Patient Perspectives on Community Pharmacy Services

TOBIAS RENBERG
Dissertation presented at Uppsala University to be publicly examined in lecture hall B21, Biomedical centre (BMC), Husargatan 3, Uppsala, Friday, November 6, 2009 at 09:15 for the degree of Doctor of Philosophy (Faculty of Pharmacy). The examination will be conducted in English.

Abstract

Community pharmacy practice is changing, putting a greater emphasis on patient involvement and empowerment than on physical drug products. Developing practice philosophies, such as pharmaceutical care, are operationalised through an ever-evolving service proliferation. There is, however, a paucity of studies addressing the patients’ subjective perceptions of pharmacy services. The few studies that measure the impact of pharmacy services on humanistic outcomes show little or no effect. This might be due to the services, or the assessment instruments used.

The aim of this thesis was to enhance the understanding of how patients perceive community pharmacy services, their preferences for community pharmacy services, and how these services could be evaluated from the patient perspective.

This was done by: 1. exploring patients’ perceptions of an existing pharmaceutical care service using in-depth interviews; 2. exploring patient preferences for the ideal pharmacy visit using Q methodology, and characterising those patient groups that have different preferences and; 3. testing the validity of the Swedish version of the Pharmaceutical Therapy-Related Quality of Life (PTRQoL)-instrument, using think aloud methodology.

Patients had vague, and sometimes erroneous, understandings about a pharmaceutical care service that they were currently receiving. They reported that the service had increased their feeling of safety, enhanced their knowledge, provided drug treatment control, and empowered them. Seven different viewpoints of the ideal pharmacy service were identified, which could be broadly divided into two groups, those emphasising the physical drug products as central to the encounter and those seeking a relationship with the pharmacist. Some differences between the group characteristics were identified, but not specific enough to guide individualised care practice. Several problems with the validity of the PTRQoL-instrument were detected. Overall, the thesis has highlighted various aspects of patient perspectives on community pharmacy services that could be used for the development and assessment of such services.

Keywords: community pharmacy services, patient perspectives, pharmacy services, pharmaceutical care, Q methodology

Tobias Renberg, Department of Pharmacy, Box 580, Uppsala University, SE-75123 Uppsala, Sweden

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A process cannot be understood by stopping it. Understanding must move with the flow of the process, must join it and flow with it.

Frank Herbert
This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


II Renberg, T., Wichman Törnqvist, K., Kälvemark Sporrong, S. Kettis Lindblad, Å., Tully MP. Client normative expectations of pharmacy encounters—a Q-methodological study of what they should and should not be. *Submitted*

III Renberg, T., Kälvemark Sporrong, S, Kettis Lindblad, Å., Tully MP. Practising individualised care in community pharmacies – variation in patient preferences. *Submitted*


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### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>BMQ</td>
<td>Beliefs about Medicines Questionnaire</td>
</tr>
<tr>
<td>CASM</td>
<td>Cognitive Aspects of Survey Methodology</td>
</tr>
<tr>
<td>FIP</td>
<td>International Pharmaceutical Federation (Fédération Internationale Pharmaceutique)</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
</tr>
<tr>
<td>MMAS</td>
<td>Morisky Medication Adherence Scale</td>
</tr>
<tr>
<td>PMR</td>
<td>Patient Medication Record</td>
</tr>
<tr>
<td>PTRQoL</td>
<td>Pharmaceutical Therapy-Related Quality of Life</td>
</tr>
<tr>
<td>SF-36</td>
<td>Medical Outcomes Study 36-item Short-Form Health Survey</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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</table>
Notes on the use of terms

Different publication formats, developing understanding and variable focus throughout the project, have resulted in differences in terminology between the papers and the thesis. The terminology used in the thesis is presented below.

Factor/cluster/group
Throughout the project, study subjects have been divided into units for various purposes. In the thesis, the word factor is reserved as a short term for “factors of operant subjectivity”, which is the main result for a by-person factor analysis (Brown 1980). A factor, in this sense, refers to the resemblance of individual viewpoints. A cluster, on the other hand, refers to a number of people who are strongly associated with a factor. Clusters, in turn, have been arranged in groups for practical reasons.

Patient/client/customer
The nature of the relationship between pharmacists and the individuals they serve is an issue commonly discussed (Austin et al. 2006). In this thesis, the term patient has been chosen, as it is dominant in research literature. In contrast, Paper II used the word client, and Paper IV avoided the conflict altogether since the relationship was irrelevant for the study aims. At Swedish pharmacies, the commonly preferred term is customer.

Patient perspective
The patient perspective, as it appears in this thesis, refers to the subjective views that patients hold about community pharmacy.

Pharmacist
In Sweden there are two pharmacy degrees: pharmacists (five-year university education) and prescriptionists (three-year university education). Working in pharmacies, they have the same legal rights and obligations. This study uses a catch-all term for both professions. When using the word pharmacist referring to a professional active at Swedish pharmacies, it thus relates to both pharmacists and prescriptionists.
Dear reader,

One of my favourite writers, JRR Tolkien, wrote in his famous novel *The Fellowship of the Ring*: “It's a dangerous business, Frodo, going out of your door... You step into the road, and if you don't keep your feet, there's no knowing where you might be swept off to”. In my personal experience, I find that this holds true for most (if not all) scientific enterprises as well. In a work of this magnitude, there have usually been numerous changes of directions. Various people with different and changing agendas have been involved. Understanding has matured and influenced the work, regarding both form and content. It is my firm belief that a brief overview of this process is of great value to anyone intending to understand the work in depth. I acknowledge your option of skipping this section and moving on to other parts such as the aims, the results and conclusions or even the acknowledgements, depending on your purpose, personal preferences and time available. However, if you do want to follow the twists and turns of this research project, you are advised to continue reading this introduction.

Let me begin by presenting myself as I currently believe that I was back in 2003 when I stepped out of the symbolic doorway of undergraduate education and onto the road of science. I was a firmly grounded natural scientist. My high school experience had been primarily in the field of natural science (with a slightly promiscuous bent towards engineering subjects) and I was a pharmacist, primarily trained in the art of discovering and manufacturing drugs. As for practical pharmacy experience, this was limited to unlicensed work in the summertime, and a six-month internship. I had done a research project in biochemistry with the undeniably irresistible title *Sterol 12α-hydroxylase in the bile acid synthesis of human and porcine livers*, and my master thesis had been in epidemiology, about heavy drug users. Although I had always enjoyed the neatness and elegance of theory in

*The real voyage of discovery consists not in seeking new landscapes but in having new eyes.*

Marcel Proust
the natural sciences, I felt that another side of me, my interest in society and human interactions, had never had a chance to bloom.

About that time, the newly-founded (2001) research group in Pharmaceutical Outcomes Research, headed by Dr Åsa Kettis Lindblad, was granted a rather large sum of money from the Fund for Research and Studies in Health Economics and Social Pharmacy in Sweden to develop the subject. The money was used to invite Dr Mary Tully from Manchester to become a visiting scholar within the group. Dr Tully brought with her the idea of a suitable project entitled Development of a Method of Assessing the Impact of Clinical Pharmacy Services on Health Status. In brief, the major idea of the project was that existing health status outcomes instruments did not necessarily cover areas of life that were affected by drug-related problems, and also that they were not calibrated to capture the types of changes that could theoretically result from adopting pharmaceutical care philosophy in community pharmacies. The aim of the original project was to use qualitative methods to understand potential relevant outcomes, and then to develop and evaluate a self-completion instrument that could be used to assess these outcomes in groups of patients.

The primary focus on community pharmacy was there from the beginning of the project, motivated by the fact that the majority of prescription medicines are distributed to patients in that way. In addition the community pharmacy setting was less studied than clinical settings, and often the pharmacist will be the only health care professional who actually meets the patient. As I was fascinated by method development and this opportunity arose, I applied for a position in the project. My supervisors-to-be, Drs Tully and Kettis Lindblad, obviously considered me suitable, and then things started to change within the project.

Theoretically, and methodologically, I was a complete novice on qualitative research at that time, and was initially heavily influenced by works of Cresswell (1998), Marton and followers (on matters of techniques, not theory) (Dahlgren & Fallsberg 1991, Marton 1981), Taylor and Bogdan (1998) and perhaps most important, Strauss and Corbin (1998). These writers are mainly rooted in what Denzin and Lincoln (2005) describe as the modernist phase of qualitative research, although I did not know that at the time. The approach was pragmatic, trying to understand people’s beliefs about the pharmacy without prior theoretical understanding of what might be going on.

The Swedish state monopoly of pharmacy ownership was still in existence (its abolishment was initiated in 2006 as a result of the general election results), and it had launched a pilot project for what would become a rather big patient medication record service in 2002. That project rested heavily on the pharmaceutical care philosophy as described by Cipolle et al. (1998). Being involved in the evaluation of the patient medication record service, Dr Kettis Lindblad had already mapped the service out as a suitable
model for pharmaceutical care interventions in the Swedish community pharmacy setting. The first study to be conducted (resulting in Paper I) was thus initiated according to plan.

There was an early realisation that patients might not necessarily frame their views of the service in terms of what outcomes it produced. Therefore we identified, translated, and used the pharmaceutical therapy-related quality of life instrument (Murawski & Bentley 2001) as a way to “funnel” the responses into outcome-related matters halfway through the interviews. The “funnelling” approach failed, as nothing was added to the analysis of outcomes expected by the patients, but still it yielded serendipitous results. Having translated an instrument that might be partially useful for our initial goal of developing a patient-centred instrument for the impact of pharmacy services, we had the chance of testing it qualitatively. We ended up with an additional full-scale study included in this thesis (Paper IV), after having applied theories of cognitive processes relevant for surveys mainly based on the writings of Sudman (1996), Collins (2003), McColl (2003) and their respective colleagues.

By now, the title of the project had changed to Assessing Patients’ Perceptions of and Preferences for Pharmaceutical Services. It was time to get the project evaluated by external assessors and decide on the future directions. Professor Marjorie Weiss and Dr Tommy Westerlund served as assessors at this half-time seminar. Two primary directions were discussed, either to continue and develop a patient-centred outcome measure for the impact of pharmacy services, or to change direction and look further at the perceptions and preferences for pharmacy services in a more general sense. The latter was chosen due to a number of reasons. First, the heterogeneity of possible services might be such that there are few, or no, generic elements that are relevant enough to include in one instrument. Second, the outcomes identified in Study I were scarce, and often measurable by other instruments that were already available. Third, the possibility to employ a fairly unusual, but promising methodology such as the Q was intriguing in itself. The possibility to develop a screening tool for patient preferences of pharmacy services was also discussed as a natural extension of the chosen direction. However, whether or not such a study would be worthwhile within the context of this thesis was never seriously considered, largely due to time restraints. The thoughts on pharmacists’ potential ability to assess patient preferences still linger though, primarily in Paper III.

Papers II and III, which were the last ones to be completed, were planned and conducted simultaneously. They are primarily to be considered as one unit, but publication format and requirements prevented them from being published as such. Paper I generated the starting point for these later studies, with the relevant patient-centred outcomes being located somewhere in the intersection between the theoretical constructs of quality of life, patient satisfaction and patient empowerment. From this pre-understanding, I delved
into the literature and came up with the model guiding the study that emanated in Papers II and III, a model compliant with the methodological considerations underpinning the Q-technique and its applications (Stephenson 1953). Several different constructs with a more or less obvious connection to patient preference for, and need of, pharmacy services were also identified as useful descriptors of pharmacy clients, primarily reported in Paper III. In the analysis and interpretation of the studies on ideal pharmacy encounters (Papers II and III) additional input was given by Dr Sofia Kälvemark Sporrong, subsequently the research leader within the group. Her background in the social sciences further deepened the interpretation, and was particularly important when both my supervisors were, for professional reasons, unable to keep as close a contact as before in the final period of thesis writing.

The research programme resulting in this thesis has been a true journey of scientific discovery and personal development. Many models, theories, frameworks, patterns, typologies and other systematic ways to describe a complex reality have passed by in my efforts to get a grip of what exactly the relevant question was in the work that is now labelled Patient Perspectives on Community Pharmacy Services. Developing an ability to see things from several perspectives and understanding the limitation of each perspective have probably been the greatest personal rewards of the entire PhD education. My theoretical conceptual development has been tremendous during recent years. When starting out, I had never heard of concepts such as hermeneutics, phenomenology or even positivism, for that matter. Now, they are at the centre of my scientific understanding. For me, this thesis is an important milestone and still, again using the words of Tolkien, it is just another doorstep from which the road goes ever on and on…

Tobias Renberg Uppsala September 25, 2009
Professionals and patients in community pharmacy practice

All is flux, nothing stays still.

Heraclitus

This thesis is concerned with patients’ perspectives on community pharmacy services. In order to understand the reason for this particular interest, the reader should first be aware of some aspects of pharmacy practice and health care development from a societal and professional perspective.

Health care trends and pharmacy

Evidence-based medicine, that is the constant reliance on the best scientific evidence available, is gaining in popularity (Sackett & Rosenberg 1995, Evidence-based medicine working group 1992, Epstein 1990). At the same time, the subjective opinion of patients is increasingly acknowledged as important for health care development and evaluation (Sullivan 2003). Patient-centredness can be defined either as the health care provider trying to adopt the patient’s perspective or as the provider trying to activate the patient (Michie et al. 2003). The latter approach comes close to the concept of empowerment, which can be seen as a process by which patients gain mastery over their lives. In this context, health is viewed as the capacity to live a full life, although there are alternative interpretations of the term (Johnston Roberts 1999). Finally, it has been argued that the epidemiological shift from acute to chronic conditions and demographic changes in the population might lead to a “care transition”, from traditional institutional health care to community-based care (Taylor & Bury 2007). As these trends permeate the entire health care sector, it is unlikely that pharmacy will be unaffected.

Although originally aiming at improving medical practice, the concept of evidence-based medicine can also be applied to pharmacy practice (Etminan et al. 1998). The patient-centred (rather than societal) approach has been touted as a necessary condition for the continuing development of quality in pharmacy care (Farris & Kirking 1993). International organisations such as the World Health Organization (WHO) and the International Pharmaceutical
Federation (FIP) have recognized the changing scope of pharmacy practice and strive to increase focus on patient care (Wiedenmayer et al. 2006, WHO 1994). An increased involvement of pharmacy in public health issues has been promoted by public bodies and explored scientifically (Garfield et al. 2007, Krajic et al. 2001, Anderson 2000, WHO 1998).

Philosophy of pharmacy practice

A common term for describing the changing philosophy of pharmacy practice is pharmaceutical care. This term exist in several different forms with different backgrounds, different emphases and different cultural and setting-specific connotations (Björkman et al. 2008, van Mil et al. 1999), most of which can be traced back to one or more of the health care trends described above. Some of the most common definitions of pharmaceutical care are cited in Table 1.

Table 1. Common pharmaceutical care definitions

<table>
<thead>
<tr>
<th>Source</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepler &amp; Strand 1990</td>
<td>“Pharmaceutical care is the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient’s quality of life”</td>
</tr>
<tr>
<td>FIP, 2009</td>
<td>“Pharmaceutical care is the responsible provision of pharmacotherapy for the purpose of achieving definite outcomes that improve or maintain a patient’s quality of life. It is a collaborative process that aims to prevent or identify and solve medicinal product and health-related problems. This is a continuous quality improvement process for the use of medicinal products”</td>
</tr>
<tr>
<td>Cipolle et al. 2004</td>
<td>“Pharmaceutical care is a patient-centred practice in which the practitioner assumes responsibility for a patient’s drug-related needs and is held accountable for this commitment”</td>
</tr>
</tbody>
</table>

Three other concepts related to pharmaceutical care are disease management (DMAA, 2009), medication therapy management (Pellegrino et al. 2009) and medicines management (Simpson 2001, Tweedie & Jones 2001) although it can be argued that these concepts do not really qualify as philosophies of practice, as they do not address the issue of why pharmacy should act in a particular way (McGivney et al. 2007).

Disease management is pragmatically focused on integrating all evidence-based health care, both treatment and prevention, in the care of a single
disease state (Holdford et al. 1998, Zitter 1994). A potential role for community pharmacists has been suggested in disease management (Holdford et al. 1998).

The definitions of medication therapy management will vary between public authorities, pharmacy organisations and managed care organisations, but it can be seen as a framework within which the pharmacist can provide cognitive services and be reimbursed for that effort (Pellegrino et al. 2009, McGivney et al. 2007). The relation between the concepts has been reviewed by McGivney (2007) from an American perspective and by van Mil (1999) from a European ditto1.

Medicines management is commonly used in the UK. The relation to pharmaceutical care is unclear (Simpson 2001). Two varying definitions are “the systematic provision of medicines therapy through a partnership of effort between patients and professionals to deliver best patient outcome at minimised cost” (Tweedie & Jones 2001) or “medicines management seeks to maximise health gain through the optimum use of medicines. It encompasses all aspects of medicines use, from prescribing of medicines through the ways in which medicines are taken or not by patients” (Keele University, 2009).

Driving forces for changing philosophy of practice

It has been argued that the value that pharmacists traditionally provided to society has become obsolete. This value was defined by pharmacists’ unique expertise in drug manufacturing and quality control. These activities have largely been removed from the pharmacy environment and increasingly routinised (Anderson 2007, Harding & Taylor 1997, Adamcik et al. 1986). Fear of down-regulation of professional status and influence could thus be understood as a driving force for changing philosophy of practice (Hibbert et al. 2002, Harding & Taylor 1997). In their seminal article on pharmaceutical care, Hepler and Strand acknowledge this theory but add that the pharmacist profession, in order to succeed in its professional project, must also have a purpose to serve the commonweal. They find this purpose in the care of patients, rather than in concern for their own profession (Hepler & Strand 1990). Thus, the purpose of developing an expanded pharmacy practice has been described as ensuring a more effective and safe drug therapy in the face of a more and more complex treatment situation where drug-related morbidity is soaring, unchecked by traditional health care (Cipolle et al. 2004).

1 The van Mil paper was presented before the medication therapy management concept made a breakthrough, primarily in the US. I would argue that medication therapy management could be seen as a managed care initiative.
Roles of pharmacists

If patients do not accept the expertise of pharmacists in the new fields that pharmacists wish to enter, their expectations and behaviours in pharmacist encounters will not support interactions desired by pharmacists (Guirguis & Chewning 2005, Biddle 1986, Solomon et al. 1985). This will be of particular concern in an effort to incorporate roles that go beyond dealing with drugs, into pharmacists’ professional practice (Harding & Taylor 1997). However, structural changes in health care delivery can create new platforms from which pharmacy practice can develop, although not necessarily deliberately (Anderson 2007, Silcock et al. 2004).

A changing philosophy of practice will also have ethical consequences. The tension between the demands on the pharmacist as a health care professional and as a businessman has been recognised for a long time (Anderson 2002, Resnik et al. 2000, McCormack 1956). The business/health care tension might influence the balancing of ethical principles. Dessing (2000) has suggested four ethical principles to guide pharmacy practice. These are, in descending order of importance: respect for the autonomy of the patient, respect for democratic principles, prevention of negative consequences of pharmacotherapy and ensuring the best possible treatment. Dessing’s principles come close to the general principles of biomedical ethics described by Beauchamp and Childress (respect for autonomy, non-maleficence, beneficence and justice) although the latter work do not rank the importance of ethical principles (Beauchamp & Childress 2001).

Pharmacy service proliferation

Professional role development and changing philosophy of practice are operationalised by the proliferation of pharmacy services aimed at patients or health care professionals. The rationale for developing pharmacy services, the setting in which they emerge, their extent and their content all vary. Services are commonly designed to be broad enough to meet core elements that are partially common to concepts such as pharmaceutical care, disease management and medication management services (McGivney et al. 2007).

Consequently, there is a plethora of definitions used to describe the services. There is no agreement on any of these definitions, although van Mil and colleagues (1999) have presented a taxonomy of activities in community pharmacies based on their orientation (patient/case/logistics) and the relationship between the pharmacist and other actors (patient/physician/none). Table 2 contains definitions that apply to this thesis.
Table 2. Service definitions relevant for community pharmacy practice

<table>
<thead>
<tr>
<th>Name</th>
<th>Proposed definition</th>
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<tbody>
<tr>
<td>Cognitive pharmacist services</td>
<td>Any services that include the direct interaction between patient and pharmacist, making use of the pharmacist’s knowledge.</td>
</tr>
<tr>
<td>Community pharmacy services</td>
<td>Any services delivered at community pharmacies.</td>
</tr>
<tr>
<td>Expanded pharmacy services</td>
<td>Any services delivered by a pharmacy beyond the manufacturing, packaging or dispensing of drugs.</td>
</tr>
<tr>
<td>Pharmaceutical care services</td>
<td>Any activities at the pharmacies that are performed because of a conscious choice to implement the philosophy of pharmaceutical care.</td>
</tr>
</tbody>
</table>

Definitions by the author.

The division of services delivered at pharmacies into carefully defined groups is likely not self-evident to the lay public. Thus, the perceptions of laypersons have to be studied either as experiences of particular services, or as perceptions of pharmacy services as a whole.

Importance of the patient perspective

Apart from the fundamental moral issue of introducing the patient perspective in all health care delivery and evaluation (Sullivan 2003, Popay & Williams 1996), there are also several practical advantages for doing so. Rosenthal and Shannon (1997) emphasise that measures of patient perceptions may be more sensitive to differences across health care delivery systems, demanding less resources to obtain, being more sensitive to positive aspects of care, and being more related to positive health behaviour than traditional measures of care quality.

Patients’ expectations of the pharmacy encounter are essential in understanding the development of interaction at the pharmacies (Austin et al. 2006, Guirguis & Chewning 2005). Different kinds of expectations are important in determining satisfaction, perception of quality and trust in providers (Gastelurrutia et al. 2006, Schommer 2000, Schommer et al. 1995).

Patients’ perspectives on community pharmacy

Patients’ or the public’s perspectives on community pharmacy services and/or the role of the pharmacists have primarily been studied using quantitative research methodologies. An exception is Cavaco and colleagues (2005), who showed that Portuguese pharmacy patients only presented vague and superficial ideas about community pharmacies.
Patient perception of pharmacy service quality is probably more related to their perception of the interaction with the pharmacist than to the actual outcome of the service (Holdford & Schulz 1999, Hassell et al. 1998). Patients involved in a pharmaceutical care project that was generally considered to be successful reported that the relationship with and support from the pharmacist was essential for the success of the programme (Garrett & Martin 2003). The provision of physical drug products has also been shown to be important in relation to the expressed demand for expanded pharmacy services (McAuley et al. 2009, Cavaco et al. 2005, Anderson et al. 2004, Hassell et al. 1998).

The formation of patient role orientation towards accepting counselling from a pharmacist depends on several factors. A low need for cognition (i.e. “the tendency for an individual to engage in and enjoy thinking”) (Cacioppo & Petty 1982) usually means low role expectations for counselling (Schommer et al. 1995). In general, expectations for expanded pharmacy services also increase when exposure increases (Brooks et al. 2008, Assa-Eley & Kimberlin 2005, Chen & Britten 2000).

It has repeatedly been shown that a large proportion of the public does not consider advice- or information-giving to be a primary function of the pharmacist, at least not when given spontaneously (Salter et al. 2007, Haugbølle et al. 2002, Traulsen et al. 2002). The reason for patients not being positive about such a role for the pharmacists could be a lack of faith in pharmacists’ competence in this field (Anderson et al. 2004), fear of asking stupid questions (Schommer 1997), having the impression that they already have all information necessary (Tully et al. 1997), perceiving that pharmacists have limited access to patient records (Kettis Lindblad et al. 2006), privacy issues (McAuley et al. 2009) and lack of therapeutic relationships (Vallis et al. 1997).

However, not all studies suggest a general resistance against pharmacists providing expanded services (McAuley et al. 2009, Garfield et al. 2007). Singh and colleagues (2003) also showed that efforts of pharmacists to form therapeutic alliances might be successful, and acknowledged by the patients.

**Comparing professionals’ and patients’ perspectives**

Differences in patients’ and other stakeholders’ views of pharmacy have been cited as an explanation for limited response to marketing strategies for such services. While there is some agreement on the nature of patients’ therapy-related needs, there is less agreement on whether the pharmacists are able to meet those needs (Bislew & Sorensen 2003). Pharmacists have expressed a desire for greater responsibility in counselling on drug selection and drug use than patients want them to have (Schommer et al. 2006). In contrast to pharmacists, patients do not perceive that pharmacists have any
responsibility to ensure the effectiveness of medication therapy (Bislew & Sorensen 2003). The patient-centred care philosophy can be contrasted with relatively passive patient behaviour and pharmacist-dominated encounters reported in Swedish pharmacies (Skoglund et al. 2003). Pharmaceutical care activities are perceived as being more beneficial by pharmacists than by patients. Patients also think that pharmaceutical care services are considered less important by the pharmacists than the pharmacists perceive them to be (Assa-Eley & Kimberlin 2005).
Given the broad scope of the change of philosophy of practice outlined above, it is impossible to make a comprehensive review of its effects. Nevertheless, many individual research efforts have strived to show the value of pharmacy services, and this chapter is intended to give an overview of their general findings. Pharmacy practice has been criticised for being too focused on the measurement of structure and process, largely neglecting patient outcomes (Tully & Cantrill 1999). Outcomes can, in turn, be subdivided into economic, clinical or humanistic outcomes, all of which must be considered (Singhal et al. 1999, Kozma et al. 1993). While clinical and economic outcomes are frequently studied in relation to pharmacy services, humanistic outcomes are often neglected. This is of particular concern for pharmaceutical care services, where such outcomes are central in the philosophy of practice (van Mil et al. 2004). Perhaps this fallacy is due to an increasing pressure of cost containment as van Mil argues, or perhaps it has to do with the problems of accurately assessing broad and individually defined concepts such as quality of life.

**Evaluations of patient perspectives in pharmacy**

Reviews that in some respect have targeted the patient perspective during the past ten years are summarised in Table 3. Presenting corresponding data for clinical and economic outcomes would be too voluminous for this thesis. Differences or fuzziness in service definitions, multi-faceted interventions, differences in settings, varying selection of end-point measures and poor study designs commonly inhibit comparison of findings. Three common constructs that allow studies of patient perspectives on the group level are (health-related) quality of life, patient satisfaction and self-rated health.
<table>
<thead>
<tr>
<th>Study</th>
<th>Aim of review</th>
<th>Notes on patients’ perspectives</th>
<th>Notes on study design</th>
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<tbody>
<tr>
<td>Pickard et al. 1999</td>
<td>Describe the published literature that uses health-related quality of life as an outcome measure to evaluate pharmacist interventions.</td>
<td>The impact of pharmacist interventions on health-related quality of life is uncertain as different studies show different results. Studies used generic (always the SF-36) and disease-specific measures.</td>
<td>Study design, sample selection and sample size can be improved in the study of pharmacists’ interventions impact on health-related quality of life.</td>
</tr>
<tr>
<td>Beney et al. 2000</td>
<td>Review the effect of pharmacists providing services other than drug formulation or dispensing, focusing on health services utilisation, costs and patient outcomes.</td>
<td>Seldom measured. When measured, quality of life effects were small, or not shown.</td>
<td>Services are often poorly defined in studies. Pharmacists’ interventions are seldom compared to interventions by other professionals.</td>
</tr>
<tr>
<td>Tully &amp; Seston 2000</td>
<td>Review of the patient outcomes and health care system costs attributable to pharmacists’ reviewing and monitoring services in ambulatory care or community pharmacy.</td>
<td>Studies on patient satisfaction showed equivocal results. Where studied, quality of life changes little or not significantly.</td>
<td>Studies are heterogeneous in many ways, complicating comparisons. The quality of study designs varies.</td>
</tr>
<tr>
<td>Roughhead et al. 2002</td>
<td>Assess the value of pharmacist professional services in the community setting.</td>
<td>Health-related quality of life is commonly used as a study outcome. Often the services have no effect on these measures.</td>
<td>Common methodological limitations concern the open and non-random selection of study participants.</td>
</tr>
<tr>
<td>Finley et al. 2003</td>
<td>Review the impact of pharmacist-provided services directed at patients with mental illness.</td>
<td>Positive impact on patient satisfaction.</td>
<td>Studies vary in settings (in- or outpatient) as well as the nature of the service (treatment recommendations, patient education, prescribing and education of staff). Study designs are commonly weak.</td>
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<tr>
<td>Study</td>
<td>Aim of review</td>
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<td>Rollason &amp; Vogt 2003</td>
<td>Examine the effects of pharmacist interventions on the reduction of polypharmacy in the elderly.</td>
<td>Although pharmacist interventions commonly reduce the number of drugs used by the elderly, the real impact of this on the wellbeing of patients is not shown in the vast majority of studies.</td>
<td>Methodological quality is often poor, with broad and ill-defined study objectives.</td>
</tr>
<tr>
<td>McLean &amp; MacKeigan 2005</td>
<td>Review community-pharmacy based studies of pharmaceutical care for patients with asthma to understand factors contributing to positive outcomes.</td>
<td>Health-related quality of life is improved in some studies. There are uncertain effects on patient satisfaction.</td>
<td>The pharmaceutical care concept is differently operationalised in the studies compared. The quality of study design varies.</td>
</tr>
<tr>
<td>Machado et al. 2007a</td>
<td>Identify patient outcomes sensitive to pharmacists’ interventions in diabetes management, and quantify their impact.</td>
<td>Only a few studies studied humanistic outcomes, and then it was predominantly quality of life. Little or no impact of pharmacists’ interventions was described.</td>
<td>Studies in many settings, such as medical clinics, community pharmacies, ambulatory clinics, hospital wards etc. Study quality was systematically assessed and found to be fair.</td>
</tr>
<tr>
<td>Machado et al. 2007b</td>
<td>Identify patient outcomes sensitive to pharmacists’ interventions in hypertension management, and quantify their impact.</td>
<td>Eight studies that evaluated quality of life with generic or disease-specific instruments were reviewed. One of them showed that quality of life was sensitive to pharmacists’ interventions.</td>
<td>Study quality was systematically assessed and found to be fair.</td>
</tr>
<tr>
<td>Holland et al. 2008</td>
<td>Determine the effects of pharmacist-led medication review in older people.</td>
<td>Few studies reported on quality of life issues. Those that did showed small or non-significant effects.</td>
<td>Study quality was systematically assessed and found to be fair.</td>
</tr>
<tr>
<td>Machado et al. 2008</td>
<td>Identify patient outcomes sensitive to pharmacists’ interventions in hyperlipidaemia management, and quantify their impact.</td>
<td>Only two of the reviewed studies reported data on quality of life, both using the SF-36 instrument. A positive impact was found in at least some dimensions, but study design prohibited evaluation of the size of the effect.</td>
<td>Studies in many settings, such as medical clinics, community pharmacies, hospitals and patients’ homes. Study quality was systematically assessed and found to be good.</td>
</tr>
</tbody>
</table>
Quality of life is a broad term including many factors beyond the control of health care. It is often difficult to operationalise at the generic level (Leplège & Hunt 1997), in part because individuals define quality of life differently (Fagerlind et al. 2009, Stenner et al. 2003). To be useful for scientific purposes, quality of life often has to be broken down into components or focused at a specific disease or other context (Farquhar 1995, Wilson & Cleary 1995). Generic health-related quality of life (HRQoL) measures might be insufficiently sensitive to measure the effects of pharmaceutical care services (Volume et al. 2001, Hanlon et al. 1996). They are not always equally relevant, or even equivalent in meaning, to different target populations (Crealey et al. 2003, Mallinson 2002, Hill et al. 1996, Jenkinson et al. 1996).

Self-rated health can also be used as a crude measurement, as a part of the patient perspective. It is subjectively constructed of both biological and cultural origin. In addition, it is related to both morbidity and mortality (Jylhä 2009). This is perhaps the reason why self-rated health is included in the widely used Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) (Ware & Gandek 1998, Ware & Sherbourne 1992). However, the comprehensiveness of self-rated health might also lead to low specificity (Jylhä 2009).

Finally, patient satisfaction is a valuable subjective measure for evaluating services (Larson et al. 2002, MacKeigan & Larson 1989). It must be noted though, that patients use different standards to evaluate different kinds of services. Cognitive pharmacy services are evaluated in relation to the perceived ideal functionality and possibly to some extent in relation to what is available in other pharmacies. Tangible service aspects (waiting time etc.) are evaluated in relation to past experience (Kucukarslan & Schommer 2002).

**Pharmaceutical therapy-related quality of life**

A concept intended to capture the patient-perceived effects of pharmacotherapy (and as a natural extension, effects of pharmacy services) is pharmaceutical therapy-related quality of life (PTRQoL) (Murawski & Bentley 2001). In essence, it is conceptualised as the gap between the maximum HRQoL obtainable after drug treatment and the level actually experienced. HRQoL in this context is limited to the aspects that can be affected by the consumption of pharmaceuticals. The inherent burden of medication use or the memory of medicine use, is assumed to be due to either negative biophysiological actions of drugs or psychosocial effects. A schematic overview of the concept is given in Figure 1.
Figure 1. Overview of the PTRQoL concept. Simplified from Murawski & Bentley 2001.
Summary of introduction

To study the phenomenon of disease without books is to sail an uncharted sea, while to study books without patients is not to go to sea at all.

Sir William Osler

Community pharmacy practice is developing, inspired by a changing philosophy of practice. This practice put the needs of the patient in focus, rather than the physical drug products or the business aspects of pharmacy. Despite being at the centre of the evolving practice philosophy, research on patients’ subjective perceptions and expectations of pharmacy services is sparse. Service evaluations that try to address humanistic outcomes, such as quality of life, often show little or no impact, although it is uncertain whether this is due to the service or to the measurements used for evaluations.
Aims

A new vision of development is emerging. Development is becoming a people-centred process, whose ultimate goal must be the improvement of the human condition.

Boutros Boutros-Ghali

The aim of this thesis was to enhance the understanding of how patients perceive community pharmacy services, of their preferences for community pharmacy services, and of how these services could be evaluated from the patient perspective. In particular, the following research questions were addressed:

• How do patients perceive a pharmaceutical care service?
• What outcomes do patients expect from a pharmaceutical care service?
• What different viewpoints are present among patients regarding the nature of an ideal pharmacy encounter?
• What characterises patients holding different views on ideal pharmacy encounters?
• How can a qualitative analysis of patients’ responses to a translated version of the pharmaceutical therapy-related quality of life questionnaire inform the development of the concept and the questionnaire?
Study setting

Consider a spherical cow in a vacuum...

Classic joke about oversimplified models in science, unknown origin

Although the practice of pharmacy varies around the world, there seems to be some agreement about some central themes for practice, including rational use of drugs, medicines management and pharmaceutical care (Anderson 2002). Still, all social science research must be situated in one or more specific settings. This particular research programme focused on encounters between pharmacists and patients at physical community pharmacy sites in Sweden. The patient group consisted of people using medications continuously. In Paper I, a particular service was studied as a model for expanded pharmacy services.

Interpersonal encounters at community pharmacies

A community pharmacy is a physically existing retail shop for pharmaceutical preparations, where the patient interacts with the staff. The natures of the encounters are variable from case to case, sometimes interpretable as health care encounters and sometimes not (Austin et al. 2006). Prescription status (new or refill), patient age, patient gender and above all, patient question-asking behaviour have effects on the type of information provided in pharmacy encounters (Schommer & Wiederholt 1997). Advocates of community pharmacy as an arena for increased health care initiatives usually stress that it is an easy accessible route to meet with highly trained health care professionals (Garfield et al. 2007, Anderson 2000).

The view that the pharmacy encounter is only shaped by a patient and a pharmacist together is a simplification of matters. There are other significant agents such as physicians, nurses, pharmacy technicians, third party payers, friends, relatives and so forth. Salter and colleagues (2007), for example, showed that the patient-physician relationship was considered so important in medicines management that it reduced the perceived value of pharmacist intervention. In addition, the physical environment at community pharmacies will undoubtedly affect the encounters (Anderson et al. 2004). Nevertheless,
this research programme is primarily concerned with the interaction between a pharmacist and a patient at the community pharmacy, as this is a key feature that distinguishes pharmacy practice from encounters at other retail shops (Dingwall & Wilson 1995).

Community pharmacy in Sweden

In a comparison between six European countries, Sweden was described as having few but big pharmacies and relatively low margins on drug sales (Garfield et al. 2007). From 1971 until July 2009, the sale of medicines to individuals was regulated by a state monopoly and organized by a single state-owned chain (Statute 2009, Westerlund & Björk 2006). The staffing at Swedish pharmacies is generally broader than in comparative countries. The rate of prescriptionists to pharmacists (see the notes on use of terms above) within the state monopoly was about five to one during the study period, and at smaller pharmacies, there were usually no pharmacists employed (Garfield et al. 2007, Westerlund & Björk 2006). Compared to the UK, unlicensed staff have greater responsibilities in Swedish pharmacies, but they also have a higher degree of training (Hassell et al. 2002). It is likely that the Swedish pharmacy structure will change due to new actors appearing on the market following the 2009 re-regulation, although it is still uncertain how.

The patient medication record service

The study subjects in Paper I, and some of the subjects in Paper IV were enrolled in a patient medication record (PMR) service². The service was introduced on a trial basis in 2002, and it was based on the pharmaceutical care philosophy (Cipolle et al. 1998). In addition to standard dispensing and counselling, the service included documentation of counselling for follow-up purposes, a comprehensive drug summary of all drugs, and relevant patient factors. In addition, booked in-depth counselling sessions with patients were offered. More detailed information about the service could be found in a company report from the national corporation of pharmacies in Sweden (Swedish only) (Läkemedelsprofiler 2003), Paper I, or studies by Montgomery and colleagues (2008, 2007). The pharmacists perceive the service as developing their professional role, although being time-consuming, and sometimes hard to promote to managers and physicians (Montgomery et al. 2007).

² At the time of the study, the service was labelled “Läkemedelsprofiler” in Swedish.
Methodological framework

Real reality bears the seal of imagination.

Mahmoud Darwish

Scholarly inquiry is always dependent on epistemological, ontological and theoretical assumptions, whether they are explicit or implicit. A brief review of issues that are relevant for this thesis will be presented in this section. Special attention will be given to Q methodology as this way of describing subjectivity is the least used, and is essential for understanding prominent parts of the work reported in this thesis.

Subjects’ reporting of subjectivity

This thesis draws on four different models for how subjectivity can be expressed. Table 4 show how the different models apply to each paper. The first model is psychometric and based on comparative judgment. According to this commonly applied model, an answer to a question is derived by identifying a relevant “psychological continuum” and comparing the given stimuli (the question) to the values available on this continuum (Thurstone 1927). An attitude, regardless of whether it is innate or learned, is a “range in which responses move” and one can assume that if several attitudes concern the same social issue, they cluster together in groups (Likert 1932). The groups of attitudes of Likert’s and psychological continuums of Thurstone are assumed to be real, relatively stable entities that can described in general terms.

The second model is the phenomenological lifeworld model. In this model, originally developed by philosophers like Husserl, Heidegger, Merleau-Ponty and Gadamer, all people live immersed in a pre-reflective, pre-scientific lifeworld (Denzin & Lincoln 2005). In reflecting and making

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3 The use of the letter Q in this case has no particular meaning. Different types of factor analysis have been named with arbitrary letters to distinguish them from each other (McKeown and Thomas 1988).

4 Phenomenology in this context refers to a philosophical standpoint emphasising issues of ontology and epistemology. In some texts, phenomenology refers to a specific method or methodology. No explicit phenomenological method has been used in any part of this work.
up theories (reaching a higher level of abstraction) about lived experience, the complexity of the entire lifeworld is not possible to articulate or understand. The aim of the researcher is to identify common themes that will help to explain the studied phenomenon (Shepard et al. 1993). Meaning is created as the researcher adopts his or her own perspective about what to look for in an account of a specific lifeworld (Giorgi 1985).

The third model of subjectivity emanates from behavioural science and is labelled Q methodology. In this model, subjectivity is self-referential as it only makes sense in relation to the way the individual perceives the world (Stephenson 1953). Subjectivity cannot be divided into dimensions or scales, but the entire pattern of one study subject must be kept intact throughout the research process (Mrtek et al. 1996).

The fourth model applied in understanding subjective accounts is based on the cognitive tasks involved in responding to a stimulus, which might produce different forms of response error (Collins 2003, Tourangeau et al. 2000, Sudman et al. 1996). The concern for the impact of cognitive task performance has spawned a movement among researchers using surveys, labelled cognitive aspects of survey methodology (CASM) (McColl et al. 2003, Sirken et al. 1999). The model used in this thesis consists of four components: comprehension, retrieval, judgement and response, each of which contains several compulsory and optional psychological processes. The application of the cognitive components of the response process are not likely linear, but rather iterative and interactive (Tourangeau et al. 2000).

Table 4. Application of different models for reporting subjectivity

<table>
<thead>
<tr>
<th>Paper</th>
<th>Model</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Phenomenological model</td>
<td>The model is used throughout the analysis. The issue is to capture how study subjects experience their participation in the PMR service. Their narratives were interpreted from three different perspectives set by the unfolding understanding of the researcher.</td>
</tr>
<tr>
<td>II</td>
<td>Q methodology</td>
<td>The entire study was carried out assuming that people are able to make self-referential judgements of stimuli they are subjected to.</td>
</tr>
<tr>
<td>III</td>
<td>Q methodology</td>
<td>Clusters were identified by having study subjects make self-referential judgements of a given set of stimuli. Several of the scales used and reported were developed assuming that study subjects share similar understanding of the psychological continuum.</td>
</tr>
<tr>
<td></td>
<td>Comparative judgement</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Comparative judgement</td>
<td>The validity of the PTRQoL concept depends on study subjects all experiencing the inherent burden of drug treatment in a similar way.</td>
</tr>
<tr>
<td></td>
<td>Cognitive task</td>
<td>The framework applied when looking for problems with the questionnaire was based on the cognitive task model.</td>
</tr>
<tr>
<td></td>
<td>Phenomenological model</td>
<td>The think-aloud descriptions were interpreted in the light of the CASM theory assigned by the researcher.</td>
</tr>
</tbody>
</table>
More on Q methodology

In Q methodology, subjectivity is assumed to be expressions of “inner behaviour” (i.e. yearnings, wishes, ruminations, fancies and so forth). The individual psychological significance of each stimulus is dependent on the inner frame of reference for the individual (Stephenson 1953). This means that each individual is able to perform Q-sorts, i.e. organise the importance of various stimuli on an ordinal scale depending on self-referential psychological significance (Brown 1980). In a Q-methodological study, this rating is done on an arbitrarily set distribution according to a specific instruction, called a “condition of instruction” (McKeown & Thomas 1988). The shape of that distribution has been shown to be of limited importance, although performing the sorts often gets easier if it is a normal distribution. Most people tend to have stronger opinion on just a few stimuli in any given set of stimuli (Brown 1980).

The individually ordered Q-sorts can be compared by arranging them in a Q-factor matrix and performing a by-person factor analysis (Brown 1980, Burt & Stephenson 1939, Stephenson 1935). The procedure mathematically derives common themes, or “factors of operant subjectivity” that explain similarities between the sorts (Brown 1980). Factors are described by identifying factor exemplars (sorts with a close relation to that factor, and weak relation to other factors) and calculating a factor array (typical sort for a hypothetical “ideal” factor exemplar) (McKeown & Thomas 1988). These are, in turn, interpreted subjectively (McKeown & Thomas 1988, Brown 1980).

Q methodology has been pointed out as especially useful in pharmaceutical care research, since the cornerstones of pharmaceutical care are subjective in nature (Mrtek et al. 1996). It allows the researcher to identify clusters of people holding similar views, rather than clustering items on a scale (Barbosa et al. 1998, McKeown & Thomas 1988). As individual patterns are kept intact and study subjects can associate with several clusters at once, Q methodology is often superior to cluster analysis (Morf et al. 1976).

A critical step in performing a Q-methodological study is that the understanding of the phenomenon does allow the researcher to create stimuli, or statements, that cover all relevant aspects of the phenomenon (Cross 2005, McKeown & Thomas 1988, Hilden 1958). A theory about the phenomenon could be useful for the sampling of statements (Q-sample) as well as for the interpretation of the results, although the free sorting procedure enables the respondents to express subjectivity differently than given by theory (Stephenson 1953).
Generalisability of contextually situated research

As all understanding of the social world is contextually situated, generalisations should be viewed as working hypotheses rather than conclusions when applied to other settings (Cronbach 1975). According to phenomenological philosophy, the account of the study subject is intimately linked with the context within which it is created (Shepard et al. 1993), and generalisations are only directly applicable to the setting from which the original data emanated. For all other settings, a reflective understanding of both the source and the target context are necessary (Greenwood & Levin 2005).

Generalisation of qualitative research is achieved through emerging theory (Strauss & Corbin 1998). One case contradicting existing theory will invalidate the theory and require it to be reformulated. This is true in quantitative research as well (Lewin 1935), but hard to practise as outliers tend to blend into large masses of data (Greenwood & Levin 2005). The concern for the single case is similar in Q methodology (McKeown & Thomas 1988, Stephenson 1953).
Procedures and techniques

*Life grants nothing to us mortals without hard work.*

_Horace_

The empirical data that provide the backbone of this work have been collected and analysed in several different ways. Data collection includes two different types of verbal interviews (semi-structured and think-aloud), one respondent-driven statement sorting procedure (Q-technique) and the administration of a questionnaire. Data were analysed using the constant comparison method for qualitative research, by-person factor analysis for Q-sort data and descriptive statistics for questionnaire data. Interpretation was performed using the perspective of usefulness, which is the potential for results being applicable and useful for developing community pharmacy practice. Table 5 contains a methodological summary of the papers presented in this thesis.

Table 5. _Methodological overview of studies in this thesis_

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Ethical approval</th>
<th>Study population</th>
<th>Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Qualitative interviews</td>
<td>Not required, consultative statement given (registration number: 2004:M-147)</td>
<td>12 participants enrolled in a patient medication record service</td>
<td>Constant comparative method, conventional content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Q methodology</td>
<td>Not required</td>
<td>90 participants, using long-term (&gt;3 months) medication</td>
<td>By-person factor analysis, subjective interpretation</td>
</tr>
<tr>
<td>III</td>
<td>Questionnaires</td>
<td>Not required</td>
<td>Same as Study II</td>
<td>Descriptive statistics</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative “think-aloud” interviews, concurrent probing</td>
<td>Not required, consultative statement given (registration number: 2004:M-147)</td>
<td>16 participants using drugs on a regular basis</td>
<td>Constant comparative method, directed content analysis</td>
</tr>
</tbody>
</table>
Study population

Study participants were mainly recruited at community pharmacies in the mid-East of Sweden; a few were recruited by snowballing. They were all adults (over 18 years old), and used medicines regularly to treat a variety of medical conditions. The recruiter used subjective judgement to exclude individuals with poor understanding of Swedish, and those suspected of suffering from cognitive impairment. For Studies I and IV, recruiting was done by pharmacists working regularly in the pharmacies, and for Studies II and III by a researcher.

For the verbal interviews, participants were recruited using theoretical sampling (Strauss & Corbin 1998). Age, gender and number of drugs were monitored to get a wide variation of respondents. For Paper I, this sampling procedure resulted in directing the recruitment towards women for the last three interviews. Nine of the participants from the study reported in Paper I also contributed to Paper IV. Recruitment was terminated when the analysis of at least two consecutive interviews did not further alter the structure of the findings. At this point, saturation (i.e. the point where additional data collection yields a negligible return concerning understanding of the issue under study) (Strauss & Corbin 1998, Taylor & Bogdan 1998) was considered to be achieved.

Papers II and III included the same participants. These were approached after having presented a prescription at the pharmacy. Recruitment was conducted at various times of the day to receive a variety in the customers available for the study. This was the only theoretical component of the recruitment process. In Q methodology, a pragmatic sampling strategy will suffice (McKeown & Thomas 1988). In total, 90 participants completed the sorting, although five did not follow the instructions and were omitted in the subsequent analysis. This sample size was considered sufficient (McKeown & Thomas 1988, Brown 1980), but sampling does not guarantee that all relevant factors are uncovered in a particular study (Brown 1980).

Data collection – semi-structured interviews (Paper I)

Semi-structured interviews are interviews that are conducted according to a pre-defined protocol, topic or interview guide. This aide sets the general agenda to be discussed but allows deviations in both format and content (Fontana & Frey 2005). Targeting patient-perceived outcomes of an expanded pharmacy service, and based on the pharmaceutical care philosophy (Hepler & Strand 1990), five areas of inquiry were formulated in the interview guide. Each of these concerned whether the respondents believed that their participation in the PMR service had changed their:
• medication-taking behaviour
• general opinion about drugs
• satisfaction with pharmacy services (both information received and interaction with staff)
• ability to perform daily life activities
• general feeling of well-being (or health).

The interview guide was tested in a pilot with three study subjects. As a result, the final interview guide (Appendix 1) became a little more specific and more focused on the actual experience of the study subjects. The PTRQoL part was included to check if directing the interviewees towards known humanistic outcomes at the end of interviewing would trigger any additional thoughts about service outcomes (it did not). This part was reported in Paper IV (see below).

Interviews were conducted at the pharmacies or at other locations chosen by the respondents themselves (usually their homes). Patients were allowed a certain freedom on this matter in order to make them feel more confident and involved in the interview situation; this is a prerequisite for a good and informative interview (Taylor & Bogdan 1998). Each interview, conducted in Swedish, lasted about 45 minutes. The interviews were recorded and transcribed verbatim.

Data collection – Q-sorting (Paper II)

The pharmaceutical care literature and Paper I suggested that relevant aspects of patients’ perspectives on community pharmacies could be found by exploring how they related to quality of life, satisfaction and empowerment in the community pharmacy environment. Scientific studies on these subjects were retrieved and reviewed. 5 Based on this review, a factorial model of possible pharmacy service expectations was constructed (the forerunner to the final model described in Table 6).

Three or four statements were constructed for every combination of dimension modes. The statements were constructed so that they could be understandable by anyone familiar with the community pharmacy environment, and they all emphasised the encounter between the pharmacist and the patient. Three members of the Pharmaceutical Outcomes Research Group sorted the statements into the dimensional modes and gave comments on both the statements and the model. Based on disagreements and comments, both the model and the statements were revised by the author.

5 In total, 54 papers were included in this unsystematic review. They are not listed here, due to space restrictions. The list is available from the author upon request.
This procedure was repeated twice, using different reviewers. The final model is shown in Table 6.

The 3x3 factorial design stipulates a Q-sample size divisible by 27. The number of iterations was set to two, as 54 statements are a suitable amount to handle for most topics (Barbosa et al. 1998, Hilden 1958). The statements are listed in Appendix 2, and the exact layout of the forced normal distribution is given in Figure 2. The condition of instruction was: Describe an ideal pharmacy visit for collecting prescription medicines, using “least like I want it” and “most like I want it” as outside reference points.

Table 6. Factorial model guiding the Q-sample generation

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Possible modes</th>
<th>Mode descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality assessment base</td>
<td>Technical</td>
<td>It is important that the pharmacy is organised in a specific way, or that expectations on details that are not related to pharmacist competence are fulfilled (such as personal treatment or accessibility).</td>
</tr>
<tr>
<td></td>
<td>Process-oriented</td>
<td>It is important that something takes place during the encounter.</td>
</tr>
<tr>
<td></td>
<td>Result-oriented</td>
<td>The result is important, not the encounter per se. This is regardless of the nature of that result, which may be something with a physical form (such as getting drugs) or something non-material, such as knowledge.</td>
</tr>
<tr>
<td>Focus of pharmacy encounter</td>
<td>Drugs</td>
<td>The encounter should focus on drugs and their objective properties. Information about health does not belong in this mode.</td>
</tr>
<tr>
<td></td>
<td>Drug use</td>
<td>The encounter should focus on how the patients use, or do not use, their drugs. Non-pharmacological treatment does not belong in this mode. Information-giving, counselling and discussion all belong in this mode, as long as they pertain to drug use.</td>
</tr>
<tr>
<td></td>
<td>Health care/lifestyle</td>
<td>The encounter should address the health of the patient in a wider context than just their drug treatment. Lifestyle advice, diagnostics and treatment monitoring are parts of this mode.</td>
</tr>
<tr>
<td>Power relationship (between pharmacist and patient only)</td>
<td>Pharmacist-driven</td>
<td>The principal responsibility for driving the encounter rests with the pharmacist.</td>
</tr>
<tr>
<td></td>
<td>Collaborative</td>
<td>The principal responsibility for driving the encounter is divided between the patient and the pharmacy staff.</td>
</tr>
<tr>
<td></td>
<td>Client-driven</td>
<td>The principal responsibility for driving the encounter rests with the patient. Pharmacy staff should only be available as support if requested by the patient.</td>
</tr>
</tbody>
</table>

The Q-sorts were performed in the presence of a researcher who gave both written and verbal instructions for the sorting procedure. A systematic approach to the task was encouraged, as was the continuing adjustment of the sort until the study subjects felt it to be representative of their viewpoint.
About half of the study subjects performed the sorts at University premises, at the same time as five to seven other participants. The other half performed the sorts on a one-to-one basis with a researcher (some at home, and some at the University). Performing a Q-sort (including filling in the questionnaires described below) took about 45 minutes, although it varied between approximately 30 minutes and 2 hours.

Figure 2. Distribution and condition of instruction for the Q-sort. (Image from Paper II)

Data collection – questionnaire (Paper III)

The 12-page, 45-item questionnaire was handed out in conjunction with the Q-sorts. Most items had multiple choice answers. As study subjects were already involved in a time-consuming procedure, it was assumed that questionnaire length would not discourage them from participating. The questionnaires were marked with identification numbers, making it possible to couple them with the Q-sorts without identifying the study subject.

The importance of a good form design has long been recognised (Barnard et al. 1979). The graphical layout was primarily guided by the idea that the questionnaire should be simple, consistent, organised, natural, clear and attractive (Mullin et al. 2000, Oppenheim 1992).

Items in the questionnaire

The selection of items was guided by one out of two principles:

- Things that are fairly easy to assess and often emerge at pharmacy encounters. If specifically related to some of the

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6 Not reproduced in the thesis due to copyright restrictions of some parts.
clusters, these measures can be used as guides for the pharmacist in suggesting what services to offer at the encounter.

- Measurements that have been shown to be related to treatment outcomes. Concern has been raised that the “worried well”, who already have control over their health situations, might be a significant target group for open health care interventions, potentially wasting resources (Montgomery et al. 2007, Conrad 1987).

The identified measures were:

- demographics (age and gender)
- main language
- self-rated health
- experience with work in the health care sector
- social relations (living situation, children)
- educational level
- economic vulnerability
- cognitive representation of drugs
- medication adherence
- drug treatment (number of prescription medications used daily/when needed, use of OTC products and/or herbal drugs/other treatments)
- frequency of pharmacy use (to collect own prescription medication and for all purposes)

Ethnicity and/or race is an important aspect in the study of pharmacy practice, although it is a concept that is hard to operationalise beyond vague ideas about lingual, religious, cultural, historical or territorial identity (Bissell et al. 2003). In this questionnaire, ethnicity was approximated by self-reported main language of the study subjects, which is admittedly a crude measure. Nevertheless, language is a feature often distinguishable for health care staff. It was considered important to include at least some measure of ethnicity as it is related to disparities in health care (Nsiah-Kumi et al. 2009, Chuan et al. 2008, Wendel et al. 2006).

The actual nature of social support, and what measures of social support are relevant for mediating health effects, are still not fully understood (Hawkley et al. 2003, Uchino et al. 1996). Still, previous research has shown that varying degrees of social support have an impact on consulting behaviour, (Skomo et al. 2006). It is also strongly correlated to all-cause mortality (House et al. 1988). In this questionnaire, social support was measured by a single question about the habitual relationship with other adults. Subjects were also asked if they had children living at home (including, if so, their ages), as parents are a group that has been described as

Educational level was hypothesised to be a key variable. Associated with a number of behavioural and material constructs, educational level can be used as an important proxy for mortality (Laaksonen et al. 2008, Schrijvers et al. 1999, Lantz et al. 1998) and morbidity (Hoogendijk et al. 2008, Sainio et al. 2007, Strand & Tverdal 2006). Furthermore, it is likely that educational level correlates to the need for cognition (Cacioppo & Petty 1982), a construct that has been shown to be important for role orientation towards pharmacy consultation services (Schommer et al. 1995). Likewise, it was assumed that experience from the health care sector could affect the view on the role of pharmacy.

Self-rated health is a common and strong predictor for mortality and morbidity (Jylhä 2009). Differences between single-item self-rated health measures are often marginal, and they are all considered to target the same latent health construct (Jürges et al. 2008, Eriksson et al. 2001). This study employed a five-point scale ranging from excellent to poor health. The correlation between mortality and self-rated health (lower self-rated health correlates with higher mortality) is maintained even if controlling for social class (McFadden et al. 2009), functional status, or co-morbidity (DeSalvo et al. 2006).

In addition to being associated with positive health outcomes (assuming that drug therapy is beneficiary) (Osterberg & Blaschke 2005), good adherence is also associated with positive health outcomes for placebo, suggesting that there is a “healthy adherer” effect. Good adherence and positive health outcomes are both likely to be effects of a general healthy lifestyle (Simpson et al. 2006). It is likely though, that the size of the net effect attributable to good adherence will depend on the disease state (Sokol et al. 2005). Adherence was measured with the eight-item Morisky medication adherence scale (MMAS) (Morisky et al. 2008).

Cognitive representations of drugs are cornerstones for understanding medication adherence and non-adherence (Pound et al. 2005, Isacson & Bingefors 2002, Horne & Weinman 1999). The beliefs about medicines questionnaire (BMQ) was used to measure these issues (Horne et al. 2001, Horne et al. 1999). A Swedish version of the BMQ has previously been used in various Swedish settings (Bondesson et al. 2009, Mårdby 2008, Ramström et al. 2006). The BMQ is scored in five subscales, three that pertain to beliefs about medicines in general (overuse, harm, and benefit) and two that pertain to beliefs about the specific drugs taken by the subject (necessity and concern) (Horne et al. 2001, Horne et al. 1999).
Data collection – think-aloud interviews (Paper IV)

An instrument designed to measure PTRQoL (see above) has been developed7 (Murawski et al. 2002, Murawski & Bentley 1998). It is a three-page questionnaire, including 33 items, divided into nine different subscales: social embarrassment, positive belief in medications, empowerment, supply/continuance, logistics, confusion, harm, sick role and stigma.

The translational procedure was influenced by the concepts of equivalence as described by Hui and Tarandis (1985), Herdman and colleagues (1998, 1997) and Streiner and Norman (1995). Guillemin et al. (1993) proposed a guideline for the cross-cultural adaptation of HRQoL instruments that also served as an inspirational source.

First two professional translators made two independent translations of the questionnaire. Two researchers involved in the project, both native Swedish speakers, compared the translations and produced a consensus version and a number of conceptual questions considered crucial for the translation. These questions were discussed with an additional researcher in the project (native British English speaker) and one of the original constructors of the American instrument. Additional members of the Pharmaceutical Outcomes Research Group at the Department of Pharmacy, Uppsala University, were invited to give comments on the translation. The Swedish version of the PTRQoL was compiled by the author using these various sources for comments. Topics discussed in the translational procedure gave rise to several probes used in the think-aloud interviews.

The PTRQoL instrument was given to study subjects (some in conjunction with the interviews performed in Paper I). They were told that the purpose of the study was to evaluate the questionnaire, and that they should think aloud and be explicit about how they arrived at the answers they put down (Drennan 2003, Sudman et al. 1996). The interviews were conducted either at pharmacies or at other locations chosen by the respondents to improve the comfort of the study subjects. Think-aloud interviews can be effectively combined with concurrent and/or subsequent probing (Baker & Robinson 2004, Collins 2003). When encountering an expected or unanticipated problem with the questionnaire, the interviewer intervened with a probing question to elicit how study subjects handled that particular issue. The pre-established probes printed out in Appendix 1 were omitted at the discretion of the interviewer if already answered in the concurrent think-aloud process. The interviews were recorded and transcribed verbatim. The questionnaires were kept.

7 Not reproduced in the thesis due to copyright restrictions.
Data analysis – constant comparison method (Papers I and IV)

The coding process was similar to the extraction of meaning units in psychological phenomenology as described by Giorgi (1985). After having formed a rough idea about the nature of the complete interviews, text segments that carried meaning in relation to study objectives were derived from the text. These text segments were labelled and grouped thematically.

The constant comparison method used (Strauss & Corbin 1998, Taylor & Bogdan 1998) is a technique where the researcher simultaneously codes and analyses data. Every coded piece of data is compared to the emerging analyses, allowing the discovery of new themes and concepts, as well as variations in the final results (Strauss & Corbin 1998). Coding and grouping was performed using the NVivo software from QSR International (QSR International 1999).

Using the classification of Hsieh and Shannon (2005), the analysis of data could be described as conventional in Paper I and directed in Paper IV. In Paper I, three main themes were identified through induction (nature of the service, functions of the service and outcomes of the service). As these themes are not mutually exclusive, and exist simultaneously, it was decided that the entire data set should be coded separately for each main theme, and that the results should be merged after analysis.

In Paper IV, in contrast, the entire data collection design and initial analysis perspective of the researcher was influenced by CASM theory, as described above. Thus the entire result was also fitted into that framework. Think-aloud interviews are commonly performed in controlled laboratories and analysed quantitatively according to protocol (Bickart & Felcher 1996, Sudman et al. 1996). However, the value of using think-aloud techniques together with qualitative analysis is gaining acceptance (Drennan 2003, Aanstoos 1983).

Data analysis – by-person factor analysis (Paper II)

Each statement was given a value corresponding to the column in which it was placed, in the forced distribution depicted in Figure 2. A complete correlation matrix of the 85 useful Q-sorts was calculated and subjected to principal components factor analysis (McKeown & Thomas 1988). Varimax rotation, which is a suitable method for exploratory work, was performed to derive clear factor arrays (Kaiser 1958). A seven-factor solution was selected according to the principles suggested by Brown (Brown 1980). The calculation of the correlation matrix, the factor analysis and the rotation was performed using a specialist programme, PQmethod (Schmolck & Atkinson 2002).
The factor arrays (Appendix 3) were subjectively interpreted by two independent researchers and final interpretation was settled by consensus. Interpretation was primarily based on the strongly positive and negative scores displayed for various statements in the factor arrays (McKeown & Thomas 1988, Brown 1980). The factors were grouped together, based on the criterion that grouping would be useful for developing pharmacy practice.

Data analysis – statistical tests (Papers II & III)

The factorial model in Paper II (Table 6) was tested by performing single group ANOVA on the average factor scores within each dimension (Brown 1980). Comparisons that reached an a priori set level of statistical significance (p<0.05) were further analysed using pairwise t-tests to separate the modes (using a significance level of p<0.05).

The fairly broad groups identified in Paper II were used as comparison groups in Paper III. This was considered appropriate, based on the practical usefulness of the grouping. To avoid contamination in the comparison groups it was decided that, for inclusion, a particular subject must:

- be loading to at least one factor in a particular group at the significance level of p<0.01,

- have no statistically significant loading on any of the factors in the other group.

Consequently, 60 study subjects were included in the group comparison. Continuous variables (age, self-rated health, BMQ scores, MMAS score) were compared using t-tests. Categorical variables were compared using $\chi^2$-tests. The significance level was set to p<0.05.

Ethical considerations

Looking at ethics from a regulatory stance, it may be noted that none of the sub-studies in the thesis required approval by an ethics committee in Sweden at the time of data collection, as participation was voluntary and there was no intervention aimed at affecting the study subjects. Nevertheless, for two of the studies (Papers I and IV), a consultative statement was sought from an ethics committee.

The anonymity of the study subjects was protected in a number of ways. First of all, data is presented at an aggregated level, and not as individual narratives. In Papers I and IV, where individual quotes are used to illustrate findings, the complete individual stories cannot be identified. Furthermore,
the participating pharmacies are not named, and individuals are given aliases to protect their identities.

The researchers involved strived for a relationship to the study subjects that was characterised by openness, veracity and privacy. The study purpose and general outline was described and briefly explained to the study subjects. It was made clear that the researchers were acting independently of the pharmacy. Furthermore, the freedom of participation was stressed. Study subjects were informed that their participation was voluntary and that they could withdraw at any time without having to explain anything. Their treatment at the pharmacy would be unaffected by their decisions to refuse participating in part of or the whole study. Study subjects were given time to think about their participation, and their formal consent was required.

Although being a common trend in the social sciences (Greenwood & Levin 2005), this work did not set out to be emancipatory. Rather, its purpose can be described as practical, gaining interpreted knowledge that would benefit pharmacy practice (Habermas 1966).
Summary of findings

If I could I would always work in silence and obscurity,
and let my efforts be known by their results.

Emily Brontë

The findings of this thesis can be divided into three parts. Paper I reports on patients’ perceptions of an existing pharmacy service, Papers II and III report on the division of ideal expectations for pharmacy encounters into clusters and Paper IV reports on the validity of a measure intended to capture a relevant patient outcome for medicated patients.

Experience of a pharmaceutical care service (Paper I)

Study subjects were all aware that they had received the PMR service and were satisfied with that fact. However, the meaning attributed to this service was vague and often not reflected upon. For most subjects, the service was not easily discussed as a stand-alone service disconnected from other pharmacy services, or even other health care experiences. Three main, sometimes overlapping perspectives from which the service could be described were identified; they were the nature of the service, the function of the service and the outcomes of the service. A summary of the study findings is given in Table 7.

Nature of the service

The service was perceived as having been developed to meet different objectives. These included meeting societal problems (such as drug costs or poor prescribing behaviours), adding to drug knowledge in general, meeting the needs of the individual patients, and commercial objectives to benefit the pharmacies. Gaining control of drug treatment was also commonly described as the objective of the service, although study subjects differed in whether they believed it was the responsibility of the pharmacies or the patients to keep that control.
Table 7. Summary of categories defined and described in Paper I

<table>
<thead>
<tr>
<th>Nature of the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objectives perspective</td>
</tr>
<tr>
<td>Control of drug treatment</td>
</tr>
<tr>
<td>Internal/external</td>
</tr>
<tr>
<td>Research</td>
</tr>
<tr>
<td>Societal/commercial/individual aims</td>
</tr>
<tr>
<td>Means perspective</td>
</tr>
<tr>
<td>Technical solutions</td>
</tr>
<tr>
<td>Increased consultation time</td>
</tr>
<tr>
<td>Continuity of care</td>
</tr>
<tr>
<td>Computer support</td>
</tr>
<tr>
<td>Practical interventions</td>
</tr>
<tr>
<td>Drug summary</td>
</tr>
<tr>
<td>Professional involvement</td>
</tr>
<tr>
<td>Access to pharmacist competence</td>
</tr>
<tr>
<td>Treatment change and support</td>
</tr>
<tr>
<td>Discussion and information</td>
</tr>
<tr>
<td>Technical AND professional aspects</td>
</tr>
<tr>
<td>Safety control</td>
</tr>
</tbody>
</table>

Function of the service

- Supporting the patient
  - Reassurance about drugs
  - Practical support
  - Direct treatment support
- Supporting the physician
  - Referral of relevant problems
  - Safeguard against mistakes
  - Emergency care decision base
- Facilitating patient-physician communication
  - Information transfer
  - Freeing up time
  - Preparation of patient
  - Professional agent

Outcomes of the service

- Patient Outcomes
  - Health
  - Knowledge and understanding
  - Drug-taking behaviour
  - Emotional well-being
- Other effects
  - Drug treatment changes
  - Practicalities

Merged version of tables in Paper I
There were also various views on the *modus operandi* of the service. While some considered it a technical solution (increased consultation time, software solutions and automated procedures), others considered it an opportunity to obtain additional professional input on their drug treatment, with some arguing that pharmacists hold a unique competence in health care. Those talking about the combination of technical and professional aspects of the service did so when referring to the service as principally being about safety control. Not all the tasks the interviewees described as being part of the service, such as generic substitution or referral to monitored dosage systems, were actually included in the service.

**Function of the service**

There were different views on what the function of the PMR service was in overall health care. Some considered it a function supporting physicians. According to them, the service provided a safety net for catching poor decisions on behalf of the physicians, served physicians with relevant knowledge and detected patients in need of medical care. Others believed the service aimed at the drug-related\(^8\) needs of the patient, helping them to use their medications properly. A third function that was identified was that the service could facilitate the communication between the patient and physician. It improved drug information transfer, increased quality time in consultations and empowered the patients in relation to their physicians.

**Outcomes of the service**

The emotional outcomes of the PMR service were the most salient according to study subjects. They perceived that they were safer with the service than without and that they received some kind of special treatment. Subjects also considered the service a source of knowledge and understanding about drugs, sometimes coupled with an increasing motivation to comply with a prescribed regimen. Practical effects such as package size changes or specific labelling of products were attributed (in error) to the PMR service.

Direct health outcomes that could be attributed to the service were not apparent to the study subjects. When directly prompted, some did infer some effects that might have been indirectly attributable to the service. But in general, health outcomes were not associated with the service.

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\(^8\) All instances that referred to the service as supporting the patient, referred to drug-related needs.
Clustered viewpoints on ideal pharmacy encounters (Papers II and III)

Seven factors were extracted, and in total they accounted for 54.4% of the variance in the data. Two broad groups of factors were identified. One group emphasised the drug product as the centre of the pharmacy encounter, henceforth called traditionalist, and one was mainly concerned with getting personal support, henceforth called relationship-focused. The raw factor arrays are given in Appendix 3. Table 8 lists the labels put on each factor, as well as their groupings.

Table 8. Factors of operant subjectivity regarding subjects’ preferences for the ideal pharmacy encounter

<table>
<thead>
<tr>
<th>&quot;Traditionalist” group</th>
<th>Emphasises drug products</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor I</td>
<td>Independent drug shopping</td>
</tr>
<tr>
<td>Factor II</td>
<td>Logistics of drug distribution</td>
</tr>
<tr>
<td>Factor III</td>
<td>Drugs before drug use before health care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>&quot;Relationship-focused” group</th>
<th>Emphasises personal support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor IV</td>
<td>Competence as individual support</td>
</tr>
<tr>
<td>Factor V</td>
<td>Individualist professional relationship</td>
</tr>
<tr>
<td>Factor VI</td>
<td>Just take care of me</td>
</tr>
<tr>
<td>Factor VII</td>
<td>Practical health care and lifestyle support</td>
</tr>
</tbody>
</table>

The independent drug shoppers (described by Factor I) portrayed the ideal pharmacy encounter as a traditional shopping encounter. Pharmacies should have good quality drugs and be able to answer questions when prompted to do so. Focus by the pharmacists on other aspects such as drug use or health, or other health care initiatives were not encouraged by Factor I. Factor II seemed to equate pharmacies with drug distribution solutions. The capacity for a good logistic solution came to the forefront, as did the possibility to get drug-specific information accompanying the drugs. Factor II rejected discussion of health care matters with the pharmacists. Study subjects that were identified as Factor III exemplars had the most clear-cut opinion on what kind of focus the pharmacy encounter should and should not have: drugs before drug use before health care. Nevertheless, they rejected the idea that pharmacies should be business-oriented. Taken as a group, traditionalists were more likely than relationship-focused patients to:

- have Swedish as their main language. (p=0.014)
- have an academic degree. (p=0.013)
- disagree with statements that implied that pharmaceuticals are overused. (p=0.044)
- disagree with statements that implied that pharmaceuticals are harmful substances. (p=0.044)
- report a higher number of pharmacy visits overall. (p=0.038)
Among the study subjects, no statistically significant differences could be detected regarding age, gender, self-rated health, experience with working in the health care sector, living situation, economic vulnerability, specific beliefs about the own medications (neither necessity nor concerns), medication adherence, drug use pattern or frequency of pharmacy visits to collect personal prescription medicines.

The kind of support sought by the factor exemplars in the relationship-focused group varied. Factor IV sought knowledge and empowerment from the competent pharmacist. Factor V exemplars sought a more personal contact and did not seem to care so much about the actual outcomes of the encounter. Factor VI exemplars expressed a desire for practically anything that meant that the initiative for action should come from the pharmacist, but shunned conversation. Finally, Factor VII exemplars felt positive about encounters that focused on health, lifestyle or feeling good.

Validity of the Swedish PTRQoL instrument (Paper IV)

In general, the Swedish translation of the PTRQoL instrument was considered easy to understand and answer. Combined think-aloud and concurrent probing techniques coupled with qualitative analysis, as used in this study, will yield more information on problems rather than benefits of the concept and/or instrument.

Regarding questionnaire understanding, willingness to actually read instructions was low. It was difficult for subjects to interpret what medicines the questionnaire was referring to, or how to answer if an item related only to some and not all medications they were taking. Some items were also perceived as virtually impossible to answer, as the study subjects did not consider themselves to have sufficient objective knowledge to do so. In theory however, the PTRQoL instrument does not demand objective knowledge, as it is only asking for subjective emotions on behalf of the study subject. Finally, items that theoretically belong to different domains were considered similar.

When processing the information given in the questionnaire, additional problems arose. Even though they expressed negative feelings towards a particular issue some subjects did not feel that it would be fruitful to answer that this affected their quality of life negatively when they saw no alternative to their current situation. Also, the applicability of certain items to all respondents was challenged, as well as their potential to have a negative impact on quality of life.

Finally, in formulating answers to the questionnaire subjects varied in their opinions on what response options should be available, as well as in their use of the scales. There were mixed interpretations throughout the questionnaire, even by the same subjects about different questions.
Discussion

*Great minds discuss ideas; Average minds discuss events; Small minds discuss people.*

*Eleanor Roosevelt*

This research programme contributed to the understanding of the complex and diverse representations that are held by chronically medicated patients about services delivered at community pharmacies. It also provided some insights on how such services might be evaluated from the patient perspective. Paper I explored actual experiences with a comprehensive pharmaceutical care service, including the perceived outcomes. Paper II was different as it explored views on what would constitute an ideal pharmacy encounter. It also separated study subjects into clusters, based upon their perspectives. Paper III explored the characteristics of people holding different views of the ideal pharmacy encounter on a group level. The differences were not specific enough to be used for guiding individual care. Paper IV turned attention back to the outcomes of pharmacy services and added knowledge about how these services could be more routinely evaluated using a self-completed questionnaire.

The main strength of the study is the various routes to understanding patient perspectives that give rise to a complex and rich description. Both the actual experiences and the ideal preferences are important for service development. Before discussing the implications of the findings, a few notes on methodology deserve to be mentioned.

**Methodological considerations**

Taking the stance of hermeneutic phenomenology, this thesis could be criticised for being weak in addressing the interplay between researcher and study subject, both immersed in their respective lifeworlds (Crist & Tanner 2003, Draucker 1999). Also, the direct accessibility of their lifeworlds through the stories told by study subjects may be questioned. Additional data input, such as observations and theory-guided interpretation might have been appropriate from this point of view (Crist & Tanner 2003, Draucker 1999, Shepard *et al.* 1993). These approaches would certainly have strengthened
the emancipatory qualities of the phenomenological parts of this study. Nonetheless, such an emancipatory ideal was never explicitly stated in this work. The aims were more pragmatically oriented, to identify an understanding of the patients’ perspective that could enlighten development of expanded pharmacy services.

In Paper II, two raters were used to interpret the meaning of the factor arrays. This was not the case in Papers I and IV, where I did all of the analyses myself, although discussing the findings with my co-authors. The reason for this could be traced to the different models of subjectivity involved. In the phenomenological case, the interview structure and analysis framework is not fixed. A relevant interpretation will require that the researcher is “submerged” in the data material, something that is seldom feasible for anyone but the interviewer (Morse 1997). In Q methodology, by contrast, factors are supposed to exist in the factor arrays. They just have to be subjectively (not arbitrarily) interpreted by researchers (McKeown & Thomas 1988).

Contradictory to recommendations, the condition of instruction for the Q-sort was written to measure a theoretical construct (ideal encounter) rather than actual experience (Barbosa et al. 1998, McKeown & Thomas 1988). It is impossible to disentangle actual experience from this ideal. Both constructs are likely to influence service perception (Boulding et al. 1993, Zeithaml et al. 1993). The choice to use a theoretical condition of instruction was dictated by the study aims, and it is interesting to see how theoretical new developments position themselves in relation to existing services. Together with the fairly advanced statements, this choice produced a rather complex sorting task, which might have lowered the precision of the findings.

The effort required to produce a Q-sort limited the sample size, which might have given power difficulties for the statistical analyses of some variables in Paper III, especially since so many constructs were tested. This was the main reason for using crude groups for comparison, rather than the individual factors. The advantage of such an approach is that it will likely only produce statistical significance for variables that differs enough to be relevant (Robson 2002).

Study coverage
To give the whole picture of patients’ perspectives of services delivered at community pharmacies would indeed be a Sisyphean labour. Below, some particular groups will be briefly outlined, whose voices may not have been sufficiently studied within the framework of this thesis. The methodological approach used does ensure that the findings of the performed studies may still be valid (see the Generalisability section, above), although by no means complete.
The sampling method used was inefficient in enrolling study subjects from socially marginalised groups. Four out of 85 (4.7%) study subjects performing the Q-sorts reported that they were lacking financial means to manage unexpected expenses, while the Swedish population mean has varied between 12.1% and 18.7% between 1980 and 2005 (ULF survey 1975-). The necessity for study subjects to be fairly proficient in Swedish, although required for this kind of data collection, has probably reduced the likelihood of finding study subjects from immigrant groups. Two-thirds of the study subjects in Papers II and III reported having a university degree, compared to the corresponding figure for Sweden of 22% (and for Uppsala 37%) (Statistics Sweden 2009).

The study subjects were all recruited at fairly urban pharmacies (albeit with different characteristics), owned by a single company. Different views on pharmacy have been previously reported depending on the pharmacy setting (Traulsen et al. 2002, Abu-Omar et al. 2000). The upcoming rise of several different pharmacy owners in Sweden, chains and locals, will add to this complexity, although it is uncertain how and how much.

The selection of the PMR as a model for expanded pharmaceutical services was natural, as it was the most comprehensive service that was being implemented at the time of the study. It is however, just one service. No other services were studied; had there been such, they might have yielded additional or different insights.

The validation of the Swedish version of the PTRQoL instrument (Paper IV) is only partial. It does not cover the psychometric properties of the scale, nor does it capture all aspects of the cognitive processes required to answer it. The findings could nevertheless be used for making significant improvements to the questionnaire, using fewer study subjects, before embarking on a full scale psychometric validation process (Collins 2003). It is possible that the think-aloud methodology will discriminate against the views of less articulate study subjects (Sudman et al. 1996). The impact of this will be smaller, using a qualitative rather than a quantitative approach to analysis.

Implications for patients

A truly individualised care will require large resources for every patient. The findings in this thesis will help develop pharmacy services in accordance with the experiences and preferences of patient groups. In particular, patients expect services to aim at increased control over drug treatment, increasing their (feelings of) safety, empowerment and increasing drug knowledge. Also, the expressed service preferences among patients are divided between a drug-focused group and a relationship-focused group, where the former stands out more clearly in the material. Based on the findings of Paper III, no
obvious clues were identified to help pharmacies direct services at particular patient groups.

The current pharmacy reimbursement system is focused on the delivery of drugs to patients who have them prescribed (at least in Sweden), but not on building relationships or providing cognitive services. This system will satisfy the preferences of patients primarily associating with a drug-focused factor (Paper II), but neglecting the preferences of the others. Naturally, reimbursement systems cannot be solely based on the preferences of the patients. In line with a patient-centred philosophy however, it is crucial that such preferences are studied and taken into account (Kizer 2002). This thesis only reveals a rough image of the patient view on pharmacy services, but at least it can serve as a starting point for patient-centred service development.

A similar reasoning could be applied to the public regulations that control pharmacy practice. It is mainly the supply of drug products that is regulated. Legal obligations to assure proper counselling do exist (Statute 1992), but these only apply in relation to the dispensing of drugs. In effect, patients seeking other types of services from community pharmacies do not have the same public guarantees about the quality of services.

In Denmark it has been shown that an explicit concern for the needs and desires of the medication users not necessarily translate into political practice in a political reform (Noerreslet et al. 2005). It is not clear why this occurred, but it may be argued that studies investigating patients’ needs and desires constitute a structural pre-requisite for including such findings in policy decisions. The research programme reported in this thesis offers important insights into the patient perspective on community pharmacy services that could be used as basic data for policy decisions.

Professional implications (including professional ethics)

The study of patients’ perceptions of the PMR service reported in Paper I adds to the existing knowledge that patients do not always have a clear idea about what to expect from community pharmacy (Cavaco et al. 2005, Bislew & Sorensen 2003). The variety of experiences and expectations (Papers I and II) may call for a diversified strategy in meeting the needs of patients. This diversification could be extended to different degrees but should at least offer both drug-focused and relationship-focused approaches. Health care initiatives, besides the drug-oriented consultations, are generally not considered desirable. Instead, services that aim to increase patients’ feelings of safety with drug use, their knowledge about drugs and their empowerment to take control of their treatment stand a fair chance of being concordant with patients’ preferences. Such approaches capitalise on the professional role of pharmacists as described by Dingwall & Wilson (1995), bringing social meaning to drug treatment. Any profession is dependent upon its
relationship with both the general public and policy makers. By aligning professional development with the public identity of that profession, the basic professional privileges (gaining public credentials and professional autonomy) will be more easily obtained (Freidson 1994b).

The division of patients into clusters is valuable for developing the professional services delivered at pharmacies, as it may help guide the encounter to be more fruitful. There is a danger, however, that if they rely too heavily on typecasts, pharmacists risk ritualising care. This would only serve to de-professionalise pharmacists (Harding & Taylor 1997, Freidson 1994a), and fail to address individual needs and desires of patients that go beyond the suggested stereotypes.

This thesis reveals that patients’ expectations of community pharmacy are neither consistently associated with a business nor a health care standpoint. Together with the superficial understanding revealed in Paper I, this suggests that the pharmacist profession as a group has some liberty in choosing their future direction. However, Paper III highlights the difficulties in providing individual guidance to patients in the community pharmacy environment. Understanding the values and preferences of patients is crucial to delivering services that balance the important ethical principles of beneficence and patient autonomy (Beauchamp & Childress 2001, Dessing 2000). It should be noted that patient preference for active care on behalf of the pharmacist was particularly pronounced in only one of the identified Q-clusters (Paper II, cluster 6: Just take care of me). However, people in that cluster do not want to engage in the exchange of information with the pharmacist either. Whether this finding is due to passivity on behalf of the patients or overconfidence in the capacity of the pharmacists to act without background information is uncertain. To summarise, the capacity for community pharmacy to deliver pharmaceutical care based on a holistic perspective, may be limited by patients’ actual desires to receive such services in that context.

However, looking at patient-centredness from the perspective of activating and empowering patients, rather than adopting their perspective, has initially been a much more rewarding strategy when it comes to health outcomes (Michie et al. 2003). Many of the outcomes that were identified by the patients in Paper I, and some of the ideal descriptions of pharmacy encounters in Paper III, could also be considered as delivering components of empowerment.

There is a key difference between these two approaches to delivering patient-centred expanded pharmacy services (adopting the patient perspective versus empowering patients). The difference is that while the first requires a full therapeutic relationship between patient and pharmacist, where personal information on all aspects of life is freely shared, the latter is more limited to an ancillary service where the patient controls the disclosure of information.
Noteworthy in this context is that this research programme has only focused on community pharmacy. It is possible that pharmacists clinically active in primary care or hospital settings might be perceived differently and therefore be able to perform a wider range of holistically oriented health care services. Adopting such roles might in time alter the perception of pharmacists in community pharmacy as well.

Managerial implications

Determining the patients’ point of view is an important aspect of making any pharmacy service successful (Holdford & Kennedy 1999). Although there have been attempts to develop pharmacy services according to the expectations and desires of patients (Bislew & Sorensen 2003, Craig et al. 2001), these attempts are rare, at least those using rigorous scientific approaches.

The patient perspective on community pharmacy services has, in this thesis, been shown to be vague and variable. This is problematic for pharmacy managers, as the fostering of long-term perceptions of quality (and patient satisfaction) in service delivery depends on patients having precise, explicit and realistic expectations (Ojasalo 2001). On the other hand, study subjects seem satisfied with the service received. This is probably due to low expectations, as described in the Patients’ perspectives on community pharmacy section (Boulding et al. 1993, Oliver 1981), or to the fact that patients tend to value intangible aspects of service delivery higher than actual performance (Holdford & Schulz 1999).

Understanding the varying expectations shown in the clustered ideal views of pharmacy will help managers to tailor services for these groups (Broderick 1999). Choosing services that are in line with patients’ role expectations will provide an advantage in a competitive market. The different characteristics of the traditional and relationship-focused groups that are suggested in Papers II and III will be useful for advertising and marketing decisions at a group level, even though they are not necessarily specific enough to guide individual encounters. The exact nature of the patient expectations must be further studied although, as ideal expectations, “should-be” expectations, and “will-be” expectations are conceptually different and will have different impacts on patient satisfaction (Santos & Boote 2003, Kucukarslan & Schommer 2002, Broderick 1999).

It must also be noted that if we strive to achieve a change in pharmacy practice, it is not enough to understand the perspectives of the patients. Processes of change among all stakeholders (pharmacists, third party payers, prescribing professionals) must be studied further and strategically addressed (Roberts et al. 2005, Balfour & Clarke 2001, Miller et al. 1998).
Implications for research

Pharmacy has been concerned with demonstrating its value to society (Kheir et al. 2004, Indritz & Artz 1999). This thesis adds to that discussion by pointing out the value patients perceived from the delivery of a pharmaceutical care service, and the ideal services that they would value. Focusing on the nature of patients’ perceptions of community pharmacy service, the prevalence of these perceptions has not been addressed here. Quantification is a desirable expansion, if the findings are to be used in policy formation or marketing decisions to develop new services. This is applicable to both the experiences described in Paper I and the preferences studied in Paper II.

From a scientific point of view, it would also be interesting to contrast the service preferences expressed in Paper II with a qualitative study based on a phenomenological perspective. While this study considered these preferences to be measurable forms of “inner behaviour”, the latter approach emphasises the description as a negotiated representation of the lifeworlds of the study subjects and the researcher. This might deepen the understanding of these preferences and develop different structures to stratify the patients for service development purposes.

The limited number of study subjects made the findings of Paper III somewhat tentative. A larger study, one that identifies group or cluster by endorsement of a description rather than a time-consuming Q-sort procedure, might enable a more elaborate statistical testing of the findings. Such studies could be narrower; for instance they could be defined by a particular group (e.g. the elderly or users of multiple medicines) or a specific disease state. Additional measures, such as disease perception, self-efficacy, need for cognition or more elaborate measures of socioeconomic, ethnic or social relations should be considered.

This thesis has demonstrated the feasibility of using the Q-methodological approach to the study of subjectivity in the field of health services research, as well as the usefulness of the CASM framework in qualitative studies of questionnaire validity.

Furthermore, Paper IV explored validity aspects of a promising questionnaire that could be used for more routine measurement of some of the patient perspectives when delivering expanded pharmacy services. The concept of PTRQoL is interesting, as it specifies a particular concern that might be relevant for the selection of pharmaceutical products, or effects of services that are mediated through the use of medicines. However, the Swedish version of the PTRQoL questionnaire was shown to have substantial potential for improvement, although the further development of the questionnaire would be dependent on the concept being valid. Minor problems with the instrument do not necessarily have to invalidate the questionnaire altogether. Differences among study subjects in understanding
of the study concept, and in answering the particular measure will inevitably render all summary measures invalid from some viewpoint. These inconsistencies and variations are not necessarily important at the population level, though, and could be treated as mere measurement errors (Norman 2003).

The generic broad scope of the study subjects (regular medication users) as well as the services (virtually all services) are valuable to get an overview of patients’ perspectives on community pharmacy services. It might be, however, that the findings are not specific enough for particular service development. Thus, performing additional studies aimed at particular societal groups (preferably the disadvantaged groups whose voices were underrepresented in this study), particular disease groups or additional services would be a welcome addition to the work presented here.
Conclusions

*One's first step in wisdom is to question everything – and one's last is to come to terms with everything.*

*Georg Christoph Lichtenberg*

- Patients had superficial and varying understandings of a pharmaceutical care service in which they were currently enrolled, although in general they reported that they were satisfied with it. It was difficult for patients to separate the contents of the service from other health care experiences.

- Patients expected the pharmaceutical care service to increase their feeling of safety with drug treatment, enhance their knowledge and understanding of drugs, provide control over drug treatment and empower them.

- Patient expectations of an ideal pharmacy encounter were divided between a traditional group, emphasising the drug product, and a relationship-focused group, emphasising personal support. The former group contained three factors that were labelled *independent drug shopping, logistics of drug distribution, and drugs before drug use before health care.* The latter group contained four factors labelled *competence as individual support, individualist professional relationship, just take care of me and practical health care/lifestyle support.* Together, the seven factors accounted for 54.4% of the variance in the data.

- Patients in the traditionalist group were more likely than patients in the relationship-focused group to have Swedish as their main language, to have an academic degree, and to disagree with statements implying that pharmaceuticals are overused and harmful. Traditionalists also reported more pharmacy visits overall. Individual variation was large, and these findings were judged to be of little importance as guiding factors in the individual pharmacy encounter.

- Possible threats to the validity of the Swedish PTRQoL instrument were identified, including difficulties in defining what treatment was to be considered when answering,
neglecting instructions, calibrating answers when negative outcomes were perceived as unavoidable and interpreting specific items. The findings could provide significant information for further development of the questionnaire and raises issues about the supporting theoretical framework.

Apart from answering the specific research questions, this research programme showed that both Q methodology and qualitative approaches using CASM as an interpretative framework were useful for understanding various aspects of patient-reported subjectivity about health services issues.

The heterogeneity of patients’ perspectives on services provided by community pharmacies has been highlighted. Policy makers, service providers and evaluators might benefit from further studies of these perspectives, as “one size fits all” services seem an unlikely route to satisfy patients’ understanding of and preferences for community pharmacy services. The superficial understanding shown by patients of the community pharmacy role may act as a barrier to developing pharmacy practice, but still allow more freedom on the part of the pharmacy profession than would a strong role orientation opposing the desired professional role.
Acknowledgements

Gratitude is when memory is stored in the heart and not in the mind.
Lionel Hampton

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There are probably more names that deserve to be in here. I’m sorry that I didn’t remember you when writing this. If you remind me, I’ll buy you a beer (or equivalent) to make up for this miserable failure.

Thank you all!
Populärvetenskaplig sammanfattning
(Lay summary in Swedish)

*Mitt språks gränser är mitt universums gränser.*

*Ludwig Wittgenstein*

Ett flertal av öppenvårdsapotekens nyckeluppgifter, såsom läkemedels-tillverkning och kvalitetskontroll, har avvecklats från de enskilda apoteken. Det finns en tendens att rådgivning standardiseras samtidigt som komplexiteten i individuella läkemedelsbehandlingar ökar. De ekonomiska och kliniska konsekvenserna av felbehandlingar uppmärksammas alltmer. Mot denna bakgrund håller farmaceuter över stora delar av världen på att ompröva sin roll i hälso- och sjukvården. I allt större utsträckning försöker de övergå från försäljning av, och i bästa fall rådgivning kring, enstaka läkemedel till rådgivning kring en patients samla läkemedelsanvändning. Trots att denna förändring pågått under en längre tid, finns det förhållandevis få vetenskapliga studier som undersökt hur patienter ser på apotek och dessas roll i samhället. Denna avhandling har försökt belysa detta på några olika sätt.

För det första har patienter som deltagit i en specifik rådgivningstjänst (läkemedelsprofiler) intervjuats om sina erfarenheter. Resultatet visar att uppfattningarna om tjänstens syfte, innehåll och effekter varierar kraftigt. Ökad kontroll över läkemedelsbehandling en och en känsna av ökad trygghet var centrala begrepp i patienternas beskrivning av tjänsten. De ansåg också att tjänsten ledde till att de var bättre förberedda inför sina läkarbesök. Medan en del ansåg att den kompetens som tillhandahölls på apoteken var unik och bidrog till något nytt i deras behandling, så ansåg andra att tjänsten var ett substitut för uppgifter som läkarna inte hade tid att utföra.

För det andra har patienter med regelbunden läkemedelsanvändning fått beskriva sin syn på ett idealt apoteksbesök. Sju olika synsätt identifierades. Tre av dessa lyfte fram den fysiska läkemedelsprodukten som central. Medan en grupp beskrev sig som självständiga kunder, fokuserade en annan

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9 I den internationella vetenskapliga litteraturen så benämns ofta apotekets besökare som patienter, snarare än kunder, klienter eller konsumenter. I detta sammanhang så används begreppet patient som en benämning på personer som regelbundet brukar läkemedel.

För det tredje så undersöktes det om ett frågeformulär, som ska mäta effekten av läkemedelsanvändning på patienternas livskvalitet, var tillförlitligt. Detta skedde genom att patienter fick fylla i formuläret samtidigt som de högt talade om hur de tänkte när de svarade. Flera problem rörande förståelsen av formuläret och hur svaren formulerades identifierades. För patienterna kan studieresultaten innebära en ökad möjlighet att få ett större utbud av tjänster på apoteken som bättre kan anpassas till olika gruppers önskemål och behov. För de farmaceutiska professionerna, kan fynden användas för att identifiera möjliga sätt att expandera sin yrkesroll och bättre utnyttja sin kompetens. Andra arbetsuppgifter, framförallt de som tangerar vårdsektorns traditionella område, blir svårare att applicera i en apoteksmiljö, bland annat på grund av patienternas syn på sådana tjänster.

Ägandeförhållandena på apotek har inte berörts i avhandlingsarbetet, men fynden skulle kunna användas av olika aktörer när de planerar sin önskade positionering på den omreglerade apoteksmarknaden. För forskningen på området slutligen, bidrar avhandlingen framförallt med två metodologiskt spännande angreppssätt, den så kallade Q-metodologin som användes för att studera det ideala apoteksbesöket, samt den tänka-högt variant som användes vid utvärderingen av livskvalitetsinstrumentet.

Överlag visar avhandlingen på en nyanserad bild av hur patienter uppfattar apotek. Det verkar troligt att apoteken har en stor uppgift framför sig, om de vill skräddarsya sitt bemötande och sina tjänster efter patienternas önskemål, likväl som efter deras medicinska behov.

10 I Sverige finns det två stycken, apotekare (fem års universitetsutbildning) och receptarier (tre års universitetsutbildning). Detta är ovanligt i ett internationellt perspektiv, där det oftast bara finns apotekare, och mindre akademiskt kvalificerad personal, på apoteken.
The greatest obstacle to discovery is not ignorance - it is the illusion of knowledge.

Daniel J. Boorstin


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Appendices

Appendix 1
Interview guide (English translation, Papers I and IV)

Consent:
You have been given written information about this study. I just want to assure you that you have the right to abstain from answering a question and that you can at any time cease your participation in this study without having your relationship with the pharmacy or its staff altered. Do you think it is OK to participate in this interview about how the patient medication record has affected you on these conditions?

Short description of myself. No connection with the pharmacy.

Introductory questions:
Since I’d like to know who I am talking to, I would like you to give a brief description of who you are.
What do you believe the patient medication record service is about?
Tell me about your experiences with having a patient medication record.

Behaviour:
How did you take your medicines before you got a patient medication record?
How do you do now?

Attitudes and knowledge:
What do you think about your medicines today?
What did you think before you got your record?
How about medicines in general?
Have you learned anything about your medicines / medicines in general from the project? What?

Satisfaction:
Tell me how you experienced a pharmacy visit before.
How is it now?
Can you tell me more about…
The information you get now and the information you previously got at the pharmacy
The personal contact at the pharmacy
Important/not so important aspects for you in order to be satisfied when leaving the pharmacy

Quality of life:
How did you experience your health before you got a patient medication record? How is it today?
Is there anything that you can do now, that you couldn’t do before? (or the other way round) Tell me more…

Can you tell me a little about how XXXX have been affected by the project?
- Everyday activities
- Social ability
- Subjective health perception
- Emotional aspects

Expectations:
What did you think that you would gain from being in this project?
How did it turn out?
Why do you think that Apoteket AB [National Corporation of Swedish Pharmacies] want to pursue this project?
- expectations
- perspective on motives

Roles:
Have you visited a physician (nurse, physiotherapist etc.) after you started having a patient medication record? How was that?
How was it before?
- Professional roles within health care
- Confidence

Roundup, part 1:
Are there any other aspects of your life that have been affected by the patient medication record project? Which, explain?
Explain that the customer is supposed to think aloud when filling in the questionnaire, and that he/she should be prepared to answer questions as he/she does so. The purpose is to evaluate the questionnaire, not the customer’s attitudes about their drugs. Start by reading the instructions and the questions aloud and then comment on what you think about the text and how you expect to arrive at your answer.

Potential probes:
- How did you reason when you answered that item?
- I noticed that you hesitated when answering that item, why?
- What does … mean to you?
- Why do you think that…?

Item 6
- What do you think about when reading the words ”handle my medications in a special way”?
- What do you think about when reading the words ”auxiliary means” [note that this item had to be rather heavily transformed to cope with translation]
- If you should rephrase this item, what words should you use?

Item 7
- How would you define “a dose”?

Item 8
- How would you define “the dose”?

Item 12
- What does it mean to ”keep track of one’s medicines”?

Item 25
- If you were to rephrase this item, what words should you use?

Item 29
- If you were to rephrase this item, what words should you use?

Item 33
- If you were to rephrase this item, what words should you use? (there is a risk that this item could be interpreted in two ways. On the one hand, it might be interpreted to be uncertainty about the purpose of the medication, or on the other hand it could be an uncertainty that emanates from disagreement with /distrust of the physician)

Final probes
- Do you believe that there is any difference between the terms “läkemedel” [approx drugs] and “mediciner” [approx medicines]. If so, what is it?
- Did the questionnaire instructions work?
- What did you think about the answer options?
Was there anything that you perceived as difficult or uncomfortable when you filled in the questionnaire? Why?

What did you think about the questionnaire?

Part 3
What do you believe your patient medication record has meant for you?

Demographic data:
- Age
- Gender
- Occupation/Education
- Civil status
- Number of medications

How did you feel about the interview?
Is there anything you would like to add?

Thank you for participating
Appendix 2
Q-sample (English translation, Paper II)

Please notice that the original sample was constructed in Swedish, and that this translation is only intended to give an overview of its content. To be used in other settings, cross-cultural adaptation and professional translation need to be performed.

- The pharmacist’s connections with the physicians make it 100% certain that I get the right drug on my prescription. 
  \textit{(technical / drugs / pharmacist-driven)}
- The pharmacist can give me the best value-for-money drugs. 
  \textit{(technical / drugs / pharmacist-driven)}
- The pharmacy has a computer system that helps me and the pharmacist together to make a summary of all the medicines I use. 
  \textit{(technical / drugs / collaborative)}
- There is plenty of time to discuss side effects. 
  \textit{(technical / drugs / collaborative)}
- The pharmacy is a store where you buy drugs, and just like in other stores, the customer is always right. 
  \textit{(technical / drugs / client-driven)}
- The pharmacy is easy accessible [geographically] and has a wide range [of drugs], so that I easily get the drugs I order. 
  \textit{(technical / drugs / client-driven)}
- The pharmacist spends as much time with me as necessary to explain how I should use my drugs. 
  \textit{(technical / drug use / pharmacist-driven)}
- There is so much knowledge at the pharmacy, so they can inform me about how to use my drugs, both verbally and in written format. 
  \textit{(technical / drug use / pharmacist-driven)}
- The system with a “personal pharmacist” means that I always get to discuss the drug use with the same person. 
  \textit{(technical / drug use / collaborative)}
- There is a private area where the pharmacist and I can discuss how I should use my medicines. 
  \textit{(technical / drug use / collaborative)}
- It is easy to get hold of a knowledgeable pharmacist at the pharmacy. If I want them to, they are able to judge how I use
my drugs.
(technical / drug use / client-driven)

- There is plenty of time for me to tell how I take my medicines.
(technical / drug use / client-driven)

- The pharmacist has many ways of informing me about how I should take care of myself, so there is always something that is suitable in my case.
(technical / health care – lifestyle / pharmacist-driven)

- The pharmacy has enough staff and short queues, so the pharmacist is never hurried when he/she has to instruct me about a sound lifestyle.
(technical / health care – lifestyle / pharmacist-driven)

- A pharmacist, rather than an assistant, takes the time to discuss a healthy lifestyle with me.
(technical / health care – lifestyle / collaborative)

- Since the pharmacist is friendly and helpful, it feels good to plan together how I could feel as well as possible.
(technical / health care – lifestyle / collaborative)

- The pharmacy has sufficient opening hours, so that I can collect health information when I need it.
(technical / health care – lifestyle / client-driven)

- There is a private area where I have the chance to ask about sensitive issues regarding my health.
(technical / health care – lifestyle / client-driven)

- The pharmacist makes a thorough professional review of my drugs.
(process-oriented / drugs / pharmacist-driven)

- The pharmacist tells me about side effects that are probable in my case.
(process-oriented / drugs / pharmacist-driven)

- The pharmacist and I discuss my drugs, and agree on who will contact health care if questions occur about them.
(process-oriented / drugs / collaborative)

- I get to speak to the pharmacist about the medicines I have been prescribed.
(process-oriented / drugs / collaborative)

- When I have questions about my drugs, the pharmacist answers them.
(process-oriented / drugs / client-driven)

- I decide what is important for me with my drugs, and then the professional pharmacist finds a container that suits my wishes.
(process-oriented / drugs / client-driven)
• The pharmacist makes certain that he/she asks about how I intend to use my drugs.
  (process-oriented / drug use / pharmacist-driven)
• The pharmacist gives spontaneous advice about how to use my drugs.
  (process-oriented / drug use / pharmacist-driven)
• The pharmacist and I see to it that we agree about how best to take my medicines.
  (process-oriented / drug use / collaborative)
• It is an opportunity for an in-depth conversation about drug use.
  (process-oriented / drug use / collaborative)
• The pharmacist gives me good advice on drug use, but only if I ask for it.
  (process-oriented / drug use / client-driven)
• I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.
  (process-oriented / drug use / client-driven)
• The pharmacist checks my laboratory test results because he/she understands such things better than I do.
  (process-oriented / health care – lifestyle / pharmacist-driven)
• The pharmacist controls whether I reach my treatment goals.
  (process-oriented / health care-lifestyle / pharmacist driven)
• The pharmacist and I cooperate to evaluate my total medical situation.
  (process-oriented / health care – lifestyle / collaborative)
• I can discuss minor health issues with the pharmacist, i.e. issues that you don’t ask the doctor about.
  (process-oriented / health care – lifestyle / collaborative)
• I take all decisions myself regarding my health. The pharmacist double-checks that the decisions have been appropriate.
  (process-oriented / health care – lifestyle / client-driven)
• If I ask, the pharmacist judges the appropriateness of all treatments I intend to use, not just the drugs.
  (process-oriented / health care – lifestyle / client-driven)
• The pharmacist gives me good quality medicines.
  (result-oriented / drugs / pharmacist-driven)
• The pharmacist makes certain that I get the drugs I need.
  (result-oriented / drugs / pharmacist-driven)
• Through a dialogue with the pharmacist, I learn quite a lot about my drugs.
  (result-oriented / drugs / collaborative)
• I work with the pharmacist, and we see to it that I take control over my drugs, and not the other way round.
(result-oriented / drugs / collaborative)
• I get the drugs that I and my doctor have agreed upon.
(result-oriented / drugs / client-driven)
• I ask questions, and the pharmacist answers. This way, I get new knowledge about my drugs.
(result-oriented / drugs / client-driven)
• The pharmacist supplies me with new knowledge regarding how to use my drugs.
(result-oriented / drug use / pharmacist-driven)
• When the pharmacist tells me how to use my drugs properly, I feel safe.
(result-oriented / drug use / pharmacist-driven)
• After a pharmacy visit, when the pharmacist and I have worked together about how and when to take my drugs, I feel like a VIP.
(result-oriented / drug use / collaborative)
• I leave with good questions for the physician visit when I have discussed my drug use with the pharmacist.
(result-oriented / drug use / collaborative)
• I learn how to handle my drug treatment by asking the pharmacist about things I want to know.
(result-oriented / drug use / client-driven)
• After the pharmacy visit, I feel safe with the drug treatment I have chosen.
(result-oriented / drug use / client-driven)
• The pharmacist checks my health situation, and sees to it that I feel as well as possible under the circumstances.
(result-oriented / health care – lifestyle / pharmacist-driven)
• When I leave the pharmacy, the pharmacist has taught me a lot about supplements and alternatives to drug treatment.
(result-oriented / health care – lifestyle / pharmacist-driven)
• The pharmacist and I work together in order to make me feel good after the visit, because that is what is really important.
(result-oriented / health care – lifestyle / collaborative)
• My discussion with the pharmacist results in concrete advice about a healthy life.
(result-oriented / health care – lifestyle / collaborative)
• At the pharmacy visit, I supply myself with knowledge about how to express medical concerns so that health care professionals can understand what I mean.
(result-oriented / health care – lifestyle / client-driven)
• The pharmacy is like a health marketplace, where I can get drugs, lifestyle advice, blood pressure measurements or whatever I need.

(result-oriented / health care – lifestyle / client-driven)
Appendix 3
Factor arrays (English translation, Paper II)
Describe an ideal pharmacy visit when you are about to collect prescription medicines

<table>
<thead>
<tr>
<th>Least like I want it</th>
<th>Most like I want it</th>
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<tbody>
<tr>
<td>Column -5</td>
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The pharmacist controls that I reach my treatment goals. It is an opportunity for an in-depth conversation about drug use.

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</table>

Table: Needs for an ideal pharmacy visit when about to collect prescription medicines

- There is a private area where I can discuss my health concerns with the pharmacist.
- The pharmacist checks my medical history and drug allergies.
- The pharmacist provides comprehensive information about the medications.
- The pharmacist reviews my drug interactions and potential side effects.
- The pharmacist offers alternative medications if necessary.
- The pharmacist provides detailed instructions on how to take the medications.
- The pharmacist answers all my questions and concerns about the medications.
- The pharmacist offers ongoing support and follow up.
- The pharmacist provides a summary of my medications and dosages.
- The pharmacist offers reminders for upcoming appointments or refills.
- The pharmacist ensures that all my medications are dispensed accurately and safely.
- The pharmacist offers educational resources and support materials.
- The pharmacist offers discounts or financial assistance if needed.
- The pharmacist offers exceptional customer service and responsiveness.
- The pharmacist offers a seamless and efficient pharmacy experience.
- The pharmacist offers personalized care and attention.
- The pharmacist offers a convenient and accessible location.
- The pharmacist offers a wide selection of medications.
- The pharmacist offers a loyalty program or rewards for repeat customers.
- The pharmacist offers a painless and stress-free medication collection experience.
- The pharmacist offers a commitment to patient safety and quality assurance.
- The pharmacist offers a commitment to patient privacy and confidentiality.
- The pharmacist offers a commitment to patient well-being and satisfaction.
- The pharmacist offers a commitment to continuous improvement and innovation.

Note that original sorts were performed and analysed in Swedish

The translation is not validated
Describe an ideal pharmacy visit when you are about to collect prescription medicines

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<tr>
<th>Column</th>
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<tr>
<td>-5</td>
<td>I decide what is important for me with my doctor, and then the pharmacist should find a container that suits my wishes.</td>
</tr>
<tr>
<td>-4</td>
<td>The pharmacy is a store where you buy drugs, and just like in other stores, the customer is always right.</td>
</tr>
<tr>
<td>-3</td>
<td>I take all decisions regarding my health myself. The pharmacist double checks so that the decisions have been appropriate.</td>
</tr>
<tr>
<td>-2</td>
<td>The pharmacist makes a thorough professional review of my drugs.</td>
</tr>
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<td>-1</td>
<td>The pharmacist supplies me with new knowledge regarding how to use my drugs.</td>
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<tr>
<td>0</td>
<td>The pharmacist tells me about side effects.</td>
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<tr>
<td>+1</td>
<td>The pharmacist's connections with the physician make it 100% certain that I get the right drug on my prescription.</td>
</tr>
<tr>
<td>+2</td>
<td>The pharmacist gives me good quality medicines.</td>
</tr>
<tr>
<td>+3</td>
<td>The pharmacist gives me new knowledge that is probable in my case.</td>
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<tr>
<td>+4</td>
<td>The pharmacist has made the pharmacy a place where I have been prescribed.</td>
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<tr>
<td>+5</td>
<td>The pharmacist has told me what my doctor said about not using my drugs.</td>
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**Factor II**

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Describe an ideal pharmacy visit when you are about to collect prescription medicines

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My discussion with the pharmacist result in concrete advice about a healthy life.
The pharmacy is like a health marketplace, where I can get drugs, lifestyle advice, blood pressure measurements or whatever I need.

The pharmacist understands how to use my medications.
The pharmacist gives me good advice on drug use, but only if I ask for it.

There is a private area where I have the chance to ask about sensitive issues regarding my health.

I can use the competence of the pharmacist as support, when I decide what drugs to take and when to take them.

The pharmacist tell me about my drugs properly, I feel safe.

The pharmacist tells me when to use my 2 drugs, and not the other way around.

The pharmacist and I discuss my drugs, and agrees on whether I will contact health care if questions about them occur.

I learn about new knowledge regarding my medications.

The pharmacist supplies me with new knowledge regarding how to use my drugs.

I get what is important for me with my drugs, and then the pharmacist finds a container that suits my wishes.

The pharmacy has a computer system that helps me and the pharmacist to make a summary together of all the medicines I use.

The pharmacy is easy accessible [geographically] and have a wide range [of drugs], so that I easily get the drugs I order.

When I have questions about my drugs, the pharmacist answers them.

The pharmacist's connections with the physicians make it 100% certain that I get the right drug on my prescription.

The pharmacy is easy to get hold of a knowledgeable pharmacist at the pharmacy, if I want to, they are able to judge how I use my drugs.

I get the drugs that I and my doctor have agreed upon.

Factor III

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The pharmacist gives me good advice on drug use, but only if I ask for it.
The pharmacist is a store where you buy drugs, and just like in other stores, the customer is always right.

The pharmacist has many ways of informing me about how I shall take care of myself, so there is always something that is suitable in my case.

The pharmacist makes certain that I get the drugs I need.

The pharmacist gives spontaneous advice about how to use my drugs.

When I have questions about my drugs, the pharmacist answers them.

Through dialogue with the pharmacist, I learn quite a lot about my drugs.

The pharmacists connections with the physicians make it 100% certain that I get the right drug on my prescription.

The system has a “personal pharmacist”, results in that I always get to discuss the drug use with the same person.

The pharmacist is a computer system that helps me and the pharmacist to make a summary together of all the medicines I use.

There is plenty of time to discuss side effects.

I leave with good impressions of the physician visit when I have discussed my drug use with the pharmacist.

The pharmacist supplies me with new knowledge regarding how to use my drugs.

The pharmacist tells me about side effects that are probable in my case.

I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.

The pharmacist tells me about side effects that are probable in my case.

The pharmacist gives me good advice on drug use, but only if I ask for it.

The pharmacist is a store where you buy drugs, and just like in other stores, the customer is always right.

The pharmacist has many ways of informing me about how I shall take care of myself, so there is always something that is suitable in my case.

The pharmacist makes certain that I get the drugs I need.

The pharmacist gives spontaneous advice about how to use my drugs.

When I have questions about my drugs, the pharmacist answers them.

Through dialogue with the pharmacist, I learn quite a lot about my drugs.

The pharmacists connections with the physicians make it 100% certain that I get the right drug on my prescription.

The system has a “personal pharmacist”, results in that I always get to discuss the drug use with the same person.

The pharmacist supplies me with new knowledge regarding how to use my drugs.

The pharmacist tells me about side effects that are probable in my case.

I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.

The pharmacist tells me about side effects that are probable in my case.

The pharmacist gives me good advice on drug use, but only if I ask for it.

The pharmacist is a store where you buy drugs, and just like in other stores, the customer is always right.

The pharmacist has many ways of informing me about how I shall take care of myself, so there is always something that is suitable in my case.

The pharmacist makes certain that I get the drugs I need.

The pharmacist gives spontaneous advice about how to use my drugs.

When I have questions about my drugs, the pharmacist answers them.

Through dialogue with the pharmacist, I learn quite a lot about my drugs.

The pharmacists connections with the physicians make it 100% certain that I get the right drug on my prescription.

The system has a “personal pharmacist”, results in that I always get to discuss the drug use with the same person.

The pharmacist supplies me with new knowledge regarding how to use my drugs.

The pharmacist tells me about side effects that are probable in my case.

I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.

The pharmacist tells me about side effects that are probable in my case.

Factor IV

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Describe an ideal pharmacy visit when you are about to collect prescription medicines

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<tr>
<td>The pharmacist makes certain that he/she asks about how I intend to use my drugs.</td>
<td>The pharmacist controls that I reach my treatment goals.</td>
<td>If I ask, the pharmacist/judge the appropriateness of all treatments I intend to use, not just the drugs.</td>
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<tr>
<td>The pharmacist checks my laboratory test results because he/she understands such things better than I do.</td>
<td>I can discuss minor health issues with the pharmacist, i.e. issues that you don't ask the doctor about.</td>
<td>The pharmacist check my health situation, and see to it that I feel as well as possible under the circumstances.</td>
</tr>
<tr>
<td>The pharmacy is a store where you buy drugs, and just like in other stores, the customer is always right.</td>
<td>The pharmacist and I work together in order to make me feel good after the visit, because that is what is really important.</td>
<td>I learn how to handle my drug treatment by asking the pharmacist about things I want to know.</td>
</tr>
<tr>
<td>I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.</td>
<td>The pharmacist makes a thorough professional review of my drugs.</td>
<td>I can use the competence of the pharmacist as support, when I decide what drugs to take, and when to take them.</td>
</tr>
<tr>
<td>The pharmacist gives spontaneous advice about how to use my drugs.</td>
<td>The pharmacist gives me good quality medicine.</td>
<td>At the pharmacy visit, I supply myself with knowledge about how to express medical concerns so that health care can understand what I mean.</td>
</tr>
<tr>
<td>The pharmacist and I discuss my drugs, and agree on who will contact health care if questions about them occur.</td>
<td>The pharmacist supplies me with new knowledge regarding how to use my drugs.</td>
<td>The pharmacist supplies me with new knowledge regarding how to use my drugs.</td>
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<tr>
<td>The pharmacist and I cooperate to evaluate my total medical situation.</td>
<td>I take all decisions regarding my health myself. The pharmacist double checks so that the decisions have been appropriate.</td>
<td>The pharmacist and I discuss my drugs, and agree on who will contact health care if questions about them occur.</td>
</tr>
<tr>
<td>After a pharmacy visit, I feel satisfied with my drugs, and I feel like a VIP.</td>
<td>I pose questions, and the pharmacist answers. This way, I get new knowledge about my drugs.</td>
<td>After a pharmacy visit, I feel satisfied with my drugs, and I feel like a VIP.</td>
</tr>
<tr>
<td>It is an opportunity for an in depth conversation about drug use.</td>
<td>The pharmacist makes certain that I get the drugs I need.</td>
<td>I pose questions, and the pharmacist answers. This way, I get new knowledge about my drugs.</td>
</tr>
<tr>
<td>Through a dialogue with the pharmacist, I learn quite a lot about my drugs.</td>
<td>The pharmacists has sufficient opening hours, so that I can collect health information when I need it.</td>
<td>Through a dialogue with the pharmacist, I learn quite a lot about my drugs.</td>
</tr>
<tr>
<td>There is plenty of time for me to tell how I take my medicines.</td>
<td>I get to speak to the pharmacist about the medicines I have been prescribed.</td>
<td>There is plenty of time for me to tell how I take my medicines.</td>
</tr>
<tr>
<td>I leave with good questions for the physician visit when I have discussed my drug use with the pharmacist.</td>
<td>When I leave the pharmacy, the pharmacist has taught me a lot about complements and alternatives to my drug treatment.</td>
<td>I leave with good questions for the physician visit when I have discussed my drug use with the pharmacist.</td>
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**Factor V**

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| The pharmacy is like a health marketplace where I can get drugs, lifestyle advice, blood pressure, measurements or whatever I need. | The pharmacist supplies me with new knowledge regarding how to use my drugs. | The pharmacist and I discuss my drugs, and agrees on who will contact healthcare if questions about them occur. | The pharmacist gives me good advice on drug use, but only if I ask for it. | The pharmacist checks my health status, and sees to it that I feel as well as possible under the circumstances. | The pharmacist and I cooperate to evaluate my total medical situation. | The pharmacist tells me about side effects that are probable in my case. | There is so much knowledge at the pharmacy, so they can enlighten me about how to use my drugs, both verbally and in written format. | I work with the pharmacist, and see to it that I take control over my drug, and not the other way round. | I take all decisions regarding my health myself. The pharmacist double checks so that the decisions have been appropriate. | Since the pharmacist is friendly and helpful, it feels good to plan together how I am to feel as well as possible. |

| The pharmacist, rather than an assistant, take the time to discuss a healthy lifestyle together with me. | The system with a ‘personal pharmacist’, results in that I always get to discuss the use drugs with the same person. | The pharmacist and I discuss my drugs, and agrees on who will contact healthcare if questions about them occur. | The pharmacist checks my health status, and see to it that I feel as well as possible under the circumstances. | The pharmacist and I cooperate to evaluate my total medical situation. | The pharmacist and I work together in order to make me feel good after the visit, because that is what is really important. | Through a dialogue with the pharmacist, I learn quite a lot about my drugs. | The pharmacist makes certain that I get the drugs I need. | The pharmacist spends as much time with me as necessary to explain how I shall use my drugs. | The pharmacy has a computer system that helps me and the pharmacist to make a summary together of all the medicines I use. | The pharmacist gives spontaneous advice about how to use my drugs. |

**Factor VI**

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<td>The pharmacy is a store where you buy drugs, and just like in other stores, the customer is always right.</td>
<td>The pharmacist makes certain that he/she asks about how I intend to use my drugs.</td>
<td>The pharmacist and I discuss my drugs, and agree on who will contact health care if questions about them occur.</td>
<td>The pharmacist's connections with the physicians make it 100% certain that I get the right drug on my prescription.</td>
<td>I take all decisions regarding my health myself. The pharmacist double checks so that the decisions have been appropriate.</td>
<td>After a pharmacy visit, when the pharmacist and I have worked together with how and when to take my drugs, I feel like a VIP.</td>
<td>The pharmacist checks my laboratory test results because he/she understands such things better than I do.</td>
<td>It is an opportunity for an in-depth conversation about drug use.</td>
<td>The pharmacist makes certain that I get the drugs I need.</td>
<td>The pharmacist and I see to it that we agree about how to best take my medicines.</td>
<td>The pharmacy has a computer system that helps me and the pharmacist to make a summary together of all the medicines I use.</td>
<td>The pharmacist gives me good quality directions.</td>
</tr>
<tr>
<td>The system with a 'personal pharmacist', results in that I always get to discuss the drug use with the same person.</td>
<td>The pharmacy and I work together in order to make me feel good after the visit, because that is what is really important.</td>
<td>There is a private area where I have the chance to ask about sensitive issues regarding my health.</td>
<td>The pharmacist controls that I reach my treatment goals.</td>
<td>There is plenty of time for me to tell how I take my medicines.</td>
<td>A pharmacist, rather than an assistant, take the time to discuss a healthy lifestyle together with me.</td>
<td>The pharmacist gives spontaneous advice about how to use my drugs.</td>
<td>When the pharmacist tells me how to use my drugs properly, I feel safe.</td>
<td>The pharmacist and I see to it that we agree about how to best take my medicines.</td>
<td>There is a private area where I and the pharmacist can discuss how I shall use my medicines.</td>
<td>There is plenty of time to discuss side effects.</td>
<td>The pharmacist makes a thorough professional review of my drugs.</td>
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Acta Universitatis Upsaliensis

*Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Pharmacy 105*

Editor: The Dean of the Faculty of Pharmacy

A doctoral dissertation from the Faculty of Pharmacy, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Pharmacy*. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Pharmacy”.)