term plan for POP management based in tertiary hospitals where management of complications is possible. The majority of clinicians cited zonal hospitals situated in different parts of Nepal as their place of choice. The researcher agrees with this view that there is a need to strengthen the zonal hospitals in the periphery for the long term plan. However, the Government needs to see the arguments (explained below) from different sectors for not being able to take responsibility for POP management at the present time. The Nepal in Context chapter explained about the different levels of hospitals under the heading 'the health care system'. However, the opinions from the clinicians working in different sectors were not congruent. According to clinicians working in the government hospitals routine POP surgery in zonal hospitals is unlikely to be achieved due to the lack of trained manpower, infrastructure and equipment. However, these challenges are not insurmountable; if addressed then routine, sustainable POP surgery throughout Nepal would be possible. The additional recommendation was to establish either separate hospitals for POP management or a urogynaecology sub-speciality unit in all tertiary hospitals. The researcher considered this as a valid proposal and strongly supports the recommendation. The time is right for Nepal to have sub-speciality within the urogynaecology unit which only manages problems related to pelvic floor disorders.

The clinicians working in the medical colleges proposed involving medical colleges in the Government program for management of POP. The medical colleges can provide quality care at reasonable cost and will benefit as they have trained manpower to teach medical students. The researcher agrees with this view because although there is a need to strengthen the zonal hospitals; until the manpower and infrastructure changes, the medical colleges in different parts of Nepal are a reliable option. The medical colleges have enough

knowledgeable manpower and infrastructure to allow better care of all aspects of management, including follow up. Involving medical colleges further strengthens the requirement for research and monitoring which could be integrated into the academic teaching and learning. However, a third viewpoint provided by clinicians working in private clinics was considered unsuitable. They proposed giving the opportunity to all gynaecologists who are capable of managing POP cases. As the government is already experiencing difficulties in monitoring and supervision of gynaecologists making the assurance of quality care problematic. The study considered it an invalid proposal.

#### **8.4.3.3 Expanding preventive approach**

There are multiple factors that contribute to the development of POP. As the causative factors are many, there is no single approach to prevent the problem. This study confirms the major risk factors as childbirth and hard work for Nepalese women. The former needs a medical approach in prevention whereas the latter requires a socio-cultural, non-medical change.

#### **8.4.3.4 Medical Prevention of POP**

A preventive approach is vital, especially in a country like Nepal, where the dependence upon international aid for the management of health related problems is not sustainable. Obtaining funds and making POP treatment free of cost was a very positive endeavour the country made for women, but questions remain over its sustainability. When the funds provided end, what will be the fate of those who are still suffering? In due course, without a preventive approach the problem will continue. Hence, equal emphasis on prevention as well as treatment is urgently needed.

The service guideline (2008) for POP management mentions an awareness programme at the time of screening. The clinical protocol (2012) also recognises its importance under a separate heading. However, considering major risk factors the case for medical prevention will be discussed under the headings below.

#### **8.4.3.5 Safe delivery practice**

Improved use of maternal health services is an indicator for reducing maternal mortality and morbidity. Maternal health services, described in the Chapter Two reflect the service status and show their poor availability and inadequate utilization (Carlough and McCall 2005).

Local Traditional Birth Attendants (TBA) are not recognised as SBA by the WHO because they are generally not trained to deal with birth related complications. Maternal and child health workers (MCHW) who have completed a 15 week course on maternal and child health and a further six weeks refresher course in midwifery skills are playing a key role as community level birth attendants in Nepal (Chhetry et al. 2005). A finding of the current research showed mismanagement by health professionals at different levels in the health centres aggravating POP development. Probable explanations for this sub-optimal care are, firstly the difficulty for the health workers of changing old practices and adopting new technologies, and secondly the low numbers of available trained manpower. These challenges can be recovered either by conducting refresher courses regularly for health workers to update their skills and adopt recent advances in maternity care or by equipping health centres with more SBA. The Government intend to improve births attended by SBA to 90% by 2030 (Sustainable Development Goal 2015) SBAs are therefore a key intervention to reduce maternal mortality and morbidity associated with pregnancy and childbirth. Improvement of access to maternal health services and the availability of SBA at every birth can bring significant changes to women's and their families' health and can help prevent POP.

#### **8.4.3.6 Post-delivery care**

Lack of adequate rest after child birth is stipulated as being associated with the development of pelvic organ prolapsed. In a qualitative study, the strongest message to women in the rural areas is that there is no need for rest before and during delivery. Because of the household work burden and lack of supportive family members many women are forced to work immediately after delivery (Subedi 2010). The need to improve their position and so improve their health status has been discussed earlier at the individual level.

At the level of health care organisation, the awareness of pelvic floor exercises was identified as lagging. Post-delivery rest, balanced diet as required and pelvic floor exercises (Kegel exercise) during the post-partum period can help prevent POP (Kumar and Malhotra 2008). The women were not aware of pelvic floor exercises however post-delivery rest and diet has was a concern for them. The SBA training manual covers many aspects to improve maternal health during pregnancy, delivery and the post-partum period. However, the training manual does not mention pelvic floor exercises (Kegel exercise) in Post-partum care. Pelvic floor muscle training is effective to improve the of symptoms of POP. A randomised controlled

trial on the effectiveness of pelvic floor muscle training has shown reductions in the stage and symptoms of POP (Braekken et al. 2010; Hagen et al. 2009). When a nation is moving forward with the hope to deliver all women by SBA, the absence of pelvic floor muscle training in post-partum care misses a significant opportunity to prevent a major reproductive morbidity. Hence, it the Government must add pelvic floor exercises to post-partum care in the SBA training manual. The next recommendation to the government health system, is to incorporate a POP prevention and management programme, which would run in all 75 districts simultaneously and bring a visible change to women's lives. It could also be argued that the intervention would also reduce costs to the health care system as fewer women would need surgical repair of POP.

#### **8.4.3.7 Reducing multiple childbirth**

Childbirth is an established risk factor for the development of POP (Jelovsk and Christopher, 2007). Women with POP were found in the study to have had many children. Giving birth to many children was found to be associated with some common factors such as not getting access to family planning, the need for a son and the insecurity brought about by the deaths of children. Reducing multiple childbirth is possible by improving the socioeconomic change which has been discussed earlier at the women's level. However, access to family planning is discussed below.

Family planning is a priority health programme; the study findings suggest a lack of access to the family planning service in rural areas. In Nepal less than half of married women of reproductive age use any family planning methods. Additionally, 26% of rural women want to time or space their pregnancies, but have an unmet need for family planning. This unmet need for family planning in Nepal is higher among women with low incomes and living in the most remote areas (Shrestha et al. 2012; UNFPA 2010). However, the family planning adoption study in 2002 shows that couples in Nepal discuss the adoption of family planning (Sharan and Thomas 2002). Similarly, findings also showed an improvement in the use of family planning methods with time when compared to their parents. A reduction in the fertility rate as presented in the Chapter Two is an indicator of the utilization of family planning methods. However, the need identified by this study is to improve access to family planning among the unmet need groups. The Government should focus on the groups with unmet needs in remote areas.

The preventive approach is a long process which needs multi-sectoral involvement as many precipitating factors combine to give rise to POP. The medical approach to prevention is one important part but the findings from this study suggest that this approach alone will do little to reduce the rate of POP. The effort must be across all different sectors (including non-medical) and reflected in policy change. Factors which can usefully be categorised as non-medical are discussed in the next section within the Government level.

## **8.5 The Government level**

Access to health care in relation to accessibility and affordability was identified within the Government level. The Literature review chapter presented Nepal's basic infrastructure, its geographical distribution and poor developmental activities as causes for increased work load. The next section explains key elements of women's increased work load and discusses possible solutions for the prevention of POP. To improve the situation the result of the findings suggests the Government takes responsibility for improving health facilities making them more accessible and affordable.

### **8.5.1 Factors contributing for POP development**

The Nepal in Context chapter, argues that poor socio-economic conditions in the rural areas contribute to women's low status, and continued risk of developing POP. There are important reasons, confirmed in this study, why women should be enabled to develop their potential beyond their current roles which include a lot of hard physical work. The development activities in rural areas are inadequate and inefficient. As a result, women need to do laborious, manual work consuming energy and time. The study confirms that a woman's persistent, physical labours contribute, as a non-medical cause, to her development of POP. This is also supported by other studies in Nepal (Bodner et al. 2007; Gurung and Rana 2007; Dangal 2008). Additional material which supports developmental activities as a part of practice development will be provided later in this Chapter. Childbirth though remains the strongest precursor for the development of POP, however, this study identifies that issue is not only childbearing but childbirth when associated with hard physical work contributes to POP development. Policies for POP management must therefore reflect a multi-agency approach and critically, within the Nepali context, involve a preventive approach beyond the health care level.

### **8.5.2 Non-medical Prevention of POP**

Workload for women, living in rural areas, is identified as a leading cause of prolapse. The Nepal in Context chapter give details about routine tasks that add hours to the already long work days because of basic infrastructure problems such as: access to water, cooking fuels, electricity and transportation. Nepal's socio-cultural, economic and geographic nature aggravates the situation more. This study confirms that work load is an unavoidable risk factor for women and appears much more powerful contributor to prolapse than the factors related to childbirth. Thus, the study results suggest that to improve the situation effort will be required from individuals as well as the Government efforts in rural development activities.

The patient participants recounted their hard work and gave the example of the collection of water from a distant place. This is a basic need, the researcher feels that it is not possible to advise them not to carry water as it is essential in their daily life. Instead, the way forward is for Government to identify solutions to improve the supply. The Government of Nepal proposed targets for the SDGs, include 95% of households having access to piped water supplies and improved sanitation by 2030. A similar target has also been set for electricity supply. The plan is to generate 10,000MW electricity and decrease energy intensity by 0.8% per annum. With this 99% of households will have access to electricity, and only 10% of households will use firewood (Sustainable Development Goal 2015).

Livestock management includes fodder collection, another routine daily task which consumes women's time and energy. The farm based agro forestry practice is for home gardens, planting trees on and around agriculture fields, commercial crops grown under the shade of trees or agriculture crops inter-cropped with commercial trees (Regmi 2003). If farmers implement these strategies for improved fodder production through farm based agro forestry to manage their livestock it will also help to improve health of the women by reducing their workload.

As most of the population in the rural communities are farmers by occupation, keeping livestock increases work load. To reduce the workload of women, electrification or installation of biogas plants can be an alternative. Biogas has been considered as an energy generator, an environment protector and also produces fertilizer for agriculture. These all are associated with the improvement in the health status of communities and assist in the overall

improvement in the economy. A study done in Rupendehi district by Van Vliet showed a reduction of workload by a minimum of 2 to a maximum of 7 hours per day and an average time saving of approximately 3 hours per day (BSP 1992). Promotion of alternative energy is recommended as a sustainable health-giving strategy.

Transportation facilities call for serious attention to increase access and improve peoples mobility in remote areas. Through the provision of such services, it can reduce rural poverty by facilitating people to have better access to services (education, health, finance and markets), obtain goods and income, and to participate in social, political and community activities. Rural roads can greatly reduce women's time and labour burden. Improvement of physical access to health care has already been described in the health care organisational level.

All the measures discussed here reflect on women's workload in rural areas. As women's excessive physical labours are a non-medical reason behind the development of POP, the nation's developmental activities which include addressing the basic needs for living in rural areas will reduce these burdens. The rural developmental activities therefore need to be improved through National rural development plans. Alongside such developmental activities the economy will improve. With improved economy and better access to many developmental endeavours, women become more able to make independent decisions for their better health. This research provided insight through the POP lens where gaps in policy related to rural developmental activities need to be addressed and incorporated into health care along with other disciplines. Younis et al. (1993) predicted that for sustained impact, development and medical responses need to work together taking into consideration the socioeconomic practices and contexts that affect women's reproductive health (Younis et al. 1993). In order to evaluate the effect of rural developmental activities on health, interdisciplinary research is required which integrates health with other disciplines. Policies for POP management must therefore reflect a multi-agency approach, without the Government bringing rural development plans to reduce the work burden of women, the prevention of POP is just not possible.

## **8.6 Summary**

The discussion chapter followed the conceptual module. The position of women in society was regarded as an important factor contributing to the development of POP. Poverty, lack

of education and socio-cultural disempowerment together with lack of access to health care facilities were associated factors for the delay in seeking health care. POP was found to hamper the QOL of women significantly. The physical domain was found to affect all other domains of QOL. Initiatives for the treatment of POP were found to be associated with an improvement in QOL for the majority of women. However, the need for assessment of all physical symptoms prior to proceeding with surgery as correction of physical symptoms was found to be associated with improved QOL. Management of POP needs to refocus with a shift to PCC. Many concluding points are embraced within the discussion. These points are presented separately in next Chapter.

## **Chapter 9: Conclusion and Recommendations**

### **9.1 Introduction**

This chapter begins by presenting the overall key conclusions. Separate conclusions and recommendations are presented based on the research findings which relate to the impact of POP from a QOL perspective; an approach for prevention of POP; and POP management, its weaknesses and the need for practice development. This informs the status of management policy and will guide the need for change in existing policy. This chapter ends by reflecting on the contribution to knowledge of this study.

### **9.2 Overall key conclusions**

The key conclusions are

- The position of women in the society is associated with the development of POP
- The physical domain is the main domain effecting other domains of QOL (social, psychological and economic)
- There is a need to improve existing management policy
- There is a need to upgrade the knowledge and skills of manpower at all levels involved in the management of POP
- There is a need to expand preventive approaches beyond the health care level

### **9.3 Impact of POP from QOL perspective**

Following the development of POP, mobility was found to be severely affected by all the physical symptoms. The women's QOL depended upon their ability to work for the family. The physical domain, therefore, was identified as the main domain affecting almost all other domains of QOL. The correction of all physical symptoms was found to correct problems in the other domains. Management of POP, thus needs to re-focus on correcting all physical symptoms completely in order to improve the QOL of women. This is possible with assessment of all the symptoms and signs, offering management to the women in relation to their needs and providing good post operative care. Women, who were identified living with poor QOL even following surgery, were either the ones who were not assessed effectively and completely for all the physical symptoms and thus underwent incomplete correction, or those who faced complications following surgery.

### **Recommendations for Policy makers**

1. Develop a plan to train the manpower for screening, evaluation and management of POP.
2. Prepare sufficient manpower for POP management through competency based training.
3. Improving the masters training programme in gynaecology by updating the course and training content.

### **Recommendation for health care workers**

1. Health care workers should gain adequate knowledge and skills so that they can offer treatment as per the needs of the patient.
2. At the level of health care organization there should be continuous refresher courses in the form of continuous medical education.

### **Recommendation for the upcoming research**

1. Most of the post surgical morbidity related issues in the field of POP have been studied by utilising quantitative method. To identify QOL after management, research with mixed methodology should be taken forward.
2. This qualitative study identified that women who were still living with poor QOL after management were not participating in follow up studies. Therefore, to identify the actual picture on post surgical morbidity, a further recommendation will be to conduct research to identify of the reasons for this drop out.

### **9.4 POP management and its weakness**

There are no statistics available for the actual prevalence of POP in Nepal. The Government designed the prevention and management programme without knowing the actual prevalence. This creates doubt regarding the outcome of the intervention period. The Government program was focused on reducing prevalence over a certain period of time. Different compromises were identified leading to poor quality of management at different levels: screening, assessment, management and follow up. The time and manpower constraints in the remote places made the screening and assessment superficial. Lack of awareness about the clinical protocol and guidelines also challenged the situation further. Failure of the guidelines to mention different modes of management led to clinicians choosing the same mode of management for all. Poor post-operative care and follow up was

an identified issue leading to women developing complications, this needs the urgent and thorough attention from the clinicians and policy makers. Follow up, irrespective of the availability of funds the care was absent. This finding must be noted by the Government and treating clinicians to improve post-operative care and follow up in order to improve the lives of women.

### **Recommendations for Policy makers**

1. A national survey to bring out the actual prevalence from the hidden populations should be made. This will help to identify need for planning intervention in the future.
2. The focus on reducing prevalence was found to have significant effect on QOL of patient. Therefore, instead of focusing on reducing prevalence over a short period of time, policy makers should plan over the long term for the prevention and management of POP.
3. Future government policy should aim to reduce the reliance on surgical camps.
4. Zonal hospitals located in different places of Nepal are the recommended sites to develop for POP management. In the long term, policy makers should plan to upgrade these sites by equipping them with knowledgeable and skilled manpower, instruments and infrastructure.
5. There is need to revise the protocol and guidelines for the management of POP. The revised protocol and guidelines has to be adopted by everyone involved in the management of POP.

### **Recommendation for health care workers**

1. Health care workers should utilise their best knowledge and skills for the optimum patient outcome. Health care workers should be made aware that both over and under correction is harmful to the patient.
2. Follow up of the patient is as fundamental as treatment. Health care workers should follow the guidelines on post-operative care and follow up.

### **Recommendation for the upcoming research**

1. Lack of trained manpower was an identified reason for compromise while managing POP. Irrespective of funding for follow up, the follow up was found inadequate and usually absent. Reasons for not providing follow up were not explored in detail in this study but need to be explored in future.

## **9.5 An approach for prevention of POP**

The study identified the context for the development of POP is related to the position of women in Nepalese society. Prevention of POP was included together with management in the National programme, but prevention was inadequately addressed. The government is trying to improve all four dimension of access (availability, accessibility, affordability and acceptability) however; acceptability from the level of individual is still a challenge which may be due to the Government not being aware of the position of women in society. Various forms of intervention have to be adopted in awareness programs which reflect the women's position. This will not only bring forward the affected women but will also motivate future generations for prevention.

### **Recommendations for Policy makers**

1. The government should incorporate a preventative program within the Government reproductive health care system.
2. Pelvic floor exercises as a part of post partum care should be incorporated into the SBA training manual.
3. The preventive approach identified in this study should move beyond the health care level. As non-medical prevention of POP is possible by improving position of women in the society. The Government should promote the rural development activities, which help reduce the work burden for women thus reducing the development of POP.

### **Recommendations for health care workers**

1. Considering the position of women, various forms of health awareness programmes to improve acceptability should be taken up as a responsibility by health care workers.
2. While screening for POP, the screening program should not be limited to screening only. As a first approach it should create awareness for prevention and spread lessons on living a prolapse free life for this as well as future generations.

### **Recommendations for the upcoming research**

1. Though the research aimed mainly at finding the impact of surgical management, the researcher moved beyond to identify the reasons behind the development of POP among Nepalese women. It helped the researcher identify the non medical and major factors associated with the development of POP. This challenged the

need for intervention in prevention not only at individual and health care level but also at the Government level. Future research should be directed at prevention utilizing a multi or interdisciplinary approach, for example involving health workers, anthropologists and policy makers in rural development.

### **9.6 Practice development**

The surgical camps in remote areas though not a sustainable programme are needed in Nepal considering women's position, poor access to health care, lack of trained manpower and infrastructure for management. Again the initiatives taken for the treatment of POP, though paternalistic, seem successful, as surgery for POP was found to be associated with an improvement in QOL for the majority of women. However, the management needs to refocus on PCC in order to improve the holistic care and lives of the women. The reason why PCC is yet not possible in Nepal is related to the lack of knowledge and skill of the service providers at different levels. Adoption of PCC will require empowerment in a form of education to both groups. For women, choosing best amongst the options offered by the clinician and for people involved in management at different levels, offering different modes of management according to the needs of the patient. Therefore, such a shift to person centred care will require emancipatory practice development at all levels involved in management.

### **Recommendations for Policy makers**

1. Emancipatory practice development also requires improved infrastructure. For a sustainable and long term plan, the option recommended by this study is to provide a regular service from tertiary level zonal hospitals. The infrastructure development requires preparation for prolapse management along with other services. With the availability of the infrastructure including the necessary equipment, quality care becomes possible.
2. The Nepal Government should think about developing a sub-specialty in Uro-gynecology and place them in tertiary care centers all over Nepal.

## **9.7 Post script**

The encouragement for this study was obtained by the experiences of dealing with patients who underwent POP surgery. The approach to the clinician was guided by the research itself which helped by identifying the need to improve the QOL of women. In this research process, the researcher identified some of the recommendations for future research which are not from the findings but emerged through the research journey. Here the researcher identified the focus on improving the QOL of women suffering from POP shifted towards the wider community.

- While going through the data analysis, the researcher identified the need to add an additional group of participants. They were the policy makers firstly, as the research aimed to identify the need to improve future policy for managing POP. Secondly the need for anthropological research involving close family members, exploration of their accounts would have been much better in identifying the QOL of women. Therefore, utilization of these different groups is recommended for future research.
- As this study is a purely qualitative study, when compared with quantitative studies, the number of participants is small. The outcome would have been better with using a mix of methods, including quantitative and qualitative components. Utilization of standard tools for measuring QOL and the addition of a qualitative component is recommended for future research by this study.

## **9.8 Contribution to knowledge**

Through this study, researcher made an effort to understand the effect of management of POP among Nepalese women. As a part of knowledge creation the emphasis was given on research process which brought insight for POP management utilising two different groups of people involved in the management. The ideas emerged through the research journey, through participants accounts about POP development and their experiences in management. Understanding the project itself and reflecting about her own practices and experiences in the management of women with POP were very rich and greatly contributed to her knowledge and impacted in her practice and hopefully in policy in the long run. The difficulties women face before, during and after management of POP added strength to the study and challenged the established management advocating a change to improve the

management policy from the level of the individual, the health care organizational and the Government thus improving the QOL for women.

Apart from the key messages there was additional knowledge contributed through this study. While aiming to bring change in the management and improve the QOL for women, the researcher found herself changing her practice (Reflexive account in Chapter Seven). She started listening more about the women's problems, evaluating in detail and explaining to patients about their problem and its possible solutions. She identified a level of satisfaction within herself and noticed with patients after adopting PCC. The researcher then initiated change in her work place advocating other of her peer clinicians to adopt PCC.

This qualitative study identified the reasons for favoring the paternalism and explained why PCC is yet not possible in Nepal. The weaknesses of adopting PCC are firstly, a lack of trained manpower involved in management at different levels. Because of lack of knowledge and skill, clinicians are not in a position to offer suitable management for different options. Secondly the lack of infrastructure for managing POP, making surgical camps a choice. Similarly, at the level of the individual, PCC is yet not possible because women were not in a position to select the treatment for them. Since women lack education they were bound to accept the given treatment. Identification of the reasons favoring paternalism would not have been possible through quantitative research. Obtaining person-centred care, though complex, is not impossible via empowerment of both care giver and care taker.

Collecting women's stories about their lives with POP helped to find the root for development of POP. As a part of knowledge creation, transfer of preventive knowledge was identified as one of the reasons for development of POP. POP was found running in generations in families. But, was never a topic discussed among family members. This identified that the gap in the transfer of preventive knowledge can be breached through health awareness programmes. The role of health care workers from different disciplines in bringing awareness for prevention comes with huge responsibility and a need for high motivation. The transfer of preventive knowledge was also identified among clinicians, nursing staff, and the physiotherapists group where irrespective of their knowledge, they were not been able to deliver to women. This gave the message that the gap in transferring knowledge is not related with only those whose voice cannot be heard but happens also among educated groups. This gap has been identified by Esmaili and Salsali (2014) as a

barrier to person centred care where they mentioned it is due to a lack of common understanding of teamwork. Understanding the value of knowledge transfer among all multidisciplinary specialities, the researcher started working with a physiotherapist and started pre-natal exercise classes along with Kegel exercise for pregnant women. The transfer of knowledge identified through this study will not be limited only to POP prevention but will motivate a change of practice that reduces gaps in transferring knowledge.

The ultimate knowledge created through this study, though consistent with the management of POP, becomes applicable to almost all disorders where aetiology is associated with socio-cultural, geographical and economic factors. The findings are not only for the management of POP, it is equally important for similar management and understanding for other disorders for example: Fistula in women, Hernia, Hydrocele, Cataract, etc. As these aetiological backgrounds are the same and the effects are similar too. The intervention required for the management of these can be adopted from this study finding by identifying the need to change the overall health care management policy.

### **9.9 Dissemination of results**

This research is researcher's personal journey where she tried to answer her curiosities related with QOL following management of POP among Nepalese women. Though, this research is not funded by the Government of Nepal, this research has brought many issues needed to improve POP management policy to the Government. The Government had not done any preliminary homework or any pilot studies before launching free POP management. As this study has taken a qualitative approach involving clinicians as well as women who underwent surgery for POP, it has identified the need to change policy that will help to improve women's life.

The researcher has presented her findings in national conference organized by 'Nepalese society of Obstetrics and Gynecologists' on 2<sup>nd</sup> April 2016. The findings were appreciated by many where she also received suggestions for presenting at an international conference. The researcher anticipates organizing conference to share her research findings and experiences with gynaecologists along with policy makers. Besides presenting in conference, the research will be published in academic journals.

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## **Appendix 1: Invitation letter**

(for women)

Project:

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

Dear participants,

Namaste!

My name is Anjana Dongol Singh. I am a PhD student in the School of Health, Community and Education Studies at Northumbria University. As a part of my studies, I am undertaking a research project. You are being invited here to take part in my research.

The study I am doing is on pelvic organ prolapse management in Nepalese women. I will be exploring the factors that impact on quality of life before and after its management. Identification of the factors which still persist after its management as well as hearing about issues women report before seeking treatment will help to bring about holistic care.

For this research I need to study a group of women who have already experienced pelvic organ prolapse management. If you decide to participate, you will be invited for interview so that I can talk to you about your experiences. The session will be digitally recorded. Your name will be anonymised and all the information gathered will be kept confidential.

If you wish to participate, please contact me at the number listed below.

Thanking you.

Anjana Dongol Singh

██████████

████████████████████

██

## **Invitation letter**

(for Clinician)

Project:

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

Dear participants,

Namaste!

My name is Anjana Dongol Singh. I am a PhD student in the School of Health, Community and Education Studies at Northumbria University. I have to conduct research study as a part of my study. You are being invited here to take part in the research study.

The study I am doing is on pelvic organ prolapse management in Nepalese women. I will be exploring the factors that impact on quality of life before and after its management. Identification of the factors which still persists even after its management will help to consider it even before and during its management which will finally help to bring about holistic care.

For this research I need to study a group of clinicians who are involved in pelvic organ prolapse management. If you decide to participate, you will be invited for interview so that I can talk to you about your experience of pelvic organ prolapse management. The session will be digitally recorded. Your name will be anonymised and all the information gathered will be kept confidential.

If you wish to participate, please contact me at the number listed below.

Thanking you.

Anjana Dongol Singh

[REDACTED]

[REDACTED]

[REDACTED]

## **Appendix 2: Information sheet**

(for women)

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

My name is Anjana Dongol Singh. I am a PhD student in the School of Health, Community and Education Studies at Northumbria University. I am undertaking a research project as a part of my studies. You are being invited here to take part in the research study. Before you decide to participate it is important for you to understand why the research is being carried out and what it will involve. Please go through the following information carefully and ask if anything is unclear or if you would like to have more information. You will be asked to sign a participation consent form if you decide to take part.

#### **What is this study about?**

We all know pelvic organ prolapse is a huge problem in Nepal. My study tries to find out how this problem affects different aspects of women's lives. I will be exploring the factors that affect quality of life before and after its management. Quality of life is expected to improve after its management. Identification of the factors which still persist after its management as well as problems women report before treatment will help us to bring about holistic care.

#### **Why I have been chosen?**

You have been chosen because you are a Nepali woman with experience of pelvic organ prolapse management. You know better the quality of life with and without pelvic organ prolapse. You are the one who can share experience before and after its management. I believe that your contribution to this research will be of great help to bring out the points which need to be addressed for its prevention and management.

#### **What I am being asked to do?**

If you agree to participate in this study, the researcher will contact you and plan a meeting on a certain date and time at your convenience to collect the information via interview. There will be a face to face interview which will be recorded digitally. The interview will explore your experiences of various aspects of pelvic organ prolapse before and after its management. The whole procedure should take no longer than 2 hours.

**What happens if I do not want to participate?**

It is not compulsory to take part. Participation in this research is completely voluntary and is up to you to decide whether you want to participate or not. If you do not participate there will be no consequences and it will not affect your treatment or care now or in the future too or your relation with the hospital staff in any way.

**What would happen if I agree to participate and then change my mind?**

You have full right to withdraw from the research at anytime without giving a reason. The time limitation provided to withdraw the data in this study is within 3 months of the data collection or after initial analysis when you will not be identifiable. If you withdraw from the study the researcher will destroy the data (recorded with personal information). Withdrawal will not affect your treatment or care now or in the future too or your relation with the hospital staff in any way.

**What are the potential benefits?**

This study is aimed to explore the factors affecting quality of life of the Nepalese women who experience pelvic organ prolapse. It will identify the factors which persist even after its management and through consideration of aspects before and during its management holistic care can be developed.

Indirect benefit to the participant is that it may help to find out whether further management is required for the participant or not.

**How will the data be collected?**

The data will be collected by interview and will be digitally recorded.

**Will what is said will be anonymous and confidential?**

The information after collection will be anonymised and kept in a very confidential way. It will be stored with safety in the locking system of computer so that nobody except the researcher can log-on. Irrespective of this if disclosure occurs the data will be considered as invalid and destroyed according to the law and policy of university.

**What will happen to the data that are gathered?**

The information after collection will be rendered anonymous as soon as possible so that no participant can be identified from the raw data. All the names will be changed to a coding system. The coded data will be kept in the locked computer. The data will be destroyed after the final report is published and the thesis is accepted by the university according to the Northumbria University's retention policy.

**How will the research report be disseminated?**

The research report will be part of the PhD thesis. The research findings will be published in a journal or presented at a conference. Anonymised finding without personal name and detail will be published or presented.

**Potential risks of being involved:**

There is chance that you may have feelings of anger or embarrassment, or experience events of psychological or emotional distress or discomfort from the participation in the research. In such situations I will fully support the participant and I try my best to restore the situation to normal. I will explain the situation and provide support and offer solutions. I don't mind postponing interview for few minutes, hours or even days if it is felt to be appropriate. We can complete the interview at a later date. If professional attention is required I will arrange for clinical consultation. However, financial compensation from researcher is not available.

**Reimbursements:**

The researcher will not reimburse the participants for participation in the study.

**Who do I contact if I want to ask more questions regarding this study and if I want to take part?**

Please feel free to contact the researcher at any time if you have any questions.

**Contact details of the researcher**

Anjana Dongol Singh



Thank you. If you feel like participating please sign the attached consent form.

## **Information sheet**

(for clinician)

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

My name is Anjana Dongol Singh. I am a PhD student in the School of Health, Community and Education Studies at Northumbria University. I am undertaking a research project as a part of my studies. You are being invited here to take part in the research. Before you decide to participate it is important for you to understand why the research is being carried out and what it will involve. Please go through the following information carefully and ask if anything is unclear or if you would like to have more information. You will be asked to sign a participation consent form if you decide to take part in.

#### **What is this study about?**

We all know pelvic organ prolapse is a huge problem in Nepal. My study tries to find out how this problem affects different aspects of women's lives. I will be exploring the factors that affect women's quality of life before and after its management. Quality of life is expected to improve after its management. Identification of the factors which still persist after its management as well as consideration of reported problems before treatment will help to bring about holistic care.

#### **Why I have been chosen?**

You have been chosen because you are a clinician involved in the care and management of Nepali women with pelvic organ prolapse. You know about the quality of life with and without pelvic organ prolapse. You will be able to share your experiences both before and after its management. I believe that your contribution to this research will be of great help to bring out the points which need to be addressed for its prevention and better management.

#### **What I am being asked to do?**

If you agree to participate in this study, the researcher will contact you and plan a meeting on a certain date and time according to your convenience to collect the information via interview. There will be a face to face interview which will be recorded digitally. The interview will explore your experiences of the different aspects of pelvic organ prolapse and its management. The whole procedure should take no longer than 2 hours.

**What happens if I do not want to participate?**

It is not compulsory to take part. Participation in this research is completely voluntary and is up to you to decide whether you want to participate or not. If you do not participate there will be no consequences and it will not affect your relationship now or in the future too with the researcher and other hospital staff in any way.

**What would happen if I agree to participate and then change my mind?**

You have full right to withdraw from the research at anytime without giving a reason. The time limitation provided to withdraw the data in this study is within 3 months of the data collection. If you withdraw from the study the researcher will destroy the data (recorded with personal information). Withdrawal will not affect your relation with the researcher and the hospital staff in any way.

**What are the potential benefits?**

This study is aimed to explore the factors affecting quality of life of the Nepalese women who experience pelvic organ prolapse. It will identify the factors which persist after its management and consider women's experiences before and during treatment, which will help to bring about holistic care.

Indirect benefit to the participant is that it may help him or her to uncover gaps in management which need addressing in order to promote for holistic care.

**How will the data be collected?**

The data will be collected by interview and will be digitally recorded.

**Will what is said will be anonymous and confidential?**

The information after collection will be anonymised and kept confidentially and will be stored with safety in the locking system of computer so that nobody except the researcher can come and log-on. Irrespective of this if disclosure occurs the data will be considered as invalid and destroyed according to the law and policy of university.

**What will happen to the data that are gathered?**

The information after collection will be rendered anonymous as soon as possible so that no participant can be identified from the raw data. All the names will be changed to coding system. The coded data will be kept in the locked in computer. The data will be destroyed after the final report is published and the thesis is accepted by the university according to the Northumbria University's retention policy.

**How will the research report be disseminated?**

The research report will be part of the PhD thesis. The research findings will be published in a journal or presented at a conference. Anonymised finding without personal name and detail will be published or presented.

**Potential risks of being involved:**

There is chance that you may feel anger or embarrassment or experience psychological or emotional distress or discomfort resulting from the participation in the research. In such situations I will fully support the participant and I try my best to restore the situation to the normal. I will explain the situation and provide support and offer solutions I don't mind postponing the interview for few minutes, hours or even days if necessary and continue and complete the interview at a later date. If professional attention is required I will arrange for clinical consultation. However, financial compensation from researcher is not available.

**Reimbursements:**

The researcher will not reimburse the participants for participation in the study.

**Who do I contact if I want to ask more questions regarding this study and if I want to take part?**

Please feel free to contact the researcher at any time if you have any questions.

**Contact details of the researcher**

Anjana Dongol Singh



Thank you. If you feel like participating please sign the attached consent form.

## Appendix 3: Consent Form

(for women)

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

This study is on pelvic organ prolapse. It will be exploring the factors that will effect on quality of life in different aspect before and after its management. Identification of the factors which still persist after its management as well as problems women report before treatment will help us to bring about holistic care.

If somehow participant like to withdraw the data the time limitation provided in this study is within 3 months of the data collection or following anonymisation.

Before giving consent please go through the details and tick the boxes below:

|  | Yes                      |                          |
|--|--------------------------|--------------------------|
| No   |                          |                          |
| I have read and understand the purpose of the study and have had the chance to ask questions about the study and these have been answered to my satisfaction.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that it is not compulsory for me to take part and if I do not take part or if I withdraw at any time without giving a reason there will be no consequences left and it will not affect my treatment/education/care now or in the future, or my relation with the hospital staff in any way. | <input type="checkbox"/> | <input type="checkbox"/> |
| I am willing to be interviewed and I understand that the interview will be recorded and typed up by the researcher.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I am aware that my name and details will be kept confidential and it will not be possible to identify me from this information and no further contact will be made with me.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that the information I give in this study may be used in the future as part of further work on this subject.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to take part in this study.  | <input type="checkbox"/> | <input type="checkbox"/> |

-----  
Signature

-----  
Date

-----  
Participants name

I, the project researcher, confirmed that I have fully explained the nature and purpose of the research study and its benefit that is expected. The possibility of discomfort, distress, risk and requirement of medical care may arise as a result. It is my understanding that the above participant understands it before signing the informed consent. I have also tried my best to answer all queries asked with respect to the research.

-----  
Signature

-----  
Date

-----  
Researcher name

## Consent Form

(for clinician)

### **Pelvic Organ Prolapse Management in Nepalese Women: An Exploration of the Factors Effecting Quality of Life**

This study is on pelvic organ prolapse. It will be exploring the factors that will effect on quality of life in different aspect before and after its management. Identification of the factors which still persists even after its management will help to consider it even before and during its management which will finally help to bring about holistic care.

If somehow participant like to withdraw the data the time limitation provided in this study is within 3 months of the data collection or following data anonymisation.

Before giving consent please go through the details and tick the boxes below:

|  | Yes                      | No                       |
|--|--------------------------|--------------------------|
| I have read and understand the purpose of the study and have had the chance to ask questions about the study and these have been answered to my satisfaction.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that it is not compulsory for me to take part and if I do not take part or if I withdraw at any time without giving a reason there will be no consequences left and it will not affect my treatment/education/care now or in the future, or my relation with the hospital staff in any way. | <input type="checkbox"/> | <input type="checkbox"/> |
| I am willing to be interviewed and I understand that the interview will be recorded and typed up by the researcher.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I am aware that my name and details will be kept confidential and it will not be possible to identify me from this information and no further contact will be made with me.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I understand that the information I give in this study may be used in the future as part of further work on this subject.  | <input type="checkbox"/> | <input type="checkbox"/> |
| I agree to take part in this study.  | <input type="checkbox"/> | <input type="checkbox"/> |

-----  
Signature

-----  
Date

-----  
Participants name

I, the project researcher, confirmed that I have fully explained the nature and purpose of the research study and its benefit that is expected. The possibility of discomfort, distress and risk may arise as a result. It is my understanding that the above participant understands it before signing the informed consent. I have also tried my best to answer all queries asked with respect to the research.

-----  
Signature

-----  
Date

-----  
Researcher name

## Appendix 4: Ethical approval letter



**Professor Kathleen McCourt FRCN**  
Dean

**This matter is being dealt with by:**  
Research and Enterprise Office  
School of Health, Community & Education Studies  
Room H007  
Coach Lane Campus East  
Newcastle upon Tyne  
NE7 7XA  
Tel: 0191 215 6701  
Fax: 0191 215 6083  
E-mail: [julie.blackwell@northumbria.ac.uk](mailto:julie.blackwell@northumbria.ac.uk)

Anjana Singh

[REDACTED]  
Kathmandu  
NEPAL

6 February 2012

Dear Anjana

**School of HCES Research Ethics Panel**  
**Title: Uterovaginal Prolapse Management in Nepalese Women: An Exploration of the Factors Affecting Quality of Life**

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent CRB and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:  
<http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard>

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

Professor David Stanley  
Chair, School Research Ethics Review Panel

*Vice-Chancellor*  
Professor Andrew Wathey

Northumbria University is the trading name of the University of Northumbria at Newcastle

## Appendix 5: Amendment request form



### Project Amendment Form

|  |   |
|--|---|
| <b>Project Name:</b> Uterovaginal Prolapse Management in Nepalese Women: An Exploration of the Factors Affecting Quality of Life | <b>Date original ethical approval received:</b><br>6 <sup>th</sup> Feb 2012 |
| Principal Investigator: Anjana Dongol Singh  | Project ref:  |
| Date: 13 <sup>th</sup> March 2012  |   |

Description of Amendment/Change:

I would like to conduct a pilot study first. It was not included in my ethical approval and in my IPA. The pilot study will be conducted exactly same as in the ethics.

Reasons for Amendment/Change:

1. Can get a lot of information about the study
2. Can prepare appropriate questions so as go get rich data

Anticipated Implications:

Will be applied in the study

Acceptance/~~Rejection~~

Signature:

A handwritten signature in blue ink, appearing to read "Anjana Dongol Singh".

Date: 13.3.12

Follow-up action passed to:

Reason for Rejection:

## Appendix 6: Ethical approval letter from Kathmandu University

KATHMANDU UNIVERSITY  
SCHOOL OF MEDICAL SCIENCES



Date: April 20, 2012

To,

Dr Anjana Dongol  
Assistant Professor  
Department of Obs/Gynaecology  
Kathmandu University School of Medical Sciences  
Dhulikhel, Kavre

Dear Dr Anjana

The institutional Review Committee of Kathmandu university School of Medical Sciences/Dhulikhel Hospital (IRC-KUSMS) reviewed and discussed your application to conduct study entitled "Uterovaginal prolapse management in Nepalese women: an exploration of the factors effecting quality of life" on 20<sup>th</sup> April, 2012.

The Committee has approved the protocol.

Your protocol approval number is: **14 /12**

The IRC-KUSMS expects to be informed about the progress of the study, any changes in the protocol and patient information/informed consent and asks to be provided a copy of the final report.

Yours Sincerely,

  
\_\_\_\_\_  
Dr. Dipak Shrestha  
Member Secretary, IRC-KUSMS



**Appendix 7: Scheduled Visits at data collection sites**  
**For participant recruitment and Data collections**

| s.no. | Date                                    | Visit Place           | Note  |
|-------|---|-----------------------|---|
| 1     | 5 <sup>th</sup> Nov 2011                | Manekharka            | 1 <sup>st</sup> visit for selection of patient. Total 21 women came.<br>6 cases of prolapse seen  |
| 2     | 9 <sup>th</sup> Dec 2011                | Dhading               | General routine visit done after returning from UK<br>Planned for Pap test<br>Planned for screening POP   |
| 3     | 13 <sup>th</sup> Jan 2012               | Dhading               | Pap test performed, 56 women came there.<br>Follow up of POP done for data collection   |
| 4     | 9 <sup>th</sup> March 2012              | Dhading               | Routine visit. Total 30 women came.<br>Selection for data collection  |
| 5     | 23 <sup>rd</sup> March 2012             | Manekharka            | Total 51 women came. 12 cases with POP.<br>Selection of patient for data collection.  |
| 6     | 6 <sup>th</sup> April 2012              | Dhading               | Women were not informed properly so only one case of prolapse came.<br>Planned data collection next time.   |
| 7     | 10 <sup>th</sup> /-12 <sup>th</sup> Apr | Janakpur              | Selection of women for data collection  |
| 8     | 8 <sup>th</sup> June 2012               | Dhading               | Planned data collection   |
| 9     | 13 <sup>th</sup> July 2012              | Dhading               | Planned data collection   |
| 10    | 20 <sup>th</sup> August<br>2012         | Maternity<br>Hospital | Data collection   |
| 11    | 27 <sup>th</sup> August<br>2012         | Maternity<br>Hospital | Data collection   |
| 12    | 14 <sup>th</sup> Sept 2012              | Dhading               | Data collection   |
| 13    | 30 <sup>th</sup> Sept 2012              | Dhading               | Data collection Pilot FGD   |
| 14    | 22 <sup>nd</sup> Nov 2012               | Manekharka            | Data collection   |
| 15    | 10 <sup>th</sup> May 2013               | Dhading               | Data collection   |
| 16    | 16 <sup>th</sup> May 2013               | Bahunepati            | Planned selection of women (recruitment).<br>None of the women informed by outreach staff appeared<br>Planned to left this place and move to Dapcha |

|    |                            |           |  |
|----|----------------------------|-----------|--|
| 17 | 20 <sup>th</sup> May 2013  | Dapcha    | Data collection Focus group discussion (main study)                          |
| 18 | 12 <sup>th</sup> July 2013 | Dhulikhel | Data collection OTO from clinician   |
| 19 | 30 <sup>th</sup> July 2013 | Kathmandu | Unsuccessful data collection due to time constrain                           |
| 20 | 4 <sup>th</sup> Aug 2013   | Kathmandu | Data collection OTO from clinician   |
| 21 | 5 <sup>th</sup> Aug 2013   | Kathmandu | Data collection OTO from clinician   |
| 22 | 8 <sup>th</sup> Aug 2013   | Kathmandu | Data collection OTO from clinician   |
| 23 | 11 <sup>th</sup> Aug 2013  | Kathmandu | Data collection OTO from clinician   |
| 24 | 13 <sup>th</sup> Aug 2013  | Kathmandu | Unsuccessful data collection OTO from clinician due to time constrain        |
| 25 | 21 <sup>st</sup> Aug 2013  | Janakpur  | Data collection 3 OTO from clinicians  |
| 26 | 5 <sup>th</sup> Sept 2013  | Kathmandu | Data collection FGD from clinician   |
| 27 | 26 <sup>th</sup> Sept 2013 | Tipeni    | Nearly 7 cases seen and selected one for data collection<br>OTO from a woman |
| 28 | 3 <sup>rd</sup> Oct 2013   | Tipeni    | Data collection OTO from a woman   |

## **Appendix 8: Impression about visits**

### **Manekharka (Mountain region)**

Visit day - 5<sup>th</sup> Nov 2011

Manekharka is one of the most beautiful places in Nepal. It is 71 km north east from Dhulikhel and 101km from Kathmandu. We were around 6 people all together. The access to Manekharka is available by local bus but we visited there in our hospital vehicle. Half of the way, the road was good. Once we left the black road and started moving up the mountain the road was found very bad. It was bumpy and the dusty. We have to climb up and again go down and then cross a river by driving through it. This we did 3 times till we reached the place. There were no bridges. It was an unbelievable experience for me. I was told that in a year, we can hardly expect to make five visits. Then I realized what they meant when they said that. The road allows only one vehicle at a time. So, for local bus they have fixed time to come and go so that they don't meet in between. The roads are accessible from the month of November till March. Once the rainy season start, then the access completely stops because of the poor road and the river. I was wondering how people survive during these rainy days there? The story must be told, so we have to go and see the people there.

What I saw in Manekharka: It is about 1700 m above sea level. I can see beautiful scenery while coming nearby this place. I really enjoyed watching small waterfalls, paddy fields and houses made of stone at certain distance. Another surprise for me was the electricity generated from those small waterfalls. Whoever thought of this, I don't know, but it was brilliant. It helps people have facility of electricity even though there is no facility for transport. On the way I saw many people passing by wearing typical himali dress having smiles on their faces. It was around 18.00 hrs when we reached there. We went directly to our outreach centre. It was an old house, two-storey building. They were using the ground floor as a health centre. It was very cold after sunset but there was electricity supply from 6pm to 6am.

Early morning we went to see the pond called Mahadev Pokhari. There we saw a line of women of middle age all carrying heavy loads of grass and wood on their backs, with a head

strap. The walking speed of everyone was the same and at certain distance apart making up the queue. It takes them nearly 4 hrs to go, collect and come back with grass for cattle and wood for burning. This is their normal daily activity. Later on I realized that this is one of the causes of POP: lifting heavy weights.



Figure 9: Team involved for recruitment of participants at Manekharka



Figure 10: Women carrying heavy load at Manekharka

We saw about 21 women on that day. There were about 6 cases of POP. Most of them were of the age group 50-60 but they looked much older. Most of the women of this age group

reported similar types of complaints like body ache, backache, and discharge from vagina and all surprisingly were not complaining very much. All of them were using a ring pessary to manage their POP. That was again a surprise for me. I found that whoever had given the ring pessary (I do not know) they had counseled the women very well. They were provided with a card for cleaning or changing ring pessary at 3 monthly intervals and they were still carrying out this procedure and were happy with this. I took a deep breath of satisfaction. I bade them good bye, assuring them that I would see them once again at the next visit. I was really happy at the end of the day.



Figure 11: Sharing information to participants at Manekharka

### **Dhading(Hilly region)**

Visit day –13<sup>th</sup> Jan 2011

Dhading is the only outreach clinic of the hospital that lies in west. It is 65 km west of Dhulikhel and 35 km west of Kathmandu. It is in hilly region. The access compared to Manekharka, we can say is better. We have to drive the vehicle through a river only once here. The road used to be bad during the rainy season, with mud making the road too slippery. We had to drive along some very sharp turnings where we felt like we might die here. We are all used to this kind of journey. We actually feel these days that a normal journey without such adventure is boring. I started working with the women here since 2005. This is our last

Friday visit according to Nepali calendar. Patients in the area were informed of cervical cancer screening and for follow up and screening of POP from the previous visit and throughout the month as well.



Figure 12: Sharing women's reproductive health related issues in Dhading

Total 56 cases were seen with the help of hospital team. Among them we screened 9 POP cases of different degrees and 11 cases of POP after management came for follow up. These 20 cases were asked to wait for some time so that I could talk to them together.

Follow up was also done and I was very happy that 11 patients came. Some of them were operated on 6 years ago. One patient didn't recognize me but when I asked her where and who did your operation? She told me 'Anjana' operated on me. And then she asked me 'is she still working there?' When I told her that I am Anjana she hugged me. This is the beauty of working in a community.

There were some new cases of POP screened. All of them were brought by patients who have already undergone management. This is how we are getting more and more cases at every visit. Once the screening programme was over I got an opportunity to talk to all of them in a group. I introduced myself as the researcher and also gave them a little information about the study and its benefits I told them the date they should come if they wished to participate in the study in the health centre. I noted everybody's name, address and phone number. There were patients with different grades of prolapse; some were symptomatic and

some were not. Plans were made for the ones with symptomatic prolapse for management in Dhulikhel Hospital.

I consider today as a successful day. In one routine general visit I got an opportunity to do 5 different tasks. Starting with general check-up, cervical cancer screening was done. I got a chance to screen cases of POP, follow up the cases who had already undergone management for prolapse and a most important one; the recruitment of a sample for data collection. At the end I observed a place for the interviews to take place and then we returned home.

### **Janakpur (Plain region)**

Visit day – 10<sup>th</sup> – 12<sup>th</sup> April 2011

Janakpur is in the plain region in Janakpur Zone. This place is famous culturally. I was there for total 3 days starting from 10<sup>th</sup> till 12<sup>th</sup> April 2012. MrAkhilesh was there to help me out. He completed his Bachelor in Public Health last year and was working in one of the NGOs. He was the one who arranged all the programs for me as he is from the local place, knows many people and has been involved in other research also.

We started our work in the morning. We visited many houses where women lived who had undergone hysterectomy. It was a surprise to find that all of them underwent hysterectomy for other purposes than prolapse. The information about my study was given to MrAkhilesh by phone which he unfortunately had misunderstood.

In this short visits to households where I got an opportunity to meet about 6 patients I learned a lot from them. I was quite sure from this short visit that people will not develop prolapse here. The reason behind is that all of the women are very fond of going for hysterectomy. It is as if for any problem of the genital tract they were advised to have surgery by the doctors. It has now become a fashion in the community; have your uterus removed and no other problems related to your uterus will arise. This is easily accepted by the husband and family. This ignorance of the people has been taken advantage of by the clinicians. I felt pity for the women who became victims, felt pity for the clinicians as well who don't know of any other management except removing uterus. I felt pity for the community because they are the ones who have forbidden women's education and empowerment. I felt pity for the nation for

bringing always political instability. Because of which the development of our nation is stalled. I could have been in a situation like this and thought how lucky I was lucky to be born in Kathmandu. I really don't want to talk about politics here but this short visit made me think of these wider issues. Made me realize where we are and how far we have, or have not, travelled. We have only 14 zones, so why can't each zone develop equally? Without education nothing can be changed. Here I noticed it was still forbidden for the women. How can any real development be possible in this place?

My next stop was a visit to the zonal hospital. Janakpur zonal hospital was the biggest hospital for that area. On the way to the hospital I saw a big advertisement board with the name of doctors and their specialty. It was up to 10ft long. The advertisement grew bigger as we came near to the hospital. There were no other shops for about half a kilometer except for medicine shop (pharmacy) and private clinics. I agree that medicine shop should be available near the hospital; but if hospital is there why so many clinics?

When I saw the hospital from outside I imagined how it would be on the inside. It was too crowded everywhere. There were no restrictions on the number of patients and their families. I started with the emergency room. I saw a patient having intravenous fluids, lying in bed. It was a surprise for me to see that the whole family was sitting on the same bed. This is the culture here they said 'if somebody gets sick we all come like this'.

We went to see the maternity wing. There we saw a delivery. I was happy because the person conducting delivery was a Skilled Birth Attendant (SBA). This is the program to universalize the mode of delivery, making it the same everywhere in the developing world. The main aim of my visit to this hospital was to have a meeting with the gynecologists and plan for data collection and recruitment of patients. We couldn't meet a gynecologist in hospital as she had already left and would not be returning for a week because of personal reasons. We got the chance to talk with the nurse in charge. We were given permission to look into the names list of the patient who had undergone prolapse management. Mr Akhilesh understood about the project well and he promised to provide me with the necessary information within few weeks. It was again a satisfying time for me.

I was told that I could gather a lot of information from a place called Mithila Art. I went to that place. This place was famous because of the art done by a women's group. Many people around the world come to see the place. First of all I went to see the director and informed him about the aim of my visit. He requested that I give a women's health related talk with the group working there. That was a very good opportunity for me to talk to the ladies working there. There were around 25 ladies to whom I talked about women's reproductive health related issues. Here I managed to include Prolapse. I explained to them its cause, its symptoms, its management and its prevention. The discussion part was very interesting as they were pleased to have a lady gynecologist in front of them. They didn't know why they were gathered together as they were told only to gather by the chief. Feeling uncomfortable at the beginning of the talk and feeling shy they covered half of their faces with the dhoti. They opened up slowly as I made them comfortable. Some of the ladies were smart and encouraging others who were having difficulties to share their problem. Later on they started asking many questions related to the problems they were facing. The session lasted for nearly two hours. As it was getting late we quickly visited the art and crafts and came back.



Figure 13: Sharing women's reproductive health related issues in Janakpur

What I learned from there was not the thing I perceived in the morning. Prolapse problem is still a major issue in the plain region. Again I have to go to the periphery to find the patient. Lots of women have prolapse. The main causes of prolapse here are too many and too frequent childbirths. Routine activity for women in the plain region is less vigorous compared to the women living in the mountains and hilly regions. Heavy work will be mainly

done by the men. I noticed however, a lack of education, confusion and lack of confidence, lots of societal influences, early marriage, lack of health education and family planning in women living in the plain region.

## Appendix 9: Informed consent sample

स्वीकृति पत्र  
(विरामीको लागि)



### अध्ययनको विषय

नेपाली महिलावर्गमा आइड खस्ने रोग/समस्याको व्यवस्थापन: यसले समस्याग्रस्त महिलाको जीवनस्तर सुधार/विकासमा नयाँ खोजनीति ।

यो अध्ययन महिलावर्गमा आइड खस्ने समस्यासँग सम्बन्धित छ । यस समस्याको विभिन्न कारक तत्वहरूको खोजनीति गरी यस समस्याले जीवनस्तरमा कति प्रतिकूल असर पार्छ र यसको व्यवस्थापन पूर्व र व्यवस्थापन पश्चात के कति भिन्नता छ खोजनीति गरिनेछ । यस अध्ययनमा संलग्न अनुसन्धानकर्ताले यस समस्याको विभिन्न कारक तत्वहरूको खोजनीति गर्नेछ । यसको व्यवस्थापन पश्चात जीवनस्तरमा विकास/सुधारमा फरक भएन भने अन्तमा पूर्णरूपमा सुधार सेवाको लागि आवश्यक व्यवस्थापन गरिनेछ ।

स्वीकृति दिनु पूर्व निम्न बुँदा हेरी ठीक चिन्ह लगाऊ :

- मैले यस अनुसन्धान/अध्ययनको बारेमा पढेको छु र यसबारे राम्ररी बुझेको छु । तसर्थ मलाई यस समस्या सम्बन्धि अन्तरवार्तामा संपूर्ण प्रश्न सोध्न मैले अनुमति दिएको छु । र यसको जवाफ मैले आफूलाई सन्तुष्ट हुने गरी जवाफ दिएको छु ।
- मैले बुझेको छु कि मैले यो अनुसन्धानको अन्तरवार्तामा सहभागिता नगरे तापनि वा अनुसन्धानको बीचमै कुनै कारण नदिई अन्तरवार्ताबाट सहभागिता नभई स्थगित गरेमा पनि मेरो स्वास्थ्य परीक्षण/स्वास्थ्य शिक्षा/स्वास्थ्य सेवामा वर्तमान र भविष्यमा हुने सेवामा साथै अस्पताल वा अस्पतालको कर्मचारीसँग कुनै नकारात्मक असर पर्दैन ।
- म अन्तरवार्तामा बस्न ईच्छुक छु र मलाई पूर्ण ज्ञान छ कि यस अन्तरवार्ता भिडियो रेकर्ड गरिएको छ । यसको अनुसन्धानकर्ताले मैले बोलेको कुरा टिपिरहेको छ ।
- मलाई पूर्ण जानकारी छ कि मेरो नाम, ठेगाना लगायत विस्तृत विवरण संपूर्ण अन्तरवार्ता पश्चात गोप्य राखिनेछ । मैले यी सुचना दिएमा मेरो व्यक्तीगत परिचय कहीं कतै खुल्ने छैन र खोल सक्दैन र अन्य दिनहरूमा मलाई कुनै सम्पर्क राख्ने छैन ।
- मलाई पूर्ण जानकारी छ कि यी सुचनाहरू यस अध्ययन अनुसन्धानका लागि प्रयोग गरिनेछ र भविष्यमा समेत यसै परियोजनाको लागि प्रयोग हुने छ ।

६. मलाई यस अध्ययनमा सहभागिता गर्न ईच्छुक छु ।

Dil Kumari  
सही

10/5/2013

मिति

Dil Kumari Pandey  
सहभागिको नाम

म, यो परियोजनामा अनुसन्धानकर्ताले मेरो सहभागिलाई पूर्ण रूपले यस अध्ययन अनुसन्धानको प्रकृति र यसको उद्देश्य तथा यसबाट फाइदा हुने बारेमा बुझाईएको छ । अन्यथा स्वास्थ्य सेवाको आवश्यकतामा असुविधा, आकुलता (अभाव), जोखिम र स्वास्थ्य सेवाको आवश्यकता रहन्छ । म पूर्ण विस्वस्त छु कि माथिको सहभागिले यो फाराममा हस्ताक्षर गर्नु पूर्व यी सब कुराको जानकारी हुनुहुन्छ । यस सहभागिले अनुसन्धानको विषयमा उठाइएको सवाल र जिज्ञासाको पूर्ण रूपले जवाफ दिएको छ ।

Anjana Dangol Singh  
सही

10/5/2013

मिति

Anjana Dangol Singh  
अनुसन्धानकर्ताको नाम

दिनकारी  
पाठे

## **Appendix 10: Example of verbal consent**

### **Recorded and translated for women participant who is illiterate**

R - I have explained you everything about this research isn't it?

WDK- Yes.

R - In this research Umm I am taking your interview. Are you willing to participate for this?

WDK - Yes, yes. Why not (laughing) Yes. Sharing the problem I have faced. Now, at present it is fine.

R - And you are going to participate on it.

WDK -Yes, its ok for me.

R - You know many things about prolapse.

WDK-Everything, about mine...

R - Your experience about your problem.

WDK - My experience.

R - Yes. Can you give your signature for consent? Can you write?

WDK - Signature

R - Can you write?

WDK - No, I can't write. Now?

R - If you can't write I will take the consent paper back and write your name for you. Is that ok?

WDK - Ok, I do not know anything you see. Now ..

R - It's ok.

WDK - I am not educated.

R - Not educated?

WDK -Yes.

R - It's ok. This is also enough for me.

WDK - Ok

R- Now, we are going to start interview. I am starting you with the questions ok

WDK – Ok

## **Appendix 11: Topic Guide: Research questions for the different groups**

The researcher had presented the research questions to four different groups of participants. Though the questions were similar the researcher modified the way of asking questions for the different groups. The researcher kept the aim and objectives of her study uppermost throughout data collection.

### **For Patient Focus Group**

1. What do you think the problem of prolapse is?
2. Why do you think prolapse is a very common problem in Nepal?
3. What range of problems do you face when living with prolapse?
4. Can you please share your ideas about the treatment of prolapse?

### **Checklist**

1. Knowledge about POP
2. Causes of POP
3. Problems (Self, Husband, Family, Society)
  - a. Physical, social, psychological, economic
4. Knowledge about management
5. Factors for delay in treatment
6. Views about management

### **For Patient one to one interview**

1. How did the problem of Prolapse start?
2. What are the different problems you started having with the development of Prolapse?
3. Why have you not sought care?
4. Explain the journey you went through for getting treatment?
5. What improvements and difficulties, if any, did you face after management of prolapse? Can you explain the changes you faced after treatment?
6. Have you got any wishes or suggestions for service providers about management of the problem?

## **Checklist**

1. The time of development and knowledge about POP
2. Physical, social, psychological and economic problems
  - a. Can you explain the physical problems you had with development of POP?
  - b. Can you tell us about the different sexual problems in relation to POP?
  - c. Tell us how you think your relationship with your husband, before and after the development of POP, has changed?
  - d. Have you faced any difficulties with your family and wider community as a result of having POP Was there anything you would like to have participated in or do but couldn't because of your POP problem? Can you give an example?
  - e. Have you developed tension or gone through some sort of depression or other mental health problems? Can you elaborate these a little?
3. Knowledge about management
4. Delay in seeking health care
5. View about management (satisfaction and dissatisfaction due to problems faced during and after management)
6. Suggestions for change in management from women's point of view

## **For Clinician one to one interview**

1. Can you tell me about the POP situation in Nepal?
2. How do you like to assess a woman with pelvic organ prolapse?
3. What are the factors that affect the quality of life in a patient with pelvic organ prolapse?
4. How do you follow up a woman after managing her pelvic organ prolapse?
5. Tell me your idea about prevention of prolapse?
6. What are the things we need to improve while managing a case of pelvic organ prolapse?
7. If you are a policy maker what things would you like to change while managing pelvic organ prolapse?

## **Checklist**

- 9 Causes in relation to Nepalese context
- 10 Impact on physical, social, psychological and economic domains
- 11 Factors to analyse before intervention/management
- 12 Factors to consider during management
- 13 Factors to consider after management
- 14 Preventive ideas
- 15 Need for change in management policy  
Screening, evaluation, management, follow-up and prevention

## **For Clinician FGD**

1. How do you think prolapse effects women's quality of life?
2. How is the management of pelvic organ prolapse progressing in Nepal?
3. What is your opinion about screening and assessment of patient of pelvic organ prolapse?
4. How can we improve quality of life for a patient suffering from prolapse?
5. How can we prevent pelvic organ prolapse?
6. What are the changes we need to make in the management policy?

## **Checklist**

1. Impact on physical, social, psychological and economic domains
2. Advantages and disadvantages about camp surgery
3. Factors to analyse before management
4. Factors to consider during management
5. Factors to consider after management
6. Preventive ideas
7. Need for change in management policy  
Screening, evaluation, management, follow-up and prevention

## Appendix 12: List of tables

### Reports of POP Prevalence in Nepal

| Coverage                          | Prev. Rate (%) | Type of Quantification | Sample Size | Year of Report | Remarks/Source, Reference   |
|-----------------------------------|----------------|------------------------|-------------|----------------|---|
| Kaski                             | 11.7%          | Population based       | 300         | 2012           | Anupama Tamrakar, JHAS 2(1): 38-41                                  |
| Dolakha, Ramechhap and Okhaldunga | 27.4%          | Population based       | 3675        | 2012           | Messerschmidt L, Journal of Nepal Public Health Association         |
| Salyan, Mugu and Bajhang          | 15%            | Clinic based           | 1343        | 2011           | Khatri, RB., Health Prospect  |
| Overall estimation                | 9-30%          | Observation            |             | 2006           | Dr Rajendra Gurung, Presentation in UNFPA seminar                   |
| 8 districts                       | 10%            | Clinic based           | 2,207       | 2006           | A commissioned Study for UNFPA                                      |
| Siraha                            | 30%            | Population based       | 969         | 2006           | Survey undertaken by CAED-Women's Reproductive Rights Program-Lahan |
| Saptari                           | 42%            | Population based       | 1,301       | 2006           | Survey undertaken by CAED-Women's Reproductive Rights Program-Lahan |
| 10 districts                      | 9%             | Clinic based           | 4,518       | 2005           | A Study by Safe Motherhood Network federation                       |
| Achham/Doti                       | 25%            | Clinic based           | 2,072       | 2002           | GTZ/HSSP's mobile clinic in Doti, Achham - report                   |
| Ramechhap                         | 37%            | Clinic based           | Not known   | 2002           | Among the visitors of Manthali Health Post (Kantipur, 3/4/2009)     |

|                 |      |                  |           |      |   |
|-----------------|------|------------------|-----------|------|---|
| Dang            | 35%  | Clinic based     | 426       | 2002 | Number of women who required immediate surgery (Gorakhapatra, 28/10/59) |
| Dolakha         | 20%  | Clinic based     | 985       | 2002 | Data from the clinic (Rajdhani, 10/5/2059)                              |
| Southern Achham | 44%  | Population based | 250       | 2000 | Survey undertaken by CAED- in 5 VDCs in Achham                          |
| Jumla           | 17%  | not known        | not known | 1996 | Mentioned in GTZ/HSSP's Report  |
| Pokhara         | 1500 | Clinic based     | not known | 1960 | Mentioned in GTZ/HSSP's Report  |

Table 1: POP Prevalence in Nepal (Source- CAED report, 2006) with addition

## Nepal's Public Hospitals

### List of Nepal's Central Hospitals

| S.No. | Central Hospitals   | District  | Beds |
|-------|---|-----------|------|
| 1     | National Academy of Medical Sciences (NAMS), Bir Hospital | Kathmandu | 600  |
| 2     | Paropakar Maternity and Women's Hospital                  | Kathmandu | 415  |
| 3     | Kanti Children's Hospital                                 | Kathmandu | 314  |
| 4     | ShahidGangalal National Health Centre                     | Kathmandu | 160  |
| 5     | Sukraraj Tropical & Infectious Disease Hospital           | Kathmandu | 100  |
| 6     | B.P. Koirala Memorial Cancer Hospital                     | Chitwan   | 100  |
| 7     | Manmohan Cardiothoracic vascular & Transplant Center      | Kathmandu | 61   |
| 8     | Mental Hospital   | Lalitpur  | 50   |

Table 2: List of Nepal's Central Hospitals.

### List of Nepal's Regional Hospitals

| S.No. | Regional Hospitals  | District | Beds |
|-------|---|----------|------|
| 1     | Western Regional Hospital                                 | Kaski    | 350  |
| 2     | Mid Western Regional Hospital (Surkhet Regional Hospital) | Surkhet  | 50   |
| 3     | Central Regional Hospital (Hetauda Regional Hospital)     | Hetaunda | 50   |

Table 3: List of Nepal's Regional Hospitals

### List of Nepal's Sub-Regional Hospitals

| S.No. | Sub-Regional Hospitals         | District | Beds |
|-------|--------------------------------|----------|------|
| 1     | Narayani Sub-Regional Hospital | Parsa    | 250  |
| 2     | Rapti Sub-Regional Hospital    | Dang     | 100  |

Table 4: List of Nepal's Sub-Regional Hospitals

### List of Nepal's Zonal Hospitals

| S.No. | Zonal Hospitals           | District   | Beds |
|-------|---------------------------|------------|------|
| 1     | Koshi Zonal Hospital      | Morang     | 350  |
| 2     | Janakpur Zonal Hospital   | Dhanusa    | 200  |
| 3     | Bheri Zonal Hospital      | Banke      | 150  |
| 4     | Lumbini Zonal Hospital    | Rupandehi  | 135  |
| 5     | Seti Zonal Hospital       | Kailali    | 125  |
| 6     | Mechi Zonal Hospital      | Jhapa      | 100  |
| 7     | Sagarmatha Zonal Hospital | Saptari    | 100  |
| 8     | Mahakali Zonal Hospital   | Kanchanpur | 85   |
| 9     | Dhaulagiri Zonal Hospital | Baglung    | 35   |
| 10    | Rapti Zonal Hospital      | Dang       | 35   |

Table 5: List of Nepal's Zonal Hospitals.

Nepal's Public Hospitals. Source: Posted by Gelal Research Group.

[www.grrankings.com//list-of-public-hospital-nepal..](http://www.grrankings.com//list-of-public-hospital-nepal..)

### List of Nepal's Major District NGO Hospitals

| S.No. | Major District NGO Hospitals                              | District   | Beds |
|-------|---|------------|------|
| 1     | Dhulikhel Hospital  | Kavre      | 325  |
| 2     | Narayani Community Hospital & Research Center             | Chitwan    | 300  |
| 3     | Bharatpur Hospital  | Chitwan    | 253  |
| 4     | The United Mission Hospital                               | Palpa      | 165  |
| 5     | Sheer Memorial Hospital                                   | Kavre      | 150  |
| 6     | AMDA Hospital   | Jhapa      | 100  |
| 7     | Lamjung District Community Hospital                       | Lamjung    | 85   |
| 8     | Bhaktapur Hospital  | Bhaktapur  | 75   |
| 9     | Dhankuta District Hospital                                | Dhankuta   | 50   |
| 10    | Lahan Hospital  | Siraha     | 50   |
| 11    | Udayapur District Hospital                                | Udayapur   | 50   |
| 12    | Hetauda Hospital  | Makwanpur  | 50   |
| 13    | HDCS-Chaurjahari  | Rukum      | 40   |
| 14    | Ampipal Hospital  | Baglung    | 35   |
| 15    | Damauli Hospital (Kathmandu University Teaching Hospital) | Tanahun    | 35   |
| 16    | Okhaldunga Community Hospital                             | Okhaldunga | 32   |
| 17    | AMDA-Mechi Hospital                                       | Jhapa      | -    |

Table 6: List of Nepal's Major District NGO Hospitals.

### List of Nepal's Medical College Hospitals

| S.No. | Medical college   | District  | Year of establishment |
|-------|---|-----------|-----------------------|
| 1     | Institute of Medicine (IOM), TU                                 | Kathmandu | 1972                  |
| 2     | B.P. Koirala Institute of Health Science (BPKIHS)               | Dharan    | 1993                  |
| 3     | College of Medical Science (CMC)                                | Chitwan   | 1993                  |
| 4     | Manipal College of Medical Sciences                             | Kaski     | 1994                  |
| 5     | Nepal medical College Pvt. Ltd. (NMC)                           | Kathmandu | 1996                  |
| 6     | Nepalgunj Medical College                                       | Banke     | 1996                  |
| 7     | <u>Kathmandu Medical College &amp; Teaching Hospital(KMC)</u>   | Kathmandu | 1997                  |
| 8     | Universal College of Medical Science & Teaching Hospital (UCMS) | Rupendehi | 1998                  |
| 9     | <u>National Academy of Medical Sciences (NAMS)</u>              | Kathmandu | 2001                  |
| 10    | National Medical College  | Parsa     | 2001                  |
| 11    | Kathmandu University School of Medical Science (KUSMS)          | Kavre     | 2001                  |
| 12    | Janaki Medical College (JMC)                                    | Dhanusha  | 2003                  |
| 13    | KIST Medical College (KISTMC)                                   | Lalitpur  | 2006                  |
| 14    | Chitwan Medical College (P) Ltd. (CMC)                          | Chitwan   | 2006                  |
| 15    | Lumbini Medical College Teaching Hospital Pvt. Ltd.             | Palpa     | 2006                  |
| 16    | Nobel Medical College & Teaching Hospital (P) Ltd.              | Morang    | 2007                  |
| 17    | Patan Academy of Health Sciences                                | Lalitpur  | 2008                  |
| 18    | Gandaki Medical College (GMC)                                   | Kaski     | 2010                  |
| 19    | Nepalese Army Institute of Health Sciences                      | Kathmandu | 2010                  |

Table 7: List of Nepal's Medical College Hospitals

## Appendix 13: Pilot findings (March 2013)

### Early resumption of work soon after delivery

In Nepal women are considered impure until 'Nuaran' the naming ceremony of the newborn. Woman who delivered child, will be isolated, sleep and take food separately and be restricted to work. Again, the culture decides the time of isolation in ethnic groups.

*"In Newar cast we can purify any day and start working like before. We, after purification, are ready for work cooking food, cutting grass, bringing water from far away tap and all. In Brahman and Chhetri cast till 11<sup>th</sup> day they sit for rest in corner. On 12<sup>th</sup> day they go to cut grass, as they become healthy. They live in luxury during that time, more than in Newar cast people."*

FDGP 5

Following the purification, the routine daily activities of women start. They feel the resting time is inadequate and leads to problems.

*"Once after baby naming ceremony I was allowed to work. I used to carry heavy pot of water. Then my uterus started coming down. In our opinion after delivery we get less care, less nutrition, heavy work soon after delivery gives rise to prolapse. We think so"*

FGDP 3

Women, from these quotes receive much less time for postpartum care.

### Giving birth to many children frequently at home

Women in the rural areas give birth to many children. There are different reasons for giving birth to many children. One is being not sure about the life of the child in future. PP3 mentioned about the death of her second son who was born in the Year of the Dog. After that she delivered two daughters. They have huge worry for future security. They are not educated and will not be financially secure so they have to depend on the children.

Another reason is the importance of male child in the family. Mothers keep giving birth until they have the desired number of male children.

*"I delivered 4 female children. After 4 females there I delivered one son. And again I delivered 3 more female children hoping to have another son."*

FGDP 2

Home delivery each time and without an attendant is another factor contributing to the development of POP. Many women mentioned that the problem started soon after the first child delivery and then the problem progressed with subsequent deliveries. People in the community give birth at home.

*"It was all home delivery with me. We can't live like we wish to. Family rules regulations were strict. Have to live under supervision of in laws. We have health post nearby. I could have gone there but people around said that if you go there for delivery it costs money and they charge a lot. The amount of money you spend there can be helpful for covering all expenditure during post delivery period. Now, slowly with time I understood that it was needed actually."*

PPI

Giving birth to too many children was found to be associated with lack of knowledge regarding family planning and contraception. Many women from the FGD were not using any sort of contraception as they were not knowing about its use and availability. Woman who was nearly 50 yrs when asked about use of contraception said that she did not know about it; but one who is nearly 10 years younger agreed that she knew about different types of contraception. This shows knowledge about contraception and family planning is improving.

*"I was on temporary one; the Norplant. Husband asked me for Norplant. Permanent was not planned as we have only small son, if he dies then who will look after us and while going through operation we have heard that it may be risky and can die as well. So, we were using Norplant."*

PPI

### **Hard physical work for living**

The women as well as clinician participants mentioned that the hard work for living is giving rise to development of POP.

*"In house I have to carry water in a pot from far away tap nearly 12 times a day to cook food. In the afternoon I have to bring 2 besauna grasses after cutting for cattle."*

*If I don't do that I will not be provided with food. So, I think this is either because of lack of nutrition or hard work or what?"*

FGDP 2

The word 'besauna' is load of grass with the capacity of approximately 10-15 kilo.

### **Life with POP**

The POP showed high impact on the life of women. Feeling handicap because of discomfort and pain, difficulty in urination and defecation, fear of death, loss of togetherness and deviation of husband towards other women are the associated problems along with the development of POP. Here, researcher had evaluated lives across different domains of physical, psychological, social, sexual relationships.

### **Physical Problems**

#### **1. Feeling handicap because of discomfort and pain**

Almost all participants talked about the discomfort they faced with the emergence of the bulge. Most of them faced discomfort in walking, discomfort in carrying heavy loads, sitting, standing, squatting etc.

Despite experiencing discomfort they seemed to hide the problem and continue their daily activity and only used to share the problem when severely symptomatic. Many of them expressed that it was difficult to carry heavy loads as it used to cause pain while working and so effecting their daily life slowly. They were not able to work as before with prolapse.

*"Unlike previous days I use to have difficulties mainly during working. The more I used to work the more problems I used to face. Sometimes I feel am completely fine. The prolapse part sometimes feels like the dead piece of meat without any pain. Sometime it creates huge problem so that I can't even sit in front of others. People use to ask me 'what problem you are having?' I can't sit and stand up quickly. I have to sit slowly and get up slowly because of pain. I didn't have pain in lower abdomen much, instead used to have severe backache. It is still hurting me."*

PP1

All participants were facing difficulty during working because most of the work they have been doing is of a similar nature. In the beginning they faced discomfort which turned into more serious difficulty, slowly over time after the age of 40.

*"I developed wound in the upper thigh because of friction, and sweating aggravates more friction in upper thigh and then developed wound. Sometimes, while carrying loads we also notice discharge as well. It used to be like this. These are difficulties. Difficulties like this."*

PP2

This study shows the difficulty from prolapse hampering the mobility of the women. All patient participants mentioned this problem. When mobility is restricted, all activity the women do everyday will be affected.

### **Difficulty in urination and defecation**

The other physical problems were urination and defecation. These difficulties were expressed by some of the participants. Their problems were aggravated over. In the last few years one woman said it was so severe that she could see only misery ahead

*"Difficulty means unable to pass urine. I don't know whether prolapse has blocked the flow or what but there was always difficulty to urinate. It needs to be replaced for urination."*

PP1

*"Replace back by hand or?"*

R

*"Yes, replace back by pressing with fingers, then only I could urinate. This urinary problem started aggravating since last few years. The life was miserable after developing this urinary problem. Before that I was used to prolapse problem."*

PP1

### **Psychological problems**

Women often did not know what was happening to their bodies. PP3 shares her experience when she developed a prolapse. She felt like a dumb person. She couldn't share her concerns and became 'dumb'. She kept on living in silence, crying every day.

### **1. Fear of death**

Fear of death after suffering from POP was expressed by some participants. One of the participants developed a urinary problem gradually but according to her the last few years was intolerable.

*"Once after development of urinary problem I thought like I am going to die with this problem. I couldn't urinate properly. You can imagine what will happen if you hold urine for 2-3 hrs. I told my husband that I need to push back prolapse each time I urinate. I told him that I am going to die with this problem now."*

*PP1*

### **Sexual problems**

#### **Loss of togetherness and husband's deviation towards other woman**

One of the participants expressed her sorrow of change in the husband wife relationship. Husband used to be in the army and has a habit of going out with girls. He came to know about her problem but pretended that he didn't. Slowly the relationship started deteriorating:

*"Our love was different when it was there and not there. It was different once after development. He deviated more from me towards other women. I became an ill person for him after having POP."*

*PP2*

Her husband brought another wife and never cared and helped in the house after that. She feels very sad that due to prolapse she lost her husband.

### **Social problems**

Many women had the feeling that if society comes to know about their problem of POP they will be discriminated against. The stigma meant that they had little participation in the social activities. Negative social aspects meant that they hid the problem for longer periods of time.

## **Barriers to seeking health care**

This study shows that during the reproductive period women have lots of responsibilities. The primary job of women is to look after house and family. With this primary responsibility they will not be able to share their problems with the other family members.

Women face huge economic burdens because they know that money is required for treatment. The participant whose husband was not living with them or died seem to have huge financial problems. They have to sell land to obtain the treatment. The family income was less and money they have to pay for treatment was high. The economic burden for treatment was expressed like this

*"I used to ask how much. They used to say I needed 20-30 thousand. Couldn't swallow big bone from small neck. I inquired in health post as well. I also thought of dying with this. We talked about selling land to do surgery. Later on I came to this place and had the operation free with the help of my sister."*

FGDP 5

### **1. Hiding the problem from others**

There were many reasons presented by the participants regarding the cause of hiding. Many women felt shame and could not talk about it. It is embarrassing if somebody comes to know about the problem.

*"I use to feel like people may see this. People may see while working, sitting and all. While cleaning cooking stove it used to come out suddenly. I use to get fear that guests who came in house may see it. So, I used to hide it as much as possible"*

PP 2

PP3 shared a similar experience of feeling shame. PP1 had a different opinion about sharing to the other people in the community. She said that it is not only related with shame but they have a fear that they will feel embarrassed and people will despise her.

*"Yes, I used to have. I was afraid that they start hating me and say many things. I wished that nobody knows about my problem. Sometimes I also thought that I should have let community know of my prolapse so that the one who is socially involved will give me advice and take me to the hospital in early stage. I would not then develop*

*the severe problem and it may have prevented the surgery as well. But fear that many people will talk nonsense things made me keep quiet and my problem remained hidden."*

*PP 1*

Some of the participants belong to the family where prolapse has been running for generations. The cause of not sharing their problem was different to just shame. It is not wise to open one's mouth before elders do.

*"My mother had prolapse. She couldn't tell and we couldn't ask. She is an old lady so while sitting and changing posture we use to see that. When I see that I use to feel like am I going to develop the same problem or what. My mother is suffering from the problem since long time till now she has not told anybody, so how can I share it with others. I felt like this. This is the reason why I couldn't share to others."*

*PP 1*

Women hid the problem not only from the society but also from their husbands. Many of them accepted that they hid the prolapse from their husband at the beginning until it became symptomatic. Again there were common experiences among many participants. It is easy to share prolapse problems with other women but not with husbands. So, husbands were often unaware of the problem for long periods of time.

Women, after sharing the problem with others, found the solution for its management. PP3 after sharing her problem with her daughter went for a check up after taking advice from the teachers of her daughter. She was provided with ring pessary then she started working again. According to CP3 normally women keep on suffering for an average of ten to twelve years. They keep on giving birth with prolapse and keeps on hiding the problem until they develop complications.

### **Life after management of POP**

The participants responded in different ways after treatment. The participants were not always satisfied with conservative management but showed satisfaction after surgical correction. The themes were relief from fear of death, feeling of reborn and freedom from pain and other symptoms.

### **i. Relief from fear of death**

The participants feared undergoing surgery. They have heard that the operation can kill people and they were afraid of it. When they saw other women after surgery they had hope that they too would have quality of life after operation.

*"While coming to health centre I saw many women who have already undergone surgery for POP. I listened to them and came to know that operation is not going to kill me."*

*PP1*

### **ii. Feeling of reborn after surgery**

Many women were asked about their lives after surgery. They appear to be happy about the treatment. For them it is like being reborn. She also wished for other women with prolapse to seek treatment early.

*"Following operation I felt very good. Remembering those old days I feel very good now. Whatever, I feel easy these days."*

*PP2*

The other women also shared this same feeling but were not always completely recovered. The symptoms which had led to death wishes were remembered. The feeling of fear that a severe cough would lead to another prolapse was still there even after treatment. Women were symptomatically better after correction of bulge but worried for regaining the strength like before.

*"I am happy. I can work but I haven't resumed same power I used to have before operation. One thing is I don't think know that I will be strong enough like before operation."*

*PP1*

### **Overview of treatment policy**

From the study it is clear that patients with POP suffer for prolonged periods of time negatively affecting their quality of life. Their treatment needs to focus on aspects other than surgery to improve things. Surgical camps have benefited women in most rural areas. There are however a number of issues, emerging from the study, for health policy makers to address. These are: staff feeling insecure while working in surgical camps; dissatisfaction

over the treatment policy which only focuses on decreasing prevalence; lack of knowledge in people involved in screening; need for improved training poor or non-existent care after surgery and the need for monitoring and supervision. Clinicians, when interviewed, said that they are not bothered about social, economical, psychological problems. Their only concern is the physical problem, which they will correct according to severity.

### **Views on surgical camps**

The study shows that the POP camp policy is appropriate in a country like Nepal, where there is limited health and transportation facilities for women living in very remote areas. Such camps however are not risk free.

*"Camp somewhere is important. There are people in our remote areas where they can't come out of their house for treatment in hospitals. Even if we say that we provide treatment free, food free and stay free they will not be able to come."*

*"The advantage I found there is for the people over there. It takes 4-5 days to reach nearby district hospital. Can you imagine somebody walking that long for treatment? They will not go to any place for treatment. Will they? Isn't it?"*

CP 1

#### **i. Dissatisfaction about the treatment policy**

The surgical camps are running in different parts of Nepal. According to clinicians the programme needs to be better organized. The clinicians have participated in many camps in different places. They shared their experiences while operating on every case as they often have to compromise. It is not always possible to do what is necessary for individual cases but work must be carried out according to the schedule provided. According to CP1

*"I have also been in camp doing surgeries. What we feel is that there is a kind of insecurity and feeling of risk. I feel like I am working in a risky place in a risky environment. If we were working in the institute we feel like we have support and that so feel secure. This is right isn't it?"*

CP 1

They faced many technical difficulties while operating and have to work under much compromised conditions. For example compromise in manpower, instruments, electricity medicine etc.

The other reason for feelings of insecurity, expressed by all clinician participants, is undiagnosed related co-morbidities.

*"The patients who come there for treatment are the ones who have suffered for a long time. They will be having multiple problems like hypertension, heart problems. For such patients we can't challenge and perform on a camp basis. These sorts of problems are many there. The proper evaluation can't be performed there."*

CP 2

The clinician also felt insecure regarding provision of safety for the patient. She agrees that providing services in camps is a different thing but was surprised that proper infection prevention was not assured. Considering many things, they feel strongly that surgery should take place in hospital, not in camps or any other place. This should be a priority. Many women are suffering from prolapse. Camps may not be safe for the patient or for the clinicians. The feelings of insecurity appear to be the main reason why hospitals are considered the best place for management. The priority given was to the hospitals, at least a district hospital, where there will be at least a facility of blood bank and in case of emergency, laparotomy can be performed.

The clinicians expressed the benefit to patients coming into hospital for management in many ways, including receiving proper investigations for better diagnosis. The clinicians can better provide quality time with the patients, evaluating and counselling on the problems they were facing.

## **ii. Focus on decreasing prevalence**

When asked about their views on the existing prolapse management policy, clinicians seem not to be satisfied as the focus is only on decreasing its prevalence through surgery. The effort towards prevention is minimal. In the long run, investing in early intervention and education will be more beneficial.

*"Whoever has planned it must have planned for good. But, by doing hysterectomy only it is not going to solve the problem. We have to look at both curative and preventive ways together. Whatever is going on these days is curative, but for the future one must think of preventive approaches. We must think how we can reduce prolapse happening. It is*

*not possible to eliminate the prolapse but we can prevent it occurring. If we have to prevent, we have to choose the long term way."*

CP 2

**iii. Lack of knowledge in people involved in screening**

The clinician participant stated that persons involved in screening seemed to lack knowledge regarding prolapse and its management. There is a need for training before selection of patient CP3 said.

*"While screening: when screened by one person and managed by somebody else there will be a gap in between because the level of knowledge will not be the same. This leads to improper selection of cases."*

CP3

They reported that many of the prolapse patients screened during camp surgery may not need surgery after all. Many of them get rejected. Actually they don't know which type to select for surgery and which not to. Haphazardly they select, depending on what the patient says.

*"In one of the camp, I remember, from the screened cases, around 10-20 cases were sent in one van for operation in one of the private hospitals. Among those 20 cases I have selected myself only 5 cases for surgery. I have rejected 15 cases."*

CP 2

**iv. Need for trained personnel to manage cases**

The clinician participants mentioned selecting the right person for management. The selected person should be able to manage the case and its related complications seriously. Taking a uterus out and throwing it away is not going to solve the problem. One should not bring just anybody to do these operations. Trained personnel are imperative.

*"The surgeon should be a good one. In many places the medical officers are doing it. In many places the surgeons and others doing operations are from different fields of medicine. It is not like comprehensive abortion care. Gynaecologists should be doing the surgery with general practitioners sometimes involved. If other surgeons and physicians all start doing operations there will be a disaster. There are many who are doing this work; we don't know exactly. There must be criteria on who should be operating, where surgery should be done and how it should be done."*

CP 2

CP3 mentioned those who go to camps for doing hysterectomies are mainly those who had just learned about surgery but were not expert in prolapse management. Government had provided funds according to the number of patients and the doctors involved are fulfilling the numbers in order to earn money which can compromise equality.

**v. Attitudes of clinicians**

According to one participant there should be a good supervisor and a faithful team. Patients for surgery should be properly selected and the clinician should carry out the surgery properly.

*"If you think you can't do it, you should say 'I can't do it'. You can't just finish treatment for the sake of finishing for example stitching vaginal wall. No, no we shouldn't do so."*

CP 1

Another concern from clinicians was regarding evaluation of patient by clinicians. It is not compulsory to take out the uterus for all types of prolapse. A proper assessment will give the clinician an idea regarding appropriate management. The separation of the budget for hysterectomies is misleading the management.

*"Many people operate and remove uterus for those with cystocele alone and rectocele alone. For them we can teach some pelvic floor exercise and send them back. Young ladies with prolapse should be provided with ring pessary. It may be cured by self in some types. There are some having prolapse problem at the age of 20-21. They don't require hysterectomy. There are some people who want to increase the number of operations and do surgery to almost all. We shouldn't give that type of treatment as well. For those, what is required is according to type of prolapse."*

CP 2

CP3 agrees that the attitude of the clinicians should be challenged. It is not fair that every mass in the vagina should lead to vaginal hysterectomy. After proper assessment, depending upon the degree and symptoms management should be decided. The consequence of vault prolapse is a result of unnecessary or faulty surgery. When asked why, she answered:

*"We have a small country. The population as such is also not many. Here, we believe in quantity not in quality. For completing fast we do many in number not bothering about quality. Have to finish soon."*

CP3

*"Why soon?"*

R

*"That is what I am told. For them, they may count number of cases but for the patient it is her body. We are not treating them like humans. What to say? We are treating as just doing, for the sake of doing. Not thinking about the future consequences."*

CP3

#### **vi. Need for monitoring and supervision**

According to the clinician participants, the government who is providing money for the treatment should also insist on supervision and monitoring. The participants seemed surprised and mentioned that what is happening now is worrying

*"They are showing the number of cases of surgery only. If we look into the records may be only 25% have undergone hysterectomy really, 75% not. Again there is quantitative care only not qualitative. Actually not quantity, but quality should be improved."*

CP 2

The clinician participant considers the need for supervision in the care of needy women in the community.

*"The donor agencies should not only donate but should monitor and observe how the funds are being utilized, where they are being utilized. Camps are now becoming an earning place for the programme runner. The ones who should get facilities has not got them or got poorer facility. Proper screening, counselling and treatment should be done. It is being done by different people."*

CP 2

#### **Need for change in policy**

There are a number of issues relating to policy. They are: planning before launching; screen efficiently; recruitment of gynaecologist in district hospital; preparing teams for management of POP; surgery in hospital should be a priority; prevention should be emphasized; strengthen family planning and contraceptive use; introduce Kegle's exercises and improve health education on prolapse prevention.

#### **i. Planning before launching**

The participants believe that the POP programme starts without any criteria. There is no proper setting of the programme before launching. It is like emergency case management.

The decisions are taken with only short term goals in mind. There should be a planning of the programme at the beginning of the year which continues throughout the year so that patients receive appropriate and timely management. Rushing to complete the number of operations decided at the end of the fiscal year is not a proper way.

**ii. Screen efficiently**

The participants wished that for screening, people they should be well oriented about the screening criteria; whom to screen and select and whom not to. They recommended community health workers as they will know their area and can visit women on a door by door basis.

**iii. Recruitment of gynaecologist in district hospital**

There are total 73 district hospitals. Besides these there are some zonal and regional hospitals as well. The participants wished to recruit good gynaecologists in every district hospital. The policy of POP should be applied in all the district hospitals and there shouldn't be any time limitation imposed upon the patients. Anytime a patient presents with prolapse, the management should not be a problem.

*"It takes a long time for a small change in this place. I would like to recruit gynaecologists in every district hospital. The main reason for not wanting to work in one is insecurity and there is no proper valuation if worked outside in district hospitals. Government should think about how to retain gynaecologists in district hospital."*

*CP 1*

**iv. Emphasize prevention**

Different views were put forward by the participants on the prevention of prolapse. Firstly they expressed that planning without prevention is incomplete planning. There are different things to start and there are different things that to strengthen. CP2 mentioned that prolapse prevention awareness must be done in adolescence. It has to be done during pregnancy and also after delivery. Education for prevention is also important for family members. CP3 said mass media either through television or radio should be used to raise awareness for prevention.

**v. Strengthen delivery at health facility and family planning**

The participants blame lack of knowledge and poverty as a barrier for seeking for health facility delivery family planning.

*"For prevention part, let women not deliver too many. Strengthen family planning service. Delivery in health institute is always better. Women should have proper rest after delivery but due to poverty and workload they do not receive appropriate care. This is one of the main reasons for prolapse in our country."*

*CP 1*

**vi. Introduce Kegel's exercise**

The clinician participants think that pelvic floor exercises should be introduced as early as possible. Introducing this exercise should be a priority in the training courses of SBA. According to clinicians there is a gap in the transfer of knowledge in the prevention of POP. Everybody knows about the advantage of this exercise but it is not transferred from clinicians to nurses and from nurses to patients.

*"Kegel's exercise which is very popular now and we should be introducing them to women whom we have not done until now. In SBA (skill birth attendant) training it is not there."*

*CP 1*